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What Shapes Family Physicians' Patterns of Care for Community Patients at End of Life?

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A thesis submitted in partial fulfillment of the requirements for the degree in Master of Clinical Science

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WHAT SHAPES FAMILY PHYSICIANS' PATTERNS OF CARE FOR
COMMUNITY PATIENTS AT END OF LIFE?

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by

Joshua David Shadd

Graduate Program in Family Medicine

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Clinical Science in Family Medicine

The School of Graduate and Postdoctoral Studies
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London, Ontario, Canada

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CERTIFICATE OF EXAMINATION

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Dr. Graham Reid
Chair of the Thesis Examination Board

Abstract

Family physicians (FPs) care for the majority of community patients approaching end of life. Variations among FPs in care activities for these patients have potential implications for equitable access to care. This thesis used mixed methods to explore how FPs in southwestern Ontario, Canada care for these patients, and what shapes the variations. In the primary study, using grounded theory based on in-depth interviews, FPs described differing in the timing, location and purpose of their activities. These variations were shaped by a process of ‘making it fit’, in which FPs weighed the implications of choices in their unique contexts. In the second study, a secondary analysis of family physician survey data, FPs reported differences in their potential availability to provide care to community patients at end of life. Attitude toward FP participation in palliative care at home and remuneration by alternate funding plan were both strongly associated with potential availability.

Keywords

Family medicine, end of life care, community-based case, mixed methods, grounded theory

Co-Authorship Statement

This thesis and the studies it describes were conceived, planned and carried out by the author. In the qualitative study, all data collection was by the author, with analysis conducted jointly with Dr. Moira Stewart. In the quantitative study, all data analysis was by the author, with statistical advice provided by Dr. Stewart and Dr. Amardeep Thind. The thesis manuscript was written solely by the author, with editorial revisions suggested by Drs. Stewart and Thind.

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Chapter 1

1 Studying Family Physicians' Patterns of Care for Community Patients at End of Life

1.1 Thesis Overview

This thesis explores the variety of ways in which family physicians in southwestern Ontario, Canada organize their care activities for community-dwelling patients who are approaching end of life, and what shapes this variation.

Chapter one articulates the context for the research studies by providing an introduction to the topic, a summary of key literature, and an overview of methodologic approach.

Chapter two describes this thesis' primary research project: a grounded theory study based on in-depth interviews with family physicians describing a spectrum of patterns of care for community patients at end of life, and the influences that have shaped those particular patterns.

Chapter three describes a related study reporting a secondary analysis of survey data to examine family physicians' self-reported availability to provide medical care to community patients at end of life.

Chapter four then seeks to integrate the findings of these two studies, and suggests elements of a program of research to further explore this topic.

1.2 The terminology of end of life care

Death is not an easy subject. Using indirect language (alternative terms, metaphors, euphemisms) is a common strategy people use when dealing with difficult subjects. While indirect language may have an important social role to play, it is not necessarily helpful for clarifying meaning or deepening understanding.

In health care, we have our own indirect language for discussing the care of the dying. We provide palliative care, or hospice care, or end of life care, or supportive care, or

terminal care to patients with life-threatening, or life-limiting, or progressive, or advanced, or incurable illnesses.

In Canada, the most widely used terminology is ‘palliative care’. Derived from the Latin *palliare*, meaning to cloak or cover, the phrase was coined in the 1970s by Dr. Balfour Mount, a Montreal urologist who wanted to find a term that worked well in both French and English. Palliative care has since become the internationally accepted idiom for care focused on quality, rather than quantity, of life.

However, the phrase ‘palliative care’ shares some of the weaknesses of indirect language. It is a rich term, but not a precise one. Palliative care is a polyseme; a word with multiple, related, contextually-dependent meanings. One cannot be sure of a polyseme’s intended meaning without understanding the context in which the word is used.

The term ‘palliative care’ is commonly used with at least four different meanings. First, it may refer to any care given in the absence of curative expectations. In this usage, ‘palliative care’ stands in contrast to ‘curative care’ (e.g. ‘palliative’ instead of ‘curative’ chemotherapy). Second, palliative care may be used synonymously with end of life care, referring to any care given in the final stage of life. Third, it may refer specifically to care provided in a manner consistent with the principles of hospice palliative care, emphasizing open communication, patient-centred decision making and quality of life^{*}. Fourth, the term is used to refer specifically to those specialized healthcare providers whose work is focused exclusively on this patient population.

The subject of this thesis is not palliative care, *per se*. The focus was not on the intent of care given, as in the first and third definitions above, nor on care given early in the trajectories of incurable illnesses, nor the role of specialized providers of palliative

* In this third usage of the term, the criterion is the philosophy of care rather than the timing. Palliative care, when used in this sense, need not be restricted to the end of life, and may be appropriate at any stage of a potentially life-limiting illness, including simultaneously with curative-intent interventions. Conversely, not all care at end of life is necessarily palliative care (by this third definition). Treatments administered even on the last day of life are ‘palliative’ only when offered in a manner consistent with the philosophy and principles of palliative care.

medicine. The goal of this thesis project was simply to explore how family physicians organize care for one segment of their patient population: community patients approaching end of life. For this reason, this thesis will use the term ‘end of life care’ where possible and appropriate. Where the phrase ‘palliative care’ appears, it is used advisedly and is not assumed to be synonymous with end of life care.

1.3 Family physicians and community-based end of life care

1.3.1 The need for community-based end of life care

With our aging population comes an increasing number of deaths. Population projections from Statistics Canada forecast a steadily growing annual number of deaths for the next forty years, with a plateau being reached after 2050 at a number approximately double our current annual rate¹.

The need for community-based services is compounded by the trend toward de-institutionalization of end of life care. In Canada, the proportion of deaths which occurred in hospital rose steadily throughout most of the 20th century, peaking in the mid-1990s at 80.5%². The trend has since reversed sharply, and by 2004 the proportion of hospital deaths in Canada fell to 60.6%³. Health system planners continue seeking to increase the proportion of deaths which occur in the community both because home-based care at end of life is less costly than hospital-based care⁴⁻⁶, and because most patients tell us that home is their preferred location for end of life care⁷⁻¹¹.

1.3.2 Family physician provision of community-based end of life care

In Canada, family physicians[†] are responsible for the primary medical care of the vast majority patients in the community¹². Even (perhaps especially) for patients dealing with complex illnesses requiring hospitalizations and specialist visits, such as congestive heart

[†] Throughout the thesis, ‘family physician’ will refer both to general practitioners and certificants of the College of Family Physicians of Canada.

failure or cancer, family physicians remain central to their care and provide the bulk of medical services^{13,14}.

Family physician participation in community-based end of life care is consistent with the principles and philosophy of family medicine¹⁵⁻¹⁹. Family physicians frequently describe their participation in community-based end of life care as important, valuable, and professionally rewarding²⁰⁻²⁵. More importantly, patients want their family physicians to be involved in their end of life care²⁶⁻³¹. Family physician participation in community end of life care also impacts patient outcomes. Family physician engagement reduces emergency room usage³², reduces transitions between care settings³³, and greatly increases the likelihood of achieving a home death³⁴⁻³⁸. For all of these reasons, provincial and national policy leaders have embraced a vision of community-based end of life care which is built upon a foundation of family physician provision³⁹⁻⁴².

But family physician participation in community-based end of life care is not universal. In the 2010 National Physician Survey, only 45.7% of family physician respondents reported providing palliative medicine to their patients⁴³. The proportion of family physicians who report participating in palliative care varies in other surveys. In Quebec City, Canada 62% and in Sydney, Australia 75% of family physicians describe providing at least some palliative care^{44,45}.

Interpretation and comparison of these figures is made difficult, however, by at least two important factors. First, these surveys do not distinguish family physician respondents who practice solely in specific areas (such as sports medicine or emergency medicine) where they are unlikely to have primary responsibility for the care of community patients at end of life. Second, we do not know precisely what either the surveyors or respondents intended with the use of the term palliative care. As used in the surveys, did 'palliative care' simply mean providing medical care to people with incurable illnesses? Did it imply the provision of house calls? Was intent of care important? It is likely that the term would be interpreted variously by respondents, making it difficult to know exactly what care they were or were not claiming to provide.

Regardless of some of the difficulties in interpretation, results from these surveys clearly suggest that engagement in the provision of medical care for community patients at end of life varies among family physicians. The observation begs the questions: how does care of this patient population vary among family physicians, and why?

1.4 Research aim

The goal of this thesis was to explore the variations that exist among family physicians in the way that they organize provision of care for community-dwelling patients approaching the end of life. In Canada, family physicians are independent professionals with wide latitude to arrange their practices as they see fit to provide care for their patients. Each family physician has habits, strategies, processes and procedures which they use to arrange their activities. These organizing strategies may be formal or informal, malleable or inflexible, but together they constitute the *pattern* by which that family physician provides care to his or her patients.

The phrase ‘physician patterns of care’ has been used variously in the research literature. Sometimes it refers to a physician’s proclivity to make a particular therapeutic choice in a specific clinical situation^{46,47}. Alternatively, it has been used to describe the collective behaviour of groups of physicians^{48,49}. Neither of these represent the meaning with which the phrase is used in this thesis. In this thesis, the phrase ‘*patterns of care*’ refers to the manner in which individual family physicians organize the activities by which they care for his or her practice population.

Variations among family physicians in how they organize the care of community patients at end of life (i.e. variations in their patterns of care) may have implications for access to care, quality of care, care costs or patients’ experience of the health care system. Understanding the nature of these variations is the first step to determining their potential significance. This thesis’ research question was: what shapes family physicians’ patterns of care for community patients at end of life?

1.5 Methodologic approach

1.5.1 Premises embedded in the research question

The starting point for this enquiry was the premise that family physicians' patterns of care must be understood at both the individual level and the system level. Family physicians are independent professionals with wide latitude in how they provide care for their patients. Each family physician makes his or her own individual decisions about who their patients are, and when, where and how to provide care for these patients. To understand variations in patterns of care, we need to explore differences at the level of individual family physicians. Stange et al, in their taxonomy of family medicine enquiry, would call this the 'inner, individual' perspective⁵⁰.

However, family physicians do not operate in isolation from the broader health care system. The scope, timing, and quality of care provided by family physicians are likely to have implications for other components of the health care system. Family physicians' patterns of care for community patients at end of life are also important to the system – what Stange et al would call the 'outer, collective'⁵⁰. A rich understanding thus seeks to incorporate both individual and system-level perspectives.

A second premise embedded in the methodologic approach used in this thesis is the belief that an open, exploratory posture is required. There is some literature on this topic, but it is not sufficiently developed to provide adequate context for narrowly-focused research questions. The current need is for research designed to generate hypotheses and propose theories in order to inform subsequent outcome-oriented studies.

1.5.2 Mixed methods

A mixed methods approach is well-suited to this thesis' research question. By thoughtfully utilizing distinct qualitative and quantitative lenses to explore a common topic using separate data sources, mixed methods studies have the potential to bridge Stange's different 'ways of knowing'. Insights gained through the qualitative lens may shed new light on our interpretation of the quantitative results, or *vice versa*. In mixed

methods research, findings from one methodology may confirm, extend, or contextualize the findings from another. Mixed methods have the potential to increase the depth of understanding of results, and overcome some of the limitations of each method alone⁵¹⁻⁵³.

The research question for this thesis (What shapes family physicians' patterns of care for community patients at end of life?) was framed in a manner intended to reflect both an exploratory posture, and an openness to multiple methodologies. A mixed method approach was facilitated by access to an existing database containing family physicians' responses to a survey which included items relevant to the research question. A feasible mixed methods design was thus possible based on the collection of new qualitative data supplemented by secondary analysis of existing quantitative (survey) data.

Under the broad umbrella of 'mixed methods studies' reside a spectrum of methodological combinations suited to a variety of purposes. According to Creswell⁵¹, the assortment of mixed methodology can be categorized by four characteristics: implementation sequence (the chronologic order in which study components were conducted), priority of methodologies (the relative weighting of findings from different study components to the conclusions of the study as a whole), level of integration (the stage of design or interpretation at which the methodologies are brought together), and theoretical perspective (referring to the underlying assumptions of the researcher).

According to Creswell's taxonomy, this thesis describes a mixed methods study with simultaneous implementation, qualitative-dominant priority, integration at the level of interpretation, and a constructivist theoretical perspective.

Simultaneous Implementation

A simultaneous implementation mixed methods study is one in which both components are undertaken concurrently. Neither part of the study is dependent on progress in the other and both halves proceed in parallel.

Qualitative-Dominant

Mixed methods studies may be designed with one primary and one secondary method, or with both halves considered to be of equal importance. Of the two portions of this thesis, the qualitative study (grounded theory based on in-depth interviews with family physicians) was considered primary. It was expected that the qualitative study would provide the greatest insights into the research question. The quantitative study (secondary analysis of family physician survey data) was expected to offer separate insights into the same topic, less rich in scope though still important to the project as a whole.

Integration at the Level of Interpretation

While both of the studies which comprise this thesis address the same research aim, the two were treated as separate studies with respect to their specific research questions, data collection and data analysis. Integration of insights from the two studies occurred primarily at the stage of interpretation, only after data collection and analysis for each study had been completed. One noteworthy adjustment was made to the quantitative study on the basis of preliminary qualitative findings. This is discussed in the thesis' fourth chapter.

Constructivist Theoretical Perspective

The constructivist theoretical perspective[‡] emphasizes that an understanding of people's interactions with the world is not achieved by discovering facts, but by articulating shared insights. Each person perceives the world and its events through the lens of their own age, gender, beliefs, cultural touchstones, and lived experiences. The research participants and the researcher (who comes with his or her own lens) interact with one another using shared symbols in the form of language (symbolic interactionism)⁵⁴. The result is the development (or construction) of a shared understanding. Knowledge

[‡] The content of this paragraph draws upon multiple sources including Charmaz⁵⁴, Corbin & Strauss⁵⁵, Miller & Crabtree⁵⁶, and Richards & Morse⁵².

generation, from a constructivist perspective, is not a matter of simple discovery; it is a process of co-creation.

“...concepts and theories are *constructed* by researchers out of stories that are constructed by research participants who are trying to explain and make sense out of their experiences and/or lives, both to the researcher and themselves. Out of these multiple constructions, analysts construct something that they call knowledge.” (Corbin & Strauss⁵⁵, page 10)

1.5.3 Grounded theory and the literature review

The specific methodology adopted for the qualitative portion of this thesis was constructivist grounded theory⁵⁴. The details of this method, and the rationale for its selection, are outlined in the next chapter. One of the principles of classical grounded theory as first described by Glaser and Strauss⁵⁷, is that the literature review should be conducted only after completion of the analysis. Glaser and Strauss felt that achieving novel insights would be less likely if the analyst were unduly influenced by other authors' work. Modern grounded theorists recognize the value of familiarity with the literature at the outset of a grounded theory study, and so the proscription against the pre-project literature review is not as strong as it once was. However for this thesis we chose to follow the classical approach to this aspect of the methodology; the formal literature review was conducted after the completion of the grounded theory analysis. The description of the literature review and its results are found in the discussion section of the qualitative chapter of the thesis.

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Chapter 2

2 What shapes family physicians' patterns of care for community patients at end of life? A grounded theory study.

2.1 Introduction

2.1.1 Background

Developing systems of services to provide adequate care for rapidly growing numbers of people requiring end of life care in the community is one of the major challenges facing Canadian health care systems. Between 1994 and 2004, the proportion of total deaths in Canada which occurred outside of hospital (i.e. in the community) nearly doubled¹. Between 2010 and 2050, the total number of annual deaths in Canada is projected to increase by over 90%².

While specialty palliative medicine services exist in some cities, family physicians continue to be the primary (and in many communities only) resource for provision of medical care for community-dwelling patients approaching end of life. That family physicians maintain a central role in this care is consistent with patient preferences³⁻⁸, the values of many family physicians⁹⁻¹⁴, and the philosophy of family medicine as a discipline¹⁵⁻¹⁹. Family physician engagement is associated with reduced emergency room utilization and more home deaths for community patients at end of life²⁰⁻²⁵.

Family physician provision of care for community patients at end of life is not universal²⁶⁻²⁸. In the 2010 National Physician Survey, less than half of Canadian family physician respondents reported providing palliative care²⁸. However, because the survey did not define palliative care, it is likely that the term would have been interpreted variously by respondents, making it difficult to interpret the results. The term 'palliative care' is used in at least four distinct ways. It may refer to interventions given with non-curative intent (e.g. 'palliative' in contrast to 'curative' chemotherapy), care in the final phase of life (i.e. synonymous with end of life care), care which is provided with the intent of the principles of hospice palliative care (at any stage of a potentially life-limiting

illness, possibly including simultaneously with ‘curative intent’ interventions), or care provided by specialized providers whose focus is exclusively on this patient population. A binary survey question is likely to oversimplify a potentially complex phenomenon.

Demographic and health service utilization trends emphasize the need to understand how family physicians provide care to their community patients approaching end of life, but insights provided by much of the existing literature are limited by varying uses of the term ‘palliative care’, and a failure to account for the potential complexity of the phenomenon. That some family physicians report providing palliative care while others do not may reflect varying interpretations of the term, but it may also suggest the existence of more than one pattern of providing for the care of community patients approaching the end of life. What is required, therefore, is an exploratory approach to understanding the spectrum of family physicians’ care practices for community-dwelling patients approaching end of life.

2.1.2 Research questions

The aim of the current study was to explore the differences in family physicians’ patterns of care for community patients at end of life, and how these differences come to be for individual family physicians. The research questions were:

1. How do patterns of care for community patients at end of life differ among family physicians?
2. What shapes the development of these differences?

2.1.3 Selection of methodology

Each of the research questions could, in principle, be approached from either a quantitative or qualitative perspective. A quantitative approach could be used to measure the magnitude of differences in patterns of care, or the relative influence of various factors which affect the development of these differences. However, such quantitative approaches require an *a priori* understanding of what differences should be measured, and the extant literature does not provide this level of guidance. The need, therefore,

was for open-ended, exploratory research for which a qualitative approach was best suited. The topic of study is at a stage which requires qualitative theory-building, not quantitative hypothesis-testing.

The goal of the first research question (how do patterns of care differ?) was to understand the nature, not the degree, of differences in patterns of care. The goal of the second research question (what shapes these differences?) was to explore the principles and processes which lie behind the differences described in the first. Grounded theory, originally articulated by Glaser and Strauss²⁹, is a methodology designed to explicate the processes which underlie social phenomena. The methodology emphasizes that development of the researcher's ideas must, at every stage from sampling through to theory-building, be directly derived from (i.e. 'grounded' in) the study's data, which are most often collected in the form of in-depth interviews. Grounded theory methodology is sensitive to both the structure of relationships among relevant concepts articulated by research participants, and the process of how and why things change over time. Other qualitative techniques are designed to address other types of questions, such as the perceived meaning or lived experience of a particular incident or condition (phenomenology), or the values and behaviours of groups within society (ethnography). Of the major qualitative methodologies, grounded theory was best suited to the goals of the current project.

Grounded theory methodology has been used extensively and evolved substantially since Glaser and Strauss' original description. For the current study, the researchers adopted a constructivist grounded theory approach as described by Charmaz³⁰. The constructivist approach arose from a post-positivist paradigm and acknowledges that the knowledge generated by grounded theory research is not the 'discovery' of independent, objective truth. Rather, grounded theory researchers, together with their research participants, actively *construct* the findings through the research process. Grounded theory research results inevitably bear the fingerprints of the researchers.

In order to simultaneously make explicit and minimize this inevitable tendency for researchers to insert themselves into their research findings, constructivist grounded

theory emphasizes two practices: grounding and reflexivity. Grounding is the practice of returning continually to the data at every stage of the research process ('sticking close to the data'), to ensure that new ideas, insights, and potential connections exist in the data, and not merely in the researcher's mind. Reflexivity is the researcher's practice of constant reflection on, and writing about, how his or her own ideas, beliefs, assumptions and values may shape their perception and interpretation of the data. A statement of reflexivity appears in the discussion section of this paper.

2.2 Methods

2.2.1 Design

The present study employed the qualitative methodology of constructivist grounded theory³⁰, using in-depth interviews with practicing family physicians as the primary source.

2.2.2 Sampling and recruitment

The study was approved by Western University's Health Sciences Research Ethics Board (Appendix A). Potential participants were family physicians in active practice in southwestern Ontario, regardless of their patterns of care for community patients at end of life. Potential participants were identified through the personal networks of the investigators, recruited via letters and telephone calls and invited to participate in an in-depth interview at a location of the participant's choosing. Recruitment information included a full description of the study. All participants provided written, informed consent. Sampling was purposeful, initially by maximum variation (e.g. seeking family physicians at different career stages, rural vs. urban). Ongoing recruitment was guided by theoretical sampling, which is the grounded theory practice of focusing on the sample of ideas rather than people. The goal of theoretical sampling is to incorporate the full range of ideas relevant to the topic, not to generate a representative cross-section of participants. Sampling and data collection continued until the point of saturation at which new participants provided no new additional concepts relevant to the central theme.

2.2.3 Data collection

Data collection occurred between January and September 2011. In-depth interviews lasting between 45 and 65 minutes were conducted with each participant by the principal investigator. Each interview was conducted according to a semi-structured interview guide focused on two topics: a) a description of the participants' patterns of care for community patients at end of life and b) an exploration of how those particular patterns came to be. Participants were also asked to describe the general context of their current practice (location, duration, size, etc.). An example of the semi-structured interview guide is provided in Appendix B. Probes and clarifying questions were used frequently to confirm, extend, and deepen participants' responses. In accordance with the principles of theoretical sampling, the semi-structured interview guide and the contents of each interview evolved over the course of the project. Field notes, describing reflexivity and other contextual elements not captured on the audio recording, were made by the researcher immediately following each interview. Audiotapes were transcribed verbatim, checked for accuracy by the investigator who conducted the interview, and personal identifiers removed prior to analysis.

2.2.4 Analysis

Analysis of transcripts was supplemented by reference to field notes and proceeded in an iterative, step-wise fashion according to constant comparative methods^{29,30}, as emerging concepts were continually checked against the data of the interviews. NVivo software³¹ facilitated management of the analysis process. Initial, line-by-line coding of each transcript, intended to capture the full range of ideas expressed by each participant, was conducted independently by two investigators (the candidate and one thesis supervisor). Initial codes from each investigator were compared and merged prior to focused coding, in which initial codes were sifted and sorted to identify concepts which were common and relevant to the research questions. Axial coding, which concentrated on elaborating the relationships among categories, followed focused coding. Overlap of coding steps occurred naturally as analysis was undertaken concurrently with ongoing data collection.

Joint coding sessions, in which both investigators discussed emerging concepts, were interspersed with periods of individual analysis.

Memoing and diagramming were used by the principal investigator throughout the analysis process to summarize ideas, identify relationships between concepts, and describe the properties and dimensions of emerging themes. Rigour was strengthened by use of techniques such as questioning, seeking the negative case, and focusing on words denoting relationship or temporality. The involvement of two analysts of separate disciplinary perspectives (one family physician, one epidemiologist) at each stage of the analysis also fostered thorough analysis. Credibility of the findings was strengthened by confirming interpretations of the participants' statements with them through the course of the interview, keeping and frequently referring to raw data and written memos, and using the participants' language in the analysis where possible. Reflexivity was fostered throughout the analysis process by 'journaling' in the form of field notes and memos, and discussions with the co-investigator during joint coding sessions.

The findings of a well-conducted grounded theory study go beyond a summarization of the themes articulated by participants. Grounded theory requires not just categories, but concepts which are then put into a framework describing the relationships among them. The end product of a project utilizing grounded theory methodology is a grounded theory; a description of key concepts and the relationships among them. Good grounded theory findings are marked by credibility, originality, resonance and usefulness³⁰. The goal of the analysis process for the current study was thus to summarize the research findings in such a theory, each element of which was rigorously grounded in the data.

2.3 Findings

2.3.1 Sample

A total of nine family physicians (five male and four female) in southwestern Ontario were interviewed. Participants came from both rural and urban settings, reflected a variety of career stages, and included full-time academic family physicians, part-time clinical faculty, and community family physicians with no university appointment. All

participants described caring for community (i.e. non-institutionalized) patients at end of life.

2.3.2 Different patterns of care

Participants consistently described their care for community patients at end of life in terms of activities that they carried out for the purpose of providing this care. Patterns of care manifested as patterns of activities, and these patterns varied among participants. The differences among patterns of activities described by participants fell into three dimensions: location, timing and purpose (Figure 2-1). *Location* of activities referred to physicians' availability to meet patients' needs in different physical locations. *Timing* of activities referred to when during the week physicians made themselves available to perform care activities. *Purpose* of activities referred to the way in which family physicians intended their actions to address patients' needs. Each of these dimensions is characterized in detail below.

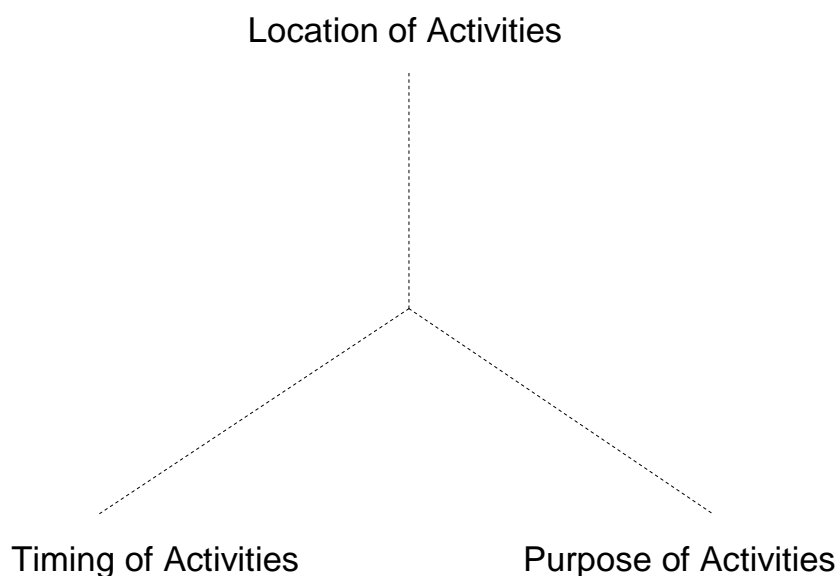


Figure 2-1: Dimensions of family physicians' patterns of activity for community patients at end of life.

The depiction of the three dimensions in this fashion does not imply that they are quantifiable or linear. It is intended to offer a visual illustration of how availability can span from lesser to greater for activities in each dimension.

Location of activities

Participants varied with respect to the range of physical locations where they engaged in activities to care for patients at end of life. All participants provided office-based palliative care for ambulatory patients, except for one participant who did not have any office-based practice. Only some participants cared for patients in hospital or long-term care settings. All participants in the sample provided house calls for community patients at end of life, but they also described a cohort of family physician colleagues who did not offer this option.

Timing of activities

Participants varied regarding the timing of their activities to meet the needs of community patients at end of life. Open access scheduling (same-day booking), designating weekly protected timeslots (e.g. Wednesday afternoons for house calls), or adding visits on to the end of the work day were some of the strategies used to create time to respond to needs of community patients at end of life. After-hours activities also varied widely, ranging from no after-hours physician availability to 24/7 personal on-call coverage.

Purpose of activities

All participants expressed a similar motivation to help their community patients at end of life. As succinctly expressed by one participant: “If I could be of any help I would do it.” However, physicians varied in their perceptions of the scope of their ability and/or responsibility to further this goal, and the means by which their actions could do so. Accordingly, participants attributed different *purposes* to their activities. Some emphasized direct care provision (e.g. undertaking traditional tasks traditionally in the nursing domain, such as mouth and eye care), while others perceived themselves primarily in a facilitative role. One participant described his role this way: “They [home care] put in a plan of action for everything, and I [the family physician] sign it.” Different participants identified a variety of specific goals for their own activities which were not necessarily shared by others (e.g. spiritual care, multidisciplinary team coordination,

facilitating completion of advance care planning documents). Thus while the overarching goal was the same for all (help my patients), participants described a spectrum of *purposes* for their individual activities.

In each of these three dimensions (timing, location, purpose), participants described their *normal extent of activities*. The normal extent of activities was the range of activities in each dimension which they would provide for most patients at end of life under usual circumstances: more or fewer locations of care, greater or lesser flexibility in timing of care, broader or narrower conceptions of their purpose. For each participant, the combination of the normal extent of their activities in each of these three dimensions together constituted their usual pattern of activities for community patients at end of life. In other words, each participant's unique pattern of activities for community patients at end of life could be characterized by their normal extent of activities in each of the three dimensions (Figure 2-2). A visual illustration of each participant's unique pattern of activities is presented in Appendix C.

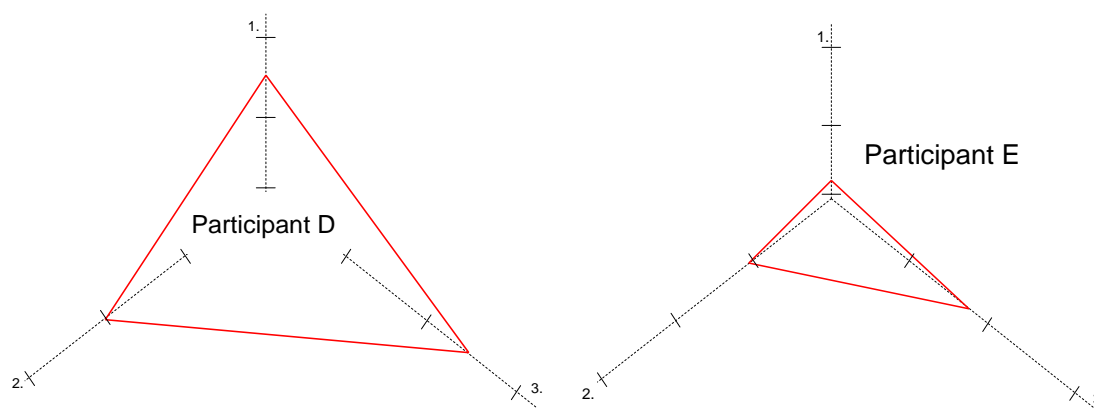


Figure 2-2: Family physicians' patterns of activities for community patients at end of life.

The normal extent of each family physician's activities in each of three dimensions (1. location, 2. timing, 3. purpose) is illustrated by the distance from the centre along the relevant axis. The dimensions are not quantifiable, but are presented for conceptual purposes only. Taken together, the normal extents of activities in each of the three dimensions represent a pattern of activities unique to each family physician. Patterns of activities for two participant family physicians are presented.

Participant D: Locations of activities: moderate-high range (office, house calls, hospital); Timing of activities: moderate-high availability (dedicated half-days, group 24/7 on-call coverage); Purposes of activities: moderate range of purposes (expressed goals and roles beyond basic symptom management)

Participant E: Locations of activities: low range (office, rare house calls); Timing of activities: low availability (rare 'fit-in' house calls, no on-call coverage); Purposes of activities: moderate range of purposes (expressed goals and roles beyond basic symptom management)

Participants did not describe links between the extents of their activities in different dimensions. Participants seemed to consider the extent of activities of each dimension independently. For example, participants who provided care in a greater number of locations did not necessarily describe more dedicated time, or a broader conception of the purposes of their activities.

2.3.3 How different patterns of care are shaped

Participants' insights into what shaped their individual patterns of activities are illustrated in Figure 2-3, and described in detail below. In reflecting upon what shaped their own patterns of activities for community patients at end of life, the overarching process participants described could be summarized as *making it fit*. Fit described both a *state of alignment* ("Doing palliative care is a real fit for me.") and a *process* by which space is made for these activities ("It fits in with everything else that happens."). Participants' patterns of activities in the care of community patients at end of life needed to fit, and were made to fit, each participant's unique circumstances.

Participants described three key aspects of this overarching process. First, they emphasized the *contexts* in which their activities must fit. Second, they described how *influences* arising from these contexts shaped their activities. Third, they articulated how they responded to these influences by *weighing the impact* of potential changes in their patterns of activities.

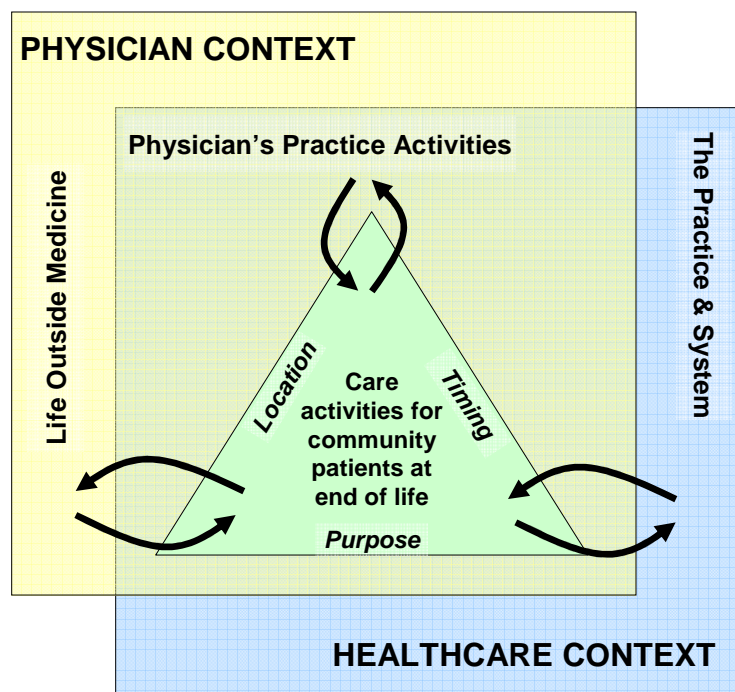


Figure 2-3: Making it fit.

Family physicians' patterns of activities for community patients at end of life are again symbolized by a triangle, in this case representing a hypothetical physician's normal extent of activities in each dimension (location, timing, purpose). This pattern of activities (triangle) exists in dynamic interaction with the physician and healthcare contexts (discussed further below – represented here by overlapping squares). Physician's practice activities are a subset of both these contexts. The physician's pattern of activities (triangle) is subject to *influences* (discussed further below – represented here by inward-pointing arrows) arising from the physician and healthcare contexts, but is also a product of choices made by physicians who *weigh the impact* of potential changes to their patterns of activities (outward-pointing arrows). The overarching theme of *making it fit* connotes both the interactive process of establishing patterns of activities, and the adequacy with which these patterns enable the physician to meet the multiple demands of the physician and healthcare contexts.

2.3.3.1 Contexts in which activities occur

For every participant, care for community patients at end of life was a subset of activities within their overall practice activities. Participants' practice activities were, in turn, a subset of the larger *physician context*, which included their lives outside of medicine, and the *healthcare context*, which included the practice as a whole and the healthcare system at large. The *physicians' practice activities* constituted the realm of overlap between the physician and healthcare contexts. Each of the three dimensions of patterns of activity for care for community patients at end of life (location, timing and purpose) must fit within these overlapping contexts.

Physician Context

Participants described their patterns of activities for community patients at end of life in relation to their unique *physician context*. The physician context included both practice activities and those in life outside of medicine. One participant illustrated the effect of other practice activities this way: “When I first started, and I literally had zero patients, I had all kinds of time and probably did more visits at home than I do now.” The contextual importance of life outside of medicine was demonstrated by another participant: “I wanted as much as I could to kind of limit my after-hours work and exposure... I hate to say the word ‘lifestyle’, but it’s true.”

Participants also identified a range of other personal conditions which formed part of the physician context, including:

- Personality
 - “It fits my personality.”
- Values & Beliefs
 - “I guess I would certainly put a part of my own faith into it too. I just sort of feel that I’m called to help.”
- Family circumstances
 - “My husband’s understanding... I’m lucky that way.”
- Personal experiences
 - “It’s a combination of my experience in life and as a physician... [A] few of my family members went through that.”

Patterns of activity to care for community patients at end of life thus had to fit both with the physicians’ other activities (both practice activities and in life outside of medicine), and their unique set of personal conditions (personality, values & beliefs, family circumstances, personal experiences).

Healthcare Context

In addition to the physician context, participants' patterns of activities for community patients at end of life were simultaneously part of the *healthcare context*. This context includes the primary care practice and the healthcare system as a whole. Physicians' practice activities, described above under the physician context, were equally part of the healthcare context and constituted the domain of overlap between the two contexts (Figure 2-3).

Participants described four key features of the healthcare context:

- Patients and their needs
 - “Even if everything could have been done over the phone, that actual face to face visit with the patient or the family means a lot... You can't substitute that.”
- Professional expectations
 - “I have to care for them. That's the whole reason why I'm a doctor. To me, it's just the spirit of family medicine.”
- Practice resources
 - “In the [Family Health Team] model that we have now...I can provide better service because I have a collaborative team...I have all the services I need.”
 - “So the way I instruct my front desk staff, they would know by now whom they would fit in right away, whom they would interrupt me during the visit to talk to, or whom they would take a message from for me to answer later.”
- System design & resources
 - “The community nurses have become my eyes and ears, so to speak, and that has really made it easier.”
 - “If it's an imminent death, then they [the home care system] are very good at responding...but when it's two or three months...those are the people that tend to, I think, get shafted a bit.”

Family physicians' patterns of activity for community patients at end of life had to fit, and were made to fit, with all these aspects of the healthcare context.

2.3.3.2 Influences governing the extent of activities

In order to understand the pattern of tides at the seaside, one must recognize the context (the lunar cycle), but also understand the nature of the influence (gravity) exerted by that context upon the phenomenon of interest (tidal patterns). In reflecting on what shaped their patterns of care for community patients at end of life, participant family physicians described *influences* which arose from the physician and healthcare contexts. Influences were how the physician and healthcare contexts affected the participants. Influences were the forces exerted by the contexts, and created pressures on participants to either extend or to restrict the scope of their activities for community patients at end of life. *Growth influences* favoured an increase in one or more dimensions of care activities (e.g. by expanding to new locations of care, providing additional hours of coverage, or addressing a broader range of needs) while *minimizing influences* had the opposite effect.

Growth Influences

The primary growth influence was the perceived needs of community patients at end of life and their families. When asked how he came to adopt his particular pattern of practice, one participant responded simply, "Because the need was there." Another participant identified how patient needs shaped her decision to provide in-hospital care: "In hospital situations, I really feel the palliative care patients need to be under a certain type of physician – [either] their family physician or a palliative care physician who visits often. Otherwise they do get lost in the shuffle."

Other growth influences arose from the healthcare context. One participant described how training in palliative care influenced his ability to provide this service to his patients: "I took some time to get additional [palliative care] training experience; therefore I'm a bit more comfortable with it." Practice structure can be another growth influence. One participant reflected on how her role as a preceptor for family medicine residents

influenced her patterns of activities: “It is important that these residents learn that experience [house calls for community patients at end of life] and have a role model.”

In addition to such growth influences from the healthcare context, further growth influences developed from the physician context. Participants identified personal beliefs (“My religious beliefs would be a driving force as well.”) and sense of reward (“I enjoy it. That why I do more of it.”) as important growth influences.

Minimizing Influences

Minimizing influences were those which favoured restriction of physicians’ activities in any of the three dimensions. These operated simultaneously with growth influences and were similarly derived from both the healthcare context and the physician context.

The healthcare context was the source of important minimizing influences identified by participants:

- Other practice demands
 - “I can’t think of a way to still be able to take care of people in their homes and do everything else as a rural family doc. Something’s got to give.”
- System issues
 - “I know that [specialist palliative care physician] program evolved because family docs weren’t doing it. So somebody had to do it and therefore they developed a system to do it, but now it’s excluding the [family] docs who do want to do it.”

Minimizing influences also arose from the physician context:

- Family obligations
 - “Sometimes I feel guilty when I take that time and I don’t come home to be with my family for supper.”
- Discomfort with palliative care
 - “Everyone has their weak points that they just are not comfortable with. And I think for a lot [of family doctors], palliative is not terribly comfortable.”

Direction of Influences Not Always Predictable

For some influences, the direction of effect (growth or minimizing) was subject to contextual factors unique to the individual physician, and thus not easily predictable. For example, changes introduced by the provincial Ministry of Health in remuneration for primary care activities (including community palliative care) were perceived by some participants as a growth influence, and by others as a minimizing influence. One participant described the impact of the remuneration changes this way: “Now we can bill mileage. You get gas money for doing house calls! It’s a huge incentive.” Another participant, in describing the same Ministry of Health agreement, came to the opposite conclusion: “Now with the primary care bonuses and the financial rewards it pays better, obviously, to be in the office.”

Fixed Limits

While most growth and minimizing influences were interpreted as relative or negotiable, some of these influences were non-negotiable and, in effect, set fixed limits on the extent of activity in one or more dimensions. These fixed limits arose from the healthcare context and governed a physician’s patterns of activities by defining either a minimum or maximum extent of activity.

One participant cited an example of a fixed minimum extent of activity imposed by her practice structure: “When I joined [this practice], there was no discussion of ‘Do you want to do this or not?’ It was ‘This is the way we do it.’ It was presumed if you’re joining us, you’re going to have a pattern of practice that fits our pattern of practice.” Another participant cited an example of system-level imposition of a fixed maximum extent of activity: “I actually had privileges at [city hospital] for palliative care and that vanished. I tried to admit someone and they had ‘lost my file’ - lost all knowledge of my existence. So that ended my inpatient palliative role.” In theory, it may have been possible for physicians to overcome some of these limits, but the changes required were either drastic (such as physically moving to a different practice) or almost completely outside of the physicians’ control (such as amending hospital policy).

2.3.3.3 Weighing the impact

In response to growth and minimizing influences, participants needed to establish choices about the extent of each dimension (location, timing, purpose) of their activities. Participants described a process of *weighing the impact* of their patterns of activities. In considering potential changes to their own patterns of activities, physicians accounted for the potential burdens and benefits for their community patients at end of life, themselves, and other stakeholders (such as the other patients in their practice).

Benefits & Burdens

From the participants' perspective, activities for community patients at end of life provided two main benefits: better care for the patients, and personal satisfaction for themselves as care providers.

- Better patient care
 - “It’s more seamless when you’re seeing them at home... So I think it is better care.”
- Personal satisfaction
 - “It’s a challenge, but it’s extremely rewarding.”

Participants also recognized the potential for these activities to create burdens for themselves, their patients, and others in the physician and healthcare contexts. All participants identified the cost in time as the major burden they experienced in order to care for community patients at end of life: “Sitting at the bedside for 45 minutes might not be the most efficient use of time... But I find that when I rush through things, I don’t feel as good about what I’ve done.” Participants also recognized that activities for community patients at end of life also had the potential to create burdens for those very patients themselves: “We try to make a point of seeing them regularly, but not impose too much on them.”

Participants also considered the burdens on other stakeholders in the physician and healthcare contexts. One participant articulated the burden of these activities on her family this way: “The driving is a big hassle and that drive equates with time, which is

time away from my family.” In the healthcare context, participants considered the impact on their staff and other patients: “If I had four simultaneously dying...that would be a big time commitment...for the office demands, because that’s booking time off my day sheets so I can make sure I go there.”

The Process of Weighing the Impact

Weighing the impact was the process by which influences (growth or minimizing) were perceived, interpreted, evaluated, and translated (or not) into changes in patterns of activities. Being closely tied to influences and contexts, the language used by the participants echoed that used to describe their contexts and influences, but here emphasized the physician’s agency in the process. As illustrated by the quotations below, *weighing the impact* was an active process of evaluating about the implications of their patterns of activities in their individual contexts. While *growth* and *minimizing influences* highlighted how the healthcare and physician contexts have an effect on the participants’ patterns of activity, *weighing the impact* denotes the other half of the equation: participants considered how their patterns of activity affected their healthcare and physician contexts.

Participants *weighed the impact* of activities for their patients:

- “One of the problems has come when we have patients from [a distance]...I like to look after my patients right till the end, but when it comes to what my wishes are versus the quality of care they’re going to get, the quality of care has to win over.”

Participants weighed the impact of their activities for themselves and their families:

- “If it really did impact my family life...I would give up that aspect of my practice [care of community patients at end of life].”
- “I don’t really want to take the time out of the office to suffer income to do a one-hour house call, so then it gets moved. Well, what do I give up? [Maybe] Saturday morning, the kids are still asleep? Or at night when I’m on call?”

This process of *weighing the impact* was highly individual and tuned to contextual considerations. This process was informal, but reflective. No participants described any type of structured analysis, but all articulated a rich and nuanced sense of the balance between the burdens and benefits within their own contexts. The outcome of the process of weighing the impact was not simply a decision regarding the extent of one or more dimensions of activities, but a sense of the *fit* between physicians' patterns of activities and their contexts.

2.3.3.4 Overarching process: making it fit

In summary, the overarching process which shaped participants' patterns of activities for community patients at end of life can be summarized as *making it fit*. Fit described both a state of alignment and a process by which patterns of activities are worked out in context. Each participant's unique pattern of activities could be understood as the combination of their normal extent of activities in each of three dimensions (location, timing and purpose of activities). These activities needed to fit in the contexts of which they were a part: the physician's practice activities as a subset of both the physician and healthcare contexts. From each of these contexts arose influences which affected, directly or indirectly, one or more dimensions of participants' patterns of activities. Fit was, in this sense, something to be found – a pattern that suited the contexts. But participants described not only *finding* a fit, but *making* a fit: they weighed the impact of different patterns of activities and made choices that accounted for the benefits and burdens to themselves, their patients and other stakeholders in the physician and healthcare contexts. The overarching theme of *making it fit* thus connotes both the interactive process of establishing patterns of activities, and the adequacy with which these patterns enable the physician to meet the multiple demands of the physician and healthcare contexts.

2.4 Discussion

2.4.1 Statement of Reflexivity

As discussed earlier, the research findings from grounded theory methodology are, in fact, ‘research constructions’ actively co-created by the participants and researchers. For this reason, the researcher’s statement of reflexivity provides important context for the interpretation of the findings.

As a family physician with a focused practice in palliative care (including community palliative care), I did not approach this topic as a disinterested outsider. I hold beliefs about the responsibilities of a family physician and the role that they should play in the care of their community patients at end of life: that they should actively participate in this care, including making house calls when necessary and provision for after-hours access to physician coverage. Although I consciously strove to maintain a neutral stance throughout the interview and data analysis processes, it is possible that my point of view affected, consciously or unconsciously, both what participants chose to say and how I interpreted their statements. Similarly, it may be that my pre-existing relationships with some of the research participants affected the manner in which I pursued (or failed to pursue) potentially challenging questions, or the manner in which they answered such questions.

As an interviewer who shared a professional background with my participants, I may have more readily grasped the meaning and nuances of some of the participants’ statements. However, I may also have been more likely to make assumptions, possibly incorrectly, about these meanings. Similarly, my participants may have made assumptions about shared knowledge or perspectives, and thus not considered it necessary to articulate some relevant ideas.

The second investigator, who conducted no interviews but participated in the analysis, is an epidemiologist without direct experience in community based end of life care. Her alternative perspective may have helped to mitigate the biases I brought to the analysis process.

2.4.2 Key findings

The goals of the current study were to identify how family physicians differ in their patterns of care for community patients at end of life, and describe what shapes the development of these differences. All participants provided care to community patients at end of life, and none considered this domain of care to be optional to their practices. However, the participants varied substantially in their availability to provide care activities in different locations, and at different times. Participants also held a diversity of views on the specific purposes of their activities.

This mixture of care activities among participants implies that there is no clear ‘standard of care’ for family physicians with respect to the provision of care for community patients at end of life. While all participants held some general goals in common, such as ‘help my patients’ or ‘support the family’, the differences arose in the details: exactly where, when, and how the participants sought to achieve these ends. There is no well-defined list of responsibilities and activities which constitutes a standard expectation of family physicians in this domain. In the absence of clear and specific expectations, participants as a group perceived themselves to possess a great deal of discretion regarding their activities for community patients at end of life. Diversity is thus the norm.

The absence of specific expectations is an enabling condition for this diversity, but it is not the cause. The roots of diversity in family physicians patterns of care for community patients at end of life are to be found in the contexts in which family physicians undertake these activities. Participants described two key contexts, the physician context and the healthcare context, which overlap in the physician’s practice activities (of which activities to care for community patients at end of life are a subset). Each physician’s unique contexts lead to distinct patterns of activities for community patients at end of life through two related dynamics: *influences* (where elements within the contexts induce physicians to either extend or restrict their activities for community patients at end of life) and *weighing the impact* (where family physicians balance the anticipated benefits and burdens of potential changes in their patterns of activities). The net process,

characterized above as *making it fit*, is one with both pro-active and re-active features. Family physicians choose patterns of activities on the basis of both principle (what is best for my community patients at end of life), and feasibility (what is possible in light of the requirements of other stakeholders in my contexts).

2.4.3 Relationship of findings to the published literature

While a general knowledge of the relevant literature is necessary at the outset of a project using grounded theory methodology, the traditional convention among grounded theorists is to delay the full literature review until after the analysis²⁹. The rationale for this practice is twofold. First, it is intended to minimize the risk of interpreting data through pre-formed lenses imported into the analysis. Second, because the concepts which arise from the analysis cannot necessarily be predicted, it is difficult to know in advance which bodies of literature will be most salient to the findings.

In accordance with this convention, the full literature review for the current project was conducted after completion of the analysis. The findings of the study suggested connections to three related, but separate, bodies of knowledge. The first literature of interest was that addressing *end of life care by family physicians*, with particular attention to issues of coordination with other care providers. Second, this study's finding that family physicians varied in the timing, location and purposes of their activities raised issues addressed in literature regarding *comprehensiveness of family physician care*. Third, the participants' descriptions of the importance of the physician context suggested that related insights could be gleaned from literature addressing *family physician work-life balance*. Literature reviews for each of these three topic areas were conducted; the search strategies are summarized in Appendix D. This section reviews the most pertinent publications in each topic area and their relevance to the current study's findings.

2.4.3.1 End of life care by family physicians and their coordination with other care providers

What the Literature Shows

Family physicians vary greatly in the number of deaths in their practice each year³²⁻³⁴. It is perhaps not surprising that some FPs describe challenges with issues ranging from identifying patients at risk of dying^{35,36}, to having conversations about end of life choices³⁷⁻³⁹, symptom management⁴⁰⁻⁴⁵, psychosocial care⁴⁶, certification of death⁴⁷ and care for the bereaved⁴⁸. These challenges may be due to knowledge deficits, lack of experience or structural, system-level obstacles^{49,50}.

Family physicians routinely collaborate with other providers (nurses, physicians and other allied health care providers) in the care of community patients at end of life⁵¹⁻⁵⁶. Family physicians' likelihood of referring to collaborating professionals for their palliative care patients is influenced by multifaceted judgments about the timeliness, effectiveness, and collegiality of potential consultants⁵⁷. Coordination of primary care with specialty care is not well-studied, but coordination can have some positive impact on health outcomes⁷. Impact of a coordinating service based outside of primary care for terminally ill cancer patients was limited⁵⁸.

Family physicians differ on whether they should hold responsibility for primary coordination care for these patients^{55,59,60}. Family physicians themselves are sometimes unclear on who holds overall responsibility with multiple practitioners involved⁶¹. In one study, patients and their caregivers described wanting their family physicians to play a coordinating role, but felt they were too often required to undertake this task themselves⁸. Case conferences to improve communication hold potential, but evidence for impact on patient outcomes is scant⁶²⁻⁶⁴.

Role negotiation is a recognized challenge. Family physicians value the input of collaborative specialty services^{62,65,66} and access to specialist palliative medicine consultations is described by family physicians as an important supportive factor to primary palliative care practice^{13,67,68}. However, the relationship between family physicians and specialty palliative medicine services has raised persistent concerns about

appropriate role differentiation^{10,49,69-73}. The involvement of specialist care is a recognized risk for increasing perception or reality of patient abandonment⁷⁴ and ‘de-skilling’ of family physicians in end of life care⁷⁵.

Previous research on family physician provision of palliative care has typically started with the assumption that some family physicians provide palliative care and others do not. These studies usually use surveys to characterize physicians who do, and who do not provide palliative care. The surveys have not defined palliative care, and have considered it in only a binary fashion (offered, not offered), leaving respondents to make their own judgments regarding what definition to use, and what threshold of service constitutes provision of care^{26-28,76,77}. The result is a potentially misleading oversimplification of the range of practice patterns adopted by family physicians in caring for patients with palliative needs.

What This Study Adds

The current study was distinct from any of the reviewed literature in that it began with the premise that all family physicians care for community-dwelling patients who are approaching end of life, whether or not these patients are identified as ‘palliative care’ patients. Instead of ‘Do you provide palliative care?’, the question asked in this study was: ‘How do you address the needs of your community patients at end of life?’ This project was the first grounded theory study to explore this topic. While participants echoed many ideas previously documented in the literature, this study adds three important insights.

The first is to propose a three-dimensional taxonomy for understanding differences among family physicians in their practice patterns for caring for community patients at end of life. Issues of *timing* and *location* of activities had been described previously, though not linked in a manner which would enable conclusions about the intersection of these two dimensions (e.g. after hours availability for house calls). Aubin’s 2001 survey of family physicians in the Quebec City region asked about ‘palliative care’ in office, home and institutional settings, and whether provision was made for after hours coverage, but it did not address after hours home visits or how family physicians responded to

urgent needs from home-bound patients during business hours²⁶. In a study of Australian family physicians' provision of palliative care, some respondents identified 'home visits' and 'live too far away for after hours care' as barriers to providing palliative care, but the survey did not address whether or not the respondents actually provided these services²⁷. Three Canadian National Physician Surveys^{28,76,77} asked about palliative care, house calls, and after hours coverage in separate sections of the survey, and one can only assume that respondents' house call and after hours services (or lack thereof) for the practice as a whole applied equally to patients approaching end of life. Differences among family physicians in the *purpose* of activities for community patients at end of life had not been identified previously, though a few studies which describe differing preferences regarding the family physician's role in coordinating care hint at this dimension^{55,59,60}. This thesis is the first study to explore all three of these dimensions simultaneously.

Second, the identification of variations among family physicians in the purpose of their activities sheds light on some of the findings of prior research described above. The challenges of role negotiation among collaborating care providers is a recurring theme in this literature^{51,55,61,69,71,72}. This study suggests that one contributing element to this difficulty may be unrecognized differences among care providers in their perceptions of the purpose of the family physician's care activities. If family physicians vary in their ideas about the purposes of their care activities, and if these differences remain tacit, it is not surprising that misunderstandings will arise between family physicians and other collaborating care providers. Differing assumptions regarding purposes of activities may be at the core of many of the challenges in coordinating care at end of life care.

Third, the current study adds to our understanding of how contextual influences shape family physicians' patterns of practice for community patients at end of life. Several surveys of family physicians have identified contextual barriers to provision of palliative care such as time required, lack of support, and poor information flow^{27,50,52}, but the surveys do not examine the real-world implications of these barriers. Burge's 2001 qualitative study of Nova Scotia family physicians' provision of palliative care identified some contextual themes (resources, family support, time and money), but did not explore

how these contexts affected physicians' activities¹³. In terms of system organization, one trial of a palliative care service intervention in London, England demonstrated no impact on the frequency of patient encounters with their family physician⁵⁸, while another trial of a different intervention in Cambridge, England showed a reduction in after hours family physician house calls⁷⁸. At the macro level, in a study of family physician care of end of life cancer patients in Nova Scotia between 1992 and 1998, Burge found that there was no change in the rate of FP office visits or house calls despite an increase in the proportion of home deaths (from 20% to 30%) among the cancer population over that same time period²¹.

The contribution of this study is that participants described *how* contextual elements, many similar to those previously identified in the literature, shape their patterns of activities. Family physician participants in this study did not consider their provision of care to community patients at end of life in isolation from other elements of their practice. They recognized that their choices regarding patterns of care for community patients at end of life have substantial implications for other aspects of their practices. None of the literature reviewed explored these implications in either direction: neither the influence of other practice demands on patterns of care for community patients at end of life, or the impact of care activities for end of life patients on other aspects of the primary care practice. The findings of this study suggest that without attention to specific contextual detail, general pronouncements regarding the influences on family physician patterns of care for community patients at end of life will be of limited practical applicability.

2.4.3.2 Comprehensiveness of care in family medicine

What the Literature Shows

Comprehensiveness of care is much-discussed in family medicine, and is seen as a core value of family medicine⁷⁹⁻⁸¹ and a key feature of effective primary care⁸²⁻⁸⁴. Despite widespread endorsement of the importance of comprehensiveness in family medicine, there is no universally-accepted definition for comprehensiveness of care or standard for measuring it. Two distinct concepts of comprehensiveness are evident in the literature.

Comprehensiveness may be measured by the range of clinical services provided in the primary practice location (screening, prevention, treatment, counseling, etc.)⁸⁵⁻⁸⁷, or by the diversity of geographic locations at which clinical services are provided (office, house calls, hospital, emergency, long-term care, etc.)^{88,89}. Many characterizations of comprehensiveness of care included elements of both range of clinical services and diversity of geographical locations^{83,90}. House calls and provision of palliative or end of life care are frequently identified as part of ‘comprehensive’ family practice^{80,84,85,91-93}. By any definition, comprehensiveness among Canadian family physicians is perceived to be declining^{84,88,91}.

What This Study Adds

In the literature, comprehensiveness is conceived as a physician attribute. While the current study was not about comprehensiveness *per se*, family physician participants generally assessed the range of services available at the level of the patient, not the physician. Their concern was not whether they themselves offered all services relevant to community end of life care, but rather whether their patient had adequate access to necessary services. In the language of this study, family physician participants considered influences arising from the healthcare context (including availability of other services) which they weighed in making decisions about their patterns of activities. Continuity of care was valued as important for patients, families, and themselves as physicians, but participants acknowledged that there were other providers in the system who could play a role. Family physician participants recognized the need to make judgments about how to best invest their time, and for some this meant giving up some elements of ‘comprehensiveness’ if patient needs could be well-met by someone else in the system.

From this perspective, it is perhaps to be expected that enhancement of clinical services outside of primary care (for community patients at end of life, or other patient groups) could result in declining out-of-office ‘comprehensiveness’, as family physicians re-allocate their resources (time) to invest in areas which are lacking for other segments of their practice population. Perhaps measures of comprehensiveness should be less

concerned with whether individual family physicians provide all these types of care at all locations, but focus instead on whether family physicians adequately coordinate access to all the necessary types of care in the range of locations.

2.4.3.3 Family physicians' work-life balance

What the Literature Shows

While a healthy work-life balance is acknowledged as a key to sustainable practice⁹⁴⁻⁹⁷, failing to achieve this balance is a common problem among physicians, including family physicians in Canada^{95,98-100}. Considerations of work-life balance shape practice patterns on multiple levels including influences on choice of discipline¹⁰¹⁻¹⁰³ and location of practice^{101,104}. Unfortunately, not all stakeholders are supportive of policy innovations aimed to addressing work-life balance problems¹⁰⁵.

What This Study Adds

Physician work-life balance was an important theme for family physician participants in this study, characterized in the analysis as *making it fit* within the physician context.

Previous studies of family physician work-life balance have focused on discrete, categorical choices: of discipline, of city, of whether or not to practice intrapartum obstetrics. The unique contribution of the current study is that it illustrates how perceptions of work-life balance can also affect smaller choices that are a matter of degree, such as how much flexibility is built into the clinic schedule, or how readily available to make oneself for after-hours house calls. The study participants recognized that balance is not simply a matter of managing the total number of hours of work, but of prioritizing among the competing demands within the practice¹⁰⁶.

2.4.4 Implications of the findings

2.4.4.1 We must recognize, and account for, diversity in patterns of care.

As professionals, family physicians are granted wide latitude in how to organize their practice activities. This flexibility is important to enable each family physician to fully utilize his or her individual strengths, and to adapt practice patterns to meet the needs of his or her unique practice population. In the care of community patients at end of life, one size does not fit all.

If healthcare systems fail to adequately account for this diversity of family physician practice patterns, the result is likely to be gaps (if it is assumed that all family physicians provide palliative care services at home 24/7) or redundancies (if it is assumed that they won't). If community care delivery systems are to be flexible enough to collaborate optimally across the spectrum of FP practice patterns, then a common language for discussing divisions of responsibility is necessary. Assumptions regarding availability and purposes of activities are dangerous. The taxonomy identified in this study – location, timing, and purpose of activities – provides a potential framework for such discussions. Refinement of the nomenclature and establishing mechanisms to facilitate discussions will be necessary.

Mismatches between care providers regarding the purposes of FP activities may be at the root of many of the recognized challenges in coordinating care for this patient population. What is perceived as helpful support by one family physician may easily be interpreted as meddling intrusion by another. Further exploration of the purposes of activities dimension may be particularly valuable.

2.4.4.2 Patterns of care cannot be divorced from their contexts.

Family physicians' patterns of care for community patients at end of life are intimately intertwined with numerous elements of their personal context, the primary care practice, and the broader healthcare system. A reductionist approach to understanding patterns of

care for community patients at end of life, in which this one element of practice is singled out for consideration, will have limited ability to affect meaningful change.

For individual family physicians, greater availability along any of the three axes (timing, location, purposes) will come at a cost: either personal, financial, or to the potential detriment of other stakeholders in their healthcare context. Any system innovations intended to enhance family physician availability to provide end of life care to community patients must be carefully considered to fit the contextual realities of the target physicians. Unintended consequences are to be expected, and evaluation designs must look for them.

2.4.5 Limitations

This study had several limitations. The number of participants was small and all were drawn from one geographic region. While data collection proceeded until saturation of the central theme (making it fit), further sampling may have yielded additional insights within sub-themes. Second, while surveys show that a substantial minority of family physicians do not report providing palliative care, none of the participants in this study described this practice pattern. Attempts were made to interview some such physicians, but none consented to participating in the study. Nevertheless, the diversity of patterns among study participants (Appendix C) suggests applicability of the findings across the spectrum of family physician practice patterns. Third, the analysis is shaped, and perhaps in some ways limited, by my perspective as a family physician with a focused practice in palliative care, including community palliative care. The implications of this have been discussed in the statement of reflexivity above.

2.4.6 Call for further research

Further research is needed to confirm, extend and apply the findings of the current exploratory study. Undertaking a similar study with family physicians elsewhere in Canada could reinforce concepts identified in this study, and yield additional insights. The ‘purpose of activities’ dimension was not fully developed by this study, and additional qualitative research to elaborate our understanding of how family physicians

conceive of the purposes of the activities they undertake when caring for community patients at end of life would be a valuable contribution. In order to foster improved collaboration, an application of the findings of this study might use the taxonomy of timing, location and purpose of activities to facilitate a structured communication between family physicians and other healthcare providers involved in the care of community patients at end of life.

2.4.7 Conclusions

Family physicians vary in the timing, location and purpose of activities by which they seek to care for community patients approaching end of life. These variations are shaped by a process of making it fit, in which family physicians weigh the implications of practice pattern choices in light of their unique contexts. Systems of care for community patients at end of life need to take this variation into account, and develop mechanisms for negotiating roles accordingly.

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Chapter 3

3 Family physicians' availability to care for community patients at end of life: A secondary analysis of family physician survey data

3.1 Introduction

3.1.1 Background

The need for community-based medical care for patients approaching end of life is growing rapidly. Two trends are primarily responsible for driving this accelerating demand for community palliative care. The first is our aging population. In 2010, there were approximately 247,200 deaths in Canada. By 2050, this number is projected to rise by more than 91% to approximately 473,300 per year¹. Equally important is the trend away from hospital-based care at end of life. Between 1994 and 2004 the proportion of non-hospital deaths in Canada rose dramatically from 22.3% to 39.4% of all deaths². The net effect of these trends is an exponential increase in the number of community-dwelling patients who will spend their final days at home.

While specialty palliative medicine services play a role in many communities, family physicians will continue to be the primary or exclusive providers of medical services for most community patients at end of life. The central role of family physicians in provision of medical care for community patients at end of life has been clearly shown³ and reflects both widely-held patient preferences⁴⁻⁹, the 'cradle to grave' philosophy of family medicine as a discipline¹⁰⁻¹⁴, and the values of many individual family physicians¹⁵⁻²⁰.

However, it cannot be assumed that having a family physician guarantees adequate access to palliative care. For patients approaching end of life, visits to the family physician's office become impossible. Urgent medical needs outside of usual office hours are likely to arise. Not all family physicians feel comfortable in providing all aspects of palliative care²¹⁻²⁸. Family physicians' willingness to provide palliative care, make house calls, and see patients after hours when necessary are all important elements of access to medical care for community patients at end of life^{29,30}. The patients of

family physicians who do not provide palliative care, or who provide it in the office but do not do house calls, or who make house calls but have no provision for after-hours coverage, have only partial access to necessary medical care.

Unfortunately, no published study directly addresses the relationship among these three critical elements of access to family physician care for community patients at end of life. There are studies on family physician provision of palliative care that address questions of house calls but not after-hours coverage³¹⁻³⁶. Another body of literature (mostly from the United Kingdom) focuses on after-hours provision of care for community palliative care patients by on-call physicians, but these studies do not explore the activities of the patients' primary family physicians³⁷⁻⁴². There is need, therefore, for research which explores simultaneously all three elements of family physicians' availability to care for community patients at end of life.

3.1.2 Research question

Using secondary analysis of data collected from a survey of all family physicians in London, Ontario and adjacent rural counties, the aim of the present study was to explore family physicians' self-reported provision of palliative care, house calls, and availability to see patients after hours. Together, these three elements constituted each physician's *potential availability* to provide care for community patients at end of life. The specific research questions were:

1. To what extent do family physician respondents to a 2004 regional physician survey report providing access to medical services related to the care of community patients at end of life (palliative care, house calls, and after hours visits)?
2. What factors are associated with these family physicians' potential availability to care for community patients at end of life?

3.2 Methods

3.2.1 Study design and sample

This study was a secondary analysis of data collected in a 2004 cross-sectional survey of all family physicians in London, Ontario and adjacent rural counties⁴³. This 85-item postal survey was approved by the Western University Health Sciences Research Ethics Board (Appendix E), and was administered using modified Dillman methods. Response rate to the survey was 731/1044 (70.0%). The final sample for this study consisted of all family physicians who described themselves as providing ‘comprehensive family medicine’ and who had complete responses on the survey questions used in the analysis for this study (n = 482). All analyses were conducted in SPSS version 20.0⁴⁴.

3.2.2 Variables

From family physicians’ responses to 18 of the 85 questions on the survey, 1 dependent variable was created and 14 independent variables were identified for the current study. Detailed variable definitions are provided in Appendix F. The dependent variable was potential availability to care for community patients at end of life (potential availability), and was comprised of three elements: provision of palliative care, provision of house calls, and availability to see non-hospitalized patients after hours as required. Family physicians with positive responses to all three elements were considered ‘high availability’, those with positive responses to any one or two of the elements were considered ‘moderate availability’ and those with negative responses to all three elements were considered ‘low availability’.

The 14 independent variables were in two categories: 7 family physician characteristics (age, gender, years in practice, complete family medicine residency, additional palliative care training, international medical graduate, attitude toward palliative care at home) and 7 practice characteristics (rural/urban, solo/group, remuneration model, teaching practice, number of patients per week, ≥ 1 free weekday clinical session, ≥ 1 after hours clinical session).

3.2.3 Analysis

Nonparametric techniques were used for analyses because the dependent variable could not be assumed to have either normal distribution or equal variances. The association between the dependent variable (potential availability) and each of the 14 independent variables was tested separately using 3x2 chi-square for nominal independent variables and independent sample Kruskal-Wallis H for continuous independent variables. Multivariable analysis, including all independent variables significantly associated with potential availability in the bivariable analysis, was then performed using multinomial logit with moderate availability as the reference category^{45,46}.

3.2.4 Power calculation and missing values analysis

Power calculations, performed with G*Power version 3⁴⁷, demonstrated that the sample with complete data on all variables had adequate power to detect a moderate effect size for each independent variable (see Appendix G). For simplicity of analysis and clarity of presentation of results, respondents with incomplete data were thus excluded from the final sample. Missing values analysis suggested that inclusion of respondents with incomplete data would have had minimal impact on study results (Appendix H).

3.3 Results

3.3.1 Study sample

Figure 3-1 summarizes identification of the sample for this study. Of 731 total family physician respondents to the survey, 583 described themselves as practicing ‘comprehensive family medicine’. Of these comprehensive family physicians, 10 lacked a response on at least one survey item needed to construct the dependent variable, and an additional 95 lacked at least one independent variable data element (see Appendix H). The final sample thus consisted of 482 family physicians with complete data.

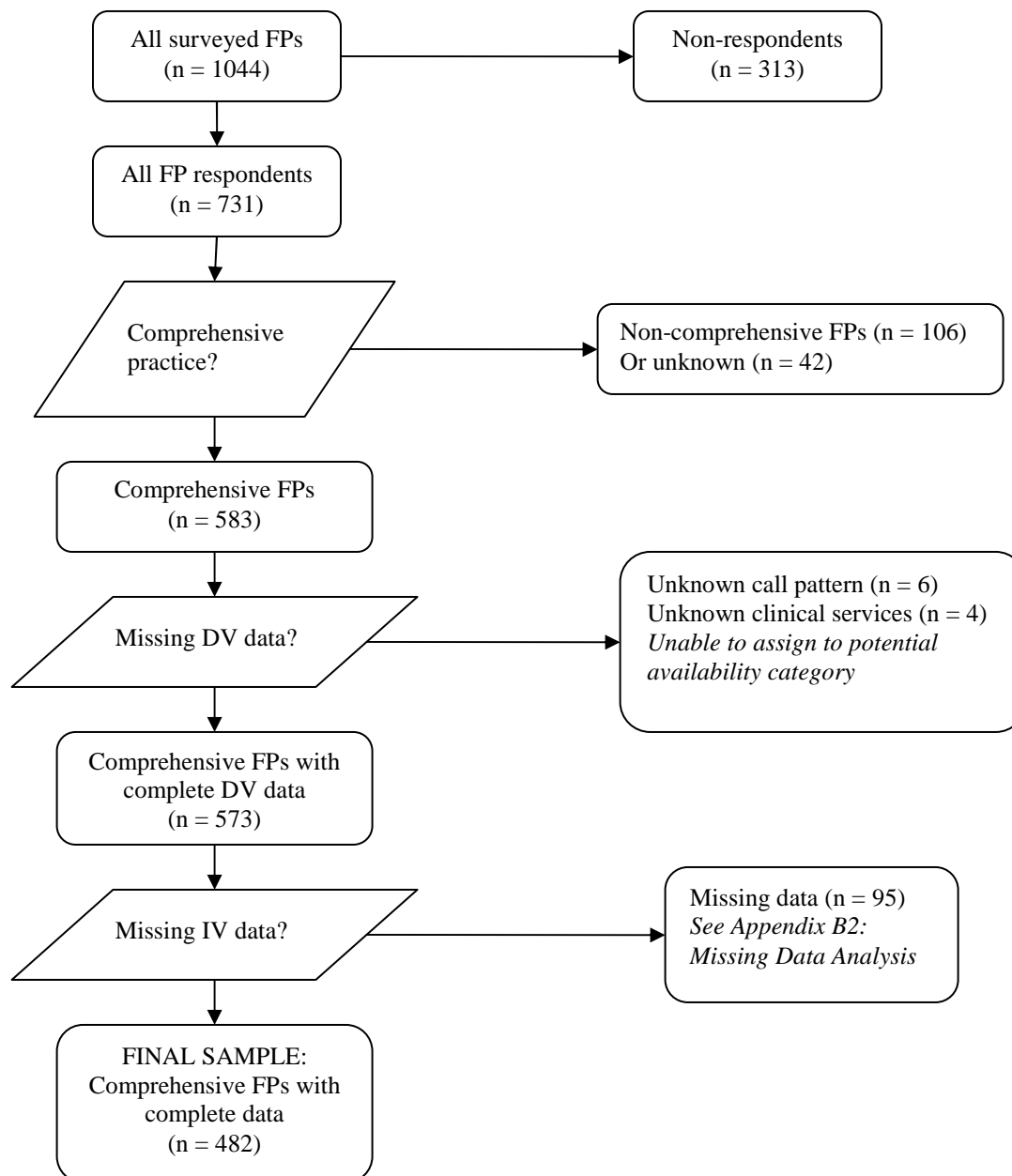


Figure 3-2: Identification of the study sample.

FP – family physician; DV – dependent variable; IV – independent variable

3.3.2 Potential availability

Family physicians were grouped into high, moderate, and low potential availability categories based on provision of palliative care, house calls, and availability to see non-hospitalized patients after hours as shown in Figure 3-2. Palliative care, house calls, and

availability after hours were provided by, respectively, 75.7%, 70.3% and 29.5% of family physicians in the sample. When combined into the dependent variable potential availability to care for community patients at end of life, 22.2% of the family physicians were in the high availability category, 64.3% in the moderate availability category, and 13.5% in the low availability category (Figure 3-2). Table 3-1 shows the characteristics of each of these potential availability category groups.

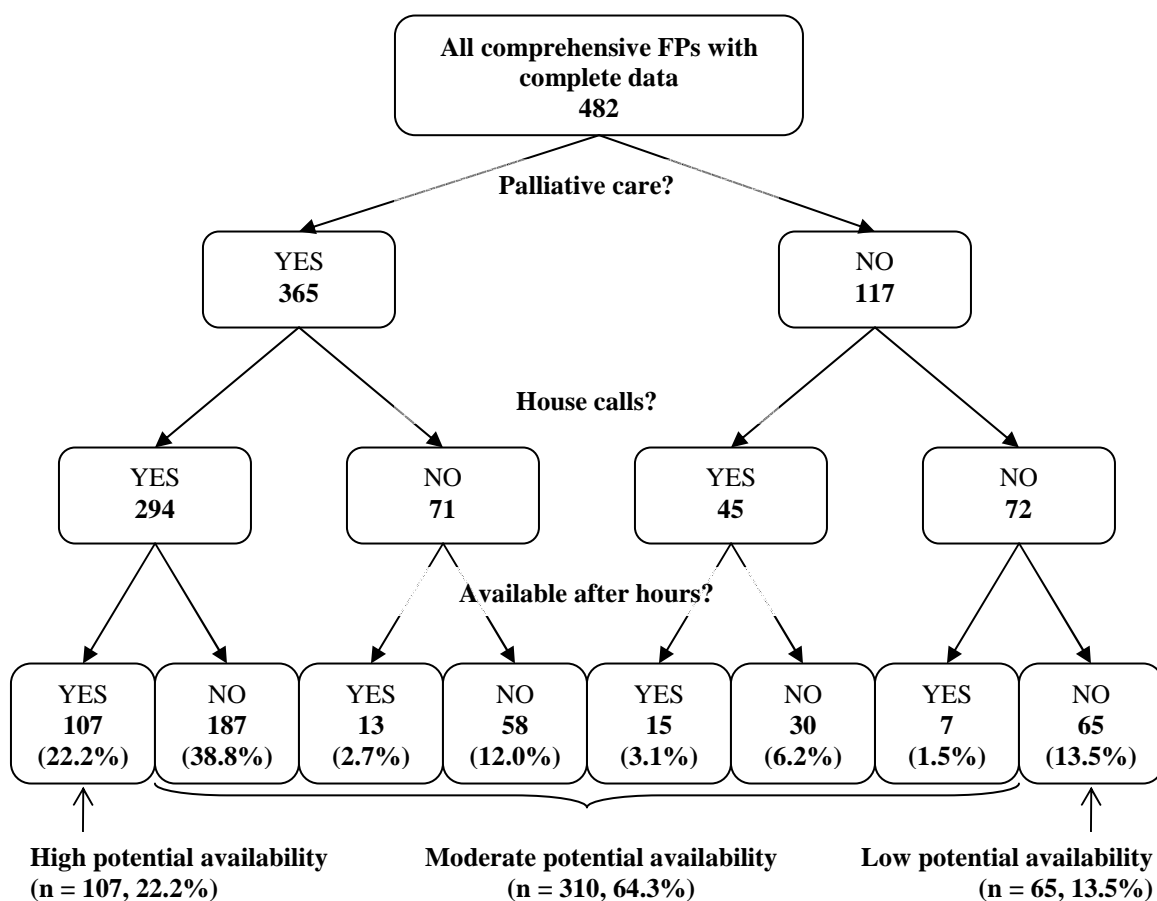


Figure 3-2: Categories of potential availability to care for community patients at end of life.

Of all comprehensive FPs with complete data (n=482): Palliative care YES 365 (75.7%), NO 117 (24.3%); House calls YES 339 (70.3%) NO 143 (29.7%); Available after hours YES 142 (29.5%), NO 340 (70.5%).

Independent Variable	All Comprehensive FPs (n=482)	Potential Availability Category		
		High (n= 107)	Moderate (n = 310)	Low (n = 65)
<i>Family Physician Characteristics</i>				
Age	48.4 (10.3)	49.2 (8.6)	49.2 (10.5)	43.6 (10.3)
Gender (% male)	71.6	76.6	75.5	44.6
Years in practice	21.9 (10.8)	22.7 (9.2)	22.6 (11.1)	16.8 (10.5)
Family medicine residency (%)	56.6	57.0	54.5	66.2
Additional palliative care training (%)	11.2	18.7	10.0	4.6
International medical graduate (%)	15.4	15.0	13.5	24.6
Attitude toward palliative care at home	3.0 (0.80)	3.4 (0.64)	3.0 (0.75)	2.3 (0.78)
<i>Practice Characteristics</i>				
Rural vs. urban (% rural)	52.1	50.5	59.0	21.5
Group vs. solo practice (% group)	55.8	61.7	54.2	53.8
AFP vs. FFS remuneration (% AFP)	44.2% AFP	61.7	44.5	13.8
Teaching practice (%)	32.6	41.1	32.9	16.9
Number of patients per week (median)	150 <i>range <25 to >250</i>	150 <i>range 25 to >250</i>	150 <i>range <25 to >250</i>	125 <i>range <25 to >250</i>
≥1 free weekday clinical session (%)	73.0	73.8	75.2	61.5
≥1 after hours clinical session (%)	45.2	61.7	40.3	41.5

Table 3-1: Characteristics of the sample.

For continuous variables (age, years in practice, attitude toward FP involvement in palliative care at home), numbers presented are the group mean, with the standard deviations in parentheses. For number of patients per week, the numbers presented are the group median.

For attitude toward FP involvement in palliative care at home, the survey item was a 4-point likert-type item with higher numbers representing stronger agreement.

FFS – fee for service; AFP – alternate funding plan

The associations between the independent variables (7 family physician characteristics and 7 practice characteristics) and potential availability are summarized in Table 3-2. Age, gender, years in practice, additional training in palliative care, attitude toward palliative care at home, rural practice location, alternate funding remuneration, being a teaching practice, and having at least one scheduled after-hours clinical session were all significantly associated with potential availability. Completion of a family medicine residency, obtaining a medical degree from outside of North America (international medical graduate), group practice, number of patients seen per week, and having at least one free weekday clinical session were not significantly associated with potential availability.

Independent Variable	Variable Type	Statistical Test	p-Value
<i>Family Physician Characteristics</i>			
Age	Continuous	independent samples Kruskal-Wallis	0.000*
Gender	Nominal	3x2 chi square	0.000*
Years in practice	Continuous	independent samples Kruskal-Wallis	0.000*
Completed family medicine residency	Nominal	3x2 chi square	0.226
Additional palliative care training	Nominal	3x2 chi square	0.009*
International medical graduate	Nominal	3x2 chi square	0.079
Attitude toward palliative care at home	Continuous	independent samples Kruskal-Wallis	0.000*
<i>Practice Characteristics</i>			
Rural vs. urban	Nominal	3x2 chi square	0.000*
Group vs. solo	Nominal	3x2 chi square	0.382
AFP vs. FFS remuneration	Nominal	3x2 chi square	0.000*
Teaching practice (y/n)	Nominal	3x2 chi square	0.004*
Number of patients per week	Continuous	independent samples Kruskal-Wallis	0.069
≥1 free weekday clinical session	Nominal	3x2 chi square	0.078
≥1 after hours clinical session	Nominal	3x2 chi square	0.001*

*statistically significant at $p < 0.05$.

Table 3-2: Bivariable analysis results.

The results of the multivariable analysis, which included all independent variables found to be significantly associated with potential availability, are summarized in Table 3-3 and Table 3-4. With moderate availability as the reference category, family physicians in the low availability category were more likely to be female, urban, and funded exclusively by fee-for-service, and less likely to be in teaching practices, or strongly endorse FP participation in home palliative care (Table 3-3). The group of high potential availability family physicians differed from the moderate availability group in location (more urban), remuneration (more alternate funding), likelihood of having at least one after hours clinical session per week (greater) and attitude toward FP participation in palliative care at home (more strongly endorsed) (Table 3-4).

Independent Variable	Odds Ratio	p-Value	Interpretation
<i>Family Physician Characteristics</i>			
Age	0.967	0.056	
Male gender	0.347	0.004*	Low potential availability FPs less likely to be male
Additional palliative care training	0.427	0.223	
Attitude toward palliative care at home	0.368	0.000*	Low potential availability FPs less strongly endorse FP participation in home palliative care
<i>Practice Characteristics</i>			
Rural practice location	0.323	0.003*	Low potential availability FPs less likely to be rural.
AFP remuneration	0.330	0.009*	Low potential availability FPs less likely to be paid by AFP
Teaching practice	0.398	0.026*	Low potential availability FPs less likely to be in teaching practices
≥1 after hours clinical session	1.429	0.299	

*statistically significant at $p < 0.05$.

Table 3-3: Multinomial logit results – low vs. moderate potential availability family physicians.

Independent Variable	Odds Ratio	p-Value	Interpretation
<i>Family Physician Characteristics</i>			
Age	0.997	0.822	
Male gender	1.133	0.564	
Additional palliative care training	1.629	0.154	
Attitude toward palliative care at home	2.450	0.000*	High potential availability FPs more strongly endorse FP participation in home palliative care
<i>Practice Characteristics</i>			
Rural practice location	0.517	0.010*	High potential availability FPs less likely to be rural.
AFP remuneration	1.971	0.008*	High potential availability FPs more likely to be paid by AFP
Teaching practice	1.320	0.283	
≥1 after hours clinical session	2.212	0.001*	High potential availability FPs more likely to have at least one after hours clinical session

*statistically significant at $p < 0.05$.

Table 3-4: Multinomial logit results – high vs. moderate potential availability family physicians.

3.4 Discussion

3.4.1 Principal results

Most family physicians reported providing palliative care and house calls, but only a minority were available to see patients after-hours if necessary. When combined into a composite variable with three levels (low, moderate, and high potential availability), the majority of comprehensive family physicians were in the moderate potential availability category. Fewer than 1 in 4 fell into the high potential availability category (providing palliative care, house calls and after-hours visits) and approximately 1 in 8 were in the low potential availability category (offering neither palliative care, house calls, nor after hours visits).

Two variables were positively associated with potential availability across both availability category comparisons: positive attitude toward FP provision of palliative care at home, and remuneration by alternate funding plan. Family physicians from rural practices were significantly less likely to appear in either the low or high potential availability categories.

3.4.2 Interpretation

3.4.2.1 Provision of palliative care and house calls

The proportion of FPs providing palliative care in the current study (75.7%) was similar to that found general practitioners in Sydney, Australia in 2007 (75%)⁴⁸, but higher than among Quebec City, Canada region family physicians in 1998 (62%)³¹, and higher than among family physician respondents to the National Physician Surveys of 2004 (36.4%)⁴⁹, 2007 (54.6%)⁵⁰ and 2010 (45.7%)⁵¹.

The results of the current study suggest a high level of engagement in palliative care in the London region, but there may be additional reasons for the difference between results of the current study and other Canadian findings. Because other studies included all family physicians, the higher proportion in the current study may be due in part to the exclusion of non-comprehensive family physicians (such as those who practice only emergency medicine or psychotherapy) who may be less likely to have primary responsibility for community patients at end of life.

When considering only those family physicians who report providing palliative care, the proportions which offer house calls and provide after hours coverage in the current study were similar to those found in Aubin's survey of family physicians in the Quebec City region. The proportion of southwestern Ontario family physicians in the current study who offer house calls (80.5%) was slightly higher than in the Quebec City study (77%)³¹, while the proportion providing after hours coverage was lower (32.9% in southwestern Ontario vs. 38.8% in Quebec City).

3.4.2.2 Interpreting the relationships among the availability categories

The categories used in the present study (low, moderate, and high potential availability) are advantageous in their conceptual simplicity and face validity: some comprehensive family physicians are more available than others to provide care for their community patients at end of life. Misinterpretations of the results could arise, however, if one assumed these categories denoted a greater or lesser amount of a single, cohesive, internally-consistent phenomenon called ‘potential availability’. The study design took three separate dichotomous variables (provision of palliative care, provision of house calls, and availability to see non-hospitalized patients after hours) and combined them into a dependent variable (potential availability). There is no reason to assume that factors associated with potential availability would have similar influences (in either magnitude or direction) on each element of the dependent variable definition. The dependent variable construct, and the categories within it, are thus adequate to illustrate the existence of variation in potential availability, and to demonstrate that this variation is non-random. The results of this study do not, however, imply a straightforward linear progression from low to moderate to high availability.

3.4.2.3 Predictors of potential availability

The associations between potential availability and family physician attitude toward participation in home palliative care and remuneration structure are potentially important. In the absence of specific directives from regulatory authorities requiring particular arrangements of family physician care for community patients at end of life, practice patterns may be shaped by perceived professional expectations, personal preferences or economic considerations. The results of this study illustrate the importance of such factors on potential availability to provide community-based end of life care.

Family physician respondents’ attitudes toward participation in home palliative care will incorporate both perceptions of their professional obligations and individual personal preferences. It is not surprising that attitude was strongly associated with potential availability across all three categories of comparison in the current study. Family

physicians who believe strongly in the importance of their participation in palliative care at home would presumably be more likely to make themselves available for these patients. Other research suggests that this is a modifiable trait: family physicians' attitudes toward palliative care can change with participation in continuing education programs⁵². The results of the current study support the assertion that efforts to change attitudes may translate into improved access to care.

While the current study was not designed to explore the nature of the relationship between remuneration structure (fee-for-service vs. alternate funding plan) and potential availability, it clearly demonstrated the existence of such a relationship. The existence of a relationship between economic factors and practice patterns reflects similar findings elsewhere^{53,54}.

3.4.2.4 Rural practice location and potential availability

Rural practice location was significantly associated with availability category in both the low-versus-moderate and moderate-versus-high multinomial logit analyses, but in opposite directions. In the low-versus-moderate comparison, family physicians from rural practices were more likely to be in the greater availability category, but in the moderate-versus-high comparison rural family physicians were more likely to be in the lesser availability categories. A post-hoc analysis showed that a greater proportion of rural than urban family physicians provided palliative care and house calls. However, the proportion of family physicians available to see non-hospitalized patients after hours was lower among rural family physicians (though not statistically significant). Rural practice location thus appears to have opposing effects on different elements of the dependent variable definition, the net effect of which is to cluster rural family physicians in the moderate potential availability category.

3.4.3 Implications of the results

The results of this study demonstrate that for community patients at end of life, having a family physician does not automatically guarantee access to necessary care in a timely fashion. Even among family physicians who describe themselves as providing 'comprehensive family medicine', some family physicians are more available than others.

If equitable access to care is a goal of the healthcare system, then variety in patterns of practice must be taken into account. Failure to do so may result in gaps in access to medical care (if it is assumed that all family physicians will provide 24/7 access to palliative care at home) or unnecessary redundancies (if it is assumed that they won't).

Second, access to medical care for community patients at end of life must be clearly defined in terms of individual elements of access to care. If the goal for community patients at end of life is 24/7 access to palliative care at home, then the relevant elements of access (conceived in this study as provision of palliative care, provision of house calls, and availability to see non-hospitalized patients after hours) need to be defined and measured independently. Simply asking family physicians whether they provide palliative care will not provide sufficient information to determine whether community patients at end of life have adequate access to necessary medical care.

Third, because attitudes regarding FP participation in palliative care at home, and remuneration by alternate funding plan were strongly associated with potential availability, efforts to enhance family physician provision of medical care for community patients at end of life should begin by focusing on these factors.

Fourth, attempts to enhance family physician availability to provide medical care for community patients at end of life may be more likely to succeed if they are focused on a specific element of access and tailored to appropriate subsets of family physicians. For example, an enhancement in fee codes payable for palliative care house calls may be likely to increase house calls among fee-for-service family physicians. It is less likely, however, to alter patterns of availability for after hours services among these physicians, or to increase house calls by family physicians who receive remuneration through a salaried or capitation-based alternate funding plan.

3.4.4 Limitations

Several limitations of this study should be noted. First, the study does not reveal family physicians' actual availability to care for community patients at end of life. As a secondary analysis of a survey regarding their overall practices, the current study took

items referring to the practice as a whole (e.g. availability to make house calls) and interpreted them as referring directly to community patients at end of life. It may be that if questioned specifically about their patterns of care for community patients approaching end of life, some of the respondents who did not report providing house calls or after-hours visits as part of their overall practice would tell us that while they do not offer these to most patients in their practices, that they do provide such services for their patients approaching end of life. Thus it may be that this study underestimates family physicians' availability to provide house calls and after-hours visits to community patients at end of life.

Second, the associations described in this study do not necessarily imply causation. Family physicians who believe strongly in the importance of their participation in palliative care at home would likely make themselves available for these patients; but it is also plausible that family physicians who provided this care came to be convinced about its importance through their experiences. Similarly, remuneration through an alternate funding plan could either influence, or be influenced by, family physicians' potential availability to care for community patients at end of life, or an independent factor may have a similar influence on both items.

Third, as with all studies based on self-report, this study is potentially subject to social desirability bias (the tendency of respondents to answer questions in a manner they perceive will be viewed favorably by others). The anonymous nature of the survey seeks to minimize this bias, yet the ideal study would observe family physicians' actual behaviours of care provision for community patients at end of life rather than relying on self-report. Fourth, the sample for this study was limited to one geographic area (southwestern Ontario) and may not be generalizable to family physicians in other jurisdictions. Finally, the data upon which this study is based are now almost ten years old. It may well be that an updated study would reveal important changes in practice patterns over the past decade.

3.4.5 Call for further research

The findings of this study demonstrate the need for additional research in at least three directions. First, the results of this study need to be confirmed (or refuted) based upon more recent data from a wider sample of family physicians. The National Physician Survey, distributed to all physicians across the country every three years, contains almost all of the data elements utilized in the current study. It would provide appropriate data for a national study analogous to this regional one.

Second, elements of family physician availability would be ideally measured by observation of physician behaviour rather than self-report. For fee-for-service physicians and alternate funding plan physicians under certain models, billing data provide an opportunity to measure behaviour with respect to house calls, after hours visits, and (with significant limitations) provision of palliative care. Physician and practice characteristics such as those examined in this study can be linked to this billing data from existing provincial data holdings, enabling more robust modeling of associations between physician characteristics, practice characteristics and patterns of care for community patients at end of life.

Third, we need to explore the relationship between family physician patterns of care, and patient outcomes. Does family physician availability actually affect patient outcomes? To what degree? Which elements of availability? How are these affects modified by context (e.g. the presence or absence of a specialist community palliative care consultation service)? Some of these questions may be answerable with existing provincial data holdings, while others would require the collection of new data.

3.4.6 Conclusions

Family physicians in London, Ontario and region vary in their potential availability to provide care to community patients at end of life. Attitude toward FP participation in palliative care at home and remuneration by alternate funding plan were both strongly associated with potential availability across availability categories. System design must take into account variability among FPs in their availability to care for this vulnerable patient population.

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Chapter 4

4 Synthesis

4.1 Aim of the research

The goal of this thesis was to explore the variations that exist among how family physicians organize their care activities (i.e. their patterns of care) for community-dwelling patients approaching the end of life. The investigation began with two premises. First, that the nature of existing literature on the subject necessitated an exploratory approach. Second, that this exploration should begin at the level of individual family physicians, but also contribute to a system-level understanding.

In order to address this aim, a mixed methods approach was adopted. The thesis project consisted of two component research studies: a qualitative grounded theory study based on original data collection using in-depth interviews with family physicians, and a quantitative secondary analysis of existing family physician survey data. The relationship between the components was one of simultaneous implementation, qualitative-dominant priority, with integration at the level of interpretation.

4.2 Review of main findings

4.2.1 Qualitative study

Grounded theory methodology was used to address two questions for this study: How do patterns of care for community patients at end of life differ among family physicians? What shapes the development of these differences?

While all participants endorsed the ultimate goal of helping their community patients at end of life, no two participants described providing this care in the same way. Patterns of care for community patients at end of life differed among family physicians in three dimensions: the *timing* of care activities (i.e. when they were available to provide care), the *location* of care activities (i.e. where they were available to provide care), and the

purpose of their care activities (i.e. the manner in which they intended their actions to address patients' need).

The overarching process which shaped individual family physician's patterns of care was summarized as *making it fit*. Participants emphasized the importance of the *contexts* (both physician context and healthcare context) in which these care activities for community patients at end of life occur, and the active process of *weighing the impact* by which family physicians consider the implications of potential adjustments to their patterns of practice. The concept of 'fit' as articulated by the participants thus had characteristics of both action (i.e. the process of making choices) and quality (i.e. the degree of alignment of the actual with a perceived ideal).

4.2.2 Quantitative study

This study utilized secondary analysis of existing family physician survey data to address two questions: To what extent do comprehensive family physician respondents to a 2004 regional physician survey report providing access to three medical services related to the care of community patients at end of life: palliative care, house calls, and after hours visits? What factors are associated with these family physicians' potential availability to care for community patients at end of life?

Most comprehensive family physicians reported providing palliative care (75.7%) and house calls (70.3%), but only a minority (29.5%) was available to see patients after-hours if necessary. Some family physicians provided all three services (high potential availability, 22.2%), and others provided none (low potential availability, 13.5%), but the majority (64.3%) were in the moderate potential availability category, providing one or two, but not all three of these services.

Family physicians with high potential availability were more likely to endorse the importance of family physician participation in community end of life care, and more likely to receive remuneration through an alternate funding plan. Compared to moderate potential availability physicians, those in the low potential availability category were more likely to be females and in non-teaching practices. High potential availability

physicians were more likely than moderate potential availability physicians to have at least one regular after-hours clinical session. Physicians from rural practices were less likely than urban physicians to be in either the low or high availability categories.

4.3 How do each study's findings inform the other?

4.3.1 Influence of mixed methodology on study design and analysis

As a simultaneous implementation mixed methods study with related, but separate, research questions, neither component study's design or analysis was directly dependent upon the other. However, each study was informed in some fashion by insights from the other. The influence was generally indirect, perhaps even unconscious. For example, while there was no formal change made to the semi-structured interview guide as a result of the quantitative analysis, the quantitative finding that physicians from non-teaching practices were more likely to be in the low potential availability category may have sensitized me as a qualitative researcher to explore this aspect in subsequent interviews.

In one case, the influence of one study on the other was more direct. The first draft analysis plan for the quantitative study did not include free weekday clinical sessions or scheduled after-hours clinical sessions as independent variables. However, after several of the family physicians interviewed for the qualitative study described how they would make house calls in their 'free' afternoons, the decision was made to revise the quantitative study to include the new independent variables. One of these new variables (regularly scheduled after-hours clinical session) was eventually found to be statistically significant in the multivariable analysis.

4.3.2 How do the quantitative results inform our interpretation of the qualitative findings?

The qualitative findings are not altered or extended, but rather affirmed by the results of the quantitative component of the thesis. While the survey was not designed to capture the same range of practice pattern variation described by participants in the grounded theory study, it certainly affirms the existence of significant variations in patterns of care for community patients at end of life. The survey results were consistent with the

qualitative observation that there appears to be no single, standard practice pattern adopted by a majority of family physicians. Variation is the norm, whether elicited in interviews or surveys.

Other aspects of the quantitative results were consistent with elements of the grounded theory developed in the qualitative study. The qualitative study emphasized the importance of both the physician context and the healthcare context. The quantitative study found relationships between potential availability and independent variables that would be part of the physician context (gender, attitude toward family physician participation in community end of life care) and with others arising from the healthcare context (teaching practice, remuneration by alternate funding plan).

4.3.3 How do the qualitative findings inform our interpretation of the quantitative results?

As a qualitative-dominant mixed methods design, the quantitative results were intended to inform the qualitative rather than the opposite. Nonetheless, some of the qualitative findings do provide insights into the interpretation of the quantitative results. Primarily, the qualitative findings remind us that the quantitative results provide only an incomplete snapshot which cannot be assumed to tell the whole story.

The quantitative study was a secondary analysis of data collected from a survey of family physicians' practices as a whole. It was not focused on the care of community patients at end of life. Many of the specific practice variations described by participants in the qualitative study were not considered in the survey. For example, some interviewees who did not normally provide after-hours services described giving their personal cell phone numbers to community patients approaching end of life. Because it was not offered as an option on the survey, there is no way to know from the survey how many family physicians make such special arrangements for their community patients at end of life.

Thus the qualitative findings remind us that the correct interpretation of the quantitative study is NOT that exactly 22.2% of comprehensive family physicians provide 24/7 availability for home palliative care. Rather the correct interpretation is: there is variation

in potential availability, and there are factors that are significantly associated with this variation.

4.4 Implications for practice

4.4.1 There is no clear standard of care. Should there be?

There is no clearly defined, widely accepted standard of services which each family physician is expected to provide to her or his community patients at end of life. There are many good reasons why family physicians have wide latitude in the way they organize care for patients in their practices, but these variations lead to genuine challenges in ensuring equitable access to medical care for community patients at end of life. This reality compels us to wrestle with some difficult questions. Should there be a clearly articulated, minimum standard of services? Who should determine this? Should such a standard be applied at the level of the individual physician, or the practice? How would such standards be implemented in practice?

The need to strengthen palliative care in primary care has been recognized in Canada and elsewhere¹⁻⁵. Some jurisdictions have begun taking major steps to accomplish this. In the United Kingdom, the Gold Standards Framework is an initiative developed within primary care, and now funded across the country by the National Health Service, to implement processes for patient identification, care planning and coordination, and clinical best practices into the primary care of community patients approaching end of life⁶. The Gold Standards Framework (GSF) has now been incorporated into the practices of more than 90% of general practitioners in the UK, and evidence is mounting for its impact⁷⁻¹³. While some elements of the GSF may not be directly transferrable to Canada, GSF components focusing on identifying, registering and coordinating care for patients approaching end of life could be implemented within our existing policy framework. Some researchers have begun to explore how GSF can be adapted for the Canadian context (F. Burge, personal communication).

4.4.2 Palliative medicine must function in both primary and consultant roles

The ideal situation would be if every Canadian had a family physician willing and able to provide primary palliative care in the patient's home. Unfortunately, at present this is not the case and, given the contextual realities which shape family physicians' choices regarding their patterns of practice, the path to achieving this goal is not straightforward. At present and for the foreseeable future, therefore, there is a need for palliative medicine services able to function in either a consultant capacity or primary care role as needed.

Palliative medicine physicians (or family physicians with a focused practice in palliative care) who make themselves available to assume primary responsibility for the care of community patients at end of life may be criticized for fostering the impression that end of life care should be provided by 'specialists' rather than family physicians, and contributing to the gradual 'de-skilling' family physicians in this realm^{14,15}. Most family physicians may be well-equipped to manage most of the medical needs of most of their community patients at end of life. For these physicians, access to a palliative medicine consultation service will be all that is required.

However as long as family physicians are human beings, there will always be some who do not wish to look death in the eye. These family physicians will minimize their involvement with dying patients and would very happily transfer care of these patients to someone (anyone!) else. What are we to do for the patients of these physicians? For these patients, is it the right thing for us to stand on the principle that palliative medicine services can be consultant only because we fear 'de-skilling' this avoidant family physician? The variations in family physician patterns of care for community patients at end of life oblige us to grapple with this question.

4.4.3 System design changes have ripple effects, some unanticipated

From the perspective of a family physician researcher with an interest in the care of community patients approaching end of life, it feels natural to conclude that there is a need to promote family physician involvement in the care of these patients. Much research, cited elsewhere in this thesis, emphasizes the value of the role that family

physicians play. A strong argument can be made, from the basis of previous research as well as the variation among family physicians observed in this thesis' studies, for further system changes designed to enhance palliative care in primary care practices. However, the findings of this thesis also sound a note of caution.

System design changes will have ripple effects, some of which may be unanticipated. Two family physicians can interpret the same changes to physician remuneration as reinforcing opposite practice patterns: one saying that the changes support provision of house calls, the other claiming that they are a disincentive to providing any services outside of the office. Programs designed to support the patients of family physicians who do not provide palliative care may, directly or indirectly, make it more difficult for family physicians who wish to provide this service to do so. Family physicians who increase their investment of time or practice resources into greater availability for the care of community patients at end of life will have to withdraw that time or those practice resources from the care of another segment of their practice population. Proposals to enhance the care of community patients at end of life must consider their implications carefully, and evaluations of any changes should include an attempt to identify unintended effects.

4.5 Implications for research: Principles for future research on this topic

Some future research directions have already been identified in chapters 2 and 3. Three suggested principles of future research on this topic area are discussed below.

4.5.1 Avoid the pitfall of polysemy

In the first chapter of this thesis, we considered the problem of palliative care as a polyseme; a term with multiple, related-but-distinct, contextually-dependent meanings. Research in palliative and end of life care must scrupulously clarify terms for research questions and participants. The key distinction is whether or not, for a particular research question, the physician's *intent* matters. As discussed in chapter one, not all palliative care is end of life care, and not all care at end of life is palliative care. To what degree are

family physicians providing care given with intent consistent with the principles of hospice palliative care?

A significant gap in the literature thus far has been the absence of studies which observe family physician provision of *palliative* care. There are numerous studies which describe family physician provision of *end of life* care, typically analyzing physician billing data retrospectively using a mortality follow-back design. These studies inform us about physician activities, but they do not provide direct insight into physician intent. Studies which have tried to look at physician intent have universally relied on self-report surveys, the weaknesses of which have been previously discussed.

In recent years, some jurisdictions, including Ontario, have introduced billing codes specifically for palliative care activities. These are billing codes that physicians utilize only for patients for whom they are providing palliative care, and are thus the first readily available, directly observable marker of care activities provided with a palliative intent. It may now be possible, based on observation of behaviour rather than self-report, to distinguish between family physician provision of *end of life* care, and family physician provision of *palliative* care. This would constitute a major advance in our understanding of the care of this patient population.

4.5.2 Measure the impact of physician practice patterns on patient outcomes

This thesis found that family physician patterns of care for community patients at end of life vary in three dimensions: location, timing and purpose of activities. What impact do these variations have on patient outcomes? Do variations in one dimension matter more than another? Do the variations in each dimension matter equally in every geographical context? Are the effects of physician practice pattern on patient outcome modified by other clinical resources available (e.g. through home care)? Answering such questions requires us to link physician practice patterns with the relevant health outcomes of their patients.

Several studies have shown an association between one of the dimensions identified in this thesis (family physician provision of house calls) and patients' ability to die at home¹⁶⁻¹⁹. However, these studies were not designed to address causation. Did patients die at home because their family physicians made house calls, or did the family physicians make house calls because the patients were dying at home? Further research exploring the links between family physician practice patterns and patients outcomes is needed.

4.5.3 Consider the perspective of complexity theory

Complexity theory is the body of theory related to the operation of complex systems. It emphasizes, among other things, our inability to adequately understand a complex system by studying its individual components in isolation (non-decomposability)²⁰. Understanding comes only by research at a granular level able to attend to the particular enablers and constraints manifest in the interrelations of system components^{21,22}. Complexity theory also sensitizes researchers to the non-linear behaviour of complex systems. These systems do not behave based on linear logic, because they manifest interdependencies among diverse agents^{23,24}. Predictable change is not achievable through top-down interventions, and these systems maintain a freedom from direct response to external influences. Attention to self-organization of local interactions is fundamental to understanding the emergence of patterns and order at higher levels²⁵.

The processes shaping patterns of practice for community patients at end of life described in this study appear to demonstrate characteristics of a complex system. Participants' descriptions suggested aspects of non-decomposability, unclear boundaries, non-linear relationships, and intrinsic feedback loops - all typical characteristics of complex systems. This thesis was not based on a complexity theory perspective, but its findings suggest that such a lens may be beneficial for future research.

4.6 Summary

This thesis employed a mixed methods approach to explore the variety of ways in which family physicians in southwestern Ontario, Canada organize their care activities for community-dwelling patients who are approaching end of life, and what shapes this

variation. Variations were described in three dimensions (location, timing and purpose of activities) and were shaped by complex interactions with multiple layers of context within which these care activities occur. Future research in this field would benefit from a complexity theory perspective, should clearly distinguish between end of life and palliative care, and must describe the impact of family physician practice patterns on patient outcomes.

4.7 References

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Appendices

Appendix A: REB approval for qualitative study



Office of Research Ethics

The University of Western Ontario
 Room 4180 Support Services Building, London, ON, Canada N6A 5C1
 Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
 Website: www.uwo.ca/research/ethics

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. J. Shadd

Review Number: 17358E

Review Level: Expedited

Review Date: August 26, 2010

Approved Local # of Participants: 21

Protocol Title: What shapes family physicians' patterns of care for community patients at end of life?

Department and Institution: Family Medicine, University of Western Ontario

Sponsor:

Ethics Approval Date: September 15, 2010

Expiry Date: August 31, 2011

Documents Reviewed and Approved: UWO Protocol, Letter of Information and Consent, Telephone Script, Recruitment letter

Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

- changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- all adverse and unexpected experiences or events that are both serious and unexpected;
- new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. Joseph Gilbert
 FDA Ref. #: IRB 0000940

Ethics Officer to Contact for Further Information

<input type="checkbox"/> Janice Sutherland (jsutherl@uwo.ca)	<input type="checkbox"/> Elizabeth Wambolt (ewambolt@uwo.ca)	<input type="checkbox"/> Grace Kelly (grace.kelly@uwo.ca)	<input checked="" type="checkbox"/> Denise Grafton (dgrafton@uwo.ca)
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This is an official document. Please retain the original in your files.

cc: ORE File
 LHRI



Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Joshua Shadd
Review Number: 17358E
Review Level: Delegated
Approved Local Adult Participants: 21
Approved Local Minor Participants: 0
Protocol Title: What shapes family physicians' patterns of care for community patients at end of life?
Department & Institution: Family Medicine, University of Western Ontario
Sponsor:
Ethics Approval Date: August 08, 2011 **Expiry Date:** August 31, 2012
Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Revised Study End Date	The study end date has been revised to June 30, 2012 to allow for project completion.	

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines, and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

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Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The UWO HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Ethics Officer to Contact for Further Information

Janice Sutherland (jsutherl@uwo.ca)	Grace Kelly (grace.kelly@uwo.ca)	Shantel Walcott (swalcot@uwo.ca)
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This is an official document. Please retain the original in your files.

The University of Western Ontario

Office of Research Ethics

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Appendix B: Semi-structured interview guide

Preamble read to all participants at the outset of the interview:

- Thank you for agreeing to participate in this interview as part of a study entitled “Influences on Family Physicians’ Patterns of Care for Community Patients at End of Life”. As you are aware, your participation is completely voluntary and you may decline to answer a question, terminate the interview, or withdraw from the study at any time without repercussions. As described in the Letter of Information you have reviewed, today’s interview will be audiorecorded for subsequent transcription, but you may ask for the recorder to be turned off at any time.
- Do you have any questions before we begin?

***** Begin audio recording *****

Every family physician has developed distinctive patterns and structures to care for the needs of their patients. (Rural doctors practice differently than urban ones, physicians in solo practices have different structures and mechanisms than those in team settings.)

My goal in this study is to understand the diversity of ways in which family physicians organize their care for community patients at end of life. (Some do home visits, others do not. Some refer to community palliative care physicians, others prefer to follow their own patients. etc.)

In the next 45-60 minutes, I would like to get to know your pattern of practice and what has shaped it. It is this second part – understanding why you do things the way that you do – that is most interesting to me, but perhaps you could begin by giving me a brief overview of your practice as a whole.

- How long have you been at this practice?
- How large is your practice?
- Partners/team members?

Tell me what happens a patient of yours is approaching end of life and wishes to remain at home?

- Does it always work out this way?
- If they have questions or concerns, who do they call? What about evenings and weekend?

Okay, thank you for that. You have given me a good overview of your practice and the ways in which you address the needs of your community patients at end of life. Now I would like to move us to a different level of thinking about this. Help me understand why this is the pattern you have adopted. What has shaped this for you?

- There are other ways of doing things. What influenced you to adopt this particular pattern?
- Has it always been like this, or were there times or places that your pattern was different? Tell me about that.
- Tell me about the decision points. What were the junctures that led away from another pattern toward this one?
- Tell me the story of the person that has influenced you the most in this regard.
- To what degree is the pattern you described intentionally chosen by you, versus shaped by external factors? What external factors have come into play and how?
- Can you imagine other ways of organizing care for community patients at end of life?
- If you controlled the whole system, would your pattern of care for community patients at end of life look different? How?
- This sounds like a different pattern. How big a difference would this make for your patients? For you?
- What constrains you from moving toward this pattern of practice now?
- What would it take for you to change your pattern of practice for these patients?
- Do you find this aspect of your practice satisfying? What contributes to this sense of satisfaction? What detracts from it?
- If these supports didn't exist, how would it change your pattern of practice?
- Are there sacrifices you have made to sustain this pattern? (e.g. financial)
- What do you think are the implications of this practice pattern for your patients?

Additional prompts: I need to know more about why...?

Why not do things...?

Why is doing things like this important to you...?

You sound like _____. Where does that come from?

Thank you for taking the time to talk today. Is there anything else you would like to add?

***** Stop audio recording *****

- Thank you for your generous participation in this study.

Appendix C: Participant family physicians' patterns of activities for community patients at end of life

Participant A

Profile: Male, late career, urban practice setting, adjunct academic appointment

Locations of activities: house calls, three long-term care homes, two hospitals (one acute care, one palliative care unit)

Timing of activities: dedicated half-days for house calls, group on-call coverage 0700h-0000h.

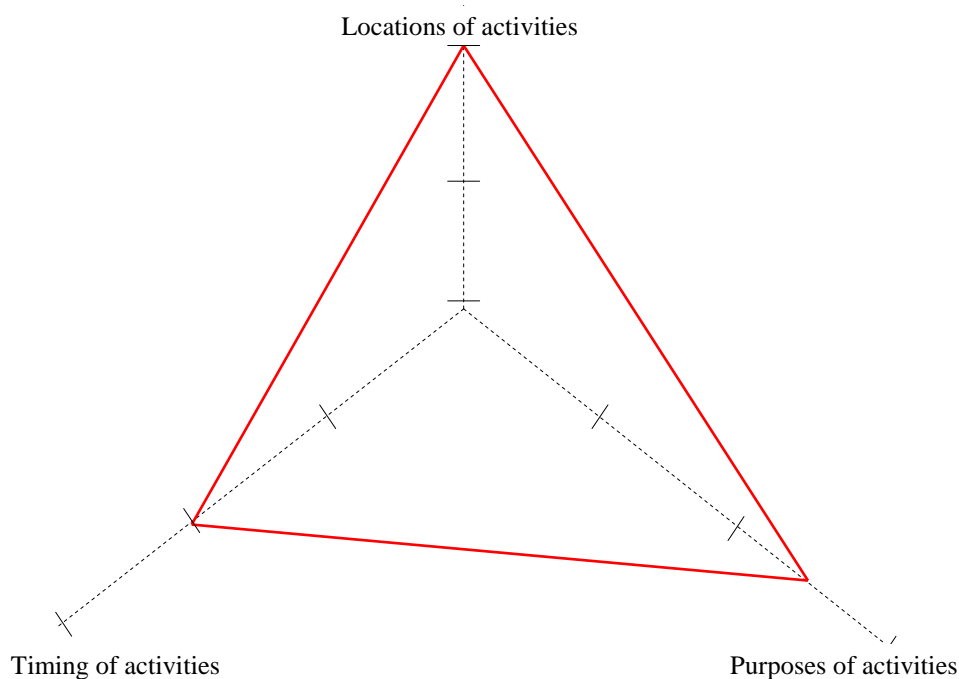
Purposes of activities:* moderate range

“I’m still the one basically assessing symptoms and treating them.”

“So when I do a consult...it's also educational for them [the referring family physician].”

“If that was like the model of practice [physician telephone support of nurse practitioners in the home so that physician house calls would not be necessary] I wouldn't look to change to that. I would still see my patients and go...”

“I like dealing with the families. I like helping them through it. I mean, getting the person from here to dead is one thing to do, but getting the family from here to them being dead is a whole other thing, which I find really fascinating.”



*Range of expressed roles and goals beyond medication prescribing for symptom management.

Participant B

Profile: Female, early career, urban practice setting, no academic appointment

Locations of activities: office, house calls, hospital palliative care unit

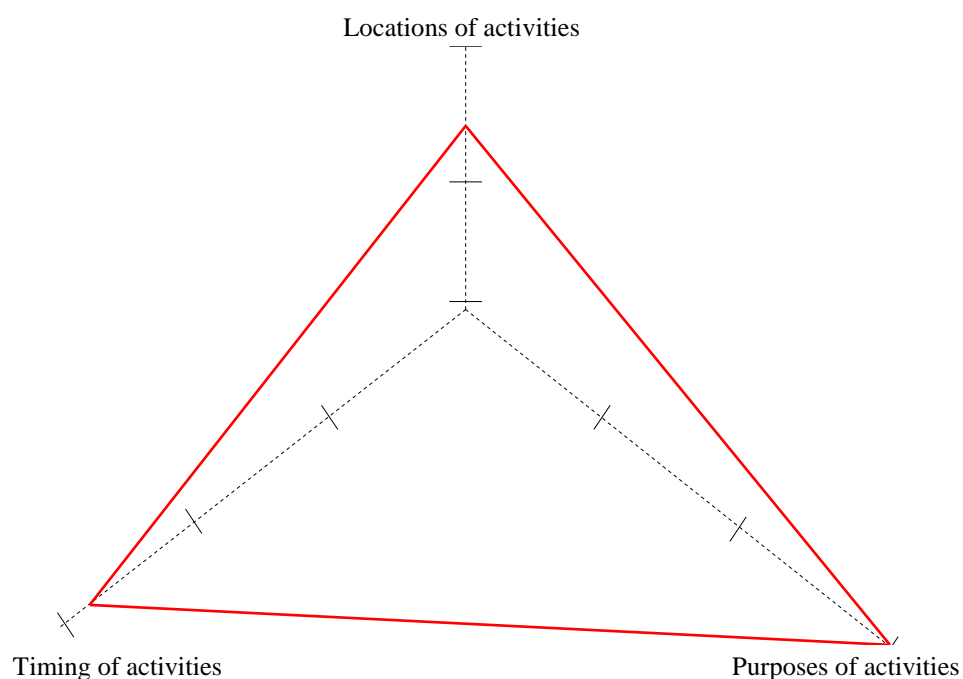
Timing of activities: one flexible half-day per week for house calls, 24/7 group on-call coverage for PCU, personal 24/7 on-call coverage for community patients

Purposes of activities:* high range

“In the beginning it’s more education...And near the end often I find myself being more just a supportive person...”

“You know that patients, they can hear you and they can sense your touch, which is comforting, so at that point I feel like that's my job, because they don't have their family members around that often.”

“I can moisten their lips. I can put Vaseline on. I can make sure that their eyes are lubricated. Kind of like the nursing little bits...”



*Range of expressed roles and goals beyond medication prescribing for symptom management.

Participant C

Profile: Female, late career, rural practice setting, no academic appointment

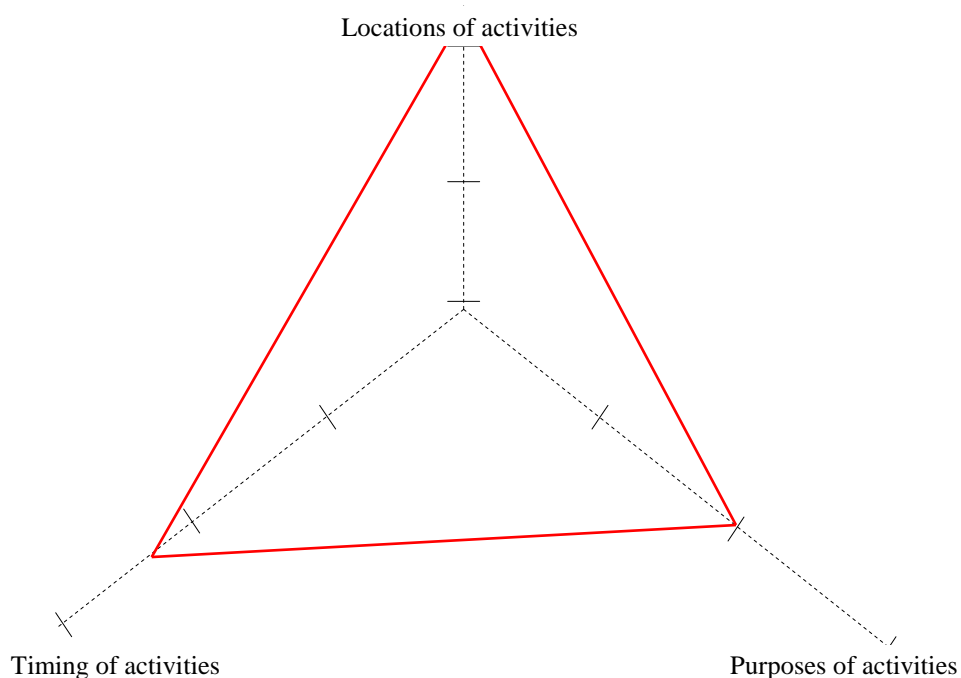
Locations of activities: office, house calls, two acute care hospitals

Timing of activities: one flexible half-day per week for house calls plus ‘fit-in’ after hours house calls, 24/7 group on-call coverage for hospital and community patients

Purposes of activities:* moderate range

“In a situation with a palliative patient at home, I usually go in there on a regular basis, either weekly or every two weeks, or sometimes everyday depending on how much service they need.”

“Sometimes when I can’t get any straight answers the patients deteriorate, I have to admit them, and we start all over again... I’ll admit them for a short quick visit; straighten out some medication; get in any consults I need, then have a team meeting before they go home so they know exactly what kind of things they’re getting done.”



**Range of expressed roles and goals beyond medication prescribing for symptom management.*

Participant D

Profile: Female, early career, urban practice setting, full-time academic appointment

Locations of activities: office, house calls, one acute care hospital

Timing of activities: regular 'fit-in' house calls, 24/7 group on-call coverage for hospital and community patients

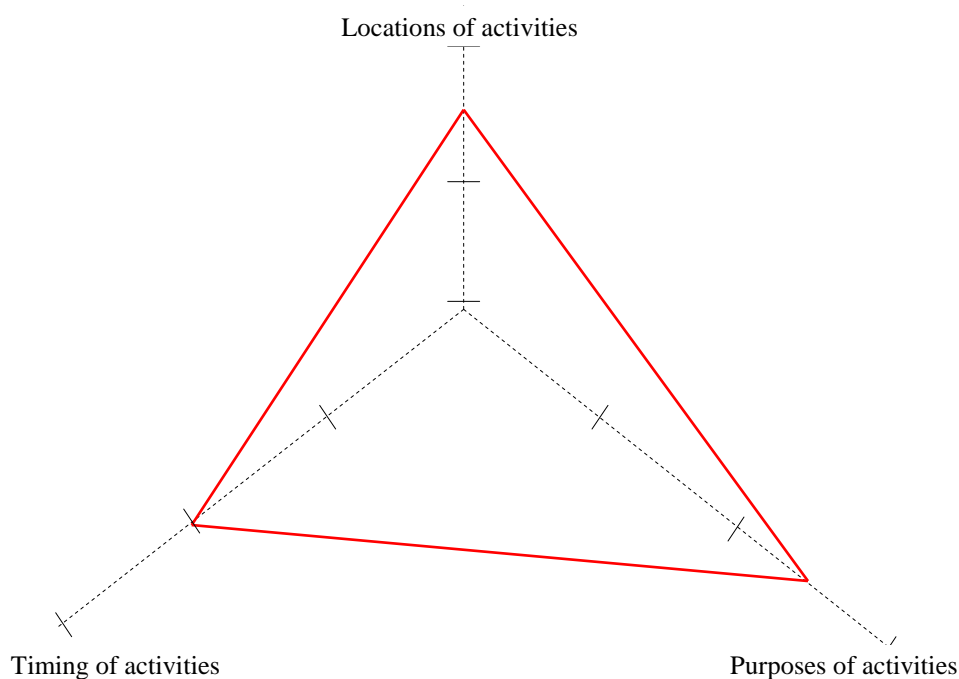
Purposes of activities:* moderate-high range

“If it’s inevitable then we actually get them into the hospital and continue on that care with familiar faces till the inevitable happens. So, from that point of view, I feel that we can be there for them in many ways and that’s a good, good thing for me, personally, and I think for the team also...”

“I call the patients by phone and, you know, touch base with them that way and tell them the resident would be coming or get feedback after the visit to see how the resident did.”

“I feel sometimes that we don’t quite understand them [our family practice patients] one hundred percent until you’ve actually seen them in their own surroundings... it takes your, your physician-patient relationship, I think, to the next level.”

“I think we kind of motivate them without giving them false hope, and lead them to believe and pray and hope, which should always be there.”



*Range of expressed roles and goals beyond medication prescribing for symptom management.

Participant E

Profile: Male, mid career, rural practice setting, no academic appointment

Locations of activities: office, house calls

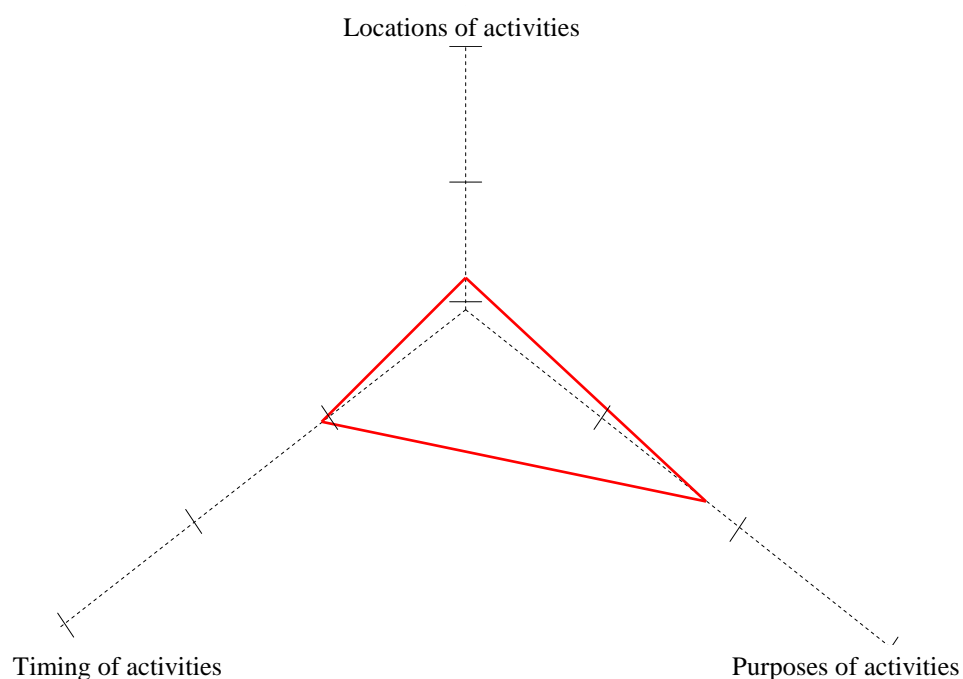
Timing of activities: occasional ‘fit-in’ house calls, no on-call coverage

Purposes of activities:* moderate range

“I always offer that [a house call]... I leave that as an option and for a simple request I will do that.”

“They [home care nurses] put a plan of action for everything and I sign it...it’s just a matter of reading it and approving it.”

“So, I mean being available just to arrange a paracentesis [by a physician in the emergency department] on a short notice that would be valuable in this situation.”



**Range of expressed roles and goals beyond medication prescribing for symptom management.*

Participant F

Profile: Male, mid career, urban practice setting, adjunct academic appointment

Locations of activities: office, house calls

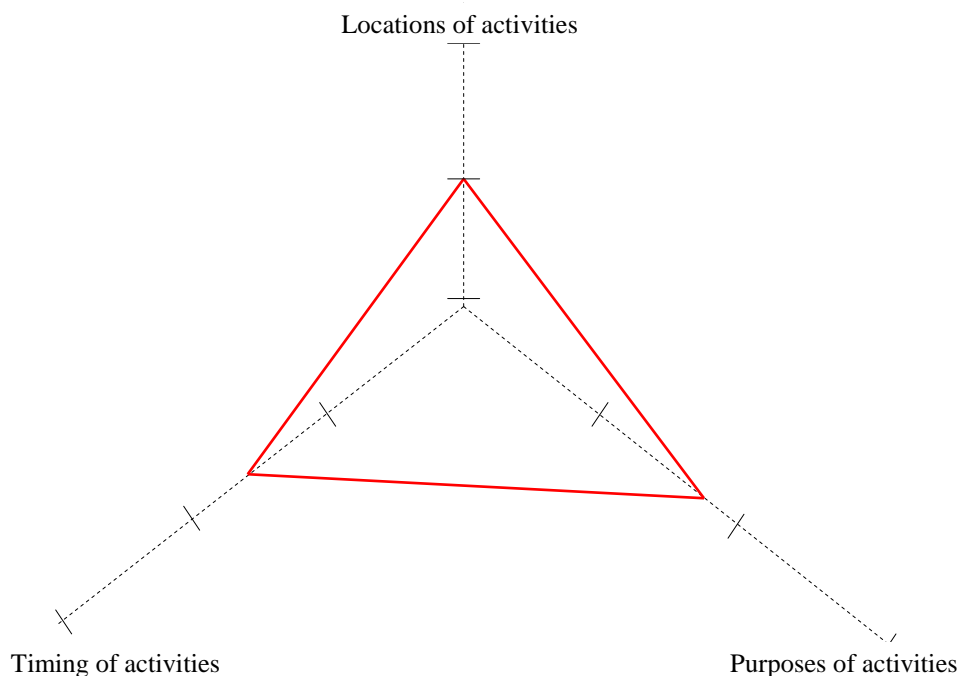
Timing of activities: occasional 'fit-in' house calls, group 24/7 on-call coverage

Purposes of activities:* moderate range

“Part of what we need to do as family doctors, as one fellow colleague put it, is expectation management...I will sometimes ask, trying to bring the conversation around to death and dying.”

“A lot of it, I think, that’s what it’s all about, it’s kind of just reassuring people, right? And, then there’s no urgency about it, you know?”

“I’ve had dying patients ask me about God, dying and death? How can you be that involved in people’s lives and caring for them and not expect?”



*Range of expressed roles and goals beyond medication prescribing for symptom management.

Participant G

Profile: Male, mid career, urban practice setting, adjunct academic appointment

Locations of activities: office, house calls

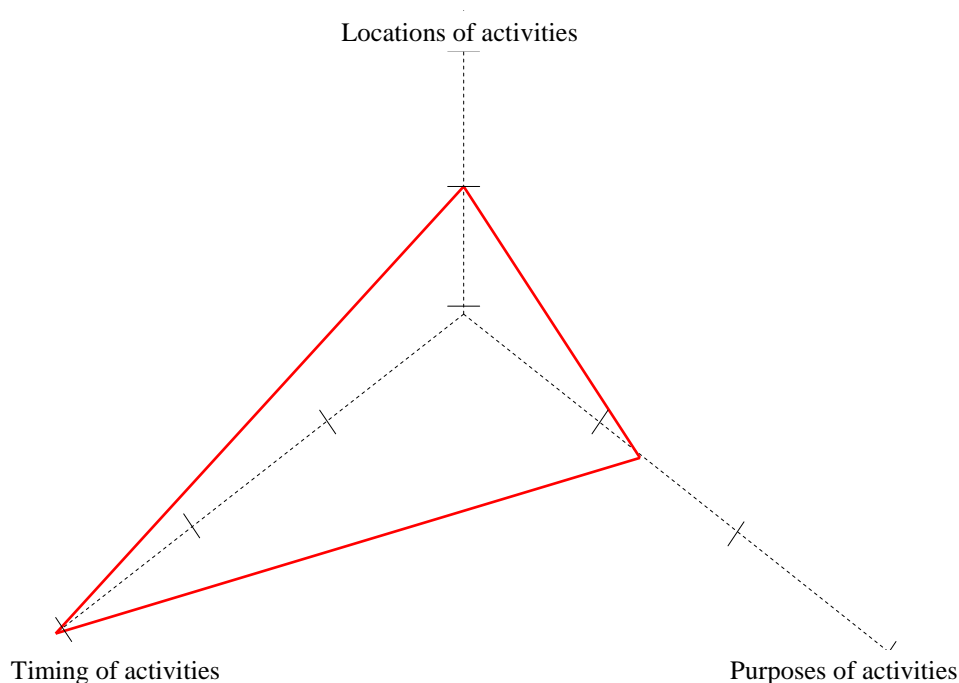
Timing of activities: one flexible half-day per week for house calls plus ‘fit-in’ after hours house calls, personal 24/7 on-call coverage for end of life care patients

Purposes of activities:* low-moderate

“For me, it’s important to just continue that line of care.”

“So as long as I can hook in with the CCAC team, you know, I have a social worker who can provide some of the family supports. I have a nurse who can provide some good intervention. You know, I can provide good intervention... I have all the services I need.”

“It’s much, much more communication and it’s not acutely fixing something. It’s the symptom management side but a lot of it is also just preparing for the ultimate.”



**Range of expressed roles and goals beyond medication prescribing for symptom management.*

Participant H

Profile: Female, early career, rural practice setting, adjunct academic appointment

Locations of activities: office, house calls, long term care, acute care hospital

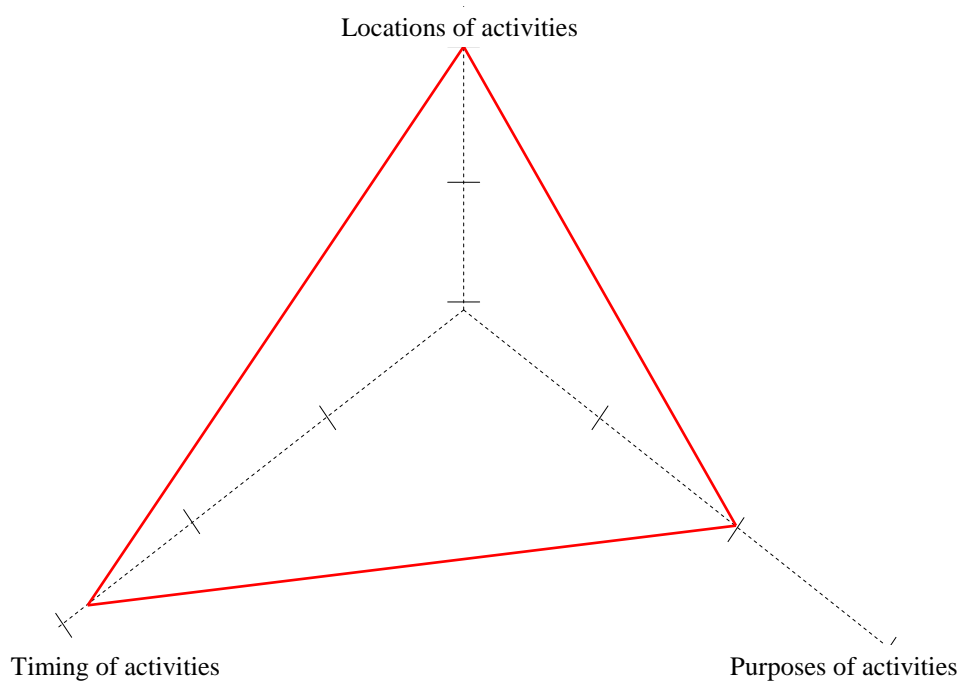
Timing of activities: ‘open access’ scheduling for all patients including house calls, group 24/7 on-call coverage for hospital and community patients

Purposes of activities:* moderate range

“If they’re in pain, I have a whole array of medications that I can use. And I can guarantee them that they’ll be comfortable.”

“I sit down and I learn more about, you know, what the family is like; what they do, what mom likes to do, what really she is passionate about.”

“Even if the visit is 5 or 10 minutes and the patient’s unconscious, I think the family really appreciates that and knows that their loved one is being cared for. Even if nothing has changed in the medication orders and everything else could have been done over the phone, that actual face to face visit with the patient or the family, I think it means a lot to patients and their families...to show that, ‘Yes, I’m still your family physician. I will be here till the end. I care for you.’”



**Range of expressed roles and goals beyond medication prescribing for symptom management.*

Participant I

Profile: Male, late career, rural practice setting, adjunct academic appointment

Locations of activities: office, house calls, long term care, acute care hospital

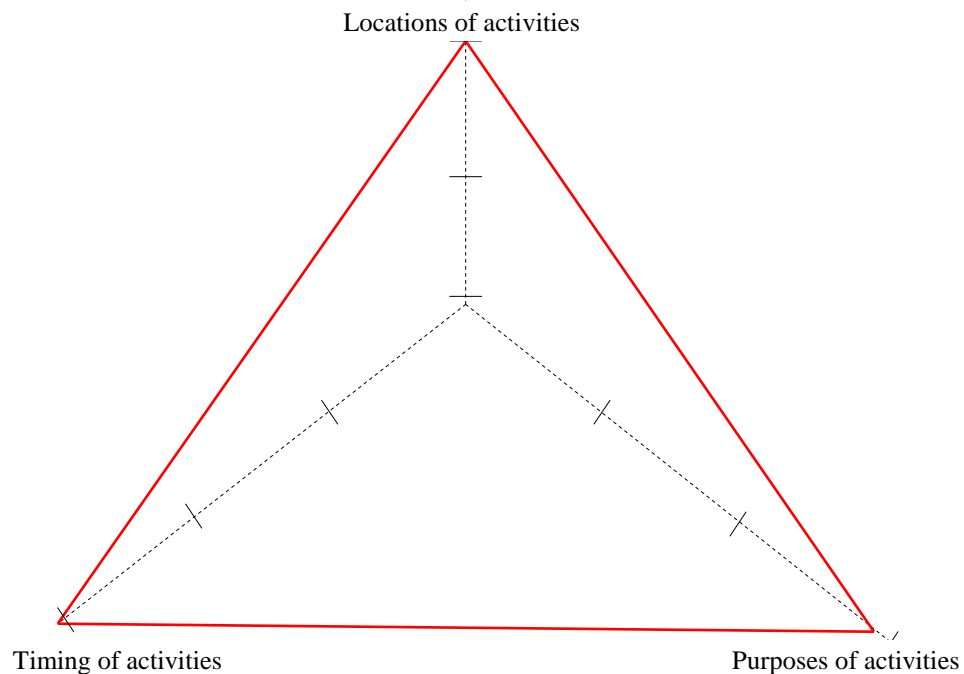
Timing of activities: two flexible half-days per week for house calls, group 24/7 on-call coverage for hospital patients, personal 24/7 on-call coverage for community end of life patients

Purposes of activities:* high range

“You sort of have to start to talk to them about those things [advance care planning]; and what needs to be in place; and how to help the family to transition.”

“Now since I have the family health team, I mean I’ll often involve our social worker as well to sort of go in and, you know, assess mood; assess what structures, supports are available for them at home.”

“I think that sometimes I will initiate the EDITH [Expected Death in the Home protocol] and sometimes CCAC will initiate the EDITH. I think it depends on who thinks about it first.”



**Range of expressed roles and goals beyond medication prescribing for symptom management.*

Appendix D: Literature search strategies and results

	MEDLINE Search Term(s)	# Results
<i>Topic 1 – Family physician provision of palliative care (with focus on interprofessional coordination)</i>		
1.	exp Family Practice/ or exp General Practice/ or exp Physicians, Family/ or exp General Practitioners/ or exp Primary Health Care/	135 868
2.	exp Palliative Care/ or exp Hospices/ or exp Hospice Care/ or exp Terminal Care/ or exp Terminally Ill/	72 100
3.	1 and 2	1970
4.	3 and English language	1742
5.	Imported to RefWorks on basis of review of titles	296
6.	Final papers included after review of abstract	187
<i>Topic 2 – Comprehensiveness in family medicine</i>		
1.	exp Family Practice/ or exp General Practice/ or exp Physicians, Family/ or exp General Practitioners/ or exp Primary Health Care/	135 868
2.	comprehensive care.mp. or comprehensiveness.mp.	3 053
3.	1 and 2	394
4.	3 and English language	343
5.	Imported to RefWorks on the basis of review of titles	32
6.	Final papers included after review of abstract	19
<i>Topic 3 – Family physician work-life balance</i>		
1.	exp Family Practice/ or exp General Practice/ or exp Physicians, Family/ or exp General Practitioners/ or exp Primary Health Care/	135 868
2.	work life balance.mp.	244
3.	1 and 2	24
4.	3 and English language	21
5.	Imported to RefWorks on the basis of review of titles	16
6.	Final papers included after review of abstract	15

All searches were most recently updated on July 26, 2012.

Appendix E: REB approval for quantitative study

SEP 3 2004



Office of Research Ethics

The University of Western Ontario
 Room 00045 Dental Sciences Building, London, ON, Canada N6A 5C1
 Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
 Website: www.uwo.ca/research/ethics

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. M. Stewart

Review Number: 10838E

Revision Number:

Protocol Title: A Profile of Family Physicians and Specialists in Southwestern Ontario

Department and Institution: Family Medicine, University of Western Ontario

Sponsor: MINISTRY OF HEALTH AND LONG-TERM CARE

Approval Date: 31-Aug-04

End Date: 31-Mar-05

Documents Reviewed and Approved: UWO Protocol, Letters of Information

Documents Received for Information:

This is to notify you that the University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has received and granted expedited approval to the above named research study on the date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

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- changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- all adverse and unexpected experiences or events that are both serious and unexpected;
- new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. Paul Harding

Karen Kueneman, BA (Hons), Ethics Officer HSREB (Expedited)
 E-mail: kueneman@uwo.ca

Faxed: Y/N
 Date: _____

This is an official document. Please retain the original in your files.

Appendix F: Variable definitions

Variable	Type	Survey Question(s)	Variable Definition
<i>Eligibility</i>			
Comprehensive Family Physicians (COMPALL)	Nominal	Q25: TYPEMED Do you practice (check ONE only): a) comprehensive family medicine b) specialty family medicine c) both comprehensive and specialty family medicine	a) OR c)
<i>Dependent</i>			
Palliative care	Nominal	Q28: PALLCARE Thinking about your patient care settings OVERALL, which of the following do you do, or provide, regularly? – Palliative care	Positive response. (Absence of response interpreted as negative)
Any house calls (ANYHOUSE)	Nominal	Q28: HOUSE A) Thinking about your patient care settings OVERALL, which of the following do you do, or provide, regularly? – House call service Q72:HOUSECAL B) How many housecalls to a patient's residence do you usually make during your working week?	Positive response to A) OR B) >0
After-hours availability	Nominal	Q24: TELPTS Below is a list of on-call activities. Thinking about your patient care setting(s) OVERALL, please check all that apply. – Do on call for non-hospitalized patients, telephone availability and see patients as required.	Positive response. (Absence of response interpreted as negative)
Potential Availability (POTAVAIL)	Ordinal		<ul style="list-style-type: none"> • High potential availability = palliative care AND any house calls AND available to see non-hospitalized patients after hours • Moderate potential availability = palliative care OR any house calls OR available to see non-hospitalized patients after hours • Low potential availability = NEITHER palliative care NOR house calls NOR

			available to see non-hospitalized patients after hours
<i>Independent</i>			
<i>Family Physician Characteristics</i>			
Age (AGE)	Continuous	Q77: BIRTHYR Your year of birth:	2004 – Year of birth
Gender	Nominal	Q78: GENDER Your gender: M/F	
Years in Practice (YEARS)	Continuous	Q81: GRADYEAR Date of your graduation with MD:	2004 – Year of graduation
Completed family medicine residency	Nominal	Q83: FMRESID Did you complete a family medicine residency?	
Additional palliative care training	Nominal	Q84: TPALLCAR Following completion of your internship or family medicine residency program, which of the following additional structured training have you received, if any? Please check all that apply. Palliative care	
International Medical Graduate	Nominal	Q85: INTGRAD Are you an international medical graduate?	
Attitude toward palliative care at home (ATTITUDE)	Continuous	Q75: FPDYHOME Please indicate your agreement or disagreement with each of the following statements (1 strongly agree – 4 strongly disagree): Family physicians should take responsibility for the care of their dying patients at home.	5 - FPDYHOME
<i>Practice Characteristics</i>			
Rural/urban (RURAL)	Nominal	Q74: POPTYPE Please describe the population PRIMARILY served by you. a) Inner city b) urban/suburban c) small town d) rural e) geographically isolated/remote	Urban = a) OR b) Rural = c) OR d) OR e)

Solo/group (GROUP)	Nominal	Q11: PRACTYPE With respect to your MAIN patient care setting, how is the practice organized? a) Solo practice b) Family physician group practice c) Family physician/specialist group practice	Solo = a) Group = b) or c)
Remuneration (FFS vs. AFP) (ALTFUND)	Nominal	Q12: FHT, FHN, FHG, CHC, HSO OTHPAT Is your MAIN patient care setting a: a) Family health team b) Family health network c) Family health group d) Community Health Clinic e) Health services organization	Alternate Funding Plan (AFP) = a) OR b) OR c) OR d) OR e) Fee for service (FFS) = no response
Teaching practice (y/n) (ANYTEACH)	Nominal	Q44: TEACH Are you currently teaching undergraduate medical students/residents? a) Yes, undergraduate medical students only b) Yes, residents only c) Yes, both undergraduate medical students and residents.	Any teaching = a) OR b) OR c) No teaching = no response
Number patients/week	Continuous	Q22: PTSSEEN What is the usual number of patients seen in a full week of practice at your MAIN patient care setting? (<25, 25, 50, 75, 100, 125, 150, 175, 200, 225, 250+)	
≥1 free weekday clinical session (FREEDAY)	Nominal	Q23: MONAM - FRIPM Please indicate the number of hours each morning, afternoon and evening that you see patients.	Free weekday session IF 0 hours indicated for any morning or afternoon session Monday-Friday.
≥1 after hours clinical session (AHCLINIC)	Nominal	Q23: MONEVE - SUNEVE Please indicate the number of hours each morning, afternoon and evening that you see patients.	Scheduled after hours IF >0 hours indicated for any evening session Monday-Friday, OR morning, afternoon or evening session Saturday or Sunday

Appendix G: Power calculation

The total sample size is 482 with alpha set at 0.05. The dependent variable type is ordinal.

For dichotomous independent variables:

Calculation used in the study: 3x2 chi-square with unequal group sizes

Analogy for power calculation: 3x2 chi-square assuming equal group sizes

Degrees of freedom: 2

Power (1- β): 0.99999 for $w=0.3$ (moderate effect)

0.488 for $w=0.1$ (small effect)

For continuous independent variables:

Calculation used in the study: Kruskal-Wallis

Analogy for power calculation: ANOVA assuming equal group sizes

Degrees of freedom: 2

Power (1- β): 0.99921 for $f=0.25$ (moderate effect)

0.486 for $f=0.1$ (small effect)

The calculations utilized to estimate power were the most similar to the actual study methods among the options available in the G-Power software program (Faul 2009).

Both power calculations are likely to underestimate the risk of type 2 error. For the dichotomous independent variables, this is because the power calculation assumes equal group sizes (which was not the case). For the continuous independent variables, the increased risk of a type 2 error is because the power calculation assumes equal group sizes and a normal distribution of the dependent variable (neither of which was the case).

There were no suitable analogies for estimating the power of multinomial logit procedures.

Appendix H: Missing data analysis

- Comprehensive FPs with complete dependent variable data = 573
- Missing data on ≥ 1 independent variable data element: 91 (15.9%)
- Comprehensive FPs with complete data: 482

1. Do family physicians with missing values differ from family physicians with complete responses?

Variable	Type	# Missing (% of N=583)	Statistic	p-Value
Potential availability	Ordinal	6 (1.0)	3x2 chi square	0.716
<i>Family Physician Characteristics</i>				
Age	Continuous	11 (1.9)	t-test	0.622
Gender	Nominal	2 (0.3)	chi square	0.064
Years in practice	Continuous	1 (0.2)	t-test	0.579
Completed family medicine residency	Nominal	1 (0.2)	chi square	0.841
Additional palliative care training	Nominal	N/A [†]	chi square	0.319
International medical graduate	Nominal	35 (6.1)	chi square	0.065
Attitude toward palliative care at home	Continuous	8 (1.4)	t-test	0.561
<i>Practice Characteristics</i>				
Rural/urban	Nominal	11 (1.9)	chi square	0.241
Solo/group	Nominal	16 (2.8)	chi square	0.294
Remuneration (FFS vs. AFP)	Nominal	N/A [†]	chi square	0.047*
Teaching practice (y/n)	Nominal	4 (0.7)	chi square	0.076
Number patients/week	Continuous	8 (1.4)	t-test	0.970
≥ 1 free weekday clinical session	Nominal	19 (3.3)	chi square	0.269
≥ 1 after hours clinical session	Nominal	19 (3.3)	chi square	0.313

[†] Due to format of survey questions for these items, absence of a response was automatically interpreted as negative, and thus there were no missing data for these items.

*statistically significant at $p < 0.05$. Missing variable cases less likely to receive remuneration via an alternate funding plan.

2. Does exclusion of family physicians with missing values change the results on bivariable analysis?

Variable	Type	Statistic	p-Value when all comprehensive family physicians included and missing values ignored	p-Value when only comprehensive family physicians with complete data included
<i>Family Physician Characteristics</i>				
Age	Continuous	ANOVA	0.000*	0.000*
Gender	Nominal	chi square	0.000*	0.000*
Years in practice	Continuous	ANOVA	0.000*	0.000*
Completed family medicine residency	Nominal	chi square	0.105	0.226
Additional palliative care training	Nominal	chi square	0.011*	0.009*
International medical graduate	Nominal	chi square	0.139	0.079
Attitude toward palliative care at home	Continuous	ANOVA	0.000*	0.000*
<i>Practice Characteristics</i>				
Rural/urban	Nominal	chi square	0.000*	0.000*
Solo/group	Nominal	chi square	0.446	0.382
Remuneration (FFS vs. AFP)	Nominal	chi square	0.000*	0.000*
Teaching practice (y/n)	Nominal	chi square	0.024*	0.004*
Number patients/week	Continuous	ANOVA	0.007*	0.049*
≥1 free weekday clinical session	Nominal	chi square	0.026*	0.078
≥1 after hours clinical session	Nominal	chi square	0.000*	0.001*

*statistically significant at $p < 0.05$.

Conclusion: Exclusion of cases with will not affect results.

Curriculum Vitae

Joshua David Shadd

APPOINTMENTS AND POSITIONS HELD

Current Appointments

- 2009 – present Assistant Professor, Centre for Studies in Family Medicine, Department of Family Medicine, Schulich School of Medicine & Dentistry, The University of Western Ontario
- 2011 – present Physician, London Health Sciences Centre, Department of Family Medicine, Parkwood Hospital, Attending Medical Staff
- 2009 – present Physician, London Health Sciences Centre, Department of Family Medicine, Palliative Medicine
- 2010 – present Scientist, Lawson Health Research Institute, London, Ontario, Canada

Previous Appointments

- 2006 – 2009 Attending Medical Staff, Kingston General Hospital, Hotel Dieu Hospital, Providence Continuing Care Centre, Kingston Regional Cancer Centre, Family Medicine, Oncology, Kingston, Ontario, Canada
- 2006 – 2009 Assistant Professor, Queen's University School of Medicine, Faculty of Health Sciences, Kingston, Ontario, Canada
- 2005 Lecturer, University of Manitoba, Department of Family Medicine, Winnipeg, Manitoba, Canada
- 2005 Consultant Staff, Winnipeg Regional Health Authority, Palliative Care Medicine Program, Winnipeg, Manitoba, Canada
- 2005 Attending Medical Staff, St. Boniface Hospital, Riverview Health Centre, Family Medicine, Winnipeg, Manitoba, Canada
- 2004 Family Physician, Winnipeg, Manitoba
- 2002 - 2003 Family Physician, Pickle Lake Medical Clinic, Pickle Lake, Ontario, Canada
- 2001 - 2002 Family Physician, Steinbach Medical Clinic, Steinbach, Manitoba, Canada
- 2001 - 2002 Attending Medical Staff, Bethesda Hospital, Steinbach, Manitoba, Canada

EDUCATION AND QUALIFICATIONS

Degrees and Diplomas

- 2008 - present MClSc, University of Western Ontario, Master's Thesis, Clinical Science in Family Medicine, London, Ontario, Canada
- 1995 - 1999 MD, Queen's University School of Medicine, Kingston, Ontario
- 1992 - 1995 BSc, University of Western Ontario, Biology, Bachelor's Equivalent, graduated with distinction, London, Ontario

Specialized Training

- 1999 - 2001 Residency, Queen's University School of Medicine, Family Medicine, Kingston, Ontario
- 2004 Fellowship, University of Manitoba, Palliative Medicine, Winnipeg, Manitoba

RESEARCH AND SCHOLARLY ACTIVITIES

Grants (since 2008)

- 2013 - 2015 Co-Investigator, Palliative care on the heart failure care team: Mapping patient and provider experiences and expectations, PI: Lingard L, Canadian Institutes of Health Research Operating Grant, Funded, 232,048 CAD
- 2012 - 2013 Co-Principal Investigator, Palliative care on the heart failure care team: Mapping patient and provider experiences and expectations, to inform guideline implementation, PI: Schultz V, AHSC AFP Innovation Fund, Funded, 143,587 CAD
- 2012 - 2014 Co-Principal Investigator, Rates of Referral from Family Physicians to Specialist Physicians in a National Primary Care Electronic Medical Record Database, PI: Shadd J, Lawson Health Research Institute, Funded, 14,910 CAD
- 2011 - 2012 Co-Applicant, Community-based End of Life Care: Toward an interdisciplinary, cross-jurisdictional program of research, PI: Bruge F, Canadian Institutes of Health Research (CIHR), Funded, 23,960 CAD
- 2011 Co-Investigator, Understanding the current use of urinary catheters on a palliative care unit, PI: Faulds C, Funded, 18,760 CAD

- 2011 Principal Investigator, Hospice Palliative Care in the South West LHIN - Current Needs and Activities, PI: Shadd J, Funded, 3,900 CAD
- 2011 - 2012 Principal Investigator, Neuropathic pain in a primary care electronic medical record database. PI: Shadd J, Research grant Neuropathic Pain Database in Primary Care (NePDAT-P) held by Dr. Dwight Moulin at Lawson Health Research Institute, Funded, 27,165 CAD
- 2010 - 2011 Principal Investigator, What shapes family physicians' patterns of care for community patients at end of life? PI: Shadd J, UWO Department of Family Medicine Research Trust Fund, Funded, 1,526 CAD
- 2010 Co-Principal Investigator, Patterns of Specialty Medical Referral in a Primary Care Electronic Medical Record Database. PI: Shadd J & Ryan BL (Co-PIs), Primary Health Care System Program, Funded, 14,719 CAD
- 2009 Principal Investigator, FIFE - Then What? PI: Shadd J. CFPC Research & Education Foundation, Janus Research Proposal Development Grant, Funded, 1,500 CAD
- 2008 - 2009 Co-Investigator, Mentoring Interprofessional Primary Health Care Teams in Collaborative Palliative Care Practice - Phase 3, PI: Dudgeon D, MOHLTC / Ministry of Training, Colleges and Universities Interprofessional Care/Education Fund (ICEF), Funded, 403,005 CAD

HONOURS AND AWARDS

- 2012 St. Joseph's Health Care Professional Staff Organization Recognition & Reward Award, For demonstrating the values of the Professional Staff Organization by excellence in clinical care, teaching, research, and administration
- 2010 - 2011 Martin J Bass Award for Postgraduate Studies in Family Medicine, For an outstanding student in the Masters of Clinical Science program in the Department of Family Medicine, 2,000, Type: Distinction, Local, Family Medicine, London, Ontario, Canada
- 2010 Dean's Award of Excellence, Team Award for the Centre for Studies in Family Medicine, Type: Distinction, Co-recipient, Schulich School of Medicine & Dentistry, The University of Western Ontario, London, Ontario
- 1996 MRC Student Research Scholarship, Type: Research award, Medical Research Council of Canada

- 1996 Harvey Sullivan Scholarship, Type: Distinction, Victoria Hospital Foundation
- 1995 Robert Bruce Scholarship, Type: Distinction, Faculty of Medicine, Queen's University
- 1995 Edgar Forrester Scholarship, Type: Distinction, Faculty of Medicine, Queen's University

PUBLICATIONS

Peer Reviewed Publications (since 2008)

1. **Shadd J**, Burge F, Stajduhar KI, Sohen SR, Kelley ML, Pesut B. It's time to define - and measure - a palliative approach in primary care. *Canadian Family Physician*. **Principal Author (In press)**
2. Lingard L, McDougall A, Schulz V, **Shadd J**, Marshal D, Strachan PH, Tait G, Malcolm A, Kimel G. Understanding palliative care on the heart failure care team: An innovative research methodology. Accepted by *Journal of Pain and Symptom Management*. **Coauthor (In press)**
3. Terry AL, Cejic S, Ryan BL, **Shadd JD**, Stewart M, Fortin M, Thind A. You and your EMR: the research perspective: Part 4. Optimizing EMRs in primary health care practice and research. *Can Fam Physician*. 2012 Jun;58(6):705-6. **Coauthor**
4. **Shadd JD**, Cejic S, Terry A, Ryan BL, Stewart M, Thind A. You and your EMR: the research perspective: part 3. Answering practice-level questions. *Can Fam Physician*. 2012 Mar;58(3):344-5. **Principal Author**
5. Ryan BL, **Shadd JD**, Terry A, Cejic S, Chevendra V, Thind A. You and your EMR: the research perspective: part 2. How structure matters. *Can Fam Physician*. 2011 Dec;57(12):1473-4. **Coauthor**
6. Ryan BL, Cejic S, **Shadd JD**, Terry A, Chevendra V, Thind A. You and your EMR: the research perspective: Part 1. Selecting and implementing an EMR. *Can Fam Physician*. 2011 Sep;57(9):1090-1. **Coauthor**
7. Corkum M, Viola R, Veenema C, Kruszelnicki D, **Shadd J**. Prognosticating in Palliative Care: A Survey of Canadian Palliative Care Physicians. *J Palliat Care*. 2011 Summer;27(2):89-97. **Coauthor**
8. **Shadd J**, Ryan BL, Maddocks H, Thind A. Patterns of Referral in a Canadian Primary Care Electronic Health Record Database: Retrospective Cross-Sectional Analysis. *Inform Prim Care*. 2011 Jul;19(4):217-23. **Principal Author**

9. **Shadd J.** Pregabalin for Neuropathic Pain: Breakthrough or Me-Too? *Canadian Journal of Diagnosis*, 2008; 25(10): 71-73. **Principal Author**
10. **Shadd J.** Should Palliative Care be a Specialty?: Yes. *Canadian Family Physician*, 2008; 54(6): 840-842. (Follow-up publications: Rebuttal; 54(7): 974. Letter to the Editor; 54(9): 1231). **Principal Author**

Non-Peer Reviewed Publications (since 2008)

1. Murray K, **Shadd J.** Dying Causes Delirium! *CARE Magazine*, College of Licensed Practical Nurses of Alberta. 2012; 26(1): 26-27. **Coauthor**
2. Murray K, **Shadd J.** Nausea and vomiting. *CARE Magazine*, College of Licensed Practical Nurses of Alberta. 2011; 25(3): 26-27. **Coauthor**
3. **Shadd J**, Brown JB. Component III: Finding Common Ground. *Unexplored Territory - Part 1*. In: Brown JB, Thornton T, Stewart M, editors. *Challenges and Solutions: Narratives of Patient-Centered Care*. London, UK: Radcliffe Publishing; 2011. p126-128. **Principal Author**
4. **Shadd J.** Component I: Exploring Health, Disease and the Illness Experience. *Frozen*. In: Brown JB, Thornton T, Stewart M, editors. *Challenges and Solutions: Narratives of Patient-Centered Care*. London, UK: Radcliffe Publishing; 2011. P. 20-23. **Principal Author**
5. **Shadd J**, Brown JB. Component IV: Enhancing the Patient-Doctor Relationship. *Unexplored Territory - Part 2*. In: Brown JB, Thornton T, Stewart M, editors. *Challenges and Solutions: Narratives of Patient-Centered Care*. London, UK: Radcliffe Publishing; 2011. p136-137. **Principal Author**
6. Dudgeon D & **Shadd J.** Palliative Care: Dyspnea. In: *UpToDate*, Rose, BD (Ed), UpToDate, Waltham, MA, 2011. [ebook]. **Coauthor**
7. **Shadd J**, Ryan BL, Thind A, Stewart M. Patterns of Specialty Medical Referral - Analysis of a Primary Health care Electronic Record Database. Report submitted to PHCS, Government of Ontario, 2010. **Principal Author**
8. Davidson L & **Shadd J.** Introduction of an ungraded portfolio: what teachers can learn about students. In: Van Melle E, Pinchin S, McEwen L, & Alexander L, editors. *Learning from Each Other: A Compendium of Innovative Teaching Strategies*. Office of Health Science Education, Faculty of Health Sciences, Queen's University, Kingston, Ontario, January, 2010, 8D; p. 55-56. **Co-Principal Author**
9. **Shadd J** & Dudgeon D. Dyspnea. In: *Palliative Medicine*, Walsh D, editor; Elsevier, Philadelphia, 2009, p. 877-881. **Principal Author**

RESEARCH PRESENTATIONS (since 2008, selected)**Poster Presentations**

- 2012/10/10 19th International Congress on Palliative Care, Presenters: Byrne J, Whitfield P, Woolmore-Goodwin S, Gutmanis I, **Shadd J**, Faulds C. Understanding the use of urinary catheters on a palliative care unit: preliminary results, Montreal, Quebec, Canada, **Presenter**
- 2012/04/29 Annual Hospice Palliative Care Ontario Conference 2012, Presenters: Piamonte M, **Shadd J**. Prioritizing Measures of Hospice Palliative Care: Stakeholder Input into a Regional Overview Document. Toronto, Ontario, Canada, **Presenter**
- 2011/06/08 2011 Trillium Primary Health Care Research Day. Presenters: Ryan BL, **Shadd J**, Maddocks H, Thind A. Variance Partitioning in Referral Patterns: Patient or Practice? Toronto, Ontario, Canada
- 2010/10/28 The Canadian Hospice Palliative Care Association Annual Conference, Presenters: **Shadd J**. Family Physician Engagement in Community Palliative Care, Ottawa, Ontario, Canada, **Presenter**
- 2009/02 3rd Annual St. Joseph's Care Group, Showcase of Applied Health Research, Presenters: Green E, Coulson K, Sanders J, Kelley ML, Marshall D, Pisco L, Rush B, Schroder C, **Shadd J**, Moxam RS, Taniguchi A, Tomalty L, Van Dijk J, Durkin L, & Dudgeon D. Mentoring primary health care nurse practitioners: Family physician dyads in collaborative palliative care practice, Thunder Bay, Ontario, **Presenter**
- 2009/03 Palliative Medicine and Supportive Oncology 2009, Presenters: Hallelujah P & **Shadd J**. Is There a Work of Dying? Ft. Lauderdale, Florida, United States, **Presenter**
- 2008/03 Palliative Medicine 2008, Presenters: **Shadd J**, Cahill C, Davidson L, Hobbs N, Pinchin S, Schroder C, & Van Melle E. Pain as a Thread: Toward a Progressive Integrated Collaborative Pain Curriculum, Scottsdale, Arizona, United States, **Speaker**

Oral Research Abstracts

- 2012/10/10 19th International Congress on Palliative Care, Presenters: **Shadd JD**. What Shapes Family Physicians' Pattern of Care for Community Patients at End of Life? A Grounded Theory Study. Research Forum Presentation, Montreal, Quebec, Canada, **Presenter**
- 2012/06/07 Canadian Society of Palliative Care Physicians, Presenters: **Shadd JD**. What Shapes Family Physicians' Pattern of Care for Community Patients at End of Life? A Grounded Theory Study. Emerging Scientific Abstract

- Presentation at the 8th Annual Advanced Learning in Palliative Medicine Conference, Kingston, Ontario, Canada, **Presenter**
- 2012/06/06 2012 Trillium Primary Health Care Research Day. Presenters: Ryan BL, **Shadd JD**, McKay S, Maddocks H. Estimating the prevalence of neuropathic pain in a primary care electronic medical record database. Toronto, Ontario, Canada
- 2010/11/16 2010 Annual Meeting of the North American Primary Care Research Group, Presenters: Ryan B, **Shadd J**, Thind A, Stewart M, Maddocks H. Specialist Referrals from Family Physicians: Who and How Many? Seattle, Washington, United States, **Presenter**
- 2010/11/14 2010 Annual Meeting of the North American Primary Care Research Group, Presenters: **Shadd J**. Family Physician Engagement in Community Palliative Care. Seattle, Washington, United States, **Speaker**
- 2011/10/04 Presenters: McDougall A, Lingard L, Arnold JMO, **Shadd J**, Shultz V, Stewart M, Patient-centred sampling units: An innovative methodological practices for studying healthcare teams. Centre for Education Research & Innovation Third Annual Research Symposium, Western University. London, Ontario, Canada, **Presenter**
- 2011/06/08 2011 Trillium Primary Health Care Research Day. Presenters: **Shadd J**, Maddocks MA, McKay S, Ryan BL. Neuropathic pain in a primary care electronic medical record database: Looking for a condition not coded in ICD or ICPC, Toronto, Ontario, Canada, **Speaker**
- 2010/06/09 Trillium Primary Care Research Forum 2010, Presenters: **Shadd J**, Ryan BL, Maddocks HL, Thind A, & Stewart M. Family Physician Referral Patterns: Who's Sending Who to Whom? Toronto, Ontario, Canada, **Speaker**
- 2010/06/09 Trillium Primary Care Research Forum 2010, Presenters: **Shadd J**. Factors Affecting Family Physician Provision of Palliative Care, Toronto, Ontario, Canada, **Speaker**
- 2009/04/20 Provincial Hospice Palliative Conference 2009, Presenters: Yuen H & **Shadd J**. Illness Trajectories: Knowledge & Attitudes of Junior Housestaff and Attending Physicians, Toronto, Ontario, **Presenter**
- Other**
- 2012/10/09 International Primary Palliative Care Research Group, Presenters: **Shadd JD**, Family physicians' patterns of care for community patients at end of life. Presentation to the IPPCRG Annual Meeting, Montreal, Quebec, Canada, **Presenter**

- 2011/06/24 Brazilian Society of Family and Community Medicine, Presenters: **Shadd J.** Theoretical Foundations of Family Medicine. 11th Brazilian Congress of Family and Community Medicine. Brasilia, Brazil, **Invited Speaker**
- 2011/06/23 Brazilian Society of Family and Community Medicine, Presenters: Brown JB, **Shadd J.** Patient-Centred Medicine: A Mini-Course, 11th Brazilian Congress of Family and Community Medicine, Brasilia, Brazil, **Invited Speaker**
- 2011/05/19 MOHLTC - Primary Health Care System Program, Presenters: **Shadd J.**, Ryan BL, Patterns of specialty medical referral: Analysis of a primary health care electronic medical record database, Kingston, Ontario, Canada, **Invited Speaker**
- 2009/04/20 Provincial Hospice Palliative Conference 2009, Presenters: **Shadd J.** Toward a Theoretical Framework for Hospice Palliative Care, Toronto, Ontario, **Speaker**