

**EVALUATING CANADA'S COMPASSIONATE CARE
BENEFIT: A GEOGRAPHIC PERSPECTIVE**

by

Melissa Giesbrecht
BA-Honours, Concordia University 2006

THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF ARTS

In the
Department of Geography

© Melissa Giesbrecht 2009

SIMON FRASER UNIVERSITY

Summer 2009

All rights reserved. This work may not be
reproduced in whole or in part, by photocopy
or other means, without permission of the author.

APPROVAL

Name: Melissa Giesbrecht
Degree: Master of Arts
Title of Thesis: Evaluating Canada's Compassionate Care Benefit: A Geographic Perspective

Examining Committee:

Chair: Nick Blomley
Professor, Department of Geography, SFU

Valorie Crooks
Senior Supervisor
Assistant Professor, Department of Geography, SFU

Nadine Schuurman
Supervisor
Associate Professor, Department of Geography, SFU

Olena Hankivsky
External Examiner
Associate Professor, Public Policy Program, SFU

Date Defended/Approved: July 27, 2009



SIMON FRASER UNIVERSITY
LIBRARY

Declaration of Partial Copyright Licence

The author, whose copyright is declared on the title page of this work, has granted to Simon Fraser University the right to lend this thesis, project or extended essay to users of the Simon Fraser University Library, and to make partial or single copies only for such users or in response to a request from the library of any other university, or other educational institution, on its own behalf or for one of its users.

The author has further granted permission to Simon Fraser University to keep or make a digital copy for use in its circulating collection (currently available to the public at the "Institutional Repository" link of the SFU Library website <www.lib.sfu.ca> at: <<http://ir.lib.sfu.ca/handle/1892/112>>) and, without changing the content, to translate the thesis/project or extended essays, if technically possible, to any medium or format for the purpose of preservation of the digital work.

The author has further agreed that permission for multiple copying of this work for scholarly purposes may be granted by either the author or the Dean of Graduate Studies.

It is understood that copying or publication of this work for financial gain shall not be allowed without the author's written permission.

Permission for public performance, or limited permission for private scholarly use, of any multimedia materials forming part of this work, may have been granted by the author. This information may be found on the separately catalogued multimedia material and in the signed Partial Copyright Licence.

While licensing SFU to permit the above uses, the author retains copyright in the thesis, project or extended essays, including the right to change the work for subsequent purposes, including editing and publishing the work in whole or in part, and licensing other parties, as the author may desire.

The original Partial Copyright Licence attesting to these terms, and signed by this author, may be found in the original bound copy of this work, retained in the Simon Fraser University Archive.

Simon Fraser University Library
Burnaby, BC, Canada

STATEMENT OF ETHICS APPROVAL

The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

(a) Human research ethics approval from the Simon Fraser University Office of Research Ethics,

or

(b) Advance approval of the animal care protocol from the University Animal Care Committee of Simon Fraser University;

or has conducted the research

(c) as a co-investigator, collaborator or research assistant in a research project approved in advance,

or

(d) as a member of a course approved in advance for minimal risk human research, by the Office of Research Ethics.

A copy of the approval letter has been filed at the Theses Office of the University Library at the time of submission of this thesis or project.

The original application for approval and letter of approval are filed with the relevant offices. Inquiries may be directed to those authorities.

Simon Fraser University Library
Simon Fraser University
Burnaby, BC, Canada

ABSTRACT

Equity of access to health services is a main interest of health geographers. Recently, consideration has extended to policy-relevant analyses that forward spatial implications. In 2004, the Compassionate Care Benefit (CCB) was implemented to provide income assistance and job security to insured Canadians who take temporary leave from employment to care for a dying person. However, since it was introduced, uptake of the CCB has been significantly low. The development and implementation of a 'spatially informed' knowledge translation strategy can result in the identification of more efficient information-sharing pathways in order to increase needed awareness about the CCB, while examining how Canadians experience and understand the program across various geographic 'scales' assists with illuminating challenges and inequities to access. Such geographic perspectives contribute valuable knowledge to program evaluation, which, ultimately can better inform decision-makers on how to more effectively meet the needs of program users and other stakeholders.

Keywords: Compassionate Care Benefit; Canada; family caregivers; spatial analysis; knowledge translation; scale

Subject Terms: Medical geography – research Canada; Unemployment insurance – Canada; Evaluation research; Caregivers

ACKNOWLEDGEMENTS

I am grateful to all the respondents who took the time to share their experiences with us and for the continued involvement of the Evaluation Taskforce. I am also thankful to Kelli Stajduhar and Nathaniel Bell for their assistance. I would also like to extend my sincere gratitude to Nadine Schuurman and Allison Williams for their valuable advice and feedback. However, I am most indebted to my supervisor, Valorie Crooks, for her encouragement, guidance, and continuous support from beginning to end. This study was funded by an Operating Grant from the Canadian Institutes of Health Research.

TABLE OF CONTENTS

Approval	ii
Abstract	iii
Acknowledgements	iv
Table of Contents	v
List of Figures.....	vii
List of Tables	viii
Chapter 1 Introduction	9
1.1 Introduction	9
1.1.1 The Increasingly Important Role of Family Caregivers in Canada	12
1.1.2 The Compassionate Care Benefit	14
1.2 Study Overview	16
1.3 Thesis Outline	19
Chapter 2 Spatially informed knowledge translation: informing potential users of Canada’s Compassionate Care Benefit	22
2.1 Abstract	22
2.2 Introduction	23
2.2.1 Background	27
2.2.2 Evaluative Study Overview	31
2.3 Part One: Determining who is likely to be a CCB-eligible family caregiver	32
2.3.1 Method	32
2.3.2 Findings.....	34
2.4 Part Two: Determining where likely CCB-eligible Canadians are located	35
2.4.1 Method	35
2.4.2 Findings.....	36
2.5 Part Three: Determining how to get information to likely CCB users and other Canadians	38
2.5.1 Method	38
2.5.2 Findings.....	40
2.6 Discussion	45
2.6.1 Implications for Creating an Information Dissemination Strategy	46
2.6.2 Engagement with the Knowledge-to-Action Cycle.....	47
2.7 Limitations	49

2.8	Conclusion	50
Chapter 3 Scale as an explanatory concept: evaluating Canada's Compassionate Care Benefit program.....52		
3.1	Abstract.....	52
3.2	Background	53
3.3	Study Overview	56
3.3.1	Recruitment	56
3.3.2	Data Collection and Participant Overview	57
3.3.3	Analytic Process.....	59
3.4	Characterizing Respondents' Use of Scalar Categories	60
3.4.1	Regional Scale: Its nature and key issues	61
3.4.2	Community Scale: Its nature and key issues	62
3.4.3	Home Scale: Its nature and key issues	64
3.5	Scalar Explanations: Implications for the CCB	66
3.6	Revisiting Scale as an Explanatory Concept	69
3.7	Conclusion	72
Chapter 4 Conclusion.....74		
4.1	Summary.....	74
4.2	Research Contribution.....	76
4.2.1	Identifying Informational Challenges	77
4.2.2	Valuing the Perspectives of Front-line Palliative Care Providers	78
4.2.3	Advancing the Use of Geographic Concepts in Applied Health Research	79
4.3	Next Steps.....	81
4.4	Conclusion	84
References.....87		

LIST OF FIGURES

Figure 2-1: Engagement with the knowledge-to-action cycle	26
Figure 2-2: Locations of likely CCB-eligible family caregivers across Canada.....	37
Figure 2-3: Two distinct suggested pathways of information dissemination	42
Figure 4-1: Knowledge-to-action cycle	81

LIST OF TABLES

Table 2-1: Deomographic profile of likely CCB-eligible family caregivers.....	34
Table 2-2: Respondents by occupational grouping.....	39
Table 3-1: FCG respondent overview.....	58
Table 3-2: HSCW respondents by occupational grouping.....	59
Table 3-3: Scalar implications for the CCB program.....	67

CHAPTER 1

INTRODUCTION

1.1 Introduction

The recognition that ‘place’ influences health is not new. Dating as far back as Hippocrates’ writing of *Airs, Waters and Places* in 400BC, attention has been given over time to the importance of culture-environment (or even people-place) interactions for human health (Meade & Earickson, 2005). These complex interactions have been studied under various interdisciplinary rubrics, such as geographic pathology, medical ecology, medical topology, geographic epidemiology, and geomedicine, among many others (Meade & Earickson, 2005), all of which have advanced highly spatial and geographic perspectives. However, it was not until the late 1970s that the specific field of ‘medical geography’ emerged as a subdiscipline within human geography (Andrews & Moon, 2005). Since this time, medical geography has advanced and developed into an established field of diverse scholars and committed researchers who aim to explore people-place-health connections using new techniques and perspectives.

Evolving since its beginnings, the subdiscipline of medical geography has undergone a particularly transformative shift over the past few decades: it has moved away from more positivist and reductionist orientations that favour disease-focused medical views and towards an increasing recognition of various constructions of well-being and social models of health and health care (Kearns & Moon, 2002). Today, acknowledgement over the many social determinants of health and the reconceptualised notions of the various ways that ‘health’ and ‘place’ can be socially constructed has allowed for the emergence of new

questions (e.g., how is ‘place’ involved in experiences of ‘health?’) and subsequent employment of a broad range of research methods (Luginaah, 2009). This transition in geographers’ conception of health-place research has resulted in the re-naming of the subdiscipline to a more encompassing ‘health geography’ (Kearns & Moon, 2002).

In Canada, health geography is a rich area of scholarship within human geography. Researchers in this area have been inspired by the shift away from more positivist paradigms associated with medical geography and are certainly at the forefront of advancing the subdiscipline (Eyles & Elliott, 2001; Luginaah, 2009). Canadian health geography research is having significant impacts, particularly with regard to policy setting in health and health care (Luginaah, 2009). In Luginaah’s (2009) recent review on the state of the subdiscipline in the Canadian context, he identifies several established areas of interest, which include: population health; health inequalities at the local, national, and international scales; disability studies; aging and health; housing and health; the health and social conditions of Aboriginal Canadians; psychosocial health; mental health; women’s health; the social construction of the human body; environmental exposure; environmental risk and policy; environmental justice; chronic diseases; and emerging epidemics. Luginaah (2009) also observes that issues of accessibility and use of health services is an area of heightened interest by Canadian health geographers. Topics of inquiry in this stream of scholarship include: health service restructuring; political action and consciousness among health care recipients; the spatial analysis of and health care using geographic information systems; and the role of informal caregiving within health care (Luginaah, 2009).

In this thesis, I contribute to the field of health geography by extending upon Canadian health geographers’ focus on issues of accessibility through examining a national health-related social program, thus moving the topic of investigation away from health

services proper. Specifically, herein I apply two distinct geographically-centred analyses to examine issues of access as they pertain to a Canadian program which aims to support those caring for dying family members and close others, namely the Compassionate Care Benefit (CCB). There is no singular definition of ‘access’ and the concept is applied in numerous ways in the health and health care literatures (Hay et al., 2006; Sanmartin et al., 2003). Often conceptualized exclusively as a more physical and/or spatial term (e.g., distance to services), the conceptualization of ‘access’ used in this study is more broad. Although particular geographic notions of access are referenced (e.g., how living in rural communities can impact one’s access to health care services due to distance and location), I focus more so on how complex social, economic and political processes, among others, intersect and thus affect people’s access to ‘information’ or forms of ‘support’. For one example, the diffusion of information is inherently spatial as it is shared through networks and across spaces and places, however, one’s cultural, linguistic, social, and/or economic status can greatly affect one’s ‘access’ to particular types of information and knowledge. Therefore, the definition of access in this study reaches beyond the physical notion of ‘access’ to also include one’s social positionality and how this may create particular barriers.

In this chapter, I introduce the general focus as well as the specific aims of this thesis research. In the next section, I provide background knowledge on a shift being experienced in Canada whereby care is increasingly taking place within the home, thus resulting in the increased responsibility being placed on family members to become informal (i.e., family, unpaid, untrained) caregivers. I then present details on one of Canada’s responses to this shift: the implementation of the CCB program. Following this, I introduce the study objectives and conclude with an outline of the thesis chapters to follow.

1.1.1 The Increasingly Important Role of Family Caregivers in Canada

Neoliberal-informed health care restructuring within Canada, as well as other Western nations, has resulted in a growing expectation for the non-profit sector (e.g., voluntary organizations, family caregivers) to play a more prominent role in the organization and delivery of health and social care services (Chouinard & Crooks, 2008; Skinner & Rosenberg, 2005). An outcome of such restructuring, and the larger push towards deinstitutionalization, is that most forms of care are more frequently taking place within the home rather than in formal institutions due to cost cutting measures (Burge et al., 2003; Lilly et al., 2007; Skinner & Rosenberg, 2005). At the same time, the literature is increasingly suggesting that Canadians wish to die at home, or in their home communities (Bacon, 2008; Burge et al., 2003; Gomes & Higginson, 2006) – a point which is being taken up as a social (rather than financial) justification for the shift away from hospital-based care at this life stage. Regardless of the motivations, this shift in the site of care away from institutions and into the community has raised a number of concerns as the responsibility for caregiving is now significantly being placed on untrained family caregivers – sometimes also referred to as informal caregivers – who often do not have the support and/or resources required meet such demands (Crooks et al., 2007; Milligan & Conradson, 2006; Skinner & Rosenberg, 2005). Within the context of Canada’s rapidly aging population, the burden on individuals to provide informal care is of great concern given the exponentially increasing numbers of people who will be in need of eldercare and end of life care over the coming years (CCC, 2009; CPRN, 2009).

Family caregivers are those people who provide care and assistance for family members and close others who are in need of support because of age, debilitating medical conditions, injury, long term illness or disability, or being at the end stages of life (CCC,

2009). Such caregivers often provide physical and emotional care and support, as well as care coordination, among other tasks, when caring for those requiring support (CCC, 2009). Typically, this care takes place in either the caregiver's or care recipient's home, but can also occur inside formal settings such as hospices, hospitals, respite facilities, group homes, and long-term care facilities. Also, reflecting the traditional gendered division of unpaid work within the home, family caregivers tend to be women (Armstrong et al., 2008; Dyck, 2005; Neumann et al., 2007; Statistics Canada, 2002; Yantzi & Rosenberg, 2008). Within Canada, these caregivers and the supports they provide are becoming the 'backbone' of the health and long-term care systems (CCC, 2009). For example estimates indicate that there are approximately 1.5-2 million family caregivers in Canada contributing annually up to \$25-26 billion of unpaid care work (Hollander et al., 2009). Further, the Canadian Caregiver Coalition (2009) reports that family caregivers frequently incur more than \$100 per month in direct costs (e.g., supplies, gasoline to get to appointments), which totals to about \$80 million in out-of-pocket costs paid for by these caregivers each year.

There are a number of stresses associated with family caregiving. For example, vast amounts of knowledge on various issues such as pain management must be mastered while simultaneously undertaking complex system navigation in order to access necessary supports and services (Ashpole, 2004; Crooks et al., 2007), thus creating an informational burden. These stresses are typically magnified when care is being provided for dying individuals, whereby there is a considerable increase in depressive symptoms, among other physical and mental impairments, exhibited by family caregivers as care recipients approach death (Grunsfeld et al., 2004; Schulz & Beach, 1999). The additional responsibility of maintaining employment while providing care, as experienced by many family caregivers, only contributes additional stress. This dual-role of providing care while remaining in the

workforce can diminish the physical, emotional, and mental health of family caregivers (CPRN, 2009; Crooks et al., 2007).

It has been estimated that due to Canada's rapidly aging demographic, the number of otherwise-employed family caregivers involved in providing eldercare (and thus ultimately end of life care) will increase from one in five to one in four in the next decade (CPRN, 2009). Statistics Canada (2002) has shown that employed people who are also serving as family caregivers for more than four hours per week are more likely to reduce their working hours, change their work patterns, or turn down a promotion or job offer than those who provided fewer caregiving hours. Such strategies have clear implications for maintaining employment and one's ability to return to work after caregiving has ceased. Those most greatly affected by the dual-demands of working and providing informal care are people who are employed for 40 or more hours per week (Statistics Canada, 2002). It is thus important that we seek ways to minimize or alleviate the dual-role burden placed on family caregivers given both their important contributions as 'shadow' health care workers and the potential negative health and employment outcomes they may experience as a result of simultaneously working and providing care.

1.1.2 The Compassionate Care Benefit

In response to the need to support family caregivers at end of life and lessen their dual-role burden, Canada's federal government implemented the CCB program in January of 2004. The primary goal of the CCB is to provide much needed income assistance and job security to workers who decide to take temporary leave from their employment to care for a terminally ill family member at risk of dying within 26 weeks (Service Canada, 2009). Successful applicants of the CCB can receive up to 55% of their average insurable earnings,

to a maximum of \$447 per week, over a six-week period to provide care. CCB recipients have the option to take the six weeks of income insurance at once, divide it into one-week periods and spread it over 26 weeks, and/or share the benefit among other eligible caregivers, thus adding considerable complexity to the CCB relative to other social programs. As Human Resources and Social Development Canada (HRSDC) administers this program as an Employment Insurance (EI) special benefit, eligible applicants must demonstrate that their regular weekly earnings have decreased by more than 40% and that they have accumulated 600 insurable hours over the preceding 52-week period. Resultantly, many Canadians are excluded from use of this benefit, including those who are self-employed¹, employed part-time, seasonal workers, unemployed, or have never been involved in the workforce. Applicants must also meet the program's definition of 'family member'² and submit a medical certificate from the doctor of the gravely ill person to confirm there is a significant risk of death within a 26-week timeframe (Service Canada, 2009).

The government's implementation of the CCB program has been applauded by many, and seen as a significant progressive step towards acknowledging the health, well-being, and employment and/or financial security needs of family caregivers in Canada (CCC, 2004; QELCCC, 2005). However, since its implementation, successful uptake of the CCB has been significantly lower than expected (Osborne & Margo, 2005). Although estimates demonstrate that more than 1.5 million Canadians provide care for dying individuals annually (Hollander et al., 2009), HRSDC reports that only 5,700 successful claims were made during the 2007/08 fiscal year, only increasing 0.5% from the previous year (HRSDC,

¹ One exception is self-employed fishers who, rather than hours worked, must demonstrate they have earned CND \$3760 in insurable fishing income (Service Canada, 2009).

² In June 2006, HRSDC expanded the definition of 'family member' to include brothers and sisters, grandparents, grandchildren, in-laws, aunts, uncles, nieces, nephews, foster parents, wards, guardians or anyone who the gravely ill person considers to be like a family member (Service Canada, 2009).

2009). These statistics, thus, contradict what we know about the reliance on family caregivers in Canada and subsequent expected increases in the numbers of people taking on this role due to Canada's aging population.

The main barriers referenced as causes for the low uptake of the CCB include the limited support the Benefit provides (i.e., for only six weeks), the two-week unpaid waiting period successful applicants must go through once their application has been approved, and the difficulty in prognosticating death within a 26-week window (Osborne & Margo, 2005; Williams et al., 2006). However, aside from more program-specific barriers, there exists a more critical obstacle to the CCB's successful uptake: the general lack of public awareness regarding the existence of the program (CCS, 2008; Crooks et al., 2007; HRSDC, 2007; Osborne & Margo, 2005). Specifically, family caregivers are not gaining access to information about the CCB program, and therefore, are unable to apply and utilize this existing benefit.

1.2 Study Overview

Evaluation research is a methodological area that closely relates to, but is distinguishable from, traditional social research. Specifically, it can be defined as “systematic, data-based inquiry to determine the merit or worth of a program, product, organization, intervention, or change effort” (Patton, 2003, n.p.). Evaluation research involves the *application* of social science and related inquiry methods for the “systematic collection of information about the activities, characteristics, and outcomes of change efforts to inform judgements about goal attainment, improve program effectiveness, identify costs and benefits, and/or inform future decisions” (Patton, 2003, n.p.). Approaches to evaluation research are vastly diverse, ranging from decision-oriented and objective-based to

experimental research, among many others. Patton (2003) identifies a number of innovative approaches that have recently emerged to solve particular problems or accomplish specific objectives, including: goal-free evaluation; responsive evaluation; empowerment evaluation; inclusive evaluation; theory-driven evaluation; realist evaluation; democratic evaluation; developmental evaluation; and utilization-focused evaluation (Patton, 2003).

The research conducted for this thesis contributes to a larger CCB evaluation study that aims to offer policy-relevant recommendations about the program which are informed by the perspectives of the program's primary users and other stakeholder groups (for full study protocol see: Crooks & Williams, 2008). Therefore, the research presented herein adopts the overarching methodology defined by the larger evaluation: Patton's (1997) utilization-focused evaluative approach. Specifically, this utilization focused evaluative approach aims to inform program improvements through the utilization of research findings with a specific emphasis upon "*intended use by intended users*" (1997, p.20, emphasis in original). Here, Patton defines 'use' as the ways in which "real people in the real world apply evaluation findings and experience the evaluation process" (1997, p.20). The objective of this methodology is based upon the premise that "evaluations should be judged by their utility and actual use" (Patton, 1997, p.20), and therefore, evaluators should approach the evaluation process and its design with a particular focus on how everything that is done will affect the use of the findings.

The three specific objectives of the larger evaluative study to which this thesis contributes are to: (1) examine the usefulness of the CCB for family caregivers and determine those elements of the program that can be changed to better meet their needs; (2) explore front-line palliative care providers' perceptions of the CCB; and (3) investigate barriers and facilitators inherent in specific workplaces and the labour market that shape

CCB uptake from the perspective of employers. Methods of data collection have included phone interviewing, face-to-face group interviewing, and keeping a ‘watching brief’ of policy and media coverage of the CCB. While this study is led by an academic team, an ‘evaluation taskforce’ consisting of members of various advocacy and governmental organization representatives is also in place to guide data collection and mobilize findings. Use of an evaluation taskforce is consistent with Patton’s (1997) utilization-focused evaluation approach as these individuals are well situated to provide input regarding the potential usability and thus uptake of the findings.

The two analyses presented herein aim to offer a uniquely *geographic* contribution to the larger CCB evaluative study. Considering the CCB’s significantly low uptake, adopting a geographic perspective has the potential to add valuable insight into specific program challenges and barriers and, therefore, to contribute important knowledge to an evaluation of the program. Particularly, the transfer of information and acquisition of knowledge is inherently *spatial* as they involve the creation of relational connections between disparate places as well as the development of information networks that link people and places (Crooks et al., 2007). This point serves as a key context for the first analysis. By conducting an analysis that focuses on the spatial aspect of information dissemination, the most effective paths and venues for disseminating information about the CCB to increase awareness, and ultimately successful uptake, of the program can be determined. Also, by gaining insight into how the CCB program is experienced at various *scales* by its intended users and other program stakeholders, specific challenges that may have otherwise been overlooked can become illuminated. The geographic concept of scale thus serves as an analytic tool in the second analysis. Such knowledge of the scalar challenges inherent in successfully accessing and utilizing the CCB program experienced by people across Canada

contributes valuable information to the evaluative process, which ultimately can inform decision-makers on how to better meet the needs of family caregivers across Canada.

In sum, the objectives of this thesis are to:

- (1) contribute to an ongoing qualitative evaluative study of the CCB;
- (2) determine the most effective paths and venues from which to disseminate information about the CCB to potential users in order to increase awareness of the program's existence; and
- (3) explore the relevance of scale as an explanatory concept used by family caregivers and other stakeholders when discussing their knowledge and experiences of the CCB program and identify the various implications such findings hold for the CCB program.

In this thesis I adopt the same aim as the larger evaluative study while demonstrating the utility of employing geographically-centred analyses in such applied research.

1.3 Thesis Outline

This thesis is organized into four chapters. In this current chapter, I have aimed to introduce the research focus and provide necessary background and contextual information. Specifically, I have provided a brief overview on the emergence of health geography in Canada. I have also introduced how specific shifts in policy have resulted in a trend whereby care in Canada is increasingly taking place within the home rather than formal institutional settings, thus resulting in an increased expectation that family members will serve as caregivers. The CCB program was also introduced and the reasons for its relatively low uptake were discussed. This particular issue has been set out as justification for the research conducted in this thesis and is directly related to the above-stated objectives. The overall aim

of this research is to better inform decision-makers on how to improve the CCB program, and ultimately, better support family caregivers in Canada.

Chapters 2 and 3 are written as independent papers that have been submitted to scholarly journals for publication. In Chapter 2, the problem involving the public's lack of awareness regarding the CCB's existence is addressed. Framed by Graham et al.'s (2006) knowledge-to-action cycle, an innovative and spatially informed three-step mixed-method analysis is conducted to identify: (1) who likely CCB-eligible family caregivers are; (2) where these individuals' households are located; and (3) how best to get information about the CCB to them. By integrating the findings from these three analytic steps, a tailored path is created from which information on the CCB can be disseminated.

In Chapter 3, I aim to apply a core geographic concept, 'scale', as an analytic tool in evaluating the CCB. Specifically, by building on notions that scale is experienced and that scalar concepts offer a vocabulary to articulate complex phenomena, this analysis explores the relevance of scale as an *explanatory concept* (Masuda & Crooks, 2007) used by family caregivers and front-line palliative care providers when discussing their experiences with and knowledge of the CCB program. Using the scalar categories employed by respondents, particular spatial challenges and inequities become apparent that hold specific implications for the CCB program. These findings provide insight into the complex ways that family caregivers and front-line palliative care providers make sense of their worlds and, more specifically, understand how federal programs in general, and the CCB specifically, operate.

Chapter 4 concludes the thesis, wherein I discuss key contributions of the two analyses. I reflect on how the approach adopted in this research has allowed for: (1) the identification of specific information challenges that hold real implications for how the CCB can and should be administered; (2) an acknowledgement of the value that front-line

palliative care providers' perspectives have in evaluating the CCB; and (3) advancement of the use of geographic concepts in applied health research. I also discuss the next steps of this research, particularly as they relate to the continued engagement with the knowledge-to-action cycle defined by Graham et al. (2006). I conclude by acknowledging the overall importance of this work, and the need to better support family caregivers in Canada.

CHAPTER 2

SPATIALLY INFORMED KNOWLEDGE TRANSLATION: INFORMING POTENTIAL USERS OF CANADA'S COMPASSIONATE CARE BENEFIT³

2.1 Abstract

Implemented in 2004 by the Canadian government, the Compassionate Care Benefit (CCB) program aims to provide income assistance and job security to caregivers who decide to take temporary leave from their employment to care for a terminally ill family member at risk of dying. Reports have cited numerous challenges with respect to the benefit's successful uptake, including the major obstacle of a general lack of awareness regarding the program's existence. Based on this knowledge, the present analysis aims to consider local contexts and potential barriers through engagement with the knowledge-to-action (KTA) cycle. Using an innovative and spatially informed three-step mixed-method analysis, we identify: (1) who likely CCB-eligible family caregivers are; (2) where these individuals' households are located; and (3) how best to get information about the CCB to them. Melding the findings from the three analytic steps generates a tailored path from which an information dissemination strategy can be guided (the intended action). Results indicate that targeted dissemination efforts undertaken outside of urban cores are likely to be most efficient in reaching potential or current CCB-eligible family caregivers. This strategy should be implemented through multiple formats and venues via two information pathways: (1) from key professionals to family caregivers and (2) from the community to the general public. Through employing a

³ This chapter has been published as: Giesbrecht, M., Crooks, V.A., Schuurman, N., Williams, A. (2009). Spatially informed knowledge translation: informing potential users of Canada's Compassionate Care Benefit. *Social Science & Medicine*, 69(3), 411-419. Copyright © 2009 Elsevier.

spatial perspective, these findings engage and usefully contribute to the KTA cycle process. Future involvement in the cycle will entail translating these findings for use in a decision-making context in order to implement an intervention. This approach can also be applied to other health and social programs where lack of awareness exists or for targeted interventions that require identifying specific populations.

2.2 Introduction

Efforts to translate knowledge gleaned through health and health services research are becoming increasingly popular due to recognition that relevant findings are often not reaching potential users, including decision-makers, in a timely manner, if at all (Graham et al., 2006; Landry et al., 2006). The central aim of knowledge translation is to overcome this ‘missing link’ between research findings and their application by moving knowledge into action. The process is complex as there is no single way to achieve knowledge translation (see Davies et al., 2000; Dobrow et al., 2006; Estabrooks et al., 2006; Graham & Tetro, 2007; Sanderson, 2000). Generally speaking, the aim of knowledge translation can be achieved by “an acceleration of the natural transformation of knowledge into use” (CIHR, 2008, n.p.), where focus is placed on interactions between those who generate knowledge and those who may potentially apply, or benefit from, it.

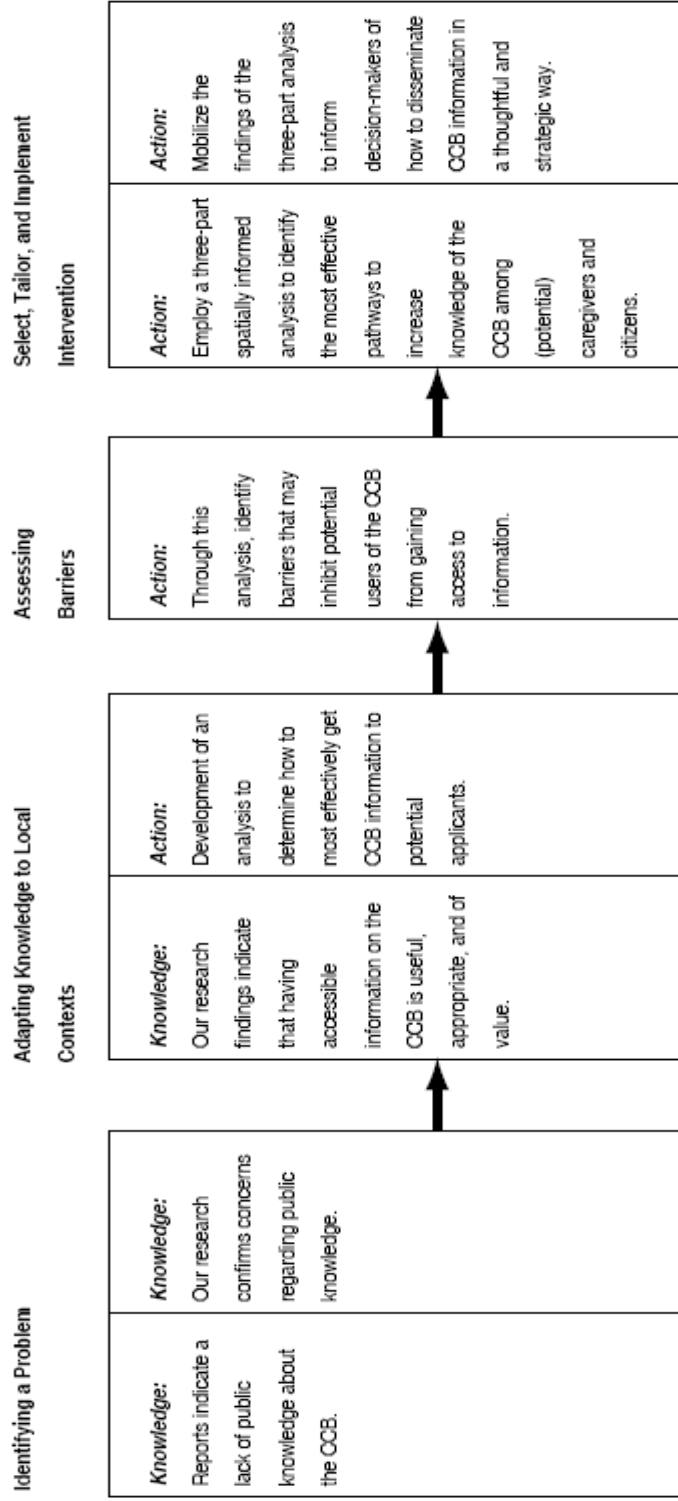
Here, we adopt a specific model proposed by Graham et al. (2006) that envisions knowledge translation as a cycle of moving research knowledge into action. This ‘knowledge-to-action (KTA)’ cycle involves numerous phases to successfully achieve knowledge translation (see Graham et al., 2006). For the purpose of this paper, we focus on a segment of the KTA cycle that begins with the identification of a problem (the knowledge) and ends with the implementation of an intervention strategy (the action). After having

knowledge about a problem or issue, Graham et al. (2006) suggest the next phase to focus on is its adaptation to local contexts. Here, attention is given to the value and usefulness of particular knowledge to individuals or groups in *specific* settings and circumstances with consideration given to their activities so that knowledge can become tailored to their context (Graham et al., 2006; Landry et al., 2006; Wallin, 2009). The next phase involves assessing, identifying, and targeting any potential barriers to knowledge use (Graham et al., 2006; Wallin, 2009). KTA efforts typically focus on organizational barriers at this stage (Davis et al., 2003); however, barriers relevant to ways in which information is presented to end users (Formoso et al., 2007) and formatted across audiences (Boaz & Hayden, 2002) are also worthy of consideration. The final phase involves the development and implementation of an intervention strategy to promote awareness and implement knowledge (Graham et al., 2006). These phases in the KTA cycle are not linear or static, but rather dynamic and can influence or be influenced by all other aspects of the larger KTA process (Graham et al., 2006).

In this paper we present on our engagement with the KTA cycle through having undertaken a mixed-method analysis to address an applied problem pertaining to Canada's Compassionate Care Benefit (CCB). The goal of the CCB program is to enable family members to take a temporary secured leave from employment to care for a terminally ill person. The findings of various studies and polls have consistently reported that few Canadians are aware of the CCB's existence and suggest that, as a result, its uptake is limited (CCS, 2008; Crooks et al., 2007; HRSDC, 2007; Osborne & Margo, 2005). Since 2006, we have been conducting a formal evaluation of the CCB program from the perspective of family caregivers. Our KTA effort, summarized in Figure 2-1, was motivated by our own and others' recognition that, problematically, information about this program is not reaching

potential users. In response to this knowledge (i.e., that information about the CCB is not effectively reaching Canadians and potential program users) we developed an innovative three-part analysis to adapt information about the program to local contexts and assess potential barriers family caregivers may experience in accessing such information. The innovation in our engagement with the KTA cycle comes from the *spatial approach* we have devised. The need to undertake such efforts, both in terms of research and knowledge translation, is underscored by calls to improve the utilization of family caregiver research to enhance evidence-based decision-making and information dissemination (e.g., Lysne, 2007).

Figure 2-1: Engagement with the knowledge-to-action cycle



Importantly, while the findings presented herein are specific to the Canadian CCB, the larger problem of program underutilization due to a lack of awareness affects a range of health and social care programs across nations. The analytic steps and spatial approach employed in this paper are thus extensible to a number of other KTA efforts focused on information dissemination regarding programs and also health interventions looking to identify specific target populations. In this paper, we address the problem of Canadians' lack of knowledge about the CCB by identifying: (1) who CCB eligible family caregivers are; (2) where they live; and (3) how best to disseminate information to them, as a way of engaging in the KTA process. In the following section we provide further details about the CCB program and the applied problem which serves as our focus. Following this, a brief overview of the larger evaluative study is provided in order to contextualize the analysis. Then, the analytic process designed to assist with achieving spatially informed knowledge translation is introduced and its findings shared. We then move to discuss both the relevance of the findings to the applied problem of focus and our engagement in the KTA cycle.

2.2.1 Background

In response to international concerns regarding the increased responsibilities being placed upon family caregivers providing care for dying relatives, many governments from the developed world have initiated programs aimed at alleviating some of the caregiving burden. These programs range from direct or indirect financial compensation to labour policy strategies and legislations (Lysne, 2007; Williams et al., 2006). Resembling similar programs found in Norway, Sweden and the Netherlands, the Canadian government implemented the CCB program in January 2004. The primary goal of the CCB is to provide income assistance

and job security to family members and close others who take a temporary leave from their regular employment to care for a terminally ill person at risk of dying within 26 weeks. Although the maximum total length of the caregiving period supported by the CCB is 8 weeks, the first 2 weeks are unfunded and known as the ‘waiting period’. Therefore, over a 6-week period successful applicants of the CCB can receive up to 55% of their average insurable earnings, to a maximum of CDN\$435 per week, to provide physical, psychological, and/or emotional care or care coordination (HRSDC, 2008a). As the CCB is an Employment Insurance (EI) program, where EI is a contributory benefits scheme paid into by workers, particular labour market participation criteria apply. As such, successful applicants are required to have accumulated 600 insurable hours over the preceding 52-week timeframe and demonstrate that their weekly earnings have decreased by more than 40% as a result of having to provide care (HRSDC, 2008a). Further, applicants must meet the definition of ‘family member’, which includes anyone who is identified as family by the care recipient, and have access to a medical certificate from the gravely ill person’s doctor confirming there is a significant risk of death within a 26-week timeframe (HRSDC, 2008a).

Although the Canadian Government’s implementation of the CCB is seen as a strong first step towards supporting family caregivers, successful uptake of the benefit has been significantly low in its first years of existence (Osborne & Margo, 2005). Estimates show that more than one million Canadians are caring for dying loved ones, and this number is expected to rise in accordance with the nation’s rapidly aging population (CHPCA, 2006). However, Human Resources and Social Development Canada (HRSDC), the federal department responsible for administering the CCB, reports that for the 2006/07 fiscal year only 5676 successful CCB claims were made nationwide (HRSDC, 2008b). The low uptake of the CCB thus contradicts what we know about reliance on family caregivers. Other main

barriers referenced as causes for this low uptake, include the limited support the Benefit provides (i.e., for only 6 weeks), the 2-week unpaid waiting period successful applicants must endure once their application has been approved, and the difficulty in prognosticating death within a 26-week window (Osborne & Margo, 2005; Williams et al., 2006). However, aside from more program-specific barriers, there exists a more critical obstacle to the CCB's successful uptake: the general lack of public awareness regarding the CCB's existence (CCS 2008; HRSDC, 2007). Specifically, family caregivers are not gaining access to information about the CCB program, and therefore are unable to utilize it during the caregiving period.

A recent poll conducted by the Canadian Cancer Society (2008) suggests that a majority of Canadians believe they will be called upon to care for an ill loved one at some point in their life. However, of the 1015 respondents, close to three in four were not aware of the CCB's existence, this in spite of expressed concern regarding the financial burden associated with caregiving (CCS, 2008). Further, a survey of 1520 Canadians conducted by HRSDC (2007) about the CCB found that 42% were not at all aware they were able to receive EI benefits to take time off work to care for a dying family member. Of the 177 respondents who had taken time off work to do so: 40% took an unpaid leave, 23% negotiated arrangements with employers, many drew upon paid vacation (19%), family (12%) or sick (9%) leaves, 5% quit their jobs, while only 2% used the CCB as an option. More specifically, when the 173 respondents were asked why they did not use the CCB, 56% explained it was because they were unaware of the program's existence. These statistics clearly indicate lack of awareness to be a major obstacle to the successful uptake of the CCB. Although efforts put forth to improve specific policy criteria, such as extending the length of the benefit or increasing flexibility surrounding the prognosis of death (see Williams et al., 2006), will most likely improve program uptake, they will be of little benefit until Canadians

gain access to information and become aware that such supports exist. Therefore, an important first step in improving the program's successful uptake involves addressing the paucity of public knowledge regarding the CCB.

In general, for family caregivers tending to dying loved ones, having access to needed information is an important determinant in distinguishing between a positive experience and a distressing one (Ashpole, 2004; Docherty et al., 2008; Dunbrack, 2005). The diversity of information required by family caregivers can range from medicinal details to social support services. Further, the information required is distinctly temporal; in the beginning needs are exigent and information is often provided all at once, while throughout the caregiving period informational needs are continually refined (Ashpole, 2004; Crooks et al., 2007; Dunbrack, 2005). Many barriers, however, exist to successfully disseminating information to this specific group. At the individual level, feelings that care professionals are just 'too busy' or that questions are not being answered satisfactorily may discourage caregivers from asking for information (Dunbrack, 2005). Furthermore, some caregivers will want as much knowledge as possible and actively seek information from multiple sources, while others may feel overwhelmed and be unable to process information (Dunbrack, 2005). Generally, the informational burden placed upon family caregivers can result in feelings of stress which, especially within the emotionally charged context of caregiving, can lead to negative health outcomes for caregivers (Ashpole, 2004; Dunbrack, 2005; Schulz & Beach, 1999). It is for these reasons that we advocate for a thoughtful approach to information dissemination about Canada's CCB.

2.2.2 Evaluative Study Overview

Since 2006, we have undertaken a national evaluation of the CCB with the goal to evaluate the Benefit from the perspective of family caregivers (for full study protocol, see Crooks & Williams, 2008). Our overall purpose is to offer policy-relevant recommendations which are informed by the needs of Canadian family caregivers through gathering input from multiple stakeholders. We have three specific objectives to (1) examine the usefulness of the CCB for family caregivers and determine those elements of the program that can be changed to better meet their needs; (2) explore front-line palliative care providers' perceptions of the CCB; and (3) investigate barriers and facilitators inherent in specific workplaces and the labour market that shape CCB uptake from the perspective of employers. The study's methodology is guided by Patton's utilization-focused evaluative approach which aims to inform program improvement through the utilization of research findings (Patton, 1997). Methods of data collection have included phone interviewing, face-to-face group interviewing, and keeping a 'watching brief' of policy and media coverage of the CCB. While this study is led by an academic team, an Evaluation Taskforce consisting of members of various advocacy and governmental organizations is in place to guide data collection and mobilize findings.

Since undertaking the larger evaluative study, key reports have been released (specifically CCS, 2008 and HRSDC, 2007) emphasising the Canadian public's lack of knowledge about the CCB. These reports confirm emerging findings from the current study and also from our pilot research (Crooks et al., 2007; Williams et al., 2006). Our engagement with the KTA cycle comes as a result of our desire to address this applied problem as researchers in order to generate actions which will promote information dissemination about the CCB program. In the three following sections, we report separately on each spatially

informed analysis that was undertaken specifically for this KTA effort. Each analysis has a distinct set of methods and findings that, when examined together, yield important information on how best to inform Canadians, and ultimately family caregivers, about the existence of the CCB.

2.3 Part One: Determining who is likely to be a CCB-eligible family caregiver

In developing an effective strategy for disseminating CCB information that will increase awareness and potential uptake, it is first critical to determine who likely program users are. Doing so defines a target population for dissemination efforts, thereby allowing for a tailored approach. This is particularly needed for a program such as the CCB that has specific eligibility requirements which determine entitlement, thus placing parameters on who may ultimately use the Benefit.

2.3.1 Method

Firstly, creating the demographic profile of a likely CCB user began with a search of the PubMed Central database in order to identify North American studies that used respondent groups of family, or informal, caregivers using relevant search terms such as ‘family caregiver’ and ‘informal caregiver.’ The search was limited to articles published after 1999, which yielded just over 150 hits. The PubMed results were then scanned in order to identify the most recent studies that had used a minimum sample size of 25 caregivers and contained a clear table or description of respondents’ demographic characteristics. Due to the limited number of Canadian studies identified, research from the United States was included in the articles selected for the demographic profile; this, however, was not seen to jeopardize the reliability of the compiled profile given the similarities in the population structures and

family caregiving demands of these two countries. In addition to these articles, grey literature reports already held by the team were also reviewed for sample size and demographic information. Upon review of the first 10 most recent studies with the largest sample sizes and most respondent detail (Canadian n=7; United States n=3), complete confirmation regarding particular variables to be included in our demographic profile was found and thus further literature was not reviewed. The studies' respondent sizes ranged from 27 (Mackenzie et al., 2007) to 501 (Hollander et al., 2002), with an average of 225. The most important study identified was Health Canada's (2002) National Profile of Caregivers, due to its large sample size (n=471) and pan-Canadian context.

Secondly, from the demographic information found in the 10 reviewed studies, common variables were culled and then amalgamated with CCB eligibility requirements defined by HRSDC to create the demographic profile (shown in Table 2-1). The included variables were selected based upon their abilities to be linked to Canada Census data (this is explained in the next section). Thirdly, to strengthen the reliability of the demographic profile, confirmation was sought from three experts with relevant domain expertise and then against an extensive database consisting of demographic variables from family caregivers (n=765) gathered from numerous research studies run by the New Emerging Team in Family Caregiving at End-of-Life. This team consists of Canadian researchers involved in studies about family caregiving at end of life and is funded by the Canadian Institutes of Health Research (see <http://www.coag.uvic.ca/eolcare/>). The database was created through compilation of data gathered from a standard demographic questionnaire administered across multiple studies. Lastly, the compiled profile was also compared to demographic data obtained from family caregiver interviews (n=57) conducted for the larger CCB evaluative

study. These multiple steps all confirmed our created profile, further demonstrating its accuracy.

2.3.2 Findings

Table 2-1: Deomographic profile of likely CCB-eligible family caregivers

Variable	Identified characteristic	Confirming study demographics	Confirming studies
Sex	Female	Mean: 72.4% female	Brazil et al. (2002, 2005); Cherlin et al. (2005, 2007); Fast, Higham, Keating, Dosman, and Eales (2005); Health Canada (2002); Hollander et al. (2002); Mackenzie et al. (2007); McPherson et al. (2008); Waldrop et al. (2005).
Age	45-65	Mean: 58.5 years of age Age grouped statistics: Brazil et al.: 79.4% =50 years+ Health Canada: 70% =45 years+	Brazil et al. (2002, 2005); Cherlin et al. (2005, 2007); Health Canada (2002); Hollander et al. (2002); Mackenzie et al. (2007); McPherson et al. (2008); Waldrop et al. (2005).
Education	High school completed	Mean: 61.5% = high school+ Mackenzie et al. (2007) Mean: 14.93 years of school	Brazil et al. (2002, 2005); Cherlin et al. (2005, 2007); Hollander et al. (2002); Mackenzie et al. (2007).
Relationship	Married or common-law	Mean: 63.8% spousal	Brazil et al. (2002, 2005); Health Canada (2002); Mackenzie et al. (2007); McPherson et al. (2008).
Employment Status	Full-time		Proxy for having accumulated 600 insurable hours over the preceding 52 weeks.

Unsurprisingly, family caregivers tend to be female, with an average of 72.4% of respondents across the included studies meeting this criterion. The majority fell over the age

of 45 years; although it is common for family caregivers to be seniors, we have limited our age to a maximum of 65 years to emphasize the CCB's employment requirement. Education was variously defined within the literature; however, in all studies the majority of participants had minimally completed high school. The most common relationship between family caregiver and recipient was spousal, averaging 49%. Lastly, full-time employment was included as a proxy for the CCB's workforce participation requirement.

2.4 Part Two: Determining where likely CCB-eligible Canadians are located

In the previous section, a demographic profile using variables applicable to the Canada Census was compiled to describe a specific population with high potential of being or becoming CCB-eligible family caregivers and can thus benefit from gaining access to Benefit information. We now focus on identifying where those people who most closely fit the demographic profile are located. Linking the profile variables to the Canada census, which is geographically specific, allows for spatial analyses to be conducted if any geographic patterns in household locations exist. Results display anticipated geographic pockets of information need for the Benefit and provide valuable data that can direct information dissemination strategies.

2.4.1 Method

Data for the spatial analysis were derived from the 2001 Canada Census at the Census tract (CT) scale. CTs define relatively stable geographic areas with populations of 2500 - 8000, averaging 4000 residents per tract (Statistics Canada, 2007). Data were retrieved for each of the five variables identified in the demographic profile (see Table 2-1) and the ratio to the total population was determined, thus allowing us to rank the CTs by fit with the

demographic profile. To generate the ranking, the standardized z-score for each variable's ratio was calculated and summed for each CT. From this, the CTs were ranked into the three categories (high, medium, and low) to identify the degree to which the population meets the specified criteria in the profile. Through the utilization of ArcInfo software, these data were then linked geographically and mapped.

2.4.2 Findings

The households of likely CCB-eligible family caregivers were found to be geographically organized into a specific pattern consistently represented across Canada. As shown in Figure 2-2, those most likely to be or become CCB-eligible family caregivers are primarily living in areas surrounding urban cores, namely suburban or 'bedroom' communities, while those least likely to do so live within Canada's urban cores. The consistency of this finding demonstrates the presence of a robust pattern that can be used as policy-relevant evidence when considering how best to disseminate CCB information to Canadians.

Figure 2-2: Locations of likely CCB-eligible family caregivers across Canada

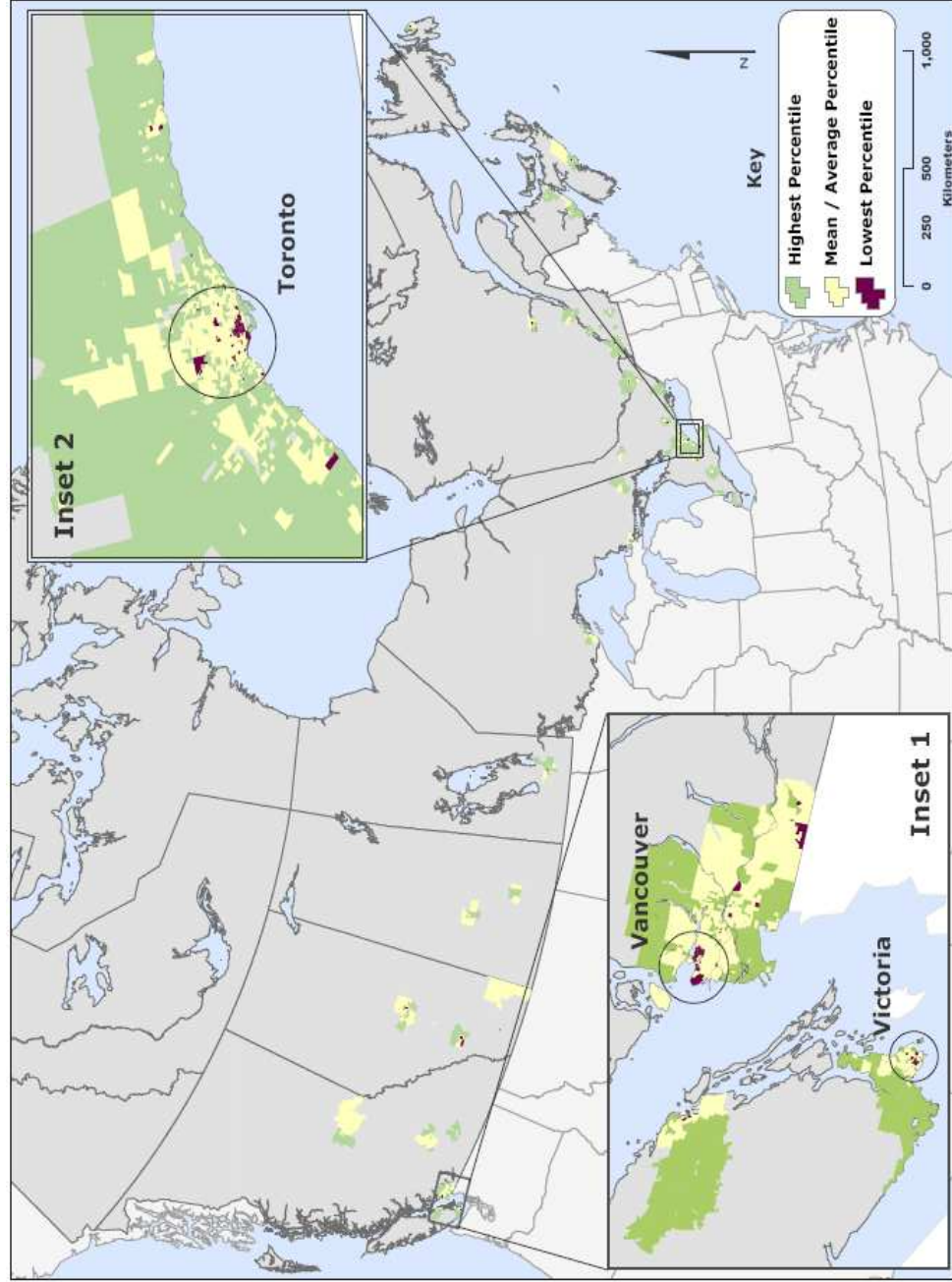


Figure 2-2: This map illustrates the locations of likely CCB-eligible family caregivers. Clearly illustrated in Inset 1, the urban cores of Vancouver and Victoria in the province of British Columbia exhibit the lowest proportion of the population who fit our demographic profile, whereas the surrounding areas display the highest proportions. This pattern is echoed in Inset 2, which depicts a highly populated area in the province of Ontario, whereby the higher percentile groupings are located in communities encircling the urban core of Toronto.

2.5 Part Three: Determining how to get information to likely CCB users and other Canadians

The previous two sections have aimed to identify *who* likely CCB-eligible family caregivers are and determine *where* individuals fitting this profile reside. The third part of our analysis adds a qualitative component by considering front-line palliative care providers' perspectives regarding specific places and people that should be targeted when disseminating CCB information. As front-line palliative care providers (e.g., nurses, oncologists, counsellors) are often a first point of contact for family caregivers seeking information, they hold valuable insight into how to inform this group. Further, as they are in direct contact with patients and their caregivers, they may also play a key role themselves in disseminating CCB information (Crooks et al., 2007).

2.5.1 Method

After having received ethics approval from Simon Fraser and McMaster Universities, perspectives about the CCB were gathered from 50 front-line palliative care providers from across the five targeted provinces of British Columbia, Manitoba, Ontario, Quebec, and Newfoundland and Labrador. These provinces were selected by the larger CCB evaluation team prior to data collection – and thus the inception of this analysis – in order to specifically represent Canada's regional and linguistic diversity. Purposeful sampling from a variety of settings (e.g., hospital, hospice, clinic etc.) and across provider occupational groups was undertaken to acquire as much diversity in employment sectors as possible, with the goal of conducting 10 interviews in each of the five provinces (see Table 2-2). The strategy for recruitment involved disseminating an information letter by e-mail outlining the study purpose and who we were looking to interview. The letter was sent directly to a range of

palliative and hospice organizations, hospitals, and clinics. Some participants were also recruited through investigators' existing professional networks and those of the study's Evaluation Taskforce. Many participants were enthusiastic about our study and actively informed other potential participants from their own professional networks, thus resulting in some further 'snowball' recruitment. Interested front-line palliative care providers were asked to reply via e-mail or call a toll-free number to schedule an interview at a time of their choosing to be conducted in either English or French.

Table 2-2: Respondents by occupational grouping

Occupation	Number of Respondents
Social Worker	11
Palliative Care Director / Coordinator	9
Clinical/Oncology/Palliative Nurse	7
Community Health/Home Care Nurse	7
Oncologist/Physician	6
Chaplain/ Pastoral Care	2
Counselor	2
Volunteer Coordinator	2
Facility Patient Care Manager	1
National Nursing Officer	1
Nurse Coordinator	1
Occupational Therapist (Home Care)	1
<i>TOTAL</i>	<i>50</i>

Forty-eight English- and two-French language interviews were conducted via telephone from November 2007 to March 2008 by the first author. The semi-structured interviews typically lasted 30 min and inquired into participants' perceptions of the CCB's usefulness, barriers and facilitators to access, experiences of recommending the CCB to a client or client's family, working knowledge of how the CCB is administered, and any suggestions for improvement. Prior to each interview, respondents were informed of their rights as a participant in a research study and provided their verbal consent to participate.

Forty-nine interviews were recorded and transcribed verbatim and one was recorded through notes as the participant preferred not to be recorded.

Following data collection, transcripts were entered into N7TM data management software and thematic analysis was conducted. Thematic analysis is commonly used to capture dominant emergent themes in a text and requires identifying patterns within a dataset where resulting themes become categories for analysis (Fereday & Muir-Cochrane, 2006). A coding scheme that integrated both inductive and deductive perspectives was developed to reflect the broader framework of our research which shaped our interview guide as well as emergent themes from the dataset (Bradley et. al, 2007; Fereday & Muir-Cochrane, 2006). The scheme was created using a five-step process involving investigator triangulation: (1) review of three randomly selected transcripts to identify initial themes, (2) drafting of a coding scheme, (3) revision of the coding scheme following discussion and further transcript review, (4) coding of five transcripts, and (5) review of coded transcripts in order to refine the scheme. Specific to the current analysis, the inductive conceptual code ‘information transfer’ was created and is heavily drawn upon; a number of deductive sub-codes such as ‘client awareness of the CCB’, ‘suggestions for informing professionals of the CCB’, and ‘suggestions for improving the CCB’ also contribute. Although not prompted to identify how to inform family caregivers about the CCB, this theme consistently emerged in reviewing the transcripts, thus resulting in our application of these thematic findings to the present analysis.

2.5.2 Findings

Participants’ responses confirm that a major barrier to the successful uptake of the CCB is a general lack of awareness regarding the program’s existence. As expressed by a

community palliative care nurse from Ontario: “...I think the biggest issue is that a lot of these people [family caregivers] aren’t even aware that it’s out there.” For some of the interviewees, they were the first people to inform a family caregiver about his/her eligibility for the program. As a palliative care coordinator from Manitoba told:

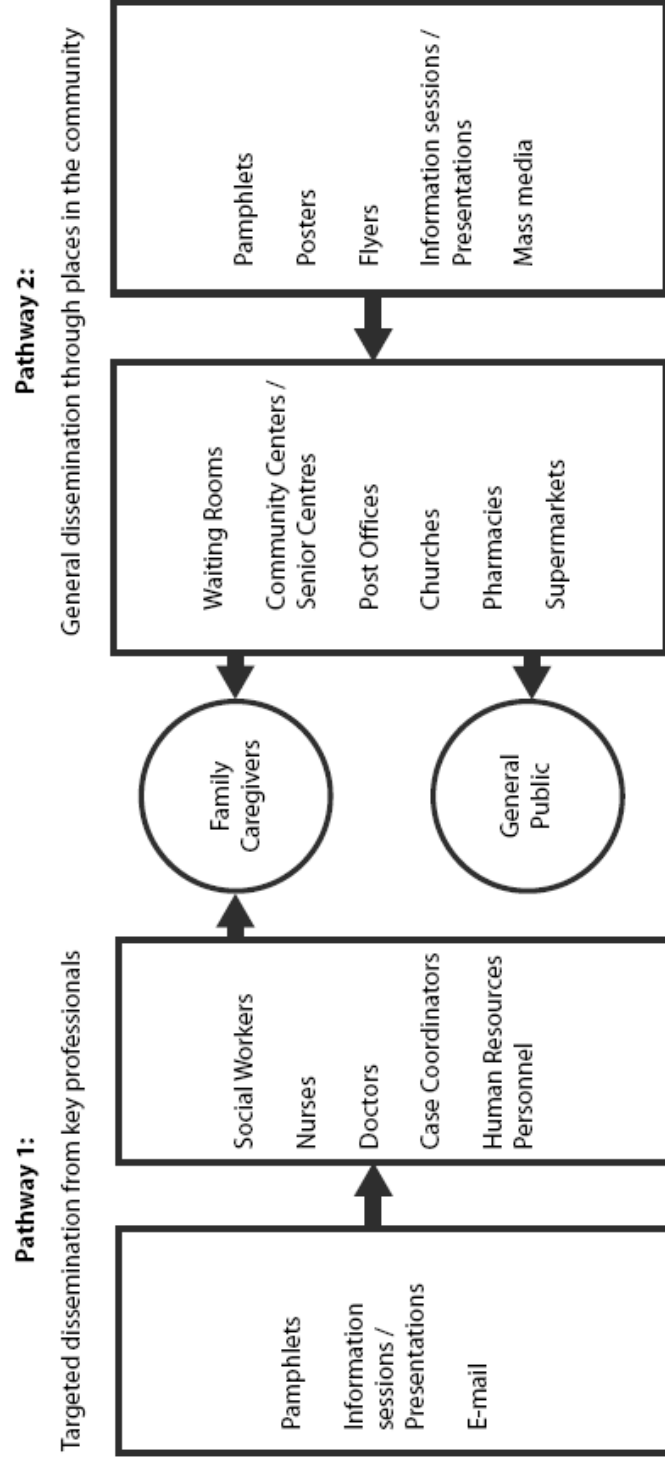
It’s [CCB] something I always... I’m the one that initiates the conversation. People don’t usually know about...it at all...

Such lack of awareness led interviewees to describe the CCB as not meeting its potential. A common suggestion for overcoming this situation was to educate care providers and publicize the CCB more generally across Canada. More specifically, analysis of the interviews revealed two distinct suggested pathways of information dissemination that should be targeted simultaneously, the transfer of information: (1) from key professionals directly to family caregivers and (2) through the community to the general population. These pathways are synthesized in Figure 2-3. In the remainder of this subsection we provide further details about these two dissemination pathways.

2.5.2.1 Pathway 1: Transfer of information from key professionals to family caregivers

Participants acknowledged that formal care providers were well positioned to inform family caregivers about the CCB; however, some professionals were viewed to be better suited to do this than others. Overwhelmingly, social workers were recognized to be most suited for this responsibility and were also most likely the ones who other front-line providers would refer family caregivers to for information. Doctors, nurses, and case coordinators were also suggested as being key people to become informed and to share CCB information with family caregivers. However, many participants felt it was the responsibility of human resources personnel in workplaces to inform employees of the CCB given that it is an EI program. Frustration was expressed about employers and human resources personnel

Figure 2-3: Two distinct suggested pathways of information dissemination



having limited or inaccurate knowledge about the CCB, thus indicating that this group could likely benefit from gaining access to accurate information about the program. A social worker from Manitoba explained: “some of the family members I deal with, they said ‘Oh I went to my employer and said I had to take time off and nobody told me that I could do this [use the CCB]?’.”

Generally, participants reported feeling responsible for informing family caregivers about social programs such as the CCB; this, however, requires becoming educated about the Benefit. A palliative care coordinator from Newfoundland stated:

Education is everything, and right now that’s something that we’re lacking. And given that I’m probably one of the first people these end-of-life patients see... and given that I for myself am admitting the lack of knowledge [about the CCB], I need more of that...

Although most participants ($n=47$) were aware of the CCB’s existence prior to the interview, some expressed difficulties in acquiring accessible information. A community health nurse from British Columbia recalled: “I don’t remember ever seeing any information on it, and I find it very startling, because I have read so much information on palliative care...” Thus, in order to effectively utilize this suggested information dissemination pathway, steps must be taken to ensure that front-line palliative care providers and human resources personnel/employers have knowledge of, and access to, information about the program.

Echoing the complexity of successfully disseminating information about the CCB to family caregivers was participants’ lack of consensus over a preferred format for receiving program details. Pamphlets providing a quick and accurate overview were the most frequently requested format as not only could they quickly inform front-line workers, but they could also be handed out to family caregivers. The second most requested format was through face-to-face information sharing via presentations, information sessions, and workshops held in workplaces and at professional conferences/meetings. Receiving

information face-to-face was viewed as desirable because it provides dedicated time for learning about the CCB and also offers an opportunity to ask questions. Although e-mail was cited as the third most frequently requested format, it was rebutted by others who stated that they were “overloaded” with e-mail or that the nature of their employment did not allow regular access to a computer. In general, interviewees’ comments point to the fact that the format of information destined to inform front-line workers – and likely also human resources personnel/employers – about the CCB should reflect the diversity of occupational groups and workplaces and thus involve a variety of formats to ensure maximum exposure.

2.5.2.2 Pathway 2: Transfer of information within the community to everyone

Participants frequently stressed the importance of informing the general public about the CCB and suggested strategies which they felt would be effective. Through this pathway, it was ‘places’ rather than ‘people’ that were identified as central to dissemination. The formats suggested for information dissemination were pamphlets, posters, flyers, and information sessions or presentations. Not surprisingly, a frequently suggested place for dissemination was the doctor’s waiting room and other clinical settings such as hospitals and oncology clinics. Human resource offices in workplaces were also suggested as places where information about the Benefit should be posted or kept on-file. Other venues identified by participants included community/senior centres, post offices, churches, pharmacies, and supermarkets.

The most frequently suggested method for informing the public about the CCB was through mass media. Television was overwhelmingly seen as the most effective venue to reach the public, and especially family caregivers. For example, a home care nurse in Manitoba explained that often caregivers leave their television sets on while they spend their

days and nights inside the home caring, thus making this an ideal medium for reaching active caregivers. Also, as a nurse in Ontario stated:

Well done ads on television are very powerful, and so I think that would reach a lot of people who are really busy...when they're flopped down in exhaustion at the end of the day...

Newspapers, radio, and mail advertisements were also suggested as useful strategies for this information dissemination pathway.

2.6 Discussion

In undertaking the above analysis, we have aimed to address an applied problem pertaining to the general lack of awareness, and resultantly low uptake, of Canada's CCB. Using a geographic approach, this mixed-method analysis has identified: (1) who likely CCB-eligible family caregivers are; (2) where these individuals' households are located; and (3) how best to get information about the CCB to them. The first step in our analysis found likely CCB-eligible family caregivers to be married or common-law females between the ages of 45 and 65 years who have completed high school and are working full-time. In our second step we linked this profile to the Canadian census and, through spatial analysis, found a distinct geographic pattern as to where those who most closely matched the profile reside: largely in communities outlying urban cores. Our third step aimed to gather suggestions from front-line palliative care providers regarding how best to inform family caregivers and other Canadians about the CCB. What emerged were two distinct paths for information sharing, the transfer of information from (1) formal care providers to family caregivers and (2) places in the community to the general public.

2.6.1 Implications for Creating an Information Dissemination Strategy

The results of this study hold significant implications for creating a strategy designed to inform Canadians about the CCB and ideally increase program uptake. Specifically, melding the findings from the three analytic steps generates a tailored path from which an information dissemination strategy can be guided. Geographically speaking, findings suggest that targeted CCB information dissemination efforts undertaken outside of urban cores via pamphlets, posters, and other such advertising are likely to be beneficial in reaching those likely to become family caregivers. Such a finding can contribute critical information to the development of a dissemination strategy through identifying weaknesses of some approaches, for example an advertisement of the CCB being posted on city billboards or inside urban transit systems, and strengths in others, such as posting advertisements inside commuter trains that bring workers from surrounding communities into urban centres. Other such critical points can be culled from the findings shared in the previous sections.

Considering the two distinct pathways of information sharing suggested by front-line palliative care providers allows for further tailoring of a dissemination strategy. As we outlined previously, it has been acknowledged that disseminating needed information to family caregivers must be done thoughtfully, with sensitivity to specific circumstances and needs (see Ashpole, 2004; Dunbrack, 2005). Most interviewees identified themselves as well positioned to share CCB information as they have an understanding of people's circumstances and are able to identify when and how best to inform family caregivers. However, potential barriers identified by the interviewees exist, whereby individual front-line care providers may not: hold accurate CCB knowledge, actively inform people about it due to the association with 'financial need' or a caregiver's denial of impending death, or be available to meet with family caregivers within a meaningful timeframe to effectively share

this information. Such barriers, and the potential for increasing family caregivers' informational burden, suggest that consideration must be given to informing the general public about the CCB via community venues and media sources. In doing so, people will ideally become aware of the Benefit prior to caregiving and inquire into the program if and when they choose to apply. As a social worker in Ontario explained:

...people absorb information when they're ready to absorb it...they might see an article in the paper about it [the CCB], but they probably wouldn't take it in. But then they might remember it when they need, and think, 'I read somewhere sometime that this was available', and then they'd ask somebody.

Our findings suggest that CCB information should be disseminated through both suggested pathways, from professionals to family caregivers and community places to the general public. Such a recommendation is consistent with the findings of the interviews, whereby interviewees stressed the importance of disseminating information in multiple formats and through multiple venues in order to ensure maximum impact. Integrating the information sharing pathways with the demographic and spatial findings from the first two steps of the analysis adds geographic value to these information sharing pathways (namely how to reach those most likely to become CCB users in the places in which they live), thus allowing for even greater tailoring of an implementation strategy.

2.6.2 Engagement with the Knowledge-to-Action Cycle

The roles that family caregivers in Canada and other countries play in caring for dying individuals are generally not fully acknowledged or valued by formal health and social institutions; as such, awareness of these roles and their value must be enhanced through research utilization and knowledge translation if we are to better support them in the care they provide (Lysne, 2007). At the outset of the paper we explained that our engagement with this three-part mixed-method analysis was undertaken to act on knowledge identifying a

problem regarding the lack of awareness about the CCB via the KTA cycle outlined by Graham et al. (2006). While there are many ways to potentially address the information dissemination gap, we believe that a dissemination strategy based on sound and geographically-centred analysis is needed given the challenges identified in sharing information with and getting information to family members providing care.

The analysis presented above has focussed on a specific segment of the KTA cycle. We have specifically aimed to learn how to best adapt CCB knowledge to the local context by determining the demographic characteristics of the population most likely to need this knowledge, and the specific places and formats which should be targeted for dissemination. We have also assessed potential barriers to achieving effective dissemination routes based on input from knowledgeable stakeholders. Lastly, the findings of our analysis are meant to result in the selection and tailoring of an intervention in order to overcome the applied problem of focus.

By focusing on geographic characteristics in our analysis, our involvement with the KTA cycle has been particularly nuanced through allowing for a heightened focus on local context and the role of spatial channels of dissemination to overcome potential barriers. Based on our analysis, a geographic perspective offers *significant* considerations that hold implications for a successful information dissemination strategy about the CCB. Information is often diffused from disparate places and through relational networks (Crooks et al., 2007), and therefore in the development of a strategy it is not surprising to learn that careful thought must be attributed to the places from which information is to be disseminated and the places and people intended as recipients.

Our engagement in the KTA cycle cannot be satisfied without the implementation of the suggested intervention strategy. As researchers we are not, however, in a position to roll-

out a national CCB advertising strategy; we thus view advocacy as the best way to advance this KTA effort. The findings of this analysis have been shared with members of the Evaluation Taskforce who have expressed an interest in both sharing them with others and also advocating for a strategy. Our own intent is to adapt these findings to a decision-making context and present a synthesis to HRSDC. As HRSDC is the office that administers the CCB, it is also the decision-making body that can combine these findings with their own knowledge and enact a strategy. Although our findings can inform the creation of a strategy, further details, such as the specific CCB messages for dissemination and monies to fund a campaign, are absolutely required. Thus, we view the analysis shared here as part of a larger whole that will ideally result in greater public awareness about the CCB and increased uptake of the program by family caregivers in need of support.

2.7 Limitations

Our reliance on existing literature to compile a demographic profile has meant that this study inherits the limitations faced by those researchers; however, by using a multi-step process of confirmation, potential deficiencies in the culled profile are overcome. Use of Canadian census data holds limitations due to lag times in the publication of data and the aggregation of variables ‘age’, ‘sex’, ‘married and common-law’ and the 20% samples for ‘high school completed’ and ‘full time employment.’ Further, the ‘high school completed’ variable was not defined by sex, so includes both males and females. Using the CT scale was viewed to provide the most meaningful spatial analysis, but results in the omission of rural and remote areas. However, most specialized palliative care services are offered in larger centres and because most front-line care providers and human resources personnel from rural and remote communities have collegial and training networks extending to more

populated areas, residents of these areas are, by default, addressed in this analysis. Further, the dissemination approach recommended in the second dissemination pathway would include rural and remote communities and not simply those identified in part two of the presented analysis.

2.8 Conclusion

Recent research has indicated that the CCB's significantly low uptake can be attributed in part to the general public's lack of awareness about the program. This study has attempted to address this problem through engagement with the KTA cycle. Using a spatially informed, three-part mixed-method analysis, we have been able to provide strategic guidance for how CCB information can most effectively be disseminated to reach those most likely to use the program, and potentially other Canadians. Findings indicate that targeted dissemination efforts undertaken outside of urban cores are likely to be most effective in reaching potential or current CCB-eligible family caregivers. More specifically, this strategy should be implemented through multiple formats via two information pathways. By integrating a unique spatial perspective, these findings have been able to explicitly consider local contexts and potential barriers. Future involvement will entail translating these findings specifically for use in a HRSDC decision-making context (Dobrow et al., 2006). Doing so will allow those who hold the power to integrate their own knowledge with our findings and ultimately enact, or at least consider enacting, a CCB information dissemination strategy aimed at increasing knowledge about, and thus uptake of, the Benefit.

Although this paper has focused on an applied problem specific to the CCB, such problems of underutilization and low uptake due to lack of awareness certainly exist for a variety of other programs found in and outside of Canada, specifically within the health and

social care realm. This problem can be particularly acute regarding newly implemented programs, whereby public awareness will most likely be relatively low. The spatially informed mixed-method analysis presented in this paper can usefully be applied to such cases. Further, considering the costs associated with general awareness campaigns, a dissemination strategy based on findings from sound analysis may provide decision-makers with information to tailor a dissemination strategy that will result in high efficiency by channelling a narrow path from which such information should flow. Our approach, particularly parts one and two of the analysis, may also be useful for targeted interventions that require identifying specific populations.

CHAPTER 3

SCALE AS AN EXPLANATORY CONCEPT: EVALUATING CANADA'S COMPASSIONATE CARE BENEFIT PROGRAM⁴

3.1 Abstract

The concept of 'scale' and usage of this term have raised much debate within human geography over the past 25 years. At the same time, these very debates have developed the concept dramatically by offering new considerations of its use in alternative and more complex ways. Building on notions that scale is experienced and that scalar concepts offer a vocabulary to articulate complex phenomena, this analysis aims to explore the relevance of scale as an *explanatory concept* used by informal family caregivers and front-line health and social care workers⁵ when discussing their experiences with a Canadian social program, the Compassionate Care Benefit (CCB). The goal of the CCB is to provide income assistance and job security to those who take temporary leave from their employment to care for a terminally ill family member. As part of a larger evaluative study on the CCB, semi-structured interviews with 57 family caregivers and 50 front-line health and social care workers from across Canada were conducted and transcripts were thematically analysed. Emerging from analysis of both datasets was the common usage of scalar concepts, specifically 'region', 'community' and 'home', by respondents to articulate seemingly unique circumstances, contrast locations and geographic units, and convey relationships and

⁴ This chapter has been submitted to *Area* with co-authorship of V.A. Crooks and A. Williams.

⁵ The occupational title 'front-line health and social care worker' rather than 'front-line palliative care provider' was selected for use in this Chapter to accommodate the audience of the journal targeted for publication.

relational connections across places. Based upon the scalar categories and issues highlighted by respondents in their discussions, particular spatial challenges and inequities are illuminated, and implications for the CCB and its administration are identified. These findings provide insight into the complex ways family caregivers and front-line health and social care workers make sense of their world and more specifically, understand how federal programs like the CCB operate. By considering how such programs are experienced in scalar ways, knowledge can be maximized and thus, informed decision-makers can more effectively meet the needs of program users.

3.2 Background

Undeniably, 'scale' has been a core disciplinary concept for geography. Today, however, treatment of the concept in human geography is questionable as scholars debate what exactly 'scale' means and how it should be employed conceptually, if at all. This debate was sparked in the 1980s as a result of political, economic and urban geographers' efforts to understand our increasingly 'globalized' world and shifting global-local relations. What emerged was a theoretical repositioning of 'scale' within the discipline, with discussions and debates about the relevance and value of this concept to geographic research continuing to this day (e.g., Brenner, 2001; Cox, 1998; Colligne, 2005; Howitt, 2002; Jonas, 2006; Kaiser & Nikiforva, 2008; Legg, 2009; Marston et al., 2005; Moore, 2008; Paasi, 2004; Sheppard, 2002; Smith, 1993; Swyngedouw, 2000). Collectively, such debate has resulted in human geographers' consensus over the general tenet that scale is not a fixed, material or given category, but is socially constructed, fluid and relational (Brenner, 2001; Howitt, 1998; 2002; Marston et al., 2005; Moore, 2008). Most also agree that scale should not reflect vertical hierarchies, whereby analysis proceeds either from a 'global' (scale as structure) scale

downwards to the 'local' (scale as agency), or vice versa, as such hierarchicalization may mistakenly stabilize existing power relations or constrain structural views (Cox, 1998; Marston et al., 2005; Smith, 1993; Swyngedouw, 2000).

An outcome of the debates characterized above is that alternative understandings and treatments of scale have emerged, thus enhancing our understanding and application of this concept. For example, Howitt (1998; 2002) contends that scales are only defined and politically contested in relation to one another, similar to notes on a musical scale. Others have emphasized network theories as a way to better understand the complex intersecting socio-spatial processes that span vertical and horizontal horizons, and thus ultimately scales (e.g., Amin, 2002; Leitner, 2004). Masuda and Crooks (2007, 257) argue for an 'experiential approach' which encourages movement "away from rigid hierarchies toward a use of scale as a representation of micro to macro level phenomena that are salient to people's everyday lives." An experiential approach embraces the complexities of everyday life, namely where interconnections and intersections of social, cultural, political and economic macro and micro processes operate in place, and emphasizes the role of human agency in shaping forces that manifest in scalar ways. Masuda and Crooks' central point is that people live out their lives in scalar ways and, as such, scale is a concept relevant to how they understand and experience the world. This point relates to Delaney and Leitner's (1997, 94-95) contention that, scales are "not simply an external fact awaiting discovery, but a way of framing conceptions of reality." In keeping with this experiential perspective, scales offer a vocabulary with which we can communicate details about complex experiences and processes that are important to us and assist us with articulating their origins (Ruddell & Wentz, 2009).

Building on the notions that scales are experienced (Masuda & Crooks, 2007), frame our realities (Delaney & Leitner, 1997), and that scalar concepts offer a vocabulary which allows us to articulate complex phenomena (Ruddell & Wentz, 2009), the analysis presented herein aims to empirically explore how people draw upon scalar categories in order to make sense of their world. Our specific purpose is to gain a better understanding of the relevance and importance of scale as an *explanatory concept* used by people when discussing complex phenomena. To achieve this purpose we draw on the findings of a qualitative evaluative study examining the perspectives that two stakeholder groups have of a particular Canadian social program, namely the Compassionate Care Benefit (CCB). The goal of the CCB is to enable workers who have made contributions to a federal benefit scheme to take a temporary secured leave from employment to provide care for a terminally ill family member (Williams et al., 2006). The stakeholder groups of focus in this analysis are Canadians who have provided care for terminally ill family members (often referred to as family caregivers [FCGs]) and also front-line health and social care workers (HSCWs) who are well positioned to inform people about the CCB. Scale was not a major area of inquiry when beginning this evaluative study, but through the analytic process emerged as an important explanatory concept drawn upon by the respondents. In other words, respondents framed their knowledge of this program (and related experiences) in scalar ways without being prompted to do so, thus building on arguments that scale is indeed a relevant concept not only to the canon of human geography, but also to people's everyday lives more generally (e.g. Delaney & Leitner, 1997; Jonas, 2006; Kaiser & Nikiforva, 2008; Masuda & Crooks, 2007; Procter & Smith, 2008; Wiles & Rosenberg, 2009). In the next section, we provide a brief overview of the CCB program and the larger evaluative study to contextualize this analysis. Following this, we introduce the analytic process and then discuss our findings on how scalar concepts

were used by respondents and, based on these findings, specific ‘scalar’ implications for the CCB program.

3.3 Study Overview

In response to concerns regarding the increased responsibilities being placed upon FCGs to provide care for dying individuals due to health care restructuring (Skinner & Rosenberg, 2005; Williams, 2006), the Canadian government implemented the CCB in January 2004. The CCB provides eight weeks of job security and limited income assistance, up to 55% of a FCG’s average insurable earnings to a maximum of CDN\$477 per week, to those who take temporary leave from employment to care for a terminally ill family member at risk of dying within 26 weeks (HRSDC, 2009). Among other requirements, CCB recipients must have accumulated 600 insurable hours over the preceding 52 weeks and demonstrate that their regular weekly earnings have decreased by more than 40% as a result of providing care (HRSDC, 2009). The present analysis contributes to a larger CCB evaluation study which aims to offer policy-relevant recommendations informed by the perspectives of the program’s primary stakeholder groups. The methodology is guided by Patton’s utilization-focused evaluative approach which aims to inform program improvement through the utilization of research findings (Patton, 1997).

3.3.1 Recruitment

Three FCG respondent groups were purposefully sought out: (1) successful CCB applicants; (2) denied CCB applicants; and (3) those who had never applied for the CCB. The diversity in these groups’ perspectives was understood to be important to the aim of the evaluative study. Occupational diversity in both training and work setting among the HSCW respondents was also sought and individuals most closely involved in providing care for

terminally ill individuals or supporting FCGs were desired participants. As the CCB is a national program, respondents were recruited from provinces selected to represent Canada's regional and linguistic diversity: British Columbia, Manitoba, Ontario, Quebec, and Newfoundland and Labrador. Extensive recruitment strategies were employed with both respondent groups in English and French, including: circulation of advertisements to relevant listservs and newsletters; e-mail notices to associations; and snowballing out from existing respondents. FCGs were recruited over an eight-month period in 2007 while HSCW recruitment took place over a five-month period in 2007-08. FCGs and HSCWs who received the study information were asked to call a toll-free number to schedule an interview in either English or French at their convenience.

3.3.2 Data Collection and Participant Overview

Upon receiving consent to participate, 57 semi-structured interviews were conducted via telephone with FCGs: 22 successful CCB applicants; 5 denied applicants; and 30 non-applicants (see Table 3-1). By province, 24 resided in Ontario, 23 in British Columbia, five in Quebec, three in Manitoba, and two in Newfoundland and Labrador. Three highly similar interview guides were used, one for each FCG respondent group. Questions inquired into their experiences as FCGs and suggestions on how to better support Canadians caring for dying family members. For successful and denied applicants, questions also pertained to the CCB's administration and other specific experiences with the Benefit program. All interviews were digitally recorded; however, some additional demographic questions were posed and hand recorded.

Table 3-1: FCG respondent overview

Age	Percentage (n=57)
Under 44	33%
45 – 54	37%
55 – 64	26%
Over 65	4%
Sex	
Female	89%
Male	11%
Relationship to Care Recipient	
Spouse	26%
Parent	5%
Child	65%
Sibling	2%
Aunt/Uncle	2%
Length of Caregiving Period	
Less than 6 months	25%
7-10 months	19%
1 – 2 years	11%
2 – 3 years	14%
More than 3 years	32%
Employment Status at Time of Interview	
Full-time	74%
Part-time	14%
Retired	9%
On leave	4%

Forty-eight English- and two French-language interviews, ten from each of the five target provinces, were conducted via telephone with HSCWs from a variety of employment backgrounds (see Table 3-2). Interviews inquired into respondents’ perceptions of the CCB’s usefulness, barriers and facilitators to access, experiences of recommending the CCB to a client or client’s family, working knowledge of how the CCB is administered, and suggestions for improvement. Forty-nine interviews were digitally recorded and one was recorded through notes as the participant preferred this method.

Table 3-2: HSCW respondents by occupational grouping

Occupation	Number of Respondents
Social Worker	11
Palliative Care Director / Coordinator	9
Clinical/Oncology/Palliative Nurse	7
Community Health/Home Care Nurse	7
Oncologist/Physician	6
Chaplain/ Pastoral Care	2
Counselor	2
Volunteer Coordinator	2
Facility Patient Care Manager	1
National Nursing Officer	1
Nurse Coordinator	1
Occupational Therapist (Home Care)	1
<i>TOTAL</i>	<i>50</i>

3.3.3 Analytic Process

Following data collection, digital recordings from both datasets were transcribed verbatim. Recordings of French-language interviews were simultaneously translated and transcribed into English. Transcripts were entered into N7™ data management software and thematic analysis was conducted. Thematic analysis involves reviewing and coding data both inductively and deductively in order to reflect existing research goals as well as any issues which are emergent – and sometimes unanticipated – from the dataset (Bradley et al., 2007; Fereday & Muir-Cochrane, 2006). The identification of patterns within the dataset during the reviewing and coding processes is pursued in order to capture dominant emergent themes which will become categories for analysis (Fereday & Muir-Cochrane, 2006). The development of coding schemes for both datasets involved a five-step process: (1) detailed review of three randomly selected transcripts to identify initial themes; (2) drafting of a coding scheme; (3) revision of scheme following discussion and further transcript review; (4) coding of five transcripts; and (5) review of coded transcripts in order to refine scheme.

Multiple investigators were involved in each step in order to enhance the consistency of interpretation and thus reliability of findings. Specific to the current analysis, inductive conceptual codes such as ‘place’, ‘home’ and ‘rural’ were largely drawn upon; however, some deductive sub-codes were also used, such as ‘FCG logistics’, ‘travel’, and ‘place of care.’ From reviewing both datasets, the common use of scalar concepts emerged from the transcripts as FCG and HSCW respondents alike articulated their experiential CCB knowledge, thus resulting in the pursuit of the present analysis.

3.4 Characterizing Respondents’ Use of Scalar Categories

Both FCG and HSCW respondents drew on the broad scalar categories of *region*, *community* and *home* in discussing the CCB. Certainly *region*, *community*, and *home* are concepts that are not exclusively used in scalar ways; however, because the respondents drew on them in order to reference both differences (e.g., nearer processes versus those happening further away) and relationships (e.g., local happenings that are informed by broader occurrences) in highly spatial and comparative ways they were, in fact, employing these categories as a way to organize and articulate their thoughts. Revisiting the main purpose of this paper, we thus contend that these scalar categories were employed by the respondents in ways that were meaningful to them and their lives in place. These categories serve as organizational structures that demarcate where particular processes and practices emerged from in relation to the CCB and also family caregiving, and how they play out in specific places and ways. In the remainder of this section, we discuss each of these scalar categories separately with a focus on characterizing their nature based upon respondents’ use, before moving to consider the implications of these findings for the CCB.

3.4.1 Regional Scale: Its nature and key issues

Because of Canada's vastness, it is often characterized by large regions that typically span multiple provinces and/or territories (e.g., the North, West Coast, Prairies). The Atlantic region is the most easterly of these and is comprised of four provinces: New Brunswick, Nova Scotia, Prince Edward Island, and Newfoundland and Labrador. According to the 2006 Canadian Census, this region is experiencing the highest levels of aging, with 14.7% of its population now over the age of 65. The region is also characterized by the highest seasonal employment rates in Canada (HRSDC, 2006), where about one in ten employees is a seasonal worker (Statistics Canada, 2004a). Further, over the past three decades Newfoundland and Labrador has held the highest unemployment rate in the country (Statistics Canada, 2004b). Respondents from Newfoundland and Labrador, the Atlantic province of focus in the present study, were more likely than those from any of the other provinces to employ the notion of regional scale to frame their discussions of the CCB and related family caregiving experiences.

The demographic challenges currently facing the Atlantic region weighed heavily upon both FCG and HSCW respondents. As a FCG from Newfoundland remarked: "the population is getting older...it's almost like a place to come to retire now. It's a very aging population here." The region's aging population was seen as especially troublesome in conjunction with 15 years of high inter-provincial out-migration of youth, specifically those aged 20-34 (Statistics Canada, 2008). As a result, the region faces obstacles regarding the provision of informal care by children for their dying parents. A palliative care nurse from Newfoundland emphasized this issue by stating that:

...we have a lot of out-migration of our younger population, going to other provinces to work. So oftentimes, that leaves a lot of the more elderly population here to function on their own...

Several other FCGs and HSCWs from Newfoundland and Labrador made this point, emphasizing that it differentiated their region from others and warrants specific attention on how to better support dying individuals and FCGs who must travel back to the region to provide informal care.

Primarily, those from Newfoundland and Labrador were the only respondents to connect their discussions more generally to the regional economy. Specifically, they commented on the challenges of maintaining an adequate regional HSCW workforce. As a palliative care nurse stated:

Because the wage for home support...workers is very low here, the turnover rate and the continuity with them is very problematic. And right now, the agencies...are having difficulty finding workers.

Certainly, their comments were underscored by the regional economic challenges mentioned above which have, in turn, led to HSCW shortages due to out-migration as well as increasing stress on health and social service systems (Public Policy Forum, 2005). One clear implication of such a reality is an increased burden on FCGs to provide care and the resulting need for supportive programs such as the CCB.

3.4.2 Community Scale: Its nature and key issues

Health Canada defines rural communities as those with populations of less than 10,000 which are removed from urban services and resources. In 2001, approximately 30% of Canada's total population resides in rural communities, as defined above (Canadian Institute for Health Information, 2006). The tendency for retirees to move to rural areas and the migration of rural youth to urban centres is resulting in the aging of rural populations and thus of rural communities (Public Health Agency of Canada, 2006). Due to their low population densities and frequent isolation, the residents of these communities face

particular challenges in accessing health services which include both geographic and temporal connotations (Romanow, 2002). Two major obstacles involve the vast distances rural citizens must travel to reach many formal health services (and the travel time required), as well as reduced local availability of HSCWs (Public Health Agency of Canada, 2006). Our findings demonstrate that it was most commonly FCG and HSCW respondents living/practicing in rural areas that used the scale of ‘community’ during their interviews.

Residents of rural communities consistently expressed particular inequities in accessing health and social services due to factors such as distance, geographic isolation and lack of transport. For example, a FCG living in rural British Columbia emphasized her frustration over the barriers these factors posed for her in providing informal care: “[There are] taxis, but you have to pay for them and there’s only one wheelchair taxi in [rural town name] so you have to book it ahead of time.” Many indicated that planning ahead to reserve rural transportation services was often problematic when caring for a dying individual as symptom exacerbations were unpredictable. Similarly, a FCG from Ontario stated:

We’re in the country and any time we needed something [e.g., medical supplies] we had to...pick it up...so we needed transportation in that way, and that was fairly important because we usually needed it in a fairly short period of time...

Furthermore, many HSCWs, and specifically home care workers, commented on the challenges inherent to providing services to dying clients living in rural communities. An oncology nurse from Newfoundland stated: “the rural communities have so little resources...we’ve got one home care nurse for a seventy kilometre zone.” This respondent continued to explain that:

...she [nurse] may have two or three palliatives on the go at one time. But one is at zero kilometres, one is at 70 kilometres, and one is at 50 kilometres. And if she makes one visit to each them in one day, that’s a whole day gone.

In addition to the vast distances HSCWs travel to reach their clients, the limited numbers of professionals who work within these communities also hinders service and supports for FCGs and dying clients. As a palliative care coordinator in Manitoba commented, even if families are “eligible to have home support workers...we don’t have them to be able to give...that’s the challenge, I think, in small communities.”

3.4.3 Home Scale: Its nature and key issues

Canadian health policy shifts have created a trend whereby care at all stages of life is increasingly taking place within the home rather than in formal institutions (Burge et al., 2003; Lilly, 2007; Skinner & Rosenberg, 2006). In conjunction with this shift is the growing desire of many to live out their final days at home, within a familiar environment, and among loved ones (Bacon, 2008; Burge et al., 2003; Gomes & Higginson, 2006). Illustrating this trend is the 51% increase in use of the Canadian home care sector since 1997 (Canadian Home Care Association, 2008). This has raised concerns as the responsibility of caregiving is now significantly being undertaken by FCGs who often do not have the support and/or resources required meet such demands (Milligan & Conradson, 2006; Skinner & Rosenberg, 2005; Williams, 2004). It is also important to consider the gendered nature of the home, in that traditionally work undertaken in this space, including that of caregiving, has been considered women’s work (Armstrong et al., 2008; Dyck, 2005; Neumann et al., 2007; Yantzi & Rosenberg, 2008). Both respondent groups, regardless of regional or community settings, when discussing the CCB frequently drew upon the scale of ‘home’.

Many FCGs expressed their preference to have their family member’s death occur at home, as they felt the quality of care there surpassed that of a hospital setting. For example, a FCG from Quebec stated:

I wouldn't have allowed my spouse to pass away...in a hospital... It was very important that...there was love too...contact that was a lot more humane at home than at the hospital.

Further, many respondents expressed frustration over the lack of public resources available for FCGs to provide quality care in the home. Although there was recognition among HSCWs that many dying individuals want to be cared for in their homes, they also identified getting needed information to FCGs as a significant challenge of such care. A palliative care nurse in Manitoba stated:

...when I think about what people are brought in for [to hospital after initially being cared for at home], a lot of time it's caregiver stress. They need more resources for the caregivers.

This point is significant as it demonstrates a relationship between home-based and institutional care, in that when care in the home is not supported the result is often end-stage reliance on hospital care due to FCG burnout.

With respect to the gendered societal expectations on women to provide informal caregiving in the home, several female FCGs expressed that they felt family pressure or a particular responsibility, as women, to take on this role. One FCG from Ontario explained: "...my brother kind of just backed out – everybody kept telling us that it was, it's a daughter's thing to care for a, um, a sick parent." Another FCG explained that she felt that, as a woman, she was the only one in the family capable of providing care in a home environment. Further, a FCG stated that:

...[y]ou've got mortgage to pay, and your kids and everything to look after. And I'm the main...my husband works as well but I make more income than he does and yet...I felt a real responsibility to be there.

Many HSCWs touch upon this issue as well. An oncology nurse from Newfoundland commented on the gendered division of caregiving work within the home:

Most of the...primary family caregivers are female, but a lot of the male members in the household...will assist the female in lifting and moving and support like that within the household.

Further, a palliative care coordinator from Manitoba emphasized that the receiving of care was also gendered, explaining that:

If the patient who's dying is male, the caregiver is usually – well, always – female, and usually a spouse. If the patient that's dying is female, there's usually another caregiver...a sister or something like that.

3.5 Scalar Explanations: Implications for the CCB

Through thematic analysis, the scalar categories of *region*, *community* and *home* emerged as important organizational artefacts that both FCG and HSCW respondents drew upon in articulating their experiences. As seen in Table 3-3, each scalar category and associated issues emphasized by respondents holds direct implications for the CCB program. Certainly, this is an important acknowledgement given the applied focus of this evaluative study. In the remainder of this section, we explore these implications.

The out-migration of Atlantic youth means that the CCB's financial and time restrictions limit FCGs from the region, who are not presently living there, in providing care for their aging family members. A Newfoundland care coordinator explained:

...in order for those children to come back [to care for their dying parents], there's a financial burden on them. They arrive typically for a week to ten days, just to offer support. But when they get here, realize that it's at the end, and can't stay because of financial difficulties.

Currently, the CCB does not hold special considerations for those who must travel significant distances, such as inter- or even intra-provincially to provide care, thus placing an unequal financial and temporal burden upon these FCGs. Further, the Atlantic's high seasonal employment and unemployment rates mean that workers from here will more likely be ineligible for employment insurance and the CCB specifically (HRSDC, 2006).

Table 3-3: Scalar implications for the CCB program

Scale	Challenges	CCB Implications
<p>Regional (i.e., Atlantic Canada)</p>	<p><i>Demographic:</i> Aging population and out-migration of youth in the Atlantic</p> <p><i>Economic:</i> High unemployment and seasonal employment; HSCW human resources shortages due to the low-paying nature of some of this work</p>	<p><i>Demographic:</i> Higher costs for family members working elsewhere to travel back to the region to provide care are not covered by the CCB program</p> <p><i>Economic:</i> Some citizens more likely to be ineligible for the CCB due to employment circumstances; Potentially restricted access to information about the CCB due to dissemination challenges</p>
<p>Community (i.e., rural communities)</p>	<p><i>Distance:</i> Increased costs for needed care-related travel for rural residents</p> <p><i>Access:</i> HSCW workload and staff shortages in rural communities may limit access to these information-rich individuals</p>	<p><i>Distance:</i> Higher out-of-pocket costs to cover travel to major urban and/or regional centres are not covered by the CCB program</p> <p><i>Access:</i> Potentially restricted access to information about the CCB due to dissemination challenges</p>
<p>Home (i.e., providing family caregiving in the home)</p>	<p><i>Home Care:</i> Lack of adequate home care support available to assist FCGs</p> <p><i>Gender:</i> Continued gendered construction of care work in the home</p>	<p><i>Home Care:</i> Lack of formal support may discourage potential or ongoing FCGs from providing care in the home when receiving the CCB</p> <p><i>Gender:</i> Women are more likely to be ineligible for the CCB due to employment circumstances while more likely to serve as FCGs</p>

Additionally, HSCWs are usually the first persons that FCGs turn to for information during the caregiving period (Crooks et al., 2007; Giesbrecht et al., 2009) and the low numbers of these workers in the region may hinder eligible FCGs to become informed about the CCB and other supports they are entitled to access.

Reimbursement for travel incurred during the caregiving period is not something currently provided by the CCB, even for those FCGs living in rural communities and traveling long distances, sometimes daily, to access supplies and services that enable them to care for a dying family member at home. A physician explained “they have things like ambulance rides to pay for, parking meters, food, gas...these are additional expenses.” CCB recipients in rural areas may thus be disproportionately burdened by the need to pay out-of-pocket for travel from the limited financial assistance received through the program. These same FCGs may also experience hindered access to information on the CCB program, similar to the Atlantic region, due to lower numbers of HSCWs in their communities. Even applying for the Benefit may be more challenging to residents of rural communities because, as a palliative care coordinator from Manitoba explains: “...not every community in rural Manitoba has an EI [employment insurance] office...and certainly there are many people who do not have access to computers.”

Having access to formal home care services is an important determinant of whether or not a dying person will be cared for at home (Gomes & Higginson, 2006), and many FCG and HSCW respondents alike remarked that potential FCGs who wish to provide physical care are discouraged from or unable to follow through with caregiving as such support is simply not accessible. Considered an ‘extended health service’, home care in Canada is uninsured and not covered by the Canadian Health Act, therefore, payment arrangements

and cost can vary widely (Canadian Home Care Association, 2008). A social worker in Quebec expressed:

I think we say that home care is universal, but it's not really universal. It's based on your finances and what you're able to provide in terms of concrete help.

Therefore, becoming a FCG is not always an option, resultantly rendering the CCB useless in that it does not provide nor guarantee equitable access to formal home care support needed by FCG to provide physical care in the home⁶. Further, women are most likely to become FCGs and provide care within the home; however it is also women who are least likely to be eligible for the CCB. As women generally make up the majority of stay-at-home parents and part-time workers they are often less eligible for employment insurance (Armstrong & O'Grady, 2004). Although women make up the majority of CCB claimants, they receive on average lower weekly benefit payments than do men because of their more limited salaries (HRSDC, 2007). This reality demonstrates the gendered inequities inherent within the CCB program.

3.6 Revisiting Scale as an Explanatory Concept

Scalar categories were drawn upon by respondents to: identify seemingly unique circumstances (e.g., youth out-migration in the Atlantic provinces), contrast locations and geographic units (e.g., travel barriers experienced in rural communities relative to urban ones), convey relationships and relational connections across places (e.g., between the quality of care being provided in the home and whether or not institutional care will be needed), and identify key differences (e.g., in the availability of HSCWs between one kind of place and another). Each of these uses highlights both comparative and spatial uses of the three scalar

⁶ Importantly, the CCB is not limited to circumstances where a dying person is being cared for in a private home. FCGs may receive the Benefit regardless of the place where the dying person resides, whether at home, in an institution, or elsewhere. The giving and receiving of care in the home was, however, a focus of comments made by both respondent groups.

categories. Summarizing their employment of the scale construct in such a way assists with understanding both how and why scalar categories are useful explanatory concepts while providing a language through which spatial processes that hold implications for the CCB can be discussed and compared in meaningful ways. The spatial processes referenced included: out-migration, changing regional economies and the resulting implications for workers in specific places, the provision of and geographic access to on-the-ground formal health and social care, and the quality of care given and received across sites. Respondents' acknowledgement that these processes emerge from differing scales provides insight as to what factors, from various spatial locations, are viewed as important to them.

People's lives are complex and simultaneously impacted by multiple processes – including social, geographic, and economic, among others – that very much complicate how the world can be understood and can also have different outcomes depending on where and how these processes intersect (Hankivsky & Christofferson, 2008). It is perhaps not surprising, then, that scalar understandings were developed and applied by respondents as a tool to understand their lived experiences where such processes complexly met. In this study, the use of the regional scalar category, for example, allowed Atlantic respondents to discuss how geographic, economic, and political processes have specific regional outcomes which have very real implications for the CCB program and its effectiveness for FCGs in the region. These same processes intersect at the community scale to affect rural Canadians, reflecting similar challenges in the provision and access of required medical services to those reported for the Atlantic region. Regarding the provision of care at home, these processes materialize into determinants which direct where death will occur, as well as who will provide care for dying family members. Such findings resonate with Masuda and Crooks' (2007, 257) call for an experiential approach to scale, whereby they emphasize that it is

through practices of scale where “the puzzling yet persistent connections between people’s lives in-place and the larger forces that shape them” become apparent. The contribution of the present analysis is that it provides empirical examples that support their conceptual argument. More specifically, findings shared herein show how inextricably interwoven scalar categories are to larger processes while demonstrating that it is through the lived experiences of these scales that different understandings emerge depending upon how they intersect (e.g., in what place, under what circumstances, by whom, and for what reason are scalar categories drawn upon?).

Not only was scale essential to respondents’ understandings of their experiences, but it was also crucial in communicating their experiences in a meaningful way. Without categorical scales to draw from, the ability to describe important details would have been an incredibly dubious task. The scales invoked in the respondents’ comments were also quite telling about how they made sense of the CCB. This is an important acknowledgement because although this applied study was focused on evaluating a federal-level program, respondents rarely made use of the ‘national’ scale, and instead favoured those of the region, community, and home. The use of more refined scalar concepts allowed them to draw comparisons, emphasize relationships, and provide a particular level of information deemed important by them. At the same time, it also shifted the focus onto those scales that had most relevance to their everyday lives and experiences. This finding confirms Ruddell and Wentz’s (2009) contention that scales, or scalar categories in this instance, provide a vocabulary for us to draw upon as needed, while also adding two important points: (1) that we should be aware of people’s motivations for drawing upon a scalar vocabulary (e.g., to shift the conversation to a more experiential level), and (2) that, more specifically, scalar

terms can offer an ‘explanatory vocabulary’ that can be drawn upon to convey complex processes to others.

3.7 Conclusion

Although debates on ‘scale’ in human geography generally remain within the theoretical realm, this analysis has attempted to reveal that scale is an explanatory concept used by people to articulate their experiences in meaningful ways. Findings indicate that FCGs and HSCWs pulled from three scalar categories, namely the *region*, *community*, and *home*, in order to make sense of the complex geographic, social, cultural, political and economic processes surrounding them and illustrates how they understood these to impact their use of the CCB program. Based upon the scalar categories and challenges expressed by respondents, particular implications for the CCB program were identified and summarized. Such findings demonstrate significance in considering scale during analytic processes and favour a more strategic approach for evaluating national programs like the CCB. In understanding how these programs are experienced across scales, as well as how realities of lived scalar experiences (i.e., geographic or economic circumstances) create barriers for potential users to gain knowledge, apply and successfully utilize such programs, decision-makers can become informed and more effectively meet the needs of program users.

Procter and Smith (2008) suggest that by considering a multitude of spatial scales, knowledge can be maximized. In the context of the present analysis, attentiveness to the use of scalar categories by respondents has confirmed this, resulting in the identification of spatial nuances and offering a new perspective on the findings of this applied, evaluative study. Such findings, particularly the identified implications for the CCB, can contribute valuable information to decision-makers as a scalar perspective illuminates issues which

otherwise may have been overlooked, particularly with regard to issues of spatial equity. Importantly, our focus on an experiential approach to scale has generated justifications for changes to be made to the CCB that would make it more responsive to users' needs. Although this scalar approach has been applied to caregiving in general and the CCB program in particular, such an approach may be useful in other studies where the desire exists to identify particular spatial challenges and inequities experienced by people in meaningful, and thus scalar, ways. As long as we continue to understand and experience our world in 'scales', and draw upon scalar categories to explain these very experiences and understandings, the concept of scale is relevant to research and can provide a depth of knowledge when applied to spatial variations composed of highly differing variables.

CHAPTER 4 CONCLUSION

4.1 Summary

In this thesis, I have presented two analyses that were conducted with the aim to contribute to a larger evaluative study currently underway on the CCB program. The purpose of this larger study is to make policy-relevant recommendations that are informed by the needs of Canadian family caregivers and input from other key informants who ultimately, can shape program uptake (Crooks & Williams, 2008). Underpinning the analyses explored herein has been an awareness that we must consider how the vastness and diversity of the Canadian landscape, in both the physical and social sense, creates particular barriers to and implications for the successful utilization of federally implemented programs, such as the CCB. Therefore, the research conducted for this thesis has aimed to demonstrate the utility of employing a *geographic* perspective as a contribution to this considerably applied larger evaluative study.

The analysis put forth in Chapter 2 was conducted in response to recent reports that have indicated a major obstacle to the successful uptake of the CCB is the paucity of public knowledge regarding the program's existence (CCS, 2008; Crooks et al., 2007; HRSDC, 2007; Osborne & Margo, 2005). Therefore, framed by Graham et al.'s (2006) knowledge-to-action cycle, the objective of the analysis was to determine the most effective paths and venues from which an information dissemination strategy about the CCB could be guided, with the goal of increasing awareness among family caregivers and other Canadians of the program's existence. The development of a spatially informed, three-part mixed method

analysis enabled the identification of specific strategies for effectively reaching those likely to become family caregivers and, therefore, benefit the most from gaining knowledge on the CCB. The findings indicate that, firstly, dissemination of CCB information should target women between the ages of 45 and 64 years who are married or common law, have completed high school and work full-time. Secondly, dissemination efforts should target specific geographic localities, namely those areas surrounding urban cores. Thirdly, the dissemination of CCB information should be implemented through multiple formats via two specific information-sharing pathways: (1) from key professionals to family caregivers and (2) from the community to the general public. Integrating the findings from each of the three analytic steps has generated a distinct pathway from which information about the CCB can effectively reach potential users. Importantly, by integrating an explicitly geographic perspective to Graham et al.'s (2006) knowledge-to-action model, the consideration of local contexts and potential barriers – two important components in the model – have become particularly nuanced. Translated into a decision-making context, these findings can contribute valuable knowledge that can increase awareness and, more importantly, successful uptake of the CCB.

Contributing to current debates surrounding the use of 'scale' in human geography research, the analysis in Chapter 3 builds upon the notions that scale is experienced (Masuda & Crooks, 2007), frames our realities (Delaney & Leitner, 1997), and also that scalar concepts offer a vocabulary from which complex phenomena can be articulated (Ruddell & Wentz, 2009). The analysis aimed to explore the relevance of scale as an explanatory concept used by family caregivers and front-line palliative care providers when discussing their knowledge of and experiences with the CCB program. By evaluating the program through the scalar categories employed by respondents during the interviews, particular challenges

and barriers to the successful uptake of the CCB became apparent. Analysis of datasets from both respondent groups revealed the common usage of three scalar concepts, specifically ‘region’, ‘community’, and ‘home’, to articulate seemingly unique circumstances, to contrast locations, and to convey relational connections across places. The findings of this analysis provided insight in to the complex ways that family caregivers and front-line palliative care providers understood their worlds and more specifically, how federal programs such as the CCB operate. Further, these findings also illuminated implications for the CCB and its administration. Considering the ways that the CCB was experienced, and the role of scalar concepts in explaining such experiences, has allowed for the development of an analysis that has much to contribute to the larger evaluative study. The findings presented in this chapter can also assist decision-makers with becoming informed on how to more effectively meet the needs of family caregivers across Canada through the CCB program.

4.2 Research Contribution

Taken together, the findings from the two research analyses previously discussed contribute valuable knowledge both to the larger ongoing CCB evaluative study, as well as to health geography research within Canada today. In the following subsections, I discuss how, when integrated, the findings of the two analyses: (1) strengthen our understanding of information challenges specific to the CCB program; (2) recognize the unique knowledge that front-line palliative care providers’ hold; and (3) advance the utilization of geographic concepts in applied health research.

4.2.1 Identifying Informational Challenges

The overarching methodology of this research has been directed by Patton's utilization-focused evaluative approach, which aims to inform program improvement through the utilization of research findings with specific attention attributed to "*intended use by intended users*" (1997, p20, emphasis in original). Findings from this research confirm that the intended users of the CCB and other key stakeholder groups believe that the program is generally not meeting its potential. As noted above, one major barrier to the successful utilization of the program raised by respondents was the general lack of awareness regarding the program's existence. This particular utilization barrier has been most scrutinized in Chapter 2.

While the two analyses included in this thesis each provide findings that separately assist with evaluating the CCB using a utilization-focused approach, when considered together, there are also more refined messages that emerge across their foci. For example, in Chapter 2 it was noted that front-line palliative care providers commonly expressed having a responsibility to inform family caregivers about the CCB. It was also found that particular barriers to enacting this responsibility exist as many explained that they, themselves, may not hold accurate CCB knowledge or may feel inhibited to suggest this program to families due to its association with 'financial need' or a family's denial of impending death. Furthermore, front-line workers also commented that they could not always ensure contact with families in time to usefully share information about the CCB with them. As was revealed in Chapter 3, this was especially so in some regions (e.g., Atlantic) or communities (e.g., rural) whereby low numbers of front-line palliative care providers and/or geographic distance may restrict families' access to information about the CCB program.

Drawing from the above example, the findings from both analyses can be used *together* to strengthen our understanding of the informational challenges that exist with regard to the CCB that ultimately pose as a barrier to program utilization. From another perspective, the spatially informed knowledge translation strategy defined in Chapter 2 is enhanced by the findings in Chapter 3, which have identified potential barriers to informational uptake in particular localities across Canada. For example, in considering the reported lower number of front-line professionals working in the Atlantic region or rural communities, relative to other regions and community types, more efforts should be placed on disseminating information through the second sharing pathway identified in Chapter 2 (from community places to the general public) in order to overcome these identified barriers and ensure uptake.

4.2.2 Valuing the Perspectives of Front-line Palliative Care Providers

With the current shift in Canadian health care towards increasing community and home-based care, community-based front-line palliative care providers are often the first points of contact for patients and their families for a number of things. As a result, numerous expectations are placed upon these workers to ensure that patients' families have access to the information and resources required to navigate the health care system and carry out caregiving work within the home or elsewhere (Penz, 2008). Therefore, a key component in the provision of quality care is the valuable work of community-based front-line palliative care providers in response to this expectation. However, little research seems to consider the benefits of including these care providers' perspectives, including in terms of what *they* expect from various supports and programs and especially with regard to the provision of end-of-life care (Jansen et al., 2009; Penz, 2008; Rose & Glass, 2006).

In undertaking this thesis research, I have recognized the unique knowledge that community and home-based formal care workers are able to contribute to inform improvements in the administration of the CCB, and thus, in doing so, contribute to overcoming the knowledge gap identified above. A common objective of the analyses was to seek front-line palliative care providers' perspectives regarding the barriers to and facilitators of the CCB's uptake. Although family caregivers are the intended users of the CCB program and as such their perspectives must be heard, front-line palliative care providers were some of the strongest advocates for developing the CCB and getting its supporting legislation enacted and, therefore, hold a valuable perspective to contribute to this evaluative study (Crooks & Williams, 2008). The analyses put forth in both Chapters 2 and 3 reveal the depth of their contributions as stakeholders in the utilization-focused evaluation process. Given how beneficial it has been to hear from these workers in the present study, there is a clear need to use their experiences to inform other research studies. For example, this could include understanding paid home care providers' perceptions of how to improve the quality and accessibility of home care. In sum, front-line palliative care providers' experiential knowledge offers unique, relevant, and invaluable information that should be included when conducting evaluations on social programs such as the CCB and in other research for which their experience and expertise is highly relevant.

4.2.3 Advancing the Use of Geographic Concepts in Applied Health Research

Together, the two analyses have contributed to demonstrating how we can employ geographic concepts in applied research, and the subsequent benefits of doing so. Particularly, by considering a more broad conception of 'access', this research has contributed to a greater understanding on how various social, economic, and political

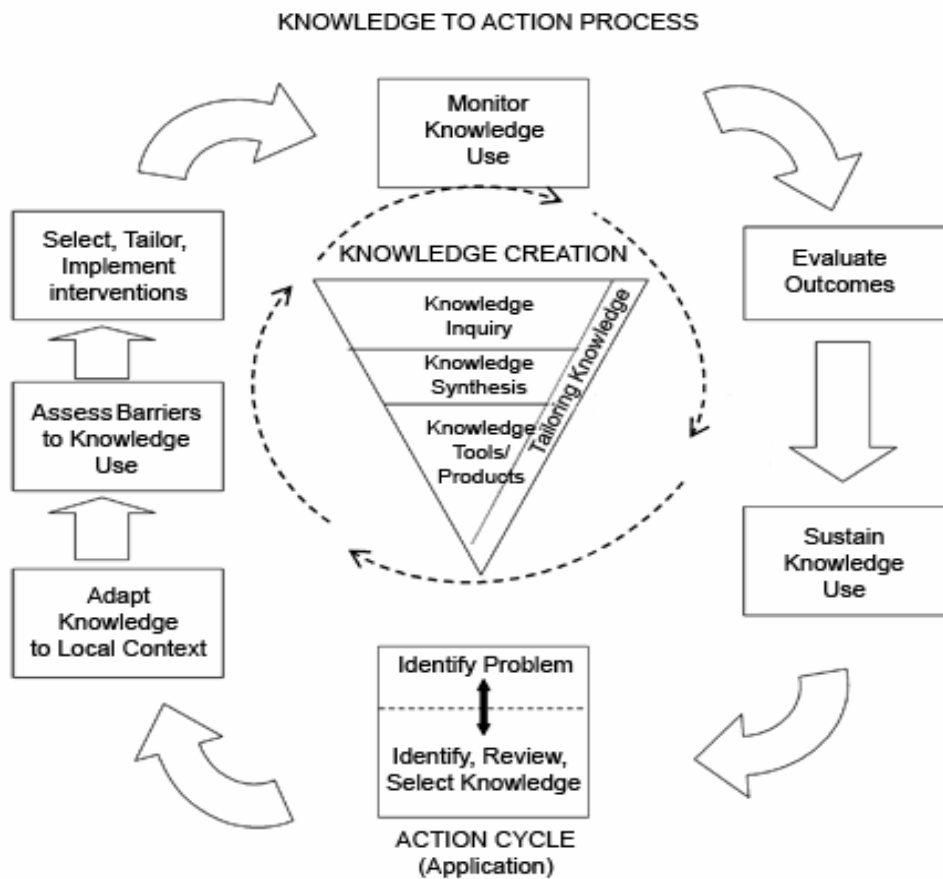
processes create barriers in accessing information and knowledge. Accessing, transferring, and translating information involves inherently spatial and geographic factors; however, there has been relatively little research that frames these processes using a geographic lens (Crooks et al., 2007). Often the transfer of information and acquisition of knowledge involves the creation of relationships and development of informational networks. Importantly, these relationships and networks are connected by information-sharing pathways that both originate and end at disparate places, and span across space (Crooks et al., 2007). Applying this geographic notion of the spatiality of information sharing and transfer, and also acknowledging how particular localities and ‘places’ hold unique barriers and challenges for the dissemination and acquisition of knowledge, has produced findings that are of tremendous benefit to the larger evaluative study.

The application of the geographic concept of ‘scale’ as an analytic tool to evaluate federally administrated programs can be especially effective in countries as vast and diverse as Canada. With great variation across such an expansive landscape, it is important to consider Canada’s heterogeneity when evaluating a national program from the perspective of its intended users and other stakeholders. In applying the concept of scale to analyze how federal programs are experienced by Canadians, unique circumstances and challenges become illuminated that may otherwise have been overlooked. Such a perspective also treats the nation as a collection of diverse ‘areas’ and ‘places’ which are variously characterized depending upon how and where multiple complex social, economic, geographic, among other, locations and processes intersect. Importantly, although the utilization of scale, and likely other core geographic concepts as analytic tools, can yield findings that are of relevance to applied research, these same findings can also contribute the advancement of these very concepts within the discipline, as shown in Chapter 3.

4.3 Next Steps

Reflecting on Graham et al.'s (2006) knowledge-to-action cycle, illustrated in Figure 4.1, and in reference to Chapter 2, an applied problem has been identified, ways to adapt knowledge to local contexts determined, and existing barriers to knowledge use have been assessed. Therefore, the next phase of this cycle involves the selection, tailoring, and implementation of an intervention strategy.

Figure 4-1: Knowledge-to-action cycle



Source: Graham et al. (2006). Lost in translation: time for a map? *Journal of Continuing Education in Health Professions*, 26(1), 12-24.

The findings presented within this thesis hold critical information for HRSDC's development of an information dissemination strategy about the CCB. Taken together, these findings contribute knowledge that can determine weaknesses of certain information dissemination approaches and strengths in others. These findings can also inform whether a particular information dissemination pathway may be more effective within particular local contexts. Such findings can usefully be translated to inform decision-makers; however, what has yet to be determined are the specific messages about the CCB that should be shared with the various stakeholder groups through this dissemination approach (e.g., family caregivers; front-line palliative care providers; human resources personnel). This is an important next step as the results from this study, and particularly the analysis put forth in Chapter 2, have pointed to the fact that, in order to avoid overwhelming people with information, only the most valuable information points about the CCB ought to be shared. To address this objective, I am currently working with other evaluative study investigators to develop a 'messaging survey' that will ask existing front-line palliative care provider respondents to rank, in terms of importance and relevance, a listing of possible information points about the CCB that need to be mobilized.

Guided by Patton's (1997) utilization-focussed evaluative approach, future steps stemming from this research and the larger evaluative study involve the utilization of the findings presented herein to inform program improvement. Findings from the analysis put forth in Chapter 3 illuminate particular challenges to the program's utilization experienced by the program's primary users and key informants. Such findings can provide the basis from which suggestions for improvements can be made which ensure the CCB is meeting its potential. Drawing from these findings, one suggestion for improving the program may be

to consider implementing a ‘travel subsidy’ for those family caregivers who must travel vast distances in order to provide the required care for their family member. Implementing a ‘travel subsidy’ for Canadian family caregivers would help to alleviate some of the financial burden experienced family caregivers, particularly for those who must either travel back to the Atlantic region, or travel considerable distances to access required health services due to residence within a more rural community. One other suggestion stemming from the findings of Chapter 3 may be to decrease the number of insurable hours required for CCB eligibility. In May 2009, there were almost three females for every male part-time worker in Canada (Statistics Canada, 2009). Based upon knowledge of the gendered nature of caregiving within Canada, decreasing the number of insurable hours required for eligibility would allow greater access to the benefit for those who will most likely need it.

In order to move the knowledge gained from this thesis and the larger evaluative study into action, the findings must be synthesized and the most important informational points determined and translated specifically for use in a HRSDC decision-making context. Doing so will enable those who hold decision-making power to integrate their own knowledge with the findings of this evaluation in order to make relevant policy adjustments to address existing inequities. Clearly, a key action being advocated for throughout this thesis has been the implementation of a CCB information dissemination strategy aimed at increasing knowledge about the Benefit with sensitivity to the geographic nuances (e.g., where potential program users reside, the challenges in disseminating information in certain kinds of places) that will ultimately shape its usefulness. Advocating for such an action through sensitive knowledge translation is another important next step stemming from this thesis. Further, advocating for program improvements informed by the ‘scalar’ perspectives of the CCB’s primary users and key informants can considerably enhance Canadians

utilization of the CCB program. I will, once again, work with other evaluative study investigators in order to translate research findings across audiences and mobilize key messages.

Considering the complexities surrounding access to the CCB program and knowledge translation, a potential area for future research is to explore more specifically the cultural component in accessing programs such as the CCB. Specifically, research is needed to better understand family caregivers' perspectives on the usefulness of the program and the barriers to successfully accessing it from a cultural standpoint. Although not a focus of this study, interviewees did touch upon this topic, especially concerning the First Nations in Canada. There is much to learn regarding how different cultures and different people residing in Canada approach death and dying and the various ideas and values surrounding dying at 'home'. Additionally, by gaining an indepth cultural understanding on how family members approach the dying process, specifically who provides care within the home and the types of care they provide, front-line palliative care providers can potentially become informed on how to better meet the needs of these families.

4.4 Conclusion

In the context of Canada's rapidly aging population, an increasing number of Canadians are becoming aware that they will be called upon to provide care for a family member who is ill and/or reaching the end of life. As the Canadian Caregiver Coalition warns: "it's not *if*, it's *when* you will become a caregiver" (2008, n.p., emphasis added). Commonly, the family caregivers who help Canadians through their final days are also in their productive working years and, thus, must manage the dual-roles of caregiving while also maintaining paid work (CPRN, 2009). In conjunction with Canada's rapidly aging

demographic, an increasing number of Canadians will soon find themselves facing this contemporary dilemma and will have little choice but to bear this dual-role responsibility.

Programs such as the CCB are legislative steps in the right direction to better supporting family caregivers; however, many aspects of this program must be improved for it to reach its potential. Without improving the CCB program, many Canadian family caregivers will remain at risk of experiencing high levels of ‘caregiver strain’ characterized by the various financial, physical and emotional burdens associated with working and providing care to family members (CPRN, 2009). The respondents in this study have raised suggested improvements; however, it will not be until more Canadians become aware of the CCB’s existence that fundamental changes to the operation of the program will have a substantial impact on improving uptake. Further, better information dissemination about the CCB may ultimately result in enhanced advocacy, due to greater awareness of the program’s limitations, which could later result in structural changes being made to the program. Therefore, to better support family caregivers in Canada it is first important to improve awareness about the CCB’s existence, and then address the specific shortcomings and inequities inherent within the program’s operation and administration.

Supporting family caregivers through programs such as the CCB has the potential to improve the quality of death and dying for individuals though lessening dual-role responsibilities (CCC, 2003; CPRN, 2009; Crooks et al. 2007). Furthermore, effectively providing financial support for family caregivers can lessen the stress and ill health triggered by managing financial burden (CCC, 2003; CPRN, 2009; Grunfeld et al. 2004). Therefore, the research presented herein is of importance, specifically in that it can contribute to strengthening the CCB. Today, the work that family caregivers offer to Canadian society remains relatively invisible. While the billions of dollars of voluntary caregiving hours they

provide annually is a significant contribution, it is really the effort, understanding, and compassion that family caregivers contribute that enables so many dying Canadians to live out their final days with dignity (CCC, 2008). For these reasons, family caregivers should be recognized, respected, valued, and celebrated. Most relevant to this thesis, they should also be supported in ways that enhance their abilities to give care to dying individuals, including through social programs such as the CCB. It is imperative for us to recognize the extraordinary effort that is made every day by family caregivers who care for dying individuals with dedication, and ensure that they are provided with all the means necessary to carry out this valuable work.

REFERENCES

- Amin, A. (2002) Spatialities of globalization. *Environment and Planning A*, 34, 385-389.
- Andrews, G. J. and Moon, G. (2005). Space, place and the evidence base, part two: rereading nursing environment through geographical research. *Worldviews on Evidence-Based Nursing* 2(3), 142-156.
- Armstrong P., Armstrong, H., Scott-Dixon, K. (2008) *Critical to care: the invisible women in health services*. University of Toronto Press: Toronto.
- Armstrong, P., O'Grady, K. (2004) *Compassionate Care Benefits not compassionate enough*. The Canadian Women's Health Network – Network magazine 64. Retrieved March 22, 2009 from: <http://www.cwhn.ca/network-reseau/7-1/7-1pg1.html>
- Ashpole, B.R. (2004). *The informational needs of informal caregivers*. Ottawa: Secretariat on Palliative and End-of Life Care, Health Canada.
- Bacon, J. (2008) *Hospice Palliative Home Care in Canada: A Progress Report*. Quality End-of-Life Care Coalition of Canada: Ottawa.
- Boaz, A., Hayden, C. (2002). Pro-active evaluators: enabling researchers to be useful, useable and used. *Evaluation*, 8, 440-453.
- Bradley, E.H., Curry, L.A., Devers, K.J (2007). Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Services Research* 42(4), 1758-1769.
- Brazil, K., Bedard, M., Krueger, P., Abernathy, T., Lohfeld, L., Willison, K. (2005). Service Preferences Among Family Caregivers of the Terminally Ill. *Journal of Palliative Medicine*, 8(1), 69-78.
- Brazil, K., Bedard, M., Willison, K. (2002). Correlates of Health Status for Family Caregivers in Bereavement. *Journal of Palliative Medicine*, 5(6), 849-855.
- Brenner, N. (2001). The limits to scale? Methodological reflections of scalar structuration. *Progress in Human Geography*, 25(4), 591-614.
- Burge, F., Lawson, B., Johnston, G. (2003). Trends in the place of death of cancer patients. *CMAJ*, 168(3), 265-270.
- Canadian Cancer Society. (2008). *Public opinion study of employment insurance benefits for caregivers*. Prepared by the Innovated Research Group Inc. Toronto, Ontario.
- Canadian Caregiver Coalition. (2009). *The Canadian Caregiver Strategy – Consultation*. Retrieved July 3, 2009 from: <http://www.ccc-ccan.ca/content.php?doc=43>

- Canadian Caregiver Coalition. (2004). *Working Paper for a Canadian Caregiving Strategy - Draft*. Canadian Caregiver Coalition Policy Paper Series, Number 3. Ottawa, Ontario.
- Canadian Caregiver Coalition. (2003). *Economic security for caregivers: a policy development process to better support unpaid caregivers*. Report from the Unpaid Caregiving Forum. Retrieved July 7, 2009 from: <http://www.ccc-ccan.ca/media.php?mid=66>
- Canadian Home Care Association. (2008). *Home Care: the next essential service*. Retrieved April 1, 2009 from: <http://www.cdnhomecare.ca/media.php?mid=1914>
- Canadian Hospice and Palliative Care Association (2006). *Advocacy Kit*. Retrieved September 17, 2008 from:
http://www.chpca.net/public_policy_advocacy/chpca_advocacy_strategy/CHPCA_2006-2007_Advocacy_Kit_complete.pdf
- Canadian Institute for Health Information (2006). *How healthy are rural Canadians? An assessment of their health status and health determinants*. Ottawa: Canadian Institute for Health Information.
- Canadian Institutes of Health Research (2008). *About knowledge translation*. The KT Portfolio at CIHR. Retrieved August 14, 2008 from: <http://www.cihr-irsc.gc.ca/e/29418.html>
- Canadian Policy Research Network. (2009). *Working and looking after mom and dad: the face of caregiving in Canada*. Retrieved July 3, 2009 from:
<http://www.cprn.com/doc.cfm?doc=1998&l=en>
- Cherlin, E.J, Fried, T., Prigerson, H.G., Schulman-Green, D., Johnson-Hurzeler, R., Bradley, E.H. (2006). Communication between Physicians and Family Caregivers about Care at the End of Life: When Do Discussions Occur and What Is Said? *Journal of Palliative Medicine*, 8(6), 1176-1185.
- Cherlin, E.J., Barry, C.L., Prigerson, H.G., Schulman Green, D., Johnson-Hurzeler, R., Kasl, S.V., Bradley, E.H. (2007). Bereavement Services for Family Caregivers: How Often Used, Why, and Why Not. *Journal of Palliative Medicine*, 10(1), 148-158.
- Chouinard, V., Crooks, V.A. (2008). Negotiating Neo-Liberal Environments in British Columbia and Ontario, Canada: Restructuring of state-voluntary sector relations and disability organizations' struggles to survive. *Environment & Planning C: Government and Policy*, 26(1), 173-190.
- Collinge, C. (2005). The difference between society and space: nested scales and the returns of spatial fetishism. *Environment and Planning D: Society and Space*, 23, 189–206.
- Cox K, (1998). Spaces of dependence, spaces of engagement and the politics of scale, or: looking for local politics. *Political Geography* 17, 1-23.
- Crooks, V.A., Williams, A. (2008). An evaluation of Canada's Compassionate Care Benefit from a family caregiver's perspective at end of life. *BMC Palliative Care*, 7(14); doi:10.1186/1472-684X-7-14

- Crooks, V.A., Williams, A., Stajduhar, K.I., Allan, D.E., Cohen, R. (2007). The information transfer and knowledge acquisition geographies of family caregivers: an analysis of Canada's Compassionate Care Benefit. *Canadian Journal of Nursing Research*, 39(3), 36-54.
- Davies, H.T.O., Nutley, S.M., Smith, P.C. (2000) *What Works? Evidence Based Policy and Practice in Public Services*. Bristol: Policy Press.
- Davis, D., Evans, M., Jadad, A., Perrier, L., Rath, D., Ryan, D., et al. (2003). The case for knowledge translation: shortening the journey from evidence to effect. *Journal of the American Medical Association*, 263, 1385-1389.
- Delaney, D., Leitner, H. (1997). The political construction of scale. *Political Geography*, 16, 93-97.
- Dobrow, M.J., Goel, V., Lemieux-Charles, L, Black, N.A. (2006). The impact of context on evidence utilization: a framework for expert groups developing health policy recommendations. *Social Science & Medicine*, 63, 1811-1824.
- Docherty, A., Owens, A., Asadi-Lari, M., Petchey, R., Williams, J., Carter, Y.H. (2008) Knowledge and information needs of informal caregivers in palliative care: a qualitative systematic review. *Palliative Medicine*, 22, 153-171.
- Dunbrack, J. (2005). *The information needs of informal caregivers involved in providing support to a critically ill loved one*. A synthesis report prepared for Health Canada. Retrieved August 15, 2008 from : <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2005-info-caregiver-aidant/index-eng.php>
- Dyck, I. (2005). Feminist geography, the 'everyday', and local-global relations: Hidden spaces of place-making. *Canadian Geographer*, 49(3), 233-243.
- Estabrooks, C.A., Thompson, D.S., Lovely, J.E., Hofmeyer, A. (2006). A guide to knowledge translation theory. *The Journal of Continuing Education in the Health Professions*, 26, 25-36.
- Eyles, J., Elliott, J.S. (2001). Global environmental change and human health. *The Canadian Geographer*, 45(1), 99-104.
- Fast, J.E., Higham, B., Keating, N., Dosman, D., Eales, J. (2005). *Family/friend caregiving and its consequences: implications for the Compassionate Care Benefit program*. A report to the audit and directorate Human Resources and Skills Development Canada. Retrieved March 28, 2008 from: http://www.ales2.ualberta.ca/hecol/rapp/publications/Family_friend.pdf
- Fereday, J., Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5(1), 1-11.
- Formoso, G., Marata, A.M., Magrini, N. (2007). Social marketing: should it be used to promote evidence-based health information? *Social Science & Medicine*, 64(4), 949-953.

- Giesbrecht, M., Crooks, V.A., Schuurman, N., Williams, A. (2009) Spatially informed knowledge translation: informing potential users of Canada's Compassionate Care Benefit. *Social Science & Medicine*, 69(3), 411-419.
- Gomes, B., Higginson, I.J. (2006). Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ*, 332(7540), 515-521.
- Graham, I.D., Logan, J., Harrison, M.B., Straus, S.E., Tetroe, J., Caswell, W., Robinson, N. (2006). Lost in knowledge translation: time for a map? *The Journal of Continuing Education in the Health Professions*, 26(1), 13-24.
- Graham, I.D., Tetro, J. (2007). Whither knowledge translation. *Nursing Research*, 56(4s), 86-88.
- Grunsfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C.C., Willan, A., Viola, R., Coristine, M., Janz, T., Glossop, R. (2004). Family caregiver burden: results of a longitudinal study of breast cancer and their principal caregivers. *CMAJ*, 170(12), 1795- 1801.
- Hankivsky, O., Christoffersen, A. (2008). *Intersectionality and the determinants of health: A Canadian perspective*. *Critical Public Health*, 18(3), 271-283.
- Hay, D., Varga-Toth, J., Hines, E. (2006). *Front-line health care in Canada: innovations in delivering services to vulnerable populations*. Canadian Policy Research Network. Retrieved July 6, 2009 from: http://www.cprn.org/documents/45652_en.pdf
- Health Canada (2002). *National Profile of Family Caregivers in Canada - 2002: Final Report*. Retrieved March 26, 2008 from: http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2002-caregiv-interven/index_e.html
- Health Canada (2004). *Health care system: family and informal caregivers*. Retrieved September 3, 2008 from: <http://www.hc-sc.gc.ca/hcs-sss/home-domicile/caregiv-interven/index-eng.php>
- Hollander, M., Chappell, N., Havens, B., McWilliam, C., Miller, J.A. (2002). *Substudy 5: Study of the costs and outcomes of home care and residential long term care*. A report prepared for the health transition fund, Health Canada. Retrieved March 26, 2008 from: http://www.homecarestudy.com/reports/full-text/substudy-05-final_report.pdf
- Hollander, M.J, Liu, G., Chappell, N.L. (2009). Who cares and how much? The imputed economic contribution to the Canadian health care system of middle aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, 12(2), 42-59.
- Howitt, R. (1998). Scale as relation: musical metaphors of geographical scale. *Area*, 30(1), 49-58.
- Howitt, R. (2002). Scale and the other: Levinas and geography. *Geoforum*, 33(3), 299-313.
- Human Resources and Skills Development Canada. (2006). *An evaluation overview of seasonal employment: November 2001*. Retrieved March 3, 2009 from: <http://www.hrsdc.gc.ca/eng/cs/sp/hrsdcd/edd/reports/2001-000443/page05.shtml>

- Human Resources and Skills Development Canada. (2009). *Employment insurance monitoring and assessment report: 2008. Chapter 5.1: EI and Individuals*. Retrieved July 3, 2009 from: http://www.hrsdc.gc.ca/eng/employment/ei/reports/eimar_2008/chapter5_1.shtml
- Human Resources Social Development Canada (2008a). *Compassionate Care Benefit*. Retrieved March 31, 2008 from: http://www.hrsdc.gc.ca/en/ei/types/compassionate_care.shtml
- Human Resources Social Development Canada (2008b). *2007 Monitoring and Assessment Report*. Retrieved September 3, 2008 from: http://www.hrsdc.gc.ca/en/employment/ei/reports/eimar_2007/toc.shtml
- Human Resources Social Development Canada (2009). *Employment Insurance (EI) Compassionate Care Benefits*. Retrieved February 11, 2009 from: http://www.hrsdc.gc.ca/eng/ei/types/compassionate_care.shtml
- Human Resources Social Development Canada. (2007). *2007 monitoring and assessment report*. Retrieved March 23, 2009 from: http://www.hrsdc.gc.ca/eng/employment/ei/reports/eimar_2007/toc.shtml
- Human Resources Social Development Canada. (2007). *EI Tracking Survey Executive Summary*. Retrieved August 14, 2008 from: http://www.hrsdc.gc.ca/en/publications_resources/por/subjects/employment_insurance/2007/51405/page08.shtml
- Jansen, L., Markle-Reid, M., Hawranik, P., Kingston, D., Peacock, S., Henderson, S., Leipert, B. (2009). Formal care providers' perceptions of home and community-based services: informing dementia care quality. *Home Health Care Services Quarterly*, 28, 1-23.
- Jonas, A.E.G. (2006). Pro scale: further reflections on the 'scale debate' in human geography. *Transactions of the Institute of British Geographers NS 31*, 399-406.
- Kaiser, R. & Nikiforova, E. (2008). The performativity of scale: the social construction of scale effects in Narva, Estonia. *Environment and Planning D: Society and Space*, 26, 537-562.
- Landry, R., Amara, N., Pablos-Mendes, A., Shademani, R., Gold, I. (2006). *The knowledge-value chain: a conceptual framework for knowledge translation in health*. Bulletin of the World Health Organization. Retrieved August 14, 2008 from: http://www.scielo.org/scielo.php?script=sci_arttext&pid=S0042-96862006000800009
- Legg, S. (2009). Of scales, networks and assemblages: the League of Nations apparatus and the scalar sovereignty of the Government of India. *Transactions of the Institute of British Geographers*, 34(2), 234-253.
- Leitner, H. (2004). *The politics of scale and networks of spatial connectivity: transnational interurban networks and the rescaling of political governance in Europe*. In Sheppard, E. and McMaster, R. (Eds), *Scale and geographic inquiry*. Malden: Blackwell, 236-255.

- Lilly, M.B. (2008). Medical versus social work-places: constructing and compensating the personal support worker across health care settings in Ontario, Canada. *Gender, Place & Culture*, 15(3), 285-299.
- Lilly, M.B., Laporte, A., Coyte, P.C. (2007). Labour market work and home care's unpaid caregivers: a systematic review of labour force participation rates, predictors of labour market withdrawal, and hours of work. *The Millbank Quarterly*, 85(4), 641-690.
- Luginaah, I. (2009). Health geography in Canada: where are we headed? *The Canadian Geographer*, 53(1), 91-99.
- Lynse, L. (2007). *Creating Strategies to Support Canada's Caregivers; 2007 and beyond*. A discussion paper for a consultation meeting hosted by the J.W. McConnell Family Foundation. Retrieved January 26, 2009 from:
<http://www.mcconnellfoundation.ca/utilisateur/documents/EN/Initiatives/Care%20Renewal/Creating%20Strategies%20to%20Support%20Canadas%20Family%20Caregivers%20.pdf>
- Mackenzie, C.S., Smith, M.C., Hasher, L., Leach, L., Behl, P. (2007). Cognitive Functioning under Stress: Evidence from Informal Caregivers of Palliative Patients. *Journal of Palliative Medicine*, 10(3), 749-758.
- Marston, S., Jones, J.P., Woodward, K. (2005). Human geography without scale. *Transactions of the Institute of British Geographers NS*, 30, 416-432.
- Masuda, J.R., Crooks, V.A. (2007). Introduction: (re)thinking the scales of lived experience. *Area*, 39(3), 257-258.
- McPherson C.J., Wilson, K.G., Lobchuk, M.M., Brajtman, S. (2008) Family caregivers' assessment of symptoms in patients with advanced cancer: concordance with patients and factors affecting accuracy. *Journal of Pain and Symptom Management*, 35(1), 70-82.
- Meade, M.S., Earickson, R.J. (2005). *Medical Geography*. 2nd Edition. New York: Gilford Press.
- Milligan, C., Conradson, D. (Eds.) (2006). *Landscapes of voluntarism: New spaces of health, welfare and governance*. Bristol: Policy Press.
- Moore, A. (2008). Rethinking scale as a geographical category: from analysis to practice. *Progress in Human Geography*, 32(2), 203-225.
- Neumann, B., Crewe, C., Clow, B., Amaratunga, C. (2007). *Priorities for Caregivers: an executive summary*. Halifax: Healthy Balance Research Program.
- Osborne, K., & Margo, N. (2005). *Compassionate Care Benefit: Analysis and evaluation*. Toronto: Health Council of Canada.
- Paasi, A. (2004). Place and region: looking through the prism of scale. *Progress in Human Geography*, 28(4), 536-546.
- Patton, M.Q. (1997). *Utilization-focused evaluation* (3rd ed.). Thousand Oaks, CA: Sage.

- Patton, M.Q. (2003). *Evaluation Research*. Encyclopedia of Social Science Research Methods. Thousand Oaks: Sage reference online. Retrieved July 6, 2009 from: http://www.sage-rereference.com.proxy.lib.sfu.ca/socialscience/Article_n301.html
- Penz, K. (2008). What are the potential factors that sustain registered nurses who provide home-based palliative and end-of-life care? *Journal of Hospice and Palliative Nursing*, 10(5), 295-303.
- Procter, K.L. & Smith, D.M. (2008). Size matters: The role of scale in geographies of health. *Area* 40(3), 303-305.
- Public Health Agency of Canada. (2006). *Rural health*. Retrieved March 20, 2009 from: <http://www.phac-aspc.gc.ca/ccdpc-cpcmc/topics/rural-eng.php>
- Public Policy Forum. (2005). *Economic Transformation in Atlantic Canada*. Retrieved March 1, 2009 from: http://www.ppforum.ca/common/assets/publications/fr/report_atlantic_canada.pdf
- Quality End-of-Life Care Coalition Canada. (2005). *Submission to the 5 year Report of the Senate Subcommittee final report Quality End of Life Care: The Right of Every Canadian*. Retrieved July 6, 2009 from: http://www.chac.ca/advocacy/briefs/palliative_qelccc.pdf
- Romanow, R. J. (2002). *Building on Values: The Future of Health Care in Canada - Final Report*. Commission on the Future of Health Care in Canada. Ottawa: The Romanow Commission.
- Rose, J., Glass, N. (2006). Nurses and palliation in the community: the current discourse. *International Journal of Palliative Nursing*, 12(12), 588-594.
- Ruddell, D., Wentz, E.A. (2009). Multi-tasking: scale in geography. *Geography Compass*, 3(2), 681-697.
- Sanderson, I. (2000). Evaluating in complex policy systems. *Evaluation*, 6, 433-454.
- Sanmartin, C., Gendron, F., Berthelot, J.M., Murphy, K. (2003). *Access to health care services in Canada, 2003. Statistics Canada*. Retrieved July 6, 2009 from: <http://www.statcan.gc.ca/pub/82-575-x/2003001/pdf/4198597-eng.pdf>
- Schulz, R., Beach, S.R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA*, 282(23), 2215-2219.
- Service Canada. (2009). *Employment Insurance (EI) Compassionate Care Benefits*. Retrieved July 3, 2009 from: http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml
- Sheppard, E. (2002). The spaces and times of globalization: place, scale, networks, and positionality. *Economic Geography*, 78, 307-330.
- Skinner, M. W., Rosenberg, M. W. (2005). Co-opting voluntarism? Exploring the implications of long-term care reform for the nonprofit sector in Ontario. *Environment and Planning C: Government and Policy*, 23(1), 101-121.

- Smith, N. (1993). *Homeless/global: scaling places*. In Bird, J., Curtis, B., Putnam, T., Robertson, G., Tickner, L. (Eds) *Mapping the Futures: Local Cultures, Global Change*. London: Routledge, 87-120.
- Statistics Canada. (2004a). *Seasonal workers by province: the Atlantic Provinces have the highest rates of seasonal workers*. Retrieved March 3, 2009 from: <http://www.statcan.gc.ca/pub/71-222-x/2004000/4153833-eng.htm>
- Statistics Canada. (2004b). *Newfoundland and Labrador: the market in Newfoundland and Labrador continues to improve*. Retrieved March 3, 2009 from: <http://www.statcan.gc.ca/pub/71-222-x/2004000/4069637-eng.htm>
- Statistics Canada. (2007). *2006 Census dictionary: Census Tract*. Retrieved August 21, 2008 from: <http://www12.statcan.ca/english/census06/reference/dictionary/geo013.cfm>
- Statistics Canada. (2008). *Canadian Demographics at a Glance*. Catalogue no. 91-003-X. Ottawa: Minister of Industry, 2008. Retrieved March 2, 2009 from: http://dsp-psd.pwgsc.gc.ca/collection_2008/statcan/91-003-X/91-003-XIE2007001.pdf
- Statistics Canada. (2009). *Latest release from the labour forces survey*. Retrieved July 7, 2009 from: <http://www.statcan.gc.ca/subjects-sujets/labour-travail/lfs-epa/t090605a1-eng.htm>
- Swyngedouw, E. (2000). Authoritarian governance, power, and the politics of rescaling. *Environment and Planning D: Society and Space* 18, 63-76.
- Waldrop, D.P., Kramer, B.J., Skretny, J.A., Milch, R.A., Finn, W. (2005). Final Transitions: Family Caregiving at the End of Life. *Journal of Palliative Medicine*, 8(3), 623-638.
- Wallin, L. (2009). Knowledge translation and implementation research in nursing: a discussion paper. *International Journal of Nursing Studies*, 46(4), 576-587.
- Wiles, J.L. & Rosenberg, W. (2009). *The role of scale in conceptualizing primary health care practice: considering social and institutional structures and systems*. In Crooks, V.A. & Gavin, J.A. (Eds) *Primary Health Care: People, Practice, Place*. Burlington: Ashgate, 75-92.
- Williams, A. (2004). Examining Palliation on Home Space: Shaping the Practice of Home Care. *International Journal of Palliative Nursing*, 10(7), 333-342.
- Williams, A. (2006). Restructuring home care in the 1990s: Geographical Differentiation in Ontario, Canada. *Health & Place*, 12(2), 222-238.
- Williams, A., Crooks, V.A., Stajduhar, K., Allan, D., Cohen, R. (2006). Canada's Compassionate Care Benefit: views of family caregivers in chronic illness. *International Journal of Palliative Nursing*, 12(9), 438-445.
- Yantzi, N.M., & Rosenberg, M.W. (2008). The contested meanings of home for women caring for children with long-term care needs in Ontario, Canada. *Gender, Place & Culture*, 15(3), 301-315.