COMPASSIONATE CARE BENEFIT PRE-IMPLEMENTATION KNOWLEDGE TOOL
DEVELOPMENT FOR CANADIAN SOCIAL WORKERS: A QUALITATIVE STUDY

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DEVELOPMENT FOR CANADIAN SOCIAL WORKERS: A QUALITATIVE STUDY

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Abstract

Increasingly, informal caregivers are providing hospice palliative care and support to dying friends and family members. These individuals must often negotiate multiple roles and responsibilities as a result of being caregivers and members of the paid labour force. Canada's federal government has recognized the burden placed on informal caregivers, and legislated the Compassionate Care Benefit (CCB) in 2004. The CCB allows informal caregivers providing hospice palliative care six paid weeks off work to alleviate some of the role strain in the provision of care. Evaluations of the CCB have recognized that the low program uptake has been primarily the result of a lack of awareness. As such, knowledge translation campaigns about the CCB are needed. Stakeholders interviewed, including family caregivers, front-line palliative providers, and employers, have suggested that Canadian social workers are the primary group in need of a targeted knowledge campaign. This research presents the results of the development of a two-stage knowledge translation intervention for social workers. First, the development of appropriate interventions are explored through a qualitative messaging survey (n=16), a focus group (n=8) and key informant interviews (n=3). Preferred intervention formats and messages are identified, and draft knowledge tools are created. Secondly, draft knowledge tools are piloted in workplaces by social workers (n=8), the results of which are captured through participant interviews. The refinement period suggested some of the constraints of space and time on knowledge translation about the CCB and tool use. Hägerstrand's time geography is explored in relation to tool use and knowledge translation. The research presented herein is relevant to policy makers, program planners, clinicians and researchers working with the fields of hospice palliative care, social work and knowledge translation. This research makes contributions to the knowledge translation and intervention development literatures through the presentation of novel methodologies and the application of time geography.

Acknowledgements

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List of Tables and Figures

Preface

This Master's thesis is comprised of two research papers which have been prepared for academic journal submission. The two main papers are presented as chapters.

Chapter Two:

Dykeman, S., Williams, A., Crooks, V.A. Pre-implementation knowledge tool development for health service providers: A qualitative study of Canadian social workers. Submitted to *BMC Health Services Research*.

Chapter Three:

Dykeman, S., Williams, A. The importance of place and time in translating knowledge about Canada's Compassionate Care Benefit from social workers to informal caregivers: A qualitative study. Submitted to *Health and Place.*

The larger CCB research program, led by Dr. Allison Williams, involves an interdisciplinary group of scholars, including geographers (Dr. Valorie Crooks, Melissa Geisbrecht, and myself), nurses (Dr. Kelli Stadjuhar), psychologists/health scientists (Dr. Robin Cohen,Dr. Kevin Brazil), and a policy advocate (Sharon Baxter) who Directs the *Canadian Hospice Palliative Care Association (CHPCA)*. This larger research program involved funding via a CIHR New Emerging Grant in Palliative and End-of-Life Care, a CIHR Operating Grant specific to the evaluation of the Canadian Compassionate Care Benefit (CCB), and multiple CIHR Meetings, Planning & Dissemination Grants.

Part of the data used in the first paper was collected via a messaging survey which was funded by a CIHR Meetings, Planning & Dissemination Grant. This survey was hosted by Simon Fraser University, under the leadership of Dr. Valorie Crooks, which explains her authorship on this paper. Under the guidance of my supervisor, I undertook full responsibility for the collection of the remaining data. This data was collected with the networking assistance of the CHPCA and funded via Dr. William's CIHR ECHO/IGH Mid-Career Scientist Award. I undertook full responsibility for the analysis of the data, and the writing of the paper. Guidance

and mentorship on the substantive material in the paper was provided by Dr. Allison Williams. Editorial assistance was provided by Dr. Allison Williams and Dr. Valorie Crooks.

The second paper provides the analysis of the primary data collected specific to the tool use. Under the guidance of my supervisor, I undertook all of the data collection and analysis, and was responsible for the write-up. Funding for this work was provided by Dr. William's CIHR ECHO/IGH Mid-Career Scientist Award. Guidance and mentorship on the substantive material in the paper was provided by Dr. Allison Williams, who also provided extensive editorial assistance.

In relation to both my RA work with Dr. Williams, together with my Master's research, I have attended, thanks to the support of Dr. Williams, five academic conferences throughout my graduate program. The first paper has been presented at an international interdisciplinary conference on palliative care, named *The International Congress on Palliative Care* (Montreal, October 2010).

CHAPTER ONE: INTRODUCTION

1.1 Research Context

Knowledge translation (KT) literature has grown exponentially in recent years. There are currently nearly 30 terms used synonymously in health research for the act of increasing research knowledge uptake into practice (Graham, et al., 2006). Despite the wealth of theoretical literature on the subject, there has been a lack of engagement from researchers on developing methodologies for translating knowledge.   Likewise, KT has not been explored through a variety of alternative conceptual theories. Although knowledge translation is inherently geographical, as it attempts to tailor knowledge to unique situations and locations (Graham, et al., 2006), there has been little consideration on the role of geography in KT. This thesis presents both a novel methodology for developing KT knowledge tools, and explores some of the applications of geography in KT. This is accomplished through an exploratory KT knowledge tool for Canadian social workers about Canada's Compassionate Care Benefit (CCB). The CCB is a welfare state program for informal caregivers providing hospice palliative care (HPC). The scope of informal caregiving and HPC in Canada are reviewed in this introduction, followed by a discussion on the need for KT about the CCB. Finally, the study objectives and ensuing chapters are outlined.

1.1.1   Informal Caregiving

Romanow (2002) estimates that 80-90% of all care in Canada is provided by informal caregivers. These are individuals, including family members and friends, who provide physical care, or emotional and psychological support for someone who is disabled, frail or chronically ill (Health Canada, 2010). Informal caregiving has been growing in recent years as health care has deinstitutionalized as a result of neo-liberal health care restructuring in Canada (Skinner &

Rosenbeg, 2005). Although informal caregivers relieve Canada's health care system, contributing over $25 billion dollars in unpaid care work every year (Hollander, et al., 2009), they take on a level of burden in the act of providing care. Informal caregiving has been associated with negative emotional, physical, social, and psychological health as a result of their caregiving duties (Schutlz & Beach, 1999; Grunsfeld et al., 2004; Swanberg, 2006). Additionally, informal caregivers report financial burden as a result of their caregiving duties. Beyond caregivers who are not in the paid labour force as a result of their caregiving responsibilities, employed caregivers report decreased work productivity and missed shifts as a result of their caregiving duties (Swanberg, 2006; Crooks, et al., 2007; Lero, 2007; CPRN, 2009).

1.1.2   *Hospice Palliative Care(giving)*

Demographic trends have further amplified the demand placed on informal caregivers. Like many other countries, Canada has a rapidly aging population. Population projections for seniors suggest that there will be a growth of approximately ten percent between 2009 and 2036 (Ontario Ministry of Finance, 2010). Subsequently, the number of deaths is anticipated to grow (Statistics Canada, 2010), increasing the need for end-of-life care provision. Hospice Palliative Care (HPC) is defined as care provided during end-of-life. Health Canada (2009) includes within the definition of HPC an interest in reducing pain and symptom management, the provision of social, psychological, spiritual and other types of support, as well as assistance for caregivers and the bereaved. Like caregivers in other sectors, informal caregivers proving HPC face negative health outcomes. This act of providing informal HPC is complicated by rapidly changing care needs of the care receiver from time of diagnosis to time of death, including pain management, and use of medical technology (Ashpole, 2004; Dunbrack, 2005; Crooks et al., 2007). Similar to other

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informal caregivers, HPC informal caregivers also report financial burden as a result of their caregiving duties, spending up to $6,000 in out-of-pocket costs in the last month of caregiving (Greaves, et al., 2002). This is significantly more than the estimated $100 per month out-of-pocket expenditures associated with other types of caregiving (CCC, 2009). Despite the need, it is estimated that upwards of 70% of palliatively ill Canadians do not have access to HPC (Carstairs, 2010), with no available statistics for the number of informal caregivers receiving palliative support. The Canadian government has recently recognized the need to develop more comprehensive services and has introduced a number of programs including the CCB, which was implemented in 2004.

1.1.3   Compassionate Care Benefit

The CCB is a federally implemented Human Resource and Social Development (HRSDC) program administered through Employment Insurance (EI). The program allows successful applicants eight weeks off work, six of which are paid, in order to provide care for a dying friend or family member. The applicants are guaranteed job security and 55% of their insurable earnings, to a maximum of $467CND/ week of leave (Service Canada, 2011).

In order to be successful, applicants must qualify for EI by demonstrating their weekly earnings have decreased by 40% in the previous payroll period, and have accumulated 600 insurable hours in the preceding 52-week period. As a result of these EI criteria, only full-time employees are currently eligible for the CCB, although EI is currently being amended to cover self-employed Canadians. In addition to meeting general EI criteria, applicants must demonstrate that the care recipient is at risk of death within the following 26-week period through medical documentation by a physician. Applicants, if not a family relation, must also be

considered "like" a family member, such as a neighbour or friend. Applicants must serve a two-week unpaid waiting period; a common feature to all EI programs (Service Canada, 2011).

While the program has been hailed as a positive policy step for informal caregivers (CCC, 2004), and despite demographic trends that would indicate otherwise, uptake of the CCB is low (Osborne and Margo, 2005). While application data are not available, HRSDC has indicated that the number of successful claims has grown slowly since implementation (HRSDC 2009). Given the increased demand for HPC and informal caregiver services, this is surprising. Reasons for this, including barriers to accessing the program, were revealed through an evaluation study conducted from 2006-2010.

As part of this evaluation study, three stakeholders were interviewed for their experiences and expectations in accessing, or helping someone access, the CCB**.** Fifty-seven in-depth interviews were conducted with informal caregivers, 50 in-depth interviews were conducted with front-line palliative care providers, and five focus groups were held with employers and human resource personnel (Williams, et al., 2010). Barriers to accessing the CCB and reasons for low uptake were discussed and triangulated across all three stakeholder groups, and included: the short length of the leave; the limited financial remuneration available; the presence of the two-week unpaid waiting period; the complicated and lengthy application process, and; the lack of national marketing.

While the program features have reduced uptake, ultimately the lack of awareness about the CCB was seen to be the primary cause for low application rates. In particular, all three stakeholder groups suggested that KT about the CCB should be enhanced. Giesbrecht, et al. (2009), have suggested that this can be accomplished through two pathways: community-based

KT to the general public and targeted dissemination through key professionals. All stakeholder groups agreed that social workers were the primary knowledge brokers for the CCB, and should be the first group to be the focus of a targeted KT knowledge tool development intervention.

1.2   Research Objective

In response to the research results described above, the purpose of this thesis is to develop a KT knowledge tool development intervention for Canadian social workers about the CCB. The research objectives include:

1. Identify messages about the CCB that social workers value for inclusion in a KT knowledge tool intervention.
2. Identify preferred knowledge tool types about the CCB for social workers.
3. Assess how the tools might be used in practice by social workers to further refine their best development.

In order to conduct this research, it is necessary to situate the research among the existing KT literature and develop a methodology for creating a social worker KT knowledge tool development intervention about the CCB program.

1.2.1   Study Overview

Knowledge translation is defined as the "dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system" (CIHR, 2010, n.p.). Opportunities for CCB KT processes were identified by first situating the research on Graham, et al.'s (2006) *Knowledge-to-Action* KTA cycle, a

formative framework on KT. According to Graham et al. (2006), the KTA cycle is a useful guide in understanding the current knowledge, or knowledge gap, and necessary next steps in moving knowledge into action. As discussed above, the evidence from the evaluation research has fulfilled the initial starting point of Graham's (2006) KTA cycle with the identification of the knowledge problem or knowledge gap. This is the starting point of the KTA cycle as we move out of the knowledge funnel. Therefore, the concerns of this KT knowledge tool development intervention are the subsequent steps of the KTA cycle, with the adaption of knowledge to the local context, the assessment of barriers to KT uptake in that context, the selection and implementation of a KT strategy, and the evaluation of KT outcomes. These considerations are illustrated in Figure 1.1, which has been adapted from Graham, et al. (2006).

Figure 1.1: Adaption of the KTA cycle to current CCB KT needs
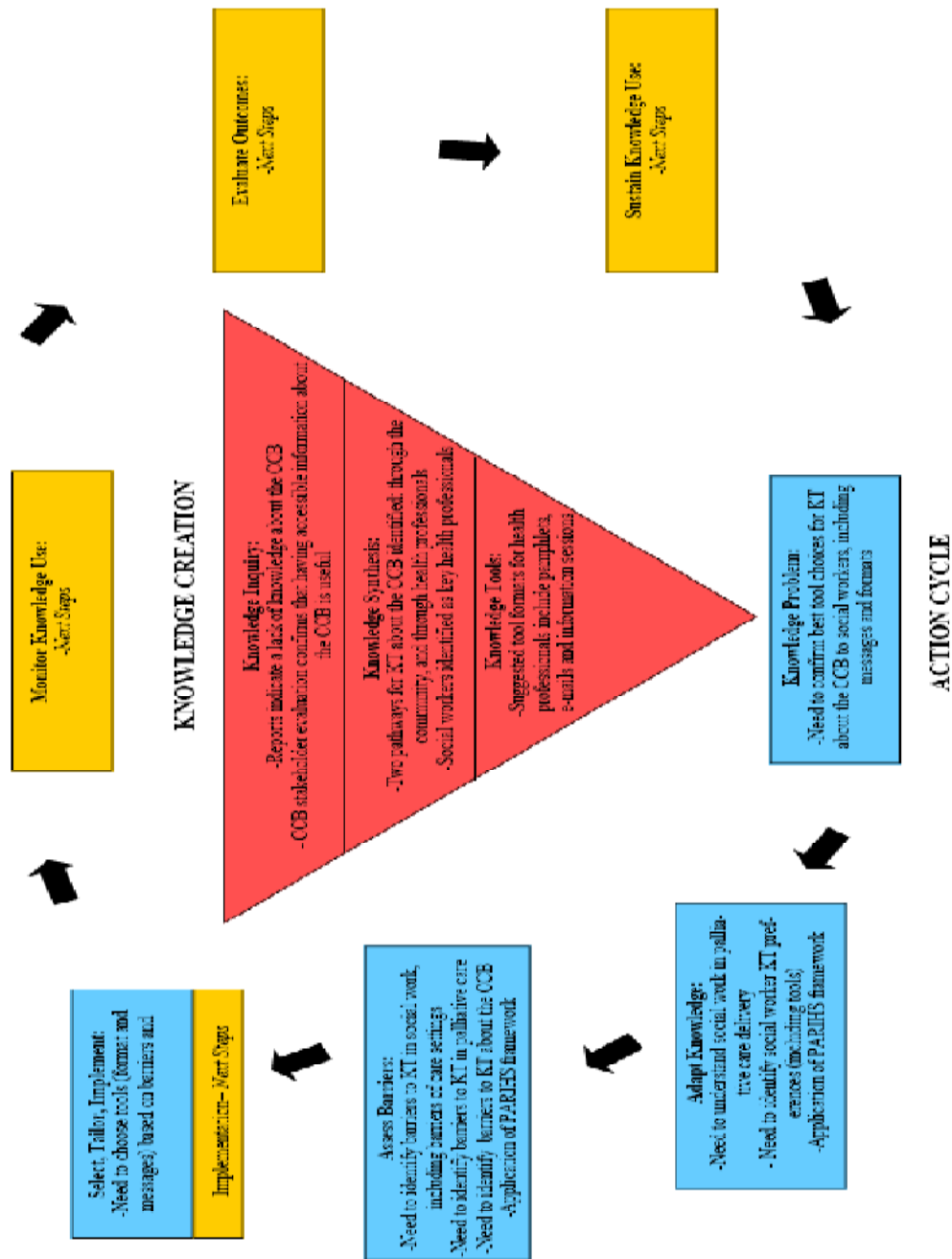
Figure 1.1 The previous research conducted on the CCB identifying the need for a KT knowledge tool development intervention is highlighted in the knowledge creation funnel. Current research objects are explored in the subsequent stages of the action cycle, along with identified next steps.

MacDermid and Graham discuss the KTA cycle as being invaluable in providing a broad step-by-step guide to KT, but note that it lacks depth in outlining specific implementation plans for each step (2009). Thus, while taking guidance from the KTA cycle, this research employs both an integrated KT design and the *Promoting Action on Research Implementation in Health Services* (PARIHS) framework (Rycroft-Malone, 2004). Both of these theoretical underpinnings, integrated KT and the PARIHS framework, are explored in this section.

Integrated KT is defined as the involvement of knowledge users during the research (CIHR, 2010). In keeping with the use of an integrated KT design, the identification and recruitment of knowledge users is important. The identification of knowledge users, together with their collaboration, helps to address and minimize any barriers in the evolving development of a KT strategy (Graham, et al., 2006). The primary knowledge users in this study are social workers, and their involvement developing the CCB knowledge tools is closely integrated within the study design. A secondary knowledge broker is the Canadian Hospice Palliative Care Association (CHPCA). The CHPCA provides leadership for end-of-life care in Canada, representing all provincial associations and more than 500 end-of-life programs or services (CHPCA, 2010). For this study, the CHPCA assisted with social worker recruitment and has also committed to overseeing sustainability of the printed educational tools upon study completion.

The PARIHS framework examines the effect of evidence, context, and facilitation on successful translation of research findings into practice. According to Rycroft-Malone, successful implementation is a function of these three factors (Rycroft-Malone, 2004). This has been illustrated in the formula: Successful Implementation = f (E, F, C), where E, F, and C are representative of the evidence, context and facilitation values (Rycroft-Malone, 2004). Evidence is characterized by research evidence, clinical experience, patient experience, local

data/information, and knowledge preferences. The unique context where the research evidence is being implemented needs to be taken into consideration, including who may facilitate the implementation and how evaluation may occur. Context is characterized by culture, leadership and evaluation. Facilitation is defined by the purpose, roles, skills and attributes of the facilitator. During any given implementation situation, these three factors may be situated on a continuum from weak to strong, whereby the stronger the factors are, the more successful implementation. Strong evidence is "scientifically robust and matches professional consensus and patients' preferences" (Rycroft-Malone, 2004, p.298). Strong context involves "sympathetic cultures, strong leadership, and appropriate monitoring and feedback systems" (Rycroft-Malone, 2004, p.298). Finally, "appropriate facilitation of change, with input from skilled external and internal facilitators" (Rycroft-Malone, 2004, p.298), characterizes strong facilitation situations. In the current study, the overarching categorizations of these PARIHS factors are used to guide tool implementation.

The PARIHS framework has been used within health research as a framework for organizing analysis of implementation studies (Helfrich, et al., 2010). It has been acknowledged for its flexibility and intuitive appeal, and as such has been employed within empirical research (Kitson, Harvey & McCormack, 1998; Rycroft-Malone, 2004; Helfrich, et al., 2010). However, a synthesis of literature on the PARIHS framework identified that the lack of conceptual mapping of research outcomes to PARIHS variables (evidence, context and facilitation) serves as a major weakness (Helfrich, et al., 2010). For this study, evidence values will be examined via a qualitative messaging survey of social workers. Questions regarding context, evidence and facilitation will be explored directly through focus group and key informant interviews with social workers.

Social workers represent a loosely defined community of practice, who, depending on specialization and geographic location, may differ widely in their conception of knowledge, and the unique context in which they practice. This limitation will be mitigated in the current study by the concurrent application of integrated KT, whereby stakeholders will shape the implementation plan according to their experiential knowledge of this context. Their input will also be used to map out tool development changes according to the PARIHS framework elements, which is an important component of the framework's utilization (Helfrich, et al., 2010).

In order to fulfill the KTA requirements, social workers have been involved in: adapting CCB knowledge to their local context; the assessment of barriers to translating knowledge about the CCB, and: developing a strategy. Stakeholder input occurred through: online qualitative messaging surveys (n=16); a focus group (n=8); key informant interviews (n=3), and; participant interviews (n= 8).   The specific methodologies and results of these data collection points are presented in two chapters, with summative research findings and implications for the community being presented in a concluding chapter.

1.3   Chapter Outline

This thesis is organized in four chapters. In this introductory chapter, relevant background research has been presented in order to situate and justify the current study. Specifically, contextual information about the role of informal caregiving in HPC has been presented alongside the development and evaluation of a support program, the CCB. Reasons for low uptake about the CCB have been presented, and the purpose for this thesis has been identified. The research presented herein has been presented in light of the KTA cycle.

Chapters 2 and 3 are presented in what follows as independent papers that have been submitted to scholarly journals for publication. Chapter 2 presents the results of the qualitative messaging survey, focus group, and key informant interviews on the CCB KT knowledge tool development intervention. In particular, the CCB messages most valued by social workers, as identified by the qualitative messaging survey, are discussed. The social worker preferred CCB knowledge tools are also presented. Final, refinements to the knowledge tools according to the PARIHS framework through social worker input are discussed.

Chapter 3 presents the results the preliminary results of CCB knowledge tools developed, as explored in Chapter 2, according to geographic notions of space and time. The knowledge tools developed were utilized by social workers over the course of six months as a final tool pilot stage. Participant interviews revealed how elements of the CCB program, as well as the daily lives of the social workers and caregivers using the CCB tools, affected tool use and knowledge uptake. As such, the results are analyzed according to Hägerstrand's (1975) time geography theory, with respect to capability, coupling and authority constraints.

As the thesis conclusion, Chapter 4 presents the summative key contributions of this thesis, including the implications for KT knowledge tool development intervention and the role of geography in KT. As well, the limitations to the research presented herein are discussed alongside possible avenues for future research directions.

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CHAPTER TWO: PRE-IMPLEMENTATION KNOWLEDGE TOOL DEVELOPMENT FOR HEALTH SERVICE PROVIDERS: A QUALITATIVE STUDY OF CANADIAN SOCIAL WORKERS[1]

2.1   Abstract

Background

In Canada, social workers are an important allied health professional group involved in delivering health and social care. Among other roles, they are key disseminators of health information. Recent research has shown that they are particularly well placed to disseminate information about health-related social programs such as Canada's Compassionate Care Benefit (CCB). The CCB offers workers a temporary, job-secured paid leave from employment to Canadian workers who are caring for friends or family at end-of-life. Despite demographic trends that would indicate otherwise, the CCB has had low uptake since its inception in 2004. It has been suggested that this low uptake is due in part to a lack of knowledge about this program among the Canadian public in general and health services providers specifically. In response to this, this article reports on the pre-implementation development of CCB knowledge tools aimed specifically at social workers.

Methods

Social worker-specific tools about the CCB were developed through a multi-step process. Messages about the CCB to be delivered via knowledge tools were determined through a computer-based qualitative messaging survey ($n= 16$). Draft tools were created and then refined for content and aesthetics through a focus group ($n= 8$) and key informant interviews ($n=3$). The *Promoting Action on Research Implementation in Health Services* framework was used to examine the context, evidence, and facilitation needed to develop social worker-specific CCB knowledge tools.

Results

The messaging survey revealed that social workers most valued CCB informational message points regarding the program's purpose, versus administrative details. Based on this finding, these messages formed the most central component of the printed information tools developed as prototypes to be shared in the focus group and key informant interviews. Posters and the pamphlets were the two tool types clearly preferred by the social workers based on the barriers they face in translating knowledge to informal caregiver clients.

Conclusions

Use of the *Promoting Action on Research Implementation in Health Services* framework enhanced our understanding about barriers and facilitators to increasing social workers' knowledge about the CCB. This suggests that the framework may serve as an invaluable pre-implementation protocol in other research focused on educational tool development for health services providers, including other allied health professional groups. Social worker involvement in this study proved valuable in identifying messages for tool content and refining tool formats. Further research is needed to evaluate tool implementation effectiveness and use in practice.

2.2   Background

Over the past two decades, health system advocacy efforts in Canada have led to

reforms that have transformed many aspects of how health care is provided to citizens

(Romanow, 2002; Marchildon, 2006). Much of this advocacy has laid the groundwork for

strengthening and expanding capacity to provide care in community settings (e.g., private

homes, community living centres) as opposed to institutional settings (e.g., hospitals)

(Romanow, 2002). Developing out of this momentum, Canada's Compassionate Care

Benefit (CCB) was created in 2004 by the federal government in order to support the

provision of informal caregiving for dying individuals, including within community settings,

by enabling workers to take a secured leave from work for this purpose (Service Canada,

2011). Health Canada considers informal caregivers to be friends or family members who

provide care or support to someone who is chronically ill, frail, or has a physical or mental

disability (Health Canada, 2002). It has been reported that approximately 23% of Canadian

adults will provide care for a seriously ill person in any given year, of whom 22% will take at

least one month off work to do so (Carstairs, 2000). These figures underscore the need for a

program such as the CCB.

In order to be eligible for the CCB, workers must be eligible for Employment

Insurance (EI) – which is a contributory benefits program - and as such must have

accumulated 600 insurable hours in the previous 52 week period (Service Canada, 2011).

The insurable hours are accrued through automatic EI payroll deductions. Additionally,

workers must demonstrate that their weekly earnings have decreased by more than 40%,

another common feature of all EI programs. Applicants must also have a physician

certificate documenting that the care recipient is at risk of death within the next six months.

Successful applicants are allowed a temporary paid leave from work with job security. The

total allowance spans eight weeks, six of which are paid. Applicants must serve a two-week

unpaid waiting period at the beginning of their leave, another EI program feature. Up to 55%

of the applicant's average insured earnings are remunerated, to a maximum of $468 CND per

week (Service Canada, 2011).

While the CCB marks a major step forward for supporting informal caregivers,

program utilization rates show that uptake is quite low (Crooks, et al., 2007; CCS, 2008;

HRSDC, 2010). Percentages of Canadians reporting awareness about the program have not

changed significantly since the program's inception; in 2004, 37% of Canadians surveyed by

EI stated they were not very aware of the program, dropping to 36% in 2010 (HRSDC, 2010).

Criticisms of the CCB program have focused on how the general lack of awareness among

Canadians may be contributing to lower-than-anticipated uptake (Crooks and Williams, 2008;

Giesbrecht, et al., 2009; HRSDC, 2010; Williams, et al., 2010). A recent evaluative study

confirmed this concern, concluding that there is a need to develop targeted knowledge

translation (KT) campaigns to increase awareness about the CCB among the general public

and also among health services providers (Giesbrecht, et al., 2009). Within the context of

health care, KT is the application of knowledge, often research results, to improve the health

of citizens (CIHR, 2010), and involves providing the right information, to the right place, at

the right time to users (Kho, et al., 2009). A significant finding of this CCB evaluation was

that social workers were thought to be best positioned to inform informal caregivers about the

program, and thus were the group most in need of being targeted by a KT campaign

(Giesbrecht, et al., 2009).

In Canada, social workers are post-secondary graduates that number almost 30,000

across the country (CIHR, 2009; CASW, 2009). Social workers are an important allied

health professional group who provide care across many settings, most often in health and

social services sector (CASW, 2008). They often work with marginalized and vulnerable

populations to provide holistic care and ensure access to support in a variety of fields

including end-of-life care, mental health, and child and youth services. Within the field of long-term and end-of-life care, social workers collaborate with patients and informal family caregivers to enhance physical, social and mental health and quality of life through counselling and promoting resources and education (CASW, n.d.). Given social workers' roles as information and resource disseminators, it is not surprising to learn that they have explicit expectations that they will be informed about the CCB so as to ensure that they are able to share information about this program with their informal caregiver clients (Giesbrecht, Crooks and Williams, 2010).

In this article we build on the finding shared above that Canadian social workers are in need of a targeted KT campaign in order to increase their own awareness of the CCB and thus ultimately inform more informal caregivers about its existence. To accomplish this we have undertaken a process of CCB knowledge tool development aimed specifically at social workers. Knowledge tools are thought to be resources with user-friendly presentations that are meant to inform specific stakeholder groups about a particular issue, and are effective ways to undertake KT (Graham, et al., 2006). Our focus on knowledge tool development for a single professional group acknowledges that such tools must be tailored to the needs of a specific audience in order to be effective and ultimately taken up into practice (Jacobson, Butterill and Goering, 2003; Bowden, et al., 2005; IDRC, 2008). In this article we examine aspects such as the desired informational content and format for such tools while considering factors such as the specific nature of social workers' work environments. After introducing our study design, which involved a qualitative messaging survey, a focus group, and key informant interviews, thematic results of the data are shared then applied to pre-implementation tool development.

Although we focus in this article on knowledge tool development for a specific Canadian allied health professional group regarding a particular social program, this research

has wider relevance. Our review of the literature reveals that no consideration has been given to knowledge tool creation for social workers previously. Thus, the current study can be seen as raising awareness of social workers' information needs and preferences, which has relevance for all social work practice and not simply that which occurs in Canada. There is also only a very limited existing literature about the pre-implementation development of knowledge tools for health services providers.

Employing active KT strategies, such as case studies and workshops at professional conferences, has been correlated with higher learning and information retention and understanding among health services providers (Bowden, et al., 2005). Departmental notices and interdisciplinary lunch-and-learns have been used successfully for the translation of public policy knowledge and health programs (Duncan, et al., 2009). Finally, "train-the-trainer" toolkits have become an extremely popular and successful KT strategy (Edmonstron and Williamson, 1998; Leaffer and Gonda, 2000; Orfaly, et al., 2005). Such toolkits have included research-based fact sheets and references, case studies and tools for further KT to other health professionals and the public, including PowerPoint presentations, posters and brochures (DiCenso, et al., 2002). This article contributes to the nascent scholarship regarding knowledge tool development for health services providers as part of a KT strategy while also serving as a template that can be adopted or adapted in other research or practical applications.

2.3   Methods

The purpose of the research was to develop social worker specific CCB KT knowledge tools that can be implemented and evaluated in the future. We have used the Promoting Action on Research Implementation in Health Services (PARIHS) framework to guide tool development (Rycroft-Malone, 2004). This framework considers the effect of *evidence, context,* and *facilitation* on successful translation of research findings into practice.

Successful implementation is a function of these three factors (Rycroft-Malone, 2004); thus, we thought it relevant to consider these factors in our pre-implementation, tool development research. *Evidence* is characterized by research evidence, clinical experience, patient experience, local data/information, and knowledge preferences. The unique context where the research evidence is being implemented needs to be taken into consideration, including who may facilitate the implementation and how evaluation may occur. *Context* is characterized by culture, leadership and evaluation. *Facilitation* is defined by the purpose, roles, skills and attributes of the facilitator. These three factors are situated on a continuum from weak to strong, whereby the stronger the factors are, the more successful implementation will ultimately be (Rycroft-Malone, 2004). In the current study, the overarching categorizations of these three PARIHS factors are used to guide tool development. In this study, *evidence* values are examined via a qualitative messaging survey of social workers (Stage 1 of our design), while questions regarding *context, evidence* and *facilitation* are explored directly through focus group and key informant interviews with social workers (Stage 2 of our design).

2.3.1   *Stage 1: Qualitative messaging survey*

The first stage of our pre-implementation knowledge tool development process involved focusing on the specific informational messages about the CCB that needed to be transferred to social workers. To do this we developed an online 'messaging survey' that asked respondents to evaluate the usefulness of 15 messages (or informational points) about the CCB being considered for potential inclusion in the knowledge tool. These messages were developed by the research team after a careful review of program administration documents. Each message was rated by survey respondents on a five-point scale according to how useful it was deemed (where the options were: highly useful to someone in my position, somewhat useful to someone in my position, neither particularly useful or not useful to

someone in my position, most likely not useful to someone in my position, and definitely not useful to someone in my position). Following ethics approval from Simon Fraser University, information about the online survey was sent by e-mail to 50 health services providers who took part in a larger evaluative study of the CCB (Williams, et al., 2010). These participants were invited to share the survey link with others.

The online survey ran from December 2009 to January 2010. In total 49 people completed the online messaging survey, 16 of whom were social workers. The social worker demographic characteristics are summarized in Table 2.1. Upon completion of the two-month data collection period, the data were summarized using descriptive statistics. Descriptive statistics were created for the entire sample and for the social worker sub-sample, which included deciphering the messages viewed as most useful to social workers.

Table 2.1: Messaging Survey Participant Characteristics

Years In Current Position	Years Specializing In Palliative Care	Province Education Received In	Province Currently Working In
15	8	Ontario	Ontario
16	24	Quebec	Quebec
15	20	British Columbia, Alberta	British Columbia
5.5	5.5	Quebec	Quebec
5	5	Quebec, Ontario, British Columbia	Ontario
2.5	2.5	Quebec	Quebec
6	8	Manitoba	Manitoba
2	2	Manitoba	Manitoba
25	25	Manitoba	Manitoba
3	19	Manitoba	Manitoba
28	27	Manitoba	Manitoba
28	27	Manitoba	Manitoba
4	4	Manitoba	Manitoba
6	30	Manitoba	Manitoba
8	8	Manitoba	Manitoba
4 months	4 months	Ontario	Ontario

Table 2.1 – The characteristics of the social workers who participated in the messaging survey are presented in Table 1. Social workers responded from a number of provinces across Canada and with differing years of experience in social work and palliative care.

2.3.2   Stage 2: Focus groups & key informant interviews

Incorporating the findings of Stage 1 and a review of the pre-implementation literature (Edmonston and Williamson, 1998; Davies, et al., 1999; Leaffer and Gonda, 2000; DiCenso, et al., 2002; Freemantle, et al., 2005; Orfaly, et al., 2005), draft knowledge tools designed to inform Canadian social workers about the CCB were created in Stage 2. An informational toolkit was developed, which included a "how to use the toolkit" introduction, together with a poster, pamphlet, panel cards, case studies, how-to-apply guide, "train-the-trainer" PowerPoint, and executive summary of the results of an evaluative study of the CCB. Thus, this toolkit included both active (i.e., case studies and "train-the-trainer" PowerPoints), with passive (i.e., printed posters and pamphlets) educational tools.

Following draft tool development, a focus group with social workers (*n*=8) from across Canada was held in Vancouver, British Columbia to further refine these tools and select best tool types. Participants were recruited by the national palliative care advocacy organization, the Canadian Hospice Palliative Care Association (CHPCA, 2010), and included social workers from the provinces of New Brunswick, Ontario, Manitoba, Alberta and British Columbia. Participants represented social worker opinion leaders, front-line providers, and administrators. The focus group was semi-structured, and the discussion probes were based on the PARIHS framework. Particular attention was paid to assessing the appropriateness of the research evidence and format of the KT tools. Additional time was spent examining the context in which the tools would be presented and the facilitation mechanisms available.

The focus group lasted approximately two hours and was digitally recorded and transcribed verbatim. The transcript was coded thematically through an adaptation of both inductive and deductive coding styles, whereby several themes were generated according to

the PARIHS framework prior to coding and additional themes were added through immersion in the data (Burnard, 1991; Pope, Zieblan and Mays, 2000; Hsieh and Shannon, 2005). Coding followed an eight-stage process adapted from Burnard's (1991) guidelines: (1) notes were made after the focus group to enhance existing ideas and theories; (2) the transcript was read and notes were made to aid in immersion; (3) the transcript was read again and a list of as many themes as possible was devised for open coding; (4) codes were grouped and collapsed into broader categories, and smaller sub-categories were developed; (5) cross-checking was done with team members to compare the validity of the analysis, after which a final coding scheme was created; (6) the transcript was re-read and coded according to the scheme; (7) text under the same code was grouped; and (8) member-checking was done. The processes of member-checking and confirmation among the investigative team serve to strengthen the rigour of the analytic process (Barbour, 2001; Hsieh and Shannon, 2005).

Following the focus group, changes were made to the draft knowledge tools. Key informant interviews with social workers were then held to obtain further feedback on these tools and their potential implementation. The key informant interviews (*n*=3) took place in Toronto, Ontario. These key informants were recruited by the Canadian Hospice Palliative Care Association via a listserv. The interviews were semi-structured, and guided by open-ended questions. As with the focus group, the interview schedule was informed by the PARIHS framework. The key informant interviews were digitally recorded, transcribed verbatim and coded thematically, both inductively and deductively (Burnard, 1991; Pope, Ziebland and Mays, 2000; Hsieh and Shannon, 2005), following the same eight-step coding process that was employed for the focus group dataset. The codes were also agreed upon by team members, and were triangulated with the focus group results to increase rigour and reliability (Barbour, 2001).

2.4   Results

The results of the two-stage research design yielded important insights about social workers' preferred knowledge tool types and messages specific to the CCB, together with the effects of social worker-specific end-of-life practice barriers on tool development. Guided by our use of the PARIHS framework, three themes emerged as most central across the data gathered in both stages of the study design: (1) choosing tool messages; (2) understanding user context; and (3) developing user-specific features and facilitation. We expand upon these themes in this section, providing direction quotes from the qualitative datasets in order allow participants' voices to come through as a way to demonstrate the 'richness' of our findings (Oxman, et al., 1995).

2.4.1   *Choosing tool messages*

The results of the messaging survey indicated that social workers valued messages about the purpose of the CCB most, followed by messages about the application process, and then messages about the remuneration details and program features. The purpose message ranked most useful was: "*The CCB program views support to a family member to be: (1) providing psychological or emotional support; (2) arranging for care by a third party; and/or (3) directly providing or participating in the care.*" Regarding messages about the application process, the message most highly ranked was: "*To receive the CCB, an Employment Insurance application must be made to the program online or in person at a Service Canada Centre.*" Though frequently labelled as 'less useful' than the other message types, the most useful program feature-type messages were equally considered to be: "*If an application to the CCB program is successful, payments will be issued within 28 days from the date the claim is filed*", and "*If multiple EI-eligible family members are applying to care for the same dying person, the 6 weeks of the CCB must be split among them.*"

When social workers were asked to select the three most important CCB messages overall, the results differed slightly from when messages were ranked separately. The top three rated messages were:

1. The goal of the CCB is to enable employees to take a temporary secured leave from work to provide care or support to a gravely ill family member at risk of dying;

2. The CCB program views support to a family member to be: (1) providing psychological or emotional support; (2) arranging for care by a third party; and/or (3) directly providing or participating in the care; and

3. Successful applicants must be eligible for Employment Insurance. This currently excludes self-employed individuals and most part-time employees, as well as those who have not worked the minimum required number of hours.

The first two messages are purpose-type messages while the third is process-type. The three messages ranked as most important, as well as the top-ranked messages from each of the three theme groups (program purpose, program features and application process) served as the initial content in the drafted KT tools.

When social workers examined the messages chosen through the messaging survey and the other slogans and informational points included in the draft knowledge tools, they offered numerous suggestions for message refinement. In doing so, they drew upon their clinical experience and values. In response to their suggestions, some messages were changed to simpler wording, or value-laden words were removed. For example, one original message developed as a poster slogan read "*Are you caring for a dying loved one?*" As a social worker critiqued this wording: "*...what do you call these people who are going to die? I don't like loved one...not everybody's loved. Some people can't stand that mother they are*

having to take care of. So I'm always trying to figure out what to say in that situation."
Numerous participants explained that it would be important to avoid value-laden words in

CCB knowledge tools because many of their clients may not be ready to accept the terminal

nature of the care recipient. Similarly, social workers wanted the wording about who was

eligible for the CCB to be made very clear. For example, one social worker shared that that

same-sex couples in the past had struggled with the concept of the caregiver relationship.

Thus, defining "family member" within the pamphlet was noted as important.

Negotiating the taboo nature of death was thought to be a barrier by social workers

enacting their role as information disseminators about the CCB. Participants wanted the

messages for the knowledge tools to be open in their interpretation of the CCB, thereby

allowing the social worker flexibility in introducing it to caregivers. For example, by using

the phrase "*gravely ill*" instead of "*dying*" participants hoped to be able to use the tools to

introduce the CCB earlier in the care pathway, reducing the likelihood of a caregiver hearing

about the CCB too late to apply. As one participant explained:

> *You just kind of wait for the door to open a little bit.*
> *Generally, what I do is say "If, and when, the time did*
> *come and the condition were to change and you felt you*
> *needed to be there more then you were able to be now,*
> *there is a program available to you." And I might leave*
> *them with the [CCB] brochure.*

The notion of introducing the CCB to caregivers before it is needed was particularly valued

by social workers to avoid someone not applying in time to get full use of the Benefit.

Negotiating the tricky issue of timing was thought to be made easier by choosing general

wording.

Although messaging survey respondents did not highly rank a message about the

CCB's two-week unpaid waiting period, all focus group and key informant interview

participants commented that it was a necessary addition to the knowledge tools. As one

social worker explained "*...a lot of people, they live sort of pay-cheque to pay-cheque. It's*

hard for them to think about like what that would look like, and can they do it.” Having all

the program features clearly laid out in the knowledge tools, including the reimbursement

rate, the length of the Benefit period and the two-week waiting period, was emphasized by

the interview and focus group participants. For this reason, the message *“Each applicant*

must serve a two-week unpaid waiting period” was included in a revised version of the pre-

implementation tools. In general, it was thought that more clearly describing the

remuneration provided through the CCB would allow informal caregivers to more easily

make informed decisions about applying to the program.

2.4.2   *Understanding user context*

The unique nature of social work practice and the sometimes limited mechanisms for

translating and sharing information spurred discussions about barriers to CCB information

dissemination. Participants discussed how busy social workers are, describing a sense of

“*...being pulled in many directions.*” Time is a barrier when coupled with the volume of new

information constantly being brought forth to health professionals. Most importantly,

however, was discussion of the impact of health care reorganization on social workers’

abilities to translate and share knowledge. As one social worker discussed:

> *...there are places where there are no longer departments of*
> *social work, which were gathering places and knowledge*
> *exchange places and professional support groups, and now that*
> *social workers are more and more just scattered to particular*
> *areas of practice, they no longer have the opportunity to get*
> *together.*

Another elaborated on the effects of health care reorganization with respect to collaboration

and mentorship:

> *...because there are no social work directors, you now have a*
> *professional practice leader in some places that is very unlikely*
> *to be a social worker. So you’re now reporting to a person*
> *who doesn’t get you, and who doesn’t pass on the same*
> *information that might be necessary to you...directors and*
> *supervisors used to do that.*

The effects of health care reorganization and the context of social work practice was thought to shape social workers' abilities to translate CCB knowledge to clients. Because of this, participants did not desire tools such as the "train-the-trainer" PowerPoint because they had little professional interaction with other social workers, which thereby limited their abilities to discuss research findings and theoretical cases with others. Instead, they valued tools that could serve two functions: increasing their own knowledge about the CCB, and increasing clients' knowledge of the CCB without requiring much more effort on their part. This emphasizes the importance of having multi-purpose knowledge tools.

The practice of translating knowledge from social workers to clients was discussed both generally and within the distinct context of end-of-life care. Social workers discussed knowing that they are holders of information that clients need, but also acknowledged that their work environments reduced their abilities to effectively transfer and translate knowledge for clients. As one participant explained: "*...often the social worker is a holder of information and has to be present at the right opportunity to present the information, because the information itself triggers much more than just what the actual information need is.*" While face-to-face interaction with clients was valued by participants, workplace context limited their abilities to achieve this. The presence of a referral system often meant that clients were left without seeing social workers, perhaps missing out on information; "*...the number of people within the system is so huge that your staff can only see a fraction of them, and it may be that that other fraction actually missed a great big chunk of people that could use the information.*" Based on this knowledge, the preferred CCB knowledge tools were ones that could be informative without necessitating the presence of a social worker to talk over the information. This preference, again, supported the development of educational outreach through printed tools.

Based on the discipline-specific and practice environment factors shared by social worker participants in this sub-section, the top two preferences for knowledge tool formats were posters and pamphlets. As one participant explained:

> *Well, I think the poster sort of fits...if you put it in the waiting rooms and things like that...I think people will sort of sit and sometimes they're bored too, and they want things to read...[the poster] is more eye catching... But if you sit down and look at it, [the pamphlet] has more detail.*

By providing a poster to catch the attention of clients who may not meet with the social worker and having pamphlets available containing in-depth information, social workers believed that clients may then be able to access information about the CCB that would have otherwise necessitated the intervention of a social worker. This is consistent with participants' desires to have a single knowledge tool or group of tools that can be used with the facilitation of social workers, as well as independently by clients.

2.4.3   *Developing user-specific features & facilitation*

Given the particular issues that inform end-of-life care and the program features of the CCB, additional refinements to the draft poster and the pamphlet – these being the most useful tool types according to participants – were suggested by social workers. Participants wanted to make knowledge about the CCB application process as accessible as possible through the knowledge tools, especially given how complex they viewed it to be:

> *And that's a big barrier....you're talking about a really short [program], so do you want to be on the phone talking to someone from Service Canada, or you do want to be with your loved one who is dying in the hospital? I've heard from a lot of people it's not where they want to put their time or energy.*

It was thought that CCB knowledge tools needed to simplify the process of applying as much as possible. In response, particular additions to the tools were made through participant input. First, a checklist was added listing all documents and information pieces that are required in order to apply. As one social worker explained, "*...a lot of times I'm telling them*

this. So now you can say, take this with you, because you know, you really need things to be

concrete and easy as possible when they have so much else."

Another refinement to the draft knowledge tools was the addition of the statement

"*contact your local social worker"*, with space provided on the pamphlet for the individual

social worker to supply her/his contact information. This feature was included as participants

discussed how they do not see all eligible clients, thereby making it difficult to share

information consistently. By providing contact information, they could try to close this gap.

Interestingly, participants wanted the contact box on the pamphlet, but not the poster. As one

social worker explained:

> *...because social workers can come and go sometimes pretty*
> *quickly, and the poster might be up for a year...personally I*
> *think the pamphlet would be the thing, because that's the thing*
> *they're taking away with them. So they've got that information*
> *there.*

Based on their experiences, the social workers valued having their contact information on the

pamphlet. This, in part, showed their recognition of the emotional burden of caregiving and

how caregivers need take-away information and the opportunity to seek guidance when

needed.

2.5   Discussion

The data gathered during this pre-implementation knowledge tool development process

yielded important information about KT practices and values for social workers as related to

the CCB. The results as they relate to the PARIHS framework are summarized in Figure 2.1.

Figure 2.1: Social worker input into tool development according to PARIHS framework

Successful Implementation	Context	Evidence	Facilitation
Stakeholder Input	-social worker community of practice identified, including preferred methods of translating knowledge -end-of-life care social work described, including referral system and user-specific barriers	-most valued messages chosen -clinical experiences with CCB applicants shared, including both clients' and social workers' experiences with accessing information about the CCB	-social worker involvement in CCB application explored, including how the CCB is introduced into conversations with informal caregiver clients
Impact on Pre-Implementation Knowledge Tool Development	-most valued tool formats identified (poster and pamphlet)	-value-laden words discarded from program messages (e.g., dying loved one) -contentious program features clearly discussed (e.g., two-week waiting period)	-local social worker contact information added -checklist added

Figure 2.1: According to the PARIHS framework, successful implementation is a function of evidence, facilitation and context. Summarized in this table is the specific input given by social worker stakeholders who participated in this study and the impact this input had on pre-implementation knowledge tool development.

The qualitative messaging survey helped define the content of the KT tools through identification of preferred message themes. The focus group and key informant interviews identified social worker-specific KT preferences and barriers. In turn, the research results guided the choice of tool content, style, and format. The final pre-implementation CCB knowledge tools developed for social workers, which include the modifications and revisions made in response to the findings of our qualitative datasets, are included in Figures 2.2, 2.3, and 2.4.

Figure 2.2: CCB Pamphlet side A

Figure 2.2: The first side of the pamphlet shown depicts the cover of the pamphlet, the back side of the pamphlet, showcasing the "contact your local social worker" box and the checklist detailing application information. The inclusion of these aspects directly reflects social workers' preferences.

Figure 2.3: CCB Pamphlet side B

About the CCB

The goal of the Compassionate Care Benefit (CCB) is to enable employees to take a temporary secured leave from work to provide care or support to someone who is gravely ill and at risk of dying.

- The CCB program views support to a family member as: (1) providing psychological or emotional support; (2) arranging for care by a third party; and/or (3) directly providing or participating in the care.

- The CCB program adopts a broad view of those considered to be a 'family member.' Program recipients can care for a gravely ill: (1) family member; (2) spouse or common-law partner's family member; or (3) person who is considered 'like a family member (for instance a close friend or neighbour).

Application Coverage

- If an application to the Compassionate Care Benefit (CCB) is successful, payments will be issued within 28 days from the date the claim was filed.

- The basic CCB rate is 55% of average insured earnings up to a maximum payment of $447 per week. You can take up to eight weeks off from work; however only six will be paid. Each applicant must serve a two-week unpaid waiting period.

- The CCB ends when the: (1) 6 weeks have been paid out, or; (2) gravely ill family member dies or no longer requires care or support, or; (3) 26-week period within which successful applicants must take their leave has expired, or; (4) maximum payable on all EI claims within a specific period has been exhausted.

- If multiple EI-eligible family members are applying to care for the same dying person, the 6 weeks of the CCB must be split among them.

How to Apply

- To receive the Compassionate Care Benefit (CCB) an EI application must be made to the program online or in person at a Service Canada Centre.

- Applicants must be eligible for Employment Insurance. This currently excludes most part-time employees, as well as those who have not worked the minimum required number of hours. Self-employed individuals will be eligible in 2011, given new eligibility criteria.

- Applications for the CCB should be filed as soon as you stop working, as a delay in filing a claim beyond 4 weeks after the last day of work may cause loss of benefits.

Applicants must provide proof (in the form of a medical certificate available through Employment Insurance) showing that the ill family member needs care or support and is at risk of dying within 26 weeks.

Figure 2.3: The second side of the pamphlet shown depicts the inside content of the pamphlet. Specific messages about the CCB were selected for inclusion based on the results of the CCB messaging survey. These messages and the layout were then fine-tuned through the key informant interviews.

Figure 2.4: CCB Poster

Figure 2.4: The poster was selected to act as an additional tool type, meant to supplement the pamphlet and target any clients who may not see a social worker. The poster messages were selected, like the pamphlet messages, through the messaging survey, and fine-tuned through key informant interviews.

Of the original multi-faceted CCB knowledge tools designed for use in the interviews and focus groups, namely a "how to use the toolkit" introduction, poster, pamphlet, panel cards, case studies, how-to-apply guide, "train-the-trainer" PowerPoint, and executive summary of the results of an evaluative study of the CCB, only two were ultimately desired by the social workers interviewed: the poster and the pamphlet. This contradicts existing research that shows that printed tools alone, when used as the sole strategy, are known to be

less effective for KT to health services providers (Oxman, et al., 1995). Although employing multiple information dissemination strategies is often more effective (Solberg, et al., 2000), social workers were adamant about reducing the complexity of the KT process by only utilizing two printed tools. The importance of tailoring KT strategies to individual user needs has been advocated for by implementation scientists (Graham, et al., 2006), and thus trusting social workers' experiential knowledge outweighs any interests in following the research evidence that suggests that incorporating non-print materials is necessary for an effective KT strategy.

Research indicates that the complexity of program features affects the success of implementation strategies, where programs that are simpler are easier to translate knowledge about via knowledge tools (IDRC, 2008). This was confirmed by social workers' repeated references to CCB features in the interviews and focus groups. They wanted messages about CCB program features to be delivered in a transparent, straight-forward manner to mitigate confusion by potential applicants about eligibility features and the application process. For example, one social worker explained the importance of putting the financial remuneration amount on the brochure, because *"someone might see that and know right away it's not worth it to them."* Likewise, a checklist was suggested for inclusion in the pamphlet in order to minimize the complexity of the program application, which is a known program barrier (Crooks, et al., 2007).

The social worker participants were implicitly concerned about the complex and uncertain nature of end-of-life care in their suggestions for refinement of the pre-implementation CCB knowledge tools. Although not discussed in the current article, this concern extended to acknowledging that the end-of-life care context is particularly challenging given the burdens unique to informal caregivers providing care. The existence of caregiver burden in the end-of-life care context is well documented in the research literature;

for example, limited time outside of caregiving duties can create issues around unclear

prognostication and negotiating new medical technology and terminology for caregivers

(Crooks, et al., 2007). As well, as discussed by social workers, the referral process may mean

that many caregivers do not see social workers and access to their knowledge base.

Examination of the knowledge needs of informal caregivers has also shown how simple, clear

resources are invaluable to this population given their overwhelming burden of managing

multiple roles and responsibilities (Ashpole, 2004; Dunbrack, 2005; Crooks, et al., 2007).

Social worker participants had a clear understanding of these knowledge needs in general and

in relation to the CCB specifically, evidenced by their focus on clarity and desire to minimize

informational burden. Furthermore, research acknowledges that end-of-life care may take

place in a variety of settings, including hospitals, long-term care institutions, community

settings, and private homes (Wilson, et al,, 2001). Social workers' focus on producing a

portable pamphlet as a KT tool demonstrates their awareness of the need for CCB

information to be transmitted to different care environments.

2.5.1   *Future Research Directions*

While evidence preferences and context-specific values were often discussed by social

workers, less was mentioned about facilitation, the third element of the PARIHS framework.

Social workers discussed their role as key knowledge brokers, and made passing references to

their relationships with other health care professionals, but did not expand further on issues of

facilitation. More information is needed on how social workers will facilitate the use of

knowledge tools to increase awareness about the CCB. This is an important direction for

future research prior to the development of a tool implementation strategy and evaluation

plan. The next step in this project is the development of an implementation strategy in

consultation with social workers and other key stakeholders, such as the Canadian Hospice

Palliative Care Association. This strategy will need to be developed quite thoughtfully given

the research evidence that demonstrates the importance of explicitly considering not only how but also where knowledge will be disseminated in order to achieve successful implementation and ultimately KT (Jacobson, Butterill and Goering, 2003; Graham, et al., 2006; CIHR, 2010).

Existing research has identified social workers as a primary knowledge broker stakeholder group with respect to the CCB. However, it is well known that not all informal caregivers have access to a social worker, especially in time to apply for the CCB (Giesbrecht, et al., 2010). As such, KT campaigns targeting other front-line health services providers, including nurses and physicians, need to be developed in order to best support informal caregivers (Giesbrecht, et al., 2009; Giesbrecht, Crooks and Williams, 2010). The current study serves as a model that can be adopted in such research. Future research may also be conducted to identify pathways for disseminating knowledge tools to the general public as a way of more broadly marketing the CCB. Some research has been conducted on this already (Giesbrecht, et al., 2009), but best tool types and barriers to implementation and uptake still need to be identified.

2.5.2   *Wider Relevance*

As KT and intervention strategies become more popular with researchers, policy makers and program planners (Graham, et al., 2006), better and more thoughtful strategies that more clearly accommodate the needs of the target group are needed. Information and research evidence is not taken up into practice because the information is not appropriately tailored to the target audience (Graham, et al., 2006). Furthermore, research is beginning to indicate that the plethora of resources being developed rapidly in light of patient-centred and consumer driven care may not always be adequately informed and may be potentially harmful (Graham and Tetroe, 2008). Often, in health and social policy and clinical care, there exists a gap between research evidence and practice (MacDermid and Graham, 2009). Substantive

studies have begun to measure how health outcomes could improve with strategic and appropriate research dissemination (Graham and Tetroe, 2007). Extensive research has identified theories about why gaps exists between knowledge and action, including the fact that behaviour, or action, is influenced by attitudes, perceived control or ability to change behaviour and perceptions about what the social norm on the behaviour is (Graham and Tetroe, 2007). In order to change behaviour, these factors must be addressed intentionally. The inclusion of stakeholder input into knowledge translation design can increase knowledge or behaviour uptake success for this reason.

This article presents an example of pre-implementation knowledge tool development that may be valuable for other researchers and also health care administrators responsible for developing informational campaigns. Research has consistently demonstrated that stakeholder input in KT interventions is highly valuable and desirable (Jacobson, Butterill and Goering, 2003; Bowden, et al., 2005; Ward, House and Hamer, 2009). However, few existing studies have attempted to identify the methods or routes through which this may be accomplished. As such, the current study serves as a useful model in this regard. Specifically, the pre-implementation process through which CCB knowledge tools were created could be applied to other printed education material interventions. This can include the method of developing draft tools based on literature and refining them through messaging surveys and stakeholder input prior to the development of an implementation strategy.

This study demonstrates the value of using the PARIHS framework (Rycroft-Malone, 2004) to guide intervention development. While this framework is more commonly used in analyzing the effectiveness of specific implementation strategies (Helfrich, et al., 2010), as we argued earlier in the article we believe that it is useful to consider what constitutes effective implementation when undertaking pre-implementation activities. Doing so will ideally lead to effective implementation. Those creating intervention strategies may wish to

similarly examine their target community of practice's values regarding facilitation, context and evidence during their pre-intervention design. The evidence component may be examined by researchers through a similar employment of a messaging survey. All three components, as shown in this paper, can also be examined and understood through qualitative interviews. The scope for these elements to positively affect the intervention has been documented here.

The method through which the KT tools were developed in this study may be useful to those involved in information production for social workers. The results of this study demonstrate some of the ways in which the nature of social work affect the use and delivery of information to that professional group. For example, the social work referral process affected the type of tools preferred by social workers. Tools that could be used to facilitate conversations by social workers, as well as be accessed independently by caregivers were preferred. While facilitation has been identified as a key component of knowledge translation by health professionals, including social workers, literature has failed to identified ways in which facilitation occurs or can be supported (Duncan, et al., 2009).

The research presented herein is particularly timely as social workers, internationally, operate more on providing knowledge and information now, and less on understanding and supporting social relationships as was more common in the past (Parton, 2008). Social workers are thus more often sought out as knowledge brokers or information holders, and should therefore perhaps be the targets of other intentional information campaigns. Given this, it will become more important to identify the mechanisms through which information can be thoughtfully developed and disseminated to social workers to fit their modern scope of practice. The refinement of the tools by social workers in this study helped identify how the nature of their work affects KT. These results may be relevant to social workers and service providers in other countries.

2.5.3   Limitations

This pre-implementation knowledge tool development study has a small sample size, and it is recognized that the results may have been influenced by the sample size and the participants' specific geographic and clinical representation. For example, all focus group and key informant participants were sampled from the Greater Toronto Area, and all participants worked in institutional settings. Community social workers were not represented. We acknowledge this limitation, and suggest that, as community care is increasing rapidly, especially with Canada's aging population (Wilson, et al., 2001), the community social worker perspective is necessary to examine in future research. Likewise, the heavily urban focus of participants' practice may have skewed the development of the tools for urban dissemination.

2.6   Conclusions

Evaluations of the CCB have determined lack of awareness to be a key barrier to program uptake (Giesbrecht, et al., 2009). Social workers were identified as the key knowledge brokers who are expected to help informal caregivers learn about the CCB. However, their self-reported knowledge about the program remains low. Guided by the PARIHS framework, we have examined the knowledge tool preferences of social workers and have developed two specific knowledge tools about the CCB for future implementation and evaluations. These tools are intended to assist social workers with understanding the feature of the CCB program and to serve as informational resources for their clients. The design of this study, while specific to the CCB and Canadian social workers, can be adopted or adapted by others wanting to take a similar approach to knowledge tool development for health services providers.

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CHAPTER THREE: THE IMPORTANCE OF PLACE AND TIME IN TRANSLATING KNOWLEDGE ABOUT CANADA'S COMPASSIONATE CARE BENEFIT FROM SOCIAL WORKERS TO INFORMAL CAREGIVERS: A QUALITATIVE STUDY[2]

3.1   Abstract

Canada's Compassionate Care Benefit, an Employment Insurance program designed to allow Canadian workers time off to care for a dying relative or friend, has had low uptake since its inception.   Research indicates that social workers are the primary health care professionals in need of a knowledge translation campaign to increase awareness about the program. Knowledge tools about the CCB were developed through social worker input, the process of which is reported on elsewhere. This paper presents the findings of a qualitative exploratory intervention. Social workers (*n=8)* utilized the knowledge tools for six months and took part in face-to-face interviews to discuss their experiences with them. Data analysis revealed references to time and space constraints when using the tools, and demonstrated the impact of Hägerstrand's time geography on knowledge translation about the CCB. The results suggest that knowledge translation about the CCB may be better targeted towards caregivers earlier on in the disease trajectory, and the knowledge tools must be disseminated to more locations. These results are valuable to policy-makers and palliative care providers, as well as theorists interested in ongoing applications of time geography in knowledge translation specific to the consumption and production of care.

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[2] This paper has been submitted to *Health and Place*

3.2   Introduction

The application of geography and concepts of place in health care research is not new, with writing on the topic dating back to Hippocrates' *Air, Waters and Places* in 400 BC (Barrett, 2000). Although the history of health geography is rich and varied, modern research on health geography changed in 1993 (Andrews and Crooks, 2009), with the introduction of Kearns' (1993) definition of place. According to Kearns (1993), places are socially significant phenomena that are shaped by individuals' perceptions and memories. Accordingly, research began to examine health care in light of this richer conceptualization of place (Andrews and Crooks, 2009).

Recent applications of health geography to informal caregiving have focused on the production and consumption of health care (Gavin and Evans, 2008). Informal caregiving is defined as the provision of support to a friend or family member who is chronically ill, disabled or frail (Health Canada, 2010). As caregivers (care producers) and clients (care consumers) of the health care system, informal caregivers reside at the interface of care provision and consumption. Understanding the places in which caregivers provide and consume care is complicated by the "increasing porous boundaries between formal care-giving and informal care" (Milligan, 2009, p.3). Other research on informal caregiving has grown to include among other research areas, spatial variations and geographic mobility in unpaid caregiving work (see for example, Young, 2005; Foley, 2008) and perspectives of feminist geography in care work (see for example, Williams and Crooks, 2008). Informal caregiving has been associated with negative health outcomes (Cameron, et al., 2002; Chentsova-Dutton, et al., 2002; Stajduhar and Cohen, 2009; Reid, et al., 2009), and informal caregivers often describe the balancing of multiple roles and responsibilities as one of the many complications of providing care or support (MacBride-King, 1999, Reid, et al., 2009).

The Canadian government has responded to the needs of informal caregivers through introducing the Compassionate Care Benefit (CCB) in 2004.

The CCB, which was legislated in 2004, allows those caring for their dying friend or family member to take paid time off work. The CCB is a contributory Human Resource and Skills Development Canada Employment Insurance (EI) Benefit. As such, applicants must have accumulated 600 insurable hours through automatic payroll deductions to the EI contributory scheme and demonstrate their wage has decreased by 40% in the preceding 52-week period.   Applicants must also demonstrate that their care recipient is gravely ill and within six months of death through provision of a signed medical certificate. If eligible, applicants can receive an eight week leave from work to provide care and support. Of the eight weeks, two are unpaid and during the remaining six weeks the applicant can receive 55% of their income, to a maximum of $468CND per week (Service Canada, 2010).

Despite demographic trends that would indicate otherwise, uptake of the CCB has been low (Osborne and Margo, 2005). Research has identified a number of recommendations for increasing uptake, including the implementation of an awareness campaign (Williams, et al., 2010). Social workers, in particular, have been identified as key health professions who have the capacity to act as knowledge brokers and help raise awareness about the CCB (Giesbrecht, et al., 2010). In this capacity, social workers will be working with the caregivers' as consumers and providers in the health care interface. This research represents the second stage of a CCB awareness campaign targeted to social workers. The first stage is now briefly described (Dykeman, et al., under review).

Printed education materials, or knowledge translation (KT) tools, were developed through social worker input in the first stage of the research (Dykeman, under review). A messaging survey elicited responses from social workers about preferred messages about the CCB, forming the content of the KT tools. A focus group and in-depth interviews provided

opportunity for refining tool formats developed through a literature review. A poster and pamphlet about the CCB were developed as the preferred KT tools, with messages focused on the CCB purpose, as well as application and remuneration details. Finally, although the KT tools were developed for social workers, ultimately social workers wanted tools they could share with family caregivers without further refinement.

The KT tools were shaped largely by the context in which social workers provided support to family members, particularly in hospice palliative care (HPC). References to the times and places where the tools would likely be used and how conversations about the CCB typically happened was evocative of the notions of time and place in time geography.   This paper presents an exploratory examination of the KT tools based on Hägerstrand's (1975) time geography. First, Hägerstrand's (1975) time geography will be explored with respect to current health research. Second, the study methods will be explained, followed by results provided in discussion with existing literature.

3 2.1   *Time Geography*

According to Hägerstrand (1975), people draw upon time and resources in order to realize projects, such as translate knowledge about the CCB. The interaction of time and space in the realization of a project is subjective to three types of constraints: "capability constraints", "coupling constraints", and "authority constraints". "Capability constraints" include the locations and livelihood of the individuals employed in the project. These locations and livelihoods, say for example "social worker" and "hospital" are entitled *stations.* "Coupling constraints" define where, when, and for how long an individual needs to collaborate with other individuals, tools and materials in order to realize their project. These collaborations, such as the social worker using a pamphlet to inform an informal caregiver, are entitled *bundles*. Finally, "authority constraints" signify the imposition of conditions of access, and are called *domains*. For example, the program application features of a resource

for informal caregivers. The whole collective of possible paths through which individuals could move according to stations and bundles are represented a *prism* (Hägerstrand, 1975).

Figure 3.1: Web model of Hägerstrand's time geography
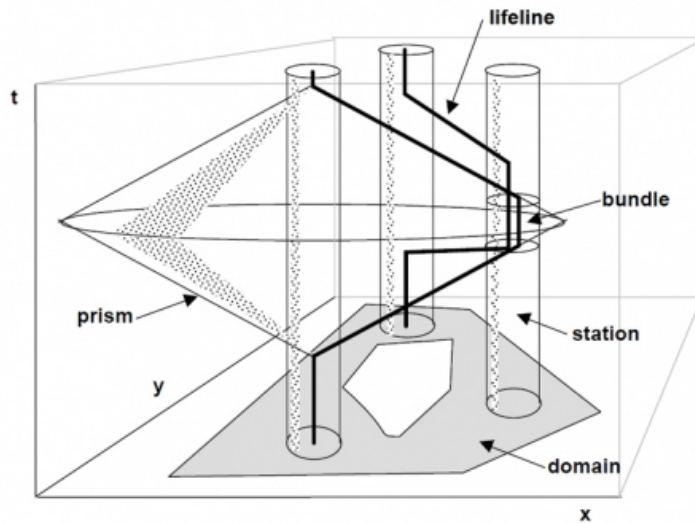
Figure 1. Some time geography elements

Figure 3.1: The movement of individual's through space and time is depicted along the x -y axis and t axes of the web model, respectively. The shaded domain is representative of authority constraints, or conditions of access. Physical locations, or stations, are depicted as cylinders, representing capability constraints. Lifelines are simply the passages through space and time. Bundles are the collaborations of individuals or resources through space and time also known as coupling constraints, and are shown as smaller cylinders within the stations. Finally, prisms are the total areas of space attainable by an individual. (Source: Hägerstand, 1975).

Hägerstrand's (1975) time geography model has been widely used and explored in research and literature as a social theory since its initial development (Pred, 1996). Despite this, researchers argue that its application in health care is far from being realized (Rainham, et al., 2010).   Research concerned with Hägerstrand's (1975) time geography has included the work of Kwan (2000), McKie, Gregory and Bowlby (2002), Takahasi, Wieve and Rodriguez (2001), and Rainham, et al., (2010) within the fields of health and social geography and sociology. Applications include the use of the model to examine the childcare landscape and labour negotiation concerns for women (McKie, Gregory and Bowlby, 2002).

Using social theory from Hägerstrand (1975), as well as later work from Giddens (1979), Melucci (1996) and Adam (2000), this paper employed a "temporal gaze" towards understanding child carescapes. This included: the basic temporal elements of caregiving as added on time-elements, such as where and for how long; the more contextual elements specific to locations including histories, meanings and patterns of social interaction, and power interactions and; an examination of the fluidity and multidimensionality of coordinating care tasks and work, including the influence of past decisions and future possibilities in negotiating caregiving (McKie, Gregory and Bowlby, 2002).

Takahasi, Wiebe and Rodriguez (2001) used time geography to examine health and social services utilization for people living with HIV/AIDS. Through in-depth interviews and survey data, daily routines and social network interactions of people living with HIV/AIDS were examined with respect to the individual and institutional level constraints that shaped the location and timing of their activities (Takahasi, Wiebe and Rodriquez, 2001). In particular, this research utilized Hägerstrand's (1975) notion of bracketing, or the temporal moments where conversations and social gatherings occurred, in order to understand access and utilization of services (Takahasi, Wiebe and Rodriguez (2001).

In both cases, access to supports based on movement throughout space was a key finding (McKie, Gregory and Bowlby, 2002; Takahashi, Wiebe and Rodriguez, 2001). The value of Hägerstand's time geography model is that it allows its user to understand the interdependence of mixed activities; clarifying the contextual structures and processes of activities (Pred, 1996). As such, it can be a valuable tool to understand how multiple individuals negotiate and utilize the health care system. In this paper, a similar application of Hägerstrand's (1975) constraints will allow us to map how social workers utilize the knowledge tools (as bundles), through space and time in order to translate knowledge about the CCB.

3.3   Methods

Prior to the start of the full study, ethics was obtained through McMaster University's Research Ethics Board (February 2010). This exploratory intervention was implemented after the first stage of the research was completed, wherein the knowledge tools were created and the implementation of the tools refined via focus groups and key informant interviews with social workers (Dykeman, et al., under review). In this research stage social workers utilized the tools for six months, and discussed their experiences in participant interviews. Data collection for this phase of the intervention occurred from October-November 2010. Participants (*n=7)* were recruited through snowball sampling in the Greater Toronto Area where existing research participants from the first phase of tool development shared recruiting information among colleagues. Participants represented a number of care locations including palliative care units in hospitals, outpatient palliative care clinics, and in the community.

Following the six month tool use period, the participants were interviewed. The interview questions were semi-structured and were based on basic questions on tool use. Questions included: "Where did you place the posters? Why did you chose that location?"; "How long did you discuss the CCB for in conversation with family caregivers?" and; "Are there any barriers to using the KT tools?" Prior to the start of the interviews, participants gave informed written consent after being informed of the research process through a letter of information, as well as verbal explanation by the interview facilitator. The interviews were conducted at the participants' workplaces, lasted approximately two hours, were digitally recorded and transcribed verbatim. The transcript was coded thematically through an adaptation of both inductive and deductive coding styles. Several themes were generated according to concepts of time and space, including notions of added on time-elements such as the location of the tools, context elements, including elements which determined where the

conversations with the social workers took place and length of the conversations. Additional

themes were added through immersion in the data (Burnard, 1991; Pope, Ziebland and Mays,

2000; Hseih and Shannon, 2005). Coding followed an eight-stage process adapted from

Burnard's (1991) guidelines. In order to enhance the rigour of the analytic process, codes

were agreed upon by team members (Pope, Ziebland and Mays 2000; Barbour, 2001).

3.4   Results and Discussion

Through analysis of the qualitative data, it became clear that the translation of

knowledge about the CCB and the use of the CCB tools were largely shaped by time and

space, much like the authority, capability, and coupling constraints discussed by Hägerstrand

(1975). Factors of the space and time constraints, in the context of using the CCB KT tools,

were linked to the CCB itself, the social worker, and the caregiver. Each of these constraints

will be discussed below in relation to the results and supporting literature.

3.4.1   Authority Constraints: Access to Hospice Palliative Care in Canada

According to Hägerstrand (1975), authority constraints or domains, signify the

conditions of access. Within the data, domains included the nature of hospice palliative care

(HPC) in Canada, the referral process whereby caregivers can access social workers, and the

CCB application process and remuneration details. As will be discussed, social workers'

stations also influenced how they received referrals and assessed caregivers who may have

benefited from information about the CCB. However, this domain was ultimately shaped by

the nature of the health care system whereby policies specific to referral process were

implemented according to location.

3.4.1.1 Health Care System Domains: Referral Process

Palliative care in Canada is delivered in a number of locations, including

institutions such as hospitals, hospices and long-term care homes, as well as within the

community (Health Canada, 2009). Access to palliative care-specific services in

Canada is typically based on identification of a palliative prognosis, although the definition varies depending on the service provider (Health Canada, 2009). Currently, palliative care falls outside of formal health care delivery in Canada, meaning access to services varies across the provinces, most notably when care is accessed in the community (Williams, et al., 2010). Within Ontario, the province sampled for this study, community services are accessed through Community Care Access Centers (CCACs), which are organized regionally through bodies called Local Health Integration Networks (LHINs) (Williams, et al., 2010). When diagnosed as palliative, the patient can access multidisciplinary care teams including physicians, nurses, social workers and spiritual advisors through either the institution (i.e. long-term care facilities and hospitals) or CCAC. As part of the comprehensive care plan for palliative patients, family members and friends can also access bereavement support workers (Health Canada, 2009). As discussed by social worker study participants, referrals are typically made by other professionals within an institutional setting. Referrals were made by CCAC case coordinators for community care social workers. In some cases, self-identification from caregivers led to referrals. A community social worker described the influence of funding structures in relation to referral patterns:

> ...at times, like the end of the year...referrals tend to ebb. The reason I think it's relevant is because I think that sometimes the referrals that we get are related to fiscal situation and we haven't had any recent referrals.

The number of referrals, and subsequently opportunities for the social worker to utilize the KT tools and discuss the CCB with caregivers, was dependant on the social worker's stations. For example, the same community social worker described getting fewer referrals than their institutional counterparts. Although palliative referrals later in the disease course have been linked to poorer resource access internationally (Osta, et al., 2008), little research exists specific to Canada with respect to the role of referrals

in palliative care specific to resource access and patient outcomes. However, this was a

clear barrier to translating knowledge about the CCB, and thereby impacted the use of

the KT tools.

3.4.1.2 CCB Domains: Application Process and Remuneration Details

Social workers discussed how the length of the application process and the two-week

unpaid waiting period made it difficult to translate knowledge about the CCB given the

palliative prognosis of their patients. As one hospital social worker described:

> Our average length of stay here for a patient is approximately
> 20 days, so by the time a patient arrives at [name of hospital],
> more often than not by the time a person arrives here it's really
> too late for Compassionate Care Benefits, because by the time
> they go through the waiting period, plus the time and effort
> applying...it's just not quick enough for people.

The length of stay for a patient varied according to the setting, as typical diagnosis,

treatment options, and number of beds available varied according to location of care.

For example, social workers described working with patients for days, months, and

years. However, most often their clients were admitted within the last few weeks of

life. Social workers described the paradox where only palliative patients were eligible

for the program, but often by the time they were diagnosed as palliative, and the social

worker had discussed the CCB with the caregiver, it was too late to consider applying

given the application process and waiting period. Interestingly, this has been

documented within CCB evaluation research, where caregivers who were not eligible

for the program often were not eligible because the care recipient had died at some

point during the application process (Williams, et al., 2010). This paradox was

heightened by the fact that caregivers needed to be emotionally ready to accept the

palliative prognosis, a process which may take up valuable time that could be spent

applying and waiting for the CCB; as such access to the program was affected by

Canada's death-denying culture (Carstairs, 2010).

As described by a participant in Ashpole's (2004) caregiver study "it is as if society disapproves of people who are seriously or terminally ill and shuns those who care for them" (p.7). The hesitancy to accept palliative prognoses is often documented in the shifting emotions of the caregivers during the palliative process (Ashpole, 2004). The caregiver's interest in the program, according to the social worker, was often influenced by the prognosis of the care recipient and the caregiver's acceptance of the palliative diagnosis. These factors often shaped the length of time the CCB was discussed in conversation, and the caregiver's interest and/or readiness to apply to the program. As one social worker described:

> I'll offer it early-on, reminding them that it is only an eight week program and it has to be shared amongst all of their family and friends. And that is a barrier to the system. People don't want to apply too early. So they then hold off and don't apply. And then it's too late sometimes when they do apply...People are afraid to use it because they don't want to use it too soon.

Social workers discussed the caregiver's acceptance of the palliative situation as a key barrier in translating knowledge about the CCB. Social workers had to be aware of and work to overcome this barrier when translating knowledge about the CCB to caregivers. As such, the CCB program features acted as authority constraints for translating knowledge it.

Social workers also discussed the nature of the application process as potentially acting as a barrier, given the fact that the paperwork involved a number of individuals at varying locations, including the caregivers workplace for the record of employment and the physician's office for the medical certificate. Social workers described the time it took to oversee and support the caregiver in applying as a function of accessing these two documents. In many of the scenarios discussed by social workers, difficulties in accessing either of the documents prolonged the application process:

> I'm having some problems with the way doctors complete the medical form. So I'm having patients after the fact, so the

> loved one's dead, calling me telling me that they got rejected
> and didn't get any money on the Compassionate Leave. And
> it's related to how that form is filled out...So a family doctor
> doesn't always fill it out correctly. Especially if they're not
> familiar with it or they're not doing it frequently.

While the above quotation discusses the role of the family physician specifically, social workers also had physicians within other workplaces fill out the medical form. The decision whether or not to approach the family physician of the care recipient, or a specialist physician within the palliative setting was often made through conversations between the caregiver and social worker. Often it was complicated by factors including the physicians' knowledge of the program, the accessibility of the physician, and the caregiver's ability to facilitate the process or their dependence on the social worker to acquire the documentation. Knowledge translation literature supports the fact that program features affect knowledge uptake, and may act as barriers to increasing program awareness or utilization (IDRC, 2008), which, according to Hägerstrand (1975), would be considered authority constraints.

The authority constraints identified by social workers document the constraints imposed by: the health care system and the palliative care referral process; the cultural nature of palliative care in Canada; and the program features of the CCB. Each constraint imposes temporal and spatial boundaries that affect access to the information and the program. This suggests that, perhaps, knowledge translation about the CCB earlier in the disease process may be valuable in order to reduce temporal constraints, as has been suggested for other palliative care programs (Osta, et al., 2008). Awareness of the domains through which knowledge about the CCB and the CCB KT tools are utilized by social workers will potentially enhance the success of translating knowledge and will be discussed in the next section.

3.4.2   Capability Constraints: Locations of Care and Work

As discussed in the introduction, capability constraints are defined by the physical locations, known as stations, in which individuals' involved in a project reside (Hägerstrand, 1975). In the case of translating knowledge about the CCB, the location of the social workers' practice defined how social workers identified locations for placing the posters and pamphlets, or spaces to introduce conversations with caregivers. Caregiver stations identified by social workers included their places of work, which affected their knowledge of the CCB and ease of access to the program. Finally, social workers discussed Service Canada as both a virtual and physical station they accessed themselves, or directed the caregivers' access, in order to obtain the medical form and submit the application.

3.4.2.1 Social Worker Station Constraints: Tool Locations

The placement of the KT tools within the social workers' practice location necessitated conscious decision-making based on a number of factors, including where social workers discussed resources with caregivers, as well as the policies and architecture and interior design within their unique workplaces. One social worker described being constrained by the fact that their unit was newly renovated, and did not them allow to put up materials. As a result, the social worker chose to keep the tools in their office and hand them out to caregivers during face-to-face interactions within the office space. The community social worker took a similar approach, due to the ever-changing locations of care provision throughout the community, and kept the tools on their person rather than in a stationary physical location. Most institutional social workers chose locations where caregivers were likely to find the information while waiting for appointments. These varied from private quiet rooms for family members, doctors' examination offices and appointment rooms, hallways and waiting rooms. Some social workers reported choosing locations because of the movement of people through those spaces, whereas other social workers chose spaces where people were likely to be sitting and waiting:

> I chose these locations because I was looking for places that the
> most amount of patients would see them. You see our layout
> there. The waiting room. There's not always a lot of
> opportunities to place things there. So I sort of looked for a
> place that a lot of people would walk by.
>
> I've chosen all of the doctor's examination rooms because
> family members sit there and wait for the doctor to arrive, so I
> have it across from where they're sitting so it's at their eye
> level.

Ultimately, all social workers attempted to place the tools in locations where family

caregivers were likely to be, even when not facilitated directly by a social worker. The

introduction of printed educational materials in care settings has been associated with

variable increases in provider and patient knowledge, with few statistically significant results

(Freemantle, et al., 2005). Despite this, printed educational materials are still widely utilized

and preferred by health service providers (Freemantle, et al., 2005), a trend which was

verified by the social workers' participants in this study. However, given the variability in

locations where palliative caregivers may reside and move, a greater range in physical

placement of tools may be called for. This may become increasingly necessary as preferred

location of death has been shifting from institutions into the community and private home

(Wilson, et al., 2001). The locus of care has also been shifted from professionals into the

voluntary sector, with more care being provided by informal caregivers including friends and

family members (Romanow, 2002). With potentially fewer care recipients and caregivers

accessing inpatient palliative care services, the need to translation knowledge about the CCB

may also need to change to accommodate more community care locations. Social workers

discussed already being aware of having to translate knowledge about the CCB outside of

their immediate workplaces, given the caregiver's movement through other stations.

3.4.2.2 Caregiver Station Constraints: Workplace Dynamics

Caregivers also had to assess workplace dynamics and their movement throughout

spaces when considering applying for the CCB. Social workers reported that for some, the

decision to apply for the program and the application process itself was influenced by the place in which the caregiver's worked. For example, one social worker described a situation where the application process took longer because of the difficulty the caregiver had in accessing their record of employment and explaining the CCB to their employer. The employers' lack of knowledge and support of the program led them to withhold the record of employment for some time. In fact, several phone calls had to be made by the social worker before the record of employment was released. In other situations, social workers discussed caregivers who applied for the CCB earlier as a result of supportive workplace environments where the CCB was being marketed and, on occasion, enhanced by workplace policies.

The expectations and experiences of employers and human resource personnel helping caregivers apply for the CCB has been documented in the CCB evaluation research, as discussed in the introduction. While workplaces must accommodate caregivers, the mechanism through which caregivers accessed CCB information and their record of employment together with the level of support they received from their workplace varied (Williams, et al., 2010). This was noted by social workers, who, in trying to help caregivers apply, often gave information to the caregiver's workplace as well.

As such, social workers travelled through a number of different stations in their effort to translate knowledge about the CCB. These stations were both physical, including their workplace location (such as the hospital and community), and abstract, including telephone conversations with their client caregiver's workplace. The stations were also primarily related to the palliative assessment and social worker's mandated roles in supporting caregivers. Social workers supported caregivers most often directly at the social worker's location of work, but also in secondary locations the social worker accessed in further facilitation of the application process above and beyond their professional expectations. This included supporting the caregiver by obtaining a signed medical certificate, whether in their

place of work, or within another care setting. Further assistance was provided when the social worker accessed the Service Canada application, either online through computers in a number of locations, or in person at a Service Canada office. Computer access was a further subset of stations; caregivers and social workers had variable access to computers, and sought out online information through a number of different locations, including personal homes, health care settings including resource rooms, and community spaces such as libraries. The movement through these stations was varied according to the social worker's ability and interest in physically moving and further facilitating the application process. Often the caregiver was also required to accompany the social worker through different stations.

Given the number of different stations, and the variation in possible paths through those stations, the use of the CCB KT tools and the translation of knowledge about the CCB are variable. In order to simplify the process, and enhance knowledge translation, it may be necessary to include more stations whereby information about the CCB is shared. This may reduce the amount of pressure faced by social workers to move themselves through multiple stations.

3.4 3   *Coupling Constraints: Resource Utilization and Collaborations*

Coupling constraints are described as the collaborations between individuals in order to realize a project and includes the physical location, point in time, and duration of the collaboration (Hägerstrand, 1975). Key coupling constraints between the social worker in the KT of the CCB include the development of a therapeutic relationship between the caregiver and social worker, and the introduction of the CCB and use of the CCB KT tools. The locations of these collaborations are entitled bundles (Hägerstrand, 1975).

3.4.3.1 Caregiver- Social Worker Bundles: Introducing the CCB

Introducing the CCB and using the KT tools may have happened at the first assessment or at a later meeting, depending on the unique needs of the caregivers and

patient. Regardless of the care location, all social workers reported variation in the

time in which CCB was likely introduced with caregivers and the length of time the

program was discussed:

> the assessment of the family system and how family members
> are coping with the health challenge- a feature is how people
> are coping financially, and that combined with stress and how
> stressed people are. So when I'm doing an assessment, which
> isn't a formal sit down and fill out a piece of paper assessment,
> it's a conversation, could be two minutes long, could be two
> hours long, or could be a bunch of conversations...

The amount of time spent discussing the CCB and using the KT tools was often related

to the type of relationship established between the social worker and the caregiver, as

well as the needs of the patient, as identified by the social worker.   Social workers

determined what information to share based on their own interpretation of the

caregiver's need, as identified through the assessment. The assessment occurred in a

number of locations within institutional settings, including: the social worker's office, a

'quiet room' or resource room, and the physician's examining office. Within

community settings, the assessment occurred in the private home of the caregiver, the

patient, or other convenient location identified.

At times, caregivers approached the social worker with information about the program

and an interest in applying. Other times, social workers informed caregivers about the

program after they had picked up the KT tools at some location themselves, and were

immediately interested in applying, or decided to apply days, weeks or months later. When

discussing these scenarios, one social worker highlighted the importance of the pamphlet

> I suspect that they read it and that they then make the decision
> that they do want to pursue getting it because they'll often
> come back with the [completed] medical form that I've already
> given them to have signed.

According to this social worker, and others, the pamphlet was used by caregivers who wished

to have time to reflect on the program information over time, and share it with other family

members in different locations before making a decision to apply. This collaborative bundle was therefore variable, according to factors such as the caregiver's interest in applying for the program and the social worker's interest and ability to further facilitate the application process after a decision had been made.

As described by the social workers, the tools were invaluable in enhancing information uptake and worked as tangible materials caregivers could continue to refer to. Literature suggests that information resources for palliative caregivers neglects different learning styles; for example some caregivers may want to consult resources as quickly as possible, while others may want to collect information to review later at a slower pace (Dunbrack, 2005). This was confirmed as social workers described using the tools differently and staging conversations differently depending on the needs and learning styles of the caregiver.

Caregivers must constantly renegotiate as the prognosis and needs of the care recipient changes, typically with growing frequency at end-of-life (Ashpole, 2004). The information needs of the caregivers change during this temporal prognosis continuum from diagnosis to death (Ashpole, 2004). Caregiver intake of information during this time period may be impaired by the information overload due to changing care needs and subsequent treatment options (Crooks, et al., 2007; Dykeman, under review). Information about the practical and physical components of caregiving are often prioritized by the caregiver, who may neglect their own emotional, physical and psychological needs (Dunbrack, 2005). Given the mandate of the CCB to support the caregiver, it may be viewed as less important by the caregiver in comparison to the care recipients' immediate care needs. Understanding the point at which to introduce information, and creating opportunities for information uptake, were key elements of the bundle where collaboration occurred between the social worker and the caregiver with respect to CCB KT.

3.4.3.2 Social Worker-Clinician Bundles: Sharing the KT Tools

Social workers also described the process of deciding whether or not to share the CCB tools with other professionals at their workplace, given referral patterns may mean social workers do not see all the caregivers accessing services at their workplace, as discussed earlier. Often, for social workers working in institutions, intensive care units were chosen as appropriate venues for additional dissemination given the care profile specific to critically ill patients. Social workers discussed an interest in broadening the dissemination of the CCB KT tools to target more patients who were not yet defined as palliative, but who had the possibility to become palliative. However, social workers also described concerns that caregivers and clinicians would overlook resources if they did not apply to their care recipient at the present moment in time, regardless of their potential usefulness in the future. For this reason, many social workers hesitated to disseminate the tools beyond their own immediate workplace, controlling knowledge translation about the CCB.

Research has indicated that in contemporary society, social workers are expected to be knowledge brokers and information holders, rather than their more traditional role of understanding and supporting social relationships (Parton, 2008). However, given the authority and capability constraints discussed earlier, the ability of social workers to couple with other individuals was compromised. While the pamphlet effectively broadened knowledge translation by acting as take-away material for caregivers, increasing the longevity of knowledge translation about the CCB, the actual collaboration between the social worker and caregiver was limited by time and settings of care. Offering other opportunities for collaboration between caregivers and clinicians may enhance CCB uptake. Evaluation research has recognized that, while social workers are the primary knowledge brokers about the CCB, knowledge

translation about the CCB occurs through other clinicians as well. Identifying preferred tools types and opportunities for KT from other clinicians may be necessary.

3.4.4 *Implications for Translating Knowledge about the CCB*

Research has recognized that places influence the social aspect of care and caregiving (Parr and Philo, 2003), and individuals are connected through institutions and organizations in the provision of care (Bosco, 2007). Social networking through spatial locations has been identified as a key element in access to support for caregivers (Milligan, 2000). Evaluation research of the CCB has identified a number of other locations and stakeholder groups where knowledge about the CCB could be translated. This research study was designed to develop knowledge tools for one of the stakeholders groups; social workers. The constraints identified suggest that broadening the KT strategy to more geographic locations and identifying locations where knowledge may be translated earlier during the disease process to enhance information uptake. This may mean including other health professionals identified by Giesbrecht, et al. (2009), such as family physicians and nurses, not only because of their contact with family caregivers, but because of their ability to introduce the CCB into conversations before social workers may be referred. Likewise, identifying venues where patients with chronic illnesses inhabit is valuable; translating knowledge about the CBB in these stations may help overcome some of the constraints of the program discussed. Potential alternative KT routes have been illustrated in Figure 3.2.

Figure 3.2: Options for increasing CCB knowledge and use of KT tools
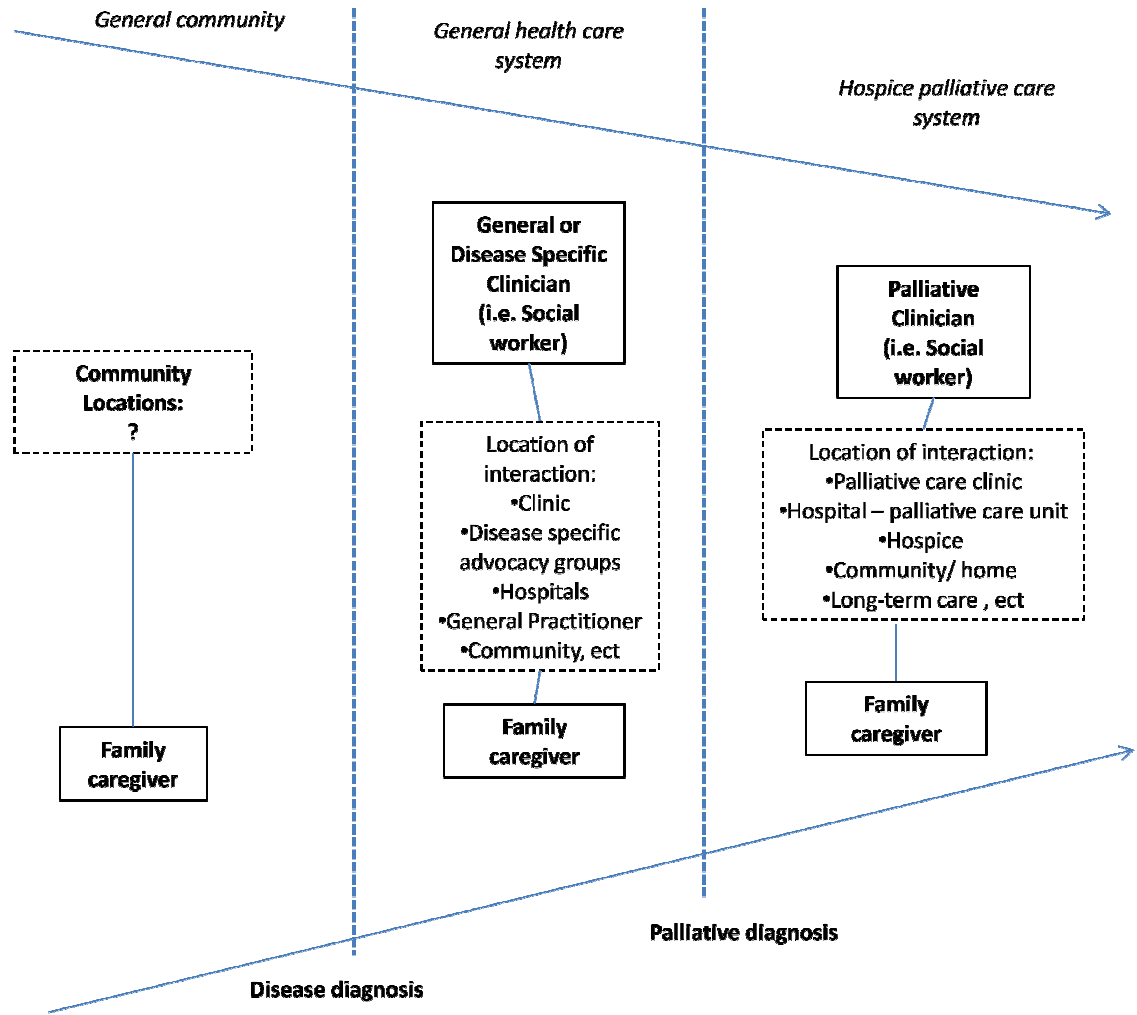
Figure 3.2: Given the coupling, capability, and authority constraints identified, broadening the translation of knowledge about the CCB to more settings of care, and earlier in the disease process may be valuable. As such, identifying new knowledge brokers, and opportunities for caregivers to collaborate with them, as well as more stations or locations of knowledge translation, may be valuable. This figure illustrates some hypothetical scenarios through which this may occur.

Ultimately, by enhancing, or broadening, the stations at which knowledge translation may occur, by redefining the clinicians who may translate knowledge, and using the tools earlier in the caregivers' journey, we may hope to alleviate some of the barriers imposed first and foremost by the authority constraints, as well as strengthen the coupling and capability opportunities. Distinctive temporal elements during the care trajectory, including diagnosis,

identification as a palliative patient, end-of-life, and post-death, have been associated with

unique information needs (Ashpole, 2004). Research-based recommendations to the

Canadian government have suggested that increased awareness about HPC in general should

be accomplished by a two-pronged approach; tailoring strategies to inform caregivers during

crisis or "just-in-time", and developing strategies to target caregivers before required

(ACART, 2006). At present, the CCB is largely translated after the patient becomes

palliative and nearing end-of-life, or "just-in-time". Given this paper's findings, it may be

appropriate to begin KT about the CCB and utilize the KT tools after initial diagnosis, before

they are required. Interestingly, advocates have suggested the CCB be extended to allow

caregivers for chronic illness access (Carstairs, 2010). This would significantly alter the KT

process of translating knowledge about the CCB given the temporal barriers earlier identified,

where caregivers accessed the CCB too late given their inability to accept the palliative

diagnosis.

3.5   Limitations

The sample size of this project was small, with acknowledged regional specificity due

to sampling from the Greater Toronto Area in Ontario, and a lack of community social

worker representation. Community social workers and representatives from other care

locations such as long term care homes and hospices warrant further investigation. As such,

the results may not be representative of social workers working in other regions or locations.

As well, the lack of formal evaluation of the KT tools and measurement of use may be

considered a limitation. However, this phase of the research project was meant to test the KT

tools as part of the tool development phase (see Dykeman, under review), and not as a formal

evaluation for actual knowledge change and program uptake rates. Future research is being

planned to explore the development and implementation of KT tools further.

3.6   Conclusion and Future Research Directions

As identified by the number of constraints discussed, KT in this situation becomes difficult given the complexity of the relationships and the variations in spatiality and temporality. No constraints were unique, but connected in iterative and overlapping manners. For example, referral patterns were informed by authority constraints, but were also affected by capability and coupling constraints. The constraints, while discussed solely by social workers in the context of using the CCB tools in this paper, have also been explored in the perspectives of caregivers to similar effect (Crooks, et al., 2007). However, little research has been done to understand the complexity and define time and place in knowledge generation and movement. This paper provides some preliminary findings that attempt to portray some of the influences of time and place on KT in HPC. Hägerstrand's (1975) time geography theory has provided the foundation upon which other social theories have developed, including Gidden's (1984) structuration theory. According to Gidden (1984), social practices are influenced over space and time by elements such as structure and agency. This approach is useful in understanding how practices are constrained and enabled, and would therefore be a useful addition to this research.

Knowledge translation is inherently geographical; most KT theories include tailoring information to the local context (see for example, Graham, et al., 2006; Rycroft-Malone, 2002). Often, the process is typified as getting the right information to the right place at the right time (Kho, et al., 2009). Researchers, policy-makers and program planners involved in palliative care, as well as the general health care system, may find the methodology of this paper of use to them in understanding the implications of space and time in knowledge translation. In particular, some of the capability, coupling and authority constraints identified may resonate with other similar programs and knowledge translation and intervention strategies.

Ultimately, the use of the CCB KT tools occurred within the context of time and place through which the social workers and caregivers moved. Despite concerns about tailoring KT strategies to local needs (Graham, et al., 2006), research has been slow to employ geographical theory in KT projects. Within the scope of HPC, as informal caregiving blurs between space and time and porosity increases (Milligan, 2009), perhaps KT needs to increase in "porosity" and scope with more rigorous application across space and time.

In many other sectors of the health care system, patients and caregivers are becoming proactive health care consumers, driven by, and causing, an exponential growth in health resources and knowledge translation (Tugwell, 2007), particularly online information (Hardey, 2001). While the quality of some of the information has been questioned (Longo, 2005), this has reduced some of the "social monopoly of expertise and knowledge" of clinicians (Turner, 1995, p.47). Knowledge translation has called for, and aided in, the creation of more quality knowledge dissemination. However, given the results of this research, the consumer-driven palliative caregiver may be somewhat of a fallacy at this point given the taboo nature of palliative care in Canada. This is despite the recognition that informal caregivers, by definition, are both producers and consumers of care (Gavin and Evans, 2008). Capitalizing on the opportunity to market palliative programs, such as the CCB, to the aging baby-boomer consumers may offer opportunities for increased uptake and awareness. Following a similar stakeholder-integrated tool development methodology may offer increased opportunities to harness this untapped market. Through greater clinician involvement, appropriate messages and strategies may be developed in order to overcome some of the inherent system and cultural barriers.

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CHAPTER FOUR: CONCLUSION

4.1   Introduction

The objectives of this thesis were specific, although the research results have broad implications. The purpose of the research was to develop a knowledge translation (KT) knowledge tool development intervention for social workers about the CCB through stakeholder input. Social worker input was gathered through several stages: (1) preferred messages about the CCB were collected through a qualitative messaging survey (n= 16); (2) preferred tool formats were identified, and tool development occurred through a focus group (n= 8), and key informant interviews (n= 3); (3) finally, a final tool refinement stage occurred through participant interviews (n= 8) whereby social workers utilized tools for six months as a tool pilot stage. Steps 1-2, outlined above, were discussed through chapter 2. The chapter presented the preferred tool messages, tool formats, and some of the concerns for tool use according to the PARIHS framework. Step 3, as outlined above, was presented in chapter 3, where tool use was discussed according to time geography theory.

As the conclusion, this chapter will present a summary of the significant results from both Chapters 2 and 3. As well, the study limitations will be briefly discussed. Contributions of the research presented herein will also be explored with respect to the wider relevance, specific to HPC policy, KT literature and geography literature. Finally, further research directions will be explored.

4.2   Overview of Significant Findings

4.2.1   Preferred CCB Messages and Tool Types

The messaging survey was disseminated to a national sample of social workers (*n*= 16), as depicted in Table 2.1. The messaging survey asked social workers to rank individual messages about the CCB on a scale from not useful to highly useful. According to the results, social workers preferred messages about the purpose of the CCB, followed by messages about the applications process and, finally, messages about the remuneration available. Top-ranked messages for each of the three message theme groups were included as the content for the knowledge tools. The messaging survey also had social workers choose their overall top three preferred messages about the CCB, two of which were purpose type messages, and one of which was a application process type message, only differing slightly from the results of the individually marked messages. The top selected messages were also chosen as the content of the KT knowledge tool intervention.

Social workers preferred the pamphlet and poster for information about the CCB. These tools were displayed in figures 2.2, 2.3 and 2.4. According to social workers, this was due to their unique community of practice, including opportunities for identifying potential CCB applicants and facilitating tool use. These concerns were explored, together with others, according to the PARIHS framework themes of evidence, facilitation and context, and serving as an opportunity for tool refinement.

4.2.2   *Implications of the PARIHS framework- evidence, facilitation and context in CBB KT*

Application of the PARIHS framework in this research allowed for further refinement of tool messages and formats, as well as exploration of potential tool uses in the facilitation of social worker and family caregiver relationships. Several tool messages were refined according to social worker preferences for evidence, as well as their contextual expertise. For example,

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social workers valued more concise messages, and argued for the inclusion of a checklist in the CCB pamphlet. As well, given the death-denying Canadian culture, social workers suggested changing the vocabulary of the pamphlet and poster to appeal to a broader audience, using the words "gravely ill" instead of "dying".

Social workers also explored options for facilitating tool use and explored how their own relationships with caregivers affected desired tools and messages. For example, although active KT strategies are associated with increased positive outcomes in the literature (DiCenso, et al., 2002), social workers preferred pamphlets as they believed them to be better suited to their needs. While notions of evidence, facilitation and context were explored in Chapter 2 specifically, similar themes were discussed in relation to constraints of time and space in Chapter 3.

4.2.3   *Implications of Time Geography- Constraints of time and space in CCB KT*

There was evidence of all three of Hägerstrand's (1975) time geography constraints (authority, capability and coupling) according to social worker reports of tool use. These constraints were evident in: the program features and application process of the CCB; the social workers involvement with the CCB, and; the social workers' relationship with the caregivers. For example, authority constraints, or those imposed by structural elements, included the nature of CCB application processes and remuneration details. Caregivers were only eligible for eight weeks of leave, and thus needed to consider when to take the CCB in order to utilize the full amount at the best time possible according to their care recipients' needs. Capability constraints, or the constraints imposed by the physical limitations of space and time, were often discussed by social workers in reference to where they placed the KT tools for best uptake. Finally, coupling

constraints, or the collaborations between individuals and resources, were exemplified by how social workers utilized the KT tools in conversations with caregivers according to the caregiver's readiness to discuss end-of-life planning. A more detailed examination of all the constraints identified was presented in Chapter 3.

Given the effects of time and space acting as potential barriers to effective use of the CCB KT tools and translation of knowledge about the CCB, this research suggests that broadening opportunities for CCB KT is necessary. Information about the CCB should be made available across a greater number of physical locations, as well as be facilitated by more stakeholders earlier on in the disease prognosis, and potentially before palliative diagnosis. Again, opportunities for accomplishing this are discussed at length in Chapter 3, and Figure 3.1, and also presented briefly in the *Wider Relevance* section of this chapter.

4.3   Study Limitations

This research was conducted through a number of separate data points, including: a qualitative messaging survey (*n*= 16); a focus group (*n*= 8); key informant interviews (*n*= 3), and; participant interviews (*n*= 8). The qualitative messaging survey and focus groups were a national sample, with social workers representing a number of different provinces and care locations. However, the key informant interviews and participant interviews were sampled from the Greater Toronto Area (GTA). As such, the tools were only used and refined, as explored in Chapter 3, within the province of Ontario, and in the relatively specific area of the GTA. As a result, the results of this study have limited national generalizability. Likewise, there is a lack of rural social worker representation. Canada is geographically vast, and although a majority of the population is concentrated in urban communities, approximately 20% of the population resides

in rural areas (HRSDC, 2011). Exploration of how rural social workers would translate knowledge about the CCB is needed. Finally, although social workers from a variety of practice locations, including hospice, hospital and community, were sampled for the qualitative messaging survey and the focus group, there was only one community social worker interviewed for the tool piloting stage. Given this, the role of community social workers in translating knowledge about the CCB, and users of the KT tools, should be explored in greater depth.

The lack of formal evaluation of the CCB tools is another limitation of this study. Knowledge translation advocates for effective translation strategy development, ending with tool implementation, monitoring and evaluation prior to large-scale dissemination (Graham, et al., 2006). While social workers reported that they viewed the knowledge tools to be successful, a formal evaluation would provide substantive proof. Opportunities for implementing a formal evaluation are explored in the future research direction section of this conclusion.

4.4   Policy Contributions

The findings presented in this manuscript indicate the HPC policy-makers should consider potential barriers to accessing palliative care services and supports according to constraints of time and space. Given the referral process, the taboo nature of HPC, the eligibility criteria of the CCB, and other constraints discussed in both chapters 2 and 3, access to the CCB is limited. At the moment, caregivers must attempt to identify when their care recipients are likely to be nearing the last eight weeks of life, in order to fully utilize the CCB. However, given the lack of formal HPC systems, and the subsequent variety of referral patterns and accesses to supports, caregivers may experience trouble in finding out about the CCB in time to apply. As such, recommendations for improving CCB policy include: broadening the eligibility criteria to allow

caregivers to access it earlier in the disease trajectory, and; extending the amount of time allowed for eligible candidates. These recommendations have been suggested in light of the CCB KT barriers, but also documented in other CCB evaluation research (Williams, et al., 2010). Furthermore, similar policy recommendations can be made to the broader HPC field.

The temporal barrier to palliative care has been documented extensively in the HPC literature (Osta, et al., 2008). Researchers agree that palliative care services are often made available too late in the palliative care period. As such, approximately 70% of Canadians do not have access to HPC (Carstairs, 2010). Currently, the definition of HPC does not have a temporal element associated with it; Health Canada (2009) states that HPC is focused on "achieving comfort and ensuring respect for the person nearing death and maximizing quality of life for the patient, family and loved ones" (n.p.). However, many services, including the CCB, are defined according to patient's months left to live. For example, caregivers are not eligible for the CCB unless their care recipient is at risk of death within the following six months (Service Canada, 2011). Difficulties in prognostication, including the biomedical unwillingness to move from a cure to care prognosis, and rapidly changing care trajectories, mean that many care recipients' become eligible for HPC too late to access many services. More clarity around HPC definitions is being demanded by advocates (Cartsairs, 2010); this research presents a case for exploring the need for including, and broadening, temporal elements of eligibility requirements.

4.5   Research Contributions

4.5.1 KT Literature

Intervention and knowledge translation methodologies have grown to include a small body of literature that highlights the importance of stakeholder input in intervention strategy

design (Jacobson, Butterill, & Goering, 2003; Bowden, et al., 2005; Graham, et al., 2006). However, although the theoretical importance of including stakeholders as knowledge brokers has been explored (Ward, House & Harmer, 2009; Duncan, et al., 2008; St-Cyr Tribble, 2008), researchers have yet to create systematic strategies for gathering stakeholder input. This research presents a unique methodology for gathering stakeholder input in KT strategies. In particular, it presents methods for gathering stakeholder input on preferred messages, tool types and opportunities for tool refinement. Although this methodology can be applied to other areas of research, the results specific to HPC and caregiving also provide important contributions to the research and policy community.

Caregiving landscapes in Canada have changed as the location of care has shifted, for the most part, from institutions to the private home (Wilson, et al., 2004). This has put much of the onus on informal caregivers in order to understand the needs of care recipients, and access knowledge and formal support through different locations and professionals. As such, informal caregivers have been described as consumers in the literature (Longo, 2005; Gavin & Evans, 2008) and presented as both consumers and producers of care in this research. Knowledge translation has reacted to the consumer nature of community-based patient-centered care, with the introduction of multiple KT strategies, including the use of decision aids to help guide caregiver and patient decisions, and consumer health summaries to inform new caregivers on treatment options (Tugwell, et al., 2007). Informal caregivers have been the focus of such KT strategies and, they, unlike formal health care providers (Nishikawa, 2011), have not been described as knowledge workers. Health care professionals in general (Nishikawa, 2011), and social workers in particular (Parton, 2008), have been described as knowledge holders and workers who influence access to and quality of care, based on their knowledge base. This is

problematic, given the fact that coupling, capability and authority constraints informed by informal caregivers influence KT and program uptake from health professionals, as shown in this research study. The role and scope of informal caregivers as knowledge workers should be explored in future informal caregiving research. For example, the locations where caregivers typically reside, according to their demographic profile, has spatially mapped been identified by Giesbrecht et al., (2009). The possibility of targeting these geographic areas for HPC KT strategies could be further explored.

Finally, this research contributes to the body of literature on the specific role of informal caregivers in HPC. Particular constraints to accessing services and translating knowledge to hospice palliative caregivers are described in both chapters. The results confirm research that indicates that KT during end-of-life care is difficult (Crooks, et al., 2007). Furthermore, the results indicate new considerations of why KT is difficult according to Hägerstrand's (1975) time geography constraints. Researchers working in HPC, or other fields where care needs and access to services is strongly linked to temporal elements such as prognosis, may consider applying time geography in an effort to illustrate and describe complex care access and KT scenarios.

4.5.2   *Geography Literature*

Beyond indicating the importance of geography in knowledge translation, this thesis identifies and contributes to the literature around a possible new domain of geography- the geography of (health) knowledge. Discourses on the geography of knowledge have traditionally related to the field of economic geographies and innovation diffusion across spatial locations (Ibert, 2007). Dissemination of knowledge has also been explored in the context of power and

geopolitics (Driver, 2003). However, although many geographers have explored health care issues through a geographical lens, including problems of accessibility and awareness (Luginaah, 2009), few health researchers have engaged with knowledge geographies in formal or consistent manners (Davies, Williamson & Day, 2004). The field of study of health knowledge/s has been recently explored as a special issue in the geographical journal *Health and Place* (2004). In codifying the field as Geographies of Health Knowledge/s, the authors suggest that there is an important tension between singular and plural knowledges, including the production of absolute truth knowledges and, the power of holding knowledge among clinicians, as well as the ability for knowledges to be produced and remain outside of formal professional contexts in health care. Finally, the editors argue that preliminary literature on geographies of health knowledge/s should explore the places and practices of knowledge creation and dissemination in health care (Davies, Williamson & Day, 2004).

The research presented in this thesis contributes to the geographies of health knowledge/s by exploring the translation of knowledge from health professional social workers, to client family caregivers. In particular, it explores issues including: navigation of the health care system and referral processes; cultural barriers to accessing information and programs, and; effects of program features on knowledge translation, including preferred messages, tool types and facilitation. In translating knowledge about the CCB and using the KT tools, social workers applied their absolute health knowledges, including knowledge of the CCB application process, and knowledge of their institutional workplace practices. As well, they negotiated alternative knowledges, including using their expertise to assess caregiver readiness to discuss the palliative prognosis and access support programs. Other researchers working within the field of health geography and exploring program access and uptake may consider exploring similar issues.

4.6   Future Research Directions and Conclusions

As described in the limitations section, the PARIHS framework does not measure actual tool success, although formal evaluations are preferred in KT strategies (Graham, et al., 2006). A formal evaluation study on the CCB KT tools developed can be accomplished through application of the *Theory of Planned Behaviour* (TpB) later on in the research process. Given the fact that HRSDC does not release CCB application data, actually measuring increased CCB application rate changes pre- and post- tool implementation is not possible. Hence, the TpB allows intervention strategies to be evaluated based on satisfaction and intent to change behavior, which has been clearly correlated to actual change in behavior and awareness (Ajzen, 1991). Through assessing tool satisfaction and intent to use, actual use and behavior change can be hypothesized fairly rigorously (Ajzen, 1991). After this initial research, further assessment will be given to the possibility of using the TpB in any additional future KT research on the CCB.

As this research suggests, broadening CCB KT to a greater number of physical locations and to more stakeholders is necessary given the constraints and KT barriers discussed in Chapters 2 and 3. Implementing a similar methodology with other identified stakeholder groups, including nurses, physicians, employers and the general public (Giesbrecht, et al., 2009), will allow for similar KT tool development and refinement. Anticipated barriers to implementing the KT tools and translating knowledge about the CCB in other locales, and with other stakeholder groups, can also be assessed by implementing Hägerstrand's (1975) time geography theory.

This thesis presents some novel methodologies for implementing an integrated KT approach through use of multiple data points to collect stakeholder input. In addition, this thesis presents an example of the usefulness of time geography in KT, thus arguing for a wider

awareness of temporal and spatial barriers to intervention development and implementation. The

concepts, methodologies, and results explored herein may be considered by those conducting KT

research, as well as geographers interested in health research, policy-making and program

planning.

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Science and Medicine,* 68, 1752-1758.

APPENDIX A: QUALITATIVE MESSAGING SURVEY

Compassionate Care Benefit Online Messaging Survey

Before You Begin

This survey is being conducted as part of a national evaluation of Canada's Compassionate Care Benefit (CCB) program. This study has been running since 2006 and is funded by the Canadian Institutes of Health Research. It involves researchers from a number of institutions. Dr. xxxxxxxx Professor at xxxxxxxxxxxxxxx, is the primary researcher.

The CCB provides income assistance and job security to family members who take temporary leave from employment to care for a terminally ill person. Our overall purpose is to make policy-relevant recommendations for the CCB. In 2007-08 we conducted interviews with 50 front-line palliative care providers and administrators from five targeted provinces: British Columbia, Manitoba, Ontario, Quebec, and Newfoundland & Labrador. We have also conducted interviews and focus groups with members of two other key stakeholder groups: family caregivers and human resources personnel. Our research points to the fact that there is generally a lack of awareness about the CCB. This is problematic as many of the family caregivers we spoke with indicated that they expected to learn about the CCB from groups such as front-line palliative care workers and administrators along with human resources professionals from their workplaces. Generally, a significant gap exists in information transfer about the CCB.

Our research team is currently developing strategies to overcome the information gap identified above. In order to develop appropriate information tools, we need to know from you and your colleagues which 'messages' about the CCB are most relevant to your practice and the questions that family caregivers are likely to ask you. By messages we are referring to specific facts and details about the CCB program.

In this online survey we ask that you evaluate a limited number of potential messages about the CCB in terms of their usefulness to you in your role as a front-line palliative care provider or administrator. **We expect that it will take no longer than 5 minutes to complete.** Our team will then use this information to assist with tailoring the messages that we disseminate about the CCB and our own research to people in positions similar to your own.

Before you get started, we'd like to assure you that this survey has been approved by the research ethics board at McMaster University If you have any concerns or complaints you may contact the McMaster Research Ethics Secretariat at 905-525-9140 ext. 23142, or email at ethicsoffice@mcmaster.ca. You can request a copy of the survey findings by including your e-mail address at the end. At the start of the survey we ask for a bit of background information. We are gathering this to better understand who it is we are hearing from, but we will not publish or present any information identifying survey respondents. This survey is being run over

a secured and encrypted server and as such there is also no way for others to identify the IP addresses of participants, thus allowing us to maintain confidentiality. Note that your employer has not been contacted about your potential participation in this study. By filling out this survey, you are consenting to participate.

Into which of the categories below does your current job primarily fall (please check one):

○ Oncologist

○ Family doctor

○ Administrator

○ Nurse

○ Other

If you answered 'other' in the previous question, please enter your occupation here:

Answer : [   ]

For how many years have you been in your current position:

Answer : [   ]

For how many years have you specialized in, or been involved with providing, palliative care:

Answer : [   ]

If applicable, in which province/country did you complete your professional training (list more than one if necessary):

Answer : [   ]

In which province do you presently work:

Answer : [   ]

Rating The Messages

Below is a listing of messages about the CCB, which is administered as a special benefit by the Employment Insurance (EI) program. They are all accurate, so please do not be concerned about evaluating them in this regard. We ask that you review them and then indicate for each its usefulness to you in your role as a front-line palliative care provider and/or administrator.

The goal of the CCB is to enable employees to take a temporary secured leave from work to provide care or support to a gravely ill family member at risk of dying.

☐ Highly useful to someone in my position (e.g., I would absolutely pass this message along or utilize it in my practice)

☐ Somewhat useful to someone in my position (e.g., I would likely pass this message along or utilize it in my practice)

☐ Neither particularly useful or not useful to someone in my position (e.g., I may or may not pass this message along or utilize it in my practice)

☐ Most likely not useful to someone in my position (e.g., I would be unlikely to pass this message along or utilize it in my practice)

☐ Definitely not useful to someone in my position (e.g., I would never pass this message along or utilize it in my practice)

The CCB program views support to a family member to be: (1) providing psychological or emotional support; (2) arranging for care by a third party; and/or (3) directly providing or participating in the care.

☐ Highly useful to someone in my position

☐ Somewhat useful to someone in my position

☐ Neither particularly useful or not useful to someone in my position

☐ Most likely not useful to someone in my position

☐ Definitely not useful to someone in my position

The CCB program adopts a broad view of those considered to be a 'family member.' Program recipients can care for a gravely ill: (1) family member; (2) spouse or common-law partner's family members; or (3) person who is considered 'like' a family member (for instance a close friend or neighbour).

☐ Highly useful to someone in my position

☐ Somewhat useful to someone in my position

☐ Neither particularly useful or not useful to someone in my position

☐ Most likely not useful to someone in my position

☐ Definitely not useful to someone in my position

The CCB can be used to care for or support a family member who is gravely ill and at risk of dying regardless of where that care recipient lives. Program recipients and dying individuals can be separated by provinces or even countries.

☐ Highly useful to someone in my position

☐ Somewhat useful to someone in my position

☐ Neither particularly useful or not useful to someone in my position

☐ Most likely not useful to someone in my position

☐ Definitely not useful to someone in my position

To receive the CCB, an EI application must be made to the program online or in person at a Service Canada Centre.

☐ Highly useful to someone in my position

☐ Somewhat useful to someone in my position

☐ Neither particularly useful or not useful to someone in my position

☐ Most likely not useful to someone in my position

☐ Definitely not useful to someone in my position

Successful applicants must be eligible for Employment Insurance and can include self-employed individuals. This currently excludes most part-time employees, as well as those who have not worked the minimum required number of hours.

☐ Highly useful to someone in my position

☐ Somewhat useful to someone in my position

☐ Neither particularly useful or not useful to someone in my position

☐ Most likely not useful to someone in my position

☐ Definitely not useful to someone in my position

CCB eligibility requires applicants to demonstrate their regular weekly earnings from work have decreased by more than 40%, and that they have accumulated a minimum of 600 insured hours in the previous 52 weeks or since the start of their last claim.

☐ Highly useful to someone in my position

☐ Somewhat useful to someone in my position

☐ Neither particularly useful or not useful to someone in my position

☐ Most likely not useful to someone in my position

☐ Definitely not useful to someone in my position

When requesting benefits through the CCB program, applicants must provide proof showing that the ill family member needs care or support and is at risk of dying within 26 weeks.

☐ Highly useful to someone in my position

☐ Somewhat useful to someone in my position

☐ Neither particularly useful or not useful to someone in my position

☐ Most likely not useful to someone in my position

☐ Definitely not useful to someone in my position

Applications for the CCB should be filed as soon as employment stops as delay in filing a claim beyond 4 weeks after the last day of work may cause loss of benefits.

☐ Highly useful to someone in my position

☐ Somewhat useful to someone in my position

☐ Neither particularly useful or not useful to someone in my position

☐ Most likely not useful to someone in my position

☐ Definitely not useful to someone in my position

If an application to the CCB program is successful, payments will be issued within 28 days from the date the claim was filed.

☐ Highly useful to someone in my position

☐ Somewhat useful to someone in my position

☐ Neither particularly useful or not useful to someone in my position

☐ Most likely not useful to someone in my position

☐ Definitely not useful to someone in my position

CCB recipients are required to undergo a two week waiting period before payments begin.

☐ Highly useful to someone in my position

☐ Somewhat useful to someone in my position

☐ Neither particularly useful or not useful to someone in my position

☐ Most likely not useful to someone in my position

☐ Definitely not useful to someone in my position

A maximum of 6 weeks of benefits through the CCB program are payable.

☐ Highly useful to someone in my position

☐ Somewhat useful to someone in my position

☐ Neither particularly useful or not useful to someone in my position

☐ Most likely not useful to someone in my position

☐ Definitely not useful to someone in my position

The basic CCB rate is 55% of average insured earnings up to a yearly maximum insurable amount of $44,000. This means a maximum payment of $468 per week.

☐ Highly useful to someone in my position

☐ Somewhat useful to someone in my position

☐ Neither particularly useful or not useful to someone in my position

☐ Most likely not useful to someone in my position

☐ Definitely not useful to someone in my position

The CCB ends when the: (1) 6 weeks have been paid out; (2) gravely ill family member dies or no longer requires care or support; (3) 26-

week period with in which successful applicants must take their leave has expired; or (4) maximum payable on all EI claims within a specific period has been exhausted.

☐ Highly useful to someone in my position

☐ Somewhat useful to someone in my position

☐ Neither particularly useful or not useful to someone in my position

☐ Most likely not useful to someone in my position

☐ Definitely not useful to someone in my position

If multiple EI-eligible family members are applying to care for the same dying person, the 6 weeks of the CCB must be split among them.

☐ Highly useful to someone in my position

☐ Somewhat useful to someone in my position

☐ Neither particularly useful or not useful to someone in my position

☐ Most likely not useful to someone in my position

☐ Definitely not useful to someone in my position

Selecting The Most Important Messages

We'd now like you to tell us which 3 of the messages you just reviewed are clearly the most important for you or someone in your position to be aware of. Please place a check mark beside these messages.
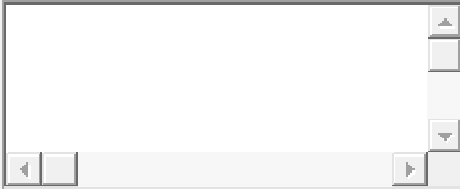
☐ The goal of the CCB is to enable employees to take a temporary secured leave from work to provide care or support to a gravely ill family member at risk of dying.

☐ The CCB program views support to a family member to be: (1) providing psychological or emotional support; (2) arranging for care by a third party; and/or (3) directly providing or participating in the care.

☐   The CCB program adopts a broad view of those considered to be a 'family member.' Program recipients can care for a gravely ill: (1) family member; (2) spouse or common-law partner's family members; or (3) person who is considered 'like' a family member (for instance a close friend or neighbour).

☐   The CCB can be used to care for or support a family member who is gravely ill and at risk of dying regardless of where that care recipient lives. Program recipients and dying individuals can be separated by provinces or even countries.

☐   To receive the CCB, an EI application must be made to the program online or in person at a Service Canada Centre.

☐   Successful applicants must be eligible for Employment Insurance and can include self-employed individuals. This currently excludes most part-time employees, as well as those who have not worked the minimum required number of hours.

☐   CCB eligibility requires applicants to demonstrate their regular weekly earnings from work have decreased by more than 40%, and that they have accumulated a minimum of 600 insured hours in the previous 52 weeks or since the start of their last claim.

☐   When requesting benefits through the CCB program, applicants must provide proof showing that the ill family member needs care or support and is at risk of dying within 26 weeks.

☐   Applications for the CCB should be filed as soon as employment stops as delay in filing a claim beyond 4 weeks after the last day of work may cause loss of benefits.

☐   If an application to the CCB program is successful, payments will be issued within 28 days from the date the claim was filed.

☐   CCB recipients are required to undergo a two week waiting period before payments begin.

☐   A maximum of 6 weeks of benefits through the CCB program are payable.

☐   The basic CCB rate is 55% of average insured earnings up to a yearly maximum insurable amount of $44,000. This means a maximum payment of $468 per week.

☐   The CCB ends when the: (1) 6 weeks have been paid out; (2) gravely ill family member dies or no longer requires care or support; (3) 26-week period with in which successful

applicants must take their leave has expired; or (4) maximum payable on all EI claims within a specific period has been exhausted.

☐   If multiple EI-eligible family members are applying to care for the same dying person, the 6 weeks of the CCB must be split among them.

Do you have any further comments (e.g. suggested changes to the wording of key messages, suggestions for venues we should target when disseminating the most important and useful messages)?

Would you like to receive a report of our findings? If so, please include your e-mail address here:

Answer :

Submit

APPENDIX B: INTERVIEW SCHEDULES

Focus Group and Key Informant Script- Creating the informational resource(s)

Sample question schedule

Main theme	Questions	Probes
Introductions and background	-What is your name? -How long have you been working as a social worker? -Where do you work as a social worker (urban/rural? Hospital, community, ect?)	-set up rapport- general discussion re job/life experiences
Palliative caregiving	-Have you had experience providing social work for people and their families nearing the end-of-life?	-What sort of experiences? -What sort of role did you play?
CCB knowledge	-Do you have any knowledge about the Compassionate Care Benefit	-please describe -have you had any experience informing someone about it? -have you helped someone apply for it? -discuss elements of the CCB with any social workers aware/not aware
Knowledge translation – defining	-Is anyone familiar with knowledge translation?	-work to define it -discuss the role of the knowledge user -discuss the point of this focus group again
Knowledge informational resource (s)- our examples	-I am going to show some different examples of knowledge informational resources that we have created about the CCB, and we can have a discussion about them	- run through informational resources, talking about what they like, and do not like, aesthetics, content, how they would be used by the social workers, anything that is not shown that would be appropriate, ect
Knowledge informational resource (s)- preferences	-what types of informational resource (s) do you prefer to have as social worker?	-do you prefer concise, take-away messages? -case studies, video, pamphlet? Ect
Using the messages	-We ran a messaging survey and had the following messages chosen as key	-Are there any messages missing in your view? -Are the messages chosen

	elements to market about the CCB. Knowing these messages, do you have any additional comments about informational resource development?	appropriate for the informational resource type?
Dissemination strategies	-Are there any specific venues for dissemination strategies we should identify?	-Where should we send the informational resources to? -What should we include when we send the informational resources? Write-ups?
Wrap up- additional questions/concerns	-anything else you would like to add/ think is important to understand when creating a informational resource about the CCB for your stakeholder group?	

Participant Interviews – Evaluating the informational resources

Sample question schedule

Main theme	Questions	Probes
Introductions and background	-What is your name? -How long have you been working as a social worker? -Where do you work as a social worker (urban/rural? Hospital, community, ect?)	-set up rapport- general discussion re job/life experiences
Reviewing the informational resources	-So, these were the different kinds of informational resources we used	-make sure everyone received the appropriate informational resources, contents
Utilizing the informational resources - sharing	have you shared the informational resource(s) with anyone	-which informational resource did you use the most? -who did you share the informational resource with? -did they find the informational resource easy to use? -did they have any additional comments about the informational resource?
Utilizing the informational resources - helping to apply	-Did you use the informational resources with someone who	-did the informational resources help them in their

	later applied for the CCB?	application process?
Utilizing the informational resource(s)- other circumstances	-Did you use the informational resource(s) for any other purpose?	*If from SCOPE group*- Do you think that being involved in the informational resource creation helped you utilize the informational resource (s) more? Were there any drawbacks to being involved in the informational resource creation?
Utilizing the knowledge informational resource (s)- pros of the informational resource (s)	-What did you like about the informational resource (s)?	-messages? - informational resource type? -aesthetics? -anything else?
Utilizing the knowledge informational resource (s)- cons of the informational resource (s)	-What did you not like about the informational resource (s)?	-messages? - informational resource type? -aesthetics? -anything else?
Other informational resource specifics	Accessibility of the informational resource (s)	-Where did you keep the informational resource (s)? -How did you distribute them to clients and/or co-workers -Does the format of the informational resource (s) allow for easy reproduction/ sharing→ are they accessible and sustainable?
Dissemination strategies	-Are there any specific venues for dissemination strategies we should identify?	-Where should we send the informational resource (s) to? -What should we include when we send the informational resource (s)? Write-ups? -Where do you usually receive your informational resources from? -Do you usually share your resources with co-workers? How? -Do you usually share your resources with clients? How?
Wrap-up- additional questions/concerns	Any additional questions/concerns/comments?	