Spatially informed knowledge translation: Informing potential users of Canada's Compassionate Care Benefit

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A B S T R A C T

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

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Introduction

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

Here, we adopt a specific model proposed by Graham et al. (2006) that envisions knowledge translation as a cycle of moving research knowledge into action. This ‘knowledge-to-action (KTA)’ cycle involves numerous phases to successfully achieve knowledge translation (see Graham et al., 2006). For the purpose of this paper, we focus on a segment of the KTA cycle that begins with the identification of a problem (the knowledge) and ends with the implementation of an intervention strategy (the action). After having knowledge about a problem or issue, Graham et al. (2006) suggest the next phase to focus on is its adaptation to local contexts. Here, attention is given to the value and usefulness of particular knowledge to individuals or groups in specific settings and circumstances with consideration given to their activities so that knowledge can become tailored to their context (Graham et al.,
The next phase involves assessing, identifying, and targeting any potential barriers to knowledge use (Graham et al., 2006; Wallin, 2009). KTA efforts typically focus on organizational barriers at this stage (Davis et al., 2003); however, barriers relevant to ways in which information is presented to end users (Formoso, Marata, & Magrini, 2007) and formatted across audiences (Boaz & Hayden, 2002) are also worthy of consideration. The final phase involves the development and implementation of an intervention strategy to promote awareness and implement knowledge (Graham et al., 2006). These phases in the KTA cycle are not linear or static, but rather dynamic and can influence or be influenced by all other aspects of the larger KTA process (Graham et al., 2006).

In this paper we present on our engagement with the KTA cycle through having undertaken a mixed-method analysis to address an applied problem pertaining to Canada’s Compassionate Care Benefit (CCB). The goal of the CCB program is to enable family members to take a temporary secured leave from employment to care for a terminally ill person. The findings of various studies and polls have consistently reported that few Canadians are aware of the CCB’s existence and suggest that, as a result, its uptake is limited (CCS, 2008; Crooks, Williams, Stajduhar, Allan, & Cohen, 2007; HRSDC, 2007; Osborne & Margo, 2005). Since 2006, we have been conducting a formal evaluation of the CCB program from the perspective of family caregivers. Our KTA effort, summarized in Fig. 1, was motivated by our own and others’ recognition that, problematically, information about this program is not reaching potential users. In response to this knowledge (i.e., that information about the CCB is not effectively reaching Canadians and potential program users) we developed an innovative three-part analysis to adapt information about the program to local contexts and assess potential barriers family caregivers may experience in accessing such information. The innovation in our engagement with the KTA cycle comes from the spatial approach we have devised. The need to undertake such efforts, both in terms of research and knowledge translation, is underscored by calls to improve the utilization of family caregiver research to enhance evidence-based decision-making and information dissemination (e.g., Lynse, 2007).

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

### Background

In response to international concerns regarding the increased responsibilities being placed upon family caregivers providing care for dying relatives, many governments from the developed world have initiated programs aimed at alleviating some of the caregiving burden. These programs range from direct or indirect financial compensation to labour policy strategies and legislations (Lynse, 2007; Williams, Crooks, Stajduhar, Allan, & Cohen, 2006). Resembling similar programs found in Norway, Sweden and the Netherlands, the Canadian government implemented the CCB program in January 2004. The primary goal of the CCB is to provide income assistance and job security to family members and close others who take a temporary leave from their regular employment to care for a terminally ill person at risk of dying within 26 weeks. Although the maximum total length of the caregiving period supported by the CCB is 8 weeks, the first 2 weeks are unfunded and known as the ‘waiting period’. Therefore, over a 6-week period successful applicants of the CCB can receive up to 55% of their average insurable earnings, to a maximum of CDN$435 per week, to provide physical, psychological, and/or emotional care or care coordination (HRSDC, 2008a). As the CCB is an Employment Insurance (EI) program, where EI is a contributory benefits scheme paid into by workers, particular labour market participation criteria apply. As such, successful applicants are required to have accumulated 600 insurable hours over the preceding 52-week timeframe and demonstrate that their weekly earnings have decreased by more than 40% as a result of having to provide care (HRSDC, 2008a). Further, applicants must meet the definition of ‘family

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**Fig. 1.** Engagement with the knowledge-to-action cycle.

<table>
<thead>
<tr>
<th>Identifying a Problem</th>
<th>Adapting Knowledge to Local Contexts</th>
<th>Assessing Barriers</th>
<th>Select, Tailor, and Implement Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Knowledge:</strong> Reports indicate a lack of public knowledge about the CCB.</td>
<td><strong>Knowledge:</strong> Our research confirms concerns regarding public knowledge.</td>
<td><strong>Action:</strong> Development of an analysis to determine how to most effectively get CCB information to potential applicants.</td>
<td><strong>Action:</strong> Mobilize the findings of the three-part analysis to inform decision-makers of how to disseminate CCB information in a thoughtful and strategic way.</td>
</tr>
<tr>
<td><strong>Barriers:</strong></td>
<td><strong>Contexts:</strong></td>
<td><strong>Barriers:</strong></td>
<td><strong>Intervention:</strong></td>
</tr>
<tr>
<td><strong>Identification:</strong></td>
<td><strong>Adaptation:</strong></td>
<td><strong>Assessment:</strong></td>
<td><strong>Select, Tailor, and Implement:</strong></td>
</tr>
<tr>
<td><strong>Knowledge:</strong></td>
<td><strong>Action:</strong> Employ a three-part spatially informed analysis to identify the most effective pathways to increase knowledge of the CCB among (potential) caregivers and citizens.</td>
<td><strong>Action:</strong> Through this analysis, identify barriers that may inhibit potential users of the CCB from gaining access to information.</td>
<td><strong>Action:</strong></td>
</tr>
</tbody>
</table>
Although the Canadian Government’s implementation of the CCB is seen as a strong first step towards supporting family caregivers, successful uptake of the benefit has been significantly low in its first years of existence (Osborne & Margo, 2005). Estimates show that more than one million Canadians are caring for dying loved ones, and this number is expected to rise in accordance with the nation’s rapidly aging population (CHPCA, 2006). However, Human Resources and Social Development Canada (HRSDC), the federal department responsible for administering the CCB, reports that for the 2006/07 fiscal year only 5676 successful CCB claims were made nationwide (HRSDC, 2008b). The low uptake of the CCB thus contradicts what we know about reliance on family caregivers. Other main barriers referenced as causes for this low uptake, from more program-specific barriers, there exists a more critical obstacle to the CCB’s successful uptake: the general lack of public awareness regarding the CCB’s existence (CCS, 2008; HRSDC, 2007). Specifically, family caregivers are not gaining access to information about the CCB program, and therefore are unable to utilize it during the caregiving period.

A recent poll conducted by the Canadian Cancer Society (2008) suggests that a majority of Canadians believe they will be called upon to care for an ill loved one at some point in their life. However, of the 1015 respondents, close to three in four were not aware of the CCB’s existence, this in spite of expressed concern regarding the financial burden associated with caregiving (CCS, 2008). Further, a survey of 1520 Canadians conducted by HRSDC (2007) about the CCB found that 42% were not at all aware they were able to receive EI benefits to take time off work to care for a dying family member. Of the 177 respondents who had taken time off work to do so: 40% took an unpaid leave, 23% negotiated arrangements with employers, many drew upon paid vacation (18%), family (12%) or sick (9%) leaves, 5% quit their jobs, while only 2% used the CCB as an option. When the 173 people from this respondent group of 177 who had not used the CCB were asked why they had not done so, 56% explained it was because they were unaware of the program’s existence. These statistics clearly indicate lack of awareness to be a major obstacle to the successful uptake of the CCB. Although efforts put forth to improve specific policy criteria, such as extending the length of the benefit or increasing flexibility surrounding the prognosis of death (see Williams et al., 2006), will most likely improve program uptake, they will be of little benefit until Canadians gain access to information and become aware that such supports exist. Therefore, an important first step in improving the program’s successful uptake involves addressing the paucity of public knowledge regarding the CCB.

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

**Evaluative study overview**

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

Since undertaking the larger evaluative study, key reports have been released (specifically CCS, 2008 and HRSDC, 2007) emphasizing the Canadian public’s lack of knowledge about the CCB. These reports confirm emerging findings from the current study and also from our pilot research (Crooks et al., 2007; Williams et al., 2006). Our engagement with the KTA cycle comes as a result of our desire to address this applied problem as researchers in order to generate actions which will promote information dissemination about the CCB program. In the three following sections, we report separately on each spatially informed analysis that was undertaken specifically for this KTA effort. Each analysis has a distinct set of methods and findings that, when examined together, yield important information on how best to inform Canadians, and ultimately family caregivers, about the existence of the CCB.

**Part one: Determining who is likely to be a CCB-eligible Canadian**

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

Firstly, creating the demographic profile of a likely CCB user began with a search of the PubMed Central database in order to identify North American studies that used respondent groups of family, or informal, caregivers using relevant search terms such as ‘family caregiver’ and ‘informal caregiver.’ The search was limited to articles published after 1999, which yielded just over 150 hits. The PubMed results were then scanned in order to identify the most recent studies that had used a minimum sample size of 25 caregivers and contained a clear table or description of respondents’ demographic characteristics. Due to the limited number of Canadian studies identified, research from the United States was included in the articles selected for the demographic profile; this, however, was not seen to jeopardize the reliability of the compiled profile given the similarities in the populations and family caregiving demands of these two countries. In addition to these articles, grey literature reports already held by the team were also reviewed for sample size and demographic information. Upon review of the first 10 most recent studies with the largest sample sizes and most respondent detail (Canadian \( n = 7 \); United States \( n = 3 \)), complete confirmation regarding particular variables to be included in our demographic profile was found and thus further literature was not reviewed. The studies’ respondent sizes ranged from 27 (Mackenzie, Smith, Hasher, Leach, & Behl, 2007) to 501 (Hollander, Chappell, Havens, McWilliam, & Miller, 2002), with an average of 225. The most important study identified was Health Canada’s (2002) National Profile of Caregivers, due to its large sample size \( (n = 471) \) and pan-Canadian context.

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

Findings

Unsurprisingly, family caregivers tend to be female, with an average of 72.4% of respondents across the included studies meeting this criterion (see Table 1). The majority fell over the age of 45 years; although it is common for family caregivers to be seniors, we have limited our age to a maximum of 65 years to emphasize the CCB’s employment requirement. Education was variously defined within the literature; however, in all studies the majority of participants had minimally completed high school. The most common relationship between family caregiver and recipient was spousal, averaging 49%. Lastly, full-time employment was included as a proxy for the CCB’s workforce participation requirement.

Part two: Determining where likely CCB-eligible Canadians are located

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

Method

Data for the spatial analysis were derived from the 2001 Canada Census at the Census tract (CT) scale. CTs define relatively stable geographic areas with populations of 2500–8000, averaging 4000 residents per tract (Statistics Canada, 2007). Data were retrieved for each of the five variables identified in the demographic profile (see Table 1) and the ratio to the total population was determined, thus allowing us to rank the CTs by fit with the demographic profile. To generate the ranking, the standardized z-score for each variable’s ratio was calculated and summed for each CT. From this, the CTs were ranked into the three categories (high, medium, and low) to identify the degree to which the population meets the specified criteria in the profile. Through the utilization of ArcInfo software, these data were then linked geographically and mapped.

Table 1

<table>
<thead>
<tr>
<th>Variable</th>
<th>Identified characteristic</th>
<th>Confirming study demographics</th>
<th>Confirming studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Female</td>
<td>Mean: 72.4% female</td>
<td>Brazil et al. (2002, 2005); Cherlin et al. (2005, 2007); Fast, Higham, Keating, Dosman, and Eales (2005); Health Canada (2002); Hollander et al. (2002); Mackenzie et al. (2007); McPherson et al. (2008); Waldrop et al. (2005).</td>
</tr>
<tr>
<td>Age</td>
<td>45–65</td>
<td>Mean: 58.5 years of age</td>
<td>Brazil et al. (2002, 2005); Cherlin et al. (2005, 2007); Hollander et al. (2002); Health Canada (2002); Waldrop et al. (2005).</td>
</tr>
<tr>
<td>Education</td>
<td>High school completed</td>
<td>Mean: 61.5% – high school</td>
<td>Brazil et al. (2002, 2005); Cherlin et al. (2005, 2007); Health Canada (2002); Waldrop et al. (2005).</td>
</tr>
<tr>
<td>Relationship</td>
<td>Married or common law</td>
<td>Mean: 14.93 years of school</td>
<td>Brazil et al. (2002, 2005); Cherlin et al. (2005, 2007); Health Canada (2002); Waldrop et al. (2005).</td>
</tr>
<tr>
<td>Employment status</td>
<td>Full time</td>
<td>Mean: 63.8% spousal</td>
<td>Brazil et al. (2002, 2005); Health Canada (2002); Mackenzie et al. (2007); McPherson et al. (2008).</td>
</tr>
</tbody>
</table>
Findings

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

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

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

Method

After having received ethics approval from Simon Fraser and McMaster Universities, perspectives about the CCB were gathered from 50 front-line palliative care providers from across the five targeted provinces of British Columbia, Manitoba, Ontario, Quebec, and Newfoundland and Labrador. These provinces were selected by the larger CCB evaluation team prior to data collection – and thus the inception of this analysis – in order to specifically represent Canada’s regional and linguistic diversity. Purposeful sampling from a variety of settings (e.g., hospital, hospice, clinic etc.) and across provider occupational groups was undertaken to acquire as much

Table 2

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social worker</td>
<td>11</td>
</tr>
<tr>
<td>Palliative care director/coordinator</td>
<td>9</td>
</tr>
<tr>
<td>Clinical/oncology/palliative nurse</td>
<td>7</td>
</tr>
<tr>
<td>Community health/home care nurse</td>
<td>7</td>
</tr>
<tr>
<td>Oncologist/physician</td>
<td>6</td>
</tr>
<tr>
<td>Chaplain/pastoral care</td>
<td>2</td>
</tr>
<tr>
<td>Counsellor</td>
<td>2</td>
</tr>
<tr>
<td>Volunteer coordinator</td>
<td>2</td>
</tr>
<tr>
<td>Facility patient care manager</td>
<td>1</td>
</tr>
<tr>
<td>National nursing officer</td>
<td>1</td>
</tr>
<tr>
<td>Nurse coordinator</td>
<td>1</td>
</tr>
<tr>
<td>Occupational therapist (home care)</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
</tr>
</tbody>
</table>
diversity in employment sectors as possible, with the goal of conducting 10 interviews in each of the five provinces (see Table 2). The strategy for recruitment involved disseminating an information letter by e-mail outlining the study purpose and who we were looking to interview. The letter was sent directly to a range of palliative and hospice organizations, hospitals, and clinics. Some participants were also recruited through investigators’ existing professional networks and those of the study’s Evaluation Taskforce. Many participants were enthusiastic about our study and actively informed other potential participants from their own professional networks, thus resulting in some further ‘snowball’ recruitment. Interested front-line palliative care providers were asked to reply via e-mail or call a toll-free number to schedule an interview at a time of their choosing to be conducted in either English or French.

Forty-eight English- and two-French language interviews were conducted via telephone from November 2007 to March 2008 by the first author. The semi-structured interviews typically lasted 30 min and inquired into participants’ perceptions of the CCB’s usefulness, barriers and facilitators to access, experiences of recommending the CCB to a client or client’s family, working knowledge of how the CCB is administered, and any suggestions for improvement. Prior to each interview, respondents were informed of their rights as a participant in a research study and provided their verbal consent to participate. Forty-nine interviews were recorded and transcribed verbatim and one was recorded through notes as the participant preferred not to be audio recorded.

Following data collection, transcripts were entered into N7™ data management software and thematic analysis was conducted. Thematic analysis is commonly used to capture dominant emergent themes in a text and requires identifying patterns within a dataset where resulting themes become categories for analysis (Fereday & Muir-Cochrane, 2006). A coding scheme that integrated both inductive and deductive perspectives was developed to reflect the broader framework of our research which shaped our interview guide as well as emergent themes from the dataset (Bradley, Curry, & Devers, 2007; Fereday & Muir-Cochrane, 2006). The scheme was created using a five-step process involving investigator triangulation: (1) review of three randomly selected transcripts to identify initial themes, (2) drafting of a coding scheme, (3) revision of the coding scheme following discussion and further transcript review, (4) coding of five transcripts, and (5) review of coded transcripts in order to refine the scheme. Specific to the current analysis, the deductive conceptual code ‘information transfer’ was created and is heavily drawn upon; a number of deductive sub-codes such as ‘client awareness of the CCB’, ‘suggestions for informing professionals of the CCB’, and ‘suggestions for improving the CCB’ also contribute. Although not prompted to identify how to inform family caregivers about the CCB, this theme consistently emerged in reviewing the transcripts, thus resulting in our application of these thematic findings to the present analysis.

Findings

Participants’ responses confirm that a major barrier to the successful uptake of the CCB is a general lack of awareness regarding the program’s existence. As expressed by a community palliative care nurse from Ontario: “...I think the biggest issue is that a lot of these people [family caregivers] aren’t even aware that it’s out there.” For some of the interviewees, they were the first people to inform a family caregiver about his/her eligibility for the program. As a palliative care coordinator from Manitoba told:

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

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

These pathways are synthesized in Fig. 3. In the remainder of this subsection we provide further details about these two dissemination pathways.

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

Participants acknowledged that formal care providers were well positioned to inform family caregivers about the CCB; however, some professionals were viewed to be better suited to do this than others. Overwhelmingly, social workers were recognized to be most suited for this responsibility and were also most likely the ones who other front-line providers would refer family caregivers to for information. Doctors, nurses, and case coordinators were also suggested as being key people to become informed and to share CCB information with family caregivers. However, many participants felt it was the responsibility of human resources personnel.
workplaces to inform employees of the CCB given that it is an EI program. Frustration was expressed about employers and human resources personnel having limited or inaccurate knowledge about the CCB, thus indicating that this group could likely benefit from gaining access to accurate information about the program. A social worker from Manitoba explained: “some of the family members I deal with, they said ‘Oh I went to my employer and said I had to take time off and nobody told me that I could do this [use the CCB].’”

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

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

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

Echoing the complexity of successfully disseminating information about the CCB to family caregivers was participants’ lack of consensus over a preferred format for receiving program details. Pamphlets providing a quick and accurate overview were the most frequently requested format as not only could they quickly inform front-line workers, but they could also be handed out to family caregivers. The second most requested format was through face-to-face information sharing via presentations, information sessions, and workshops held in workplaces and at professional conferences/meetings. Receiving information face-to-face was viewed as desirable because it provides dedicated time for learning about the CCB and also offers an opportunity to ask questions. Although e-mail was cited as the third most frequently requested format, it was rebutted by others who stated that they were “overloaded” with e-mail or that the nature of their employment did not allow regular access to a computer. In general, interviewees’ comments point to the fact that the format of information destined to inform front-line workers – and likely also human resources personnel/employers – about the CCB should reflect the diversity of occupational groups and workplaces and thus involve a variety of formats to ensure maximum exposure.

Pathway 2: Transfer of information within the community to everyone

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

The most frequently suggested method for informing the public about the CCB was through mass media. Television was overwhelmingly seen as the most effective venue to reach the public, and especially family caregivers. For example, a home care nurse in Manitoba explained that often caregivers leave their television sets on while they spend their days and nights inside the home caring, thus making this an ideal medium for reaching active caregivers. Also, as a nurse in Ontario stated:

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

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

Discussion

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

Implications for creating an information dissemination strategy

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

Considering the two distinct pathways of information sharing suggested by front-line palliative care providers allows for further tailoring of a dissemination strategy. As we outlined previously, it has been acknowledged that disseminating needed information to family caregivers must be done thoughtfully, with sensitivity to specific circumstances and needs (see Ashpole, 2004; Dunbrack, 2005). Most interviewees identified themselves as well positioned to share CCB information as they have an understanding of people’s circumstances and are able to identify when and how best to
inform family caregivers. However, potential barriers identified by the interviewees exist, whereby individual front-line care providers may not: hold accurate CCB knowledge, actively inform people about it due to the association with ‘financial need’ or a caregiver’s denial of impending death, or be available to meet with family caregivers within a meaningful timeframe to effectively share this information. Such barriers, and the potential for increasing family caregivers’ informational burden, suggest that consideration must be given to informing the general public about the CCB via community venues and media sources. In doing so, people will ideally become aware of the benefit prior to caregiving and inquire about the CCB-eligible family caregivers. However, potential barriers identified by the interviewees exist, whereby individual front-line care providers stressed the importance of disseminating information in multiple formats and through multiple venues in order to ensure maximum impact. Integrating the information sharing pathways with the demographic and spatial findings from the first two steps of the analysis adds geographic value to these findings, thereby allowing for a heightened focus on local context and the potential for spatial channels of dissemination to overcome potential barriers to achieving effective dissemination routes based on input from knowledgeable stakeholders. Lastly, the findings of our analysis are meant to result in the selection and tailoring of an implementation strategy.

**Engagement in the knowledge-to-action cycle**

The roles that family caregivers in Canada and other countries play in caring for dying individuals are generally not fully acknowledged or valued by formal health and social institutions; as such, awareness of these roles and their value must be enhanced through research utilization and knowledge translation if we are to better support them in the care they provide (Lynse, 2007). At the outset of the paper we explained that our engagement with this intervention strategy is not surprising to learn that careful thought must be attributed to the places from which information is to be disseminated and the places and people intended as recipients.

Our engagement in the KTA cycle cannot be satisfied without the dissemination gap, we believe that a dissemination strategy based on input from family caregivers and community places to the general public. Such a recommendation is consistent with the findings of the interviews, whereby interviewees stressed the importance of disseminating information in multiple formats and through multiple venues in order to ensure maximum impact. Integrating the information sharing pathways with the demographic and spatial findings from the first two steps of the analysis adds geographic value to these findings, thereby allowing for a heightened focus on local context and the potential for spatial channels of dissemination to overcome potential barriers to achieving effective dissemination routes based on input from knowledgeable stakeholders. Lastly, the findings of our analysis are meant to result in the selection and tailoring of an intervention in order to overcome the applied problem of focus.

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

Our engagement in the KTA cycle cannot be satisfied without the implementation of the suggested intervention strategy. As researchers we are not, however, in a position to roll-out a national CCB advertising strategy; we thus view advocacy as the best way to advance this KTA effort. The findings of this analysis have been shared with members of the Evaluation Taskforce who have expressed an interest in both sharing them with others and also advocating for a strategy. Our own intent is to adapt these findings to a decision-making context and present a synthesis to HRSDC. As HRSDC is the office that administers the CCB, it is also the decision-making body that can combine these findings with their own knowledge and enact a strategy. Although our findings can inform the creation of a strategy, further details, such as the specific CCB messages for dissemination and monies to fund a campaign, are absolutely required. Thus, we view the analysis shared here as part of a larger whole that will ideally result in greater public awareness about the CCB and increased uptake of the program by family caregivers in need of support.

**Limitations**

Our reliance on existing literature to compile a demographic profile has meant that this study inherits the limitations faced by those researchers as well as challenges in cumulating demographic variables where categories differ across studies, such as education and caregiver relationship; however, by using a multi-step process of confirmation, potential deficiencies in the culled profile are overcome. Use of Canadian census data holds limitations due to lag times in the publication of data and the aggregation of variables ‘age’, ‘sex’, ‘married and common-law’ and the 20% samples for ‘high school completed’ and ‘full time employment.’ Further, the ‘high school completed’ variable was not defined by sex, so includes both males and females. Using the CT scale was viewed to provide the most meaningful spatial analysis, but results in the omission of rural and remote areas. However, most specialized palliative care services are offered in larger centres and because most front-line care providers and human resources personnel from rural and remote communities have collegial and training networks extending to more populated areas, residents of these areas are, by default, addressed in this analysis. Further, the dissemination approach recommended in the second dissemination pathway would include rural and remote communities and not simply those identified in part two of the presented analysis.

**Conclusion**

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

Although this paper has focused on an applied problem specific to the CCB, such problems of underutilization and low uptake due to lack of awareness certainly exist for a variety of other programs found in and outside of Canada, specifically within the health and social care realms. This problem can be particularly acute regarding newly implemented programs, where public awareness will most likely be relatively low. The spatially informed mixed-method analysis presented in this paper can usefully be applied to such cases. Further, considering the costs associated with general awareness campaigns, a dissemination strategy based on findings from sound analysis may provide decision-makers with information to tailor a dissemination strategy that will result in high efficiency by channelling a more narrow path from which such information should flow. Our approach, particularly parts one and two of the analysis, may also be useful for targeted interventions that require identifying specific populations.

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