

## **Géographies du transfert de l'information et de l'acquisition des connaissances chez les personnes soignantes : une analyse du programme de prestations de soignant en vigueur au Canada**

**Valorie A. Crooks, Allison Williams, Kelli I. Stajduhar,  
Diane E. Allan et S. Robin Cohen**

Les auteures explorent ici une branche encore peu développée de la géographie de la santé en proposant une étude sur le transfert d'information et l'acquisition de connaissances qui s'opèrent dans le cadre d'un programme social lié à la santé. Plus précisément, elles ont analysé les conclusions d'une évaluation à petite échelle du programme des prestations de soignant en vigueur au Canada. Ce programme permet aux travailleurs admissibles à l'assurance-emploi de prendre congé dans le but s'occuper d'un proche à la fin de sa vie. Sur la base de 25 entrevues auprès de personnes soignantes, les auteures dressent des géographies du transfert de l'information et de l'acquisition des connaissances. Elles présentent d'abord le groupe de répondantes et brossent un portrait de leurs vies sociospatiales comme personnes soignantes. Elles examinent ensuite trois des thèmes qu'elles ont relevés : la connaissance du CCB; l'accès à l'information; les démarches relatives à la demande. Les auteures analysent les implications de leur recherche en ce qui a trait au fardeau des personnes soignantes, à leurs besoins en matière d'information et à la prestation des soins au Canada. Elles proposent également des avenues de recherche concernant le programme de prestations de soignant.

Mots clés : programme de prestations de soignant du Canada, transfert d'information, acquisition des connaissances, géographie de la santé, personnes soignantes

# **The Information Transfer and Knowledge Acquisition Geographies of Family Caregivers: An Analysis of Canada’s Compassionate Care Benefit**

**Valorie A. Crooks, Allison Williams, Kelli I. Stajduhar,  
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The authors explore an underdeveloped area of health geography by examining information transfer and knowledge acquisition for a health-related social program. Specifically, they discuss the findings of a small-scale utilization-focused evaluation of Canada’s Compassionate Care Benefit (CCB). The CCB allows workers who are eligible for employment insurance to leave work to care for family members at end-of-life. Using the findings of 25 interviews with family caregivers, the authors explore their geographies of information transfer and knowledge acquisition. First, however, they introduce their respondent group and provide an overview of their socio-spatial lives as family caregivers. They then examine 3 specific thematic findings: awareness of the CCB, access to information related to the CCB, and the application process. The authors discuss the implications of the findings for the information needs and burdens of family caregivers and for Canadian nursing practice. They also consider directions for future CCB research.

**Keywords:** Caregiver geographies, utilization-focused evaluation, Canada’s Compassionate Care Benefit, information transfer, knowledge acquisition, health geography, palliative, family caregiving

## **Introduction**

Health geography is a dynamic sub-discipline of human geography. Although originally founded on inquiry related to disease mapping and spatial epidemiology (Curtis, 2004), over the past decade research undertaken by health geographers has become increasingly diverse due to the infusion of new methodologies and theoretical approaches; such changes are inspired by what is referred to as the “cultural turn” (see Gesler & Kearns, 2002). For example, research related to caregiving, in both the voluntary and informal sectors, is gaining attention in the sub-discipline (e.g., Milligan & Conradson, 2006; Williams, 2002). State restructuring, social policy creation in the neoliberal state, and changing philosophies

of care are resulting in the delivery of increased amounts of care in the community (e.g., in the home, in community-based care facilities) and a simultaneous shift of the burden of care onto paid and unpaid caregivers in community settings (Milligan & Conradson; Skinner & Rosenberg, 2005; Williams, 2006). Health geographers are interested in understanding the social and spatial outcomes of such shifts and the impacts on certain groups, including unpaid family caregivers.

Information transfer and knowledge acquisition have received little attention by health geographers relative to other, more established, areas of inquiry. These processes are, however, inherently spatial, as they create relational connections between disparate places (Crooks, 2006), involve the development of information networks (Cravey, Washburn, Gesler, Arcury, & Skelly, 2001), and have outcomes that can literally and figuratively place people in more or less privileged positions (Gesler, 1999). Certainly, informal caregivers at the palliative/end-of-life (P/EoL) stage need to gain access to information in order to provide the best possible care. Ashpole's (2004) review of the information needs of Canadian family caregivers reveals that such individuals constantly need to refine their knowledge about topics such as disease progression and treatment, administration of medications, availability of home care and other social services, and coping strategies. Also, Ashpole contends that there is a distinct temporality to the information needs of family caregivers, in that these needs will be different at the various stages between the diagnosis and the death of the care recipient.

In this article we focus on the information needs of family caregivers at the P/EoL stage. However, we draw our attention away from the more standard types of information needs that Ashpole reviews and focus instead on those related to applying for and receiving assistance from a federal social caregiving program: the Compassionate Care Benefit (CCB). The goal of Canada's CCB legislation is to enable people who are employed and eligible for employment insurance (EI) to take a temporary leave in order to care for a terminally ill family member. Family caregivers who take a leave from a paid job in order to provide P/EoL care and take advantage of the CCB must not only gain information related to the care recipient's illness in a specific time frame, but also develop a familiarity with the program. This has the potential to add an informational burden onto this specific group of family caregivers.

We draw on 25 interviews conducted with family caregivers from eight Canadian provinces in a pilot evaluation of the CCB, in order to explore their experiences of negotiating the application process, accessing information, and developing a knowledge base about the program. Our purpose in undertaking this research was to examine the usefulness of the CCB for family caregivers in different types of P/EoL caregiving situa-

tions and to inform the development of a full-scale evaluation of the program.

### **CCB Overview and Context**

While it is common for family members to neglect their physical and mental health in order to provide P/EoL care (Kissane, Bloch, Burns, McKenzie, & Posterino, 1994; Stajduhar & Davies, 2005), financial and workplace obligations are more difficult to disregard. For example, in addition to having to meet existing personal financial responsibilities during the caregiving period, often by continuing to work, family members providing P/EoL care contribute, on average, \$6,000 in unpaid caregiving during the final 4 weeks of life (Greaves et al., 2002). Grunfeld et al. (2004) report that not only do family members caring for terminally ill patients experience depression and anxiety, but their caregiving has adverse impacts on work, such as missed shifts, and typically brings a financial burden, such as the cost of prescription drugs, due in part to lost income. Thus, access to financial support is a particular need of families providing P/EoL care (Scott, Whyler, & Grant, 2004). Further, in the absence of job-protection legislation, Canadian family caregivers have traditionally been dependent on the good will of their employers, even if they wish to take unpaid leave, forcing many to continue working at a time when they need to be at the bedside of their loved one. The burden of having to remain in the workforce while providing P/EoL care is significant, and it typically negatively affects the physical, emotional, and mental health of family caregivers (Grunfeld et al.). In order to alleviate such burdens on family caregivers and to support the delivery of P/EoL care outside of institutionalized settings, the Canadian government established the CCB (Williams, Crooks, Stajduhar, Allan, & Cohen, 2006).

As noted above, the goal of Canada's CCB legislation is to enable employed and EI-eligible individuals to take a temporary leave in order to care for a terminally ill family member. The benefit came into effect in January 2004 through changes to the EI Act and the Canadian Labour Code and is administered as an EI special benefit. Its establishment was based on recommendations in the Kirby (2002) and Romanow (2002) reports, the 2002 Speech from the Throne, and years of lobbying by members of the palliative care and caregiving communities.

Successful CCB applicants can receive up to 55% of their average insured earnings, to a maximum of \$413/week, over a 6-week period to care for a family member at risk of death within 6 months. The 6 weeks of income assistance can be taken at once, broken down into 1-week periods spread over 6 months, and/or be shared among family members. Successful applicants are required to undergo a 2-week unpaid waiting

period before receiving payments and to determine when payments will start (within 28 days of making the claim). In order to qualify, applicants must have worked a minimum of 600 EI-insurable hours over the preceding 52 weeks. They must also meet the designation of “family member” and provide a medical certificate from the doctor of the gravely ill family member indicating that death is imminent (i.e., within 6 months). Eligible family members are (in relation to the care recipient): child; child of spouse or common-law partner; wife/husband/common-law partner; father/mother; or father’s wife/mother’s husband or common-law partner (Osborne & Margo, 2005).<sup>1</sup>

Critics of the CCB program have focused on issues such as the 2-week waiting period (Picard, 2005), the narrow definition of “family member” (Osborne & Margo, 2005), and the labour-market participation requirements, which cannot be met by those who have been providing long-term P/EoL care (Canadian Caregiver Coalition, 2004). Further, the Canadian Women’s Health Network has pointed out the gender-based disadvantage inherent in the program, in that women are more likely to be stay-at-home parents and part-time workers who do not meet the CCB’s eligibility criteria (Armstrong & O’Grady, 2004). While significant attention has been paid to barriers to accessing the program, there has been less consideration of the actual experiences of applicants. The present study therefore makes a unique contribution, particularly with regard to its focus on information transfer and knowledge acquisition.

The CCB program and the legislative changes that shape its administration have come about in an era of neoliberally informed social policy. An ideology underpinning the creation of social policies in such a political/economic climate is that families and voluntary agencies, rather than local states, should bear the responsibility for assisting persons in need (see Chouinard & Crooks, 2005, for an explicit discussion of this in relation to another Canadian social program). Another element of policy-making in response to the current neoliberal climate has been a focus on providing care in the community as opposed to in institutional settings (James, 1999), an outcome of which has been increased reliance on the voluntary sector and unpaid labour to meet care needs (Skinner & Rosenberg, 2005). It is these types of changes to the role of the state in Canadian society that have informed the development and implementation of the CCB — a program that facilitates the provision of care by

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<sup>1</sup> The eligibility criteria and figures discussed here are those that were in effect at the time of the study. Since then, there have been two significant changes to the CCB. The maximum payment allowed per week is now slightly higher, and the definition of family member has been revised to include siblings, cousins, aunts/uncles, grandparents, and others.

family members in community settings. Complex application processes and increasingly strict eligibility requirements for social programs are also hallmarks of social policy in a neoliberal climate (Chouinard & Crooks; Roulstone, 2000). The present study provides a unique glimpse into how such characteristics of Canadian state restructuring and policy-making inform the administration of the CCB.

## **Methods**

The purposes of this pilot study were to examine the usefulness of the CCB for family members in different types of P/EoL caregiving situations and to inform the development of a full-scale evaluation of the CCB. Thus, the study was exploratory in nature and was driven by these purposes and not a solitary research question.

### ***Evaluative Approach***

Patton's (1997) method of utilization-focused evaluation was used. The objective of utilization-focused evaluation is to inform program and policy improvement using research findings. As Patton notes, "*Utilization-Focused Evaluation* begins with the premise that evaluations should be judged by their utility and actual use... Use concerns how real people in the real world apply evaluation findings and experience the evaluation process. Therefore, the *focus* in utilization-focused evaluation is on *intended use by intended users*" (p. 20; emphasis in original). Thus, this evaluative approach necessitates a focus on intended use (i.e., the usefulness of the CCB for family members in different types of P/EoL caregiving situations) and gathering the input of intended users (i.e., Canadian family P/EoL caregivers).

The method is shaped by 12 broad tasks: (1) determine readiness for assessment, (2) assess the readiness of the evaluators, (3) recruit an evaluation taskforce (ETF), (4) consider the evaluation context, (5) identify the intended users, (6) determine the evaluation focus, (7) design evaluation techniques, (8) test data-collection techniques, (9) collect data, (10) analyze data, (11) facilitate the use of the findings, and (12) assess the evaluation process. The pilot study was designed to fully complete tasks 1 through 8 while also collecting some data for task 9.

### ***Recruitment***

The sample comprised three categories of respondents from across Canada: (1) successful CCB applicants, (2) unsuccessful CCB applicants, and (3) those who had never applied for the CCB. The non-applicant group was made up of people who did not meet the prerequisites for the CCB, such as being outside the criteria of "family member" or the

minimum qualifications with respect to insurable employment (e.g., retired, self-employed, unemployed). These three groups were deliberately sampled as they were all *intended* users of the CCB, in that they had provided P/EoL care for a family member, and thus it was believed they would have useful input to offer in the pilot evaluation. Participants were recruited primarily through newspaper advertisements, newsletters of caregiver organizations, offices of Members of Parliament, and e-mail advertisements. Those interested in participating were invited to call a toll-free number where a bilingual telephone message requested that they leave contact information. They were then called to confirm eligibility and book an interview time. Eligibility criteria were minimal: participants had to be at least 18 years of age and had to have provided/be providing P/EoL care for a family member.

A total of 43 potential respondents phoned the toll-free number, of whom 25 eventually participated. Of the 18 individuals who did not eventually participate, the majority did not meet the inclusion criteria because they were long-term caregivers and were not/had not provided P/EoL care, while a few others had called to simply learn more about the CCB. Two people who had booked interviews did not follow through but did not give an explanation for this decision.

### **Data Collection**

Prior to data collection, approval was obtained from the McMaster University Research Ethics Board. Participants were interviewed by phone as this method is cost effective and is known to yield reliable data (Sturges & Hanrahan, 2004). Prior to the interview, respondents were mailed a package containing information on their rights as participants and a letter confirming the interview time and date. Once informed consent was obtained verbally, at the start of the interview, participants were asked a series of open-ended questions using a semi-structured format, followed by a limited number of demographic questions.

A semi-structured interview format was selected for data collection as it allows for a set of common questions for all participants while offering the flexibility for the probing of new topics raised during the interview (but not included in the interview guide) (Holstein & Gubrium, 1995). The questions concerned how respondents learned about the CCB, their experiences of its administration (e.g., application process), employee/employer interactions with regard to the negotiation of leave, and their experiences as P/EoL caregivers. The interviews lasted approximately 30 minutes (ranging from 20 to 50 minutes) and were audiotaped and transcribed verbatim. Data were collected over a 3-month period spanning the summer of 2005.

### ***Analytic Approach***

Data were thematically analyzed by respondent group; coding was facilitated through the use of NVivo<sup>®</sup> qualitative data-management software. Coding schemes were created for each of the three respondent groups and the constant comparative technique (Boeije, 2002) was employed in order to identify commonalities and differences within and between the groups. The coding scheme was reviewed and refined by two investigators prior to the first stage of coding, and all members of the research team read and commented on summaries of the analysis in order to strengthen the interpretation. Including such steps in the analytic process and the use of investigator triangulation in this manner served to enhance the credibility and integrity of the findings. Regular consultations with the ETF (in the form of teleconferences) and among the research team throughout the pilot study lent authenticity to the interpretation. Specifically, divergent and common issues emerging from the data set and during data collection were discussed openly and feedback was sought from individuals with different stakes in the study; these ranged from ETF policy-makers to the research assistant who had conducted the interviews. Therefore, the process was openly reflexive and thus inclusive of criticality<sup>2</sup> in data interpretation and analysis.

During the first stage of coding, the data set was organized according to the scheme that had been created. Themes emerging from the data set were discussed among the team members and with the ETF. Feedback on the themes and the comparative review of findings emerging from the different respondent groups informed the second stage of coding, which consisted mostly of eliminating redundant codes. A number of thematic codes were common to all three respondent groups: family caregiving background; caregiving logistics; employment experience before, during, and after the caregiving experience; CCB knowledge; and suggestions for improvement. For the successful and unsuccessful applicant groups, extensive codes about the process of applying for, receiving, appealing, and/or being denied the benefit were generated. Explanatory links were sought between the codes within and across respondent groups (which is part of the constant comparative process); this resulted in the emergence of the themes presented in this article as important and centrally linked to processes of information transfer and knowledge acquisition.

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<sup>2</sup>Our references to credibility, authenticity, criticality, and integrity in the analytic process are based on the assessment questions developed by Whittemore, Chase, and Mandel (2001, p. 534).



## **Respondent Overview**

The sample consisted of 25 caregivers who collectively cared for 27 P/EoL family members. Respondents resided across Canada, with the largest number residing in Ontario ( $n = 8$ ). With respect to gender, 20 were female and five male. The familial relationship of the respondent to the gravely ill person varied: seven caregivers were siblings, 16 were children, one was a grandchild, and one was a partner/spouse. The mean age was 46 for respondents (median: 51) and 71 for care recipients (median: 79). The mean length of the overall caregiving period was just under 6 years (median: 4 years). Care recipients were diagnosed with cancer ( $n = 12$ ), Alzheimer's disease ( $n = 8$ ), Parkinson's disease ( $n = 2$ ), stroke ( $n = 2$ ), and some other non-malignant advanced chronic illness ( $n = 3$ ).

Of the 25 participants, 16 were non-applicants for the CCB, four were successful applicants, and five were unsuccessful applicants. All successful applicants had provided care for less than 9 months and used the benefit primarily for arranging and providing hands-on and emotional care specifically at the terminal phase. Conversely, four of the five unsuccessful applicants had provided care for more than 1 year. The non-applicants had provided care for the longest period (an average of just under 8 years), most often prior to the palliative stage.

Many of the respondents provided irregular care (i.e., primarily during acute phases or periodically over an extended period) or temporally limited intensive care (i.e., daily care at the end-stage). Therefore, unique caregiving geographies were reported. For example, nine participants relocated out of town, province, or country in order to provide irregular or temporally limited care; 11 respondents changed residences (typically retaining their own homes), moving in with the care recipient in order to provide more intensive, hands-on care, typically for a temporally limited period; and in five instances the care recipient moved permanently in order to be closer to the caregiver.

## **Findings**

The analytic process revealed three somewhat interrelated themes regarding information transfer, knowledge acquisition, and the CCB. The first relates to how all respondents had initially learned of the CCB's existence. The other two relate specifically to experiences shared by the nine participants who had applied for the benefit. The three themes are discussed separately below.

### ***Awareness of the CCB***

Respondents were generally aware of the existence of the CCB prior to taking part in the study but struggled to learn the details, specifically in

relation to the application process. Those who had the least knowledge about the benefit were the non-applicant group; indeed, these individuals were likely to ask questions about the logistics of the benefit during the interview and to reveal an incomplete understanding of the CCB program in general.

Of the 25 respondents, 20 were aware of the benefit prior to participating in the study. These caregivers had first heard of the CCB from a variety of sources: community/support groups ( $n = 2$ ), newspapers ( $n = 7$ ), radio ( $n = 2$ ), television newscasts ( $n = 3$ ), their employment (in that their jobs required familiarity with the benefit) ( $n = 4$ ), and health professionals ( $n = 2$ ).

Several respondents commented that there was too little advertising of the CCB, leading some to speculate that this could lead to misinformation. For example, a successful applicant stated:

*I think there needs to be more [advertising]. I think it was very gung-ho there [when the CCB was first announced] and I haven't seen any of it since. And, actually, I had heard that they had cancelled [it]... Somebody just mentioned it. Maybe it was just hearsay.*

This respondent went on to suggest that better marketing or advertising of the CCB could serve to reach more potential applicants or those who may need to provide care in the future.

### ***Access to Information about the CCB***

Participants' comments indicated that being aware of the benefit's existence and having a working knowledge of its administration are two separate issues. Respondents who had applied for the benefit ( $n = 9$ ), whether successful or not, repeatedly cited difficulty accessing reliable and accurate information from a variety of sources, including the Internet and government offices. For example, one CCB recipient who had applied in order to provide care for a parent recounted her difficulty getting accurate information about the application process:

*I understood that I had to leave my job, and after leaving my job serve a 2-week waiting period and then apply for it, so that's what I did... [That I could apply before going on leave] was unclear. And it's kind of crazy, because I work in the system so it should have been clear to me but it wasn't somehow.*

When another successful applicant who had provided care to a parent was asked about her experience of receiving CCB income support, she stated:

*[The EI employees] said [that] once you wait the 2-week period and then you're plugged into the system then you...can get paid [in] up to 28 days. Like, you get your first payment within 28 days... But nobody really tells you when that is.*

Other successful applicants had also experienced difficulty finding out when their payments would start or stop, stating that the information about the benefit was lacking such details or was inaccessible in easily understandable formats.

Respondents found that even EI staff members were not always able to provide them with the information they needed. One successful applicant stated:

*They weren't really that clear about things themselves. That certainly made it that much more difficult for us.*

An unsuccessful applicant noted that government employees “weren’t organized” when describing the application process and discussing his eligibility for the benefit.

### ***The Application Process***

A total of nine respondents had completed the CCB application process. Their comments reveal it to be a difficult process to negotiate, for several reasons. Many applicants found communicating with EI staff to be a challenge. A successful applicant said:

*I got three letters in the span of 4 days telling me three different things, so that part was really confusing.*

Although not all CCB applicants had experienced this specific situation, they all related similar experiences of confusion and/or misinformation.

A successful applicant described the application process as “quite complicated” and said that it was important to be able to get assistance from government staff. The need for assistance during the application process was echoed by others:

*[The online application form] took an hour at the EI office... It's a good thing there was this lady standing behind me...helping me to do almost every step of it, because it was...not user-friendly.*

*I was very fortunate. I went into the [EI] office and they said, “Well, you can do it online on the computer.” And I said, “No, I'd rather speak with an individual.” And I think that's where to go, because you're already emotionally stressed. I'm not that great with computers, so they were very helpful.*

These comments point to the fact that many respondents needed help completing the application forms. The online forms were described as difficult to navigate and several applicants cited a preference for one-on-one assistance. One unsuccessful applicant, despite receiving assistance from EI staff, reported experiencing a “scramble with the paperwork.”

Another difficulty associated with the application process was the time required to gather the supporting documentation (e.g., medical certificate). Respondents reported having to take time off work, during an already busy period in their lives, to deal with the necessary paperwork. One unsuccessful applicant described the process as “time-consuming.” A final difficult aspect of the application process touched on by several participants was the fact that the process itself is undertaken during a period when one’s time, energy, and other resources are particularly taxed:

*I was really coping with a lot of stuff at the time and, really, to be very honest, whether I got [the CCB] or not was not my priority right at that moment. But I kind of filed it [the idea of applying] away and later looked into it... So I didn't [think about the CCB] for a little while. But then, amazingly, within a couple of weeks my sister...started improving a bit...she didn't die! So, you know, as the weeks went by I thought, "I better look into this a bit further," so that's when I did.*

This respondent’s comment is reflective of the fact that participants had to organize their time carefully during the caregiving period, as taking time to access information and apply for the CCB reduced the number of hours they could devote to the care recipient.

## **Discussion and Recommendations**

Ashpole (2004) contends that “informal caregivers are faced with taking on a new job with no previous experience, no job description to guide them or employee incentive program to encourage them, and where their own health and well-being may be at risk” (p. 32). Family caregivers need access to information so they can develop a body of knowledge regarding care provision. The data collected in the present study suggest that this group has two sets of simultaneously pressing information needs: those pertaining to the dynamics of caregiving, and those pertaining to applying for and receiving the CCB. With regard to the second set of needs, there were three temporally distinct periods during which the respondents’ information transfer and knowledge acquisition geographies were most active: when they first learned about the CCB, when they applied for it, and when they received it.

Our brief discussion of the complex nature of the caregivers' geographies reveals that several of the respondents underwent significant transitions in their daily lifeworlds in order to provide care for a relative at end-of-life. The demands of providing care, relocating and/or travelling, acquiring knowledge about managing the recipient's illness, and fulfilling other familial roles (e.g., parent, spouse) were taxing on respondents' time; having to seek out CCB information only added to the heavy burden for this specific group of family caregivers. Several applicants identified such information-seeking as problematic. They had found inaccurate or incomplete CCB information on Web sites and when visiting EI offices and speaking with administrative personnel. Having to verify information in order to enhance their knowledge about the benefit was yet another time-consuming task.

The experiential evidence described above reveals the complicated nature of applying for the CCB, including a challenging computer application process. Complex rules and regulations added to the importance of developing a personal knowledge base about the program. Respondents spoke of using numerous strategies to gain access to information about the CCB. These included searching the Internet and speaking with EI staff. Such information was then relationally connected to numerous other spaces in the caregivers' lives (including the workplace) as they applied for the benefit, the doctor's office as they sought to secure the medical certificate, the home or EI office as they completed the application process, and ultimately (for successful applicants) the caregiving space, since it was by receiving the CCB that they could have greater presence within the caregiving space. As Crooks (2006) suggests, "relational connections are drawn between these disparate spaces, which are linked by the information carried between one another" (p. 63). Thus, the respondents' geographies of information transfer and knowledge acquisition involved their developing connections between information-rich sites (e.g., EI offices) and information-use sites (e.g., doctors' offices), all of which were linked by the knowledge about the CCB they had gained over time.

Sites that were initially identified by respondents as information-rich, namely EI offices and the Internet, were later found by several respondents to be sites of misinformation or non-information. This general lack of familiarity with the application process on the part of EI staff may have been due to the newness of the program. Interruptions to respondents' spatio-temporal routines and caregiving tasks for the purpose of information-seeking were often of no avail. The risks of misinformation were high for the applicants and the care recipients. More specifically, lack of knowledge about specific details of the CCB program (e.g., when the first payment would be issued, whether one must apply for the

benefit before taking leave) can cause frustration, uncertainty, and even financial hardship.

This pilot evaluation has revealed much about both the nature of P/EoL family caregiving and the respondents' geographies of information transfer and knowledge acquisition. Our ultimate purpose in evaluating the CCB from the perspective of family caregivers was to offer recommendations for improving the administration of the program. We therefore propose that:

- advertising about the CCB be intensified in order to ensure that all those who are eligible to receive it are aware of its availability
- Web sites be kept up-to-date and old sites be made inactive
- each EI office have available at least a few staff members who are fully acquainted with and knowledgeable about the CCB
- all information about the CCB be made as clear and accessible as possible
- the computer application process be streamlined

Following through on these and other recommendations with respect to the CCB program (see Williams et al., 2006) also requires that policy-makers have a greater recognition of the burdens placed on P/EoL family caregivers during this "emotionally stressed" period.

### **Implications for Nursing Practice**

Restructuring of the Canadian health-care system has resulted in more health care being provided in the home (McKeever, 2001). One of the key components of effective home-based P/EoL care is the availability of a family caregiver (Stajduhar & Davies, 1998; Wilson, 2000). Family caregivers assume the majority of responsibility for the coordination and/or delivery of care for those dying at home (Luker, Austin, Caress, & Hallett, 2000; McCorkle, Robinson, Nuamah, Lev, & Benoliel, 1998). This puts their own health at risk. Therefore they are viewed by palliative care practitioners as patients in need of care and support in their own right (Ferris et al., 2002).

Health-care providers, including nurses, are acutely aware of the financial and health repercussions of acting as a caregiver while continuing to hold down a job (Stajduhar, 2003). Although combining paid work and caregiving has been shown to have mental health benefits (Martire, Stephens, & Atienza, 1997; Scharlach, 1994), the dual role is also associated with increased caregiver strain (Mutschler, 1993) as well as emotional and physical stress, including depression and fatigue (Lee, Walker, & Shoup, 2001; Scharlach). The CCB is a social program with the potential to ameliorate the burdens associated with the dual role, by

giving employed family caregivers the option of taking time off work in order to provide P/EoL care.

Information about the CCB would likely be welcomed by many family caregivers who might be eligible for the program. Nurses, especially those working in home care and outpatient clinics, are in a key position to inform family caregivers about the CCB, given their extensive involvement with P/EoL patients and family caregivers. These nurses could be an important conduit for such information exchange and for ensuring that family caregivers are given accurate information. Nurses are already responsible for providing information to palliative patients and family caregivers about pain and symptom management and available community supports. Information about the CCB in the form of fact sheets or pamphlets could become part of the standard package of information they offer to patients and families facing life-threatening illness. In addition, organizations such as the Canadian Nurses Association or specialty groups such as the nurses interest group of the Canadian Hospice Palliative Care Association could provide guidance on how to incorporate social policies, including the CCB, into nursing practice; this would serve to enhance the uptake of policy into the practice arena, with the aim of preventing financial hardship and negative health outcomes for families affected by terminal illness.

### **Limitations**

This study had a number of limitations, partly due to the pilot nature of the research. In addition to having an over-representation of family caregivers residing in the province of Ontario, the sample was small in size due to the untested nature of the sampling strategies. The sample comprised 25 family caregivers, of whom only nine were CCB applicants — four successful and five unsuccessful. Given the large proportion of non-applicants, the results may not be sufficiently representative of the experiences of successful and unsuccessful applicants. Also, the sample included only one partner/spouse caregiver; this group warrants further investigation, particularly since many partner/spouse caregivers are retired and thus would not meet the CCB's eligibility requirements.

### **Continuing Research**

This pilot study served as the foundation for a successful grant application (to the Canadian Institutes of Health Research) to conduct a full national evaluation of the CCB from the perspective of family caregivers. In addition to accessing a larger sample of each of the three family caregiver groups (successful and unsuccessful applicants and non-applicants), we plan to collect data from a number of key informant groups,

including employers, human resources personnel, and front-line palliative care practitioners. This work is underway and will be completed by 2009.

## Conclusion

Analysis of the P/EoL family caregiver data set reveals three informational themes: awareness of the CCB, access to information, and the application process. Despite their calls for more advertising in order to increase awareness of the CCB and ensure its continuance, a large majority of the respondents were aware of the program before taking part in the study. According to those respondents who had applied for the benefit, access to reliable, accurate, up-to-date information and to knowledgeable personnel was a key component of familiarity with the CCB program. The respondents reported a number of challenges specific to the CCB application process. These included (1) a lack of knowledge about specific details of the benefit, (2) the complicated nature of the application form, (3) the time required to gather supporting documentation, and (4) the need to undergo this process during a particularly difficult and emotionally draining period in their lives. Nurses are well situated to alleviate some of the informational burdens associated with the CCB program.

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