

Evaluating Canada's Compassionate Care Benefit

From the
Perspective
of Family
Caregivers



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About the Cover

The butterfly represents the beauty and fragility of life, as well as the finite nature of all living things. It is a powerful symbol for transformation – including the transition between life and death. The metamorphosis and emergence of the butterfly from the cocoon symbolizes the freedom of the soul upon death. The cover image of a butterfly gently cupped between two hands thus symbolizes the provision of palliative care and the compassion offered as bodily, mental, emotional, and spiritual transitions are being made during the final stages of life.

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Acknowledgements

First and foremost, we are extremely thankful for all those who chose to give their time to this study either as participants or in some other form. The ongoing contributions of the Evaluation Taskforce have also been invaluable.

Mirjana Vuksan worked with the team in her capacity as a graduate trainee at McMaster University. She coordinated the employer/human resource personnel focus groups and led several of the analyses focused on this participant group. Melissa Giesbrecht also worked with the team as a graduate trainee at Simon Fraser University. She coordinated the front-line palliative care provider interviews and led several analyses focused on this participant group. Sarah Paynter conducted the family caregiver interviews in English and oversaw recruitment in her capacity as a research assistant. Jean-François Desbiens conducted the family caregiver interviews in French. Sarah Dykeman and Rory Johnston both worked as research assistants on the study in its later phases.

This research has been funded by an Operating Grant from the Canadian Institutes of Health Research.

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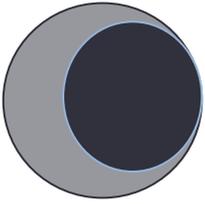


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Executive Summary

The rapid aging of Canada's population has occurred across a backdrop of fundamental shifts in health care service delivery, resulting in an increasing number of Canadians providing end-of-life care for their family members at home. The Canadian Caregiver Coalition succinctly captures the situation when it warns: "it's not *if*, it's *when* you will become a caregiver" (2009). As family caregiving has become a common practice, Canadians are increasingly becoming aware of the growing likelihood that they, themselves, will be called upon to provide end-of-life care for family members. Family caregivers who help Canadians through their final days are often in their productive working years and must manage the dual roles of caregiving while simultaneously remaining in the paid workforce. Furthermore, many Canadians provide both end-of-life care for their parents and care for their children, a phenomenon that has given them the label 'the sandwich generation'. An increasing number of Canadians will soon face this dilemma and will have little choice but to adopt the responsibilities of this dual role. In response to the anticipated demand for family caregiving at the end-of-life, the Canadian government introduced the Compassionate Care Benefit (CCB) program in January 2004. The primary goal of the CCB is to provide income assistance and job security to family members and friends who take temporary leave from regular employment to care for a terminally ill person at risk of dying within 26 weeks. Although the federal government's implementation of the CCB is seen as a strong first step towards supporting family caregivers, successful uptake of the Benefit has been low in the first years of its existence.

Since 2006, the research team that produced this report has been undertaking a study on the CCB with the goal to evaluate the Benefit from the perspective of family caregivers. This study's overall purpose is to offer policy-relevant recommendations that are informed by the needs of Canadian family caregivers by gathering input from multiple stakeholders. Fifty-seven interviews with family caregivers, 50 interviews with front-line palliative care providers, and five focus groups with employers and human resource (HR) personnel from across Canada have been conducted. The perspectives, knowledge, experiences, and suggestions gathered from these three key stakeholder groups have generated a wealth of information about the CCB.

Study findings show that most participants view the CCB as a legislative step in the right direction to better supporting family caregivers. However, it is stressed by all stakeholder groups that until there is wider awareness of the CCB's existence, the implementation of future changes designed to realize the full potential of the program will have an insubstantial impact on improving uptake. From across all three stakeholder groups, **five common suggestions for improving the CCB** have been identified:

1. Implement a CCB awareness campaign that targets all stakeholder groups and the Canadian public simultaneously through a range of formats;
2. Improve the application process to be quicker, simpler, and more sensitive to the stressful and emotional realities of CCB applicants;
3. Eliminate the required two-week unpaid waiting period;
4. Lengthen the period of support to allow for: flexibility because of the challenges in prognosticating death, a more reflective and not rushed palliative process, and caregivers to extend the paid leave after death to include time for bereavement; and
5. Increase the financial assistance to more adequately reflect the 'real' costs endured by family caregivers when taking time off work to provide end-of-life care.

This study has aimed to provide policymakers with the information required on how to improve the CCB program and better meet the needs of family caregivers in Canada. Without improving the CCB program, many Canadian family caregivers will remain at risk of experiencing high levels of 'caregiver strain', characterized by the various financial, physical, and emotional burdens associated with simultaneously working and providing care to family members. Supporting family caregivers through programs such as the CCB can lessen the stress and ill health triggered by managing dual responsibilities.

It is imperative that the extraordinary efforts made every day by Canadian family caregivers are recognized through the provision of equitable access to the necessary means required to carry out the invaluable work of caring for dying individuals, including supportive programs such as the CCB.

Introduction

Over the past two decades, Canadian provinces have restructured the delivery of their health care services, with the intent of reducing reliance on state-funded health care (Williams, in press). As a result, the financing and provision of many services have been reoriented, with the community and home now favoured as preferred sites of care. Included in this reorientation is the delivery of long term and end-of-life care, where a wide array of services have been deinstitutionalized and downloaded to the voluntary and informal sectors without the simultaneous development of services and programs to support their efforts (Crooks et al., 2007). The increasing reliance on deinstitutionalized care has had a great impact on Canada's 1.5 to 2 million family caregivers, a group that provides hands-on care, spiritual and emotional care, and care coordination worth \$25-26 billion annually while incurring \$80 million dollars annually in out-of-pocket costs (Canadian Caregiver Coalition, 2009; Hollander et al., 2009). This reliance by provincial health care systems on family caregivers has not wholly been a one-sided set of demands. Current end-of-life care research increasingly suggests that Canadians prefer to die at home or in their home communities (e.g., in long-term care facilities) instead of in hospital settings (Bacon, 2008), an indication that the trend towards care delivery in the home may be a valuable opportunity to try and meet the needs of dying Canadians and their families. Regardless of the motivation behind this shift in care settings, and in the face of the formidable financial and emotional challenges deinstitutionalized care poses to Canadian families, Canada's increasingly aging population requires an end-of-life caregiving strategy that ensures the wellbeing and dignity of dying Canadians and their family caregivers, the majority of whom are women (Williams & Crooks, 2008).

Caregiving Issues

A family caregiver is defined by Health Canada (2004, n.p.) as "...an individual who provides care and/or support to a family member, friend or neighbour who has a physical or mental disability, is chronically ill or is frail." It is estimated that upwards of 70% of all care provided for ill or dying individuals in Canada is given by family caregivers (Romanow, 2002). In the context of this report, family caregiving is used synonymously with the term "informal caregiving" and is focused specifically on the provision of care at the end of the life course. End-of-life care involves a full continuum of care ranging from pain and symptom management, to psychological, social and emotional support for *both* patients and their family caregivers (Health Canada, 2009b). This recognizes that the provision of family caregiving may result in compromised mental, emotional, physical, social, psychological and financial health due to the demanding nature of end-of-life care (Cameron et al., 2002; Chentsova-Dutton et al., 2002; Reid et al., in press; Stajduhar & Cohen, 2009).

When called upon to provide care, family caregivers must often learn complex medical care and specific technical vocabularies (Williams & Crooks, 2008; Crooks, et al. 2007). Given the nature of end-of-life care, the informational needs of family caregivers must evolve as the patient's needs alter from time of diagnosis to time of death (Ashpole, 2004). Learning to provide care may be further complicated by caregivers' desires to remain hopeful about recovery, and the generally taboo nature of death in Canadian society (Zimmermann, 2007).



Caregivers' Need for Support

As family caregivers continually refine their knowledge and provide care, they are usually also managing other roles and responsibilities, such as parenthood and employment (Kissane et al., 1994; MacBride-King, 1999). Considering that caregivers report decreased work productivity and missed shifts due to caregiving responsibilities, alongside an average out-of-pocket expenditure of \$6,000 on care costs (including medical equipment and prescriptions), financial support is greatly needed during the caregiving period (Greaves et al., 2002).

An Overview of the Compassionate Care Benefit

Broadly speaking, the goal of the Compassionate Care Benefit (CCB) program is to provide job security and limited income assistance to Canadian workers eligible for Employment Insurance who take a temporary leave from their regular employment to care for a person at risk of dying within 26 weeks. Such care is considered to be: offering psychological or emotional support, providing 'hands on' support, and/or arranging for support to be given by a third party. Employment Insurance is a contributory scheme that is paid into by full-time, non-self-employed, Canadian workers through payroll deductions, who are then able to draw upon its benefits when in need. The CCB is the newest of the five benefit programs available through Employment Insurance, having been implemented by Canada's federal government in 2004 and subsequently adopted into provincial and territorial labour codes soon after. The program's development follows years of advocacy from the Canadian caregiving and palliative care communities about the need to better support Canadian family caregivers.

The CCB program has four main eligibility requirements. The first two requirements, wherein applicants must have accumulated at least 600 hours of insurable earnings over the preceding 52 weeks and their weekly earnings must have decreased by at least 40%, are common to all Employment Insurance programs. In addition to these requirements, the CCB further requires a signed medical certificate from the gravely ill person's doctor confirming risk of death within 26 weeks and that that the

caregiver be a family member of the dying person, which includes all familial relations (e.g., common-law and by adoption) and those who are thought to be like family, such as friends and neighbours. As noted above, self-employed, casual, and part-time workers, along with those who are unemployed, are not currently eligible for Employment Insurance, and are therefore not eligible for the CCB. Applicants to the program must demonstrate that they meet *all* of the eligibility requirements in order to receive the CCB, which is done via an application form. The form can be completed online or in person at an Employment Insurance office.



The CCB program has a number of core features. Support is provided to successful applicants only during the caregiving period and not beyond (e.g., into bereavement), for a maximum of eight weeks of secured leave from employment. Income assistance through the program offers 55% of a person's weekly earnings, up to a maximum of \$447 per week. The income assistance that the CCB affords can be drawn on for a maximum of six weeks. These six weeks of support may be taken consecutively or broken up into periods consisting of no less than one week over a 26 week period. In addition, successful applicants are required to go through a two-week unpaid waiting period, which is a requirement of all Employment Insurance programs, which is why eight weeks of secured leave are provided and only six weeks of income assistance. While the CCB may be shared among multiple people caring for the same person at risk of dying (for a combined total of six weeks of support), only one of the caregivers in such a circumstance is required to go through the two-week unpaid waiting period. After completion of the waiting period, successful applicants must determine when to begin the CCB leave and payments within the 26 week period. Finally, the CCB can be taken to provide care for someone living anywhere in Canada or internationally.

Since its inception, a number of the CCB's eligibility requirements and core features have garnered significant criticism. For example, even before it was implemented, the program's short remuneration period and requirement for a medical certificate to certify that death is imminent were viewed as harsh (MacLellan, 2003). Furthermore, while initial reports from the Canadian Caregiver Coalition (2004) and Quality End-of-Life Care Coalition of Canada (2005a) primarily expressed broad gratitude for the CCB, seeing it as encouraging progress towards a concrete Canadian caregiving strategy, others were more critical of its eligibility requirements in particular (e.g., Armstrong & O'Grady, 2004; Fast et al., 2005; Health Council of Canada, 2006; Quality End-of-Life Care Coalition of Canada, 2005b).

When uptake of the CCB in its first year was far lower than expected, this was viewed as the first evidence that the program was unable to fulfill its mandate (Health Council of Canada, 2006). More recently, criticism has shifted to consideration of the general lack of awareness about the CCB among Canadians and how this may be contributing to the lower-than-anticipated uptake (e.g., Crooks et al., 2007; Giesbrecht et al., 2009; Human Resources Social Development Canada, 2007). In response to these program challenges, calls have been made for amendments to the CCB program that would do away with some of the barriers it poses for caregivers in need of support (e.g., Canadian Caregiver Coalition, 2004; Cormack, 2008; Goar, 2008, 2009; Greenaway, 2008; Picard, 2005).

Research Design

A utilization-focused evaluation approach was used for this study, with the objective of informing program and policy development (Patton, 1997). This approach involves collaboration with information users who become part of an 'Evaluation Taskforce' (ETF) and work with the academic team throughout the evaluation (Williams, in press). Much of the design of this study was informed by a pilot project, which took place between 2004 and 2005 (Williams et al., 2005). Interview and focus group data were collected from three different participant groups, characterized below. Data collection took place over two years (2006-2008) in five targeted provinces: British Columbia, Manitoba, Newfoundland, Ontario, and Quebec (see Figure 1). These provinces were selected in order to represent Canada's regional and linguistic diversity.

Figure 1: Provinces of Focus



Study Participants

- **Participant Group #1: Family Caregivers** - Fifty-seven in-depth telephone interviews were conducted with three categories of family caregivers: (1) successful CCB applicants, (2) unsuccessful CCB applicants, and (3) CCB non-applicants who may or may not have been eligible for the CCB, but did not apply. The interviews addressed: (a) to what extent the family caregivers were satisfied with the CCB; (b) perceived strengths of the CCB; (c) recommendations for improving the CCB; (d) family caregivers' satisfaction with their employers' response to taking a caregiving leave; and (e) the logistical elements of applying for and/or receiving the CCB.
- **Participant Group #2: Front-line palliative care providers** - Fifty in-depth telephone interviews were conducted with front-line palliative care providers. The interviews addressed: (a) perceptions of the CCB's usefulness and barriers/facilitators to access; (b) experiences of recommending (or choosing not to recommend) the CCB to a client/client's family; (c) working knowledge of the CCB's administration and eligibility requirements; and (d) suggestions for improvement.
- **Participant Group #3: HR professionals and employers** - Five focus groups (one in each study province) with a total of 27 HR professionals/employers were conducted. Topics addressed in the focus groups included: (a) perceptions of the CCB's usefulness and barriers/facilitators to access; (b) experience with having an employee use the CCB; (c) working knowledge of the CCB's administration and eligibility requirements; (d) strategies for supporting employees who are providing care while involved in paid labour; and (e) suggestions for improvement.

Data Collection and Analysis

1: Interviews and Focus Groups

All interviews and focus groups were audio-taped and transcribed verbatim. A qualitative data management program (NVivo) was used to organize the transcripts for analysis. Selected interviews transcripts were read by multiple investigators so as to identify emerging themes. Coding schemes were generated and applied to the transcripts as a way to manage the data. After coding was completed, the themes were compared within and between stakeholder groups, and also to the existing literature.

2: Watching Brief

A watching brief of policy documents, media reports, and other relevant items was compiled through frequent searches for updated information. The Evaluation Taskforce contributed relevant documents such as newsletters and policy briefings generated by their respective organizations. The watching brief provided a continuously evolving source for tracking issues of relevance to the CCB, including legal appeals and policy changes. The watching brief was used largely to provide important context for the various analyses conducted, and was drawn upon heavily in the Overview of the Compassionate Care Benefit section of this report (see page 3).

Participant Overview

#1: Family Caregivers

Overall, 53 English- and four French-language semi-structured interviews were conducted over the telephone with family caregivers in the target provinces (n=57). In total, interviews were conducted with 22 family caregivers who were successful in their CCB applications; five family caregivers who had applied to the CCB, but whose applications were denied; and, 30 family caregivers who had not applied to the CCB program. By province, 24 resided in Ontario, 23 in British Columbia, five in Quebec, three in Manitoba, and two in Newfoundland and Labrador. As shown in Table 1, the majority of family caregivers interviewed were women between 45 and 54 years of age. The mean age of participants was 48 and of the people they cared for was 66. Forty-one lived with the care recipient full- or part-time during the caregiving period and 16 did not. Thirty-four of the people being cared for had a cancer diagnosis while the other 23 had other chronic conditions such as Alzheimer's disease, stroke, amyotrophic lateral sclerosis, cystic fibrosis, and/or heart disease. While most participants discussed one primary disease, many mentioned secondary co-morbidities, a challenging reality of palliative care. Regarding employment status during the caregiving period, 41 reported a change from their normal work situation while 16 did not. Such changes included things such as taking paid or unpaid leave, workload reduction, working from home more, and/or using sick days and family days while caregiving.

Table 1: Family Caregiver Participant Overview

Age of Participant	Number of Participants
Under 44	19
45-54	21
55-64	15
Over 65	2
Sex of Participant	
Female	51
Male	6
Relationship to Care Recipient	
Spouse	37
Parent	14
Child	3
Sibling	2
Aunt/Uncle	1
Length of Caregiving Period	
Less than 6 months	13
7 to 1 year	11
1 to 2 years	7
2 to 3 years	7
More than 3 years	19
Employment Status at Time of Interview	
Full-time	40
Less than full-time	8
Retired	5
On leave	4

#2: Front-line Palliative Care Providers

Forty-eight English- and two French-language interviews were conducted via telephone with front-line palliative care providers (n=50). Workers who interact with family caregivers in their jobs were targeted as participants. In total, 10 interviews were conducted from each of the five target provinces. Sampling was done to recruit participants with as much diversity as possible, from a variety of settings (e.g., hospital, hospice, clinic, etc.) and across provider occupational groups was undertaken to acquire as much diversity in employment positions as possible. As shown in Table 2, this desired diversity was achieved, with participants representing all the main types of direct providers of end-of-life care. Thirty-seven of the participants held full-time employment, 12 worked part-time, and one had retired one month prior to the interview.

Table 2: Front-line Palliative Care Providers by Occupational Grouping

Occupation	Number of Participants
Social Worker	11
Palliative Care Director / Coordinator	9
Clinical/Oncology/Palliative Nurse	7
Community Health/Home Care Nurse	7
Oncologist/Physician	6
Chaplain/ Pastoral Care	2
Counselor	2
Volunteer Coordinator	2
Other	4

#3: Employer/Human Resources Personnel

Overall, there were five English-language focus groups conducted, with one being held in each of the five target provinces. There were 27 participants in attendance across these five focus groups; five attended the British Columbia focus group; six attended in Manitoba; six in Ontario; four in Quebec; and six in Newfoundland. As shown in Table 3, participants represented a variety of employment sectors, workplace settings, and sizes, and their occupations were diverse.

Table 3: Employer/Human Resources Personnel

Occupation	Number of Participants
HR Advisor/Consultant	9
HR Manager/Director/Supervisor	8
HR Generalist	3
Other HR	4
Chief Financial Officer	1
President	1
Vice President	1
Employment Sector	
Service	6
Government	4
Health	3
Industry/Manufacturing	3
Not-for-Profit	2
Professional	2
Utility	2
Other	5
Workplace Size (# of employees)	
Over 500	13
100 to 499	5
20 to 99	2
1 to 19	7

Key Findings: Family Caregivers

Family Caregiving Realities

Caring for a dying family member was viewed as a valuable experience: it was something many participants felt “willing” and “happy” to do. However, there were a number of expected and unexpected stresses associated with the realities of caregiving that sometimes challenged this sense of willingness. For example, the unpredictability of certain caregiving demands (e.g., symptom fluctuations) was a major stressor influencing other responsibilities, caregiving and otherwise. The highly emotional context sometimes challenged people’s abilities to learn and retain the vast amounts of information required to provide high-quality care (e.g., symptom management). Participants also commented on the stress associated with: having to provide particular types of physical care; giving constant attention to caregiving responsibilities; coordinating and travelling to various health care appointments (especially in rural areas); negotiating employment responsibilities and leaves; and managing the financial costs associated with caregiving. Many referred to their caregiving experience as both rewarding and busy: *“It’s just so exhausting, and it’s amazing how you can look back and say ‘what did I do today? I don’t know what I did, but you just knew you were on your feet the whole time doing something, but don’t ask me what it was.’”*

“Because I had no idea how long I was going to have to be off of work and I...you know, I had no idea how long my money was going to last. I mean, I was prepared to sell the house if I had to.”
– family caregiver

CCB Utilization Experiences

Generally, successful applicants of the CCB found the application process to be relatively straightforward and clear, although some experienced challenges acquiring the required letters from their employers and physicians. Many of these applicants had someone directly assist them with the application process, often a social worker or Service Canada employee, which reduced the burden of having to navigate the forms and process alone. Successful applicants generally felt supported by their employers and coworkers; however, some negative consequences of taking a caregiving leave were reported, such as the loss of wages, a change in employment position upon return to work, and loss of contributions towards pensions during the leave. Successful applicants also found the two week waiting period difficult to endure as there was no income support during this time period. Yet, the greatest struggle of the CCB experience, as identified by successful applicants, was determining when to begin the benefit: *“the most difficult thing was...to figure out, once I decided to go on Compassionate Leave, when the best time was to be to take that, not knowing her life expectancy.”* This was the main factor which led to the ineligibility of participants who were unsuccessful with their applications to the CCB program. In these cases the dying family member had died during the application process or the two week waiting period, thus rendering them ineligible for the benefit.

CCB Strengths & Limitations

Participants viewed the CCB to be a positive step in the right direction towards supporting Canadian family caregivers – this being its biggest strength. For successful applicants, receiving the benefit relieved some stress by providing a secured leave from employment while alleviating some of the financial burden associated with caregiving. The program’s limited period of support was, however, commonly criticized by successful applicants, denied applicants, and non-applicants alike. The limited support period offered by the

“it [CCB] gave me some sense of security in terms of - at least there’s one thing, from a financial perspective, in my life that I don’t have to worry so much about...so I could focus on my mom.”
– family caregiver

CCB was viewed by some as a major deterrent to even applying to the program. Participants were also critical of the lack of support available for family caregivers who are not eligible for EI, including those who are self-employed. Another critical limitation frequently raised was the considerable lack of awareness surrounding the CCB’s existence. For example, a number of non-applicants did not apply to the program simply because they were not aware of its existence. *“I guess the bottom line would be to make it [the CCB] more accessible, like advertise it more... that this is here and this is available for you.”*

Key Findings: Front-line Palliative Care Providers

Interacting with Family Caregivers

Front line palliative care providers are often the first point of contact for people caring for a dying family member in need of information and resources. As a result, they play a significant role in providing family caregivers with information and access to the available supports that they may need. Participants explained that a primary role of their jobs involves “asking questions” and “assessing” each family’s situation in order to understand what is needed and when and how to share information with them. As a home care nurse stated: *“...often it’s more that we’re informing them before they think they need it, because we can see what’s happening and we’re trying to prevent a crisis.”* Because of this role, front-line providers have the potential to play a key part in informing family caregivers about the CCB program, as well as assisting them with the application process. It was also revealed in the interviews that sometimes front-line providers also choose not to inform family caregivers about the CCB for a number of reasons, including its association with financial need and the reality that some family members might not be mentally or emotionally ready to acknowledge that end-of-life is near for the care recipient.

CCB Knowledge

Palliative care providers’ working knowledge about the CCB program was typically minimal. Most had heard of the CCB prior to participating in the study (47 out of 50); however, most also did not think that they had accurate knowledge about the program details. When asked to rank their knowledge of the program’s eligibility requirements on a scale from 1 (no knowledge) to 5 (full knowledge), the average response was 2.97, with only one participant indicating having full knowledge. On this same scale, participants ranked their average knowledge of what the application process involves at 2.79, knowledge of what benefits successful applicants receive at 2.35, and knowledge of how the benefit is administered at 2.57. Many were surprised that no one had recognized their key role in sharing program details and ensuring that front-line palliative care providers become informed about the CCB. Frustration was expressed over the fact that they were expected to seek out this information independently, especially considering their busy and constrained work schedules. There was variation in having knowledge of the CCB based on the different jobs participants held. For example, social workers typically had more detailed knowledge about the CCB than other front-line care providers due, at least in part, to the focus and nature of their work. In fact, other participants indicated that it was social workers to whom they would refer family caregivers so as to obtain details about the CCB program.

CCB Strengths & Limitations

Generally, participants see the implementation of the CCB program to be an important symbol of recognition for the valuable work that family caregivers provide to Canada and its health care system. Beyond this, the CCB was also seen to be useful in supporting family caregivers, particularly for two groups: those providing care for a family member with a relatively clear prognosis, and for families who could financially afford to take a leave that does not fully replace anticipated earnings during the care period. The simplicity of the medical documentation required for the application process was also cited as a program strength: *“It was an easy form for the physician to fill out. So I think people really appreciated that.”* The main limitation raised by the front-line care providers involves the limited period of support afforded by the program. Participants clearly believed that a program providing eight weeks of secured leave from work and six weeks of income assistance was far from sufficient to adequately care for a dying family member. Another major limitation identified was the lack of adequate funding the CCB provides for families, especially in cases when the caregiver is the primary earner of a household. A social worker explained: *“...a lot of people just won’t take it [the CCB]; they can’t afford to.”* A final critical limitation raised was the lack of awareness and working knowledge of the CCB program among front-line care providers. Overall, the participants felt that the CCB was not meeting its potential due to the lack of awareness surrounding the program’s existence.

“[T]hat six weeks is a big hindrance because they [family caregivers] say: ‘How do we tell when it’s six weeks? Can you let us know when it’s six weeks? What if we think it’s close to being the last six weeks, and then they go on for another month and we still want to be here? We’re cut off!’”

- front-line palliative care provider

Key Findings: Employers/Human Resources Personnel

Interacting with Family Caregivers

Employers and HR personnel reported that employees with family caregiving responsibilities had sometimes involved them in the application process to the CCB. While many participants interviewed had experience with regular Employment Insurance applications, few knew about the CCB prior to the research study.

CCB Expectations and Awareness

“I think there is too much information; I guess [the application is] 10 pages long and then it says keep clicking to get more information...I didn’t read through it very carefully because of the volume of text...”

- employer

Employers and HR personnel expressed a common expectation that the CCB should allow them to support and encourage their workers to spend as much as time as possible with their dying loved one. The current complexity of the application process, slow processing time, and short duration of the Benefit all contribute to employers’ inability to grant employees as much time as they require to provide care. Employers reported that the CCB should afford them the ability to ensure adequate income assistance for their employees while on leave, deeming the current maximum of 55% wage allotment inadequate. Participants also discussed how the CCB does not meet the kind of support expectations they hold for workers

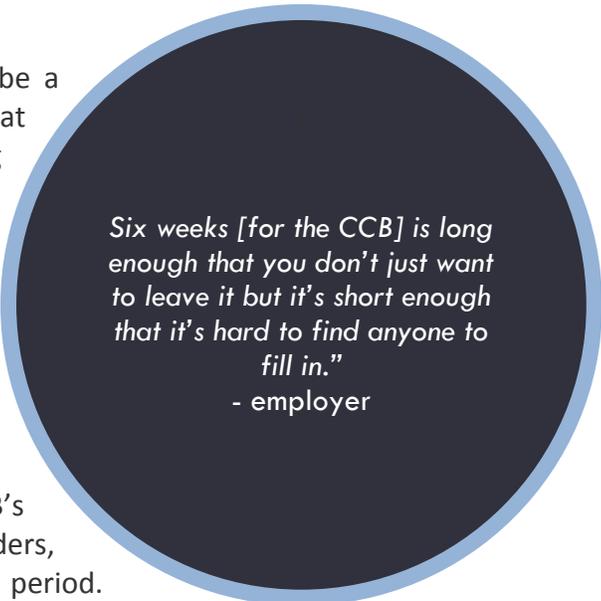
who contribute to the Employment Insurance contributory benefit scheme. The 600 insurable hours needed by the applicant only allows for a six week leave, a fraction of the 24 weeks available under the other Employment Insurance programs. The CCB's administration, most specifically its complex application process, was also seen as a problematic aspect of the Benefit amongst employers and HR personnel. Finally, participants explained that they were not usually aware of the CCB until an employee informed them, and felt inadequately prepared to help someone apply when the issue arose.

Effects on the Workplace and Administration Experiences

Employers reported that the CCB interfered with their workplace productivity, as they needed to find temporary replacement staff while the caregiver was on leave. The fact that the CCB's six week period can be taken out of succession posed further potential complications for employers. Both the applicant's position within the company and the size of the workplace had an effect on the CCB's impact within the company. An example of this is where CCB applicants who carried out specialized functions in their workplace, and/or who had been with the workplace for an extended period of time were more difficult to temporarily replace than less specialized or experienced workers. The CCB also had different impacts on companies of different sizes. Smaller workplaces might struggle to offer the same flexibility around leave policies when compared to larger workplaces where replacement staff is more readily available and workplace productivity not as affected by absent employees. Larger workplaces may also have a greater ability to integrate the CCB into their policies because of their established HR departments. At the same time, smaller workplaces discussed how they were unlikely to have to manage multiple applicants at the same time due to their smaller workforce.

CCB Strengths & Limitations

Participants thought that the CCB has the potential to be a strong social program. In general, they expressed a belief that the program was well integrated into the pre-existing workplace leave opportunities, including sick leave and vacation time. However, their common expectation to be able to fully support their employees' work-life balance has gone unmet by the current structure of the CCB. Furthermore, the ability of employers and HR departments to fully support their employees in the application process was often challenged due to a general lack of awareness about the CCB and the complexity of available information. Employers and HR personnel shared concerns about the CCB's design with caregivers and front-line palliative care providers, including inadequate wage coverage and an insufficient leave period. Concerns about the effect of the CCB on the workplace were complex and varied, reflecting the different administration experiences, workplace environments and roles of the CCB applicants found amongst the participants' companies.



Common Key Findings across All Stakeholder Groups

Generally, participants from all three stakeholder groups believed that the CCB is an important step towards better supporting family caregivers and recognizing their valuable role in Canadian society. Participants commonly mentioned that the CCB is useful and has the potential to alleviate stress for eligible caregivers. At the same time, the general sentiment shared by participants was that the CCB is not meeting its potential and that there is much room for program improvement. As a palliative care coordinator suggested: *"...it's [the CCB] improved a great deal from what it was, and so I'm thinking that that will continue, and...that changes will continue to be made... It's a work in progress is how I look at it."*

"I think that it could be a wonderful program...it is a great start... but I think it has a long way to go."
- home care nurse

CCB Awareness

Participants across the stakeholder groups clearly believe that one of the major barriers the CCB faces to reaching its potential is a general lack of awareness regarding the program's existence. As expressed by a community palliative care nurse: *"...I think the biggest issue is that a lot of these people [family caregivers] aren't even aware that it's out there."* This study's findings show that family caregivers expect to be informed about the CCB by either front-line palliative care providers or someone from their place of employment within a meaningful timeframe to effectively utilize the Benefit. Although participants from these two stakeholder groups indicated that sharing information about the CCB falls within the scope of their jobs, this requires them to have program awareness that, for the most part, exceeds present levels. Instead, it is more likely that awareness of the CCB will happen by chance, as explained by a HR professional: *"...until somebody comes and says 'I'm going to take compassionate care' and you go 'What? What's that? Let me research that'."* Further, amongst the stakeholders represented, front-line palliative care providers in particular demonstrated frustration that more efforts have not been put forth by the government to ensure that they are informed of the CCB, especially considering their critical role in increasing program awareness. It was also commonly expressed that more effort needs to be put towards informing the general public about the CCB's existence, which would allow Canadians to be more aware, while also holding the power to seek out more program information on their own.

"I am absolutely shocked that I didn't know about it, so in a way there's been a slip in the system... put it that way."
-family caregiver

Access to CCB Information

Many participants commented on the challenges of accessing CCB information, especially in quick and clear formats. Information on the CCB was typically sought out on a 'need-to-know' basis. This holds implications for members of all three stakeholder groups. For family caregivers, it means that information about the program was most commonly being sought during the stressful and emotionally-charged caregiving period, thus potentially acting as a source of burden. Meanwhile, for employers and HR professionals it means that they may be learning about the program's core features and eligibility requirements at the same time as trying to discern the more immediate concerns regarding hiring replacement workers or administering the leave through the workplace's payroll system. Acknowledging this, and the need for all stakeholder groups to become better informed about the CCB, participants

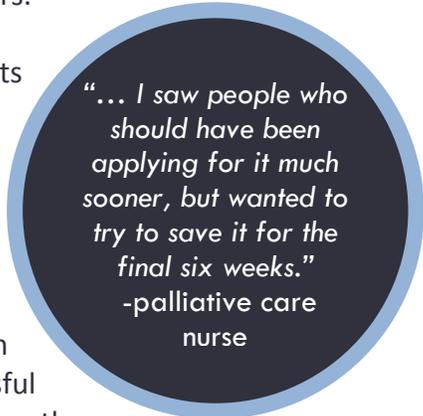
commonly stressed the need for better access to CCB information that can be made available in wide range of formats (e.g., pamphlets, posters, e-mails targeting different stakeholder groups) and in a variety of settings.

Commonly Noted Limitations

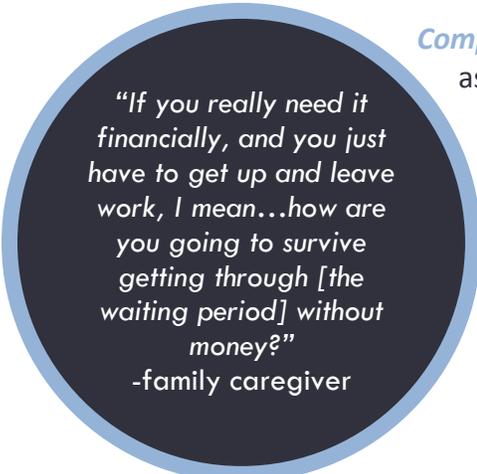
Application Process: Although some participants found the CCB application process to be fairly simple and straightforward, most found it to be complex and a major barrier to the program’s successful uptake. More specifically, the application was reported to be confusing, long, and in some cases simply overwhelming for caregivers to complete. As a result, this study’s findings demonstrate that family caregivers often require assistance with completing the CCB application, sometimes from members of the other stakeholder groups included in this study, in order to ensure they are able to successfully submit their applications.

Time frame: Although participants did not seem surprised that the CCB would have a time restriction, most believed that the eight weeks of secured leave and six weeks of income assistance currently offered is far from sufficient to adequately support caregivers. HR personnel also commented that such a short time-frame proves difficult when attempting to secure replacement workers.

Determining when to begin the leave: It was acknowledged by participants from all stakeholder groups that difficulties in predicting the time of death can leave family caregivers feeling unsure of when to start their CCB leave and receive its payments. Of particular concern is that family caregivers frequently desire to be present at the very end stages of a care recipient’s life, thus requiring prognostication at a level of precision beyond what medicine can do. This study’s findings suggest that family caregivers may delay starting the CCB in order to ensure they will be on secured leave at the very the end of life. As a result, some successful applicants are waiting too long to start the Benefit, thus not benefiting from the full six weeks of income assistance and eight weeks of leave.



“... I saw people who should have been applying for it much sooner, but wanted to try to save it for the final six weeks.”
-palliative care nurse



“If you really need it financially, and you just have to get up and leave work, I mean...how are you going to survive getting through [the waiting period] without money?”
-family caregiver

Compensation level: Clearly, participants found the limited financial assistance offered by the CCB to not be reflective of the costs associated with providing end of life care. Many stressed that in addition to these costs, caregivers’ regular bills and financial responsibilities continue during this period as well. This low payment level was suggested to be a major deterrent when considering applying for the program. Further, a position shared by many participants was that the two-week unpaid waiting period is not sensitive to the financial hardships that many family caregivers face.

Suggestions for Improving the CCB

Five common themes arose from all three stakeholder groups when participants discussed suggestions for improving the CCB. Each general theme is listed below. The *specific* recommendations made by each participant are listed in the Appendix, as well as those that fall outside of these five major suggestions for improvement.

1. Informational needs: When discussing the CCB, participants often referred to their knowledge about the CCB, or lack thereof, as well as their experiences accessing information. In general, participants thought the CCB was poorly marketed and had difficulty accessing or understanding information about it. Recommendations were made by each stakeholder group asking for more concise information and the creation of more stakeholder-specific information.

2. Application process: All three stakeholder groups cited difficulty or frustration in applying for, or instructing someone to apply for, the CCB. Participants recommended simplifying and also speeding up the application process.

3. Two week waiting period: All three stakeholder groups expressed concern about the two week waiting period and suggested eliminating it.

4. Length of the CCB leave: While some differences in responses emerged between employers/HR participant group and both the family caregivers and front-line palliative care provider participant groups in terms of how long the period of support provided by the CCB should be, participants generally recommended that the CCB should offer more time to its successful applicants

5. Financial Compensation: All three stakeholder groups commented on the inadequacy of the financial compensation the CCB affords and suggested increasing the percentage of wage replacement and/or increasing the maximum dollar amount allowed.

Conclusion

Since 2006, we have been undertaking a national evaluation of the Canadian CCB program. The study's overall purpose is to make policy-relevant recommendations that are informed by the needs of Canadian family caregivers and input from other key stakeholder groups who hold the power to shape program uptake, mainly front-line palliative care providers and employers/HR personnel. Methods of data collection have included conducting telephone interviews, holding focus groups, and keeping a 'watching brief' of policy and media coverage about the CCB.

Participants' responses confirm that there are a number of critical barriers to the successful uptake of the CCB, including: 1) the general lack of awareness regarding the CCB's existence; 2) various issues with the application process; 3) the requirement of a two week unpaid waiting period; 4) the inadequate amount of time the leave provides; and 5) the inadequate financial compensation the CCB offers. In addition to providing numerous suggestions on how to improve the CCB, the results of the present evaluation also provide valuable data to inform the development of other caregiver programs which aim to alleviate the burdens experienced by family caregivers.

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Detailed Suggestions for Improvement

Listed below are all the suggestions for improvement made by the participants, according to themes. Many of these suggestions were made by participants from two or more of the three groups interviewed.

1. Informational needs

- a) More stakeholder specific information created and disseminated in appropriate venues for that group (i.e.: In hospitals and public places for family caregivers, to appropriate front-line palliative care worker groups, such as bodies governing nurses like the VON, and to workplaces and Chambers of Commerce across the country for employers)
- b) More condense summary sheets available with concise information
- c) More marketing through printed material, national media (including television and radio), and online
- d) Make the website easier to navigate, and more user-friendly, especially cutting down on the length of information and changing to the wording to make it more accessible
- e) More information posted in the community, such as on bulletin boards in public venues (e.g., grocery stores and pharmacies)
- f) Video links on the website with informational videos showing real people applying and explaining the application process

2. Application process

- a) Speed up the application process- possibility for express process and one-day processing in recognition of the temporal nature of palliative care
- b) Have a 1-800 number where you could call and have an application package sent to you, or have someone readily available to complete the application with you over the phone
- c) Condense the application and have more user-friendly language
- d) Have specialized representatives and supports for each individual stakeholder group at Service Canada and EI Departments
- e) HR/employers suggested creating a software program, or changing the processing format, to make it easier to process the CCB
- f) Inform applicants, and those helping people with their applications, about expected application turn-around times

3. Un-paid two week waiting period

- a) Eliminate it
- b) Shorten the waiting period to several days
- c) Pay it, even retrospectively

4. *Length of the Benefit*

- a) Front-line palliative care workers and family caregivers unanimously recommended the CCB be extended in length
- b) Both front-line palliative care workers and family caregivers suggested the CCB be continued for some time after the patient's death to support the bereavement period. HR/employers suggested that if the leave had not been maxed out at the time of death, the remaining time should be allowed to be taken as bereavement leave
- c) Potential to extend the CCB after six weeks if necessary
- d) Same length of time as other EI benefits, such as Maternity Leave
- e) HR/employers suggested that the CCB be extended to the same length of leave entitlement as other EI programs
- f) HR/employers suggested that caregivers should be able to switch over to normal EI programs easily after the six weeks of the CCB is up if their care recipient still requires support
- g) In contrast to the above two points, HR/employers also expressed concerns about replacing employers who were gone longer than the current six week Benefit period, and thus were not as unanimous about their recommendations to extend the Benefit as were front-line palliative care workers and family caregivers

5. *Financial Compensation*

- a) Increase the maximum amount allowed beyond the current \$447/week cap
- b) Increase the monetary amount of wage replacement to at least 60-75% of wages
- c) Implement a non-taxable feature, or some sort of social RSP or other credit
- d) Continue contributions to pension while on the CCB
- e) Special support for those who are travelling in order to provide care, in recognition of travel expenses
- f) Allowing employers top-ups
- g) Allowing applicants to continue their pension earnings or seniority ranking uninterrupted while on the CCB

6. *Sharing the benefit:* The ability to split up the benefit between caregivers was mentioned as an area for improvement by family caregivers and HR/employers specifically.

- a) Increase the amount of time if the CCB is being shared
- b) Allow multiple family members to take six weeks of leave (rather than allowing six weeks in total to go towards each dying person)
- c) This would make it easier for HR/Employers to process the benefit , as workplaces would not need to manage splitting the benefit
- d) A longer Benefit would make sharing more worthwhile
- e) Allowing applicants to alternate days (suggested by the family caregiver group)

7. **Eligibility:** Recommendations to changing the eligibility criteria were mentioned foremost by front-line palliative care workers and HR/employers.

- a) Allowing those who are self-employed or currently not working to apply, including stay at home parents, or those who have been providing care for some time
- b) Lengthening prognosis of death 'within the following 26 weeks' to possibly 'upwards of six to nine months'
- c) Change the definition of "risk of dying within 26 weeks" to afford more flexibility for people requiring care due to unforeseen, or adverse situations, or to accommodate concerns about labelling someone as "at risk of dying"

8. **Flexibility:** Recommendations for flexibility were suggested by family caregivers.

- a) Allowing applicants to work several days out of the week
- b) Allowing the CCB to be taken more than once a year- in recognition that multiple people may want to take the full benefit, or that the patient may rebound, but need palliative care again later on

