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Clare Gardiner & Kelli Stajduhar

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Internationally transferable policy solutions for supporting employed end of life family caregivers: Canadian compassionate care benefit

Clare Gardiner [1], **Kelli Stajduhar**[2]

[1]School of Allied Health Professions, Nursing & Midwifery, The University of Sheffield, Sheffield, UK, [2]School of Nursing and Institute on Aging & Lifelong Health, University of Victoria, Victoria, Canada

Background: Policy and employment legislation are key for supporting employed end of life family caregivers. The Canadian Compassionate Care Benefit is one example of a benefit which supports employed family carers, but the potential transferability of the Benefit to other countries has not been explored.

Aim: The aim of this study was to explore the implementation and impact of the Canadian Compassionate Care Benefit and assess its potential transferability to comparable countries.

Methods: A multi-method design was used, incorporating an integrative review of published literature and qualitative interviews with stakeholders who had expertise with the Compassionate Care Benefit, from across Canada. The findings from the two phases were analysed separately and were integrated at the stage of interpretation.

Results: Fourteen interviews were conducted with stakeholders, and sixteen relevant articles were identified from the integrative review. Whilst the CCB was viewed as an important support for carers, problems were highlighted which would need to be addressed to improve access and ensure equity in other countries or settings. The results highlight the importance of a receptive socio-political landscape in driving policy change, noting political incentives and individual champions as key for negotiating policy prioritization. The lack of evidence on cost-effectiveness may impede international transferability or policy expansion.

Conclusion: Whilst the Compassionate Care Benefit has been conceived and implemented specifically for the Canadian context, there may be potential for it to be adapted for other comparable countries. Further research on the Compassionate Care Benefit, particularly around cost-effectiveness, would support international policy transfer.

Keywords: Palliative care, Family caregivers, Informal caregivers, Employment, Benefits, Policy

Background

Family caregivers provide the majority of care for people who have palliative and end of life care needs; estimates suggest they provide between 70% and 90% of all care delivered at the end of life.[1] In this context, informal or family caregivers are those in a close supportive relationship with a patient, who share in the illness experience and undertake vital care work and emotional management. They are often, but not always, family members.[2] Demographic changes including an ageing population and more people living longer with complex health conditions means the reliance on family caregivers is likely to increase over coming years.[3]

The concept of 'caregiver burden' is well established in the palliative and end of life care literature and family caregiving is known to be associated with a range of negative outcomes. Caregiver burden is a multidimensional construct encompassing physical, psychological, emotional, social and financial aspects.[4–6] The financial implications of caregiving have previously seen limited research attention, but recent social and economic changes in the UK and internationally have highlighted the devastating impact of poverty on caregiving at the end of life.[7–9] As a consequence, either through choice or necessity, growing numbers of individuals will take on a caring role whilst in paid employment, and will continue to work whilst providing care.[10]

Working carers often have to adapt and modify their paid working practices to combine employment

Correspondence to: Clare Gardiner, School of Allied Health Professions, Nursing & Midwifery, The University of Sheffield, Barber House Annexe, 3a Clarkehouse Rd, Sheffield, UK. Email: c.gardiner@sheffield.ac.uk

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and caregiving.[11] Carers may have to change jobs, use up annual leave or sick leave, or leave paid work altogether. In a recent study from Canada, more than half of employed caregivers ($n = 243$) had one employment transition over the palliative trajectory and 29% had three or more transitions.[12] Once employment changes have been made, it can be difficult for carers to resume their pre-caring role, even after the care dependent has died.[13] A study of employed family carers from the UK, New Zealand and Canada found that combining caregiving with paid employment has significant negative implications for the caregiver, eroding their self-worth and confidence and potentially leading to a sense of dependency on welfare.[13]

Policy and employment legislation are key for supporting employed family caregivers and facilitating the provision of palliative and end of life care,[14,15] but differences exist in how policies are implemented internationally and the effectiveness of such programmes.[5] In 2004 Canada introduced a federally legislated benefit called the Compassionate Care Benefit (CCB) to support end of life carers in paid employment. The CCB is available to Canadians who have made sufficient Employment Insurance contributions over their working life. The benefit provides financial assistance to informal caregivers, allowing them to take up to six months away from work to provide care to someone in the last six months of life. Caregivers receive 55% of their earnings up to a maximum weekly amount ($650/week in 2023).[16,17] The CCB is a potentially transformative public health intervention which supports family caregivers and enables them to remain in the workforce. The CCB may represent a policy solution for other countries with comparable characteristics, but the potential transferability of the CCB has not been explored.[10] The aim of this study was to explore the implementation and impact of the Canadian Compassionate Care Benefit (CCB) and assess its potential transferability to comparable countries.

Methods

A multi-method design was used incorporating an integrative review of published evidence (phase 1) and semi-structured qualitative interviews with stakeholders (phase 2). This approach was chosen to draw on both existing research and new findings to gain a comprehensive understanding of the research topic. Unlike mixed method research, multi-method research is not restricted to combining qualitative and quantitative methods but rather is open to the full variety of possible methodological combinations.[10,18,19]

Phase 1: An integrative review was conducted to explore published evidence about the CCB.[20] A comprehensive search strategy was developed, in conjunction with a Health Sciences librarian, to capture academic literature, policy documents and grey literature. Searches were carried out in five databases (Web of Science, Scopus, CINAHL, Proquest, PubMed Central) using the following Medical Subject Headings (MeSH) and keywords: Canada; Canadian; compassionate care benefit; compassionate care leave; employment insurance; employment benefit; federal benefit; carer; caregiver. Databases were searched on 31/05/23 and searches were limited to English language and documents published since 2003 (the CCB was implemented in 2004). Website searches were also conducted of organizations which hosted information about the CCB (e.g. Canadian Government, Statistics Canada). All identified studies were extracted into Endnote and inclusion and exclusion criteria were applied (Table 1).[10]

CG screened all references independently, firstly by title/abstract and then by full text. Where a second opinion was required this was provided by KS and consensus was achieved through discussion. Data were extracted from included studies and recorded in a data extraction table. Quality appraisal of studies was undertaken according to the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI) guidance and studies were assessed as low/medium/high quality on the basis of methodological quality, methodological relevance and topic relevance. No evidence was rejected due to quality appraisal, instead the appraisal informed the weight placed on the findings of different studies.[21] A narrative thematic approach was used to synthesize the data and to identify key themes from the included literature. The review protocol was not registered.

Phase 2: Qualitative designs are particularly suited to understanding policy solutions and capturing complexity. Individual semi-structured interviews were conducted with stakeholders from Canada who met the following inclusion criteria: expertise in

Table 1 Integrative review inclusion and exclusion criteria

Inclusion Criteria	Exclusion criteria
All types of original research and audit published in full	Non empirical reports, guidance documents, conference abstracts etc.
Theoretical discussions based on empirical research	Opinion pieces not substantiated by evidence
Any country of publication	
English language	
Published between 01/01/2003-31/05/23	
Studies focused on the Canadian Compassionate Care Benefit including implementation, impact, cost-effectiveness, experiences of, barriers to use.	

palliative/end of life care; aged >18 years; able to communicate in English; expertise regarding the Compassionate Care Benefit.

Participants were identified via: [1] personal contacts of the authors and professional networks across Canada and; [2] publicly available information on university, hospital, government and community organization websites. Participants were purposively sampled in order to achieve variation across key characteristics (primarily professional role and Province). Once participants had been identified they were sent an email with information about the project and those who agreed to participate were invited to take part in a semi-structured interview. The target sample size was 8–10 participants. Sample size was driven by pragmatism and an 'Information Power' approach, which takes account of a broad set of methodological principles meaning the sample size is established iteratively, based on the quality of data and sample characteristics.[22,23]

A question guide for the interviews was developed and sought views on the implementation of the CCB (Table 2). Interviews were conducted by CG either online using GoogleMeet or over the telephone. Interviews were digitally recorded and field notes were taken. Interviews lasted between 23 and 59 minutes (mean 36 mins) and all interviews were conducted in May–June 2023. Interviews were transcribed verbatim and uploaded to QSR NVIVO 12 for analysis; transcripts were not returned to participants for checking. Data were analysed using a reflexive thematic analysis approach[24] following six steps of analysis: data familiarization and immersion; methodically reviewing the data to identify codes; generating initial themes which capture patterns of meaning across the dataset; reviewing and checking themes; refining and naming themes.

Multimethod research is characterized by different approaches or methods being used in parallel or sequence and only being integrated when final inferences are made.[18] Thus, phases one and two were analysed separately and key themes were identified independently, and data were only combined at the stage of interpretation. Table 4 presents a matrix which outlines how the two phases of the study contributed to the themes.[10]

Ethical approval for the participant interviews was granted by the University of Victoria, Canada (ref 23-0175) and The University of Sheffield, UK in May 2023.

Table 2 Interview topic guide

Questions about the Compassionate Care Benefit (CCB)

- Can you tell me a little about how the CCB came about? [prompts: when, how, who drove it forwards]
- What factors do you think were most important or influential, in lobbying the Canadian government to implement the CCB?
- What were the main barriers in lobbying the Canadian government to implement the CCB?
- How do you think the general public view the CCB? [have most people heard of it? Is it viewed positively?]
- In general, do you feel the CCB is well used by end of life carers? Are there any barriers to it being used / or which create prejudicial access?
- Do you think there are any problems or issues with the CCB and the way it is implemented? If so what?
- What worked well in the implementation? Have there been any unanticipated benefits?
- Are you aware of any evidence on the cost or cost-effectiveness of the CCB? [prompts: cost-effectiveness considers the cost of running the programme and how this may be offset by gains in worker productivity]
- Do you think that the CCB would be transferable to another country such as the United Kingdom? [Please explain why/ why not]

Findings

The initial searches of the integrative review identified 158 articles, after screening sixteen articles remained and were included in the review (Fig. 1). All articles were from Canada and were published between 2006 and 2014. The sixteen articles presented data from eight individual studies (Table 3).

Twenty one individuals were contacted and invited to participate in the qualitative phase and fourteen agreed and took part in an interview. Eleven participants were female and three were male. Participants were based across Canada and all worked in professional roles that had relevance to the CCB including health and social care professionals, researchers, policymakers, and federal government employees.

Data from the integrative review and interviews generated six key themes (Table 4). Themes were: [1] socio-political context leading to the implementation of the CCB; [2] evolution of policy scope; [3] cost and cost effectiveness of CCB; [4] positive impacts on patient/carer/labour market; [5] perceived problems with the CCB; [6] transferability of CCB to other comparable countries. Each of the themes will be discussed in turn, supported by verbatim quotes from participants and data from the integrative review.[10]

Socio-political context leading to the implementation of the CCB

The socio-political landscape prior to 2004 was key to the implementation of the CCB. Key features included a perceived 'public appetite for change' and a strong advocacy landscape with lobbying from carers charities and palliative care organizations. Research highlighting the challenges faced by carers was also important and was used by advocacy organizations to support lobbying.

> I think another thing that happened was all the research reports that had been done leading up

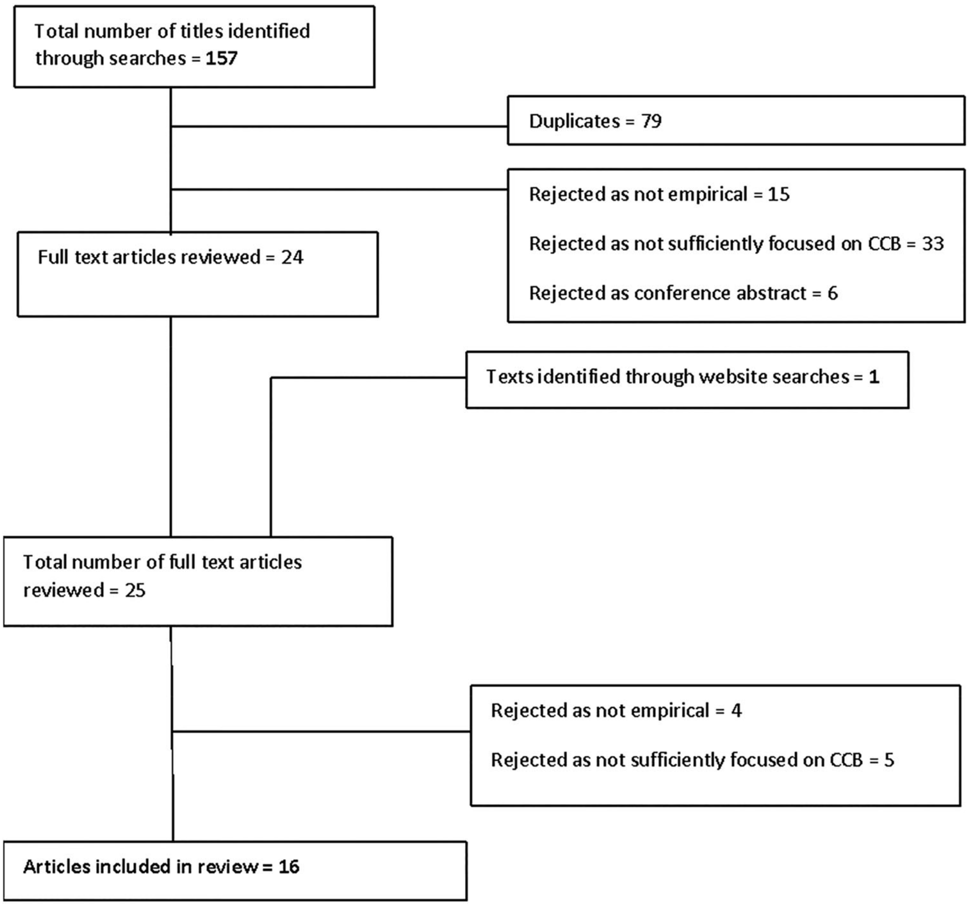

Figure 1 PRISMA diagram summarizing search results.

> to this. So, some work that was happening with some of the larger advocacy and nonprofit organizations that were doing some work. But also within Parliament, there had been reports leading up to that. (P19)

The importance of individual ‘champions’ was highlighted, in particular those in influential political positions. Individual champions were able to capitalize on the socio-political context and drive forward the implementation of the CCB as a way of ‘helping the government solve their own problems’. Nonetheless, considerable practical and political barriers had to be surmounted before the CCB was passed into legislation.[10]

> The main barrier was getting it on the agenda, getting it in the speech from the throne, that was critical. Getting it high enough on the social affairs agenda to get the approval of the social affairs committee of cabinet. Getting the right wording into the legislation. It took a lot of work. (P13)

Evolution of the CCB policy scope

When it was established in 2004 the CCB had a relatively limited scope. Since then, a number of changes have been made to the programme in order to widen the population who can benefit. These include an increased timeframe for the benefit and expanded eligibility criteria. These changes happened incrementally over time and were informed by lobbying and emerging research which criticized some elements of the CCB and raised questions about its appropriateness as a public health response for sustaining informal caregivers.[10,26,29,30,32,33,37–39]

> Well, you know, when it first came out it was much more limited with respect to the time frame and it was for only one family member and that was extended you know, as time went on hopefully as a result of some of the work that we did, you know, some of the evaluative work, you know we always hope that our research is going to impact policy. And we did find that there was changes with respect to the length of the benefit as well as who could actually apply for it. (P6)

Interestingly, when the CCB was first implemented a number of limitations were acknowledged. However, there was a sense that ‘something is better than nothing’ and getting even a flawed version of the CCB implemented was acceptable, as changes could be made to future iterations of the programme.

Table 3 Data extraction from the integrative review

Author, year	Country	Aim	Methods	Key findings	Quality appraisal
Crooks, Valorie A. Williams, Allison Stajduhar, Kelli I. Allan, Diane E. Cohen, S. Robin. 2007 (25)	Canada	To examine the usefulness of the CCB for family caregivers in different types of palliative caregiving situations and to inform the development of a full-scale evaluation of the programme.	25 qualitative interviews conducted with family caregivers from eight Canadian provinces in a pilot evaluation of the CCB	3 specific thematic findings: awareness of the CCB (of the 25 respondents, 20 were aware of the benefit prior to participating in the study), access to information related to the CCB (difficulty accessing reliable and accurate information), and the application process (difficult process).	moderate
Crooks, Valorie A. Williams, Allison Stajduhar, Kelli I. Cohen, S. Robin Allan, Diane Brazil, Kevin. 2012 (26)	Canada	(1) appreciate how intended users and other family caregivers view the programme's very nature; (2) identify programme challenges and improvements that emerge from considering family caregivers' ideal expectations; and (3) contribute to a larger evaluative study to make policy-relevant recommendations for CCB improvement.	57 qualitative interviews with family caregivers who have cared for a dying family member	Eligibility expectations – concerns around Employment Insurance (EI) contributions. Informational expectations - ideal expectation that family caregivers would be informed of the CCB prior to caregiving or while providing care. Timing expectations – 2 week unpaid waiting period should be removed. Financial expectations - respondents believed that an important part of the CCB was the provision of income assistance in addition to a secured leave from employment.	high
Drummond 2010 (27)	Canada	To critically evaluate federal and provincial income tax regimes aimed at increasing the financial security of caregivers, and also looks at shortcomings of the Compassionate Care Benefit offered through the federal Employment Insurance Act.	Theoretical discussion citing published evidence	From 2004-2009, just under $50 million has been paid to Canadians through the benefit. Slightly over 71% of claims are sucessful. Most claimants aged 25–54 years. The attachment of benefits to employment can be problematic because it renders employment and market participation the norm and care work as an exceptional circumstance. Gender disparity: ~74% CCB claimants are female, yet women are less likely than men to be eligible for EI benefits. Eligibility are even more exclusionary for those who are marginalized on account of their race, culture or disability or immigrant status. Initial estimated costs of CCB were $240million a year. Between 2004 and 2009, the CCB cost the EI programme only $50 million dollars.	moderate
Dykeman S & Williams A. 2013 (28)	Canada	Qualitative exploratory evaluation of Knowledge Translation (KT) tools based on the CCB, used with social workers.	Eight social workers used the KT tools for six months, followed by semi-structured interviews to assess tool use.	The results suggest that knowledge translation about the CCB could be targeted toward caregivers earlier on in the disease progression before the terminal diagnosis, and knowledge tools must be disseminated to more locations. Social workers provide a critical role in KT about the CCB.	moderate

Continued

Table 3 ***Continued***

Author, year	Country	Aim	Methods	Key findings	Quality appraisal
Dykeman S & Williams A. 2014 (29)	Canada	To examine how the CCB might evolve over time, by examining the evolution of a similar employment insurance programme, Canada's Maternity Leave Benefit.	National media articles were reviewed ($n = 2{,}698$) and, based on explicit criteria, were analysed using content analysis.	Recommendations based on the Maternity Leave Benefit (MLB) analysis: Increase the length of CCB leave, possibly to the length recognized as the end-of-life period by Service Canada (the last six months of life); Allow caregivers to carry some of the CCB leave over to the bereavement period; Allow multiple applicants each their own CCB leave, instead of limiting the leave to one per care-recipient; Reduce the number of qualifying hours needed for applicants who are applying again within a short time after the first leave was taken	moderate
Flagler J & Dong W. 2010 (30)	Canada	Explores whether a programme designed as part of Employment Insurance can provide comprehensive support to those informal end-of-life care-givers, and whether it is equally accessible to all Canadians.	Theoretical discussion	The CCB has its shortcomings and it is not sufficient to address the financial needs of low-income caregivers, particularly women from disadvantaged social groups and new Canadians. In order to make the CCBs programme effective, it needs to be made independent from Canada's Employment Insurance Programme and hence become a true compassionate programme that supports all the informal caregivers equally.	moderate
Giesbrecht M. 2009 (31)		Examine usefulness of the CCB for family caregivers; explore palliative care providers perceptions of the CCB; explore barriers and facilitators in the workplace and labour market that shape uptake of the CCB.	Thesis	Note - the relevant thesis chapters were subsequently published as journal articles (see 32, 33).	high
M. Giesbrecht, V. A. Crooks, N. Schuurman and A. Williams 2009 (32)	Canada	Aims to identify: (i) who likely CCB-eligible family caregivers are; (ii) where these individuals' households are located; and (iii) how best to get information about the CCB to them	(i) Literature review; (ii) spatial analysis using Census Canada data; (iii) 50 interviews with frontline palliative care providers.	Results indicate that targeted dissemination efforts undertaken outside of urban cores are likely to be most efficient in reaching potential or current CCB-eligible family caregivers. This strategy should be implemented through multiple formats and venues via two information pathways: (i) from key professionals to family caregivers and (ii) from the community to the general public.	high
M. Giesbrecht, V. A. Crooks and A. Williams 2010 (33)	Canada	To identify expectations of the CCB from the perspective of frontline palliative care providers	50 qualitative interviews with frontline palliative care providers.	Findings demonstrate that participants expect the CCB to provide: (i) an adequate length of leave time from work, which is reflective of the uncertain nature of caregiving at end-of-life; (ii) adequate financial support; (iii) information on the programme to be disseminated to carers so that they may share it with others; and (iv) a simple, clear, and quick application process.	high

M. Giesbrecht, V. A. Crooks and A. Williams 2010 (34)	Canada	To explore the relevance of scale as an explanatory concept used by informal family caregivers and front-line health and social care workers when discussing their experiences with a the Compassionate Care Benefit (CCB).	As part of a larger evaluative study on the CCB, semi-structured interviews with 57 family caregivers and 50 front-line health and social care workers from across Canada were conducted and transcripts were thematically analysed.	Implications for the CCB included: Demographic (costs for family members to travel to provide care are not covered by the CCB); Economic: Some citizens are more likely to be ineligible for the CCB due to regional (un)employment levels; Distance: Higher out-of-pocket costs to cover travel to major urban and/or regional centres; Access: Potentially restricted access to information about the CCB; Home care: Lack of formal home support may discourage carers from providing care. Gender: Women are more likely to be ineligible for the CCB due to employment circumstances while more likely to serve as carers.	moderate
M. Giesbrecht, V. A. Crooks, A. Williams and O. Hankivsky 2012 (35)	Canada	Examine how formal front-line palliative care providers understand the role of diversity in shaping Canadian family caregivers' experiences of end-of-life care.	Fifty semi-structured phone interviews with front-line palliative care providers from across Canada	Findings reveal that experiences of caregiving are not homogenous and access to services and supports are not universal across Canada. Without considering diversity, patterns in vulnerability and inequity are overlooked, and thus continually reinforced in health policy. Re-framing categorizations of caregivers can expose specific vulnerabilities and inequities while identifying implications for the CCB programme. From a policy perspective, this analysis demonstrates why diversity needs to be acknowledged in policy circles, including in relation to the CCB.	moderate
S. J. Heymann, M. Gerecke and M. Chaussard 2010 (36)	Canada	To measure how Canada's provincial and territorial public employment leave policies compare with those of other countries around the world.	We gathered data from all Canadian provinces and territories on three paid leave policies essential to health: paid sick leave for employees, paid parental leave and paid sick leave to care for family members. We then compared the Canadian policies with our data on 186 of 192 UN nations.	The federal government guarantees Canadian workers six weeks of paid leave to provide care or support to gravely ill family members. Only 39 countries guarantee such leave with pay. Most, but not all, provinces guarantee workers' job protection during compassionate care leave.	moderate
M. Vuksan, A. M. Williams and V. A. Crooks 2012 (37)	Canada	To uncover the expectations that Canadian employers/human resources (HR) professionals have of the CCB, in addition to their experienced realities of having staff utilize this programme.	Five qualitative focus group discussions with 27 employers/HR across Canada	Participants valued the CCB programme and the potential it holds for improving quality of life for caregiver-employees. Possible changes to the programme could include speeding up the processing time and eliminating the two-week unpaid waiting period. Many participants were unaware of the CCB prior to the focus group, which suggests that the CCB has been under-advertised to the key group responsible for promoting it to employees. Participants expressed a desire to have instruction about how to interpret the CCB to staff. Challenges noted with regard to 55% of income.	high

Continued

Table 3 ***Continued***

Author, year	Country	Aim	Methods	Key findings	Quality appraisal
A. Williams, V. A. Crooks, K. I. Stajduhar, D. Allan and S. R. Cohen 2006 (38)	Canada	To highlight the experiences of family caregivers caring for people with non-malignant advanced chronic illness.	25 qualitative telephone interviews were conducted with family caregivers	The CCB has a number of limitations, particularly for caregivers of patients diagnosed with non-malignant advanced chronic illness. The central limitations are: • Difficulties associated with accurate prognostication • Limited definition of 'family member' • Insufficient length of the funding period.	moderate
A. M. Williams, J. A. Eby, V. A. Crooks, K. Stajduhar, M. Giesbrecht, M. Vuksan, et al. 2011 (39)	Canada	How does the CCB operate as a public health response in sustaining informal caregivers, and whether it adequately addresses aspects of caregiver burden that are addressed within the Population Health Promotion (PHP) model.	57 telephone interviews were conducted with Canadian informal caregivers in five different provinces	Informal caregivers spoke to several of the determinants of health outlined in the PHP model that are implicated in their burden experience: gender, income and social status, working conditions, health and social services, social support network, and personal health practises and coping strategies. They recognized the need for improving the CCB to better address these determinants. Demonstrates that the CCB is not living up to its full potential in sustaining informal palliative and end of life caregivers. Effort is required to transform the CCB so that it may fulfil the potential it holds for serving as one public health response to caregiver burden.	high
Canadian Employment Insurance Commission (CEIC) 2023 (40)	Canada	The Employment Insurance Monitoring and Assessment Report presents the analysis of the impact and effectiveness of the benefits and other assistance provided under the Employment Insurance Act. Fiscal year (FY) April 2021–April 2022	Analysis of Canadian federal government data on EI benefits	Over FY21-22, there were almost 6,800 new claims established for the CCB, similar to previous fiscal year. Less than one in ten claims completed in FY21-22 had weeks of benefits that were shared among two or more caregivers (6.6%). Claims by women accounted for 70.6% of new claims. Claimants < 44 years received a smaller share of the amount paid in CCB (33.6%) than their demographic weight in the Canadian labour force (58.2%). Conversely, claimants > 45 years received a higher share of the total amount of CCB paid (66.4%) than their relative representation in the labour force (41.8%). The total amount paid in compassionate care benefits was $46.0 million in FY21-22. The average duration of CCB claims was 11.6 weeks.	moderate

Table 4 Matrix outlining how the two phases of the study contributed to the themes

Theme	Informed by integrative review	Informed by qualitative interviews
Socio-political context leading to the implementation of the CCB		x
Evolution of policy scope	x	x
Cost and cost effectiveness of CCB	x	x
Positive impacts on patient/carer/labour market	x	x
Perceived problems with the CCB	x	x
Transferability of CCB to other high income countries.		x

> Now we had hoped originally to get 10 weeks, We only got six weeks. [NAME] and I had a quick call and said 'better six weeks than no weeks'. So we both said … all right, if it's only six weeks that we can get through. (P5)

Cost and cost effectiveness of CCB

The majority of evidence on cost and cost-effectiveness came from the literature review.[27,36,40] In 2010 Drummond reported that the initial estimated costs of the CCB were $240 million a year, however between 2004 and 2009 the CCB cost the EI programme only $50 million dollars; representing roughly 3.5% of the estimated cost. Employment Insurance Monitoring and Assessment Reports are published annually by the Canadian Government and provide further detail of costs. In 2021/22 the total amount paid in compassionate care benefits was $46.0 million, compared to $43.4 million in 2020/21.[40]

There was no evidence relating to the cost-effectiveness of the CCB. However many interview participants were convinced that the CCB was cost saving from the perspective of the federal government because the financial cost of the CCB would likely be offset by carer contributions in other areas e.g. reducing hospital admissions, reducing the need for formal health care services and improving employee retention in the carer workforce.[10]

> If there is a family member who wants to stay at home, care for their loved one, so they can stay at home, which is where most people want to be and it keeps them out of hospital, then I think there would be cost savings in there at least for the health care system. (P21)

> The biggest thing like to me, one of the biggest things that this benefit was intended to do was … yes it's providing income, it's limited but … I felt like it was trying to provide a mechanism so that it would avoid people being fired as a result of having to do care. (P4)

Positive impacts of the CCB on patients, carers and the labour market

A number of positive impacts of the CCB were identified including enabling patients to be cared for and to die at home, reducing stress and anxiety, and improving wellbeing for patients. For many carers the CCB was perceived as a 'lifeline'. Carers benefited from the job security of knowing that their employment was protected, in addition to financial security and the legitimization of caregiving as a 'job'. Overall the CCB was perceived as supporting family caregivers quality of life.[37]

> Certainly when people do hear about it they think that's a great thing. It's kind of a no-brainer. (P16)

> It's a real sigh of relief … it doesn't eliminate all the pressures but it definitely eases considerably the pressures, and allows a person to sort of be focused on what is here in this moment, specifically really quality of life, not just for the patient, but for the caregiver. (p14)

From the perspective of employers, the CCB was seen to improve workforce retention and reduce staff turnover, in addition to improving staff wellbeing and promoting a compassionate working environment.[37]

> So I think it's important, and then as an employer I get that person back afterwards instead of having to go and train someone which I've already spent several years growing them and training them into a role. So it makes sense on a whole variety of levels. (P19)

Perceived problems with the CCB

A number of problems were identified with the CCB. The application process was described as complex and overly burdensome. Concerns were raised over inequity, with particular groups of carers disproportionately disadvantaged in terms of access. Eligibility for the CCB is based on Employment Insurance (EI) contributions and carers with insufficient EI contributions, often women and those from lower socioeconomic groups, are ineligible for the benefit.[25–35,37–39]

> The fact that it was attached to employment insurance meant that there were many carers who would not be eligible for a government benefit. (P9)

For applicants who are successful, the CCB only provides 55% of their income. It was noted that many carers would be unable to live on such a reduced income, particularly those on minimum wage or who are struggling with debt.[33,37,39]

> What with the cost of fuel and groceries and everything going up so much, and housing, there's not very many people who can afford to take a 50% cut in their income. So its very challenging for people. (P16)

A further source of inequity relates to the prognosis of the care dependent. Eligibility for the CCB depends on a prognosis of six months or less. This eligibility criteria restricts who can apply and tends to favour carers supporting dependents with a cancer diagnosis.[10,27,38]

> But I think this idea of six months … and it really fits a cancer [trajectory], this old idea of how people die of cancer "you're gonna die soon, you get put into hospice care, you'll die within three months or six months". But for diseases like dementia, they last 10 years, when do you take the benefit … they're gonna have it for 40 years. When do you take this benefit? How does that help you? (P10)

Interview participants unanimously agreed that the CCB is not widely publicized and most people in the general population are unaware of its existence, something that was backed up by the literature.[25,26,28,32,37]

Transferability of CCB to other high income countries

The CCB was perceived as a transferable policy solution for supporting informal carers in other high income countries, including the UK.[36] Crucial to the successful implementation of the CCB was its integration within an existing benefits programme and interview participants felt this approach could be modelled in other countries.

> If you have a platform like Employment Insurance or some kind of benefit that people get when they're out of work. I think that's been one of the positives … that it was aligned with a system that already existed rather than creating its own. So if you have an aligned system, I think that is helpful. So I think it could certainly be transferable. (P2)

Further considerations for policy transferability included theoretical framing. Williams et al.[39] suggests framing the CCB as an employment benefit means many carers are ineligible, and therefore the CCB is unable to live up to its potential as a public health intervention. Furthermore, the attachment of benefits to employment can be problematic because it renders employment and market participation the norm and care work as an exceptional circumstance against which to be insured.[27] Despite this, it was agreed that support for family caregivers should be prioritized internationally and the CCB could provide a means to do this.[10,36]

Discussion

This study aimed to explore the implementation and impact of the Canadian Compassionate Care Benefit (CCB) and establish the transferability of the CCB to comparable countries including the UK. This is the first study to explore the implementation and impact of the CCB in the context of assessing potential policy transferability.[10]

Previous evidence has established the importance of providing employment support, including financial assistance, to family caregivers of those approaching the end of life.[5,27] In the UK, evidence suggests that current welfare, benefits and employment legislation are insufficient to meet the needs of employed end of life family caregivers.[5,41] Whilst the recent Carer's Leave Act (2023) enshrines a statutory entitlement to five days leave per calendar year for employees that are providing care, there is no requirement for this leave to be paid, raising questions about who is able to benefit.[42] Internationally, caregiver policy is inconsistent and lacks coherence meaning carers needs are not prioritized.[14,15] The CCB is one of very few policies globally that provide financial assistance for employed end of life family caregivers. As such the CCB may provide a useful model for future policy developments in comparable countries such as the UK.

The results highlight the importance of a receptive socio-political landscape in driving policy change, noting that advocacy alone is insufficient without a political incentive and individual champions are key for negotiating policy prioritization. A recent policy analysis in the UK highlighted support for unpaid carers as one of the top three priorities for improving palliative care.[43] Good policy has been described as occurring where 'politics, evidence and delivery align' and the CCB provides one example of policy implementation which is deeply embedded within political systems but is also underpinned by research and engagement with policy actors.[43] Policy implementation is only the first step in ensuring that policy aims are met. Policy change happens incrementally over time and political negotiation in addition to a developing evidence base are required in order to expand policy to meet its full potential.

Whilst the CCB was overwhelmingly viewed as an important support for carers a number of challenges were highlighted which would need to be addressed to improve access and ensure equity in any other country or setting. Some groups of carers are disproportionately disadvantaged in terms of access to the CCB including those on low income, women and carers of people with non-cancer diagnoses.[44] The cumulative effect of multiple intersectional sources of inequity is likely to exacerbate these issues and further research and advocacy is required to identify innovative solutions. Linking with social policy research may be particularly valuable for developing actionable solutions for driving change.[45]

The lack of evidence on cost-effectiveness presents a further challenge to justifying policy expansion or international transferability. This reflects a lack of evidence internationally on the cost effectiveness of benefits which support unpaid carers.[46] Nonetheless, schemes which free up informal carer time have been found to be cost saving[47] and further research specifically exploring whether the cost of the CCB is offset by carer contributions in other areas, would support ongoing development of the policy scope. If the CCB is shown to be cost-neutral from the perspective of the federal government, this would provide a strong justification for scope expansion and would provide an important incentive for other countries to consider a similar benefit.

Whilst the CCB has been conceived and implemented specifically for the Canadian context, there may be potential for it to be adapted for other comparable countries and work is required to engage with policymakers to enact change. The UK National Insurance programme has many parallels with the Canadian EI programme and may offer a suitable platform for a benefit. Caregiver benefits need to adapt to the changing demographic of carers in the UK, in recognition that increasing numbers of carers are employed when they take on a caring role, and will continue to work (either through choice or necessity) during the time they provide care.

Limitations

Literature searches and interviews were restricted to English language and data or views from French Canadians may have been missed. Whilst efforts were made to identify all relevant literature, searches were not exhaustive and some literature may have been missed. Due to reasons of pragmatism, interview participants were not recruited from every Canadian Province/Territory meaning some unique perspectives could have been missed.

Authorship

CG designed the study, conducted interviews and wrote initial drafts of the manuscript. KS aided with recruitment and contributed to drafts of the manuscript.

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Data availability statement

Data are available from the authors on request.

Supplementary files

Supplementary file 1 - PRISMA 2020 checklist
Supplementary file 2 - COREQ checklist

Disclaimer statements

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Notes on contributors

Clare Gardiner is Professor of Palliative Care at The University of Sheffield, UK.
Kelli Stajduhar is Professor in The School of Nursing at the University of Victoria, Canada.

ORCID

Clare Gardiner http://orcid.org/0000-0003-1785-7054

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