


# Informal Caregiving for People With Life-Limiting Illness: Exploring the Knowledge Gaps

Journal of Palliative Care  
2022, Vol. 37(2) 233–241  
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DOI: 10.1177/0825859720984564  
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## Abstract

**Background:** People with life-limiting illness are increasingly having more care provided to them by informal caregivers (ICs) such as family members and friends. Although there is a substantial amount of literature surrounding informal caregiving, there is a paucity of research from a hospice palliative care angle. To address this knowledge gap, this scoping review explored the effects of/ challenges to informal caregiving at the end of life in Canada. **Methods:** Scoping review of the literature following Arksey and O'Malley's framework. Key healthcare and social sciences databases alongside the gray literature were searched. Relevant scholarly and gray literature sources from 2005 to 2019 were screened for inclusion criteria, and a thematic content analysis employed to summarize findings. **Results:** Of 2,717 initial search results, 257 distinct full text articles were obtained. Following deduplication and screening, 33 met inclusion criteria. Four major themes were identified: (1) Physical health challenges, (2) Psycho-socio-spiritual health challenges, (3) Financial issues, and (4) Health system issues. Gender of ICs was also found to be an important contributor to the differing effects of providing support. **Conclusions:** This review raises awareness toward ICs regarding the numerous physical, psycho-socio-spiritual, financial, and health system challenges faced during care for people with life-limiting illness. The knowledge gained will inform and advance future practice, policy, and research. Application to interventions (such as caregiver benefits) will assist to improve informal caregiving experiences and outcomes alongside quality of life. Further research is required to understand these unique experiences and the challenges of minority IC populations.

## Keywords

Canada, caregiver support, (informal) caregivers, end of life, (hospice) palliative care, and scoping review

## Background

According to recent estimates, there are 1.5 to 2 million palliative/end-of-life (EOL) informal caregivers (ICs) in Canada,<sup>1</sup> who may be defined as family members, partners, and friends of people who are dying.<sup>2</sup> Mostly female (77%), over 45 years of age, and working,<sup>3</sup> they play a vital role in providing unpaid physical, emotional and spiritual care, support, and companionship for their loved ones during the final stages of illnesses.<sup>3</sup> As the need for palliative/EOL care delivery continues to increase, the burden of care shouldered by Canadian ICs is expected to grow.<sup>3</sup>

Although providing care and support for a person approaching the end of life is often seen as rewarding, literature shows that caregiving may have detrimental effects on the health and wellbeing of ICs.<sup>4</sup> At the physical level, ICs experience challenges associated with assisting in physically strenuous daily activities of living.<sup>5</sup> At the psycho-social level, ICs are more

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likely to experience higher levels of anxiety, depression, and social isolation than formal or non-caregivers.<sup>4,6-7</sup> At the economic level, ICs incurred significant out-of-pocket medical expenses.<sup>8</sup> As the person's disease(s) progresses, ICs are often left with no choice but to reduce or to give up work entirely to provide care.<sup>7</sup> Informal caregiving may therefore lead to a loss of income and employment benefits, as well as elevated levels of financial difficulty and stress.<sup>7</sup>

Although there is a substantial amount of literature that explores the effects of caregiving on ICs, a majority of the literature does not specifically address informal caregiving in a Canadian hospice palliative/EOL care context. Furthermore, although federal interventions, such as the Compassionate Care Benefits (CCB) program, exist to provide financial support to caregivers, an evaluation revealed that barriers to accessing these benefits remained.<sup>3,9</sup> The CCB program is an Employment Insurance (EI) benefit that was first introduced in 2004. Although it is aimed to provide financial support for ICs leaving paid work temporarily to care for a terminally ill family member with significant risk of death within 26 weeks, to this day, the CCB does not meet its original objectives due to a lack of public awareness, complex application process, strict eligibility criteria, lack of flexibility, and short duration of benefits.<sup>3</sup>

Unless the effects of caregiving in an EOL care context are explored, ICs' needs will continue to go unmet, ultimately leading to worsened (health) outcomes. Hence, the purpose of this scoping review was to fill this knowledge gap by exploring the effects of/challenges to informal caregiving at the end of life in Canada. These findings can contribute to improve future hospice palliative/EOL caregiving practice, policy, and research to enhance informal caregiving experiences and (health) outcomes.

## Methodological Framework

This scoping review was conducted between July 2019 and December 2019 according to the five-stage framework outlined by Arksey and O'Malley<sup>10</sup>: (1) Identifying the research question, (2) Identifying relevant studies, (3) Study selection, (4) Charting the data, and (5) Collating, summarizing, and reporting the results.

### Identifying the Research Question

This review was guided by the research question: "*What are the effects of/challenges to caring for a dying loved one on informal caregivers in Canada?*" In July 2019, a scoping group was formed and a PICO (Population, Intervention, Context, Outcome) format defined to structure the literature search.<sup>11</sup> The population of interest were ICs and the intervention were the effects of providing care as death approaches. The context was within Canada and outcomes of interest were the health and wellbeing of ICs.

### Searching for Relevant Studies

Advanced Google/hand searches and electronic databases in the health and social sciences (Ageline, CINAHL, Cochrane Library, EMBASE, JSTOR, Project Muse, Proquest, PsycINFO, PubMed, Scopus, and Web of Science) within the University of Toronto Library were used to conduct searches for articles to be included in this scoping review. Keywords including "burdens", "Canada", "economic health", "end-of-life", "family caregiving", "financial challenges", "hospice palliative care", "informal caregiving", "physical health/challenges", "psychological health/challenges", "social health/challenges", "spiritual health/challenges", "unpaid caregivers", and "wellbeing" were used in various combinations with Boolean operators when searching for peer-reviewed scholarly articles and gray literature sources relevant to the effects of caregiving at the end of life on the health and wellbeing of ICs in Canada (see Supplemental Material).<sup>10</sup>

### Study Selection

Four independent reviewers (EYLL, AW, AA, and ZL) initially screened articles for the review. The eligibility criteria were: (1) English language, (2) Informal caregiving at the end of life (EOL described as patients with limited prognosis or terminal disease (and not restricted to those receiving hospice palliative care)), (3) Investigates the effects of/challenges to care on ICs, and (4) Stems from a Canadian context. Study design/type of article were not part of the inclusion criteria since the goal of this review—in line with Arksey and O'Malley's Framework<sup>10</sup>—was to capture the full breadth of research available for this topic. The initial selection included articles from January 2005 to July 2019. The cut-off year for the search (2005) was determined after a straw poll of major databases.

### Charting the Data

Final study selection was undertaken by two independent reviewers (EYLL and CAK). Disagreements were sent to the team and consensus was reached. Articles selected were reviewed and analyzed for data extraction (see Supplemental Material). No appraisal of the quality of the evidence was done, as the aim was to compile all current research related to the topic.<sup>10</sup> Following data charting, major patterns and themes found within the data were identified utilizing a thematic content analysis approach.<sup>12</sup>

### Collating Summarizing, and Reporting the Results

Major patterns, themes, and findings were discussed in detail about contributions to the overall scoping review purpose and research question among the team. The resulting themes were cross-referenced and reoccurring ones containing a high volume of quality material were included (see Supplemental Materials).

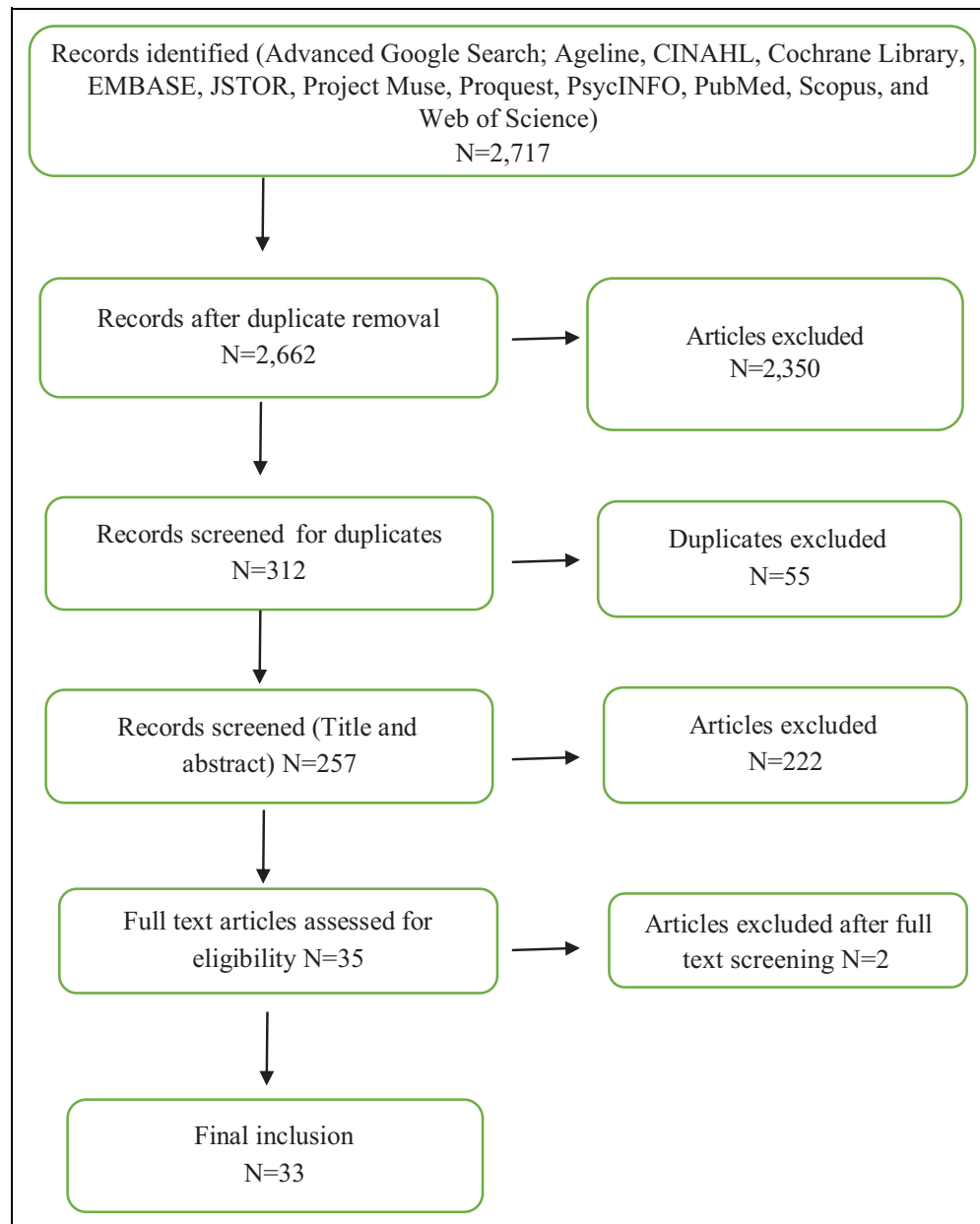


Figure 1. PRISMA flowchart.

## Results

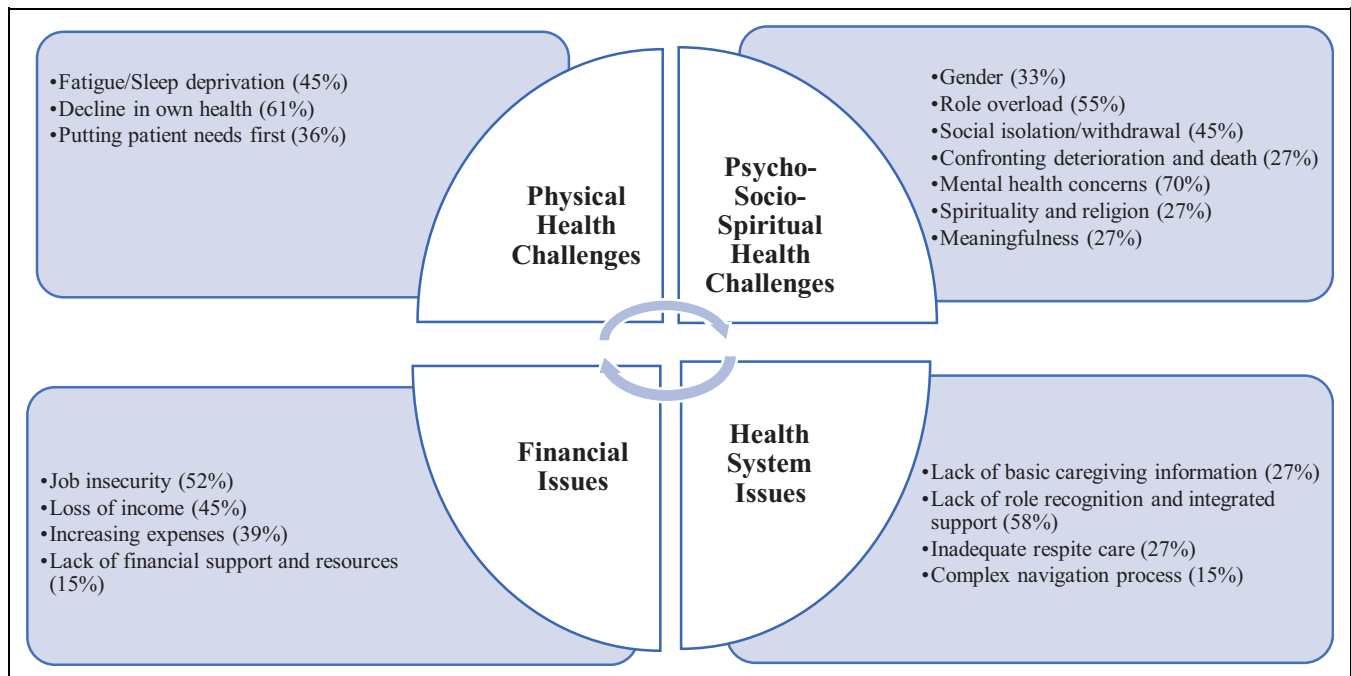
Study characteristics: Electronic databases and advanced Google searches yielded 2,717 initial results (Figure 1). We screened articles by title and abstract, then further filtered the data to publications from 2005 onward and limited to a Canadian context. A total of 312 studies matched selection criteria, further de-duplication yielded 257 unique research studies for full-text screening. Thirty-three articles (100%) met inclusion criteria for the review, comprising of qualitative studies (21), literature, scoping and systematic reviews (4), cross sectional studies (2), mixed methods studies (2), a cohort study (1), a longitudinal study (1), white paper (1), and one factsheet (1). The studies were set in variety of geographical settings,

including rural only (2), urban only (8), and both rural and urban (14). The setting of care was unpaid caregivers in home-based to institutionalized care (see Supplemental Materials). The extracted themes were organized into different categories and subcategories in conceptual order (Figure 2).

### Physical Health Challenges

In total, 24/33 articles (73%) reported that caregiving at the EOL led to physical health challenges among ICs.<sup>1,13-35</sup>

**Sleep deprivation and fatigue.** Forty-five percent (145/33) of the articles reported ICs often experiencing sleep deprivation and fatigue as a result of constant caregiving.<sup>13-26,31</sup> In particular,



**Figure 2.** Themes and subthemes emerging from scoping review.

several studies noted that providing care was physically demanding; the requirement to provide 24-hour care interfered with sleep, and the need to provide complete physical care for the person (e.g., bathing, feeding and moving) was physically taxing.<sup>21,25</sup> In particular, one study reported that many ICs were fatigued due to the constant commute back and forth from the hospital and the persons' deteriorating health.<sup>26</sup> ICs often ended up sleeping in the hospital, in a chair, or on a cot.<sup>23,26</sup> Many avoided sleep medication because it could hinder their ability to monitor the person's needs throughout the night.<sup>19-20</sup> Alterations in ICs' quality and quantity of sleep led to many psychological changes including decreased patience, increased irritability, feelings of overwhelmingness, anger, and feeling down.<sup>20</sup>

**Decline in own health.** Sixty-one percent (20/33) of the articles reported ICs experiencing a decline in their own physical health.<sup>13-17,19,22-35</sup> In a 2006 survey, 38% of Canadians who said that they had cared for a person with a serious health problem in the previous 12 months reported negative effects on their physical health.<sup>16</sup> Several articles found that ICs performing physically-demanding tasks with little or no training often resulted in severe physical injuries, muscle strains, and chronic pain.<sup>24,28</sup> Other reported health challenges included a limited attention span, reduced fertility, and the worsening of other pre-existing conditions.<sup>14-15,23-24,26,29-30,33</sup> Ultimately, articles found that many ICs put their health and quality of life at risk to provide care for their loved ones, especially those who also required care themselves and lived with various vulnerabilities, such as a disability or low income.<sup>13,16,24,26-28</sup>

**Putting needs of the loved one first.** Thirty-six percent of the articles (12/33) reported ICs often putting the needs of their loved one first and neglecting their personal health.<sup>1,13,15,17-18,20,22,24,28,30-32</sup> Additional responsibilities common to EOL made it difficult to address personal needs, leading to improper diet, poor sleep habits, and failure to use (healthcare) resources for self-care.<sup>13,20,22,24,28,30-32</sup>

### **Psycho-Socio-Spiritual Health Challenges**

In total, 26/33 articles (79%) reported that caregiving at the EOL led to psycho-socio-spiritual health challenges among ICs.<sup>13,15-20,22,24-41</sup>

**Gender.** Thirty-three percent (11/33) of the articles reported ICs experiencing gendered challenges.<sup>15,18,25-26,28,30,34,36-39</sup> Two studies in particular suggested that traditional gender role norms and expectations reinforced the ideology that women were "natural" care providers.<sup>18,39</sup> These predisposed female caregivers to significantly greater levels of strain compared to male caregivers because they generally set higher standards of care provision for themselves, were more likely to have multiple dependents to care for, less likely to receive support or recognition from family and friends, and were more likely to have other roles or responsibilities to maintain outside of caregiving for the dying person.<sup>18,25-26,28,34,36-38</sup>

**Role overload.** Fifty-five percent (18/33) of the articles reported ICs often experiencing role overload, which was defined as a subjective sense of stress associated with taking on a new role as caregiver.<sup>13,16-19,22,24,26-28,30-31,33-35,39-41</sup> Several studies showed that family members and friends often entered the

caregiver role unwillingly and with little to no knowledge or experience, leading to a general sense of overwhelmingness when confronted with the demands of the role.<sup>18,24,26,30,39</sup> ICs reported feeling unprepared to manage new caregiving tasks, helpless when unable to control medical crises, and uncertain about their abilities to fulfill their role as a caregiver successfully.<sup>13,16-19,22,24,26-28,30-31,33-35,39-41</sup>

**Social isolation and withdrawal.** Forty-five percent (15/33) of the articles reported ICs experiencing social isolation.<sup>13,15,17-18,20,22,24,26-27,30-31,35,39-41</sup> ICs often lacked the time or energy to participate in social activities because their caregiving responsibilities took priority.<sup>15,17-18,25,31</sup> ICs also reported deliberately withdrawing from social interactions to avoid awkward conversations with others who have not experienced caring for a person approaching the EOL and were therefore unable to truly understand what they were going through.<sup>15,17-18,20,24,30-31,35,39-40</sup> Furthermore, ICs also reported feeling “overlooked” when others did not express appreciation for their work or did not provide an adequate amount of assistance and support.<sup>18,31,35,39</sup>

**Confronting deterioration and death.** Twenty-seven percent (9/33) of the articles reported ICs experiencing difficulties confronting the deterioration and impending death of their loved one.<sup>13,16-18,27,31,36,39-40</sup> ICs reported feelings of helplessness, lack of control, and depressive symptoms when witnessing deterioration.<sup>13,16-18,27,29,31,40</sup> Several studies in particular also demonstrated that these feelings of emotional distress often extended into the bereavement period.<sup>16-17,29,40</sup>

**Mental health concerns.** Seventy percent (23/33) of the articles reported that ICs having difficulty adjusting to the caregiver role and/or witnessing the deterioration of the care recipient were more likely to experience greater levels of emotional distress and mental health issues.<sup>13,15-20,22,24-27,29,31-38,40-41</sup> The two most common mental health issues reported among caregivers included anxiety and depression.<sup>16-19,22,24-25,27,31,34-36,38,40-41</sup>

**Spirituality and religion.** Twenty-seven percent (9/33) of the articles identified ICs using spirituality and religion as a coping strategy for the emotional strain associated with the caregiving role.<sup>13,16-17,19-20,26,28,30,38</sup> Several studies reported that spirituality and religion provided ICs with a sense of comfort that assisted in easing their mind, making sense of their (unfortunate) circumstances, and coming to terms with their (new) reality.<sup>13,16-17,19-20,26,28,30,38</sup>

### Meaningfulness

Despite feeling overburdened, 27 percent (9/33) of the articles reported ICs describing the provision of care to people approaching the EOL as a meaningful experience.<sup>13,16-18,22,27,30-31,38</sup> Studies suggested that ICs developed a better understanding and closer bond with their loved one.<sup>13,16-18,22,27,30-31,38</sup> ICs also gained a sense of personal

growth and accomplishment for being able to “give-back” and to fulfill their loved one’s last wishes.<sup>13,16-18,22,27,30-31,38</sup>

### Financial Issues

In total, 20/33 articles (61%) reported that caregiving led to financial challenges among ICs.<sup>1,13,15-16,19,24-28,30-36,42-44</sup>

**Job insecurity.** Fifty-two percent of the articles (17/33) reported that employed caregivers experienced greater work-life conflict and were forced to take time off of work using sick days, vacation, or unpaid leave.<sup>1,13,15-16,19,24-26,28,30,32-36,42-43</sup> In particular, one study found that 29% of ICs modified their life and work arrangements in order to accommodate for excess caregiving responsibilities,<sup>24</sup> while another source indicated that 22% of ICs missed one or more months of work.<sup>28</sup> The absences at work could lead to increased feelings of decreased job security.<sup>13,31</sup> ICs might ultimately choose to quit their jobs or even retire early.<sup>13,36</sup> In addition, two studies reported that working caregivers also turned down new employment opportunities.<sup>30,33</sup> One study found that female ICs were more likely to leave the workforce due to caregiving responsibilities.<sup>28</sup>

**Loss of income.** Forty-five percent of articles (15/33) reported that as a result of the changes in work schedules, ICs often experienced high levels of financial strain.<sup>1,13,15-16,24,26-27,31-34,36,42-44</sup> In particular, four studies reported that ICs suffered a loss in income due to absences at work.<sup>13,24,26,31</sup>

**Increasing expenses.** Thirty-nine percent of articles (13/33) found that ICs providing EOL care incurred additional caregiving expenses.<sup>1,15-16,19,24,26-28,32,36,42-44</sup> One study reported that many of the costs previously absorbed by the public healthcare system appear to have shifted to patients/their families and that Canada’s 1.5-2 million palliative/EOL caregivers<sup>1,3</sup> have incurred a combined \$80 million out-of-pocket costs.<sup>3</sup> Another study estimated that the care provided by those ICs amounted to approximately \$3 million, which would have otherwise cost the healthcare system.<sup>19</sup> These costs assumed by the ICs included time spent caregiving, hospitalization, home care, medical equipment or aids, supplies, support and ambulatory care, with prescription medication, on average, being the most common financial expense.<sup>1,19,36</sup> EOL caregivers often incurred higher costs compared to non-EOL caregivers.<sup>15,28</sup> Two studies also found that ICs had to resort to using out-of-pocket funds in order to cover these costs (41% caregivers reported using personal savings), which could lead to heavy financial burden on their families, with nearly 40% of caregivers experiencing long-term financial pressures related to their caregiving responsibilities.<sup>24,43</sup>

People who are dying often prefer to die at home and thus require home care services.<sup>1,43-44</sup> Three studies found that formal home care was more expensive compared to other settings due to the large increase in outpatient services required.<sup>1,43-44</sup> In addition, when ICs lived in remote areas or were providing care at a long distance, they were likely to have increased costs due to traveling and were more inclined to miss work.<sup>33</sup>



**Lack of financial support and resources.** Fifteen percent of articles (5/33) found that ICs providing care at the EOL experienced a lack of financial support and resources.<sup>26,30-31,43-44</sup> Although financial assistance was available to some caregivers, two studies reported that it remained insufficient.<sup>26,31</sup> For instance, despite the amount of care provided by ICs, this care was largely unrecognized by employers, government and health-care providers.<sup>30</sup> Consequently, they faced challenges in receiving financial aid due to strict eligibility criteria, limitations and short duration of benefits (e.g., Canada's Compassionate Care Benefits),<sup>9</sup> which ultimately placed greater financial strain on this vulnerable population.<sup>9,26,30-31</sup> In fact, one study reported that half of the respondents (employed caregivers) felt that the federal government did nothing to help them cope with the challenges of additional caregiving responsibilities, despite knowing this was an issue.<sup>26</sup>

### Health System Issues

In total, 20/33 articles (61%) reported that caregiving led to health system issues among ICs.<sup>1,15,17-20,24-26,28,30-31,33-35,39-43</sup>

**Basic caregiving information and support.** Twenty-seven percent of articles (9/33) reported ICs experiencing a lack of basic caregiving information including medical/care knowledge, health education, information access, and support services.<sup>18-19,21,25,30-31,34,39-40</sup> Care recipients required a wide array of services which included assistance with activities of daily living, personal hygiene, pharmaceutical assistance, and other complex services such as pain management regimen and special medical tasks required of them.<sup>25,30,34,39,40</sup> ICs felt at a disadvantage while providing services because of limited knowledge, available resources, and services that could bridge this gap to empower them. Studies also addressed the lack of medical interventions and the need for ongoing support through materials, brochures or telephone helplines.<sup>18,30-31,34,39</sup>

**Role recognition and integrated support.** Fifty-eight percent (19/33) of articles recognized the need to improve IC support services including respite care, mental health services, support groups, and financial support.<sup>1,15,17-19,25-26,28,30-31,33-35,38-43</sup> The first step toward health system improvement includes the inclusion and recognition of the dynamic and integral role that ICs play as a part of the caregiving team.<sup>41</sup> Two studies reported that ICs were in need of culturally sensitive care delivery services, with a focus on role recognition.<sup>30,39</sup> Integrated role recognition is instrumental in reducing caregiver stress by empowerment and acknowledgment.<sup>39</sup> ICs also expressed a need for support systems designed to integrate individual family units and their needs at the earliest opportunity while providing continuous quality healthcare to the loved ones as an overarching goal. A holistic system will address physical, psycho-socio-spiritual, and financial challenges in a culturally sensitive manner tailored to the caregivers including but not limited to support groups, respite care, education, counsellors, and financial planning.<sup>1,15,17-19,25-26,28,30-31,33-35,39-43</sup>

### Respite care

Twenty-seven percent of articles (9/33) reported ICs experiencing challenges in respite care, any service designed to provide a short period of relief for ICs, either by family or health aides.<sup>16,19,21,25,34-35,37-38,40</sup> Respite care delivery is complicated by differences in the setting of care, the illness, life conditions, and varied expectations of the caregivers. Currently, respite care is limited in quality and formal caregivers can change at any visit.<sup>34</sup> Some ICs have recognized this service to be more disruptive than helpful as the unfamiliar caregivers require orientation to their circumstances.<sup>19,34-35</sup> Therefore, respite care needs to be tailored to the individual requirements.<sup>25,34,38</sup> A need for continued uninterrupted quality care provided by caregivers who can function as a team with the family has emerged as a defining factor in care.<sup>16,21,25,34-35,37-38,40</sup>

### Complex navigation process

Fifteen percent of articles (5/33) reported ICs experiencing challenges in navigating the complex healthcare system.<sup>20,24,30,34,41</sup> Despite the development and implementation of many policies to aid caregivers around the health system within the last decade, ICs found themselves unaware of or unable to navigate the system with these aids.<sup>20,24,30,34,41</sup> Caregivers also expressed the need to have dedicated guidance in system navigation, especially when experiencing additional constraints and complex circumstances.<sup>20</sup>

### Discussion

ICs are often the principal home care providers to dying Canadians. Unlike formal caregivers, who are trained to cope with the reality of dying, ICs often find themselves ill-equipped to handle the multitude of demands and challenges that come with their role.<sup>45</sup> In our exploration of the effects of providing care to people who are dying on ICs, we have identified human-centric themes including physical, psycho-socio-spiritual, financial, and health system challenges.

### Practice Implications

Our findings support the physical burden contributing to caregiver distress. ICs reported stress, sleep deprivation and other health issues as a result of putting their loved ones' needs before their own and providing an average of 3.5 to 9-10 hours/day of care without respite.<sup>34</sup> The chronic strain placed on caregivers also rendered them susceptible to other physical complaints.<sup>46-47</sup>

The second theme that emerged is the importance of the psycho-socio-spiritual journey that caregivers experience when providing care to a dying person. ICs face a tremendous amount of psychological strain, especially when carrying the additional emotional burden of caring for a loved one while processing their finality and approaching of the EOL. A lack of social and spiritual support systems, due either to the lack of/limited

access to interventions or being unaware of their existence, is known to adversely affect the mental health outcomes of caregivers.<sup>18,31,39</sup> This emphasizes the importance for the integration of psycho-socio-spiritual services to care providers at the earliest opportunity for more comprehensive, quality care delivery, and better health and wellbeing outcomes.<sup>48–49</sup>

Our findings also suggest that females are more likely to be an IC to their family members. Males in contrast to females tend to provide a shorter duration of service and enjoy more social support and acknowledgement. However, the data is inconclusive and further exploration of factors influencing the caregiver role of different genders is essential to address any knowledge gaps.

Our findings also suggest that informal caregiving incurs extensive medical costs. As a result, ICs often experience high levels of financial strain especially when they are required to leave or take time off work. Despite the widespread acknowledgement of their financial burdens and the implementation of several ongoing provincial/territorial/federal initiatives offering compensation to caregivers, many barriers remain to supporting and improving the financial outcomes of ICs.<sup>3,9,50</sup>

### Policy Implications

The complex needs and demands of ICs have exposed numerous system level challenges in the current healthcare climate. ICs need integrative, supportive interventions such as access to health/caregiving education, helpful resources, mindful coping strategies, and others. While European countries are actively working on acknowledging the role of ICs and developing programs such as the Integrative Palliative Care Initiative (IPC-I) to meet their complex needs, Canada is lagging behind in designing and implementing a rapid reform in this field.<sup>49,51–52</sup> Current supports such as the CCB are not always known and can be inadequate for the needs of ICs as described above. Robust policy change is required to empower ICs. Policy-makers need to recognize the contribution of ICs, for this is the first step toward a system level change and development of active strategies to lighten their burden.<sup>49,51</sup>

### Research Implications

An interesting finding that emerged from our review is the imbalance in studies addressing caring for people at end of life, which predominantly covers cancer related ICs' quality of life and implications. More research is required to explore whether the effects of providing hospice palliative care differ between a diverse range of caregivers providing a spectrum of care and to understand any possible variance in the IC experience due to differing cultural/ethnic backgrounds.

Furthermore, research is needed to clearly re-define the role of ICs in the healthcare team. Perceptions and interpretations of ICs and their roles within the team are up for subjective, public interpretation. The re-definition and the correct identification of their possible roles and needs will aid in devising strategic, targeted interventions that will improve their unique outcomes and experiences. Further research is also required to better

disseminate information to caregivers as well as to explore the experiences and the challenges that ICs in minority or underserved populations in all areas of Canada face.

As a next step to understand the caregiving impact, we have initiated a second scoping review to elaborate upon the interventions/resources available to ICs in Canada. The results of both analyses, when combined, will lead the way toward policy reform by identifying the existing gaps and solutions, and the formulation of new strategies.

### Limitations and Strengths

Limitations of our study include (1) the use of only English literature while exploring hospice palliative/EOL care in a bilingual, Canadian context, and (2) the lack of quality assessment of the included research. The former was due to a lack of language skills within the research team/ready access to translators. However, the inclusion of all types of sources to ensure comprehensive literature coverage to encompass all perspectives was prioritized in line with Arksey and O'Malley's framework.<sup>10</sup>

Strengths of our study include exploring the hospice palliative/EOL care perspective within a Canadian healthcare landscape, to recognize issues central to Canada. The studies reviewed were representative of the IC landscape in Canada considering both rural and urban settings of care. Furthermore, a comprehensive and systematic methodology was used to ensure that we obtained and addressed the broadest possible viewpoints. The implications also have relevance to North America and beyond.

### Conclusion

As we continue to move toward the delivery of care for the dying person, there is a need to recognize the central role of ICs. Informal caregiving is a strenuous undertaking that is associated with numerous physical, psycho-socio-spiritual, financial, and health system challenges, unless provided with meaningful coping strategies and support. Healthcare providers, policy makers, and researchers need to acknowledge the complexity of the issue and work toward systematic policy reform to empower informal caregivers for effective and quality care delivery. This will enhance the EOL experience for both the dying and their caregivers.

### Authors' Note

Christopher A. Klinger is also affiliated with Pallium Canada, Ottawa, Ontario, Canada.

### Acknowledgment

The authors would like to thank Heather Cunningham, MLIS at the University of Toronto's Gerstein Science and Information Center. The authors would also like to acknowledge the full support of the Quality End-of-Life Care Coalition of Canada's (QELCCC) Research and Knowledge Translation Committee. Initial findings from the work have been presented at the Hospice Palliative Care Ontario (HPCO) 2020 Annual Conference and the European Association for Palliative Care (EAPC) 2020 World Research Congress.


## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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## Supplemental Material

Supplemental material for this article is available online.

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