

Safety in Home Care for Unpaid Caregivers: A Scoping Literature Review

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Safety in Home Care for Unpaid
Caregivers: A Scoping Review

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Main Messages

- The needs of unpaid caregivers who care for family and friends receiving home care are neither clearly understood, nor adequately addressed in the Canadian health care system.
- As home care continues to grow, this will have implications for caregiver health and safety, institutionalization of home care clients, and cost to the health care system.
- Four key problems that affect unpaid caregivers' health and safety are:
 - conditions that cause or exacerbate abuse;
 - feeling trapped in the role without adequate resources or support;
 - the strain caregiving places on employment, income, and family resources; and
 - deteriorating health of caregivers due to the physical, emotional, social, and financial challenges of caregiving.
- This review highlights the urgent need to address these issues in the Canadian Caregiver Strategy, which is currently under development
- Specifically, the Canadian Caregiver Strategy should outline strategies for:
 1. Providing training programs and structured consultation for informal caregivers;
 2. Remunerating informal caregivers and including home care in the Canada Health Act; and
 3. Integrating respite care, social support, and adequate professional services into home care.

Executive Summary

Context

The past decade witnessed a steady increase in the number of informal caregivers in Canada. *Caregivers* in this report refer to unpaid individuals, often family members or friends, who are responsible for caring for a home care client. Over 4 million caregivers provide assistance to spouses, children, parents and other extended family members who are in need of support due to age, debilitating medical conditions, injuries, chronic illnesses, and disabilities. As the population continues to age, the delivery of services by these caregivers is a trend that is expected to continue.

Unpaid caregivers provide more than 80% of care needed in the home, and as such, are an invaluable component of the health sector that allows individuals to return to or remain at home, and contributes to cost-savings for the health system. In providing care, these caregivers face physical, emotional, social, and financial challenges to their safety. Understanding the safety concerns associated with unpaid caregiving is essential to sustaining this role and to preventing home care clients from being institutionalized at an earlier point in the illness trajectory.

The purpose of this scoping review was to examine the home care literature from a safety perspective in order to identify indicators of safety for unpaid caregivers.

Approach

Performing a scoping review involves analyzing existing literature from research and non-research sources to identify existing knowledge. For this study, scoping methodology was used to search and screen items, and Interpretive Description was used to analyze relevant literature in order to identify common markers for the safety of caregivers.

Results

Four caregiver safety markers related to provision of care in the home were identified. These markers also have safety implications for care recipients, family members, and the health care system:

1. **Abuse:** Psychological or physical has been reported in up to 25% of caregiver-recipient relationships. The caregiver could be either the victim or the perpetrator. Caregiver attributes such as alcohol abuse and cognitive decline increased caregiver-perpetrated abuse. Care recipients who were cognitively impaired, had dementia, or required high levels of care were at increased risk for abuse.
2. **Conscription:** Caregivers felt obliged to care for family members because there was no one else to provide care. Caregivers reported that they do not get enough information and support about learning how to provide care, managing pain, navigating the home care system, and understanding their family member's progressing illness.
3. **Economics of Caregiving:** The Canadian health care system incurred savings of \$5 billion associated with the unpaid hours put in by informal caregivers, while caregivers incurred both financial costs such as lost income and expenses for supplies and equipment, as well as drains on their physical, emotional, and social reserves.
4. **Hidden patient:** There was a general decline in caregivers' physical and mental health due to the stress of providing continuous care. Effects included depression, back problems, migraines, digestive problems, impaired blood coagulation, and decreased antibody responses.

Implications

Informal caregivers of home care clients face significant physical, emotional, social, and financial risks that threaten both their own safety and the safety of those they care for. Acknowledging the caregiver role and implementing the necessary supports will mitigate these risks to caregivers and care recipients, creating healthier individual home care environments and more sustainable home care programs overall.

Recommendations

The three recommendations resulting from this review mirror some of the outcomes outlined in the Framework for a Canadian Caregiver Strategy:

1. Formal information and training programs, structured consultation, and support must be provided for those undertaking unpaid caregiver roles.
2. Caregiver remuneration must develop such that caregivers do not face the additional stress associated with financial strain along with the demands of caregiving. The equipment and supplies necessary to maintain the client at home need to be provided, and home care needs to be included under the Canada Health Act.
3. Respite care, social support, and adequate professional services must be integrated into provision of home care so that the health of Canadian caregivers does not suffer further.

The proposed Canadian Caregiver Strategy is ideally positioned to address these recommendations directly, as well as to ensure that home care professionals are competent to assess for caregiver safety markers.

Context

Home care has grown by 51% over the past decade, and consequently, there has been a related increase in the number of unpaid caregivers. Over 4 million caregivers provide assistance to spouses, children, parents and other extended family members who are in need of support due to age, debilitating medical conditions, injuries, chronic illnesses, and disabilities. As the population continues to age, the delivery of services by unpaid caregivers is a trend that is expected to continue¹. These family caregivers provide more than 80% of care needed in the home causing them physical, emotional, social, and financial challenges.

In this report, the term *caregiver* refers to individuals who are in an unpaid role but are responsible for caring for the home care client. Caregivers are often family members or friends. Family members are individuals identified by the client as being close to him or her through blood, legal, or emotional ties and who may or may not reside in the same home as the client. Caregivers are distinguished from *providers* who are regulated and non-regulated professionals or non-professionals, and are paid employees of organizations providing home care services. Providers include members of the health team such as case managers, nurses, aides, doctors, pharmacists, and therapists.

Caregiver safety has been recognized as a priority in health care, as evidenced by recent calls for collaborative efforts by those in the public and private sectors to develop a vision for family caregiving in Canada^{1,2} and to support the development of a Canadian caregiver strategy³. Additionally, the Canadian Institute of Health Information⁴ report on supporting informal caregivers recognizes and emphasizes the toll that caregiving takes on families.

In 2008, a pilot study to capture the perspectives of home care recipients and providers on safety in home care revealed that the meaning of safety in home care varied between recipients and providers, and that home care clients were deeply concerned about the health of their unpaid caregivers and the flexibility and timeliness of home support⁵. Key informant interviews with home care researchers and experts reinforced this concern, and indicated that fragmentation and communication breakdown in home care were caused or exacerbated by multiple agencies and providers visiting a single client⁶. They also reported on the vulnerability of clients, unpaid caregivers, and providers related to exposure to infection, risk for medication mismanagement, and potential for abuse⁶. The pilot study and key informant interviews, together with a literature review on the topic of safety in home care, comprised a three-part environmental scan on the state of safety in home care.

Safety markers refer to indicators of safety related to the caregiver. These indicators may represent conditions or situations that compromise the safety of caregivers. Very little has been written directly about safety in home care, however the environmental scan indicated that previously unrecognized safety markers may exist in the body of existing home care literature, and recommended examining this literature using a safety lens. The purpose of this scoping review was to examine the home care literature from the perspective of safety in order to identify markers related to safety for unpaid caregivers.

Implications

Unpaid caregivers are an invaluable component of the health sector that allows individuals to return or remain at home, and contribute to cost-savings for the health system⁷. Understanding the safety concerns associated with unpaid caregiving is essential to sustain the role. If the needs

of caregivers are not clearly understood and supported, caregivers risk continued physical, psychological, financial, and social strain; home care clients will end up institutionalized at an earlier point in the illness trajectory⁷; and the health care system will bear the increased burden of both these outcomes.

Approach, Methodology, Rationale, Assumptions

Approach

While insight has been gained into the health, social, and economic consequences of caregiving, as well as predictors of positive or poor experiences, this information has not been synthesized from a safety perspective. This review was conducted following a scoping review approach^{8,9}, in which existing home care literature was searched, screened, and common themes identified that delineated markers for the safety of caregivers.

Evidence included in the review was obtained from three primary sources: electronic bibliographic databases, grey literature from government and professional association websites, and manual searches of publications from key Canadian home care researchers. Table 1 (Appendix A) lists the data sources used for the review. The search strategy used a combination of keyword derived from three main areas: the home care setting, individuals involved in the caring relationship, and health and illness subject areas that covered a broad range of topics. Table 2 (Appendix B) provides a detailed list of the final keyword search terms used to locate relevant evidence. Items were then selected based on established inclusion and exclusion criteria, which were refined as the search progressed. These criteria are listed in Table 3 (Appendix C).

A systematic three-stage screening process that ranked first titles, then abstracts, then full articles or documents as relevant, potentially relevant, or not relevant was used to select

evidence. A minimum of three reviewers conducted independent assessments at all stages of screening. In addition, spot-checks were conducted on ranked articles by other team members. Disagreements that arose were resolved through discussion until consensus was reached

The first level of screening included a review of titles. Articles and documents were excluded that were clearly not about home care and/or caregivers. The second stage of screening included a review of abstracts to determine if the content held information indicative of a safety-related marker for the caregiver. Items designated relevant were retained for stage three, in which the full article or document was retrieved and reviewed. Figure 1 (Appendix D) depicts the yields and ranking of yields for each stage of the screening process.

Methodology

Findings were analyzed using interpretive description methodology to identify patterns deemed to represent safety-related caregiver markers. Interpretive description consists of three elements: objective, mechanism and product. The objective of the review was to identify caregiver-related safety markers, the mechanism employed was the coding of the findings to arrive at pattern identification, and the product was the identification of patterns in the data interpreted as safety-related markers for caregivers¹⁰.

Assumptions

The assumptions guiding this review included the importance of:

- a) gaining an appreciation of the breadth of the home care literature;
- b) assuring trustworthiness of the findings through transparency in describing the methods;
- c) focusing on findings, as opposed to examining the research methodology; and

- d) remaining open to the language of home care in order to capture markers of safety not previously made explicit in the literature.

Results, Conclusions

Search Results

The majority of the documents reviewed were produced in 2007-2008. Research originated primarily from the United States, followed by Canada, and then the United Kingdom. All documents were printed in English with the exception of a news broadcast, which was printed in French. A number of grey literature documents were available in both English and French.

The type of illness or conditions of those being cared for was linked to compromised health experienced by caregivers. Caregivers were found to care for individuals experiencing a range of health conditions. Ranked in order of the number of publications reviewed, these included: Alzheimer's disease and related dementias (25 articles or documents), medically complex children (10), cancer care (9), heart failure (8), stroke (5), palliative care (4), traumatic brain injury (3), care of elderly clients (2), and HIV (1). The remaining 37 titles addressed caregiver-related factors and concerns but not associated with the care of an individual with a particular illness.

Caregiver Safety Markers

Four markers were identified that described the consequences for caregivers related to provision of care in the home: abuse, conscription, economics of caring, and the hidden patient. These were summarized in Figure 2 (Appendix E), and are described below.

Abuse

Various definitions of elder abuse related to caregivers occurred throughout the literature. The World Health Organization (WHO) definition appears to be the most comprehensive, stating abuse is: “a single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person. Abuse can take many forms including physical, psychological, sexual, financial, neglect, medication abuse, abandonment, scapegoating, and marginalization”¹¹. Home care literature primarily referred to physical and psychological abuse, and stated that the abuse may be caregiver to recipient or vice versa. Abuse was more common in husband and wife care-recipient relationships^{12,13}. Psychological abuse was reported to occur in up to 25% of cases (and was reported by home care staff in up to 16% of situations), with physical abuse in 5-6% of cases^{13,14,15}.

Certain conditions link caregiver safety and abuse. For example, caregivers who abused alcohol were more likely to perpetrate abuse¹¹, suffer from caregiver burden¹⁴, experience poor physical health or depression¹² and to neglect or financially exploit those they cared for¹¹. Additionally, caregivers of impaired elderly persons commonly experience some form of cognitive decline themselves, rendering them more likely to be abusive toward care recipients¹⁶. Finally, certain traits of care recipients also increased the likelihood of abuse by caregivers, such as higher levels of care needs, cognitive impairment¹², dementia¹³, and aggressive behaviours¹³. It should be noted that abusive relationships may pre-date receipt of home care, and therefore abusive behaviour may be a continuation of an earlier and potentially mutually aggressive relationship¹³.

The literature recommended considering abuse on a continuum and cautioned against prematurely judging the presence of abuse without a full understanding of the nature of the

relationship in the situation in question. Providers are also reminded of the importance of being able to have the conversation with clients and caregivers about abuse and how abuse is defined, as well as the legal statutes surrounding reporting of abuse¹³.

The Alzheimer's Association of Canada warns that with the aging population comes a rising tide of dementia, anticipating a 50% increase in the prevalence of dementia between 2008 and 2038 that will affect 1,125,184 citizens¹⁷. Alzheimer's disease is but one chronic illness that will require care and therefore caregivers. It is logical to anticipate that if abuse presently exists in the home care setting, care providers and decision makers need to be vigilant and prepared for recognizing, intervening and supporting caregivers and clients to mitigate the prospect of increasing incidence of abuse.

Conscription

Conscription is used in this analysis to denote situations where caregivers believed they had no choice but to provide care to a person in need. The person could be a spouse, a child, or someone to whom they had close ties. The term conscription was not used in the literature reviewed, but seemed to capture the level of responsibility that caregivers felt and described. Commonly, people assume caregiver roles simply because there is no one else to do it^{18,19,20,21}. Caregivers may enter the role reluctantly or unwillingly^{22,23}, or have a sense of being trapped and confined to caregiving tasks²⁴. Convenience was another reason caregivers assumed complex treatment regimes, particularly when it was related to care of their children²⁵. Commonly, spouses reported a sense of duty to care for one another as a result of their marriage covenant²².

Caregivers described always being there through all of the ups and downs²⁶. They noted that society assumes that a spouse or partner will provide the care necessary no matter how hard or

constant. When a patient is being discharged from hospital, it is taken for granted that those closest to the person will provide care with little recognition or reimbursement. Additionally, referrals from hospitals often provide incomplete information for home care providers, putting the caregiver in a less than desirable situation from the outset^{19,27,28}. Caregivers reported that they had inadequate knowledge about patient care overall²⁹, and received no hands-on learning³⁰. They stressed significant knowledge deficits related to pain management, navigating an uncoordinated home care system, and knowing what to expect as the care recipient's illness progressed³⁰. This lack of knowledge may well be a contributing factor to the feelings of powerlessness and helplessness that caregivers described in providing palliative care³¹ or their feelings of loss of control^{32,33}. Caregivers and clients also reported that paid care providers typically underestimated the nature and extent of care and support required^{34,35,36}.

Entire families are affected by the need to care for someone who is ill. Routines must change, and everyone must adapt to a new normal with very little formal learning to take on new responsibilities^{37,38}. Many of these situations, such as caring for medically complex children³⁹, involve the use of technology such as ventilators, demanding that beyond providing care, the caregiver and family must learn to use the accompanying technology, adjust to a completely new household routine, and absorb the impact of all of this on family structure and relationships⁴⁰.

The literature is clear on the fact that the health care system expects families to assume the home care of those close to them. What is less clear is how society intends to support these caregivers. In the first half of the twentieth century, families expected and assumed the caregiver role, but the advent of hospitals, nursing homes, and related care facilities assured subsequent generations that those in need of care would receive it outside of the home. Mounting health care costs

coupled with the graying of the population and the rise in chronic illness has caused a shift in care from the institution back to the home⁷, resulting in the conscription to care by those remaining in the home. It is anticipated that the development of the vision for family caregiving as well as the strategy for caregiving mentioned earlier will begin to mitigate the risks for caregivers as well as their sense of conscription.

Economics of Caregiving

The economics of caregiving refers to both the hidden savings to the health care system associated with informal caregiving and the costs of caregiving incurred by caregivers, families and employers. In Canada, caregivers provide more than 80% of the care for people with long term care needs, representing \$5 billion annually in unpaid labor¹ (CCC, 2008). Caregivers are making an unprecedented contribution to the wellbeing of Canadians, however there are individual, family, and societal costs associated with this sacrifice.

Most caregivers continue to be women, however 10% of Canadian men also fulfill this role. One in four employed Canadians care for an elderly dependent person, and 1.4 million caregivers regularly combine child care, eldercare, and employment^{1,20,25}. Factors contributing to economic strain on caregivers and their families included:

- giving up work and making major life changes^{41,42};
- increased risk for job loss and reduced wages due to a combination of lost time devoted to caregiving and exhaustion^{2,43,44};
- lack of critical information about available benefits and services²⁵;
- lost income incurred in keeping appointments as part of the caregiving role⁴⁵; and

- unanticipated cost of supplies and equipment associated with technology, shorter hospital stays, and reductions in reimbursements from third-party payers⁴⁵.

While some caregivers are forced to give up work, others choose to continue to work for financial as well as psycho-social reasons. They may change jobs and accept lower wages to have the flexibility necessary to meet the needs of the person in their care⁴⁶.

Another dimension of the economic cost is the exponential growth in care needs of clients. Individuals who are initially capable of managing illness-related costs often find that over time lost income, increasing care requirements, and associated costs deplete financial as well as physical, emotional, and social reserves. In many instances, when caregivers agree to provide care, the recipient's needs are limited to such things as help with medications and household tasks. If the recipient gradually returns to their former health and strength, for example after a surgery, then the caregiving is time-limited⁴⁷. Caregivers may find this experience trying, but they manage in the short term. However, situations in which the client needs little care at the outset but over time requires constant or nearly complete care have the potential to erode not only the financial security of those involved but also increase their physical, emotional, and social safety risks^{48,49}. Common conditions that are managed in the home and cause significant economic strain over time include heart failure^{26, 50,51,52,53}, end stage cancer⁵⁴, cognitive decline^{55,56}, and the care of children with diseases such as Cerebral Palsy⁴¹. The exhaustion of family resources means that caregivers who make sacrifices to provide home care may end up destitute because of it. This was the case for well-known Québec artist Gilles Carle, who suffered from Parkinson's disease for over a decade. Eventually, his finances were exhausted and

his partner was obliged to take in other individuals needing care to generate an income to maintain Gilles at home⁵⁷.

The common theme of the economics of caregiving safety marker is that at the outset, the caregiver assumed a level of responsibility they believed they could manage, but were usually unaware of the extent to which the responsibility would grow. Home care is not an insured service under the Canada Health Act, and jurisdictions fund services as best they can, resulting in variability across the country⁷. The development of a national Caregiver Strategy will contribute to identifying the financial risks incurred by caregivers, the unpaid contribution of caregivers, and the debt society owes caregivers, and make recommendations to stem the economic consequences for caregivers.

Hidden Patient

Hidden patient was chosen as a caregiver safety marker because of the volume of literature that reported a general decline in caregiver health^{46,49,50,56,58,59,60,61,62,63}. This decline in health can be attributed to a combination of four factors: caregiver attributes, client attributes, caregiver outcomes, and situational factors.

Caregiver attributes. The literature reports a number of caregiver attributes that influence their health status:

- Sense of control: In the literature, caregiver wellbeing was most frequently linked to caregivers being comfortable with the situation and knowing how to respond as changes unfolded^{32,33,43,64}.

- Age and gender: Younger women experienced increased distress, found care harder, and had a poorer perception of their mental health and overall health^{50,60,65}, while older women had more existing health problems⁶⁶, making caregiving more challenging.
- Resentment: Caregivers who experienced anger and resentment related to their role reported greater caregiver burden⁶⁷.
- Stress management: Ability of caregivers to manage stress significantly predicted their psychological health and also influenced the level of presenting behavioral symptoms in caregivers with dementia^{43,68}.
- Overall health: Good health generally predicted psychological health⁶⁹.
- Income and education: Higher caregiver income and education did not necessarily alleviate strain, and in some instances resulted in more strain and decreased quality of life^{70,71}.
- Employment: Caregivers who were working experienced more strain⁷¹.
- Relationship with recipient: In situations where the relationship with the client was less than ideal, caregivers were at increased risk for depression^{58,60}.

Recipient attributes. Care recipient attributes that posed the greatest challenges for their caregivers were dementia or cognitive decline and emotional lability^{24,48,55,58,59,67,72,73,74,75,76}.

Additional care recipient factors that caregivers reported as being psychologically challenging included: high levels of dependency⁴⁸, advanced stage of terminal illness at a young age^{65,77,78}, complexity of symptoms and conditions^{21,65,66,79}, and dependence on mechanical ventilation⁸⁰.

Caregiver outcomes. The outcomes for the caregiver most frequently reported in the literature were:

- Decline in general health, as manifested through symptoms such as back problems, migraines, stomach and intestinal problems, impaired blood coagulation, and poor antibody responses^{46,49,50,56,58,59,60,61,62,63,73,74,80,81,82,83};
- Decline in mental health, including depression, increased mental illness, and anxiety^{44,51,54,56,59,60,67,71,75,76,77,78,79,84,85,86,87,88}. Psychological distress in caregivers varies from 41-62%. The rate in the general population is 19%^{65,89};
- Sleep disruption^{25,40,52,61,62,74,75,90} is attributable to the activities related to the client including nighttime wandering, agitation, and incontinence, as well as caregiver reactions to providing those activities including feelings of depression, loneliness, helplessness, and inability to cope; isolation from family and friends, and changes in roles and relationships with the care-recipients⁹⁰; and
- Feeling stressed^{24,52,70,82,91,92,93,94} and part of the stress response is due to a lack of perceived control to manage the daily caregiving tasks and demands⁵⁰.

This evidence substantiates the likelihood that many caregivers are at risk of becoming patients themselves, and when they do become patients, the clients they are caring for are often hospitalized because there is no one else to care for them⁶¹. Understanding the links between caregiving and poor caregiver health outcomes has led to some interventions aimed at reducing caregiver burden, including treating depression, providing psychosocial support, skills-training, meeting information needs, providing respite care, and providing spiritual and emotional support^{30,76,95}. The two factors noted in the literature that contributed most positively to the caregiving experience were respite care and support.

Situational Factors: Respite Care and Support. The need and value of respite care for caregivers is well known⁹⁶, and in the absence of adequate respite, caregivers experience major stress⁴⁸. We also know that caregivers must feel satisfied that the care recipient's needs will be met in a way that meets the caregiver's approval before they feel able to discuss respite^{27,95}. Caregivers of clients with complex needs, particularly older caregivers, need reassurance that respite will be provided and in a manner in which they would approve^{66,97}. This is particularly true of older caregivers^{66,97}.

The importance of support to caregivers was highlighted in three dimensions: social, community, and the health care team. Caregivers expressed the value and importance of support from family and friends and stated it helped them to keep well and able to continue meeting client needs^{43,53,59}. Caregivers experience isolation because they need to stay in with the client and often sacrifice participation in community groups and activities. This however, does not mean they do not want to be connected to their communities. Many caregivers placed high value on the community maintaining contact with them^{18,81}. Health care teams that functioned smoothly, accurately assessed client and caregiver needs in a timely fashion, and intervened appropriately were also considered an invaluable support⁷⁰.

Conclusions

The purpose of this scoping review was to find previously unidentified information related to the safety of caregivers in the existing home care literature. Four key safety markers were identified: abuse, conscription, economics of caring, and the hidden patient. This review revealed that caregivers find themselves in the caregiving role often with little preparation or consultation. This role places the physical, emotional, social, and financial safety of the caregivers at risk.

Even when individuals believe they are taking on the role with their “eyes wide open,” the very nature of caring at home for an ill family member or friend is seldom predictable, and can quickly and unexpectedly increase in intensity and severity. This has direct impact on the safety markers for caregivers described in this review. An exponential rise in care requirements can exacerbate and even trigger abusive situations. It can increase the sense of loss of control and of being conscripted. It can tax a caregiver’s work life, financial stability, and social resources. And it can be detrimental to the overall health of the caregiver. In providing an invaluable service, caregivers may risk their support systems, their life savings, their employment, and their health.

Recommendations

Attention needs to be given to full acknowledgement of the caregiver role including the supports necessary to mitigate the risks involved to the caregivers and to those that they care for. Interestingly, much of what is recommended here mirrors some of the outcomes outlined in the Framework for a Canadian Caregiver Strategy. It is anticipated that the developing Canadian Caregiver Strategy will address this directly as well as require that home care professionals be competent to assess for the safety markers.

Our recommendations are:

1. Formal information and training programs for those undertaking unpaid caregiver roles must be provided. Additionally, structured consultation and support is needed for those expected to assume the caregiver role.
2. The remuneration of the caregiver, which has begun to a limited extent in some jurisdictions, needs to continue in such a way that caregivers do not face the additional

stress associated with financial uncertainty along with the demands of caregiving. The equipment and supplies necessary to maintain the client at home need to be provided, and home care needs to be included in the Canada Health Act.

3. Respite care, social support, and adequate professional services must be integrated into the home care system so that the health of Canadian caregivers does not need to suffer further. The proposed Caregiver Strategy is ideally charged with outlining how this will happen.

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References

1. Canadian Caregiver Coalition (2008). A Framework for a Canadian Caregiver Strategy. Ottawa, ON: CCC.
2. Rose, K. (2006). Elder Care: A Responsibility That Requires a Collaborative Effort. Adapted from Work-Life Effectiveness: Bottom-Line Strategies for Today's Workforce. *WorldatWork Journal*, 15(2).
3. Brain Injury Association of Canada. (2009). *BIAC-ACLC supports the establishment of a Canadian caregiver strategy*. Ottawa, ON: BIAC.
4. Canadian Institute of Health Information. (2010). *Supporting informal caregivers –The heart of home care*. Ottawa, ON: CIHI.
5. Lang, A., Macdonald, M., Storch, J., Elliott, K., Stevenson, L., Lacroix, H., Donaldson, S., Corsini-Munt, S., Francis, F., & Geering Curry, C. (2009). Home care safety perspectives from clients, family members, caregivers, and paid providers. *Healthcare Quarterly*, 12, 97-101.
6. Macdonald, M., Lang, A., & MacDonald, J. (Submitted). "Mapping a Research Agenda for Home Care Safety: Perspectives from Researchers, Providers, and Decision-Makers," *Canadian Journal on Aging*.
7. Canadian Home Care Association (2008). *Home care the next essential service: Meeting the needs of our aging population*. Mississauga, ON : CHCA.
8. Arksey, K., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19-32.
9. Canter, L. W. (1996). *Environmental Impact Assessment*. USA: Irwin McGraw-Hill.
10. Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal for Qualitative Methods*, 3(1), 1-20.
11. WHO, (2006). *Facts on alcohol and violence: elder abuse and alcohol*. Geneva: WHO.
12. Beach, S., Schulz, R., Williamson, G., Miller, L., Weiner, M. & Lance, C., (2005). Risk factors for potentially harmful informal caregiver behaviour. *Journal of the American Geriatrics Society*, 53(2), 256, 260.
13. Cooper, C., Selwood, A., Blanchard, M., Walker, Z., Blizzard, R., & Livingston, G., (2009). Abuse of people with dementia by family carers: Representative cross sectional survey. *British Medical Journal*, 338, b155.
14. Government of Canada, (2009). *Elder abuse: it's time to face the reality*. Ottawa, ON: Government of Canada.
15. Selwood, A., Cooper, C., Owens, C., Blanchard, M., & Livingston, G. (2009). What would help me stop abusing? The family carer's perspective. *International Psychogeriatrics*, 21(2), 309-13.
16. Miller, L. S., Lewis, M. S., Williamson, G. M., Lance, C. E., Dooley, W. K., Schulz, R., & Weiner, M. F. (2006). Caregiver cognitive status and potentially harmful caregiver behaviour. *Aging and Mental Health*, 10(2), 125-133.
17. Alzheimer's Society of Canada (2010). *Alzheimer's disease fact sheet*. Toronto, ON: Alzheimer's Society of Canada.
18. Carnevale, F.A., Alexander, E., Davis, M., Rennick, J., & Troini, R. (2006). Daily living

with distress and enrichment: the moral experience of families with ventilator-assisted children at home. *Pediatrics*, 117(1), e48-e60.

19. Dow, B., & McDonald, J. (2007). The invisible contract: shifting care from the hospital to the home. *Australian Health Review*, 31(2), 193-202.
20. Duxbury, L., Higgins, C., & Schroeder, B., (2009). *Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada*. Canadian Caregiver Coalition.
21. Hearson, B., & McClement, S. (2007). Sleep disturbance in family caregivers of patients with advanced cancer. *International Journal of Palliative Nursing*, 13(10), 495-501.
22. Bigony, M., (2007). *Perceptions of the nurse-caregiver relationship and its influence on the utilization of respite care services by spousal caregivers of patients diagnosed with dementia*. Doctoral Dissertation. District of Columbia: The Catholic University of America.
23. Metier, Gerry, CBC, (2010). Dealing with dementia [video]. CBC-TV, Connect with Mark Kelly. Retrieved from <http://www.cbc.ca/connect/2010/01/dealing-with-dementia.html>
24. Bertrand, R.M., Fredman, L., Saczynski, J., (2006). Are all caregivers created equal? Stress in caregivers to adults with and without dementia. *Journal of Aging and Health*, 18(4), 534-551.
25. Koshti-Richman, A., (2009). Caring for a disabled child at home: parents' views. *Paediatric Nursing*, 21(6), 19-21.
26. Brannstrom, M., Ekman, I., Boman, K., & Strandberg, G. (2007). Being a close relative of a person with severe, chronic heart failure in palliative advanced home care -- a comfort but also a strain. *Scandinavian Journal of Caring Sciences*, 21(3), 338-44.
27. Stevenson, L., McRae, C., Mughal, W. (2008). Moving to a culture of safety in community home health care. *Journal of Health Services Research and Policy*, 13, Supplement 1, 20-24.
28. VON Canada & The J. W. McConnell Foundation (2007). *The Care Renewal Experience*.
29. Docherty, A., Owens, A., Asadi-Lari, M., Petchey, R., Williams, J., Carter, Y.H. (2008). Knowledge and information needs of informal caregivers in palliative care: a qualitative systematic review. *Palliative Medicine*, 22(2), 153-71.
30. Dunbrack, J., (2005). *The information needs of informal caregivers involved in providing support to a critically ill loved one: A synthesis report prepared for Health Canada*. Ottawa, ON: Health Canada.
31. Milberg, A., Strang, P., & Jakobsson, M. (2004). Next of kin's experience of powerlessness and helplessness in palliative home care. *Support Care Cancer*, 12(2), 120-8.
32. Munck, B., Fridlund, B., & Martensson, J. (2008). Next-of-kin caregivers in palliative home care--from control to loss of control. *Journal of Advanced Nursing*, 64(6), 578-586.
33. Vallerand, A. H., Saunders, M. M., Anthony, M. (2007). Perceptions of control over pain by patients with cancer and their caregivers. *Pain Management Nursing*, 8(2), 55-63.
34. Sharpe, L., Butow, P., Smith, C., McConnell, D., & Clarke, S. (2005). The relationship between available support, unmet needs and caregiver burden in patients with advanced

- cancer and their carers. *Psychooncology*, 14(2), 102-114.
35. Neufeld, A., Harrison, M.J., Hughes, K., Stewart, M. (2007). Non-supportive interactions in the experience of women family caregivers. *Health & Social Care in the Community*, 15(6), 530-41.
 36. Sherwood, P., Given, B., Given, C., Schiffman, R., Murman, D., Lovely, M. (2004). Caregivers of persons with a brain tumor: A conceptual model. *Nursing Inquiry*, 11(1), 43-53.
 37. Farran, C. J., Loukissa, D., Perraud, S., & Paun, O. (2004). Alzheimer's disease caregiving information and skills. Part II: Family caregiver issues and concerns. *Research in Nursing and Health*, 27(1), 40-51.
 38. Guberman, N., Lavoie, J. P., Pepin, J., Lauzon, S., Montejo, M. E. (2006). Formal service practitioners' views of family caregivers' responsibilities and difficulties. *Canadian Journal on Aging*, 25(1), 43-53.
 39. Rodriguez, A., & King, N. (2009). The lived experience of parenting a child with a life-limiting condition: A focus on the mental health realm. *Palliative Support Care*, 7(1), 7-12.
 40. Heaton, J., Noyes, J., Sloper, P., & Shah, R. (2005). Families' experiences of caring for technology-dependent children: A temporal perspective. *Health and Social Care in the Community*, 13(5), 441-50. doi: 10.1111/j.1365-2524.2005.00571.x
 41. Moskowitz, J. T., Butensky, E., Harmatz, P., Vichinsky, E., Heyman, M. B., Acree, M., Wrubel, J., Wilson, L., Folkman, S., (2007). Caregiving time in sickle cell disease: psychological effects in maternal caregivers. *Pediatric Blood Cancer*, 48(1), 64-71.
 42. Young, A. J., Rogers, A., & Addington-Hall, J. M. (2008). The quality and adequacy of care received at home in the last 3 months of life by people who died following a stroke: A retrospective survey of surviving family and friends using the views of informal carers evaluation of services questionnaire. *Health and Social Care in the Community*, 16(4), 419-28.
 43. Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., Swinton, M., Zhu, B., & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Journal of the American Academy of Pediatrics*, 115(6), 626-36. doi:10.1542/peds.2004-1689
 44. Spector, J. and Tampi, R. (2005) Caregiver Depression. *Annals of Long Term Care*, 13(4), 34-40.
 45. Winkler, M. F., Ross, V. M., Piamjariyakul, U., Gajewski, B., Smith, C. E., (2006). Technology dependence in home care: Impact on patients and their family caregivers. *Nutrition in Clinical Practice*, 21(6), 544-556.
 46. Hawranik, P. G., Strain, L. A. (2007). Giving voice to informal caregivers of older adults. *Canadian Journal of Nursing research*, 39(1), 156-172.
 47. Halm, M. A., Treat-Jacobson, D., Lindquist, R., Savik, K. (2007). Caregiver burden and outcomes of caregiving of spouses of patients who undergo coronary artery bypass graft surgery. *Heart Lung*, 36(3), 170-87.

48. Armstrong-Esther, C., Hagen, B., Sandilands, M., Williams, R., Smith, C., (2005). A longitudinal study of home care clients and their informal carers. *British Journal of Community Nursing*, 10(6), 284-91.
49. Ranmuthugala, G., Nepal, B., Brown, L., & Percival, R. (2009). Impact of home based long term care on informal carers. *Australian Family Physician*, 38(8), 618-20.
50. Bakas, T., Pressler, S. J., Johnson, E. A., Nauser, J. A., & Shaneyfelt, T. (2006). "Family caregiving in heart failure," *Nursing Research*, 55(3), 180-8.
51. Chubinski, S. (2007). *Physical and emotional health among caregivers of heart failure patients*. Doctoral Dissertation. Indiana University. Retrieved from Pro Quest <http://gradworks.umi.com/32/78/3278249.html>
52. Molloy, G. J., Johnston, D. W., & Witham, M. D. (2005). Family caregiving and congestive heart failure: Review and analysis. *European Journal of Heart Failure*, 7(4), 592-601.
53. Pattenden, J. F., Roberts, H., & Lewin, R. J. (2007). Living with heart failure; patient and carer perspectives. *European Journal of Cardiovascular Nursing*, 6(4), 273-79.
54. Rivera, H.R., (2009). Depression Symptoms in Cancer Caregivers. *Clinical Journal of Oncology Nursing*, 13(2), 195-202.
55. Nordberg, G., von Strauss, E., Kareholt, I., Johansson, L., & Wimo, A. (2005). The amount of informal and formal care among non-demented and demented elderly persons - results from a Swedish population-based study. *International Journal of Geriatric Psychiatry*, 20(9), 862-79. doi:10.1002/gps.1371
56. O'Rourke, N., Cappeliez, P., & Neufeld, E. (2007). Recurrent depressive symptomatology and physical health: A 10-year study of informal caregivers of persons with dementia. *Canadian Journal of Psychiatry*, 52(7), 434-41.
57. Sainte-Marie, Chloé, (2009). Maison Gilles Carle [video]. Québec: Dumont 360. URL: <http://vtele.ca/emissions/dumont360/archives/2009/11/1750/5673.php>
58. Eters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, 20(8), 423-28. doi: 10.1111/j.1745-7599.2008.00342.x
59. Lindsay, J., Anderson, L. (2004). Dementia/Alzheimer's disease. *BMC Women's Health*, 25(4), Suppl. 1:S20.
60. Mahoney, R., Regan, C., Katona, C., & Livingston, G. (2005). Anxiety and depression in family caregivers of people with Alzheimer disease: The LASER-AD study. *American Journal of Geriatric Psychiatry*, 13(9), 795-801. doi:10.1176/appi.ajgp.13.9.795
61. Rausch, S. M., Baker, K., & Boonmee, J. (2007). Sleep disturbances in caregivers of patients with end-stage congestive heart failure: Part I--the problem. *Progress in Cardiovascular Nursing*, 22(1), 38-40.
62. Rittman, M., Hinojosa, M. S., & Findley, K. (2009). Subjective sleep, burden, depression, and general health among caregivers of veterans poststroke. *Journal of Neuroscience Nursing*, 41(1), 39-52.
63. Soskolne, V., Halevy-Levin, S., & Ben-Yehuda, A. (2007). The context of caregiving, kinship tie and health: A comparative study of caregivers and non-caregivers. *Women & Health*, 45(2), 75-94.

64. Dracup, K., Evangelista, L. S., Doering, L., Tullman, D., Moser, D. K., & Hamilton, M. (2004). Emotional well-being in spouses of patients with advanced heart failure. *Heart and Lung: The Journal of Critical Care*, 33(6), 354-61
65. Dumont, S., Turgeon, J., Allard, P., Gagnon, P., Charbonneau, C., & Vézina, L. (2006). Caring for a loved one with advanced cancer: Determinants of psychological distress in family caregivers. *Journal of Palliative Medicine*, 9(4), 912-921.
66. Saunders, M. M. (2008). Factors associated with caregiver burden in heart failure family caregivers. *Western Journal of Nursing Research*, 30(8), 943-59. doi: 10.1177/0193945908319990
67. Croog, S. H., Burleson, J. A., Sudilovsky, A., & Baume, R. M. (2006). Spouse caregivers of Alzheimer patients: Problem responses to caregiver burden. *Aging and Mental Health*, 10(2), 87-100
68. Campbell, J. (2008). *Behaviors in persons with dementia: A dyadic effect of caregivers' stress process?* Doctoral Dissertation. Florida: University of Florida. Retrieved from Pro Quest <http://gradworks.umi.com/33/34/3334453.html>
69. Franzen-Dahlin, A., Larson, J., Murray, V., Wredling, R., & Billing, E. (2007). Predictors of psychological health in spouses of persons affected by stroke. *Journal of Clinical Nursing*, 16(5), 885-91. doi:10.1111/j.1365-2702.2006.01744.x
70. Diwan, S., Hougham, G. W., & Sachs, G. A. (2004). Strain experienced by caregivers of dementia patients receiving palliative care: Findings from the palliative excellence in Alzheimer care efforts (PEACE) program. *Journal of Palliative Medicine*, 7(6), 797-807. doi:10.1089/jpm.2004.7.797
71. Fletcher, B. S., Paul, S. M., Dodd, M. J., Schumacher, K., West, C., Cooper, B., Lee, K., Aouizerat, B., Swift, P., Wara, W., & Miaskowski, C. A. (2008). Prevalence, severity, and impact of symptoms on female family caregivers of patients at the initiation of radiation therapy for prostate cancer. *Journal of Clinical Oncology*, 26(4), 599-605. doi:10.1200/JCO.2007.12.2838
72. Gort, A. M., Mingot, M., Gomez, X., Soler, T., Torres, G., Sacristan, O., et al. (2007). Use of the Zarit scale for assessing caregiver burden and collapse in caregiving at home in dementias. *International Journal of Geriatric Psychiatry*, 22(10), 957-62.
73. McLennon, S. (2008). *The physical and mental health of spouse caregivers in dementia: Finding meaning as a mediator of burden.* Doctoral dissertation. Retrieved from Pro Quest <http://gradworks.umi.com/33/10/3310502.html>
74. Mills, P. J., Ancoli-Israel, S., Känel, R. v., Mausbach, B. T., Aschbacher, K., Patterson, T. L., Ziegler, M. G., Dimsdale, J. E., & Grant, I. (2009). Effects of gender and dementia severity on Alzheimer's disease caregivers' sleep and biomarkers of coagulation and inflammation. *Brain, Behavior, and Immunity*, 23(5), 605-610.
75. Rowe, M. A., McCrae, C. S., Campbell, J. M., Benito, A. P., & Cheng, J. (2008). Sleep pattern differences between older adult dementia caregivers and older adult noncaregivers using objective and subjective measures. *Journal of Clinical Sleep Medicine*, 4(4), 362-69.

76. Schulz, R., Boerner, K., Shear, K., Zhang, S., Gitlin, L.N., (2006). Predictors of complicated grief among dementia caregivers: a prospective study of bereavement. *American Journal of Geriatric Psychiatry*, 14(8), 650-58.
77. Given, B., Wyatt, G., Given, C., Sherwood, P., Gift, A., & DeVoss, D. (2004). Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum*, 31(6), 1105-17.
78. Swore Fletcher, B. (2007). *Symptoms in family caregivers of patients undergoing radiation therapy for prostate cancer*. Doctoral Dissertation. University of California. Retrieved from Pro Quest <http://gradworks.umi.com/32/74/3274641.html>
79. Garand, L., Dew, M. A., Eazor, L. R., DeKosky, S. T., & Reynolds, C. F.,3rd. (2005). Caregiving burden and psychiatric morbidity in spouses of persons with mild cognitive impairment. *International Journal of Geriatric Psychiatry*, 20(6), 512-22. doi:10.1002/gps.1318
80. Kuster, P. A., & Badr, L. K. (2006). Mental health of mothers caring for ventilator-assisted children at home. *Issues of Mental Health Nursing*, 27(8), 817-35. doi:10.1080/01612840600840588
81. Barrow, S., & Harrison, R. A. (2005). Unsung heroes who put their lives at risk? Informal caring, health and neighbourhood attachment. *Journal of Public Health*, 27(3), 292-7. doi:10.1093/pubmed/fdi038
82. Brehaut, J. C., Kohen, D. E., Raina, P., Walter, S. D., Russell, D. J., Swinton, M., O'Donnell, M., & Rosenbaum, P. (2004). The health of primary caregivers of children with cerebral palsy: How does it compare with that of other Canadian caregivers? *Journal of the American Academy of Pediatrics*, 114(2), 182-19.
83. Gallagher, S., Phillips, A., Drayson, M., & Carroll, D., (2009). Caregiving for children with developmental disabilities is associated with a poor antibody response to influenza vaccination. *Psychosomatic Medicine*, 71(3), 341-344.
84. Hash, K. (2006). Caregiving and post-caregiving experiences of midlife and older gay men and lesbians. *Journal of Gerontological Social Work*, 47(3-4), 121-38.
85. Molyneux, G. J., McCarthy, G. M., McEniff, S., Cryan, M., & Conroy, R. M. (2008). Prevalence and predictors of carer burden and depression in carers of patients referred to an old age psychiatric service. *International Psychogeriatrics*, 20(6), 1193-202. doi:10.1017/S1041610208007515
86. Pirraglia, P. A., Bishop, D., Herman, D. S., Trisvan, E., Lopez, R. A., Torgersen, C. S., Van Hof, A. M., Anderson, B. J., Miller, I., & Stein, M. D. (2005). Caregiver burden and depression among informal caregivers of HIV-infected individuals. *Journal of General Internal Medicine*, 20(6), 510-14. Doi:10.1111/j.1525-1497.2005.0073.x
87. Thompson, A., Fan, M. Y., Unutzer, J., & Katon, W. (2008). One extra month of depression: The effects of caregiving on depression outcomes in the IMPACT trial. *International Journal of Geriatric Psychiatry*, 23(5), 511-6. doi:10.1002/gps.1929
88. WHO, (2009). *Elder abuse and alcohol = L'alcool et la violence à l'égard des aînés*. Geneva, World Health Organization.
89. Hudson, P. L., Hayman-White, K., Aranda, S., & Kristjanson, L. J. (2006). Predicting family caregiver psychosocial functioning in palliative care. *Journal of Palliative Care*,

- 22(3), 133-40.
90. McCurry, S.M., Logsdon, R.G., Teri, L., Vitiello, M.V., (2007). Sleep disturbances in caregivers of persons with dementia: contributing factors and treatment implications. *Sleep Med Rev*, 11(2), 143-53.
 91. Bruce, D.G., Paley, G.A., Nichols, P., Roberts, D., Underwood, P.J., & Schaper, F. (2005). Physical disability contributes to caregiver stress in dementia caregivers. *The Journals of Gerontology, Series A, Biological Sciences and Medical Sciences*, 60(3), 345-9. doi:10.1093/gerona/ 60.3.345
 92. Cameron, J.I., Herridge, M.S., Tansey, C.M., McAndrews, M.P., & Cheung, A.M. (2006). Well-being in informal caregivers of survivors of acute respiratory distress syndrome. *Critical Care Medicine*, 34(1), 81-86.
 93. Travis, S.S., Kao, H.S., Action, G.J., (2005). Helping family members manage medication administration hassles. *Journal of Psychosocial Nursing & Mental Health Services*, 43(11), 13-5.
 94. Williams, J. K., Skirton, H., Paulsen, J. S., Tripp-Reimer, T., Jarmon, L., McGonigal Kenney, M., Birrer, E., Hennig, B. L., & Honeyford, J. (2009). The emotional experiences of family carers in Huntington disease. *Journal of Advanced Nursing*, 65(4),789-98. Doi: 10.1111/j.1365-2648.2008.04946.x
 95. Torjman, S., Makhoul, A., (2008). *Caregivers and dementia. The Caledon Institute of Social Policy*. Ottawa, Canada.
 96. Stanberry-Beall, J. K. (2007). *Building a case for lifespan respite: The effects of formal respite care on caregivers of family members with chronic dependencies*. Doctoral Dissertation. University of Delaware. Retrieved from Pro Quest <http://gradworks.umi.com/32/47/3247572.html>

Appendix A

Table 1: Data Sources for Literature Review

Table 1 Data Sources
Electronic Bibliographic Databases Searched
Biznar
Cumulative Index to Nursing and Allied Health Literature (CINAHL)
Cochrane
Dissertation Abstracts
eBrary
EMBASE
Medline/PubMed
PsycINFO
ScienceResearch
Sociological Abstracts
Social Science Research Network (SSRN)
Social Services Abstracts
UpToDate
Web of Science
Grey Literature Searched
Canadian government websites
Professional associations websites

Appendix B

Table 2: Keyword Search Terms

Table 2 Keyword Search Terms				
(a) Setting:				
Home care				
Home nursing				
(b) Individuals in Caring Relationship				
Caregiver				
Carer				
Client				
Family				
Patient				
(c) Health and Illness Subject Areas				
AIDS/HIV				
Alzheimer's (falls)				
Anxiety / Fear / Hope / Invisible				
Cancer				
Caregiver				
Congestive				
heart				
Chronic disease (management)/ Risk management				
Chronic obstructive pulmonary disease (COPD)				
Dementia				
Depression				
Disabled/Handicapped				
(children)				
Elder				
abuse/Abuse				
End of life/Palliative care / Terminal care				
Evidence-based approach/best practices				
Frail or vulnerable elderly/diminished capacity				
Medication/diversion/Polypharmacy				
Mental health/illness (psychological/psychiatric)				
Pediatics				
Quality of care/Quality of Health care/Safety				
Renal failure				
Respite care				
Stroke				
Technology				

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Safety in Home Care for Unpaid Caregivers: A Scoping Review

Investigators:
Macdonald et al., 2010

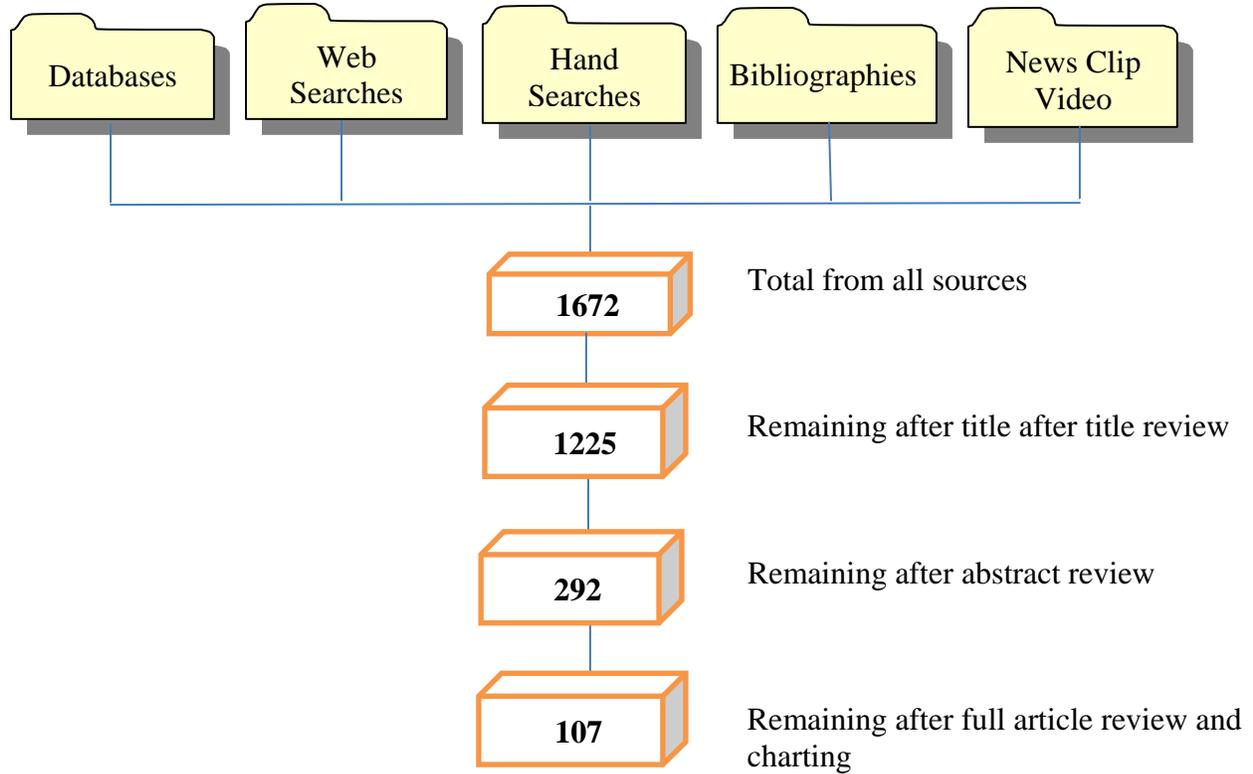
Appendix C

Table 3: Criteria Guiding the Section of Literature

Table 3 Criteria Guiding the Section of Literature
<p>Inclusion All studies related to caregivers across the lifespan Published between 2004-2009 Published in Australia, Canada, Denmark, Finland, Israel, Norway, Sweden, United Kingdom (England, Ireland, Scotland, Wales), and United States Published in English or French Across all illness conditions Documents published by the government of Canada or Associations related to home care</p> <p>Exclusion Literature regarding settings such as hospice, nursing homes, shelters, assisted living, convalescent homes</p>

Appendix D

Figure 1: Sources and Yield from Literature Search



Appendix E

Figure 2: Key Safety Markers

Abuse	Key Safety Markers
	Abuse - Potentially harmful behaviours
	Conscription - Duty, expectation
	Economics of caring
	Financial costs
	Exponential caring
	Hidden patient
	Depression - Anxiety
	Sleep deprivation - exhaustion - fatigue