

La sécurité dans les soins à domicile pour les prestataires de soins¹ bénévoles : un vaste examen de la documentation

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¹ Le masculin est utilisé dans le présent document sans aucune discrimination et uniquement dans le but d'alléger le texte.

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Ce projet fut
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Messages clés

- Les besoins des aidants naturels bénévoles qui prennent soin d'un parent ou d'un ami recevant des soins à domicile ne sont ni clairement compris ni adéquatement comblés par le système de santé canadien.
- À mesure que les soins à domicile continuent à se répandre, cette méconnaissance aura des conséquences sur la santé et la sécurité des aidants naturels, sur l'institutionnalisation des clients à domicile et sur les coûts du système de santé.
- Quatre problèmes clés qui touchent les aidants naturels sont :
 - les conditions qui causent ou exacerbent les abus;
 - le sentiment d'être coincé dans un rôle sans des ressources ou du soutien adéquats;
 - la pression que le rôle d'aidant naturel exerce sur l'emploi, le revenu et les ressources familiales; et
 - la détérioration de la santé des aidants naturels en raison des exigences physiques, émotionnelles, sociales et financières de la prestation de soins.
- Le présent examen met en lumière la nécessité de s'attaquer à ces problèmes de toute urgence dans la Stratégie canadienne en matière de prestation de soins, présentement en cours d'élaboration.
- Plus précisément, la Stratégie canadienne en matière de prestation de soins devrait définir des stratégies pour :
 1. offrir aux aidants naturels des programmes de formation et de consultation structurés;

2. rémunérer les aidants naturels et inclure les soins à domicile dans la Loi canadienne sur la santé; et
3. intégrer les soins de répit, le soutien social et des services professionnels adéquats dans les soins à domicile.

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Sommaire

Contexte

On a assisté au cours de la dernière décennie à une explosion du nombre de prestataires de soins informels au Canada. Dans le présent rapport, *prestataires de soins* se rapporte aux personnes bénévoles, souvent des membres de la famille ou des amis, qui sont responsables d'un client recevant des soins à domicile. Plus de quatre millions prestataires de soins fournissent de l'assistance à un conjoint, un enfant, un parent et autre membre de la famille élargie qui a besoin de soutien en raison de son âge, de maladies débilitantes, de blessures, de maladies chroniques et d'incapacité. Du au vieillissement continu de la population, la prestation de services deviendra une tendance de plus en plus nécessaire.

Les prestataires de soins fournissent plus de 80 % des soins à domicile nécessaires et, de ce fait, sont une composante inestimable du secteur de la santé, permettant aux patients de retourner à la maison ou d'y demeurer, contribuant ainsi à réduire les coûts du système de santé. Dans la prestation de ces soins, les prestataires sont confrontés à des défis physiques, émotionnels, sociaux et financiers qui mettent leur sécurité en danger. La compréhension des problèmes relatifs à la sécurité des prestataires de soins est essentielle pour maintenir leur rôle et prévenir l'institutionnalisation des clients à un stade plus précoce de leur maladie.

La présente étude avait pour objectif d'examiner la documentation du point de vue de la sécurité afin d'identifier des indicateurs de la sécurité des prestataires de soins.

Approche

Cet examen a nécessité l'analyse de la documentation de sources de recherche et autres afin de déterminer l'état des connaissances. Dans le cadre de la présente étude, nous avons utilisé une méthodologie de délimitation de l'étendue pour chercher et visionner les articles et la description interprétative pour analyser la documentation pertinente afin d'identifier des marqueurs communs de la sécurité des prestataires de soins.

Résultats

Nous avons identifié quatre marqueurs de la sécurité des prestataires de soins liés à la prestation des soins à domicile. Ces marqueurs pourraient aussi avoir des conséquences sur la sécurité des clients, des membres de leur famille et du système de santé :

1. **Abus** : Des abus psychologiques ou physiques ont été déclarés dans près de 25 % des relations entre clients et prestataires de soins. Le prestataire de soins pouvait aussi bien être la victime que l'agresseur. Les problèmes d'alcool et de déclin cognitif des prestataires de soins exacerbent les comportements violents. Les risques sont particulièrement élevés pour les clients qui souffrent d'atteintes cognitives ou de démence ou qui ont besoin de beaucoup de soins.
2. **Conscription** : Les prestataires de soins se sentent obligés de s'occuper des membres de leur famille parce qu'il n'y a personne d'autre pour le faire. En outre, ils se plaignent de ne pas recevoir assez d'information et de soutien pour les aider à fournir les soins, soulager la douleur, se débrouiller dans le système des soins à domicile et comprendre l'évolution de la maladie du membre de leur famille.

3. **Économie des soins** : Le système de santé canadien a réalisé des économies de 5 milliards de dollars grâce aux heures de travail non payées des aidants naturels, tandis que ceux-ci sont aux prises avec des coûts financiers, comme la perte de revenus et l'achat de fournitures et d'équipement, sans compter l'épuisement de leurs ressources physiques, émotionnelles et sociales.
4. **Patient caché** : La réduction générale de la santé mentale et physique des prestataires de soins a été constaté, en raison du stress lié à la prestation continue de soins. Parmi les effets constatés, mentionnons des symptômes dépressifs, des maux de dos, des problèmes digestifs, une mauvaise coagulation du sang et une diminution de la réaction des anticorps.

Implications

Les prestataires de soins des clients recevant des soins à domicile sont confrontés à d'importants risques physiques, émotionnels, sociaux et financiers qui menacent leur propre sécurité et celles des personnes dont ils s'occupent. La reconnaissance du rôle du prestataire de soins et la mise en place des soutiens dont ils ont désespérément besoin atténueront ces risques aux prestataires de soins et aux clients, en créant un milieu individuel plus sain et des programmes de soins à domicile plus durables.

Recommandations

Les trois recommandations qui émergent du présent examen reflètent les résultats définis dans la Stratégie canadienne en matière de prestation de soins :

1. Nous devons fournir des programmes formels d'information et de formation, de la consultation et du soutien structurés aux personnes jouant le rôle de prestataires de soins.

2. Nous devons établir un système de rémunération des prestataires de soins afin que ceux-ci n'aient plus à affronter, en plus du stress lié à la prestation de soins, un stress financier additionnel. Nous devons fournir l'équipement et les fournitures nécessaires au maintien à domicile du client, et les besoins liés aux soins à domicile doivent être prévus dans la Loi canadienne sur la santé.
3. Nous devons intégrer les soins de répit, le soutien social et des services professionnels adéquats dans la prestation des soins à domicile afin que les prestataires de soins canadiens n'aient pas à souffrir plus longtemps.

La Stratégie canadienne en matière de prestation des soins proposée est le cadre idéal pour suivre directement ces recommandations et pour faire en sorte que les professionnels des soins à domicile acquièrent les compétences pour évaluer les marqueurs de la sécurité des prestataires de soins.

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.

Approche, méthodologie, rationale et assomptions

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.

Résultats, 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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Annexe 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

Annexe 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				
Chronic disease (management)/ Risk management				
Chronic obstructive pulmonary disease (COPD)				
Dementia				
Depression				
Disabled/Handicapped				
Elder				
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)				
Pediatrics				
Quality of care/Quality of Health care/Safety				
Renal failure				
Respite care				
Stroke				
Technology				

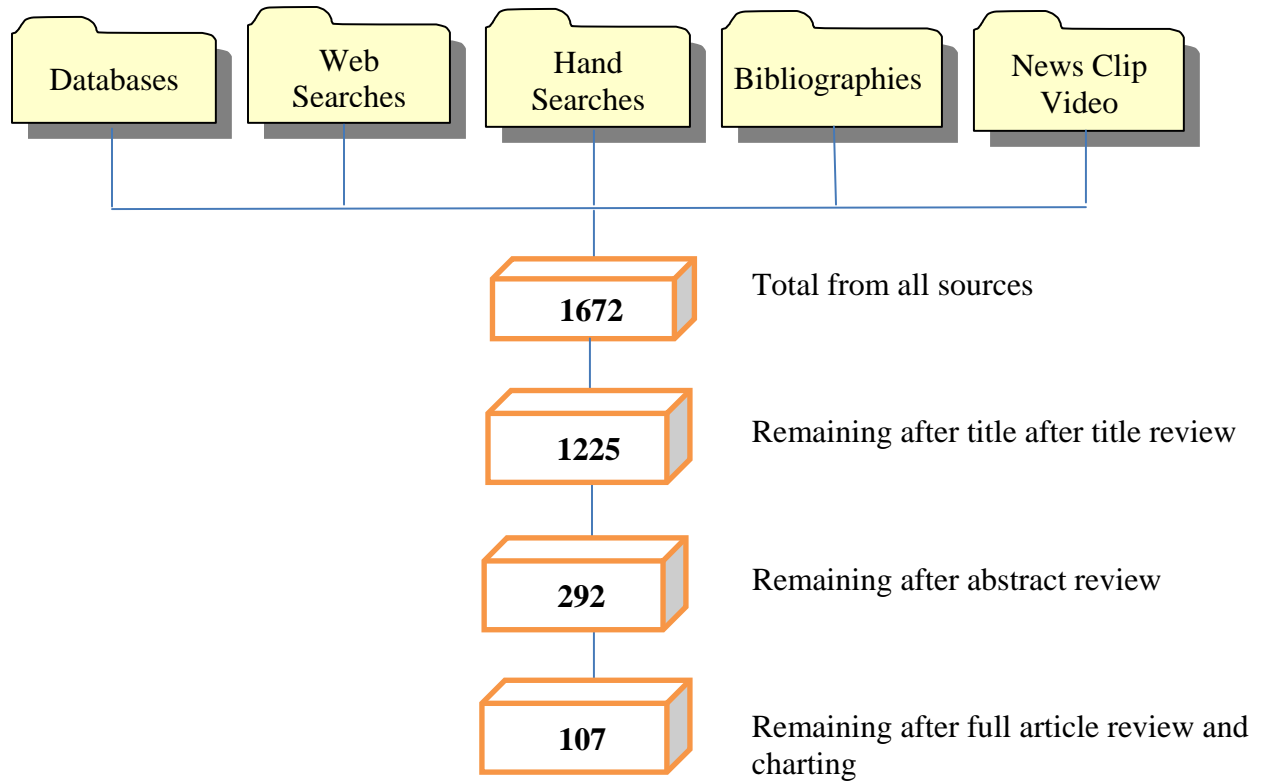
Annexe C

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>

Annexe D

Figure 1: Sources and Yield from Literature Search



Annexe 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