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Home Care Safety Markers: A Scoping Review

Marilyn Macdonald PhD a, Ariella Lang PhD b, Jan Storch PhD c, Lynn Stevenson PhD d, Susan Donaldson MHSc e, Tanya Barbara MA a & Kristine Iaboni MA f

a Dalhousie University, Halifax, Nova Scotia, Canada
b VON Canada, Ottawa, Ontario, Canada
c University of Victoria, Victoria, British Columbia, Canada
d Vancouver Island Health Authority, Victoria, British Columbia, Canada
e Canadian Home Care Association, Port Perry, Ontario, Canada
f VON Canada, Montreal, Quebec, Canada

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Home Care Safety Markers: A Scoping Review

MARILYN MACDONALD, PhD
Dalhousie University, Halifax, Nova Scotia, Canada
ARIELLA LANG, PhD
VON Canada, Ottawa, Ontario, Canada
JAN STORCH, PhD
University of Victoria, Victoria, British Columbia, Canada
LYNN STEVENSON, PhD
Vancouver Island Health Authority, Victoria, British Columbia, Canada
SUSAN DONALDSON, MHSc
Canadian Home Care Association, Port Perry, Ontario, Canada
TANYA BARBARA, MA
Dalhousie University, Halifax, Nova Scotia, Canada
KRISTINE IABONI, MA
VON Canada, Montreal, Quebec, Canada

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Address correspondence to Marilyn Macdonald, PhD, Dalhousie University, 5869 University Avenue, P.O. Box 15000, Halifax, NS B3H 4R2, Canada. E-mail: marilyn.macdonald@dal.ca

Abstract:

Safety in home care is a new research frontier, and one in which demand for services continues to rise. A scoping review of the home care literature on chronic obstructive pulmonary disease and congestive heart failure was thus completed to identify safety markers that could serve to develop our understanding of safety in this sector. Results generated seven safety markers: (1) Home alone; (2) A fixed agenda in a foreign language; (3) Strangers in the home; (4) The butcher, the baker, the candlestick maker; (5) Medication mania; (6) Out of pocket: The cost of caring at home; and (7) My health for yours: Declining caregiver health.

Introduction

Client safety is a new frontier within the homecare context. Given the dramatic increase in the amount of care provided within the home and the complexity inherent in care delivery within this context...
sector, it is essential to develop our understanding of safety and or antecedents to safety. To this end a scoping review of the homecare literature focused on Chronic Obstructive Pulmonary Disease (COPD) and Congestive Heart Failure (CHF) was conducted. The review was focused on these two chronic illnesses based on the prevalence and burden of COPD and CHF, the volume of homecare literature, and study resources.

Globally (COPD) affects 64 million people. The European Union accounted for 13.8 million (EU COPD Coalition), the United States of America 16 million (COPD International) and Canada approximately 772,200 (Public Health Agency of Canada, 2011). Canadians affected described their health as fair to poor, or steadily declining (PHAC, 2011). Worldwide 26 million people have Congestive Heart Failure (CHF) including 5.7 million Americans (Centre for Disease Control), 6.5 million Europeans, and approximately 350,000 Canadians (Canadian Heart Failure Network; Lopez-Sendon, 2011). Individuals living with these chronic illnesses do so at home, and the majority of care is provided by family caregivers (Reinhard, Levine & Samis, 2012; Canadian Home Care Association, 2008).

Background

The Canadian Home Care Association reported that from 1997 to 2007 homecare grew by 51% (CHCA, 2008). The prevalence of COPD and CHF in the population means increasing demands on homecare, and is associated with considerable client, caregiver, and societal burden. Clients have multiple health problems including dementia, experience sensory loss, and persistently use acute care services (Reinhard et al., 2012; Hirdes, 2011; Mitchell, 2010). Their caregivers are usually middle aged or older, and are required to coordinate client care that grows exponentially
with little assistance resulting in negative experiences and depression (Reinhard et al., 2012). The financial cost associated with CHF and COPD annually in the United States is 34 and 32 billion respectively (CDC; COPD International).

Client safety research is an area largely neglected within the homecare context. This has resulted in a significant knowledge gap regarding homecare safety in general, and specifically in how it relates to homecare recipients and their unpaid caregivers (Lang & Edwards, 2006).

Purpose

The purpose of this scoping review was to identify markers that can be linked to safety in homecare for clients and/or caregivers.

Methods

Overview

The aim of a scoping review is to achieve breadth rather than depth on a topic. These reviews do not typically begin with a defined question like a systematic review, but rather remain open to what the literature may reveal throughout (Arksey & O’Malley, 2005; Weeks & Strudsholm, 2008). Team members worked in a collaborative manner to share information and make decisions throughout the review process. The following section describes the sources, search terms, inclusion and exclusion criteria, synthesizing process and analysis of the data.
Sources

The primary sources used to obtain evidence for this review included: (a) electronic bibliographic databases (12); (b) grey literature from government and professional association websites (5 sources); and (c) manual searches of publications conducted on professional journals and academic periodicals. The full list of data sources used for this literature review is listed in Table 1.

Search terms

The initial search strategy of including COPD and CHF in the subject, key word and descriptor fields yielded very few articles therefore the team used the search strategy of placing COPD and CHF in the title fields with an established list of search terms included in the subject/keyword(descriptor) fields (see Table 2), and terms to be excluded from the search process (see Table 3). This produced 376 potential articles. Further screening resulted in 180 articles included in this scoping review.

Inclusion/Exclusion

The criteria employed in identifying relevant publications included geographical location of study, publication and language. The literature deemed relevant and used for the review was published between 2004 and 2011; though a significant portion was published between 2007-2009. All publications are in English, except for grey literature available in French and English.
Table 3 lists the criteria guiding the selection of literature included as well as excluded in the final review.

Triaging process

This process involved three stages, with designated team members ranking the titles, abstracts or full-text articles as: (a) relevant, (b) potentially relevant or (c) not relevant. In stage one all titles retrieved were ranked by four members of the research team. Those titles ranked as relevant and potentially relevant were carried over to stage two. In stage two, the abstracts of all relevant and potentially relevant articles were reviewed and ranked by four team members. Only articles ranked as relevant from stage two were carried over to stage three. In stage three, all full-text relevant articles were placed in batches and assigned to team members for review. Seven team members were involved in the review process of stage three. Figure 1 summarizes the review process.

Analysis

All full text articles and documents identified as relevant in stage three were reviewed by team members and entered in an article summary table that included: author, year, title, purpose, method/methodology, findings, and a brief summary. The data were then analyzed using interpretive description methodology (Thorne, Kirkham & O’Flynn-Magee, 2004) to identify patterns deemed to represent safety markers for clients and/or caregivers. The definition of terms used in the manuscript is appended in Table 4.
Results and Discussion

Seven markers were identified as relevant to safety in homecare for clients and/or caregivers: (1) Home alone, (2) A fixed agenda in a foreign language, (3) Strangers in the home, (4) The butcher, the baker, the candlestick maker (5) Medication mania, (6) Out of pocket: The cost of caring at home, and (7) My health for yours: declining caregiver health. These markers are intentionally presented in this order to illustrate how they are linked to each other and to client and caregiver health and safety.

Home Alone

Individuals suffering from chronic illnesses such as COPD and CHF often face symptoms that restrict their ability to engage in social activities, hobbies and other interests. The marker ‘Home Alone’ refers to homecare clients’ (and often their caregivers’) perceptions that they have been left by themselves to deal with their illness. This perception is a result of feelings of seclusion, lack of support and decreased socialization experienced by clients with live-in family or spousal support, as well as those who live alone.

Researchers have found that clients with COPD and CHF are frustrated and are no longer able to participate in their social support networks due to diminished physical ability to visit friends and family, as well as limited engagement in previously enjoyed hobbies and activities (Aldred, Gott & Gariballa, 2005; Cortis & Williams, 2007; Elofsson, 2004). Specifically, it is the unpredictability of their illness and health status, as well as the presence of symptoms such as breathlessness, fatigue, insomnia, headaches, falls and reduced mobility, that contribute to clients
being housebound or highly dependent on others for commitments inside and outside the home (Aldred et al., 2005; Brännström, Ekman, Norberg, Boman & Strandberg, 2006).

Homecare clients describe feeling abandoned or neglected by friends and family members whose visits became less frequent as the illness progressed (Brännström et al., 2006; Elofsson, 2004). These feelings of abandonment extended to include health care professionals as well. Clients with COPD and/or CHF reported feeling that they were left on their own to manage an illness; an illness they may not fully understand due to a lack of communication, education and information provided by health care professionals (Aldred et al., 2005; Brännström et al., 2006; Hopp, Thornton & Martin, 2010). Homecare clients who live alone were shown to experience greater loneliness than those who lived with a spouse (Brännström et al., 2006). In addition, these clients had a higher risk for non-adherence to prescribed medication and dietary restrictions, both significant safety issues, thus likely requiring more frequent follow-up and support (Brännström et al., 2006; Davidson, Paull, Rees, Daly & Cockburn, 2005; Sauvé, Lewis, Blankenbiller, Rickbaugh & Pressler, 2009). Researchers also identified living alone as a predictor of depression and anxiety in clients with COPD and CHF (Albert & Zeller, 2009; Havranek, Spertus, Masoudi, Jones & Rumsfeld, 2004). Depression and anxiety are important safety markers for clients as they are associated with higher mortality, an increased degree of health care usage, reduced quality of life, and an overall negative impact on an individuals’ ability to function (Hasson, Spence, Waldron, Kernohan, McLaughlin, Watson, et al., 2008; Yohannes, Willgoss, Baldwin & Connolly, 2009).
A “Fixed” Agenda in a “Foreign” Language

A “fixed agenda” refers to the reality that the information provided to clients and their families about how to manage their chronic illness at home often follows a pre-determined script that does not recognize the specific information needs required for each case. Often, this information is provided using clinical terminology or medical jargon described by clients as hearing a “foreign” language. The barriers to effective transmission of relevant information identified in this scoping review included: a) lack of time for communication from health care professionals, b) varying difficulties in client or caregivers’ reception of information, and c) problems in understanding the technology necessary for safe care.

Lack of Time for Adequate Communication by Health Care Professionals

Despite the information needs of clients suffering from COPD and CHF at home, evidence suggests that there is a perceived lack of time and effort by health care professionals in communicating such information to clients and answering questions based upon individual client needs (Aldred et al., 2005; Hopp et al., 2010). Lack of specific guidance or explanations about an illness or about symptoms may also lead to increased hospitalizations (Hopp et al., 2010) or create unnecessary client anxiety that may contribute to a mismanagement of health symptoms (Hasson, Spence, Waldron, Kernohan, McLaughlin, Watson et al., 2009) and increase strain for caregivers when making decisions about homecare (Hasson et al., 2008).
Client and Caregiver Reception of Information

Individual client and caregiver characteristics influence effective communication and capacity to receive information (Michaels & Meek, 2004; Myers, Grant, Lugn, Holbert & Kvedar, 2006; Sauvé et al. 2009; Scherr, Kastner, Kollmann, Hallas, Auer, Krappinger, et al., 2009). For example, several researchers have identified that cognitive impairments, such as memory loss and decreased functionality resulting from illness or medications, may challenge a client’s ability to learn and thereby create safety concerns because self-care decisions are based on misunderstanding the shared information (Bartoli, Zanaboni, Masella & Ursini, 2009; Dansky, Vasey & Bowles, 2008; Horton, 2008; Law & Lehoux, 2004; Slater, Neander & Carey, 2006).

Reception of information can be further confounded by cultural and language barriers due to differences in the care management and information needs of clients from different cultural backgrounds (Evangelista, Ter-Galstanyan, Moughrabi & Moser, 2009). This poses a safety risk because the care needs required for this group of clients may not be fully met. Therefore, there is a need to avoid a “fixed agenda” for providing information to homecare clients (Horton, 2008).

Technology Concerns

Technology was found to pose an additional challenge to the reception of information for clients with a diagnosis of COPD and/or CHF. Technology is regarded as a positive and important tool that increases self-management and monitoring capacity among homecare clients and increases communication between clients and health care professionals. However, impairments such as diminished attention and slower motor reactions associated with CHF have been shown to
challenge a client’s ability to properly learn, utilize and maintain devices, equipment or technology (Bartoli et al., 2009; Myers et al., 2006; Radai, Arad, Zlochiver, Krief, Engelman & Abboud, 2008; Sauvé et al., 2009; Scherr et al., 2009).

Strangers in the Home

Homecare is a unique environment where clients and their families have authority in the home, and health care professionals and personal support workers are guests within their clients’ homes. “Strangers in the home” refers to the number of professionals and personal support workers and staff from various agencies involved in most homecare settings, contributing to the client’s home life and feelings of safety being somewhat contested while searching for continuity in care providers.

The Search for Continuous Care

Depending on the model, the delivery of homecare can alter the routine of the home setting, leaving the client and family feeling somewhat uneasy while striving to remain in charge. Models that involve the use of several agencies may result in numerous individuals from various agencies engaging with a client in a manner that lacks coordination (Chattoo & Atkins, 2009). This lack of coordination leaves clients feeling overwhelmed by various people coming into the home. Communication between health care professionals and personal support workers from multiple agencies can also be difficult, which can pose safety risks associated with either the omission or duplication of specific care delivery tasks for clients (Aldred et al., 2005; Corsello & Tinkelman, 2008; Hasson et al., 2008).
Clients and their families valued continuity of care from their personal support workers and health care professionals with whom they can build effective and supportive relationships (Barnett, 2005; Boyd, Worth, Kendall, Pratt, Hockley, Denvir, et al., 2009; British Thoracic Guideline Development Group, 2004; Davidson et al., 2005). Without continuity of care, it becomes extremely difficult for clients and caregivers to develop trust for any one health care professional, thereby limiting their ability to communicate effectively with these individuals (Aldred et al., 2005). This limitation in trust and communication also decreases comfort levels in the home as clients feel like a burden to these strangers (Hasson et al., 2008).

The Butcher, the Baker, the Candlestick Maker

The role of the caregiver in the context of homecare is multifaceted. Unlike the team of health care professionals that are trained and prepared for varying situations, caregivers receive no such formal education or training. The caregiver, in attempting to meet all the responsibilities and changing expectations, becomes “the butcher, the baker, the candlestick maker” and any other role that is required in caring for a loved one. This attempt to be everything within the caregiver role can cause strain and result in safety risks for both the client and caregiver. This marker encompasses two main issues for caregivers that link to safety: a) increasing responsibilities and b) changes in roles.
Increasing Responsibilities

Caring for a client at home is complex. Most care within the home is carried out by family members who face multiple responsibilities and expectations with little preparation or information regarding managing an illness (Aldred et al., 2005; Clark, Reid, Morrison, Capewell, Murdoch & McMurray, 2007; Hasson et al., 2009). Demands and responsibilities placed on them continue to intensify as the ill family member’s capabilities decrease. The caregiver must therefore fulfil the physical and social functions and needs of the client (Goodlin, 2009), particularly when personal support workers or health care professionals are unavailable or off duty. Many times, caregivers are expected to take on these responsibilities without hesitation, help or support from other family members or health care professionals (Aldred et al., 2005) despite their already intensifying burden, stress and drained levels of functioning (Ågren, Frisman, Berg, Svedjeholm & Strömberg, 2009).

The more the client relies upon the caregiver, the greater the increase in safety risks; since there are more things to remember, do, and take care of for their loved one and for themselves. These responsibilities place a considerable burden on caregivers (Abernethy, Currow, Clarke, Newton & Davidson, 2009; Goodlin, 2009; Leff, Burton, Mader, Naughton, Burl, Inouye et al., 2005; Narsavage & Chen, 2008; Saunders, 2008), and these overwhelming tasks can create many unforeseen safety risks for both caregiver and client at home. For example, managing multiple and growing tasks can lead to added exhaustion and declining health for the caregiver (Brewin, 2004; Hwang & Dracup, 2010), decreased emotional wellbeing within the caregiver (Bakas, Pressler, Johnson, Nauser & Shaneyfelt, 2006; Luttik, Lesman-Leegte & Jaarsma, 2009a), an
inability to cope with stress due to their caregiver role (Bakas et al., 2006; Pressler, 2009) and negative perceived caregiver outcomes such as a deteriorating future outlook and diminished financial wellbeing (Bakas et al., 2006; Bennett, Bakas, Johnson & Shaneyfelt, 2004; Hasson et al., 2009).

Changes in Roles

As roles and responsibilities change, caregivers may feel they are losing their self-sufficiency and independence (Freydberg, Strain, Tsuyuki, McAlister & Clark, 2010). Not only do many caregivers work outside of the home, they continue working within the home (Saunders, 2010). These changes within the caregiver’s life may leave them feeling resentful and burdened on top of the already stressful task of taking care of their loved one (Aldred et al., 2005; Nordtug & Holen, 2011; Spence, Hasson, Waldron, Kernohan, McLaughlin, Cochrane et al., 2008). Caregivers identified negative role changes such as taking on multiple roles (e.g., wife, husband, daughter, son, sibling, nurse, doctor, etc.; Harris, 2007; Spence et al., 2008) and undertaking tasks that were previously the responsibility of the current client (e.g., housework and cooking for many men, gardening and house maintenance for many women, or managing all household finances; Bennett, Bakas, Johnson & Shaneyfelt, 2004; Hasson et al., 2008; Hwang, Luttik, Dracup, Jaarsma, 2010). These changes in roles frequently led caregivers to feel as though their identity was lost (Brewin, 2004; Spence et al., 2008).

On the other hand, clients reported feeling badly or frustrated watching their spouses contend with what they saw as ‘gender-specific’ work, such as male spouses doing domestic labour and female spouses performing general house maintenance activities such as mowing the lawn.
may result from the inability of the client to continue fulfilling the roles and responsibilities they previously held themselves (Aldred et al., 2005). Feelings of frustration and worry that develop as a result of taking on the caregiver role may even lead to aggravation or incidences of violence toward the client by caregivers (Brewin, 2004; Woolfe, McMillan & Conway, 2007).

Medication Mania

Medication management is a challenge when living with chronic illness. Individuals with COPD, for instance, vary widely in relation to lung function, co-morbidities, cognitive functions, hand strength and lifestyle; all of which impact on the number and types of medications and devices used, as well as the degree to which these are properly managed (Caress, Luker, Chalmers & Salmon, 2009; Fromer, Goodwin & Walsh, 2010). The safety marker “Medication Mania” refers to the myriad of medications needing organization and monitoring by clients, caregivers and health care professionals within the homecare system and is characterized by changing medication regimes and overcoming medication related barriers.

Multiple Medication Regimes

The management of medication poses a significant safety concern for homecare recipients and caregivers. Clients and their caregivers are commonly responsible for multiple medications (Caress et al., 2009; Hwang et al., 2010; Slater, Neander & Carey, 2006; Triller & Hamilton, 2007; Upadaya, Lee, Saldarriaga, Verma, Sedrakyan, Nystrom et al., 2004), with some of these medications needing specific and complex devices, techniques or guidelines for administration (Fromer et al., 2010; Quinn, 2005). Failure to execute one step or adding an additional step in a
medication regime can considerably diminish its efficacy, as well as present potential safety concerns, such as worsening symptoms or increases in the frequency of exacerbations (Fromer et al., 2010). Furthermore, if the purpose of the medication is not clearly explained or understood this can impact on how or if clients continue to take a particular medication. For instance, VanderSchaaf, Olson, Billups, Hartsfield & Rice (2010) reasoned that participants stopped using inhalers because they felt they were not effective in relieving their symptoms, when the actual purpose of the inhaler was not to relieve symptoms but to prevent exacerbations. This example highlights important safety implications that are intertwined with medical literacy and adequate medical education to help clients and caregivers manage medications safely.

It is evident from the homecare literature that without a certain level of medication literacy and proper medication management by clients, caregivers and health care professionals, the health status of clients can decline (Horne & Payne, 2004; Morgan, Masoudi, Havranek, Jones, Peterson, Krumholz et al., 2006; Schmidt, Sheikzadeh, Beil, Pattern & Stettin, 2008).

Barriers to Medication Management

Variations in managing medications were also caused by barriers the clients and caregivers faced when making decisions regarding their medication treatments (Dickson & Riegel, 2009). Issues or areas of concern leading to resistance in medication management include:

- Confusion and knowledge deficits regarding their medications and how to take them (Morgan et al., 2006; Polzien, 2007; Roberts, Leeder & Robinson, 2008; Smith, 2010; VanderSchaaf et al., 2010);
Lack of physical ability (e.g., inability to open medication bottles; Dickson & Riegel, 2009)

Unwanted or unpleasant side effects with taking the medication (e.g., increased urination from diuretics, insomnia, fatigue, sexual dysfunction, etc.; Freydberg et al., 2010; Horne & Payne, 2004; Smith, 2010);

Obstacles in the healthcare system (e.g., difficulties getting in touch with healthcare personnel, tiring travel time, long waiting time, supply shortages, medication costs, etc.; Clark et al., 2007; Davidson et al., 2005; Lundman, Brännström, Hägglund & Strandberg, 2009; Upadaya et al., 2004; VanderSchaaf et al., 2010).

Overall, medication management in the context of homecare is emphasized as a significant safety marker that may jeopardize the health and safety of the client.

Out of Pocket: The Cost of Caring at Home

The economics of caring is a growing issue within the homecare context. Responsibilities for patient care are increasingly being moved from public institutions to client homes. This creates a personal burden, both economic and emotional, for homecare clients and their caregivers, thus raising safety concerns regarding their physical, psychological and economic well-being. Recipients of homecare frequently find themselves ‘out of pocket’ from the high expenditures, lack of funding, and other personal and financial costs of receiving care at home.
Out of pocket for Equipment and Services

Many homecare recipients experienced high personal expenditures for health-care equipment and services. For example, Hasson et al. (2009) reported that many caregivers had made modifications to their homes, such as installing modified shower facilities as caregivers and clients did not want to face long waiting lists or shortages of available equipment through funded programs. Clients and caregivers vary in their personal capacity to incur additional costs, and this can result in inequities in the degree of quality and safety of homecare. For those with limited funds, incurring costs may well increase stress. For example, clients with COPD often require oxygen therapy. For these clients, the ability to access treatments such as liquid oxygen therapy holds benefits that include the provision of a lighter more convenient source for oxygen therapy outside the home. But as Law (2005) indicates, this type of oxygen is associated with costs four times higher than standard oxygen therapy. If the liquid oxygen therapy is not covered by public funding, then clients and caregivers are faced with the difficult decision to go with the more cumbersome traditional forms of portable oxygen, go without, or incur high costs out of their own pockets for the more convenient liquid portable oxygen (Law, 2005). Safety implications are significant because when the more portable forms of oxygen are not feasible, those clients may make the decision to forgo using oxygen during outings completely, creating a health safety risk (Law, 2005).

Challenges to Navigating the system

Homecare clients have also expressed frustration in their attempts to navigate various systems for publically funded services and equipment. Those who can, incur the costs for the resources...
required privately, increasing financial stress; while those who cannot afford the private path are left feeling helpless and without the resources they need. Clients also expressed that overall support and advice regarding the economic or financial side of receiving care at home was not readily available (Brewin, 2004; Hasson et al., 2009). For example, in Hasson et al.’s (2009) study, participants reported that information on available support services was sporadic and that the only information on benefit or funding programs came from hospital and clinic pamphlets, which were very limited in detail. Similarly, Brewin’s (2004) study examining the quality of life of caregivers found that participants were confused as to what assistance programs they would qualify for. These examples illustrate those who cannot afford to pay are at a higher risk because they are waiting longer for needed equipment and services.

Caring, Work and Wages

The costs of caring at home include growing financial burdens, stress in overseeing household bills and health expenditures for services and equipment, and changes in financial well-being or status for both the client and the caregiver (Bennett et al., 2004; Hasson et al., 2009; Hwang & Dracup, 2010). These changes are amplified by reduced working hours for pay due to an illness or caring for those who are ill. For instance, clients with a chronic illness are often forced to stop working years earlier than expected due to their poor health (e.g., decreased mental and physical capacity to work without the necessary rest; Brewin, 2004; Lundman et al., 2009). Likewise, family caregivers commonly decrease their working hours to part-time status, take pay-cuts to acquire flexible schedules, or incur travel costs in order to provide care for their loved ones (Brewin, 2004; Mendoza, Martin, Garcia, Arós, Aizpuru, De Los Cobos, et al., 2009). Caregivers
then have to adjust not only to a reduced income, but also to lower status employment, sometimes going from more ‘professional’ roles to ‘menial’ work (Brewin, 2004). These adjustments result in the family’s increasing financial stress and negative outlooks regarding their present and future economic state, often leading to depression and poor health (Bennett et al., 2004; Brewin, 2004; Evangelista et al., 2009; Hwang & Dracup, 2010; Suwanno, Petpichetchian, Riegel & Issaramalai, 2009). Overall, the health and well-being of homecare clients and family caregivers are put at risk due to the economic costs of managing care at home.

My Health for Yours: Declining Caregiver Health

The health of caregivers is largely affected by their caregiving responsibilities, which are often complex, and ever-mounting. Many caregivers experience real and perceived expectations that compel them to be present for their loved ones 24 hours a day, often to the detriment of their own health. Therefore, caregivers often end up sacrificing their own health for the care and health of their loved ones.

Taking on the Caregiver Role

Health care responsibilities have been increasingly transferred from public institutions to the family (Jónsdóttir, 2008). For instance, family caregivers tend to be the one’s providing the majority of care within the home for clients with a major chronic illness (Jansen, Wouters, Schols & Spruit, 2008; Luttik, Jaarsma, Lesman, Sanderman & Hagedoom, 2009; Pressler, Gradus-Pizlo, Chubinski, Smith, Wheeler, Wu et al., 2009; Quinn, 2006). When individuals take on the caregiver role, they often feel obliged to meet all expectations of caring while balancing
their usual domestic tasks. As a result, the caregiver role has been compared to “being on a rollercoaster,” as the caregiver is trying to maintain normality in the home despite abnormal circumstances (Brännström, Ekman, Boman & Strandberg, 2007b), such as lack of respite care, divergent opinions between caregiver, health care professional and client, and long, strenuous hours in the caregiving role (Boyd et al., 2009; Brännström, Ekman, Boman & Strandberg, 2007a; Hasson et al., 2009; Heart Failure Society of America, 2010; Saunders, 2008; Wilson, Ross, Goodridge & Davis, 2008; Woolfe et al., 2007). The caregiver is ‘on call’ 24 hours a day, trying to balance activities and relaxation for themselves and their loved one. This has been shown to lead to caregivers’ feelings of burden and of resentment (Brännström et al., 2007a; Brännström et al., 2007b) culminating in caregiver ill health.

Caregiver Health Decline and its Consequences

Declining caregiver health is an example of a negative health issue facing caregivers who manage clients at home (Hasson et al., 2008; Molloy, Johnston & Witham, 2005). The literature has indicated the following health-related issues for caregivers:

- Significant stress and pressure (Hasson et al., 2008; Luttik, Blaauwbroek, Dijker & Jaarsma, 2007; Wolfe et al., 2007)

- Fatigue, loss of concentration and lack of sleep (Hasson et al., 2008; Hasson et al., 2009; Luttik et al., 2007; Spence et al., 2008)

- Feelings of helplessness, guilt and frustration about their situation (Agren et al., 2009; Brewin, 2004; Harris, 2007; Hasson et al., 2009; Spence et al., 2008)
• Confusion and tension between wanting to prolong a loved one’s life and knowing they must plan for a loved one’s death’ (Brännström et al., 2007a; Chattoo & Atkin, 2009)

• Lower quality of life (Luttik et al., 2007)

• Increased depression (Harkness, 2009; Narsavage & Chen, 2008; Saunders, 2008)

• Feelings of social isolation (Ågren et al., 2009; Hwang et al., 2010; Molloy et al., 2005)

These consequences have been shown to restrict caregivers in pursuing their own activities (Pressler et al., 2009; Saunders, 2008). In addition, poor physical health and distress may influence the ability of caregivers to give safe care (Ågren et al., 2009; Pressler et al., 2009; Rohrbaugh, Shoham, Cleary, Berman, & Ewy, 2009) or make appropriate decisions for their loved ones (Harkness, 2009). This, in turn, can result in increased hospital readmission for the client (Molloy et al., 2005; Narsavage & Chen, 2008), and increased morbidity (Luttik et al., 2007) and mortality in caregivers (Luttik et al., 2007; Saunders, 2008).

Conclusion

This scoping review confirmed significant safety related information not previously identified that is meaningful for clients and caregivers. The literature reviewed did not unilaterally link client and caregiver safety, therefore some markers appear more client than caregiver focused and vice versa. Client and caregiver health and safety are linked through the identified markers. Clients and caregivers felt left on their own to manage; that the information they were provided was not what they needed; that they did not get to know their providers yet
were expected to take on a variety of responsibilities including managing many medications. In order to remain at home they incurred numerous out of pocket expenses. This cascade of markers culminated in the caregiver experiencing health problems that limited ability to care for the client placing the health and safety of both at risk.

References


Fromer, L., Goodwin, E., & Walsh, J. (2010). Customizing inhaled therapy to meet the need of COPD patients. Postgraduate Medicine, 122(2), 83-93.


Heart Failure Society of America (2010). Executive Summary: HFSA 2010 Comprehensive Heart Failure Practice Guideline. Journal of Cardiac Failure, 16(6), 475-539.


Table 1: Data Sources for Literature Review

<table>
<thead>
<tr>
<th><strong>Electronic Bibliographic Databases Searched</strong></th>
<th><strong>Grey Literature Searched</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>British Nursing Index</td>
<td>Canadian government websites: Canadian</td>
</tr>
<tr>
<td>CINAHL</td>
<td>Agency for Drugs and Technologies in Health</td>
</tr>
<tr>
<td>Cochrane</td>
<td><strong><a href="http://www.cadth.ca/en/products/health-technology-assessment">http://www.cadth.ca/en/products/health-technology-assessment</a></strong></td>
</tr>
<tr>
<td>EMBASE</td>
<td>Institute for Safe Medication Practice</td>
</tr>
<tr>
<td>Medline</td>
<td><strong><a href="http://www.ismp-canada.org/index.htm">http://www.ismp-canada.org/index.htm</a></strong></td>
</tr>
<tr>
<td>Ovid</td>
<td>Professional association websites: Institute of Electrical and Electronics Engineers</td>
</tr>
<tr>
<td>PsychInfo</td>
<td>Conference Proceedings, 1st Transdisciplinary</td>
</tr>
<tr>
<td>ProQuest Dissertations and Theses Full Text</td>
<td>Conference on Distributed Diagnosis and Home Health</td>
</tr>
<tr>
<td>PubMed</td>
<td>Healthcare</td>
</tr>
<tr>
<td>Theses Canada Portal</td>
<td>National Institute for Health and Clinical Excellence</td>
</tr>
<tr>
<td>Web of Science</td>
<td><a href="http://pathways.nice.org.uk/pathways/chronic-heart-failure">http://pathways.nice.org.uk/pathways/chronic-heart-failure</a></td>
</tr>
<tr>
<td></td>
<td><strong><a href="http://pathways.nice.org.uk/pathways/chronic-obstructive-pulmonary-disease">http://pathways.nice.org.uk/pathways/chronic-obstructive-pulmonary-disease</a></strong></td>
</tr>
</tbody>
</table>
Table 2: Search Terms

Setting:

Home care  Home health aides  Hospital-based home care services
Home care services  Home care services
Home nursing  Private home care

Individuals in Caring Relationship:
<table>
<thead>
<tr>
<th>Care recipient</th>
<th>Family caregiver</th>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver</td>
<td>Formal caregiver</td>
<td>Spouse</td>
</tr>
<tr>
<td>Carer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client</td>
<td>Formal health care</td>
<td>Unpaid care</td>
</tr>
<tr>
<td>Family</td>
<td>Informal caregiver</td>
<td>Unpaid care</td>
</tr>
<tr>
<td></td>
<td>Paid care</td>
<td></td>
</tr>
</tbody>
</table>

*Health and Illness Subject Areas:*

- CCHF: Chronic obstructive pulmonary cardiac failure
- Congestive heart failure
- Lung disease
- Heart failure
- Obstructive lung disease
- COPD: Respiratory tract disease
Influential Factors

Benchmarking  Improvement  indicators  Risk  mitigating
Best management practices  Literacy  factors
Best practices  Medical innovations  Safety
Biomedical technology  Medical technology  Safety education
Biopharmaceutics  Medical therapy management  Safety management
Client safety  Medicine  Sleep deprivation
Clinical pharmacology  Mental health services  Sleep disorders
assurance
Caregiver burden  Patient  fatigue  Technology
Caregiver safety  Patient  safety  Total quality
Caregiver stress  Patient  satisfaction management
Drug safety  Pharmaceutical preparations  Quality
Drug therapy  Pharmaceutical technology  Quality control
Drugs  Pharmacology  Quality of life
Health care quality  Pharmacy  Quality improvement
Health care quality indicators  Risk
Health status indicators  Risk factors
Table 3: Criteria Guiding the Selection of Literature

<table>
<thead>
<tr>
<th>Inclusion:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-text articles with abstracts</td>
</tr>
<tr>
<td>Literature published in French and</td>
</tr>
<tr>
<td>countries: Australia, Canada,</td>
</tr>
<tr>
<td>Denmark, England, Finland, Ireland,</td>
</tr>
<tr>
<td>Israel, Norway, Scotland, Sweden,</td>
</tr>
<tr>
<td>United Kingdom, United States, and</td>
</tr>
<tr>
<td>Wales.</td>
</tr>
<tr>
<td>Literature focusing on health</td>
</tr>
<tr>
<td>conditions: CCHF, COPD.</td>
</tr>
<tr>
<td>Studies focusing on caregivers.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exclusion:</th>
</tr>
</thead>
</table>
Literature that includes the following keywords and terms: adolescents, Alzheimer disease, brain diseases, cardiac arrest, cerebrovascular disease, coronary disease, coronary heart disease, children, dementia, diabetes, heart disease, infant, newborn, pediatrics, pediatry, perinatology, schizophrenia, senile dementia, stroke, and renal failure.

Literature published prior to 2004.

Literature published in countries outside of those expressed in the inclusion.

Literature published in languages other than French and English.
Table 4: Definition of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client</td>
<td>Term used to define those individuals who are receiving health care services within the home. Using the term ‘client’ acknowledges the autonomy and choice individuals have in pursuing and obtaining health care services. It also serves to break the hierarchical patterns that often exist when individuals are seen as, or identify as, patients within the health system.</td>
</tr>
<tr>
<td>Caregiver</td>
<td>Refers to “individuals who are in an unpaid role but are responsible for caring for the client. Caregivers are often family members or friends. Family members are individuals identified by the client and/or caregiver as being close to the client through blood, legal, or emotional ties and who may or may not reside in the same home as the identified client” (Macdonald &amp; Lang, 2010, p.8). Caregivers may live with the client to whom they provide care or live separately from the client, visiting as needed. In this review, two populations of caregivers were then identified: live-in caregivers and visiting caregivers.</td>
</tr>
<tr>
<td>Personal Support Workers</td>
<td>The regulated and non-regulated workers who are paid employees of organizations providing home support services. These workers may assist with personal care, bathing, meal preparation and housekeeping. They may work with, but are a separate body from, health care professionals such as nurses, therapists, case managers, pharmacists, and doctors.</td>
</tr>
<tr>
<td>Well-being</td>
<td>The term ‘well-being’ relates to both client and caregiver in this scoping review and encompasses the physical, emotional and psychological health of these two populations.</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Safety Marker</td>
<td>Refers to indicators of safety related to the client and/or caregiver. These indicators may embody conditions or situations that compromise the safety of home care clients and caregivers, but may not habitually be acknowledged or identified as such (Macdonald &amp; Lang, 2010).</td>
</tr>
</tbody>
</table>
FIGURE 1  Sources and Yield from Triaging Process. R = Relevant; PR = Potentially Relevant; NR = Not Relevant (color figure available online).

Electronc Databases | Grey Literature | Manual Searches
---|---|---

376 Papers pulled based on

Following Title Review:

Stage 1: Title Review: 151 R
8 were not full
143

Stage 2: Abstract Review: 143 R
37 R 61 PR 40 NR
138

Stage 3: Full-text Review: 180 R
These became

Stage 1: Title Review: 170 R
3 were not full articles & 29 did not have
3 55