

State of the Knowledge Regarding Safety in Home Care in Canada: An Environmental Scan

May 2009

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The research team for this Environmental Scan is comprised of researchers, health care professionals and decision makers, all of whom are also members of The CPSI Core Safety in Home Care Team. This pan-Canadian team was convened to advance research in home care safety by: (1) identifying and establishing collaborative partnerships, (2) identifying research

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priorities, (3) collecting pilot data to support a larger grant application, and (4) pursuing grant funding opportunities to conduct patient research in home care safety.

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Main Messages

This environmental scan includes the findings of a pilot study conducted with home care recipients and providers; key informant interviews from across Canada; a literature review in three key home care areas; and an inventory of exemplars of research and programs in this field. From these findings, the research team developed recommendations for researchers, decision makers and policy makers.

Recommendations for Researchers:

1. Involve clients, family members, caregivers, and providers in order to understand their varied perspectives as well as their respective vulnerabilities, needs and strengths.
2. Elicit the elements of a definition of home care safety from stakeholders.
3. Develop a definition of home care safety. It is unlikely that a unilateral definition will be possible. It should be conceptual in nature, with clearly articulated elements that may be tailored to individual clients/situations with each element potentially having a different relative importance.
4. Identify and explore multiple study methods and various relevant sources of visual and textual data to capture the multidimensionality of home care safety.

Recommendations for Decision Makers:

1. Shift the way organizations and practitioners provide care in response to the emerging home care safety landscape.

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2. Consider a model of practice that enables the provider and the client(s) to co-create a health-promoting environment conducive to risk-mitigation for all involved.
3. Focus on staff education to build the knowledge and competencies required to work in a different way with clients that is directly linked to the new model of practice.
4. Develop organizational procedures/standards that reflect the ‘flexible’ definition of safety, and therefore enable the proposed model of practice.
5. Designate, as a high priority, technology enabled documentation to facilitate the transfer of information within the home and across the health care continuum.

Recommendations for Policy Makers:

1. Recognize that home care safety has fundamental differences than safety in institutional settings and as such, strategies and interventions to mitigate the safety risks require some different approaches and policies.
2. Designate, as high priority, the development and implementation of an electronic health record system that links across sectors of the health care system.
3. Focus and prioritize primary health care and home care reform for those clients with chronic illnesses with the goal of preventing and/or diminishing hospital (re)admissions.
4. Consider the needs of informal caregivers in funding approaches. Opportunities need to be embedded in service authorization and funding for caregivers to be the recipients of services, and to be able to access respite care that will enable them to continue to fulfill the critical role that they play.

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Executive Summary

Introduction

As part of the CPSI Core Safety in Home Care Team initiative to enhance the understanding of safety in home care, an environmental scan was conducted. Home care is one of Canada's fastest growing health care sectors and this report emphasizes the importance of expanding the focus on patient safety to include home care. This report provides a platform for future work of the CPSI Core Safety in Home Care Team. It includes the findings of a pilot study conducted with home care recipients, their family members, caregivers and providers; key informant interviews with researchers, health care providers, as well as policy- and decision-makers from across Canada; an expanded literature review in three key areas of home care; and an inventory of past and current exemplars of research and programs in this field.

Methods

An Advisory Committee was convened to, provide direction and guidance to the research team around the (a) creation of a list of names and coordinates for potential key informants (b) development of the interview guides used for the pilot study and key informant interviews and (c) determination of key areas to extend the literature search in home care safety.

A pilot study was conducted within Alberta Health Services in Edmonton and the Vancouver Island Health Authority. Semi-structured audio-taped interviews were conducted with clients, their family members, caregivers and providers (N=15). Participants were asked to discuss their experiences, challenges, and insights regarding home care safety from their varying perspectives.

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Key informants (N=24) from Eastern, Central and Western Canada were asked to reflect on what they perceived to be risks, concerns and issues related to home care safety. In addition, they shared their perspectives specific to family members, caregivers, providers and the built environment. Main concerns affecting home care safety, gaps in knowledge, priorities for research and exemplars were also elicited.

The literature search was conducted using seven databases (CINAHL, PsycINFO, Pubmed, Cochrane Library, Medline, Up-to-Date and Web of Science) for the years 2000-2009. The three key areas pertaining to home care namely caregiver, end-of-life care and chronic disease management were searched for safety related issues. An inventory highlighting past and current research projects and reports relating to home care safety was compiled.

Findings

Pilot Study:

The perspectives of recipients regarding home care safety differed from those of providers. Even though recipients described situations of unsafe or risky experiences related to home care, by and large they considered their home to be a safe haven. Being at home meant that they were in control. Home care recipients described making decisions, while recognizing that these decisions were not always in line with or endorsed by their provider. In contrast, providers' concerns were geared mostly toward the physical safety of the client, similar to the patient safety concerns reported in the institutional based literature. This information is an important reminder that, in home care, providers cannot determine the standard of safety independently of recipients' perspectives. Furthermore, it highlights the need for a home care safety definition that is broader,

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more flexible and acknowledges that clients, family members and caregivers can and will make choices that are considered risky when viewed from the more common institutional perspective. Although clinical standards are essential to home care, a single set of standards for home care safety that encompass the multidimensionality and personal preferences involved is not reasonable or desirable. Rather, evidence-informed guidelines that mitigate risks associated with decision-making within this complex home care context are preferable.

Key Informant Interviews:

Analysis yielded four themes: fragmentation, vulnerability, erosion of home as a haven, and incongruence in home care.

Fragmentation referred to: 1) the disconnect between approaches to care provision in acute care and home care; 2) multiple providers and multiple agencies delivering care in one home; and 3) difficulties in communication.

Vulnerability addressed the potential safety threats to the emotional, physical, social and functional health of recipients and providers. Four sources of vulnerability were identified: 1) Isolation; 2) exposure to infection; 3) medication mismanagement; and 4) potential abuse.

Most people consider home as a haven. Homes are not designed or typically conceptualized as a place where health care is provided. When necessary modifications are made to the home and complex medical technologies designed for the acute care sector are introduced, this medicalization of personal space renders the home environment similar to a hospital room but without the support and resources present in a hospital.

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Incongruence in home care referred to: 1) unregulated health care workers' responsibilities versus their knowledge and skill (as provided by their training); 2) healthcare professionals practicing in a knowledge era yet being bereft of access to current knowledge (evidence based practice); 3) expectations of families versus the level of resources and support available and/or provided.

Literature Review:

The home care literature is vast. It holds information pertaining to the various issues, concerns, and challenges yet seldom are links made explicitly to home care safety. Although not intended to be a comprehensive and exhaustive review of the home care literature, *caregivers*, *palliative/end-of-life care and chronic disease management* were the topic areas selected because they depict a broad range of diagnoses, needs and services in home care. The aim of this literature review was to mine and extract the indicators relevant to safety from the current home care literature. In order to broaden our perspective of home care safety and emphasize the need for further research a number of safety related issues were uncovered in each of the topic areas. These include poorer health for the *caregiver*; changing clinical status, inadequate pain/symptom management, invisibility, potential for abuse and failure to provide primary bereavement care for *palliative/end-of-life* situations; and vulnerability to earlier decline, polypharmacy and lack of appropriate technology for *chronic disease management*.

Recommendations

For Researchers:

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4. Identify and explore multiple study methods and various relevant sources of visual and textual data to capture the complexity and multidimensionality of home care safety.

For Decision makers:

1. Shift the way organizations and practitioners provide care in response to the emerging home care safety landscape.
2. Consider a model of practice that enables the provider and the client(s) to co-create a health-promoting environment conducive to risk-mitigation for all involved.
3. Focus on staff education to build the knowledge and competencies required to work in a different way with clients that is directly linked to the new model of practice.
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1.0 PURPOSE

This report describes the current state of knowledge around home care safety and presents the findings from the environmental scan conducted as part of the Canadian Patient Safety Institute (CPSI) *Core Safety in Home Care Team* initiative.

2.0 BACKGROUND

Since 1997, the number of home care clients in Canada has increased by 51% (Canadian Home Care Association, 2008). Yet, patient safety research is predominantly focused within institutional settings. CPSI in collaboration with VON Canada recognized this gap and in response have spear-headed a number of initiatives. First, was a foundational report entitled “Safety in Home Care: Broadening the Patient Safety Agenda to Include Home Care Services” (Lang & Edwards, 2006), which summarized findings from: a literature review, key informant interviews (N=20) and a national invitational roundtable. This report highlighted that: patient safety is a failure of systems rather than of humans; there are many change processes required to create safe environments; organizational culture and workplace factors are critical; and that patients have a key role to play in their care and thus must be part of the patient safety discourse. Themes central to home care safety included: the inextricably linked relationships and communication among clients/families and caregivers/providers; unregulated and uncontrolled settings, autonomy and isolation; the multidimensionality of safety (physical, emotional, social,

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functional); a diminishing focus on prevention, health promotion and chronic care; challenges of human resources and maintenance of competence (Lang & Edwards, 2006; Lang, Edwards, & Fleischer, 2008).

Given that most patient safety research is institutional based and geared towards physical factors/issues, and that research pertaining to home care safety is just beginning, the results of Lang & Edwards' review of the literature were limited. Nonetheless, they recognized the existence of a large volume of home care research and recommended further exploration of this literature. They recognized that although such studies may not directly address safety, they would most likely shed additional light and generate insights into the issues and risks around providing care in the home environment. Furthermore, an expanded review of the literature would also help to identify the indicators of safety in home care related to emotional and social factors for all involved rather than just focusing on physical factors.

In 2008 CPSI subsequently convened the *Core Safety in Home Care Team* to identify priority research areas and to advance patient safety research in home care. Addressing safety in home care presents unique challenges and requires a fundamental rethink of underlying assumptions and guiding frameworks that have been used to examine patient safety in institutional settings. Research on safety in home care is needed to identify: the types and patterns of safety concerns for clients, family members, caregivers and providers; how family involvement in care delivery affects safety; how to attend to safety given that many variables cannot be regulated or controlled in private homes; the impact of advances in treatments, assistive devices, medications and technology on safety; the patterns and health/illness profiles of home care clientele; and the challenges of transitions, communication and continuity of care

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among an array of recipients, as well as paid and unpaid providers. Leading edge research in this field requires inter-disciplinary teams of researchers, practitioners and decision- and policy-makers using a wide array of research and knowledge translation/exchange methods. Increasingly, clients are seen as playing a significant role in their care (Lang & Edwards, 2006; Lang, Edwards & Fleiszer, 2008). It follows that they must also be part of the discourse on patient safety (Harrison & Verhoef, 2002). In order to conduct research that builds on what is already known and that is conceptually coherent, this environmental scan aims to provide insights and recommendations to researchers, decision- and policy makers around home care safety.

3.0 OVERVIEW OF REPORT

This report nourishes and enriches the previous findings documented in the Lang and Edwards (2006a) paper titled “Safety in Home Care: Broadening the Patient Safety Agenda to Include Home Care Services”, as well as provides a platform for the work of the CPSI Core Home Care Safety Team. It is important to note that the work of this team is focused on identifying issues related to safety in home care. This work in no way is intended to overlook the many strengths and benefits of home care programs across this country. In fact as the team continues to pursue its work we will undoubtedly uncover safety related indicators that already exist under the guise of quality and that home care has already addressed. This environmental scan includes; (a) a pilot study conducted with clients, family members, caregivers, and providers; b) key informant interviews with a wide range of respondents including researchers, decision- and policy-makers, service providers, regulatory bodies, and formal organizations; c)

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an expanded literature review of three key areas relevant to home care safety; d) a current and promising inventory of completed/current/and planned research projects, tools and interventions, safety programs, projects and frameworks. This environmental scan illuminates potential sources of safety concerns in home care as well as identifies existing pockets of excellence and thereby assists in determining intervention and research priorities around home care safety.

4.0 METHODS

4.1 Advisory Committee

The first step was to convene an Advisory Committee to help guide the work of the research team. The advisory committee was composed of researchers, decision-makers, health care providers and administrators that had already expressed their interest to CPSI about participating in and contributing to knowledge development around home care safety. At key intervals in the development and analysis phases of the environmental scan, the Advisory Committee met with the research team via teleconference to suggest potential key informants to be interviewed, collaboratively develop interview guides (Appendices A and B), help determine the direction of the literature review, participate in the analyses, and provide feedback on the final report.

4.2 Pilot Study

Semi-structured interviews (N=15) were conducted with clients, family members, caregivers and providers in the homes of clients receiving home care services within Alberta Health Services Edmonton and the Vancouver Island Health Authority. Following ethical approval, case managers from each organization helped to identify and recruit potential

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participants. They briefly described the study to potential participants, in person or by phone, and asked permission to release their name(s) to the researcher. Those who expressed interest and who granted permission, were contacted by the researcher who explained the study in greater detail, answered any relevant questions, and then set a convenient appointment time. All participants signed consent forms prior to their interview. Interviews ranged from 60 – 90 minutes in length, were audio-taped, transcribed verbatim and analyzed.

Clients had at least one diagnosed chronic condition and were receiving home care services at the time of the study; some, for as little as three weeks and others for as long as five years. They ranged in age from 40-to-93 years of age while their family and caregivers ranged in age from 16-to-89 years. Providers' experience with home care (i.e., home support workers, licensed practical nurse, occupational therapist and nurse manager) ranged from eight months to twenty years.

4.3 Key Informant Interviews

Key informants, jointly identified by the research team and Advisory Committee, were contacted via e-mail communication that outlined the purpose of the environmental scan and extended an invitation for participation in a 45-minute audio-taped semi-structured telephone interview. Twenty-four key informants were interviewed in French or English, depending on their preference. There was regional representation from Eastern, Central and Western Canadian provinces.

4.4 Literature Review

Lang and Edwards (2006a) recognized the dearth in the literature regarding home care safety. They recommended an expanded exploration of the home care literature to identify

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indicators related to safety. In planning this review the research team uncovered a vast amount of home care literature on both adults and children. The time and resources of this grant could not cover such a review. Thus, the decision was made to restrict the review to three substantive areas common to home care of the adult (i.e., caregiver, end-of-life and chronic disease management). These three areas were chosen because they depict a broad range of diagnoses, needs, and services in home care.

The literature review was conducted using electronic databases, including Medline, CINAHL, Pubmed, PsychINFO, Up-To-Date, Cochrane Library and Web of Science. The searches were limited to publication years 2000-2009. The search strategy included key terms; home care safety, patient safety, informal carer/caregiver, end-of-life care, palliative care, chronic disease and disease management. The abstracts of 192 peer-reviewed, research and review articles (38 caregiver, 28 chronic disease management and 126 end-of-life care) were retrieved and individually rated by 4 members of the research team as (1) relevant, (2) potentially relevant, and (3) not relevant, A detailed itemized search strategy appears as Appendix E. The articles were synthesized in an extraction table where researchers again rated them for their relevancy. Thirty-one articles were retained for review; 14 caregiver, 8 end-of-life care, and 9 chronic disease management.

4.5 Inventory: Exemplars of Current and Future Research and Programs

In conjunction with the literature review and key informant interviews, information was extracted to construct an inventory of completed/current/and planned research projects, tools and interventions, safety programs, projects and frameworks pertinent to home care safety. This inventory appears as Appendix C.

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4.6 Analysis

All interviews were completed between July 1, 2008 and January 27, 2009. These interviews were transcribed verbatim. Interpretive description was used to analyze the transcripts. Interpretive description acknowledges the constructed and contextual nature of much of the health-illness experience. It addresses the ever increasing complexity and interrelatedness of the concepts of safety, home care, and clinical practice. The methodological objective was to develop a credible conceptual explanation of the phenomenon of safety in home care. Data were independently reviewed and analyzed by a research assistant and core members of the research team, and themes were developed.

4.7 Clarification of Terms

It is necessary to clarify the distinction in terminology used throughout this report regarding the difference between caregiver and provider. “Caregivers” are often family members or friends, who are unpaid, but are frequently the primary person responsible for caring for the client. “Providers” are professionals or non-professionals, regulated or unregulated, who are employees of organizations providing home care services to clients and their families. This includes, but is not limited to case managers, nurses, respiratory, occupational, speech and physical therapists, as well as homemakers.

5.0 FINDINGS

This environmental scan set out to build upon and expand the findings discussed in the Lang & Edwards’, (2006) Safety in Home Care: Broadening the Patient Safety Agenda to Include Home Care Services. The findings from this scan in part confirmed the foundational

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work but also offer new insight from many perspectives into the current state of knowledge regarding home care safety. The results presented in this report focus on what is considered new knowledge in home care safety and in so doing highlight areas of concern from the perspectives of recipients, providers and decision-makers.

5.1 Pilot Study

Pilot studies are primarily intended to test logistics and in this case served as an opportunity to test the semi-structured interview guides with several different participants (i.e., clients, family members/caregivers and providers). Pilot study findings are inherently limited but are beneficial in two ways (1) they yield data that gives a general idea of what a main study may reveal, and (2) they are incorporated into the design of the eventual main study. The pilot aided in determining the feasibility of this form of research, and will help direct the *CPSI Core Home Care Safety Team* for future research endeavours in home care safety. The pilot study was published by Longwoods Publishing in a special edition of Patient Safety Papers of Healthcare Quarterly (Lang, Macdonald, Storch, Elliot, Stevenson et al., 2009) and was one of four articles featured at Canada's Forum on Patient Safety and Quality Improvement 2009 that was held in Toronto, Ontario.

Analyses of the interview data from the pilot study revealed three main themes, namely: 1) the meaning of home care safety; 2) safety concerns; 3) and the place of technology in the future of home care.

5.1.1 Meaning of home care safety

Home care had a special meaning for clients and their families. For them, home care meant they could be at home and in charge (i.e. in charge of their care, their surroundings, their

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life in general). They described making decisions, while clearly recognizing that these decisions were not necessarily always in line with what their provider preferred or was trying to accomplish. For example, one client said,

“Sometimes they [home care providers] agree with what I am doing and sometimes they don’t agree.”

Home care safety meant something different to every client sampled, suggesting that the care that is provided through home care needs to be negotiated with the stakeholders in each situation. Ultimately it was the clients, their families, and caregivers who decided what they would or would not do, agree to or accept.

When participants were asked what ‘home care safety’ meant, the perspectives of recipients diverged from those of providers. This was an instructive finding since it has led us to question the use of the term *home care safety* with home care recipients, when in fact, this term did not seem to resonate with them. Terms such as “concerns” or “challenges” regarding home care may be more appropriate and meaningful when communicating with clients, family members, or their caregivers.

Generally speaking, home was considered a haven or a safe place for these home care clients. Although they were able to describe examples of unsafe or risky experiences and situations, these participants did not think in terms of issues relating to *home care safety*. In terms of safety specific to the health care delivered, participants expected that those entering their home would get to know them, provide competent care, and give them or arrange for them the necessary supportive care in a flexible and timely manner.

The providers, on the other hand, considered safety in a more traditional medicalized way; completing resident assessments to determine risks (e.g., falls), making sure clients received medications in *blister paks* to minimize medication errors, and ensuring clients used proper disposal containers for syringes and needles. These provider concerns were primarily geared towards the client and focused almost exclusively on physical safety. As such, they were closely aligned with the more common patient safety concerns in institutional settings reported in the literature, highlighting the differing perspectives regarding home care safety. This pilot revealed that within the context of home care, providers should not be determining the standard of safety independently of recipients' perspectives.

Our pilot also reinforced the Lang and Edwards (2006b) findings that safety of the home care client is inextricably linked to all involved. As one client who had access to a very limited support system explained, she routinely had difficulty keeping track of her morphine doses, and feared she had occasionally “doubled-up” before driving herself to her appointments. Although she recognized that her difficulty impaired her capacity to perform activities of daily living, including driving, this did not change the fact she had to continue to manage her health status under conditions of considerable risk to herself and others.

By virtue of the unique characteristics of individuals and their homes, the approach to home care safety cannot rely on the creation of one standard that is expected to be fully enacted for all. In the institutional setting, standards are set so that patients will receive a certain standard of care regardless of their socio-economic or cognitive status. In home care, financial means can significantly impact on opportunities to maximize safety. Some clients and families have the financial means and abilities to purchase all needed equipment, make renovations, hire the

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necessary help, and transform the home to meet their needs, while others live in unsanitary and unsafe conditions because of the inability to make the necessary changes to their physical environment. For these clients, priorities in the delivery of safe home care must attend not only to the traditional physical/psychosocial care, but must also attend to physical space of the home that can involve arranging for safety aids up to and including arranging extermination services. The critical nature of this situation is multiplied given that the safety of the recipients and providers are inextricably linked in home care because the client's home is also a workplace. Lack of basic safe working conditions can actually become a limiting factor in receiving services. As one case manager described,

“It’s always the neediest person who you’re loathe to say, ‘Well, when you figure it (rodent infestation) out, then we’ll get a worker.’”

5.1.2 Safety Concerns

Many of the issues voiced by participants in this pilot study focused on their concerns for the health and wellbeing of caregivers. Family caregivers are often central to the success of home care, but are easily made invisible as long as the client is maintained at home and all is going well. One case manager explained,

“Families are tired,” and “if they didn’t look after their own health, they didn’t keep themselves safe in that whole process (of care giving).”

When caregivers neglect their own health they are putting themselves at risk, as well as the health and wellbeing of the identified client. Moreover, safety extends beyond the physical to include emotional, sociable and functional safety (Lang & Edwards 2006b). Current systems of home care assign limited resources at fixed times. The home care client status, like that of the

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hospital patient, may change rapidly. Therefore, resources needed to manage must be flexible, responsive, and available as needed to support home care recipients in order to effectively manage the client at home, maintain and promote their health, as well as the health of their caregiver, while mitigating the risk for everyone involved. For clients with chronic illness, who may experience periods of remission of their symptoms, regular visits by the health provider might not be required. Yet cancelling a visit may be rendered difficult because they fear they will not be able to restore regular visits when needed.

Some family members or friends caring for these clients work 24 hours a day, seven days a week, and many try to continue their work outside the home. Given that this recognizable scenario is regularly part of the home care landscape, safety for the client is increasingly acknowledged as being inextricably linked to the safety of family members, caregivers, and providers (Lang and Edwards 2006b; Lang et al. 2008). Family and other informal caregivers often make promises out of love and a sense of responsibility to keep the client at home, without being aware that this objective may be beyond their capacity (Stajduhar 2003; Stajduhar and Davies 1998).

Caregivers invested in safety devices such as motion sensors, or sound monitoring devices because they worried about the client at nighttime. Consequently the caregivers may be awakened several times during the night, thus adding to their fatigue. Fatigue becomes a safety concern when caregivers need to make critical decisions regarding administering medications, and other care required by the client. Family caregivers could not look forward to the end of a shift for some rest and relaxation like paid providers since they were always on duty.

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Decisions regarding client services in home care must take into account what the family and/or caregiver need to help care for the client, as well as what they need to maintain and manage their own health and wellbeing. One participant described the downward spiral, which can occur when the needs of caregivers are not met,

“You (the family caregiver) are coping, coping, and coping, and then one more thing happens and then it’s like you just aren’t coping anymore.”

Clients requiring chronic home care services such as the participants in this pilot study, are likely to require institutional placement if their caregiver becomes ill.

5.1.3 Vision

In addition to sharing their perceptions and concerns regarding home care safety, participants also offered their insights and vision for home care. The need for increased home support was acknowledged, and some suggested that salaries of home support workers be improved, that family/caregivers be paid or compensated, and that housekeeping services be ameliorated. Organizations and health care systems should accommodate to the predictable as well as unpredictable care needs of clients, family member(s) and caregiver(s) using a care needs approach rather than an income-based approach. Self-managed care programs are recommended, in which recipients negotiate with agencies, preferably for the care they believe they need.

Technology was identified as an opportunity to help enhance home care safety. Homes equipped with alarm systems, motion sensors, sound monitors and other monitoring systems enabled these clients to feel safer and to obtain help in the event of emergencies. At the same time that these systems offered clients and families peace of mind, they were also considered a mixed blessing. Feeling safer comes with a cost, and the family and/or caregiver who are

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constantly responding to these alarms often pay the cost. Constant responding causes their fatigue level to increase. Perhaps homes of the future could be constructed in the anticipation that they may become places of care. The built environment can have many mobility and toileting aids, as well as be made accessible for all activities of daily living. Not everyone, however, will have the means to access such environments.

Provider participants identified the need to have access to Global Positioning System devices to make visible their location at all times. These providers were often on the road, crossing a wide variety of neighborhoods and the elements as well as a range of potentially risky home situations (i.e., aggressive patients, unclean conditions, unknown and potentially dangerous animals such as dogs). As such, they may also benefit from safety-proofing programs that guide them in staying safe during the provision of care and in transit to and from care settings.

5.2 Key Informant Interviews

Key informants were asked to reflect on what they perceived to be risks, concerns and issues related to safety in home care. In addition, they shared their perspectives specific to family members, caregivers, providers and the built environment. Main concerns affecting home care safety, gaps in knowledge, priorities for research and exemplars were also elicited. The analysis of the reported risks, safety concerns and issues yielded four themes: fragmentation, vulnerability, erosion of home as a haven, and incongruence in home care.

5.2.1 Fragmentation

Key informants referred to three types of fragmentation: the disconnect between approaches to care provision in acute care and home care, the fragmentation related to multiple

providers and multiple agencies delivering care in one home, and fragmentation resulting from difficulties in communication.

In discussing fragmentation as a disconnect between sectors, informants voiced concerns that when a client leaves the acute care sector, a home assessment does not typically occur as part of discharge planning. When a home assessment does occur, the timing is often problematic and in many cases occurs either too early or too late relative to the client's return home. One informant commented,

“One of the key gaps is the actual time that lapses between discharge from hospital and first [home care] visit. And it was often my experience that it was either way, ridiculously too soon... Or it was ridiculously too long [after]... By the time you got in there, they were in crisis.”

Illness alters needs and capacities. This can result in a previously safe home environment becoming less amenable to the evolving situation of the client, family and caregivers; consequently, desired outcomes may be impaired.

A disconnect between sectors is further evidenced by the contrast in the approaches to involving families. Informants reported that in caring for clients in acute care, healthcare professionals tend to “do for” families: family collaboration is somewhat optional. In contrast, the focus in home care is to help the client, family and caregivers learn to manage without the presence of providers, collaboration is essential. The difference in these approaches resulted in a fragmented care trajectory, with important repercussions for the safety of all involved.

Informants reported that stronger linkages between health sectors would have a positive and risk mitigating impact on safety. One informant suggested,

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“When you go home, you are going to be responsible for this- let’s start learning now how to change this dressing or take this new medication or whatever it happens to be.”

Informants also proposed the integration of home assessments into discharge planning, as a potential solution to more seamless care trajectories. This aligns with findings from a randomized controlled trial evaluating an intervention aimed at improving the transition between acute and home care for chronically ill older adults (Coleman, Parry, Chalmers, & Min, 2006). The authors recommended that family involvement be an ongoing process beginning early during the hospital admission.

The contracting of services in home care to various agencies was seen as a contributor to the fragmentation of service delivery. Informants described that with many agencies comes a multitude of philosophies of care, and frequent ambiguity regarding responsibility for certain aspects of home care, leading to potential oversight. One informant described this issue and said,

“There are problems when 2 services are being offered in one home, but each service provider is unaware of what the other is offering. Some aspects of patient care may not be covered at all because each one thinks that the other is taking care of it.”

Informants reported that fragmentation permeated many aspects of the actual care offered to home care recipients. Particular attention was focused on documentation. Multiple agencies delivering services in one home typically means multiple records. Care providers may not consistently have access to these multiple records, further contributing to a fragmented system and potentially compromising care and safety to all.

Another aspect of fragmentation within home care is tied to the “revolving door” phenomenon, which describes the multitude of home care providers that have unfettered access

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to private homes. This phenomenon poses challenges to, among other things, adequate communication and continuity of care.

5.2.2 Vulnerability

Vulnerability refers to the potential safety threats to the emotional, physical, social and functional health of recipients and providers of home care. Informants identified four main sources of vulnerability: Isolation, exposure to infection, medication mismanagement and potential abuse.

Isolation: The isolation inherent in home care heightens the vulnerability of all involved. Informants elaborated on the isolation of providers and linked this reality to their increased vulnerability to physical, psychological and emotional safety challenges. Many viewed isolation as a prominent barrier to the creation of a culture of safety and as a challenge to advocacy as they would require the involvement of dispersed people and parties. Furthermore, home care can be intimate, and performed in isolated places by individuals who, when faced with complex or dangerous situations, do not have easily accessible peers or resources. One informant provided the following example of vulnerability of workers,

“This man was all by himself. He would lie on the floor in a dark room and so you would have to kneel down and dress his scrotal abscess. It was a very uncomfortable feeling, you were by yourself, no one else around, nothing ever happened that was untoward except that you felt very vulnerable.”

Informants reiterated that home environments that are not adapted to the provision of safe care could jeopardize the physical safety for those providing care. To exemplify this, one informant said,

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“You have patients who don’t have the financial means to buy what they need. You have restrictions on some of the mobility aids.”

Moreover, all who work in the homes of clients are exposed to very personal aspects of their lives that the client and family may not have otherwise chosen to disclose. The context is unique, professional boundaries can easily be blurred as friendships develop, and the work occurs in a “familiar” space, rather than a hospital or clinic. Informants spoke of the complex relationships in home care and the risks in developing intense emotional attachment to clients and families. One informant explained that,

“[Nurses] get very attached to these people (...) They get to really know these people, a lot of them are lonely, they are shut in, they are kind of cling to the social contact of the home care nurse coming in (...) it places a real emotional burden on the nurse that is different from what you get in acute care.”

On the other hand, the delivery of home care services can be organized in such a way that a multitude of providers, come and go. This approach impedes the formation of therapeutic relationships; each worker remains a stranger although they are providing care. They are concomitantly care providers and strangers.

Caregivers play a pivotal role in home care, they provide the majority of the care the client needs. They too are extremely vulnerable to a multitude of safety threats. Informants believed that families are, at times, conscribed into the care giving role, despite possible reluctance or discomfort around the tasks associated with the care required by their loved one(s).

One informant commented,

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“Your expectations of them rise and the burden for them rises, and so, do we even give them the opportunity to say, ‘No I can’t take that on?’”

Families and caregivers are seldom asked whether or not they wish to provide the required care at home. One informant suggested that the readiness of family members to provide care be evaluated. Family members and caregivers with healthcare related education or experience were thought of as even more vulnerable. When resources are limited, families and caregivers may implicitly be conscripted to the care-giving role. Within this context of low-resources, home care workers and professionals may be harming families and caregivers unintentionally and actively compromising their well-being by overloading them with care-related responsibilities. At times, home care workers and professionals may unknowingly provide them with more information than they can handle. One informant described an instance where the home care organization imparted too many responsibilities on a family member,

“The line crossed where we weren’t allowing her to be the wife anymore, she was the caregiver”.

Exposure to Infection: Providers may spread infections as they travel between homes. Although it is known that workers and their equipment may be “vectors for infection”, cleaning this equipment remains a challenge. As explained by one informant,

“In terms of the home and what makes it really unique is infection with our MRSA and C-Diff and what not, and one of the big concerns is the equipment that the worker carries with them.”

Furthermore, carrying out care in a non-hygienic home environment also increases the potential for the transmission of infections.

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Medication Mismanagement: The presence of medications holds potential safety threats. In particular, informants referred to concerns about the trafficking of medication, medication diversion (i.e., medication prescribed for the client being used by someone other than the client), intentional incorrect administration and children inappropriately accessing the medication. Incorrect administration can happen with the client, family member or caregiver.

Potential for Abuse: Home care recipients (i.e., clients, family members, caregivers) and providers are vulnerable to various forms of abuse (i.e., emotional, social, physical and financial). With a myriad of individuals entering and leaving the home informants identified that the potential for abuse is augmented. Informants described instances when individuals have accessed homes by posing as home care providers. At times, family members may also commit abusive acts towards the care recipient and vice versa. Furthermore, family members may control who comes in and out of homes and it was suggested by the informants that this power could be used to mask or hide abuse.

5.2.3 Erosion of Home as a Haven

Most people consider home as a haven not only in a physical but also in the psychological sense. Homes are intended to be restorative and restful places of dwelling. They are not designed or typically conceptualized by most as a place where health care is provided. One informant explained that,

“We are now increasingly bringing in all kinds of equipment: dialysis machines, respirators, IV’s, all that stuff that we use in the hospital, right? And then we just transport it into the home even though it’s not designed to be used in a home. It’s designed to be used in hospital.”

When necessary modifications are brought to the home and complex medical technologies designed for the acute care sector are introduced, this medicalization of personal space renders the home environment similar to that of a hospital room, without the support and resources present in a hospital. Informants saw this “medicalization of personal space” as regularly taken for granted by providers during the delivery of home care services. One informant commented,

“We are introducing equipment, people coming and going three - four times a day with keeping people at home for so long which is excellent, but I struggle with that, how we change and medicalize their space and...often it becomes almost our space.”

Some informants noted that the “medicalization of personal space” might have a particularly strong impact on children in the home, a common challenge when young clients with chronic needs are receiving home care. They explained,

“This is a new area where now the worker in the home will key into the fact that the 4-year-old child is watching dad have painful dressing changes, for example.”

While the “medicalization of personal space” is intended to contribute to physical safety, this erosion of the home as a safe haven may also be compromising emotional and social safety for clients, families and caregivers. For example, one informant elaborated on the social risks (i.e., invasion of privacy and issues of confidentiality) and stated,

“It [home] becomes the center of communication. So you could be having a treatment at home, and I could be coming for tea, and I can be reading everything about you on your fridge.”

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5.2.4 Incongruence

Three areas of incongruence in the home care sector were identified:

- 1) Unregulated health care workers' responsibility versus their knowledge and skill (as provided by their training).
- 2) Healthcare professionals practicing in a knowledge era yet being bereft of access to current knowledge (evidence based practice).
- 3) Expectations of families versus the level of resources and support provided.

Informants commented on the difficulty in standardizing the training of unregulated care providers. A lack of standardization and the often inadequate training were considered to have a negative impact on home care safety. One informant mentioned,

“We have people with the least education in our entire system doing the most intimate and isolated work.”

Indeed, the role of home support workers often entails bathing and dressing clients, activities during which the client may be exposed and vulnerable. Informants also commented on the poor working conditions in home care, particularly on the lower salaries when compared to the acute care sector, and the unpaid travelling time. Some believed that poor working conditions contributed to the challenges in recruiting and retaining competent home care workers, who at times find themselves unprepared to provide the holistic care congruent with the philosophy of home care. Informants urged that the motivation, knowledge and skill level of home care workers be evaluated systematically, using tools tailored to home care.

Informants described the reality of health professionals working in home care, who face particular challenges keeping their knowledge up-to-date as healthcare technology, the

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pharmaceutical domain and care practices rapidly evolve. The inaccessibility of relevant evidence-based clinical information and the fragmentation of home care resources are examples of these challenges. Healthcare professionals may have very little access to what is necessary in order for them to maintain professional competence in the provision of safe home care. This was thought to be in sharp contrast to the variety of equipment and diagnoses home health care professionals are exposed to on a daily basis. One informant stated,

“You go in, you see something that you have never seen before and then you are on your own.”

Some informants believed that limited resources impact the extent to which providers can incorporate teaching and listening in the support of families and caregivers. In home care, the assistance received is to help families and other caregivers manage the other 22-23 hours of care. Teaching and listening can be the most important interventions, yet these require time, follow-up and a variety of resources that are not easily available. The expectation of families and caregivers are also incongruent with the resources, support and knowledge they possess as explained by one informant who stated,

“Workload is high; I think that’s a given reality. So if you’re a clinician going in and you come across a caregiver, or be it a daughter or someone who’s capable, it’s like you’ve hit the jackpot.”

In home care, there is an expectation that families will do almost as much, if not more than the paid workers without the necessary education or training. One informant stated,

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“...anything from wound care to shunt care, to peritoneal dialysis, the management of how to do it, when to do it, all of those things require that the family be intellectually up to it and of course, well educated”.

There are a multitude of challenges to offering a standardized training to family caregivers, one of them being the unique nature of each home and the wide variety of home care needs of clients and caregivers. One informant elaborated on this by stating,

“It gets into family members being trained: if auntie Betty starts drooping on one side of the face, it’s not good (...) how do you train families to assess?”

Key informants identified that it may also be difficult for caregivers to access reliable, up to date and relevant information to further their own knowledge and skills. Sometimes, it is a matter of lack of available resources, while at other times, clients and caregivers may not be aware how to access the existing resources.

5.3 Literature Review

The home care literature is vast. It holds information pertaining to the various issues, concerns, and challenges yet seldom are links made explicitly to home care safety. Given the scope and limits of this environmental scan the expanded review of the home care literature was limited to three key areas. Although not intended to be comprehensive nor exhaustive the purpose of this review was to extract the indicators relevant to safety from the following topic areas: *caregiver, palliative/end-of-life care and chronic disease management*. These were chosen because they depict a broad range of diagnoses, needs and services in home care. This literature review is focused exclusively on reporting the risks and safety concerns and therefore does not

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examine the various interventions and practices, which improve home care safety. This review broadens our perspective of home care safety and emphasizes the need for further research.

5.3.1 Caregiver

The caregiver, most often characterized as a spouse or child of a client, is a major determinant of successful transitions from the hospital to home (Gitlin et al., 2003) as well as maintaining and sustaining the client at home. Caregivers provide support and care for endless hours, day after day, to individuals debilitated by illnesses such as stroke, cancer or dementia who require prolonged care in the home. The role demands flexibility, dedication and resilience and is often an assumed position for which most caregivers are unprepared. The foremost safety related indicator identified for the caregiver was poorer health status with the recognition that the physical, emotional and social well being of the caregiver is inextricably linked to the care recipient (Lang & Edwards, 2006).

Caregivers are faced with stressful and tiresome situations and the relative burden arguably affects not only the quality of care provided to clients (Carretero, Garces & Rodena, 2007; Greenberger & Litwin, 2003) but also their own health as well. Overall, caregivers experience poorer health status than the ‘normal’ population (Kristjansen & Aoun, 2004). They can experience emotional suffering and physical deterioration directly affecting the amount and type of care they are capable of providing. Despite the sense of satisfaction often described by caregivers, the role is also associated with anxiety, depression, loss of concentration, caregiver fatigue, sleep and anxiety disorders (Kristjansen & Aoun, 2004). Factors contributing to increased vulnerability include care burden, restricted activities, fear, insecurity, loneliness, facing death and lack of support. These are in contrast to: continuing previous activities, hope,

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keeping control, satisfaction and good support, which decrease vulnerability (Proot et al., 2003). Given this, caregivers are often described as the ‘hidden patient’ with the recognition that the needs and concerns of this population, as easy as they are to overlook, are important indicators for the quality and safety of care provided (Kristjansen & Aoun, 2004). Thus, available and quality services are a necessity to provide support and mitigate the risks of caregivers attempting to manage care that is often beyond their capacity (Forbes et al., 2008). It is clear that caregiver’s emotional, physical and social needs determine the degree of care they are capable and able to provide to support their loved one to remain in the home (Carretero, Garces & Rodena, 2007; Greenberger & Litwin, 2003; Hudson et al., 2008; Kristjansen & Aoun, 2004; Visser et al., 2004).

5.3.2 End-of-Life Care

Home is often seen as an idealized place of death; it is a social space that promotes privacy, relaxation, autonomy and self-expression (Exley & Davina, 2007). The romanticized assumptions about home care, particularly as a place of death, fail to acknowledge the complexity and inherent tensions of dying at home (Exley & Davina, 2007). Homes are often reorganized to accommodate hospital equipment, a family member takes on the complex and difficult role of the primary caregiver and consequently, the atmosphere of the home and family adapt to these challenging life adjustments. The indicators that emerged as important when considering end-of-life care included: a changing clinical status, adequacy of pain and symptom management, invisibility, and potential for abuse.

Changing Clinical Status: The dynamic changes and transitions of a terminal illness are a source of concern when implementing safety and comfort measures in the home. Changes in a

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care recipient's physical or psychological state often result in uncertainty over the capacity as well as the limitations of home care; and safety concerns, such as pain and symptom management, challenge a family's decision for a home death (Appelin & Bertero, 2004). Palliative home care services are theoretically designed to ease this sense of insecurity or uncertainty by providing safe and quality home care to clients with a terminal illness. However, knowledge gaps and minimal safety related research are challenges to the development of safety guidelines in the home care sector.

Certain phases of terminal illness often carry increased risks for patient safety. When a care recipient transitions from active involvement in daily activities to bedbound status, is a specific phase of greater risk (Doyle-Brown, 2000). This period poses the potential for risk of injury or falls because it is associated with weakness and confusion. Precursive/seminal behaviours, such as anorexia, needs for sleep, weakness and confusion, and cardinal behaviours, such as incontinence and falls, have a significant impact on safety and have important implications for care giving during this time (Doyle-Brown, 2000).

Inadequate Pain and Symptom Management: A number of studies have focused on pain and symptom management as giving rise to significant safety issues specific to end-of-life care. Inadequacies related to pain and symptom management can make patients feel anxious that their time at home is limited and powerless that they are not able to influence their life situation (Appelin & Bertero, 2004). Patient's difficulties range from obtaining the prescribed medications to managing multiple symptoms and consequently, patients' experience ineffective pain management (Shumacher et al., 2002). In addition, a number of symptoms (e.g., uncontrolled

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pain, psychological burden, weakness, nausea and vomiting and respiratory distress) were associated with a resultant inpatient admission (Armes & Addington-Hall, 2003).

Appropriate and adequate symptom assessment is heavily dependent on the informal caregiver's knowledge and interpretation of symptoms, which highlights the disadvantages of either not having that health care background or not having a caregiver at all. Thus, inadequate symptom assessment leads to ineffective symptom management and threatens the client's ability to stay at home (Armes & Addington-Hall, 2003; Appelin & Bertero, 2004; Schumacher et al., 2002). Miscommunications between family members and the health care team can result in misinterpretations about what to expect in terms of the involvement of providers (Appelin & Bertero, 2004). Communication break down is a safety risk yet when it works it can create a sense of trust and security for all involved.

Invisibility: Palliative/end-of-life care has been considered the reserve for people living with cancer. However, there are many more groups of people who require palliation and end-of-life care including but not limited to chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), dementia and renal failure. A lack of home care services for these groups renders individuals vulnerable to disease exacerbation and more frequent hospital admission. When compared to lung cancer care, individuals with COPD receive less care and are more likely to die in the hospital (Habraken et al., 2007). The COPD population requires home care services similar to the lung cancer population yet the current invisibility of the needs of this population renders them unlikely to obtain the support and services needed to remain at home. The lack of appropriate services for this population creates an unsafe and unsupported home

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environment diminishing their likelihood of having the choice of a home death (Habraken et al., 2007; Harris, 2007).

Potential for Abuse: Abuse is defined as neglect or physical, financial or verbal maltreatment, assault or violence. Protection is warranted to both vulnerable patients and to caregivers who can both be the victims of abuse (Payne, 2007). In the terminal phase of illness, there is a greater associated risk for elder abuse with an increasingly evident vulnerability. The literature indicates that family caregivers most often perpetrated abuse and that the group most vulnerable to abuse is men (Payne, 2007). Two hypotheses exist for this unusual susceptibility: first, women may be avenging previous abuse by the male victim or second, it may be the continuation of a pattern of aggressive behavior despite the increased vulnerability of the male client's illness. This safety concern emphasizes the need for safety research independent of institutions to capture safety concerns specific to home care.

5.3.3 Chronic Disease Management

There are competing demands on resources for home and community support. Thus, the increasing demand for home care services in Canada has resulted in a shift from a health promotion and preventative focus to post-acute care. Post acute care in the absence of health promotion and illness prevention is a less effective and more expensive method of care delivery (Markle-Reid et al, 2006). Resources for home care are scarce but the quality and safety of care cannot be compromised. Rather, services must be expanded to meet this demand and provide appropriate care to those who need it. Chronic disease management represents a major sector of home care that is associated with the following potential safety concerns: vulnerability to earlier decline, polypharmacy, and lack of appropriate technology.

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Vulnerability to earlier decline: Failure to provide clients with primary and secondary health prevention renders them more vulnerable to an earlier decline and to more frequent hospitalizations. A general theme in the COPD literature is a lack of available services in the health care system to manage the progression of the disease and treat exacerbations, and this, in and of itself, is a safety concern (Harris, 2007; Habraken et al., 2007). Harris (2007) reported feelings of isolation, helplessness and fear in managing acute breathlessness for COPD patients. Their caregivers experience incredible strain as they take on multiple roles and experience many of the same losses as patients (Harris, 2007).

Clients living with non-cancer diagnoses have more challenges in accessing consistent and holistic home care (Stuart, 2003; Harris, 2007). Furthermore when their chronic illness is finally perceived as terminal, it is often too late for the client, family members and caregivers to avail themselves of home care (Stuart, 2003). The typically poor transition from chronic disease management to terminal care is associated with potential safety concerns (Stuart, 2003).

Polypharmacy: Medication adverse events are the most notable safety concern for older adults receiving home care and account for one in six visits to the emergency room (McGraw and colleagues 2008). For many chronic illnesses, such as COPD, coronary artery disease, CHF and diabetes, a multi-drug regimen is considered standard treatment (Ballentine, 2008). Some of the safety factors include an increased number of side effects, the capacity of the clients to safely take their medications, the risks for medication diversion, and the possibility of children accessing medications in the home. There is a need to maximize the outcomes of polydrug therapy while minimizing the associated safety concerns to create a healthy balance that will allow this population to optimize their health and remain at home (Ballentine, 2008).

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Lack of Appropriate Technology: The use of advanced technology can contribute to more effective disease management, improved health outcomes and home care services (Coughlin, Pope & Leeder, 2006). Technology can be used to monitor clients' status and improve communication and collaboration among clients, families and health providers thus enabling a transition to state of the art health care delivery. The use of technology may contribute to a host of innovations including but not limited to the mitigation of safety risks, promotion of enhanced monitoring, access to timely information, coordination of services and education related to patient symptoms and conditions (Coughlin, Pope & Leeder, 2006).

6.0 DISCUSSION

This environmental scan has added to our knowledge regarding safety in home care. Recommendations to consult recipients and providers of home care about their perspectives on safety, as well as an expanded review of the home care literature (Lang & Edwards, 2006) underpinned this scan while driving the pilot study and the literature review. Central to the findings of the pilot was that the perspectives of recipients regarding home care safety diverge from those of providers. Even though recipients were able to describe examples of unsafe or risky experiences and situations related to the home care they received, in general they considered their home to be a haven or a safe place. Being at home meant that they were in control. They described making decisions, while clearly recognizing that these decisions are not always congruent with or endorsed by their provider. In contrast, the provider concerns were geared primarily toward the client and focused almost exclusively on physical safety, similar to institutional patient safety concerns reported in the literature. Ongoing research and safety

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related interventions need to be sensitive to these divergent perspectives and work in collaboration with all involved (Lang et al., 2009).

The notion of standards for home care needs to undergo a re-visioning process in light of consistent and persistent informant reports that the context of home care is highly variable. In order for all Canadians to have access to home care a single standard or set of standards will likely be insufficient.

This environmental scan identified a number of safety related issues beyond those reported in the foundational work (Lang & Edwards, 2006b). These issues include:

- Caregiver health status
- Increased vulnerability for recipients and providers
- Fragmentation of both home care services and communication in the delivery of services
- Erosion of home as a haven with the potential consequence of increasing psychological risk for children and families
- Inadequate training for the unregulated home support workers resulting in unmet recipient and provider needs
- Failure to implement electronic technology to support providers in completing timely documentation and information retrieval
- Potential for various types of abuse (physical, emotional, social, financial)
- Lack of adequate services for the chronically ill (i.e., COPD, CHF, & renal failure) leading to diminished health and well being, as well as increased medication errors and hospitalizations
- Homes are also places of work

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7.0 RECOMMENDATIONS

For Researchers:

1. Home care research must involve clients, family members, caregivers, and providers in order to understand their differing perspectives as well as their respective vulnerabilities, needs and strengths, particularly within contexts of greatest risk and (i.e., medication management, palliative care, frail elderly, etc.).
2. Development of research priorities must be in collaboration with the various home care stakeholders.
3. Continue the research exploring the perspectives of recipients and providers in home care in order to elicit the elements of a definition of home care safety.
4. Develop a definition of safety within the home care sector. It is unlikely that a unilateral definition will be possible, but this definition should be conceptual in nature, with clearly articulated elements that may then be individualized for the client(s), such that within individual situations, each of the elements may have a different relative importance.
5. Given the complexity of home care safety, future research needs to identify and explore multiple study methods and various relevant sources of visual and textual data to capture its multidimensionality. Such an approach will help us to understand and compare results across several sources of data and to synthesize the data to capture meanings, construct theoretical relationships and explain these theoretical relationships in ways that are meaningful and applicable in home care.

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For Decision makers:

1. Consider a model of practice that supports care delivery and which enables the provider and the client(s) to co-create a health-promoting environment conducive to risk-mitigation for all involved. This will require a shift in the way organizations and practitioners typically provide care.
2. Focus on staff education to build the knowledge and competencies required to work in a different way with clients, which is directly linked to the new model of practice.
3. Continue staff education and opportunities for reflection to ensure the ongoing development of evidence informed practice.
4. Develop organizational procedures/standards that reflect the ‘flexible’ definition of safety, and therefore enable the proposed model of practice.
5. Develop safety related interventions in collaboration with home care clients, family members, caregivers and providers.
6. Designate technology enabled documentation to facilitate the transfer of information within the home and across the health care continuum as a high priority
7. Review and/or develop communication systems that follow clients across the health care system targeting high-risk situations such as, but not exclusive to clients with complex medication regimes, and clients at risk for falls.

For Policy Makers:

1. Recognize that home care safety has fundamental differences than safety in institutional settings and as such strategies and interventions to mitigate the safety risks require some different approaches and policies.

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2. Designate development and implementation of the electronic health record that links across sectors of the health care system as high priority.
3. Optimize organizational opportunities for access to new safety related technologies to mitigate risks and support recipients and providers of home care.
4. Focus and prioritize primary health care reform and home care reform for those clients with chronic illnesses such as COPD, CHF and renal failure with a goal to preventing or diminishing hospital (re)admissions.
5. Consider the needs of informal caregivers in funding approaches. Opportunities need to be embedded in service authorization and funding for caregivers to be the recipients of services and to be able to access respite care that will enable them to continue to fulfill the critical role that they play. The nature of the respite care must be such that it promotes caregiver health and well-being.

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Appendices

APPENDIX A – PILOT STUDY INTERVIEW GUIDE

Similar guide used for clients with appropriate wording amended

Interview Guide, Family Members & Unpaid Providers

1. Tell us a little bit about yourself and the person you care for
 - Length of time providing home care
 - Types of care provided
2. Describe for us your involvement in the following
 - Meals
 - Shopping
 - Housework
 - Household management
 - Personal care
 - Laundry
 - Medications
 - Appointments
 - Social interaction
 - Emergencies
3. Describe for us how the home care system works in your community
 - How did you start providing home care?
 - What are the costs involved?
4. Describe for us what providing home care means to you
 - What are you required to do?
 - What needs to be done by others and how does this happen?
5. Describe for us what safety in home care means to you

- How safe do you feel?
 - Is there anything that makes you feel unsafe?
6. Describe for us what you consider to be safety concerns related to providing home care services
- Who is the overall manager of the care?
 - Do you feel prepared to provide the care that you give?
 - Do you feel your home is set up for the care you need to provide? If not what would it take to set your home up to provide home care safely?
 - How are visits from professionals that come into your home to support you in home care scheduled?
 - How are decisions made about the visit schedule?
7. Describe for us what you would consider to be a safe and effective home care service.
8. If you were organizing home care describe how you would do it?

APPENDIX B – KEY INFORMANT INTERVIEW GUIDE

State Of The Knowledge Regarding Safety In Home Care In Canada: An Environmental Scan

**Research Team: Ariella Lang, Marilyn Macdonald, Jan Storch, Lynn Stevenson,
Kari Elliott & Helene LaCroix**

Appendix B Interview Guide

Thank you so much for taking the time to do this interview. This interview is an integral part of an environmental scan being conducted as part of the Canadian Patient Safety Institute (CPSI) *Core Safety in Home Care Team* initiative. The goal is to investigate and increase our understanding of patient safety and home care. Please feel free to expand on any of the questions. Before beginning, please consider and indicate if you would like to have your name listed as having contributed suggestions. In addition, we are asking if you would consent to having this interview digitally recorded.

Questions for Key Informants

Theme 1...Definitions

What comes to mind when you consider patient safety in home care?

Probe: For example, how would you define safety in home care? What are some of the safety issues?

Theme 2...Family/Caregiver

In home care, the family has been identified as the focus of care. What additional safety issues does this focus present that differ from the safety issues in hospital settings?

Probe: For example, family members are often responsible for care, and may be exposed to medical equipment or medication not otherwise found in the home.

Theme 3...Home/Setting

Additionally, in home care, the home is the setting or environment for the care provided. What safety issues does this reality present that differ from the safety issues in hospital settings?

Probe: For example, there is no custodial service, there may be narrow doorways, outside stairs may be in need of repair and there is no access to a lift, etc.

Theme 4...Factors affecting patient home care safety

What are other priority factors that may adversely affect home care safety?

Probe: For example, human resource constraints, staff burnout, nursing work-life in the community, family caregivers, other caregivers who may not be regulated the same way caregivers are regulated in a hospital, multiple caregivers, etc.

Theme 5...Gaps in knowledge

We are interested in what you consider gaps in knowledge regarding home care safety. As you may know, the Canadian Institutes of Health Information identifies 5 types of home care services (acute care substitution, rehabilitation, end of life care, long term care supportive, and chronic disease prevention and maintenance). Do you have more familiarity with one of these areas in particular? Could you describe the gaps in knowledge re: safety in health care for the area(s) with which you are most familiar?

Theme 6...Priorities

In your opinion, what are the priorities for research regarding home care safety ? Please be as specific as possible.

Theme 7...Building capacity

Research requires research capacity. What are the current gaps or barriers to conduct home care safety research in Canada? What are the priorities for building capacity to conduct leading-edge research on home care safety in Canada?

Theme 8...Exemplars

Are there exemplars, in Canada or elsewhere, where patient safety systems or research projects tailored to home care have been developed or where research on home care safety is underway? Are there any key reports or important literature of which you are aware, including peer-reviewed?

Theme 9...Trends

Often, we see trends in different forms of care. What trends or changes in home care are you seeing and do these trends have safety implications?

APPENDIX C – INVENTORY OF EXEMPLARS

Highlighted – Information from key informant interviews

Past		
Exemplar	Work	Explanation
Lang & Edwards (2006) Canada	Broadening the Patient Safety Agenda to Include Home Care Services	The report tackles the significant knowledge gap about safety in home care. The key informant interviews, literature review and roundtable discussion highlight the mitigating risks and unique challenges to home care which demand a major rethink of the use of institutional frameworks and assumptions in this setting.
Miller, Hollander & MacAdam (2008) Canada	The Continuing Care Research Project for Veterans Affairs Canada and the Government of Ontario	The project evaluates the success of OSV/VIP initiative and the cost effectiveness of long term home care, supportive housing and facility care. Furthermore, they obtain information about contributions of long term care and home support services and information to contribute to the policy implications in Canada for health services for the elderly.
Hollander Analytical Services Ltd. And Nunavik Regional Board of Health and Social Services for Health (2008) Canada	An Assessment of Continuing Care Requirements in First Nations and Inuit Communities	A national study of systems of care delivery for First Nations and Inuit persons with ongoing care requirements. Sought to provide an understanding of the gaps in the continuing care services available in both First Nations and Inuit communities and to develop options for the provision of continuing care services in First Nations and Inuit communities.
Gerontological Advisory Council (2006) Canada	Keeping the Promise: The Future of Health Benefits for Canada's War Veterans	This report is a proposal to Veterans Affairs to amalgamate their three existing health and social programs into a Veterans Integrated Services (VIS) for more efficient and comprehensive system for war veterans across Canada.
Hurley et al. (2004) United States	Promoting safer home environments for persons with Alzheimer's Disease: The home safety/injury	With recognition of the many safety concerns associated with Dementia for both care recipient and caregiver, Hurley et al. developed a Home Safety/Injury Model. The three components of home safety/injury model are: safety platform, person with dementia and risky behaviours.

	model	
Suter et al. (2008) United States	Home-based chronic care: an expanded integrative model for home health professionals	The Home-based Chronic Care Model (HBCCM) is designed uniquely for home health to manage care of individuals living with chronic disease. It is based on 4 pillars of care: high touch delivery system, theory based self management, specialist oversight and use of technology.
Frank & Brien (2008) Canada	The Safety Competencies: Enhancing Patient Safety Across the Health Professions	The safety competencies steering committee of CPSI developed this framework of interprofessional patient safety competencies to accelerate the patient safety curricula. The framework is suitable for use by all health care providers in a multitude of settings.
Windwick et al. (2008) Canada	Canadian Disclosure Guidelines	The Canadian disclosure guidelines have been implemented to promote a patient's right to be informed if involved in an adverse event. The guidelines endorse a clear and consistent approach to disclosure and emphasize the importance of team work and support for learning from these events.
Markle-Reid et al. (2005) Canada	The Comparative Effects and Expense of A Proactive, Nurse-Led Multifactorial and Interdisciplinary Team Approach to Falls Prevention For Older At-Risk Home Care Clients	The project addresses the effects and expenses of an innovative approach to home care service delivery for older adults at risk for falls. The project also addresses an innovative approach to reducing adverse events in the community setting and identifies the determinants and costs of falls/fall injuries.
Tamblyn et al. (2006) Canada	Reducing Injuries from Medication-Related Falls by Generating Targeted Computerized Alerts for high Risk Patients within an Electronic Prescribing System	Medication-related falls are a common problem among elderly people residing in the community. The purpose of this study is to introduce a computerized electronic prescribing and drug management system to identify high risk patients and make recommendations to modify medications to reduce risks for those individuals.
Van Ineveld et al. (2006)	Planning for Patient Safety: Exploring	This is an exploratory study intended to identify perspectives of key stakeholders on the current process of discharge planning as well as

Canada	strategies to reduce a person's risk of adverse events when transitioning between day hospital and community based care	communication between day hospitals and community settings. The intent is to identify a definition of adverse events in this setting and multidisciplinary strategies to reduce risks for adverse events.
Canadian Home Care Association High Impact Practices (2008) Canada	Supporting Frail Seniors to Stay Safe at Home British Columbia's Northern Health and Interior Health communities	This project aims to provide frail seniors in the community with coordinated, multidisciplinary care which includes client-centred care and around-the-clock clinical responsibility to allow them to stay in their homes. The outcomes the project strives to accomplish include increased independence, quality of life and improved utilization of health services for frail seniors and their caregivers.
Canadian Home Care Association High Impact Practices (2007) Canada	Clinical Pharmacy Services in Home Care South-East Regional Health Authority	This pilot project involved pharmacists as a member of the home care team to provide a clinical pharmacy services to individuals recently discharged from hospital and considered high risk for potential adverse drug events.
Canadian Home Care Association High Impact Practices (2006) Canada	Enhanced Palliative Care Program Hamilton Community Care Access Centre	The program aims to help individuals suffering from a terminal illness to receive timely access to end-of-life care. The Enhanced Palliative Care program involved a multidisciplinary team that enhanced the knowledge and abilities of health care providers and informal caregivers in various support areas such as pain management and spiritual questions.
Canadian Home Care Association High Impact Practices (2006) Canada	EMPCare@home Technology achieves improved client self-management of chronic disease and enables pre-emptive care New Brunswick	The telehome care project was implemented to provide timely staff intervention and enhanced patient education to improve outcomes for clients with chronic disease.
Dr. Alan Forster	Research on adverse events in	Forster,A.J., Clark, H.J., Menard, A., Dupuis,N., Chernish,R., &

<p>Ottawa Health Research Institute</p> <p>2003, 2004</p> <p>Canada</p>	<p>home care</p>	<p>Chandok,N., et al. (2004). Adverse events among medical patients after discharge from hospital. <i>Canadian Medical Association Journal</i>, 170, 345-349.</p> <p>Forster AJ, Murff HJ, Peterson JF, Gandhi TK, Bates DW. (2003). The incidence and severity of adverse events affecting patients after discharge from the hospital. <i>Annals of Internal Medicine</i>, 138, 161-7.</p> <p>Both studies highlight the serious medical consequences suffered by patients due to a fragmented health care system</p>
<p>Ross-Baker University of Toronto</p> <p>2004, 2007</p> <p>Canada</p>	<p>Research looks at the adverse events in home care (after discharge from acute care)</p>	<p>Ross-Baker, G., Norton, P.G. (2004) Adverse events and patient safety in Canadian health care, 3, 353-354. (Commentary).</p> <p>Masotti, P., Green, M., Shortt, S., Hunter, D. & Szala-Meneok. (2007). Adverse events among medical patients after discharge from hospital, <i>Healthcare Quarterly</i>, 10, 63-69. (cited allusions to the topic of adverse events in home care in his studies)</p>

Present/Planned

Exemplar	Work	Explanation
<p>Butler et al. (2009)</p> <p>Canada</p>	<p>Medication Reconciliation in Home Care</p>	<p>A Medication Reconciliation pilot project has been implemented in home care agencies across Canada. The findings will be used to develop a framework to aid home care providers in implementing medication reconciliation into their practice in a way that recognizes the unique challenges to this setting.</p>
<p>Gantzel & Allec (2009)</p> <p>Canada</p>	<p>Working Alone in Community Health Services and Housing</p> <p>Winnipeg Regional Health Authority</p> <p>Presented at Edmonton IV Conference</p>	<p>This presentation highlighted the Working Alone policies and procedures developed to improve the safety of home care providers in the Winnipeg region. The project includes definitions of roles, Working Alone tools and guidelines for how to safely provide care in the home.</p>

Doran et al. (2009) Canada	Safer Care Through Information and Communication Technologies Presented at Edmonton IV Conference	This project addresses the patient safety trends for health care planning related to the impact on home care demographics and the emerging health care technologies. The aim is to implement advanced communication technologies into health care delivery for better access to information, remote monitoring and decision support.
Hoffman et al. (2008) Canada	Building a Safer System: The Canadian Adverse Event Reporting and Learning System (CAERLS)	A CPSI consultation paper was put together to initiate discussion and rally support for this pan-Canadian initiative tackling the issue of reporting adverse events in the health care sector; an issue consider to be a key patient safety indicator in Canada. The next steps for CAERLS are consultations, planning, implementation and evaluation of the process.
Lang et al. (ongoing) Canada	Safety in Home Care: Perspectives from Clients, Family Members, Caregivers, and Providers	Funded by the Canadian Institutes of Health Research (CIHR), this study is exploring the experiences, challenges, and insights regarding safety of those receiving and providing palliative home care services in Quebec urban settings.
Lang et al. (ongoing) Canada	Safety in Home Care: Focus on Medication Management	Funded by the CIHR, this study is examining and comparing across four Canadian provinces (AB, ON, QC, NS) the experiences, challenges, and insights surrounding the safety of medication management for home care recipients and providers of home care services.
Canadian Institute for Health Information (CIHI) and interRAI (2008) Canada	Clinical Assessment Protocols (CAPS)	CAPS in Canada have been introduced for use in community based health services such as home care and long term care. The protocols are designed to assist care providers in identifying clients at risk and providing best practices in order to improve outcomes. CAPS is an international development.

APPENDIX D – REVIEW OF THE LITERATURE

Authors	Title	Quantitative	Qualitative	Sample	Key Findings
Appelin & Berterö (2004)	Patients' experiences of palliative care in the home: a phenomenological study of a Swedish sample.		X Giorgi's phenomenology	6 informants: patients diagnosed with terminal cancer receiving palliative care at home.	<p>4 themes of patients' palliative care in the home experiences:</p> <ul style="list-style-type: none"> - safe but unsafe home - sense of powerlessness - change of everyday life - hope and belief in the future <p>Overall theme of “uncertain safety” where patients felt safe and secure in their own home even though they felt dependent on relatives and family members. When problems emerge, patients felt anxious and felt that their time at home was limited. The state of uncertainty and feeling of not being able to influence one's life situation gives experience of powerlessness.</p> <p>District nurses should learn the family's needs and communicate with patients to eliminate insecurity.</p>
Armes & Addington-Hall (2003)	Perspectives on symptom control in patients receiving community palliative care.		X Qualitative case study	10 terminally ill cancer patients living at home in the UK. The main carer and health care professional were asked to	<p>A number of symptoms have been shown to be associated with inpatient admission of palliative patients: uncontrolled pain, psychological symptoms, weakness, peak of any symptom, nausea and vomiting and respiratory distress.</p> <p>Adequate symptom control is dependent on: Symptom assessment where informal carers play a significant role in interpreting, reporting and monitoring patient symptoms in order to effectively convey this information to the health care professionals.</p> <p>Symptom management was identified as a key factor in allowing the patient to stay in the home. Adherence to</p>

				participate.	medications is a major determinant of adequate symptom management.
Ballentine (2008)	Polypharmacy in the elderly: maximizing benefit, minimizing harm.	X Literature review		Literature review conducted in the US.	<p>For many chronic illnesses (CAD, CHF, diabetes, hypertension, COPD) multi drug regimens improve outcomes. New standards for treatment goals coupled with the fact that many elderly develop multiple chronic illnesses can lead to what appears to be a necessity for polypharmacy.</p> <p>Need approaches to polydrug therapy that maximize outcomes and minimize harm.</p> <p>All medications should be assessed regularly, updated according to the dynamic changes of the disease process and verified with the patient and informal caregiver to enhance safety and effectiveness of prescribing.</p>

<p><i>Doyle-Brown (2000)</i></p>	<p>The transitional phase: The closing journey for patients and family caregivers.</p>	<p>X Discussion paper</p>			<p>The transition period, characterized by 4 precursive/seminal behaviours and 2 cardinal behaviours, is the time of greatest risk to injury and falls due to increased confusion and weakness.</p> <p>These characteristics although not experienced by all terminal patients potentially have the greatest impact on patient safety and the greatest implications for care giving. It is usually during this phase that caregivers make the decision to move the patient to another home/facility.</p> <p>The first fall or first period of incontinence brings about the realization of the magnitude of the care giving role and often ill preparedness for that role.</p> <p>Health care workers are encouraged to educate caregivers and patients on the transitional phase; what to expect and how to cope with it. This will reduce physical and emotional risks associated with this phase.</p>
<p>Carretero, Garces & Rodenas (2007)</p>	<p>Evaluation of the home help service and its impact on the informal caregiver's burden of dependent elders.</p>	<p>X Experimental design, field study Objective and subjective assessment of HHS</p>		<p>Dependent elders (n=296) and their informal caregivers (n=117), both users and non-users of Home Health Services (HHS) in</p>	<p>Care burden is high in both carers of HHS users and non-users. Mean burden is higher for carers of HHS non-users but not statistically significant.</p> <p>HHS focused chiefly on providing instrumental care with little focus on the organization of respite resources and psychological services for informal caregivers.</p> <p>Despite general satisfaction and higher quality of care noted with HHS, quality and continuity of care by informal caregivers with high burden run the risk of endangering the dependent elder. Thus HHS is not sufficient in decreasing care burden.</p>

				Spain.	
Coughlin, Pope, & Leedle (2006)	Old age, new technology, and future innovations in disease management and home health care.	X Discussion paper			<p>Technology that can monitor patient's status and improve communication and collaboration with patients/families/health care professionals can enable the transformation of health care delivery</p> <p>Individuals with the most complex needs, and thus are highest risk, make up approximately 1% of the population but use 20-30% of total costs. Health problems of those at greatest risk often isolate themselves from family, friends and coworkers especially individuals who are aging. Isolation, depression and decreasing health status send them into a downward spiral and they often are disconnected from care systems/receive disjointed care.</p> <p>Telehealth technologies being implemented (using telephone, video conferencing, internet based devices) to provide remote monitoring, consultations and education. Technologies used to monitor, manage and motivate patient health status.</p> <p>Home health care nurses who typically see 10 patients a day can now see 20-30 patients using telehealth.</p>
Exley & Davina (2007)	A critical examination of home care: End of life as an illustrative case.		X Qualitative interviews	93 interviews conducted in the UK in total: 30 with 19 terminally ill patients	Home is a social space where individuals are relaxed, where privacy can be maintained, where individuals' needs can be met and choice/autonomy preserved. It is the preferred site of care and the social space of the home is privileged over the social space of institutions where the need for organization and batch living clash with caring ideals. The data indicates that presuppositions do not acknowledge the complex reality of home care and mask some inherent

				<p>with cancer in study 1; 52 with 27 palliative care patients and 18 of their carers. 7 post-bereavement interviews with carers in study 2 and 11 interviews with 12 bereaved carers in study 3.</p>	<p>tensions.</p> <p>Implications of home care for family carers:</p> <ul style="list-style-type: none"> - Home as a social space - Intrusions and reorderings - From institutional intrusions to emotional traces - Body care and identity work - Caring about and caring for whom?
<p>Forbes, Markle-Reid et al. (2008)</p>	<p>Availability and acceptability of Canadian home and community-based services: perspectives of family caregivers of persons with</p>		<p>X Focus groups Qualitative interviews</p>	<p>n=36 rural and urban family caregivers in Ontario, Manitoba and Saskatchewan.</p>	<p>Symptoms of dementia (wandering, incontinence, aggressive behaviour) exceeded caregivers physical and emotional capacity to manage care alone</p> <p>Too often a crisis situation developed before formal assistance was sought.</p> <p>Two overarching themes determining the use and satisfaction with home care services:</p> <ol style="list-style-type: none"> 1) availability of services 2) acceptability of services

	dementia.				
Gitlin et al. (2003)	Effects of the home environmental skill-building program on the caregiver-care recipient dyad: 6-month outcomes from the Philadelphia REACH Initiative.	X RCT		Enrolled 255; n=190 family caregivers of community residing persons with Alzheimer's.	<p>Studies show that families tend to implement environmental strategies to cope with safety concerns and need professional guidance to apply strategies to other behavioral problems.</p> <p>No statistically significant interactions found for race or any other care recipient functioning measures.</p> <p>Women on average had more hours worked, received less help with ADLs and showed more improvement with intervention/control than men.</p> <p>ESP improved outcomes in 3 areas at 6 months: objective burden, subjective burden and well being.</p>
Greenberger & Litwin (2003)	Can burdened caregivers be effective facilitators of elder care-recipient health care?	X Cross sectional study Randomized sampling		240 informal caregivers (spousal or filial) in Jerusalem.	<p>Results suggest that quality care giving can coexist with burden given ample resources. The most important resources are caregiver sense of competence and support from professional health care providers.</p> <p>The study reports relatively high levels of resources and competency coexisting with moderately high levels of burden.</p> <p>Five major findings: 1) personal and social care giving resources are interrelated 2) higher burden levels associated with lower resources 3) use of formal social support positively related to burden 4) caregiver competence and outcome variables of adherence facilitation were positively related to burden 5) Self confident caregivers and those empowered by health professionals will tend to be more active health wise, more</p>

					assertive in seeking out guidance and more likely to put the latter into practice
<i>Habraken et al. (2007)</i>	Health care needs in end-stage COPD: a structured literature review.	X Structured literature review		9 publications were included in this literature review from the Netherlands.	Bradshaw classification of need was used to categorize the needs of clients living with COPD in the community setting: <ol style="list-style-type: none"> 1. normative need 2. felt need 3. expressed need 4. comparative need <p>Overall, they found that very few studies have focused on health care needs of end stage COPD population.</p>
Harris (2007)	COPD and coping with breathlessness at home: a review of the literature.	X Literature review			Two main themes arise from coping with breathlessness at home: <ol style="list-style-type: none"> 1) Coping with acute breathlessness is associated with feelings of isolation, fear and helplessness. It is associated with increased fatigue as predominant symptom. This strain is evident for both the care recipient as well as the carer. The psychological and physical problems in the last years of life are intense and health care professional involvement is low. 2) Hospital at home and support in the community can be provided as an alternative to admission to hospital. Telephone interventions and community nurse led teams were effective in the early detection of symptoms and reduction in hospital admissions.
Hudson et al.(2008)	Evaluation of a psycho-educational group programme for family caregivers in	X Session and program evaluation, administration of demographic	X Semi-structured interviews, facilitators' journals	44 of 74 caregivers from 6 home-based palliative care	Home death is significantly increased if family caregiver receives comprehensive preparation and support. <p>Psycho-educational interventions are shown to decrease caregiver burden, increased caregiver quality of life, and increase knowledge of patient symptoms.</p>

	home-based palliative care.	questionnaire		services in Australia finished all 3 time periods. Use of multivariate analysis of variance	Partial support that the program demonstrates increased levels of preparedness, competence, social support, rewards, optimism, less unmet needs and burden.
Kristjansen & Aoun (2004)	Palliative care for families: Remembering the hidden patient.	X Review		Review is based in Canada.	<p>The first step is to identify the family: the biological family, family of acquisition, family of choice and family of friends. It is important to identify the family unit to prevent leaving a member out who may need support.</p> <p>Family members tend to be overlooked by health care professionals and are deemed the 'hidden patient.'</p> <p>Family members may experience several health problems during the care giving role and in the bereavement period resulting in poorer health than the 'normal healthy' population. Health problems are multifaceted; physical deterioration, emotional strain, social issues, mental disorders and functional deficits.</p>
Markle-Reid (2006).	Health promotion for frail older home care clients.	X Two armed, single blind RCT		242 older people (more than 75 years) eligible for personal	<p>With modest reorganization of the delivery of existing home care services, statistically significant enhancements in quality of life can result.</p> <p>Statistically significant lower per person cost of prescription medications in the nursing group compared with usual care.</p>

				support services through a home-care program	
McGraw, Drennan & Humphrey (2008)	Understanding risk and safety in home health care: the limits of generic frameworks.		X Semi-structured Purposive sampling	District nurses and home carers from two contrasting sites in UK District nurse managers n=17 Community staff nurse n=10 Internal home care managers n=10 Home carers n=7	Home is quite different than hospital setting: the material and physical dimension of the home environment are far less controlled/controllable than clinical environment. Furthermore, patients in hospital setting often receive services from one organization and patients in home care from many services. Medication contributes to the well being of older people and medication errors have serious consequences for patients. Adverse drug events/iatrogenic disorders are an important cause of morbidity (as many as 1 in 6 admissions to hospital from adverse drug event). A new taxonomy named framework of factors influencing medication management in domiciliary care (FFIMED) was developed specifically for the home care setting. This taxonomy is comparable to the FFICP taxonomy used in institutional settings
Payne (2007)	Safeguarding adults at end of life: audit and case analysis in a palliative care setting.		X Audit and case analysis	48 inpatient beds, 600 home care and 100 day care cases in the	Physical, emotional and financial abuse or neglect are safety concerns for both the care recipient as well as the caregiver. Cases of abuse reflect the difficulty in providing care at the end of life and highlight the vulnerability of this population in the absence of proper support. Abuse at end of life often arises where there are long term

				UK were used for audit and case analysis.	relationship problems in the family, leading to additional stress on family caregivers arising from mental ill health of the patient and patterns of family organization that are unhelpful. Perpetrators of abuse were more likely women to men which likely reflects long standing power imbalances which are suddenly shifted making men the vulnerable victim.
Proot et al. (2003)	Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity.		X Grounded theory	<p>Patients n=13</p> <p>Family caregivers currently providing care to a terminally ill patient n=13</p> <p>Bereaved caregivers n=14</p> <p>Professional caregivers n=13</p> <p>Study based in the Netherlands.</p>	<p>Caregivers find themselves in a situation with a number of mental and physical burdens which may cause caregiver fatigue and eventual burnout. This situation may make the family members feel vulnerable and if so, constant balancing between burden and coping is needed.</p> <p>Vulnerability increasing factors:</p> <ul style="list-style-type: none"> - Care burden - Restricted activities - Fear - Insecurity - Loneliness - Facing death - Lack of support <p>Vulnerability decreasing factors:</p> <ul style="list-style-type: none"> - Continuing previous activities - Hope - Keeping control - Satisfaction - Good support
Stuart	Transition	X		Study is	There is a disconnect between when life sustaining disease

(2003)	management: a new paradigm for home care of the chronically ill near the end of life.	Review of model		based in the US.	<p>management interventions should end and terminal care should begin (especially with the non-cancer chronic disease population). It is hard to distinguish when comfort measures take over. This period is termed the transition period.</p> <p>Transition management model guides the transition from acute to end of life care.</p> <p>Advanced Illness Management is now under development and is designed to provide palliative care and transition management to patients who have increasing difficulty qualifying for home care. The model would combine elements of both acute and palliative care practice.</p>
Visser et al. (2004)	The end of life: informal care for dying older people and its relationship to place of death.	<p>X</p> <p>Large survey</p> <p>Retrospective data from interviews and questionnaires</p>		56 people who were primary caregivers of older relatives in the last 3 months of life in the Netherlands.	<p>In the last three days of their lives: older people with a resident caregiver were more functionally limited than those with a nonresident caregiver.</p> <p>Burden of informal care remains the strongest association with place of death. Excessive strain on informal caregivers is suggestive of admissions to hospital.</p> <p>Resident caregivers had a more demanding task load and fewer resources available than nonresident caregivers and thus run a higher risk of becoming overburdened.</p>

APPENDIX E – LITERATURE REVIEW STRATEGY

Initial search for literature:

- Three topic areas:
 - End-of-life care
 - Chronic disease management
 - Caregivers
- Databases searched:
 - CINAHL
 - PubMed
 - Medline
 - Web of Science
 - PsychINFO
 - Cochrane Library
 - Up-to-Date
- Key terms included:
 - Informal caregiver
 - Caregiver
 - Caregiver burden
 - Care giving
 - Family member
 - Chronic disease management
 - Chronic disease
 - Disease management
 - Vulnerable elderly
 - Frail elderly
 - End-of-life care
 - End-of-life
 - Terminal illness
 - Palliative care
 - Home care
 - Home health care
 - Community
 - Patient safety
 - Safety
- Articles retrieved were peer-reviewed, research and reviews
- Research assistants and team members independently rated the articles retrieved for their relevancy. The group convened via teleconference to compare, discuss and reconcile ratings.
- Articles were rated accordingly:
 - 1) Relevant
 - 2) Somewhat relevant
 - 3) Not relevant
- 89 articles were retrieved for review
- Articles rated as 1 or 2, were kept for another round of review.

- The research team again evaluated articles and rated them for their relevancy using the same guidelines as above as well as limiting the publication dates from 2000 to 2009.
- 37 articles were retrieved for review

Secondary search for literature:

- Research team began a secondary search for literature in order to obtain a more comprehensive review of literature.
- The literature was searched one topic at a time using a key term and key author search.
- The databases and key terms remained the same as the initial search for literature.
- Key authors were determined by:
 - Key term search (2 or more articles by one author retrieved)
 - Research team's knowledge of researchers in the field
- Articles were limited to publication dates from 2000 to 2009
- Methodology and number of articles retrieved from each database were recorded for each of the topic areas.
- 192 articles were retrieved from the initial and secondary searches combined:
 - 38 caregiver
 - 28 chronic disease management
 - 126 end-of-life care
- An additional hand search through palliative care journals was conducted to ensure that a comprehensive review of end-of-life care articles was retrieved. No further articles were retrieved.
- Research team rated the 192 articles for their relevancy and fit within the scope of the literature review. The research team convened via teleconference for each topic area.
- 42 articles were retained for further exploration in a data extraction table.
 - 21 caregiver
 - 11 chronic disease management
 - 10 end-of-life care
 - The data extraction table included the following information:
 - Title
 - Author
 - Date
 - Year of publication
 - Study design
 - Sample population
 - Type of study
 - Purpose of study
 - Results of study

- The bibliographies of the 42 articles were searched for other relevant articles.
- 31 articles were retained for use in the literature review:
 - 14 caregiver
 - 9 chronic disease management
 - 8 end-of-life care
- 2-3 page summary was written for the data compiled in each of the topic areas.