SAFETY IN HOME CARE:

BROADENING THE PATIENT SAFETY AGENDA TO INCLUDE HOME CARE SERVICES

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EXECUTIVE SUMMARY

Introduction

This report on patient safety in home care was prepared at the request of the Canadian Patient Safety Institute and the Victorian Order of Nurses Canada. An earlier version of the report included a literature review and preliminary findings from key informant interviews. It was used as a background document for an invitational roundtable meeting on patient safety that was held in Edmonton on May 2nd, 2006. This final version of the report includes the literature review, final analysis and key findings of the key informant interviews, and a summary of the discussions at the roundtable. This report represents a shift towards addressing the need for new knowledge in the field of safety in home care in Canada.

Methods

An advisory committee provided overall direction for the project, names and coordinates for key informants to be interviewed, and comments on earlier versions of the background paper. A research group also provided guidance in similar capacities. Medline, the Cumulative Index to Nursing and Allied Health Literature, and the Cochrane Library were searched for the years 1995-2006. Key search terms included: patient safety, safety in home care, risk mitigation in home care, home care and safety, and adverse events and home care. Major reports on patient safety from Canada, the UK, Australia, and the U.S.A. were also retrieved. Current definitions of patient safety were identified, emergent shifts in thinking on patient safety and assumptions underlying patient safety initiatives were summarized, and conceptual frameworks for patient safety were reviewed. Illustrative research questions relevant to patient safety in home care that align with key concepts on patient safety are presented.

Key informants, identified by the advisory committee and research group, were invited to participate in audio-taped, semi-structured telephone interviews to identify the issues for safety in home care. Interviews were transcribed, coded, and emergent themes were identified.

Prior to the invitational roundtable, participants were asked to read the background paper (Lang & Edwards, 2006) and consider some questions. A facilitated discussion was held at the roundtable, during which small groups of participants considered safety issues in home care. The top three safety issues and the top three actions to improve safety in home care were identified. Discussion and feedback to the large group was also audio-taped and transcribed for analysis.

Findings

Literature Review:
Six major reports on patient safety were located and more than thirty research articles were reviewed.

Many definitions of patient safety are generic enough to include the home care setting. However, most of the major reports on patient safety are written with an orientation to the institutional environment. Emergent shifts in thinking about patient safety that are evident in the literature include: patient safety is a failure of systems rather than a failure of humans, there are many change processes required to create safe environments, organizational culture and workplace factors affect patient safety, and patients have a key role to play in their care and thus must be part of the patient safety discourse.

There is recognition of the need for common frameworks to guide patient safety initiatives and taxonomies to classify near misses and adverse events. These are prerequisite to the development of complementary approaches and common indicators for safety initiatives across healthcare organizations.

Much of the research on patient safety has been conducted in institutionalized environments with a predominant focus on intra-organizational systems. Paid care providers rather than informal caregivers have been the focus of attention. Research studies reviewed that are relevant to safety in home care included qualitative and quantitative studies of home care technology, interpersonal patient-provider interactions, communication among professionals, and transitions from hospital to home care environments.

Five conceptual frameworks were identified. Four were specific to patient safety while the fifth was a broader framework for multi-level and multi-strategy interventions. Embedded within each of the frameworks are systems thinking, and recognition of socio-ecological determinants of patient safety issues. However, none of the frameworks were specifically developed for the home care setting.

Key Informant Interviews:

Twenty individuals were interviewed. They reflect diverse disciplines and work in a variety of settings including academic institutions, healthcare organizations, and professional associations. The following themes emerged from the interviews regarding the factors that influence safety in home care:
- Family is the unit of care
- Safety of client, family, caregiver and provider are inextricably linked
- The unregulated and uncontrolled setting of individual homes
- The multiple dimensions of safety – physical, emotional, social, and functional
- Autonomy and choice for clients, families, and caregivers
- Isolation – clients living alone and caregivers and providers working alone
- Communication on many levels
- Maintaining and developing knowledge, skills, and competence
- Diminishing focus on prevention, health promotion, and chronic care
- Human resource challenges – magnified in home care

Invitational Roundtable Discussion:

Forty individuals participated in the roundtable. The top three safety issues raised were:
- conventional institutional focus on the physical safety of the identified patient rather than considering the client, family, caregiver, and provider as interlinked within a broader conceptualization of safety (i.e. emotional, social, functional) in home care;
- problematic communication and co-ordination among service sectors, providers, caregivers, family, and clients in home care;
- challenges of a fit between technology and the built environment, in the context of uncontrolled and unregulated settings, such as individual homes that were not designed for healthcare

The top three actions to improve safety in home care were: research; education, knowledge, and tools; and policy. There was strong consensus regarding the urgent need for research on safety in home care including:
- a national survey to identify safety issues in home care;
- in-depth qualitative studies to elicit clients' and families' perceptions of what safety in homecare means to them;
- the strengths and deficiencies related to patient safety in home care.

Conclusions

There is an urgent need for research on safety in home care. Addressing safety in home care presents unique challenges and requires a major rethink of underlying assumptions and guiding frameworks that have been used to examine patient safety in the institutional environment. Research on safety in home care needs to: a) address the patient, family, and other unpaid caregivers as the unit of care; b) reflect the influences of an unregulated and uncontrollable home environment on the use of technology and the provision of care; and c) tackle the challenges of transitions, communication, and continuity of care amongst an array of paid and unpaid care providers. Leading edge research in this field will require a critical mass of interdisciplinary researchers, practitioners, and decision-makers as well as an application of a wide array of research methods.

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BACKGROUND

The Canadian Patient Safety Institute (CPSI) and the Victorian Order of Nurses (VON) Canada have jointly identified a knowledge gap in our current understanding of safety in the home care sector. A coordinated and collaborative approach to exploring and addressing the need for new knowledge in this field has therefore been undertaken in collaboration with Capital Health-Edmonton. An invitational roundtable meeting was held in Edmonton on May 2nd, 2006. It was a critical step towards identifying research priorities in home care safety for Canada. In preparation for this, Drs. Ariella Lang and Nancy Edwards were invited to prepare a background paper.

OVERVIEW OF REPORT

This report begins by outlining the methods used to develop the paper. Included is a review of the literature, with particular attention to: current definitions of patient safety; emergent shifts in thinking about safety in home care that have begun to take hold; key assumptions underlying research on patient safety in institutionalized environments; and, key concepts and potential indicators for safety in home care. It follows with a summary of studies related to home care. Conceptual frameworks of potential relevance to safety in home care are described. The findings from 20 key informant interviews and an invitational roundtable discussion of 40 participants are presented. Finally, a discussion, summary remarks, and recommendations for education, policy, and further research are offered.

METHODS

There were two separate work groups that guided the preparation of this report. The first was an advisory committee composed of Carolyn Hoffman (Canadian Patient Safety Institute), Judith Shamian (VON Canada), and Marguerite Rowe (Capital Health, Edmonton), who provided overall direction, recommendations of key informants to be interviewed, questions for roundtable discussants to ponder, as well as review and commentary for this paper. The second was a research team comprised of colleagues across five provinces, who are currently participating in research and/or healthcare delivery initiatives targeting patient safety in the hospital and the home. A teleconference with this research team also provided guidance regarding priority literature to search, questions to include in the key informant interview guide, and recommendations of names for key informants.

Literature Review

There were two phases for the literature review. The first was conducted in the electronic databases Medline, The Cochrane Library, and the Cumulative Index to Nursing and Allied Health Literature. The literature searches were limited to publication years 1995-2006 and were designed to retrieve articles that covered general patient safety and home care topics. Key ideas searched included patient safety, patient safety in home care, risk mitigation in home care, home care and safety, and adverse events and home care. The results of this search were supplemented by previously identified key patient safety reports from Canada, the U.K., Australia, and the U.S.A. (Baker & Norton, 2002; Institute of Medicine,1999; Sorensen et

al., 2004; UK National Patient Safety Agency, 2005). The second phase of the search, examined grey literature, including the websites and reports of patient safety institutes in these same countries.

Key Informant Interviews

Consultation with both the research team and the advisory committee led to the development of the interview guide (Appendix A). The guide was piloted with a key informant and revisions were made. Key informants identified by the advisory committee and the research team were contacted by Carolyn Hoffman (CPSI) to briefly describe the initiative and the roundtable, as well as to invite them to participate in a 45 minute audio-taped semi-structured telephone interview. Dr. Lang conducted all of the interviews.

Invitational Roundtable Discussion

Prior to the invitational roundtable, participants were asked to read the background paper (Lang & Edwards, 2006) and consider three questions: 1) What are the key factors affecting safety in home care in Canada?; 2) Is there evidence that describes these factors/issues and the gaps in our understanding of these issues?; and 3) How can we ensure that this important dialogue and work continues? The participants were provided with an opportunity to share their unique perspectives and to guide the process of broadening the patient safety agenda in Canada to include safety in home care. During the roundtable, top three safety issues in home care and top three actions to improve safety in home care were discussed by participants in small groups. Feedback to the large group was audio-taped and transcribed.

ANALYSIS

Twenty audio-taped key informant interviews were completed between April 7 and April 28, 2006. These interviews were transcribed verbatim and a thematic analysis of the transcripts was conducted. Data were independently reviewed, coded by the co-authors, and themes developed. Thematic analysis was also conducted for the transcripts from the roundtable discussion.

CLARIFICATION OF TERMS

Prior to presenting the findings, it is necessary to highlight a distinction in the terminology used in the following discussions (i.e. difference between caregiver and provider). "Caregivers" are often family members or friends, who are in an unpaid role, but are often the primary person responsible for or charged with 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, therapists, homemakers.

FINDINGS

Literature Review

Current definitions of patient safety:

A review of major reports from healthcare literature and organizations addressing patient safety yielded a number of definitions. A summary of examples are provided in Table 1. We did not locate a definition of safety specifically in the context of home care.

Table 1: Current definitions

Reference	Definition
Davies, Hébert, & Hoffman (2003)	"The reduction and mitigation of unsafe acts within the health-care system as well as through the use of best practices shown to lead to optimal patient outcomes." (p. 12)
Institute of Medicine (1999)	Moving patient safety practices beyond error reduction and risk management through a broader perspective of the complexities embedded in the process of care is fundamental in building safer healthcare systems.
National Steering Committee on Patient Safety (2002)	"The state of continually working toward the avoidance, management and treatment of unsafe acts within the health-care system." (p. 37)
Buckle et al. (2003)	"The *Design for Patient Safety…* builds on and reinforces the new patient safety approach to move away from a 'blame culture', towards one that encourages learning and recognizes medical accidents to be the culmination of failures in the healthcare system." (p. 11)
Sorensen et al. (2004)	"Patient safety is a new construction that takes health, organizational, and social relations in health and construes them in novel ways, according to emerging interesting harm prevention in general and patient safety in particular." (p. 18)
Barraclough (2004)	"A safer healthcare system is one that places consumers in the centre and harnesses the experiences of patients and their carers to drive improvements." (p. 13)
UK National Patient Safety Agency (2005)	"The process by which an organization makes patient care safer. This should involve risk assessment, the identification and management of patient related risks, the reporting and analysis of incidents, and the capacity to learn from and follow-up on incidents and implement solutions to minimize the risk of them recurring." (p. 37)

Emergent shifts in thinking:

There are some emergent shifts in thinking about patient safety that have begun to take hold. These are reflected in major reports, research studies, and the mandates of accreditation and patient safety institutes that are leading the patient safety agenda. Notable shifts in the patient safety field include:

- Patient safety is increasingly viewed as a failure of systems rather than a failure of humans (Institute of Medicine, 1999; National Steering Committee on Patient Safety, 2002).
- Creating a safer environment for patients involves "multiple processes of change, including organizational and practice change" (Sorensen et al., 2004, p. 25).
- It is essential to promote a patient safety culture within organizations (Affonso, Jeffs, Doran, & Ferguson-Paré, 2003).
- There is a need for common frameworks, taxonomies, and indicators that would allow us to develop complementary approaches and indicators for tackling and assessing patient safety among healthcare organizations (Chang, Schyve, Croteau, O'Leary, & Loeb, 2005).
- Important lessons can be learned from other sectors and disciplines with a long history of addressing adverse events (Lehoux, 2004).
- Many workplace factors (such as leadership, governance, employee fatigue, team communication) affect patient safety (Sorensen et al., 2004).
- Patients have a key role to play in their care and must be part of the discourse on patient safety (Harrison & Verhoef, 2002).
- Patient safety involves lowering and mitigating the risks of adverse events.

Key assumptions:

Much of the research on patient safety has been undertaken in institutionalized environments. This section outlines some of the key assumptions that are implicit in this literature. These assumptions, which are listed below, also highlight the limited generalizability of patient safety research conducted in institutionalized environments to the home care environment.

- The term "system" is most often used to mean an intra-organizational system rather than an inter-organizational system. The predominant focus is on organizational / institutional system, rather than on the wider healthcare system involving many service delivery organizations from different sectors (i.e. acute care, home care, long-term care).
- Managers and administrators can shape the institutional environment socially (i.e. providing leadership for a change in the patient safety culture), organizationally (i.e. changing accountability and reporting structures for patient safety), and physically (i.e. providing the infrastructure required for assembling performance indicators on patient safety, managing technology).
- Those providing patient care are paid employees and/or work under the auspices of a "supervising institution," such as students (Chang et al., 2005).
- Patients consent to treatment provided while under the care of an institution and its employees.
- Evidence-based medicine and evidence-based healthcare trumps other considerations such as patient preferences (Hanratty et al., 2002).
- There are resources available to build the infrastructure required to support patient safety.
- There is continuity in the organizations providing patient care (Meredith et al., 2002).
- The physical institutional environment for the delivery of care can be modified to provide protection for employees, mitigating their risk as healthcare workers (Affonso et al., 2003).

Many of these assumptions are not applicable to the home care setting. For example, home care often is comprised of providers from various organizations and sectors who must create an interface for coordination and communication that has different dimensions of complexity than that within an institutionalized setting. The term patient safety itself reflects the intra-

organizational focus on patients in hospitals. However, the care and safety of clients in home care settings cannot be attended to without including the family, caregivers, and providers in the equation (Harrison & Verhoef, 2002; Lehoux, 2004).

Unlike paid employees working under the auspices of a "supervised institution," most of the care provided in the home is by family and/or caregivers under the indirect "supervision" of a nurse or other health professional. Thus, the infrastructure required for assembling performance indicators for family and/or caregivers and unregulated workers is not evident within home care. In the home, clients, family members, and caregivers ultimately have control and can choose to place their preferences ahead of the evidence. Furthermore, the fact that there are multiple stakeholders (client, family members, friends, caregivers) who may or may not agree on the way to proceed provides a more challenging scenario than within a hospital setting where the professionals predominantly direct the care.

Homes are designed for living, not for providing healthcare. While the physical environment for the delivery of care in institutionalized settings can be modified to provide protection for employees, mitigating their risk as healthcare workers, this is much more difficult to address in the home care environment. This pertains not only to the technology and supplies that need to meet certain quality and safety standards, it also applies to existing policies and procedures, as well as being able to run down the hall for collegial or supervisory assistance when necessary. In contrast, home care is often a solo expedition with equipment and supplies that are not generally designed specifically for home care use. Little or no immediate backup or support for providers (paid or unpaid), geographical variation (topography, rural), and isolation for clients, family, caregivers, and providers are just some of the elements impacting safety for home care recipients and providers.

Key concepts for patient safety:

The 2004 Australian *Report on the establishment of the patient safety research network* identifies four emerging key concepts from the literature on patient safety and medical errors, including: the environment of health, organizational factors and implementing change, human psychosocial factors involved in change, and patient as co-producer of health (Sorensen et al., 2004). These key concepts have some relevance for research in home care. Table 2 summarizes examples of relevant research on safety in home care and examples of how these concepts might be used to frame future research questions for safety in home care.

Table 2. Key concepts

Key Concepts from Report (Sorensen, 2004)	Illustrative Conclusions from Studies Relevant to Safety in Home Care	Examples of Potential Research Questions for Home Care
The environment of health – the context, environment, and culture of the healthcare system all influence open disclosure of near misses and adverse events.	Families using high-tech home care might be asked to provide technical and moral assistance, while coping with profoundly modified family dynamics. In certain cases, providing assistance implies inflicting pain and discomfort. (Lehoux, 2004, p. 3). There is potential for dialogue between service providers and decision-makers to inform clinical practice (Modin & Furhoff, 2004).	What is the nature of practitioner-unpaid caregiver-patient dialogue about critical incidents and their resolution? How is the complexity of health services delivery in the unregulated home environment managed? How is decision-making and responsibility for safety shared among home care clients, family members, unpaid caregivers,

	"Consumers must be included in healthcare decisions as recipients of services and major players in the transition processes related to their care" (Harrison & Verhoef, 2002, p. 1031). There is a need to develop strategies for nurses and patients to: negotiate shared control of care, service routines, and resources; establish appropriate role identities; develop trust (Spiers, 2002). A starting point for further research and development would be the investigation and description of the comprehensive care of patients with home nursing (Modin & Furhoff, 2004).	and among unregulated and regulated healthcare workers? What are the inter-organizational communication channels used to mitigate safety risks for home care? How do fragile and deteriorating home care support systems impact the delivery of safe care by regulated and unregulated home care staff? What factors influence the disclosure of adverse events and near misses by clients and unpaid care providers when regulated workers are not present in the home?
Organizational factors and implementing change – new models of governance for organizations will change our construction of "organisational intelligence" for patient safety and harm prevention (p. 22).	The shift of care from the hospital to the home "has had an enormous impact on care recipients, their families and friends, and in-home service providers" (Coyte & McKeever, 2001, p. 20) and is changing the meanings, material conditions, spatio-temporal orderings and social relations of both domestic life and health-care work" (Modin & Furhoff, 2004, p. 2; Cartier, 2003). Home care programs have been shifting the provision of care from health promotion and prevention for individuals with chronic health needs, to substitution functions to meet the more pressing need for postacute care (Markle-Reid et al., 2006a, p. 2). Future intervention studies need to incorporate a theoretical model, and focus more on the process of delivering care to identify the relative contribution of each component of the intervention, and the synergistic effect of the sum of the parts (Elkan et al., 2001).	What are the features of effective reporting systems between home care and other organizations regarding safety? How do alternative models of governance and financing for home care services influence safety? How can inter-organizational "intelligence" on safety in home care be shared? What are the effects and expense of alternative models of home care that focus on prevention and health promotion vs. post-acute care?

Human psychosocial factors involved in change demand inclusion of approaches focused on more holistic human factors, and movement beyond customary technological concerns and error management. Communication is core, but often marginalized in research efforts. The interaction of people's attitudes, values and discourse practices are crucial to understanding how the culture of safety is expressed in the practice of healthcare.	Little research documents the effectiveness of an in-home health promotion intervention on quality of life, mental health (depression), perceptions of social support, or examines specific sub-groups of home care recipients who benefit most (Markle-Reid et al., 2006a, p. 3). The need to move beyond a discussion of the benefits of technology to patient's health, to a consideration of both positive and negative impacts of technology on the patients' daily life (Lehoux, 2004, p. 8).	What strategies would support the synchronous uptake of safety strategies among paid and unpaid, employed and volunteer home care providers? How do human factors and technology interact in the home care environment among regulated and unregulated workers? What typology might be used to identify home care environments at higher risk for lapses in safety? What are the incentives (regulatory or otherwise) that might be put in place to support the implementation of safety strategies and reporting on safety issues by unpaid care providers? What are the indicators of safety in the home care environment?
Patient as co-producer of health – opportunities for increased self-management and control by patients have been provided by action research in the areas of medicine, socio-technical systems, and information accessibility.	Consumers are vulnerable to both clinical and organizational processes and need to be asked about those organizational processes that relate to managing the boundaries between sectors (Harrison & Verhoef, 2002, p. 1048). The nature of home care nursing creates paradoxical positions of mutual empowerment and threat for both nurses and patients (Spiers, 2002, p. 1034).	From the perspective of patients and unpaid caregivers, how can safety in the home environment be improved? What types of brief encounters might be offered by home care agencies to better support patients and unpaid caregivers to self-manage their illnesses?

Indicators for patient safety:

Safety indicators in acute care settings have been developed. Indicators for home care to support reporting on safety and ongoing quality improvement initiatives are needed.

The Canadian Council on Health Services Accreditation (CCHSA) initiated a *Patient Safety Strategy* in 2004 (CCHSA, 2004; 2003). This organization summarized an environmental scan of performance indicators for patient safety from accreditation bodies in the U.S.A., the U.K., Australia, and Canada (CCHSA, 2005). The CCHSA also highlighted the work done by the Organization for Economic Co-operation and Development to engage an international expert panel in the selection of indicators for patient safety. Five areas of patient safety have been targeted by the CCHSA: culture, communication, medication use, work life / workforce, and infection control (CCHSA, 2006).

Authors of a CCHSA report concluded that (CCHSA, 2005):
- many of the patient safety indicators used by accreditation bodies were originally developed and tested in the U.S.A. by research bodies (e.g. Agency for Healthcare Research and Quality - AHRQ);
- patient safety indicators have a strong clinical focus, a share a common *ancestry* with hospital-based clinical indicators; they are often derived from administrative data;
- "there are fewer patient safety indicators developed for use in community settings where there is not the same capacity for data coding and collection" (p. 18).

The establishment of several Canadian Institutes for Patient Safety (e.g. *Canadian Patient Safety Institute*, *Manitoba Institute for Patient Safety*, and *Institute for Safe Medication Practices Canada*) points to the importance of this complex issue. The objectives of these institutes are inclusive of patient safety issues in the home care environment. In some provinces, such as Quebec and Ontario, support services have been established to raise awareness (i.e. Patient Safety Support Service in Ontario) and/or to address issues of cultural change for healthcare workers (Le Group Vigilance in Quebec).

While the identification of common indicators is critical, Chang et al. (2005) also highlight the need for a common taxonomy to classify near misses and adverse events. They identify this as a pressing need that must be addressed if common data is going to be collected and aggregated to provide a more comprehensive picture of patient safety issues. Their classification scheme, derived from a number of existing models, consists of five complementary nodes:
- Impact – the outcome or effects of medical error and systems failure
- Type – the implied or visible processes that were faulty or failed
- Domain – the characteristics of the setting in which an incident occurred and the type of individuals involved
- Cause – the factors and agents that led to an incident
- Prevention and mitigation – the measures taken or proposed to reduce incidence and effects of adverse occurrences

Summary of studies related to home care:
A brief summary table of some of the literature reviewed is included (Appendix B). It provides type of study, methods, sample, key findings, and interpretations for each of these articles. Research studies reviewed, that are relevant to safety in home care, included qualitative and quantitative studies of home care technology, interpersonal patient-provider interactions, communication among professionals, and transitions from hospital to home care environments.

Conceptual frameworks of relevance to patient safety in home care:
Determinants of patient safety issues that have commonalities across institutional settings are reflected in various conceptual frameworks. Perusal of the literature revealed that existing frameworks were developed for, and used within, acute care environments designed for patient care, and thus have only limited applicability for home care settings.

Most recently, Downie et al. (2006) described a conceptual framework, *Patient Safety Law Matrix*, from the legal and regulatory aspects of the justice system (Appendix C, Figure 1). This matrix brings together different areas of law that have impacts on patient safety. It "is a tool for analyzing the state of patient safety law in a jurisdiction" (Downie et al., 2006, p. 10).

Another such framework is Affonso & Doran's (2002) model entitled *Culture of Discovery in Patient Safety* (Appendix C, Figure 2). It is conceptualized through four action blocks for ensuring safe systems in healthcare: build technology tools, apply human factors designs,

reform organizational culture, and deliver processes to optimize safe care. Although designed for a program of research this model has yet to be tested.

Another notable framework is Baker & Norton's (2001) *Conceptual Model of Effective System Change Strategy* (Appendix C, Figure 3). It outlines the relationship between three processes namely *culture*, *measurement*, as well as *system tools and change strategies*. The model propounds that only when all three components are in place is there an effective strategy for systems change. Root cause analysis (RCA) may be viewed as one important aspect for the *system tools and change strategies* process.

Hoffman et al. (2006) state that their *Canadian Root Cause Analysis Framework* can be used in any setting throughout the continuum of healthcare (Appendix C, Figure 4). Although it has the potential to be applied in a home care setting, its focus, as is the focus of the other frameworks, is on a particular adverse event. Given the uncontrolled and unregulated nature of a home care environment, as well as the diversity of knowledge and abilities of individuals involved in the provision of care (i.e. family, friends, caregivers, unregulated workers, various professionals), it would be inadequate to apply an acute care patient safety framework on to safety in home care.

One "school" of conceptual frameworks that has begun to inform some safety research across the continuum of care is represented by research that subscribes to various socio-ecological views of healthcare systems and communities. All of these approaches share a specific attention to key relationships, processes, and structures across multiple layers of the healthcare system and community that influence the safety and quality of care and care environment. This is reflected in Edwards et al.'s (2004) *Multiple Interventions Framework* (Appendix C, Figure 5). Ecologically informed frameworks are also discussed in relation to other safety issues in public health. These approaches to safety research share some commonalities with researchers who analyze safety and risk in modern healthcare as the problems inherent to complex adaptive systems (Amalberti, Auroy, Berwick, & Barach, 2005).

Five conceptual frameworks have been identified. Four were specific to patient safety while the fifth was a broader framework for multi-level and multi-strategy interventions. Embedded within each of the frameworks are systems thinking, and recognition of socio-ecological determinants of patient safety issues. However, none of the frameworks were specifically developed for home care.

Key Informant Interviews

With the exception of one individual who did not respond, all of the key informants who were contacted agreed to be interviewed or to coordinate for a replacement participant from their organization. These 20 key informants reflect diverse disciplines (i.e. nursing, medicine, pharmacy, medical engineering), hold a variety of positions (i.e. executive directors, presidents, vice presidents), and work in many different types of organizations (i.e. academic institutions, direct healthcare service providers, regional health authorities, professional associations). They are from seven Canadian provinces and one US state. Their rich and insightful descriptions of issues, concerns, gaps, and priorities related to safety in home care were more concordant than discordant. In general they shared a socio-ecological perspective and acknowledged that the conventional institutional client safety perspective does not fit in the context of home care, but rather that a "different set of glasses" are needed to inform the emerging safety agenda in home care. Although all the key informants agreed to be identified as contributors, any verbatim quotes used in this report are not identifiable. All quotes in this report are identified by letters of the alphabet which have been randomly assigned to key informants.

The interview guide for the key informants was designed to ask about issues in home care safety from several angles and perspectives. The aim was to elicit a comprehensive range

of issues. Several central, common themes emerged from the interviews and are presented below:

1) Family is the unit of care:

This idea is based on the premise that the family is the context in which individuals learn about health and about how to mobilize resources, strengths, and potential in order to reach their goals (Feeley & Gottlieb, 2000). This also includes the idea that paid providers are "guests in people's homes" and that the illness or particular health condition is superimposed on the "life" of the client and their family (i.e. family dynamics, finances, employment, health conditions of other members, etc.). As such, the safety of the family, and/or all those living in the home, influence and are influenced by the health situation and the home care services provided. It is important to acknowledge the magnitude of the responsibility for providing care, which is imposed on clients, families, and caregivers. It is estimated that, by choice, 80% or more of all the care for community dwelling, functionally impaired older people are provided entirely from informal care providers (Clark, 1996). While many caregivers find caregiving rewarding, it is often at the expense of their own health and well-being (Cox, 1993). But more importantly, it is imperative to attend to the angst and distress that may accompany their involvement (i.e. performing painful treatments, intimate care) regardless of how willing they are to take on the tasks of care.

The informants recognized the importance of considering the family as the unit of care. The following remarks help to illustrate this:

- "…not just the patients and families are on the healthcare team, it's actually the other way around. We're actually on their team. We've got the power dynamic wrong because we have become very focused on the expertise that we bring as providers to that care interaction and we soon forget that the experience is just a small piece of a life…" [F]

- "…And you can have a situation where the patients… everything is fine with the patient… But the son that lives there has a mental health illness that is not being… correctly managed, which can impact the whole situation. And how do we handle that? And how do we go about that? You know…say, he or she decided that they weren't taking the medication and they have a history of violence... And… those kinds of things… So other family members can actually impact the care that is delivered to the patient as well…" [S]

- "…The homecare nurse is there for a very short period of time. She is a visitor in the home of the patient and the family. And the need to not only understand the patient and the family experience, but to actually help families provide and be active care participants. I think if we see more care moving from acute care to the community, that that role of the family is going to be increasingly important. … What you can't do, is when you have people in acute care, is treat family like furniture. And then all the sudden, when they… you know, you leave our doors, it's over to you, family! You know, you're on!" [F]

- "The philosophy of care is changing, but it is not fully where it needs to be to work well with families so they are seen as part of a team. We need to maximize the teams so that the care is provided well and that there is excellent communication across the team. When I say team I believe it includes the client and the family. Patient safety is impacted by how effective the team is." [O]

- "… what the family dynamic actually looks like … we've had situations where maybe the family dynamic is very volatile, very dysfunctional and it's very difficult to separate those things out if you're actually in that home providing care. …the brother, the sister, the aunt and uncle who is involved in the care may have mental health issues of their own or may have family violence issues, all those types of things become part and parcel … of the care that you're delivering than if somebody is in a hospital bed...." [G]

2) Safety of client, family, caregiver, and provider is inextricably linked:

The safety issues for client, family, caregiver, and provider are interconnected, interrelated, and influenced by one another. More specifically, the health condition of the identified client will affect the health and relationships within their family; similarly, the health of individual family members, as well as the level of family functioning, will affect the health of all. Also, caregivers are particularly vulnerable because they are often responsible for the bulk of the client care, at the expense of their own health and well-being (i.e. burnout, fatigue, depression). Furthermore, challenges to the caregiver's health and safety will ultimately impact on the client and the family. The safety challenges that the providers face (i.e. uniqueness of physical home environments, excessive workloads, breadth and immediacy of knowledge required) will also impact the quality and appropriateness of the care they provide, and ultimately, the risks for themselves and for recipients of their care. Some examples to demonstrate this are:

- "I find it difficult to define patient safety as if it is something different than provider safety…if the care provider (paid or unpaid) is not feeling safe, then the client, likely, is not safe… We attribute a level of either knowledge of skills or competence to them that they may or may not have or they may or may not be comfortable with… …the difference I would see is in acute care, we tend to look at patient safety as error management. … The notion is the provider is not feeling safe and the client, likely, is not safe also. So if I look at mobility issues for a client in the home, tend to be mobility issues for provider and unsafe environment, you know, environmental features… So for example, neighbourhood lighting, you know, those kinds of things…for a client, tend to be unsafe also for a provider. So I find it difficult to keep tease out the two." [R]

- "We know that there is increased incidence of depression in caregivers which will impact on the identified patient." [A]

- "I always had to understand that while the unit of care is broader than the patient, the need of the two may also be very, very different. And you have to address both, and you also have to… Myself as a nurse… I have to sort out where is the center of my care? Is the center of my care the individual? Or is the center of my care the broader unit of care? When the needs of those two things are different and the demands of those two things are different... … And it's easy when two things are in synch. It's problematic and more high risk, I think, for safety on both sides when those things are not in synch and we can't make those things come into synch because they're coming with an external history that we had not controlled or influenced. And so you're faced with constant ethical dilemma because of that. … you make the patient the default of your care at the jeopardy of your family." [C]

- "So we're asking people... …expect people to be available to provide care, which is not necessarily always possible. Is there income support for the family members that may have to take time off? Or there has not been until recently. I know for end of life care, there is now a program where family members can take some time off. … So I think there's that gap in knowledge as well, so that family members don't know what supports are available to them both in terms of income, but also in terms of care for themselves… Because if they are put into a situation where they are providing care to a family member, they may be neglecting their own personal safety and health." [B]

- " …when you are faced with that, say at a managerial level… …I certainly can remember situations where, you know, there were guns in the home and there had been a history of ... And you know, the client refused to have those locked up … So, you know, then you have to make a decision: well, can we provide care? And then that's a really hard question. You know, when you get in… Because sometimes, and certainly I know as a manager …I had to

make a stand for the staff which was very, very difficult because patients or clients or family just didn't… or decided not to understand the issues of the care provider. It's very complex!" [S]

- "Perception of safety by the nurse in terms of their work … What [was] found is that nurses reported shortening their home visits when they have felt unsafe and that has tended to compromise client care. So that is the link between nurse safety and client safety. Very different from hospital setting. At home nurses work in isolation. If there is an identified situation then we have to send two nurses in, but that is after the fact." [P]

- " So much of the care in the community is done by unpaid caregivers whether it be family or friends or others, as opposed to in institutions… The care for the majority of people is done by the professionals who are paid to do that. So there is an element of risk, an element for service providers in burn out and staff. But there is also the risk for the client and the family which I think when I look at the population… We look after, quite often, the reason people end up back in hospital is due to the caregiver burnout… breakdown of the caregiver as opposed to the health and wellbeing of the patient. So there are some safety elements there as well. And how do you best support the caregiver to continue in their caregiving role?" [M]

3) The unregulated and uncontrolled setting of individual homes:
The focus of safety in home care is about mitigating the risks in diverse, uncontrolled, and unregulated environments. Risks exist in all healthcare settings; the significant difference between examining and understanding risks in acute and home care is appreciating the lack of uniformity that exists in home care versus acute care environments. Homes are not designed for healthcare, they are designed for living. Therefore, healthcare is superimposed on the circumstances of peoples' lives. There are no national standards in place regarding the physical environment in which home care services are provided. This reality is a stark contrast to institutions of care. Some examples to demonstrate this are:

- "…we realize that some of the technologies of home care can both facilitate home care and cause harm. We look at the processes in which home care is delivered from a human factors perspective, as well as the user interfaces around medical devices as related to patient safety…patient safety in home care is a human factors issue…there are ways of mitigating risks in the home by using human factors to inform proper work flow design and proper technology deployment in the home... We're assuming that the actions of the caregiver or the patient are correct based on normal human behaviours. For example, there is no point in blaming a patient because they accidentally turned off their ventilator when the user interface was so poorly designed it forced them into that error. You have to assume the end user has either physiological impairments in terms of vision and/or dexterity, they have behaviour problems in terms of natural fears or anxieties (being pin pricked). The human factors assumes that those are all correct and all assumed. [D]

- "… technologies require changing a number of things in the house… the house itself can become dangerous for the patient… thinking about an old lady who has difficulty walking using a walker and she has to carry with her oxygen tubes and then walk in the house… the house itself becomes something that can be a safety trap… it's not just for this patient, it's for the whole family..." [T]

- "Some of the factors that are often underestimated is the architectural obstacles. Not all the houses are similar and because of those variations, some of them are not adaptable …to a sufficient extent to the use of technologies… …we don't understand much about the role of technology into the development and maintenance…in home care, because we tend to assume that technology is what makes it possible and we don't necessarily look at how technologies also create constraints." [T]

- ”… in the hospital there is a lot of policy around the environment in terms of proximity of electrical outlets, lighting, use of gases at each bedside. All of that is regulated …none of those exist in the patient home and I am not aware of any standards around environment for home care. The acute care setting is highly structured in terms of the qualifications of the caregivers and that does not exist in the home. Many technologies used in home care, compared to the acute care setting, are relatively less sophisticated and don't have the level of rigor of technologies... Those to me present unique safety issues in the home because of the lack of structure and policy around the environment and technologies used in home care." [D]

- "…the physical environment is certainly one of the main issues that can either work for you or against you, both from the client's perspective and from the nurse's perspective as well. It's very difficult,.. …I think we're always in a situation where you're improvising to a large extent. …You sort of have to work with, as you know, whatever presents. And sometimes it may be in a less than ideal physical environment. …how clean the actual environment is, …if you're trying to give care, you're obviously not going to have at your disposal, …beds that can be lift up, trays that you can move about, and …to dispose of sharps and contaminated material and… there is the impact that the physical environment has on your client in between actual visits. …Are there risks for falls? Medication storage… …access to service, telephone access... So all of those sorts of things come together … in terms of the physical environment and the factors that may present for the nurse that may impede her care in different ways…" [G]

4) The multiple dimensions of safety – physical, emotional, social, and functional:

Physical safety of the identified client remains the primary focus when addressing safety in the acute care setting. A broadening of the conceptualization of client safety is necessary in home care because there are a myriad of players and factors involved. The range of physical environments (i.e. location within the community, physical layout of homes), diversity of the people involved, and the relationships within and between them, supports the need to expand the definition of safety in home care to include emotional, social, and functional factors.

Emotional safety refers the psychological impact of receiving home care services. It is often distressing, or anxiety-provoking for a client and family to adjust to and cope with various elements of their health condition and the corresponding home care services (i.e. learning to manage medications, changes in client health status, treatments, medical technology). Eligibility criteria for home care services are based primarily on physical needs; maintenance and promotion of mental health has not been explicitly identified as a role for home care. For example, depression and substance abuse are prevalent and can have tremendous impact on the provision of services and the health of clients and their family (Markle-Reid et al., 2006b).

Social safety addresses the idea of where the client lives in the community, who lives with the client, who visits the home, and the nature of the client's social support network. The prevalence of and opportunity for various forms of abuse is also an important consideration with regards to social safety of all the players providing and receiving home care. *Functional safety* is about how the health condition or the provision of care affects the activities of daily living.

Some descriptions of this theme are:

- "Patient safety would include both the physical and the functional and the psychological aspect of safety… It's not so much keeping her physically from harm, safety for her is maintaining her functionality and independence." [C]

- "…what I find pretty difficult to deal with is that these are chronic patients… They are not too old and they get used to their disease and they get skilled in doing a number of things … But over time, they don't get better. They get older. And they get weaker. So what I find particularly difficult is to say: how can we take this time dimension into account? Because over time, people will lose a number of skills. The safety threats might increase just because

they don't… they're not in control of everything. They lose sight or they lose other skills. And not everyone around notices those subtle changes…" [T]

- "Mental health has always been left out of the basket of home care services; it's always been another sector's responsibility. There are client overlaps, but the two systems don't work that well together. I don't think it is something that the home sector has a great competence in. What needs to happen is that we don't work in silos. Clients need to be seen as a person." [O]

- "And, you know, you have a lot of that same stress if somebody is in the hospital depending what the nature of the illness is, especially if it's an end of life situation or if it's an acute, potentially fatal, condition. But in the home setting, some people get very anxious with having their home environment or their home routine disrupted… where they may cope somewhat better if the person is cared for in a hospital environment, and they have to go to visit their family member in the hospital, rather than having all these changes happen to their personal environment." [B]

- "The more that we support her home, and the worse her disease gets, but the more successful the care of maintaining her at home, the more damage it does to her extended family which… is my family and my sister's family because we have given up part of our own life and our family's life in order to care for her." [comment on a home care client with Alzheimer who lives alone] [C]

- "We know that there is increased incidence of depression in caregivers which will impact on the identified patient. … We tend to focus on physical health and medical model. Need to consider determinants of health" [A]

5) Autonomy and choice for clients, families, and caregivers:

A particularly unique aspect of being in the home care setting, given that care happens on clients' "home turf," is that the client, family, and caregiver autonomy and choice are at the forefront. This means that the provider can offer health education and recommend strategies and suggestions for care, but ultimately the clients will decide what they do. Thus, ethical care offered by providers must be closely aligned with the values, needs, and decision-making of the clients and those around them. Examples of this theme are:

- "…the need in home care to emphasize more the balance of physical safety versus all the other aspects of functioning and safety. … This need to balance choices such as keeping somebody at home functioning is physically unsafe … where psychologically, it produces the greatest safety … by protecting their dignity, their sense of self, their values and their lifestyle choices." [C]

- "…what is the client prepared to live with? …with what risk? What also from a practical, professional view, what is the risk that we can manage for our service providers and what we will not accept from a client?" [M]

- "I think the priority is to look at the ethics around balancing a safety agenda with quality of life and personal autonomy... I think there are huge ethical issues around trying to address safety in the absence of other considerations." [L]

- "…when the family, as a unit, doesn't agree... What we have sometimes is… … an example – "Do not resuscitate," was one of the issues…. And at the ninth hour, you get the daughter coming in from the U.S. that totally disagrees with the whole thing and, you know, wants things changed." [S]

- "Let me give you an example: we've had some issues with professionals who have required a lift to move patients from a wheelchair to a bed, or from a wheelchair to a tub… and the family has balked at this and so has the client. They said quite clearly: "well, my wife can transfer me. Why won't the nurse?" Well, you won't sue your wife when she drops you, but you will sue the nurse. So there is an element of that when you are moving into family choice and client choice, that puts people more at risk… not only for the client but also for our nurses and our therapists, our homemakers..." [M]

- "There is an ethical issue missing about the discussion around home care and safety. When you get to be 80, you lose the right to make our own decisions. Adults have the right to make their decisions even if they are the wrong decisions. Part of my fear of all the safety stuff, even though I am a big supporter of it, is a paternalistic thing emerging where we are going to save people at all costs, not that we are going to provide people with information so that they can make the decision." [H]

6) Isolation – clients living alone and caregivers and providers working alone:

Another unique aspect of home care is the reality of isolation. Many home care clients are elderly and live alone. Even those with families and/or caregivers cannot access professional support at all times when the need arises, leaving them feeling vulnerable and uncomfortable in problem-solving on their own. Further to this, providers are relatively isolated in their work. They travel alone to places that can be challenging to access, they work predominantly without the proximal supervisory or collegial support of coworkers, and they often do not have timely and easy access to a range of medical supplies, equipment, and technological resources. Below are some illustrations of these ideas:

- "It's a lonely kind of work; you don't have the opportunity to talk to your colleagues, get support when providing care…" [O]

- "…what protection and what some of the issues are for nurses who go into those environments sometimes in very rural, isolated areas where you could be, you know, the next neighbour could be ten miles down the road type of thing…" [G]

- "You know, I think the isolation and some of the loneliness issues … and situations with clients who don't have a lot of family or informal support but still insist on remaining at home or want to do that because that's who they are…" [L]

- "There is a real element of safety there, for the client, as well as for the caregiver as they are having to perhaps to provide care in a home at 3 am and being on their own. And so the risk factor for service providers there…" [M]

7) Communication on many levels:

Communication is also an important theme in terms of safety in home care. There is a challenge for the provider to engage in therapeutic conversations with clients, families, and caregivers about their health, and in particular about safety issues. There is also a challenge for the provider to engage with caregivers and other family members for whom the provision of home care has an impact. Furthermore, coordination and communication between different providers, often across organizations and sectors is a complex issue – in particular, at the interfaces along the continuum of care. A specific example pertains to documentation, and the lack of a central repository for sharing client and family information. Another example is around creating and managing care plans with all those participating in the care – including the client, family, and caregivers. The following excerpts comment on these notions:

- "…the communication piece is not there because they go in hospital, they get… new medication but the pharmacist doesn't put a new label on the medication bottle. And then the

nurse comes and she's going to give the same dose that's on her record because there is no doctor's order. And then of course the patient says: No, no, no, that was changed. And then you have to go through the whole thing of trying to call the pharmacy and call the hospital..." [S]

- " … the dynamics in the relationships in healthcare are such that we silence the voices of patients and families. I mean, if you are trying to speak up, then you are problem patient. Or you are a problem family. …We got to get away from notion that the patient and family is the problem. They're not the problem! … the patients and families and us, the providers, are on the same side! We both want the same thing. We both want the patient to get well. We both want a good outcome. But we tend to point fingers, you know, on both sides of the… You know, patients and families pointing at staff, and staff pointing at patients and families. What we need to do is get a dialog going that says: we're actually both on the same side in this issue." [F]

- "The number of unregulated workers, and workers going in… to some of the homes can be a real effect on safety because its so hard to trace… something unsafe happening, but you can't quite trace back to the root cause… It's harder than ever … because the communication between the care providers isn't always as strong. Especially if you don't have RNs talking to RNs…, who might understand each other's signal and language… but you are talking between RNs and some unregulated provider, whether it's a homemaker or a care aid, that to me, is … difficult…" [E]

- "So we know that one of the ways of making systems safer is to get rid of those hierarchies, power hierarchies where there is between team members and I would submit between patients and families and providers." [F]

- "There is certainly much greater potential for miscommunication or lack of communication all together. I mean, the greater the number of caregivers, and the more diverse their background, the more potential for confusion and miscommunications. …one of the most important keys to a good outcome of care, when we have more than one caregiver, is good communication. …And my sense is, …for example, in the so-called collaborative primary care practices where they talk about the need for communication. …if you've got caregivers co-located… I'm not sure that you could even start to deliver good homecare if you don't have a completely wired and connected set of care givers. And that means a full electronic health record and full connectivity of the health providers that are linked. And of course we don't have that probably anywhere today." [K]

8) Maintaining and developing knowledge, skill, and competence:

Unlike working on a specialized unit in a hospital, home care providers must maintain a *breadth* of general and specific knowledge. This poses a significant safety challenge because of the diversity and varied frequency of health conditions and treatments. It is not unusual to come across particular conditions or treatments only once every few months, making it difficult to maintain competence. This is heightened by: the trend for earlier discharge from hospitals and the corresponding increase in the acuity of clients receiving home care services; the lack of resources for continuing education and proficiencies; and the isolated nature of the practice of home care. The aforementioned challenges and safety issues regarding evolving knowledge, skill, and competence are not exclusive to providers, but also pertain to the clients themselves, as well as their families and caregivers. The following comments exemplify this:

- "It's the competency of the nurses. And I struggled with that a lot as a manager. Because we might only get one or two, even if you were only doing a blood transfusion, you might get one, you might get two of those and then not for six months. … So how do we ensure that our nurses are safe to provide the care?… Do we have repeat sessions? Do we have repeat testing? And I worried about that a lot because… we weren't as competent as we should be

because we don't see them as often. Which brings up another problem for you as a manager, because you got to test and retest and do all that kind of stuff to try and keep a competency level up." [S]

- "… the family is often expected to provide a lot of the care in home care situations and they may or may not be well suited or trained for the provision of that care. I know, when I worked in pharmacies, I often had a lot of questions from either formal or informal caregivers…They have a lot of questions, and don't necessarily always have a lot of support or places that they can turn to. … So there is a lot of potential for mistakes to happen with medications when they are being administered by people who may not have a full understanding around the medication." [B]

- "Well, in a community setting... the family… are providing… most of the care that is required. And that involves not only the administration of medications or… the dressings and things but it also includes monitoring progress… it is particularly challenging…. The patients will develop symptoms then they don't necessarily know the cause of the symptoms. They may think it's normal for people to feel that… they may be very important symptoms of various problems. And I guess because they don't necessarily understand the nature of the problem, they don't always seek care… until later … [Q]

- The caregivers are often the ones left caring for the clients in the home environment. They don't have the proper equipment, they don't … necessarily have the proper training to provide this care. They may not have the cognitive ability to take in whatever training they get. Unfortunately, we have a home care system where the funder, being the government, expects families to pick up this care giving piece. Families are not always prepared to pick up that piece so... Families are at risk, they are at risk for burnout. (i.e. a palliative client needing 24/7 with only 1 or 2 care providers). The actual amount of home care you can get through the system is fairly minimal when you look 24/7 for 7 weeks. We have an institutional factor that is constantly downloading that level of care to the community." [O]

9) Diminishing focus on prevention, health promotion, and chronic care:

A significant proportion of the population receiving home care services are frail elderly persons with a number of complex co-morbid conditions. In the past, the goal was to help these frail elderly avoid institutionalized care, through maintenance and preventive functions, as well as health promotion strategies to keep them safely in their homes and communities for as long as possible. That notion has been eroded with the downloading of acute care clients into the home care sector, because resources are redirected to the post-acute population. This has resulted in a more reactive than proactive approach to home care services. The following remarks help to illustrate this:

- "…the opportunity for more education and looking towards secondary prevention sometimes get too involved with treatment of care as opposed to looking at the primary and secondary prevention pieces. And how willing is the client to look at those types of things if he or she thinks you are just coming in to dress the ulcer on their foot? Are they prepared to engage and be ready to listen to you about nutrition, exercise…" [M]

- "Chronic disease prevention and maintenance… huge issues in terms of chronic disease prevention being done adequately... It isn't done systematically. We could be a much better support for disease management. To do it well is has to be done systematically and there is a huge opportunity there to do it better and get better outcomes." [O]

- "Shift away from prevention. There are less services to patients with chronic and more complex needs. The system is more reactive than proactive. No plans for ongoing care." [A]

- "Long term care supportive – has been eroded with the acute care substitution that has gone on in home care. There are a lot of countries doing this a lot better than we are and who know a lot more about what's required to support good long term care at home. I think we need to be looking at that research. Unfortunately that population (frail elderly) does not have a lot of political clout so it is fairly easy for governments to take away services and reduce support without it being visible to the population. I think we really don't know what has been the affect on the frail elderly population with the acute care substitution that has been occurring." [O]

10) Human resource challenges – magnified in home care:

As is the case throughout the healthcare system, insufficient human resources is a persistent problem in home care. It is not exclusive to the pool of professionals, but also includes unregulated workers (i.e. personal support workers, homemakers). In general, wages for home care providers are lower than those in the acute care sector. For example, in some provinces, personal support workers and homemakers could make similar or more income working at a fast-food franchise, where working conditions might not be as stressful. There are a number of other factors that contribute to depleting human resources: the numerous and diverse environments and working conditions; the isolation; the job insecurity due to employers loosing and modifying their home care service contracts; and the lack of resources and time devoted to continuing education and staff development. Here are some examples:

- "…this is very tough work that we expect these aids to do… it's amazing we have as many people as we do that are willing to do it. …it's … very rewarding, or can be, but it can also be pretty tough work! …we're in crisis in terms of recruitment of healthcare aids. So we're just living in trepidation everyday that we don't have some major client incident because of … not being able to find a support person to go in or … the person doesn't come or… And I think it's our number one safety risk for that reason that… those are often the services that keep people at home and if we can't provide them, then it's scary! And there's a short term solution… part of it here is wages but it's much bigger than that. …it's not work that young people are aspiring to. The training costs have gone up and so you're not going to spend money on education to get a job that pays you 11$ an hour. Society, we … give lip service to valuing that kind of work …for the paid aid people or for informal care givers…" [L]

- "It's the age old problem in community in that our service provider organizations are strapped for human resources … I'll just use nursing for an example …a nurse working in the community probably makes $10,000-15,000 less than what she or he would make if they worked in an institution. So in order to attract people, there has to be some sort of looking at how you would manage that gap in salary…" [M]

- " … nurses are expected to respond to whatever referral comes forward and … to set priorities based on what's presenting on any given day… you may have a series of clients lined up to be seen today but then if you have referrals come in and you don't have the capacity in your workday to incorporate all of them, then somebody waits until tomorrow. And it's obviously not as easy as … calling for relief or having somebody float over from another unit." [G]

- "… [Are] we going to see a generational change when demographics sort of moves on? … we are going to have a whole host of situations where paid care providers are not prepared to provide the care in the unsafe situation they see themselves in." [R]

- "There is not a very good continuity of care in homecare, unfortunately. … When doing some home visits one time, I went into this gentleman's house and he said: I want you to sign this for me. I said: Sign this? He said: I'm counting the number of nurses. It was a wound dressing we were going to see. I'm counting the number of nurses who have been in here and I'm up to a 147 now. So, every day, there would be a different person." [S]

In summary, thematic analysis of the 20 key informant interviews revealed the ten common themes just discussed. Despite the range of informants' disciplines, positions, and organizations, there was convergence and overlap in the priorities and gaps identified regarding safety in home care. Furthermore, as a whole, the comments have created a foundational portrait of safety in home care. A review of the list of themes is as follows:

- Family is the unit of care
- Safety of client, family, caregiver and provider are inextricably linked
- The unregulated and uncontrolled setting of individual homes
- The multiple dimensions of safety – physical, emotional, social, and functional
- Autonomy and choice for clients, families, and caregivers
- Isolation – clients living alone and caregivers and providers working alone
- Communication on many levels
- Maintaining and developing knowledge, skills, and competence
- Diminishing focus on prevention, health promotion, and chronic care
- Human resource challenges – magnified in home care

Invitational Roundtable Discussion

The roundtable was held on May 2nd, 2006 with over 40 individuals reflecting various professional and organizational affiliations in the delivery of home care services. The top three safety issues raised by the roundtable participants were: 1) the conventional institutional focus on the physical safety of the identified patient rather than considering the client, family, caregiver, and provider as an interlinked unit within a broader conceptualization of safety (e.g., emotional, social, functional) in home care; 2) problematic communication and co-ordination among service sectors, providers, caregivers, family, and clients; and, 3) challenges of a fit between technology and the environment in an uncontrolled and unregulated setting such as individual homes which are "designed for living not for providing healthcare".

Participants emphasized the importance of understanding and supporting the roles of the entire unit (client, family, and care providers). For example, a participant stated:

> "We don't see the individual going back into the home as part of the unit, that has multiple, cultural factors, multiple uncontrollable factors… We are fitting into their life, as opposed to, asking them to fit into our system".

Several of the small groups emphasized the need for improved communication and co-ordination, especially during the transition period from hospital to home care. One participant commented:

> "…we have a very poor and inadequate process right now for transitions from an institution to home care. We move from a situation that is very much professional care driven, medical care driven, to an environment that's very loose with multiple factors and multiple variables…we don't even have continuity in institutions for the most part but we even have less continuity in home care."

References to the impact of the environment were woven throughout the discussions. Participants raised concern regarding the use of technology and increasingly complex treatments in homes not designed for healthcare. Accessibility to homes, their physical setup, and varying degrees of cleanliness were just some of the environmental issues raised. For example, a participant stated:

> "Where the person lives often hampers the ability to be able to provide safe care… the willingness of workers to go into questionable situations…with respect to the gun in the home, you know, pets walking across the dressing tray…"

Other top safety issues that were identified were medication reconciliation, wound care, falls prevention, and workplace issues (e.g. regulated versus unregulated providers, casual versus

part time, lack of standards). Although there may be limited research on safety in home care, participants agreed that there is evidence for at least some of the main safety issues identified for home care.

> "we've learned that there are many areas that are pertinent to home care that we do have evidence for… a strong issue came out today about the importance of family caregivers, the family as a unit of care, there is tons of literature on systems and intervening with the families…certainly, there is also enough evidence around prevention of falls, wound care, and medication reconciliation that could be implemented across the country right now."

The top three actions to improve safety in homecare identified by roundtable participants were: 1) research; 2) education, knowledge, and tools; and 3) policy. Overall, there was consensus that research on safety in home care is urgently needed including a national survey and in-depth qualitative studies to elicit clients' and families' perceptions of what safety in homecare means to them. For example, a participant stated:

> "We can establish the administrative data…but then there are slices of other areas, when it comes to the client and the family caregiver unit…we don't understand."

Other participants believed that research was needed to identify the strengths and deficiencies in the home care system so that "we'll be much more focused on what it is that we are trying to fix". Moreover, there was discussion amongst participants about the urgency of knowledge transfer and exchange as well as implementation of interventions with existing strong evidence.

> "there are lots of things we don't know. There are some things we do know and have good evidence for (falls prevention, wound care, medication reconciliation) and we still have a tough time acting on the things we do know…we need to close the loop."

The need for education, training, and mentoring was discussed by most groups. Some participants felt that healthcare professionals needed more education and training on how to be good team players. Some participants talked about the difficulties that "people on the ground" have in accessing evidence and suggested that infrastructures be put in place to help support the access to evidence and the transfer of knowledge into practice. Raising awareness of the issues of home care safety among policy makers and other key stakeholders was seen as an essential strategy because the home care sector is often the "invisible member of the healthcare sector." The creation of a critical mass of researchers, decision-, and policy-makers was seen as a vital step in helping to move the home care safety agenda forward, such that: "numbers get-buy-in, where sentiment gets a nod, but not necessarily action." Lastly, some participants talked about the need for standardized tools which would permit comprehensive assessments of the home "to clarify and identify the needs and the risks" of clients and their families.

DISCUSSION

There is an urgent need for research on safety in home care. The existing literature on safety focuses predominantly on the physical safety of patients in acute care settings, which was conveyed by the current definitions as well as key assumptions, concepts, and current indicators for patient safety. However, the literature does suggest that there has been a shift towards recognizing the complexity of the system and how it affects patient safety, while moving away from the culture of blame.

Overwhelmingly, research on patient safety is focused on institutions such as hospitals that provide healthcare. These are regulated systems designed for providing healthcare with a multitude of credentialed professionals and support staff guided by supervisors and administrators. The environment for home care is much less controlled with much of the care being provided by unregulated workers, family, and caregivers in settings that were designed for living and not for providing healthcare (Coyte, Baranek, & Daly, 2000). Thus, the care and safety of clients in home care settings cannot be attended to without including the family

members, the unpaid caregivers, and the paid providers in the equation (Harrison & Verhoef 2002; Lehoux, 2004).

Though several issues have been identified and researched, the overall state of safety in home care in Canada is relatively unknown. The unique nature of individual homes, relationships among clients, families, and caregivers, both within and outside the home, and the multitude of care providers involved make the provision of safety in home care complex and challenging. Moreover, the vulnerability of home care staff who work predominantly without the proximal supervisory support of colleagues and the uniqueness of each home setting cannot be overlooked. The literature points to the importance of multifaceted socio-ecological approaches to safety in home care. Conceptual frameworks that appear promising given the nature of safety in home care are those which are ecologically-oriented and recognize that improvements in safety must be offered in the context of complex adaptive systems (Amalberti et al. 2005; Markle-Reid et al., 2006a).

The main limitation of the review of the literature was its dominant focus on the patient safety literature. Given that most patient safety research is hospital based and focused on physical factors/issues, and that research pertaining to safety in home care is just beginning, the results of this literature search were limited. However, there is a broader field of research that has been undertaken in the home environment. This includes, but is not exclusive to, studies of health promotion and chronic illness management interventions by home care providers. While such studies have not directly addressed safety, they generate insights into the issues of providing care in the home environment that would be of relevance for research on safety in home care. They also help to identify the indicators of safety in home care that include emotional and social factors vs. physical factors alone.

Thematic analysis of key informant interviews yielded rich and insightful perspectives which had significant overlap regarding their understanding of the complexity of issues facing safety in home care. Identification of the ten common themes that emerged from the interviews, attests the notion of safety's complexity in the home care setting. For example, there is a general consensus that safety in home care must been viewed through a different lens than the traditional way patient safety in hospital settings has been conceived. Homes are designed for living and not for providing healthcare. Clients, families, and caregivers come from a multitude of cultures and backgrounds and are not usually trained to provide the care which is increasingly more demanding. Due to the uncontrolled and unregulated nature of the home environment (we are guests in their home), the complexity of health (physical, emotional, functional) concerns for the identified client, family, and caregivers, which are superimposed on their life, the multitude of players (who may or may not agree on a course of action), and the ultimate right for the identified patient and/or significant others to chose preferences over evidence, safety in home care must be about mitigating risk for all. A safety risk for the client, family, caregiver, or provider will impact on the others. The information gleaned from the key informant interviews also highlights the need to elicit the perspectives of clients, family members, unpaid caregivers, and providers about the multitude of challenges and issues associated with safety in home care.

The discussions at the roundtable reinforced the limitations of the literature review. Furthermore, the findings and central themes from the key informant interviews also resonated with the roundtable participants.

- Safety in home care is about mitigating risks for clients, family, caregivers, and providers which are inextricably linked to each other. Several key informants describe a shift towards an increase in the level of acuity of clients being discharged earlier from hospitals. In particular, they refer to the frail elderly with complex medical, emotional, physical, functional, and social concerns. Clients are sent home often with inadequate support or preparation, knowledge, and/or capabilities for themselves or their family and caregiver to mitigate the risks of receiving home care. In hospitals there is consideration

of the value of appropriate Nurse-to-patient ratio for providing quality care within a relatively controlled and safe environment. In contrast, as the patient moves into their home, they and their family and caregiver are expected to take on similar duties without the support or infrastructure that was present in the hospital.

- Applying the notion of patient safety from the hospital sector (i.e. error detection and adverse events) is too narrow and may be inappropriate for home care. Safety in home care requires a broader definition to encompass the complexity of health conditions and family dynamics, as well as the unregulated and uncontrollable nature of providing healthcare services in peoples' homes. The focus of safety in home care needs to be on prevention and mitigation of risks for the client, the family, the caregiver, and providers in order to promote the physical, emotional, functional, and social health of those receiving and providing home care services.

- The patient, family, and caregiver need to be considered as the unit of care. The illness or health condition, albeit complex, is only a portion of their lives and is superimposed on other life issues that clients and their families are dealing with (marital and family relationships, finances, employment, life transitions, etc.) As such, it requires a different and more complex set of skills to engage and collaborate with more than one person at a time. Assessing and integrating individual perceptions, their relationships with each other, and family functioning are challenging but indispensable considerations for contributing towards safety in home care.

- There is recognition that although we can engage clients and families in conversations and collaborate with them to mitigate risks, at the end of the day they have the autonomy to *make the decision to eat the extra piece of cake or keep their grandmother's throw-rug*. An ethical balance is required as the backdrop for home care services. We are asking family members and caregivers to inflict pain, participate in intimate acts often without attending to their respective needs, preferences, or capacities.

- Healthcare technology, for the most part, is not designed for home care. Yet, this technology is being used in the home.

- There is no national standard for assessment of individual homes and families to provide safe home care and there is a lack of use of standardized evidence-based tools for assessment of the safety of the home environment. Society in general tends to understand the value of child-proofing the home yet that notion has not been incorporated into home care. Application of human factors principles in home care is imperative with recognition of inevitable risks when family and caregivers are providing most of the care 24/7.

- Challenges exist for maintaining continuity of care, transitions, and coordination across sectors and the healthcare continuum. There is a lack of seamless communication infrastructures, such as an electronic health records. Power differentials among paid providers (i.e. doctors and nurses), as well as between providers and clients, family, and caregivers contribute to the communication quandary.

The combination of the literature review, the key informant information, and the knowledge developed at the roundtable provides a comprehensive set of gaps and priorities for future research and other initiatives directed at improving and ensuring safety in home care. These include:

- what the major safety concerns are (i.e. physical, emotional, functional, and social) in home care for clients, family, caregivers, and providers;
- how to work proactively to prevent and mitigate safety risks;
- what the mental health issues are for clients, families, caregivers, and providers and how they impact the safety of all involved;

- how to develop and evaluate a communication infrastructure, in particular the electronic communication, and to facilitate continuity across the continuum of care;
- what the influence is of an increased proportion of home care funding and services directed at post-acute care clients, in lieu of prevention and health promotion for the larger proportion of clients with chronic co-morbid health conditions;
- what the impact is of caregiver burden on the physical, emotional, functional, social safety of clients, families, caregivers, and providers;
- what the costs are, in terms of health and money, to patients, families, caregivers, providers, and society to not attend to prevention and mitigating safety risks for these different populations (especially, the "*cost of doing nothing*");
- what are effective strategies to increase safety given the uniqueness and diversity of each home care situation;
- what are valuable knowledge transfer strategies for evidence-based home care practice (i.e. medication reconciliation and wound care)…

It is clear that attention to safety in the home care sector is essential. The partners in this initiative (CPSI, VON Canada, and Capital Health-Edmonton) have created the platform to further explore this agenda. It is important to note that by undertaking this, Canada will be providing international leadership for safety in home care. As is the case in Canada, most countries focus on patient safety in the acute care sector. Although there are some similarities between institutional patient safety and the home care sector, framing the research within a socio-ecological perspective (Edwards, Mill, & Kothari, 2004; Markle-Reid et al., 2006a) will help us to better understand the complexity of safety in home care. The role of the family, caregivers, and providers in implementing this agenda is of utmost importance.

Addressing safety in home care presents unique challenges and requires a major rethink of underlying assumptions and guiding frameworks that have been used to examine patient safety in the institutional environment. Research on safety in home care needs to: a) address the client, family, and other unpaid caregivers as the unit of care; b) reflect the influences of an unregulated and uncontrollable home environment on the use of technology and the provision of care; and c) tackle the challenges of transitions, communication, and continuity of care amongst an array of paid and unpaid providers. Leading edge research in this field will require a critical mass of interdisciplinary researchers, practitioners, and decision-makers as well as an application of a wide array of research methods.

CONCLUSION

Research on safety in home care in Canada is at an early stage of development. Despite significant changes in the location of care (from hospital to home), as well as epidemiological and demographic trends (increase in chronic disease, an older population), the patient safety literature continues to focus on institutionalized settings (e.g. hospital, long-term care, ambulatory care clinics). Largely absent from the safety literature is a discussion of the non-institutionalized environment. This is the environment in which home care services are delivered. Research is urgently needed to advance our understanding of the issues and challenges associated with safety in home care and to identify strategies designed to mitigate the risks associated with providing home care in Canada.

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APPENDIX A – INTERVIEW GUIDE

Thank you so much for taking the time to do this interview. As you know CPSI and VON Canada are spearheading this initiative for safety in home care. A roundtable discussion of 50-60 stakeholders will take place in Edmonton on May 2, the aim of which is to set a research agenda for patient safety in home care.

We are conducting these interviews with 12-18 key informants, identified by Carolyn Hoffman at CPSI, Judith Shamian at VON Canada, and our team at University of Ottawa. The purpose of these interviews is to assist us in the preparation of a background paper to be used as a springboard for the roundtable discussion in May.

Please feel free to expand on any of the questions that I will be asking you today. Before we begin I would like to ask you if you wish to have your name listed as having contributed suggestions. Would it be OK with you to turn on the digital recorder?

Questions

Theme 1 ….Definitions
How would you define patient safety in home care?

Theme 2 ….Family/caregiver
In home care the family is the unit of care and the home is the setting for the care provided. What additional safety issues do these realities present that differ from safety issues in hospital settings?

Theme 3 ….Factors affecting patient safety in home care
3. What are the other priority factors that may adversely affect patient safety in home care? Probes: Human resource constraints, staff burnout, nursing work-life in the community, unregulated care providers, family caregivers etc.

Theme 4 ….Gaps in knowledge
4. 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). Which one of these areas are you most familiar with? Would you please describe the major gaps in knowledge regarding patient safety in home care for the area that you are most familiar with?

Theme 5 ….Priorities
5. In your opinion, what are the priorities for research regarding patient safety in home care? Please be as specific as possible.

Theme 6 ….Building capacity
6. To do research requires research capacity. What are the gaps in our current capacity to do patient safety research in home care in Canada? What are priorities for building capacity to conduct leading-edge research on safety in home care in Canada?

Theme 7 ….Exemplars
7. Are there exemplars, in Canada or elsewhere, where patient safety systems or research project tailored to home care have been developed or where research on patient safety in home care is underway?

Authors	Title	Qualitative	Quantitative	Sample	Key findings	Interpretation
Affonso et al. (2003)	Patient safety to frame and reconcile nursing issues	X Focus groups		503 nurses participated in a national survey during 33 focus groups in 22 Academic Health Sciences Centres across Canada.	Mentions health systems and hospitals, but does not mention home care. Describes a reconceptualization used to align issues identified by nurses with a Patient Safety Framework to illustrate how nurse executive leaders can reconcile patient care issues. 4 proposed pillars of discovery. Suggests 5 approaches on how nursing can build safer care practices. (80)	Academy of Canadian Executive Nurses (ACEN) can provide leadership in the Academic Health Sciences Centres across Canada on this issue by modeling the suggested approached. Multidisciplinary research cluster at the Uof T working on pilot projects that explore processes of care and factors influencing safer practices. (79)
Christakis & Allison (2006)	Mortality after the hospitalization of a spouse		X Cox-regression analysis and fixed-effects		Illness and/or death of a spouse may have health consequences for partners. (726) Partners may show an increase in harmful behaviour. (727)	Findings can inform the delivery of health services. Interventions should be timed to riskiest time frames for partners. Implications for policymakers. (729)
Forster et al. (2004a)	Ottawa Hospital patient safety study: Incidence and timing of adverse events in patients admitted to a Canadian teaching hospital		X Random Sample Used standard methods	502 randomly selected patients admitted to 2 acute-care facilities in Ottawa for acute care non-psychiatric illness over 1 yr	Adverse events are relatively common. The unit of analysis was the hospitalization. Calculated event rates per 100 hospitalizations. 12.7% hospitalizations in a Canadian teaching hospital associated with adverse events. 38% of all adverse events preventable. 61% occurred before the patient was admitted (majority	A higher rate of pre-hospital adverse events needs to be confirmed. A larger, multi-centre Canadian study is underway and may help shed light on this intriguing finding. Regardless, it is clear that quality improvement efforts must address ambulatory as well

Authors	Title	Qualitative	Quantitative	Sample	Key findings	Interpretation
					were associated with adverse drug events.)	as hospital care.
Forster et al. (2004b)	Adverse events among medical patients after discharge from hospital		X prospective	328 patients consecutively discharged home or to seniors residence, with and average of 71 yrs	1 in 5 discharged patients from a Canadian teaching hospital experienced adverse events (AE) related to their medical care. Most common AEs were adverse drug events. ¼ of patients had AEs after discharge and 50% of those were preventable or ameliorable.	Findings of this study similar to previous one despite differences in study population (average age this study 71yr vs. previous 57yr). Need to identify if other patient populations (surgical services, community care hospitals) are at similar risk. Need to evaluate methods of improving safety after discharge.
Hanratty et al. (2002)	Doctors' perceptions of palliative care for heart failure: Focus group study	X Focus groups		General practitioners and consultants in cardiology, geriatrics, palliative care and general medicine	All groups thought that poor support in the community contributed to repeated hospital admissions. District nurses and social services were a higher priority than sophisticated forms of palliative care. Priorities identified for the future were developing the role of the nurse, better community support for primary health care, and enhanced communication between all the health professionals involved in the care of patients with heart failure.	Many of the organizational and professional issues are not particular to patients dying with heart failure, and addressing such concerns as the lack of coordination and continuity in medical would benefit all patients. Research suggests that specialist nurses may reduce the number of hospital admissions and improve disease management for patients with heart failure discharged back to the community. (584)
Klein-	Collaborating to	X		147 survey responses	92% reported that the video was	The audiovisual format can

Authors	Title	Qualitative	Quantitative	Sample	Key findings	Interpretation
Fedyshin et al. (2005)	enhance patient education and recovery			from discharged CABG patients transitioning to the home setting	helpful to their recovery, at least to some degree. 84% felt the video answered questions they otherwise would have called their healthcare provider to ask. The project was possible because of successful collaboration between library staff and clinicians.	increase understanding, overcome educational barriers such as low literacy, and can be delivered in a cost-effective manner. Patients received a greater amount of information to enhance self-care during the recovery period without consuming more nursing time.
Harrison & Verhoef (2002)	Understanding coordination of care from the consumer's perspective in a regional health system	X Exploratory using Grounded Theory		33 consumers transitioning from acute to home care and registered for short-term home care services. Mean age 65 yrs.	Consumers can and should be involved in healthcare decisions. Their involvement includes various components. (1043)Providers need to work as coaches to prepare consumers for their role as coordinators of their care. (1047) Consumer as a temporary organized member of team. (1947) Managers need to foster a culture that values consumer voices. (1046)	Need to study the interface between the healthcare system and other determinants of health (1049). Future studies could include assessing the organizational role of the consumer, and potential circumstances of too much consumer involvement. (1059).
Lehoux (2004)	Patients' perspectives on high-tech home care: A qualitative inquiry into the user-friendliness of four technologies	X Interviews with patients, careers, and direct observation from nurses		16 patients 6 carers 16 nurses All associated with primary care organizations and hospitals delivering home care within a 100 mile radius of Montreal.	Home care technology transforms the patient's life both inside and outside the home. Policies aimed at increasing the provision of home care must carefully integrate principles and resources that support the appropriate use of technology and the close monitoring of patients must	Policies aimed at developing home care must clearly integrate principles and resources supporting the appropriate use of technology. Close monitoring of patients should be part of all technology-enhanced home

Authors	Title	Qualitative	Quantitative	Sample	Key findings	Interpretation
					be part of all technology-enhanced home care programs.	care programs.
Markle-Reid et al. (2006a)	Health promotion for frail older home care clients		X Two-armed, single-blind, randomized control trial	242 older people (more than 75yrs) eligible for personal support services through a home-care program	With modest reorganization of the delivery of existing home services, statistically significant enhancements in equality of life can result. (10) (12) Statistically significantly lower per person cost of prescription medications in the nursing group compared with usual care. (10)	Implementation of efficient care reforms for older people requires a comprehensive rethinking of entire delivery systems. (12) Need to reinvest in nursing services for health promotion for older clients receiving home care. Further studies need to incorporate a theoretical model and focus on process of delivering care to identify the relative contribution of each component of the intervention and the synergistic sum of the parts (11)
Markle-Reid et al. (2006b)	The effectiveness and efficiency of home-based nursing health promotion for older people: A review of the literature	X Literature review, synthesis of definitions, conceptual frameworks			Identifies 4 categories of assumptions. Suggests 5 key findings and an alternative theoretical approach (65)	There are both intellectual and political tensions in conceptualizations of frailty in relation to older adults. (65) (64) …if frailty is defined predominantly in terms of physical losses, assessment and management strategies will focus solely on this aspect. (65)

Authors	Title	Qualitative	Quantitative	Sample	Key findings	Interpretation
						A common definition of frailty would enhance the comparability and generalizability of research involving older adults.
Meredith et al. (2002)	Improving medication use in newly admitted home healthcare patients: A randomized controlled trial		X Parallel group, randomized and controlled trial	259 Medicare patients aged 65 and older (mean age 80) admitted to two of the largest health home care agencies in the USA over a 2 yr. period	Intervention greatest for therapeutic duplication, with improvement for 71% of intervention and 24% of control patients, an attributable improvement of 47 patients per 100.

A program congruent with existing personal and practices of home health agencies improved medication use in a vulnerable population and was particularly effective in reducing therapeutic duplication. | Intervention could be implemented with minimal use of outside resources.

Present challenge to find ways to incorporate procedures to detect and modify suboptimal medication use into the routine care provided to home health patients. |
| Modin & Furhoff (2004) | The medical care of patients with primary care home nursing is complex and influenced by non-medical factors: A comprehensive retrospective study from a suburban area in Sweden | | X Retrospective | 158 patients receiving primary care home nursing for a period for more than 2 weeks. Mean age 83 yrs | The majority of patients with primary-care nursing also received both inpatient and outpatient specialized medical care. (5)

More than 50% were admitted to hospital during the study year with more than 15 specialties (medical) represented. (4)

Use of systems resources across the board higher for patients needing specialized care. (5)

Functional and social factors influenced the chance of a patient having made outpatient visits to specialized medical care. | Shift from the hospital to home make the care of patients with home nursing an important area for investigation from the perspectives both of patients and of healthcare workers. (2)

There is a lack of knowledge about the factors that influence the care of these patients apart from medical necessities, necessary for planning purposes.

Is the care organized so |

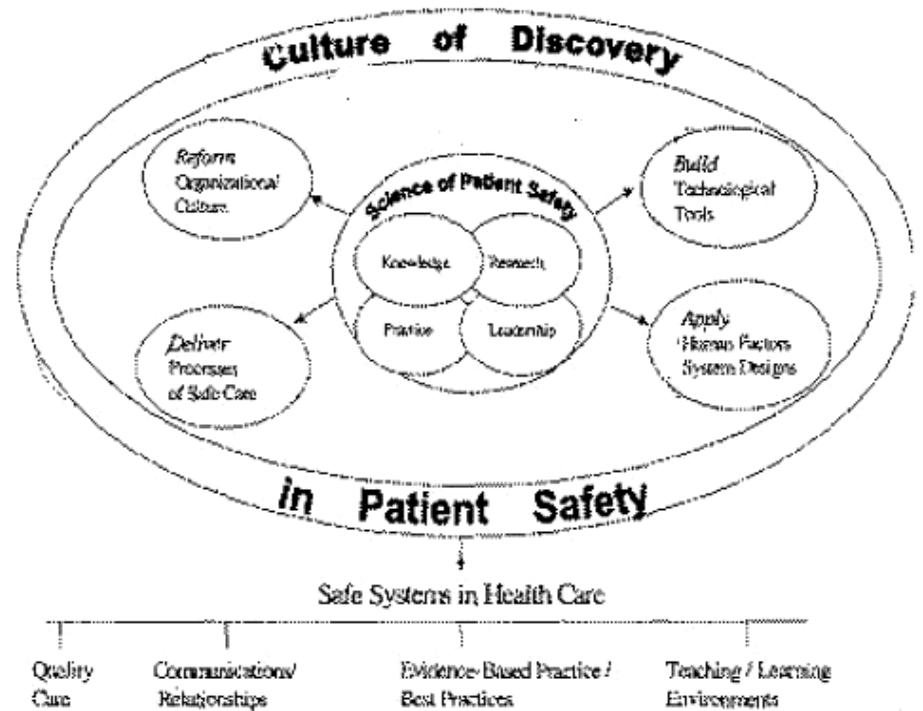| Authors	Title	Qualitative	Quantitative	Sample	Key findings	Interpretation
						that old patients with multiple diseased and reduced functions need the help of a relative to get outpatient specialized medical care?
Spiers (2002)	The interpersonal contexts of negotiating care in home care nurse-patient interactions	X Qualitative ethnology for video-based research. Semi-structured interviews and 31 videotaped interactions		3 home care nurses and 8 home care nursing patients aged 25 to 86. Patients recruited from a large metropolitan home healthcare agency in the US, captured in 31 video-taped visits. Nurses, patients, careers, and family participated	6 interpersonal contexts identified: - Negotiating territoriality - Negotiating shared perceptions of the situation. - Establishing an amicable working relationship - Synchronizing role expectations - Negotiating knowledge - Sensitivity to taboo topics.	We have valued nurse/patient interactions in which the nurse is able to safeguard the personal integrity and dignity of the person and assumed that relationships characterized by lack of threats will be successful. (1054) Further exploration is needed of the effectiveness of moving from teaching communication ideals to helping nurses raise their awareness of their ability to strategize and negotiate using everyday language for therapeutic purposes.
Varcoe et al. 2004	Ethical practice in nursing: Working the in-betweens	X Interpretive/ constructivist		87 nurses from a variety of clinical settings including home care and community care in 4 communities in a Western Canadian province; 19 focus groups	Working within a shifting moral context. Contradiction between doing what seemed to be "good" and contextual forces constraining them form making ethical choices. (319)	Nurses need ethical theory that is close to their moral experiences and contextual realities. (323) Ethical theory has potential to give nurses skills to understand organizational and societal forces, and provide guidance.

APPENDIX C – CONCEPTUAL FRAMEWORKS

Figure 1. *Patient Safety Law Matrix* Applied

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Figure 2. *Culture of Discovery in Patient Safety*

Affonson, D.D. & Doran, D. (2002). Cultivating Discoveries in Patient Safety Research: A Framework. *International Nursing Perspective*, 2 (1), 33-47.

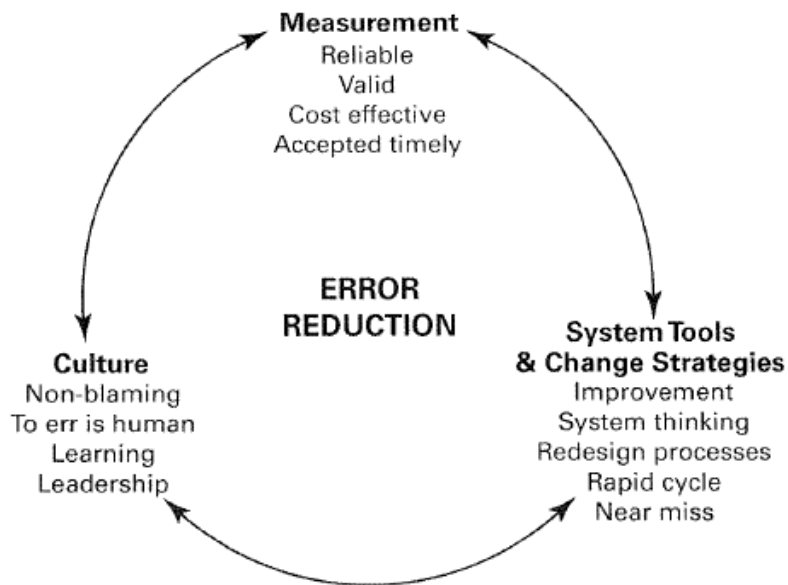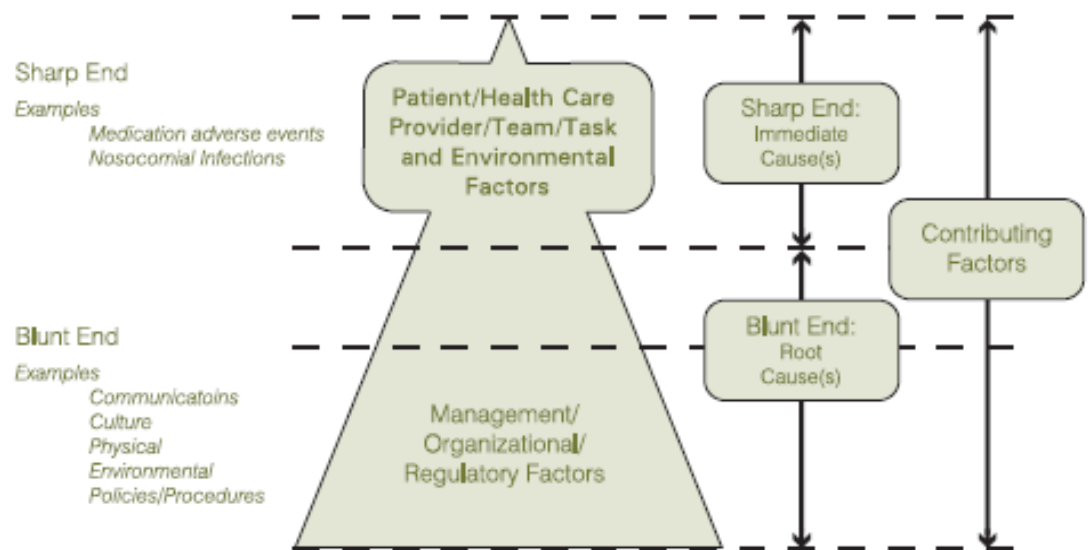Figure 3. *Conceptual Model of Effective System Change Strategy*

Figure originally published in Baker, R. & Norton, P. (2001). Making patients safer! Reducing error in Canadian healthcare. *HealthcarePapers*, *2*(1):21. Reprinted by permission of Longwoods Publishing.
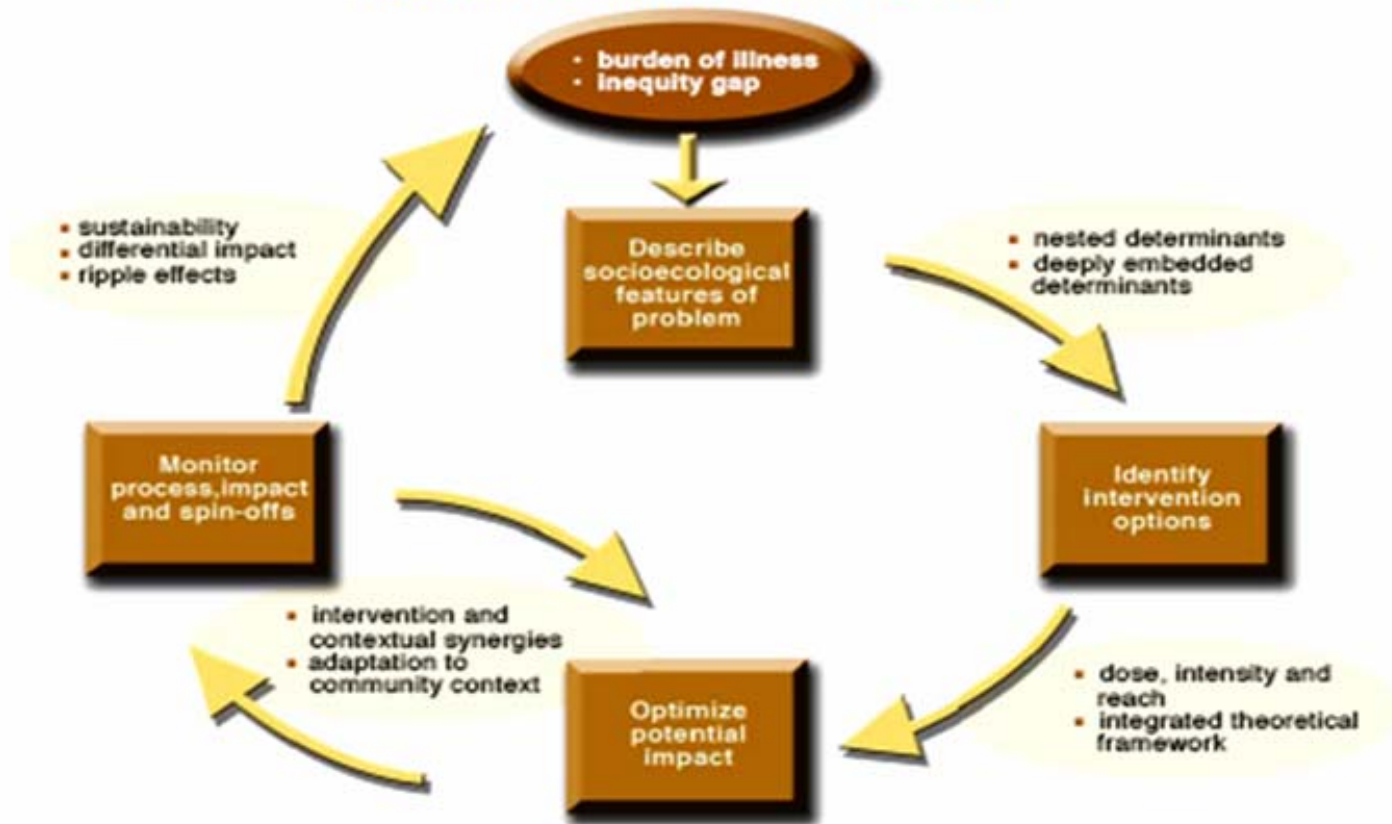
Figure 4. *Canadian Root Cause Analysis Framework*

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Figure 5. *Multiple Interventions Framework*

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