Safety in Home Care: Thinking Outside the Hospital Box

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Rethinking Healthcare Safety for Home Care

Canada's aging population and rising healthcare costs have resulted in an increased number of chronically ill people and heightened demand for acute care. As a result, a growing group of clients is being cared for at home by family and friends, and there has been a 51% increase in home care clients since 1997 (Canadian Home Care Association 2008). Many, if not most, of these home care clients are elderly individuals with chronic health problems or people who require end-of-life care (Canadian Institute for Health Information 2006).

The complexity of the cases now handled at home increases the already-heavy pressure on family, caregivers and paid providers, a situation that can create and amplify serious safety issues (Macdonald et al. 2010; Stevenson et al. 2008). These safety threats are not limited to clients. Findings from various qualitative research studies focusing on the experiences and perspectives of those providing care in the home have confirmed that families, caregivers and paid providers can all face significant risks in a home care environment (Lang et al. 2006, 2008, 2009b; Macdonald et al. 2011).

However, because home care is so fundamentally different from the regulated and controlled environment of acute care (Lang et al. 2006), improving safety in home care requires a fundamentally different philosophy and approach. The challenge is to rethink our ideas of healthcare safety in the context of home care, and then follow through by developing and applying safety practices for the home. These practices must be client- and family-centred, include safety for providers and, above all, be flexible enough to adapt to an immense range of circumstances. Future qualitative and quantitative research will provide further insight into the impact of the home environment on care for specific populations and will guide the development of strategies to mitigate risks associated with care in the home.

Different Setting, Different Risks

Research funded by the Canadian Patient Safety Institute, Canadian Institutes of Health Research and others has led to significant headway in understanding factors in home care that contribute to its unique risks and safety challenges. Examples of these projects are listed in the sidebar.

According to the World Health Organization (WHO 2009), contributing factors are circumstances, actions or influences that may trigger a safety incident or increase the risk of an incident. Identifying those factors is an essential part of assessing threats and reducing risks. While our team is unaware of research outlining the quantification of the scale of harm to both unpaid and paid caregivers, we have learned the importance of considering the context of the home and the way many factors intertwine to influence safety there.

Unpaid family members, friends and neighbours provide more than 80% of care in home settings, contributing annual hidden savings of $5 billion to the Canadian healthcare system

(Canadian Caregiver Coalition 2008). Family members usually become caregivers without remuneration and with little acknowledgement of their service; but taking care of family exacts a high toll: "caregivers risk their support systems, their life savings, their employment, and their health" (Macdonald et al. 2010: 22). Caregivers, however, often feel pressured to assume care because there are few options available (Lang et al. 2009b Macdonald et al. 2010; Stadjuhar 2003).

In institutions, 24-hour care is primarily provided by experienced and regulated care providers; at home, family caregivers are often unprepared for the extent of the care they have to give when paid care providers are not there (Lang et al. 2009b; Macdonald et al. 2011). Family caregivers find themselves responsible for complex, around-the-clock care, such as helping with mobility, toileting and pain control and possibly dealing with confusion and wandering. Caregivers' sleep is further disrupted by technology, such as alarms and monitors, leading to fatigue.

Fatigue is a potential safety risk to home care clients because it may affect decisions (about medication or care) or lead to actions that can create a dangerous situation (Lang et al. 2009a). Further, fatigue and the psychological and physical impacts of stress on caregivers can lead to depression or substance abuse (Lang et al. 2008), endangering both caregiver and client, with their potential to lead to physical and psychological abuse (Macdonald et al. 2011). All these factors add up to a significant risk that caregivers will become patients themselves, ultimately increasing, rather than easing, the demand for healthcare (Macdonald et al. 2010).

Clients tend to like home care because they are in familiar surroundings and feel more in control of their life (Lang et al. 2009a). But homes are designed for living, not healthcare; and since they are not controlled and

Projects Furthering the Understanding of Home Care Safety Factors

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regulated like institutional settings, they are often not particularly suitable locations for healthcare. Homes may be dirty, which affects the ability of care providers to deliver safe and quality care and increases the risk of infection for clients. Hazards, such as trailing electrical cords, scatter rugs and clutter, increase the risk of falls for the client and the risk of musculoskeletal injuries for caregivers and providers. While care providers can make recommendations to reduce these risks and improve safety in the home, clients and family members decide to follow or not follow these recommendations (Lang et al. 2009a).

All of these factors show how the safety of care providers, caregivers and clients is intertwined, and why threats to the

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safety of family, unpaid caregivers and paid providers must not be severed from client safety. By the same token, implementing strategies to improve safety for providers also benefits clients and families (Lang et al. 2009a; Stevenson et al. 2008), whereas not dealing with safety issues leaves everyone involved vulnerable to harm (Lang et al. 2009a; Stevenson et al. 2008; WHO 2009).

Safety in home care is viewed differently by different people. (Different language is also used in home care, with patients and family talking about *concerns* and *challenges*, rather than *safety*.) Paid providers tend to consider only the client, whereas clients also worry about their caregivers (Lang et al. 2009a). Providers focus on physical safety (such as falls), medication errors and safe syringe disposal – all reflecting institutional priorities and philosophical assumptions (Lang et al. 2009a). But there are also ethical concerns for paid providers, faced with the challenge of providing care in the presence of known risks – infestation, weapons in the home and unsanitary conditions. These risks affect providers' safety and can therefore affect patients' access to services – if they do not provide care, who will? (Stevenson et al. 2008).

Looking after someone in an environment designed for living, not healthcare, is already a challenge; but paid and unpaid carers repeatedly report problems with discharge information that lead to inadequate preparation for home care and no appropriate risk assessment before clients are sent home (Stevenson et al. 2008). Hospital discharge planners frequently underestimate the level of patient care that will be needed at home, resulting in a lack of equipment and other supports. This can put caregivers, providers and clients at risk (Macdonald et al. 2011). However, despite these concerns, paid providers, caregivers and clients are willing to accept a high level of risk when giving or receiving care at home.

Defining the Risks of Care at Home
Our research with experts in home care delivery on threats

to safe care shows that these threats can be grouped into four themes – the fragmentation of services, vulnerability of patients and providers, erosion of home as a haven and incongruence of what is expected and what is available in home care (Macdonald et al. 2011). *Fragmentation* includes the disconnect between how care is provided in acute care and home care and the impact of having multiple providers and multiple agencies providing care in one home.

Vulnerability covers the potential threats to the emotional, physical, social and functional health of recipients and providers. People can be vulnerable because of isolation, exposure to infection, medication mismanagement and the potential for abuse.

Home means something unique to each client, caregiver and family (Lang et al. 2009a), but most people consider it their haven. That sense of safety is eroded when the home is "medicalized," that is, changed to accommodate care. Bringing in technology designed for acute care makes the home start to resemble a hospital room. The sense of the haven is further eroded because the support and resources are not immediately at hand, as in a hospital; instead, they are delivered by an army of strangers who seem to come in an endless stream through a revolving door.

Incongruence in home care arises from (1) unregulated healthcare workers' responsibilities versus their knowledge and skills, (2) healthcare professionals not having access to current knowledge and in-time information and (3) the expectations of families about what resources and support are available for home care versus the reality of what is provided.

But the goal of home care isn't to create a hospital at home, with a transformed environment and standardized care (Lang et al. 2009b). In home care, the provider is a guest who has to collaborate with clients, caregivers and families (Hartrick Doane and Varcoe 2005) to determine what might improve safety. Providers should negotiate with clients and families to define care needs and safety goals in order to achieve the best outcomes possible, including keeping the client out of hospital and preventing caregivers from becoming patients themselves (Lang et al. 2009a).

Our Research in Progress
WHO's patient safety research motto is "better knowledge for safer care" (WHO 2011). This also sums up our current work on safety in home care and our ultimate goal of helping to develop guidelines that will enhance home care safety and bring about better individual, family, community and organizational outcomes.

Several nationally funded studies are under way. The first is looking into the different perspectives on home care safety of clients, families, caregivers and providers within a palliative care context in Quebec. A second, four-province study (Alberta, Ontario, Quebec and Nova Scotia) focuses on medication management safety in the households of chronically ill seniors.

The third study, intended to lead to the development of tools and strategies to reduce adverse events, is composed of five subprojects looking at the nature and scope of adverse events in home care, along with client and provider views on safety. One of the subprojects (in British Columbia, Manitoba and New Brunswick) is on safety at home for seniors living with chronic obstructive pulmonary disease and congestive heart failure. In conjunction, researchers are conducting a scoping review looking for safety markers in home care for these two populations. As well, part of the team is researching the "human factors" in home care. Human factors is a discipline that identifies and addresses mismatches between people, tools and environments – in home care, these are the kind of situations that arise when people try to deliver care with tools and in places not well suited to the task. The knowledge gained from these interrelated pan-Canadian studies will help develop health policies, education strategies and client-, family-, caregiver- and provider-centred clinical practice guidelines.

Moving Forward
Approach
Given the fundamental differences between institutional and home care, it stands to reason that how we conduct research, make decisions and provide care to promote safety are also different. The intricate and unique context of home care requires us to look through a different pair of glasses when developing knowledge, recommendations and best practices – different, to ensure that the results are measured and evaluated in terms of home, not institutional, care. These different lenses will yield better insight into how to align the inseparable needs of clients, unpaid caregivers, families and paid providers to mitigate hazards (Lang et al. 2006; Stevenson et al. 2008). Researchers, policy and decision-makers and practice leaders must continue to collaborate to advance knowledge on home care safety.

Developing Knowledge
The research agenda for home care safety should be developed with input from both providers and recipients of home care, as well as policy and decision-makers, and be informed by documents such as *A Framework for a Canadian Caregiver Strategy* (Canadian Caregiver Coalition 2008). Both quantitative and qualitative methodologies must be used to capture all the varying perspectives, experiences and features of home care.

The Canadian Caregiver Coalition (2008) developed a framework for a caregiver strategy because (1) it realized that individuals are living longer, increasing the likelihood of developing a chronic illness; (2) families are smaller today, with many women delaying child-bearing and in the workforce, limiting the number of available caregivers; and (3) to safeguard against the shifting of public responsibility for home to unpaid caregivers. The framework principles are respect, choice and

self-determination, and the framework strategies mirror much of the safety in home care evidence generated to date.

In future, home care research should focus on the development of a model that supports client- and family-centred care and creates an environment where risks are not necessarily eliminated but are at least mitigated to a level the clients and caregivers are prepared to accept for themselves and their situation.

Recommendations for Policy and Practice
Based on existing evidence, recommendations related to policy and practice are in order. As a prelude to this work, discussions of how the system will collaboratively address, implement and sustain safety recommendations unique to home care need to take place. Policy and decision-makers should prepare to

- implement learning strategies to build staff understanding of and competency for providing care in the home environment;
- develop policies to ensure consistency in compensation, respite, training and ongoing support for unpaid caregivers across Canada;
- designate funds for home care–specific research; and
- implement technologies to support information flow across the care continuum.

Sustainable practice changes will have to reflect the experience of home care clients, their families and caregivers as well as paid providers in dealing with safety challenges. Evidence-informed guidelines should be flexible, client- and family-centred and adaptable to the nature of the home.

Transitions in care (from acute to home care, or as acuity increases) are some of the most dangerous and unsafe times for home care clients, and guidelines should cover improvement in handing off care. We strongly recommended establishing clear and consistent processes for

- identifying and assessing home care risks – a "short, provider-centred tool" could increase uptake and provide a mechanism for communication between management and care providers (Stevenson et al. 2008);
- involving the client, families and caregivers in care planning prior to and after discharge; and
- communicating with clients, families and caregivers about home care risks before transfer to home care.

Conclusion
Choosing home care – as an individual in need of treatment and support, or as a society by shifting policy and resources – is a move away from highly structured and standardized care. It is a choice many are glad to make. Some slip into it, adapting day by day to changing health; some have little choice. Until now, safety has largely been defined by institutional norms and standards;

but as we shift to providing more care in home environments, we can no longer afford to leave the issue unexplored. Clients prefer to be at home, expectations are high of family caregivers, demand for home care is rising and transitions from hospital to home are not all smooth and orderly. The combination of these

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factors can lead to safety risks in home care for all involved. Given that care needs are increasingly complex and that the safety of clients, caregivers and providers are intertwined, collaboration to address risks is essential. Patients, families, paid providers and caregivers deserve to be educated on the risks of home care and the options for managing them, and then allowed the dignity to choose what risks they can accept. HQ

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