



Home Care Safety Perspectives from Clients, Family Members, Caregivers and Paid Providers

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Abstract

There is a growing demand for home care services in Canada. Yet, overwhelmingly, research on patient safety has focused on institutional settings. The Canadian Patient Safety Institute convened a Core Safety in Home Care Team of researchers and decision-makers to identify priority research areas and to advance patient safety research in home care. As part of this initiative to investigate and extend our understanding of home care safety, key informant interviews were carried out with a wide range of respondents including researchers, decision-makers, service providers and regulators. In-depth audiotaped interviews were conducted in two Canadian provinces. Interpretive descriptive analyses revealed three main themes: the meaning of home care, safety concerns and the place of technology in the future of home care. Given the multidimensionality and complexity of home care as well as the challenges and strains involved, the risk to all the players is becoming increasingly evident.

The demand for home care services is growing in Canada (Canada Institute for Health Information 2003). There has been a 51% increase in the number of home care clients since 1997, with over 900,000 receiving services in 2007 (Canadian Home Care Association 2008). Yet, overwhelmingly, research on patient safety has focused on institutional settings. Moreover, there has been an augmentation in the medicalization of private homes, resulting not only from the escalating threshold for admission to hospital but also from the increasing acuity of patients at the time of their discharge. This shift in care setting has been facilitated by the explosion of “hospital at home” services and the ever-growing availability of mobile technology (e.g., hemo- and peritoneal dialysis, long-term intravenous catheters and oxygen/inhalation therapy) (Williams 2002). The physical environment, socioeconomic status, family dynamics and cognitive and physical abilities of the client and caregivers are essential factors to be considered when delivering services.

Family members or friends who are unpaid caregivers are often untrained, elderly and contending with their own health challenges. They frequently lack sleep as they provide around-

the-clock care. This is in stark contrast to the institutional setting where there are two or three shifts of professionals who provide care. Care at home constitutes a complex socioecological challenge for patient safety. Providers can engage clients, families and caregivers in conversations and collaborate with them to reduce risks, but home care recipients must often make decisions about managing medications and treatments with minimal professional supervision (Lang and Edwards 2006b). Further research on home care safety needs to: (1) address the client, family and unpaid caregivers as the unit of care; (2) reflect the influences of an unregulated and uncontrollable home environment on the use of technology and the provision of care; and (3) tackle the challenges of transitions, communication and continuity of care among an array of paid and unpaid care providers (Lang and Edwards 2006a).

In 2008, the Canadian Patient Safety Institute convened a Core Safety in Home Care Team of researchers and decision-makers to identify priority research areas and to advance patient safety research in home care. This team undertook an environmental scan and carried out key informant interviews with researchers, decision-makers, service providers and regulators. The purpose of this study was to describe the experiences, challenges and insights regarding home care safety from the perspectives of clients, family members, caregivers and paid providers.

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Method

Interpretive description was used to develop a conceptual explanation of home care safety. Fifteen semi-structured interviews were conducted in the homes of clients receiving home care services within Capital Health Edmonton and the Vancouver Island Health Authority. Client participants had at least one chronic condition and were currently receiving home care services, some for as little as three weeks and others for as long as five years. They ranged in age from 40 to 93 years, whereas their family caregivers ranged from 16 to 89 years. All home care service providers were paid by the healthcare system and had worked in home care for a minimum of six months. The experience of providers (i.e., home support workers, a licensed practise nurse, an occupational therapist and a nurse manager) in home care ranged from eight months to 20 years.

Family members, unpaid caregivers and providers were interviewed at a time and location convenient to them. Audiotaped interviews ranged from 60 to 90 minutes. Field notes were also recorded following each interview. These data

were transcribed, coded and constantly compared. Data were synthesized to capture meanings, construct theoretical relationships and explain the theoretical relationships in ways that are meaningful and applicable in home care. The categories provide a meaningful explanation of the participants' perspectives of home care safety in response to the research question, What are the experiences, challenges and insights of clients, family members, caregivers and providers regarding home care safety?

Findings and Discussion

Analyses of the interview data revealed three main themes: the meaning of home care, safety concerns and the place of technology in the future of home care. Home care had a special meaning for the clients and their families. For them, it meant they could be at home and, in being at home, remain in charge. They described making the decisions, while clearly recognizing that these decisions were not necessarily congruent with what the provider preferred or was trying to ensure. For example, one client said, "Sometimes [home care providers] agree with what I am doing, and sometimes they don't agree." *Home* meant something different to every individual; therefore, the care that is provided via home care needs to be negotiated in each situation. Ultimately, it was the clients, their families and caregivers who decided what they would or would not do or accept.

Interestingly, when participants were asked what *home care safety* meant, the perspectives of recipients diverged from those of the paid providers. Clients, family members and caregivers spoke with ease about home care but seemed less sure about how to respond to questions specific to home care safety. This was a particularly instructive finding since it has led us to question the use of the term *home care safety* with these home care recipients when, in fact, this term did not seem to resonate with them. Terms such as *concerns* or *challenges* regarding home care may be more appropriate and meaningful when speaking with clients, family members and their caregivers. Generally speaking, home was considered a haven or a safe place for these home care recipients. Even though they were able to describe examples of unsafe or risky experiences and situations, these participants did not think in terms of issues around *home care safety*. Home care recipients expected that those entering their home would get to know them, provide competent care and give them or arrange for them the necessary supportive care in a flexible and timely manner.

The providers, on the other hand, considered *safety* to mean completing resident assessments to determine risks (e.g., for falls), making sure clients received medications in blister packs to minimize medication errors and ensuring clients used proper disposal containers for syringes and needles. These provider concerns were geared primarily toward the client and focused almost exclusively on physical safety. As such, they were closely aligned with the more common institutional patient safety concerns reported in the literature, highlighting the differing

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perspectives regarding home care safety. Within the context of home care, providers cannot determine the standard of safety independently of the recipients’ perspectives, because such standards will have an impact not only on the client but also on the safety of everyone involved. Thus, providers and recipients need to work in concert to develop home care safety standards. For example, one client with limited financial resources and no support except for home care services had difficulty keeping track of her morphine doses; she feared she had occasionally doubled-up before driving herself to her appointments. Although she recognized that her difficulty impaired her ability to perform activities of daily living, including driving, this did not change the fact she had to continue to manage under circumstances of considerable risk to herself and others.

By virtue of the unique characteristics of individuals and their homes, there cannot be one standard of home care safety for all. In the institutional setting, patients receive a certain standard of care regardless of their socioeconomic or cognitive status. In contrast, home care safety pertains not only to physical aspects but also to emotional, social, functional and financial aspects. In home care, some clients and families have the financial means and abilities to purchase all needed equipment, make renovations, hire the necessary help and transform the home to meet their needs. At the opposite end of the continuum are the individuals who have limited financial means and live in unsanitary and unsafe conditions. For these clients, priorities in the delivery of safe home care must attend not only to the traditional physical and psychosocial care but also to care pertaining to the home, which can involve arranging for safety aids and extermination services. This is critical: the client’s home is also a workplace, and it should not be a limiting factor to receiving services. One case manager described the current trend in the allocation of home care services by saying, “It’s always the neediest person to whom you’re loathe to say, ‘Well, when you figure it [rodent infestation] out, then we’ll get a worker.’”

Safety Concerns

Family caregivers are central to the success of home care but are easily made invisible as long as the client is maintained at home and all is going well. One case manager explained, “Family members are tired ... if they didn’t look after their own health, they didn’t keep themselves safe in that whole process [of caregiving].”

Current systems of home care assign minimal resources at fixed times. The status of the home care client, like that of the

hospital patient, can change rapidly, and the accompanying resources needed to manage must be sensitive to and focused on the client, family and caregiver. These resources must be flexible, responsive and available as needed to support home care recipients in order to effectively manage the client at home, maintain and promote the client’s health and mitigate the risk for everyone involved.

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

Sometimes caregivers invest in safety devices such as motion sensors or sound-monitoring devices because they worry about the client at nighttime. Consequently, the caregivers are awakened several times during the night and become very fatigued. Fatigue is a safety concern because caregivers need to make critical decisions regarding giving medications and the care required by the client. Family caregivers cannot look forward to the end of a shift for some rest and relaxation like paid providers do; they are always on duty. Therefore, decisions regarding client services in home care must take into account what the family or caregivers need to help them care for the client, as well as what they need to maintain and manage their own health and well-being. One participant described the downward spiral that can occur when the needs of the unpaid caregiver are not met: “You are coping, coping and coping. And then one more thing happens, and you just aren’t coping anymore.” Clients requiring chronic home care services, such as the participants in this pilot study, are likely to require institutional placement if their caregiver becomes ill.

Vision

In addition to sharing their perceptions and concerns regarding safety in home care, participants also offered their collective insights and vision for home care. The need for increased home support was acknowledged, and some recommended that salaries of home support workers be improved, that family members and caregivers be paid and that housekeeping services be improved. Systems of care need to be able to accommodate predictable as well as unpredictable care needs of clients, family members and caregivers using a care needs approach rather than an income-based approach. Self-managed care programs whereby clients and families negotiate with agencies, preferably for the care they believe they need, are recommended.

Technology was identified as a way to enhance home care safety. Homes equipped with alarm systems, motion sensors, sound monitors and a whole host of systems enabled clients to feel safer and to obtain help in the event of emergencies. At the same time that these systems offered clients and families peace of mind, they were also perceived as a mixed blessing. Feeling safer comes with a cost, and that cost is often paid by the family caregiver who is constantly responding to these alarms and becoming fatigued.

Perhaps homes of the future could be constructed in the anticipation that they may become places of care from time to time. The built environment can have many mobility and toileting aids, as well as be made accessible for all activities of daily living; however, not everyone has the means to access such environments.

On the safety front for providers, a need was expressed to have access to Global Positioning System devices to make visible their location at all times. Providers are often on the road, traversing a wide variety of neighbourhoods and the elements, as well as a range of potentially risky home situations (i.e., aggressive patients, unclean conditions, unknown and potentially dangerous animals such as dogs, etc.). As such, they may also benefit from programs that guide them in staying safe during the provision of care and in transit to and from care settings.

Conclusions

This pilot study revealed that the perspectives of recipients regarding home care safety diverge from those of paid providers. Also, family members and caregivers are often asked to bear extensive levels of responsibility to ensure the health and safety of the clients while enabling them to remain at home. Even though recipients were able to describe examples of unsafe or risky experiences and situations related to the home care they receive, in general they consider their home to be a haven or a safe place. Being at home means that they are in control. They described making decisions, while clearly recognizing that these decisions are not always congruent with or endorsed by their provider. In contrast, the provider concerns were geared primarily toward the client and focused almost exclusively on physical safety, similar to institutional patient safety concerns reported in the literature.

This information is an important reminder that, in home care, providers cannot determine the standard of safety independently of recipients' perspectives. Furthermore, it reinforces the need for a definition of *home care safety* that is broader, more flexible and acknowledges that clients, family members and caregivers can and will make choices that are traditionally, from an institutional perspective, considered risky. Although clinical standards are essential to home care, a single set of standards for home care safety that encompass the multidimensionality and personal preferences involved is not reasonable or desir-

able. Rather, evidence-informed guidelines that mitigate risks associated with decision-making within this complex home care context are preferable.

The findings from this pilot study highlight the need for further research to examine and understand the differing perspectives of home care recipients and providers, particularly within contexts of greatest risk and vulnerability (i.e., medication management, palliative care, frail elderly, etc.). Such research must include a clear sense of the family members and caregivers providing the care as well as their respective vulnerabilities and needs. Given the complexity of home care safety, future research needs to identify and explore multiple study methods and various relevant sources of visual and textual data to capture its multidimensionality. Such an approach will help us to understand and compare results across several sources of data and to synthesize the data to capture meanings, construct theoretical relationships and explain these theoretical relationships in ways that are meaningful and applicable in home care. Study methods can include interviews, household walkabouts, kitchen-table talks, focus groups, and photographs of safety issues identified in homes by clients, family members, caregivers and providers. The product of such a research approach will be a theoretical explanation about what is common within home care safety across participants and their particular contexts (Thorne et al. 1997, 2004).

Until such time as further research delineates what safety in home care means to recipients and providers as well as the challenges associated with mitigating the inevitable risks, there are two areas on which we can focus our efforts. First, health-care providers must involve clients, families and caregivers in decisions about the type and amount of home care and the timing needed to provide appropriate and responsive care. This may mitigate the risks, thus providing an improved measure of safety for all involved. Second, it is essential to remain cognizant that perceptions of risk and safety are often varied and incongruent among the various stakeholders. Therefore, providers need to navigate the provision of home care services through a lens of negotiation and mitigation of the risks for all involved.

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