Mapping a Research Agenda for Home Care Safety: Perspectives from Researchers, Providers, and Decision Makers*

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RÉSUMÉ

Le but de cette conception qualitative et interprétative était d'examiner les perspectives des chercheurs, des pourvoyeurs de soins de santé et et des décideurs aux sujets des risques principaux, des préoccupations et des problèmes émergents rattachées à la sécurité de soins à domicile qui informerait une ligne d'enquête de recherche. La sécurité, tel qu'elle s'applique spécifiquement à ce context des soins à domicile, n'a pas encore été définie. Par conséquent, afin de profiter de diverses parties prenantes sur les questions de securité relatives aux soins à domicile est nécessaire afin d'informer les orientations stratégiques pour la recherche future. Afin de commencer à tracer un programme de recherche, une analyse en trois parties de l'environnement a été realisée: (a) une étude pilote avec les bénéficiaires et les fournisseurs de soins à domicile; (b) des entretiens avec des informateurs clés, les chercheurs, les fournisseurs de soins de santé, et les décideurs; et (c) une revue de la littérature dans trois domaines thématiques. Seulement les résultats des entrevues des informateurs clés sont présentés ici.

ABSTRACT

The purpose of this qualitative interpretive design was to explore the perspectives of researchers, health care providers, policy makers, and decision makers on key risks, concerns, and emerging issues related to home care safety that would inform a line of research inquiry. Defining safety specifically in this home care context has yet to be described; consequently, gaining insight from various stakeholders about safety issues relevant to the home care sector is necessary in order to inform strategic directions for future research. To begin to map a research agenda, a three-part environmental scan was conducted: (a) a pilot study with home care recipients and providers; (b) key informant interviews with researchers, health care providers, policy makers, and decision makers; and (c) a review of literature in three topic areas. Only the results of the key informant interviews are reported here.

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* This study was funded by the Canadian Patient Safety Institute (CPSI). Ariella Lang is currently supported as a Chercheure Boursière by Fonds de la Recherche en Santé Québec (FRSQ). We extend thanks to Serena Corsini-Munt for her help as project coordinator and for her skill in helping with the key informant interviews. We thank Farraminah Francis for her hard work and help with the analysis of the interview transcripts. We also thank the other members of the research team – Jan Storch, Lynn Stevenson, Susan Donaldson, Hélène LaCroix, and the advisory committee – for their time, support, and feedback. The authors declare that they have no competing interests. MM prepared the research proposal, conducted interviews, analyzed the data, and revised the manuscript as needed for publication. AL prepared the research proposal, conducted interviews, analyzed the data, and edited several editions of the final manuscript. JM prepared the initial draft manuscript for submission.

Manuscript received: / manuscrit reçu : 07/05/10

Manuscript accepted: / manuscrit accepté : 18/02/11

Mots clés : soins à domicile, sécurité, conception intérpretative, informateurs clés, une analyse d'environnement, programme de recherches

Keywords: home care, home safety, interpretative design, environmental scan, research agenda

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doi:10.1017/S0714980811000055

Introduction

Home care has undergone tremendous growth since the 1990s, assuming an essential role in the transformation of health care and the concomitant shift to meeting the health care demands and needs of Canadians "closer to home". In 2007, approximately 900,000 Canadians were receiving home care, a 51 per cent increase in one decade (Canadian Home Care Association [CHCA], 2008). Home care includes a wide range of health services delivered at home to recovering, disabled, chronically ill, or terminally ill persons of all ages. Such individuals are in need of medical, nursing, social, or therapeutic treatment (e.g., wound care, medication management), assistance with essential activities for daily living (e.g., bathing, dressing, and eating), and/or help with instrumental activities (e.g., housework and meal preparation) (Health Canada, 2004).

Home care, which is not an insured service according to the Canada Health Act, varies widely across the country. For the most part, each jurisdiction has a maximum service limit with the exception of British Columbia, Nunavut, and the Northwest Territories. Nova Scotia and Newfoundland set dollar limits for acute care services; Saskatchewan, Manitoba, Quebec, New Brunswick, Nova Scotia (for chronic care), and the Yukon set limits so that the cost of home care services does not exceed the cost of institutional care delivery (CHCA, 2008). The provision of professional health care services and supportive care enables people to remain or return to their homes, regain and improve their health and quality of life, and maintain a level of independence. However, managing and delivering these diverse services often involves a number of health care agencies and providers, includes family and/or friend caregivers with varied capacities, and requires functioning in unregulated, uncontrolled, and unpredictable settings. Defining and enhancing safety in this complex home care context has yet to be described (Lang & Edwards, 2006).

Ensuring safety in the home care sector requires a coherent body of research to inform practice and policy. Establishing an appropriate line of inquiry begins by gaining the perspectives of relevant stakeholders. Individuals have varying understanding of the sources of problems, ways to name them, methodologies to understand them, and proposed strategies to address them. Combining various insights, experiences, and perceptions creates a "big picture" perspective about how to proceed with research (Fiske, 2004). The purpose of this study was to explore the perspectives of researchers, health care providers, as well as policy makers and decision makers about the main risks, concerns, and issues related to home care safety. Policy makers are considered to be individuals who set plans instituted by government, and decision makers are responsible for resources and decisions related to policy implementation. The findings will inform a platform for future research in home care safety.

Methodology

The qualitative methodology of interpretive description guided this study (Thorne, 2008; Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). *Interpretive description* (ID) is an inductive analytic approach "designed to create ways of understanding clinical phenomena that yield applications implications" (Thorne, p. 1). ID has three key elements: an objective, mechanisms, and a product. In our study: (a) the objective was to develop an explanation of the issues related to safety in home care; (b) the mechanism was semi-structured interviews with key informants; and (c) the product included the patterns that explain the commonalities related to safety in the provision of home care, which then inform recommendations for future research.

Participants

A purposeful sample ($n = 24$) of researchers, health care providers, policy makers, and decision makers from across Canada with expertise related to home care and the Canadian health care system in general were selected for inclusion in the study. The key informants were jointly identified by the research team and members of an advisory committee of home care experts (comprising researchers, decision makers, health care providers, and administrators with a vested interest in patient safety) set up by the research team for study purposes. Participants were chosen based on their extensive experience in practice, policy, and research related to home care and the Canadian health care system in general. The participants represented eastern, central, and western Canadian provinces and a variety of health care delivery sectors including Veterans Affairs, Aboriginal health, publicly funded home care, and for-profit home care. An invitation to participate was extended through an email that described the purpose of the study, the reasons for their selection to participate, and study expectations.

Data Collection

Data collection included audio-recorded telephone interviews conducted between July 2008 and January 2009. A semi-structured interview guide was used, with questions structured to elicit participants' understandings of safety issues related to clients, family members, and caregivers; additionally, the guide had questions regarding providers, conditions, and factors that influence home care safety. The 45-minute interviews took place at a time convenient to the participants and in

Table 1: Sample study questions

1. Describe what comes to mind when you consider safety in home care.
2. In home care, the family and client are a unit of care. Describe how this dynamic influences safety in home care.
3. Explain how safety in home care differs from the hospital setting.
4. Describe what types of knowledge regarding safety in home care would be beneficial in the provision of home care services.
5. Explain what you see as the priority areas for research in home care.

their preferred language of French or English. The audio recordings were transcribed verbatim. Table 1 lists sample questions.

Data Analysis

Consistent with interpretive description, data were coded and constantly compared. Codes that were similar were grouped, but pattern identification was delayed until several interviews were coded in order to determine if a particular grouping represented a pattern. Four patterns were identified followed by the theorizing of outliers (Thorne, 2008). This involved looking at coded data that did not fit with one of the four patterns that ultimately emerged from the study to determine if these data represented a completely new pattern or if they did not contribute any further meaning to our understanding of safety in home care.

This theorizing of outliers used in ID replaces the frequently employed data saturation approach used in most qualitative studies. Data were first reviewed and analyzed independently by four members of the research team. Patterns were then compared across research team members in a face to face meeting, with patterns retained that captured commonalities in the data and that related easily to home care safety. These findings were then shared with members of the advisory committee to elicit their feedback on the patterns' meaningfulness and applicability for home care.

Rigor

The trustworthiness of study findings in the ID tradition are maintained through epistemological integrity, representative credibility, analytic logic, and interpretive authority (Thorne, 2008). *Epistemological integrity* was maintained by acknowledging that the participants were the holders of knowledge, and this knowledge was elicited via the interview process, analyzed, and interpreted as patterns that explained safety in home care. *Representative credibility* was achieved by triangulation of the findings among researchers and with an advisory committee of experts in home care. *Analytic logic* was provided by describing the analysis process and maintenance of an audit trail. *Interpretive authority* was achieved by developing patterns from the data, relating the patterns to one another, and supporting the explanation using the participants' direct words.

Results

Four patterns were identified from the analysis of the data: (a) fragmentation in services; (b) vulnerabilities for clients, caregivers, family members, and health care providers; (c) erosion of the home as a safe haven; and (d) incongruence between care demands or expectations by clients and the service capacity of providers.

Fragmentation in Services

Fragmentation existed in three forms: (a) as a disconnect in approach to client involvement in care in the hospital versus in the home; (b) as multiple agencies and providers serving a single client; and (c) as communication breakdown.

Client involvement. Participants clearly understood that acute-care clients may have limited ability to help with their own care. Hospital personnel need to consider that as soon as clients begin to stabilize, the clients should become involved with self-care as soon as possible so they can be readied for returning home. In home care, providers are focused on assisting clients and families to manage on their own as quickly as possible. The more congruent the approach to care in both sectors, the more likely it is that clients and families will be prepared to cope at home.

> When you go home, you are going to be responsible for this, let's start learning now how to change this dressing or take this new medication.

Multiple agencies and providers. Every decision maker we interviewed pointed to the care fragmentation risks associated with the presence of multiple agencies and providers in a single household. It becomes difficult to determine exactly where accountability rests; consequently, clients and families often end up as the coordinators of these services whether they are able to or not. Providers who strive to be accountable struggle to stay abreast of what services are entering homes since the providers are not present at all times. Multiple agencies delivering services in a given home typically means multiple records for that home. Health and support care providers may not have adequate access to the various records. As one participant suggested, "You can go into a client's home and have the chart set in one place or recommend it be left in one place. And you go in, and guess what: the chart's not there." Consequently, providers may be unaware of important information related to critical incidents or changes in conditions and services.

Clients worry about having many individuals provide care and services because they want to get to know who is coming into the home. Clients also want to get to know and to trust those providing services so they can feel safe.

There are problems when two services are being offered in one home and each service provider is unaware of what the other is offering. Some aspects of patient care might not be covered at all because each provider thinks that the other is taking care of it. As one study participant observed:

> And the one thing that struck me was that every time a nurse came to dress the wounds, it was a different person. So for 10 visits I had to start from scratch with every nurse. The instructions, the scheduling – I thought it would be easy to do, but I found that something in the system was not working properly. So I can just imagine how difficult it is for older people who might have a few care providers come and go a day. How difficult it must be for them to see a new face so often. I had the feeling like nobody cared. No continuity of care.

Clients and families become confused about who to turn to with their health questions. One participant recalled concerns expressed by a client:

> Who do I listen to? [I have to] Go to a diabetic clinic for this, to show me how to use my medication and my blood glucose sugar, but I also have a nurse coming to do home care and asking me about my diet and also asking me about my medication and yet may not know what kind of information the diabetic clinic gave me.

Communication breakdowns occurred related to the timing of home assessments in preparation for discharge and in the timing of initial visits for service provision. These breakdowns lead to potential compromises to client safety. Home assessment visits prior to discharge might be necessary to determine the adaptability of the home for equipment needs or at times for security reasons (i.e., to determine if the location is safe for a client or for a care provider). Transitioning from an acute-care setting to a home care setting was consistently identified as a time when safety concerns manifested. Home assessments do not typically occur as part of hospital discharge planning, which results in disruptions to care. Thus, some problems can go undetected while other problems can surface when visits are poorly timed:

> One of the key gaps is the actual time that lapses between discharge from hospital and first [home care] visit. And it was often my experience that it was, either way, ridiculously too soon … or it was ridiculously too long [after]. By the time you got in there, they [clients] were in crisis.
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> What ends up happening is clients and caregivers come home, and they have not had things prepped such as having an OT [occupational therapy] assessment or PT [physiotherapy] assessment … to see if the basic needs of the client are met. These things take a bit of time and can add stress to the family and caregiver.

Fragmentation in communication was not limited to the point of care. Various components of the system must work together if there is a chance to create solutions for the safety concerns in home care. Yet:

> …everyone seems to work within their own pocket … these pockets that pay for health care do not communicate. As long we have every pocket owner thinking that they must protect their own pocket … if we involve family more in care – including paying for that care – we have not eliminated the problem, only switched the pocket from which it is to be paid … but, I think connecting the dots could benefit all of us.
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> Few supports are in place to encourage agencies and providers to work synergistically together: Like a client could be discharged from a hospital and be referred to a diabetic clinic in the region, but at the same time be receiving visiting nursing from [name of organization]. The nurses don't know that the client is linked to the clinic. There is no communication between the client and the community care services with regards to medication management and all those things that could really prevent long-term effects and keep that client healthy at home. It's so focused on tasks but not necessarily the whole holistic picture.

Vulnerabilities for Clients, Caregivers, Family Members, and Health Care Providers

The term vulnerability implies some level of risk and in this study was a pattern that emerged from the descriptions that participants, experienced in home care, provided. For example, participants reported situations in which risks to the emotional, physical, social, and functional health of both recipients and providers existed. They felt four sources rendered recipients and providers vulnerable: (a) exposure to infection, (b) medication mismanagement, (c) isolation, and (d) potential for abuse.

Exposure to infection. The quality of care received by clients is partly determined by the status of the home environment. Diverse home environments pose challenges for providing all of the requested or required services, with some homes perceived as "just not suitable". Lack of snow removal, poor lighting, small spaces, and clutter contributed to potential injuries, fire hazards, and challenges for delivering safe care. The presence of rodents, bugs, large numbers of domestic animals, and unsanitary conditions made it particularly difficult to perform clean or sterile procedures:

> Our worker couldn't work in the home as it was covered in feces – dog poo and cat poo – all over the place. Our supervisor had said she had never seen anything like that. How can you have a client just out of the hospital deal with that?

There is always a possibility that providers may spread infections as they travel between homes, and proper cleaning of equipment in a home setting remains a challenge: Participants recounted the challenges encountered with caring for clients who contracted infections in hospital such as methicillin resistant staphylococcus aureaus (MRSA) and C-difficile. These infections are highly transmissible and providers worried about the transmission. Hand washing is the most effective barrier to transmission, yet providers expressed concern related to the equipment they carry to conduct their work and whether the equipment had the potential to be a source of infection transmission.

Medication mismanagement. The incorrect administration of medication by clients, family members, or caregivers, which has occurred both accidentally and deliberately, was described by the study participants. Accidental or unintentional errors in a prescribed medication regime were attributed to miscommunication among providers and to improper supervision:

> Risk of miscommunication on how the medication has been prescribed by the physician or the client's understanding of how to take the medication – how it has been prescribed, how it is being taken, omissions, mixing doses, prescribed but not taken, drug interactions – like taking some herbal medications and not letting the caregivers know … [all these are] definitely a risk.

One participant suggested that approaches to medication supervision need to be examined, as she recalled a client who mistakenly took the wrong medication:

> She had an episode of taking 66 pills in one day … But this was a reaction to everyone – her doctor, her family, everyone constantly reminding her: "Take your pills, take your pills." So she sat down one day and took them all.

Family members and caregivers may lack the knowledge and training related to complex medication regimens:

> I have also spoken to family caregivers who in some cases are involved in administering a lot of pills, injections, schedules, and a lot of complicated medical issues. And some of them complained that they do not have a medical degree – and are not doctors – and they are scared when they have to administer some of these things because they don't know what they are doing.

Deliberate choices to change medication regimens were also identified. Participants and caregivers made choices to adjust medication doses, or to stop and start medications without medical advice. In some cases, medications were deliberately withheld by family members who took the medications themselves or sold them.

Isolation. Clients, caregivers, and providers carry out their day-to-day care work in relative isolation from the human and physical resources offered in an institutional setting. When a loved one is hospitalized, the client (patient) receives the necessary care and supplies. Hospital providers know they have a colleague nearby to consult as needed; moreover, the workplace is secure and paid providers do not need to wonder what environmental challenges lay ahead. In home care, however, clients, family caregivers, and paid providers alike work in isolation from such resources, and despite the fact that most clients prefer to be at home, the isolation can be challenging, and paid providers may not know what environmental challenges await.

Caregivers, who are commonly family members, meet the majority of in-home care needs for the client and, accordingly, might face safety risks. Study participants believed that often families are conscripted into caregiving roles despite their possible reluctance or discomfort with the tasks required. Families and other nonmedical caregivers might not be asked if they wish to provide the required care at home, as reflected in a participant's comment, "Your [professional medical] expectations of them rise and the burden for them rises, and so, do we even give them the opportunity to say, 'No I can't take that on'? "

Caregiving responsibilities by family members were sometimes perceived as escalating to a point where they unintentionally interfere with or jeopardize important familial relationships: "The line [was] crossed where we weren't allowing her to be the wife anymore, she was the caregiver."

Concern for the safety of family members was not confined to the caregiver, as participants described the potential risks for children in the home. Access to medications and improper supervision were described:

> The younger client population will have issues with drugs and alcohol being left in places where the children residing in the home can access them … children being left unattended or being left in

> the presence of the client, but not being safely cared for.

The participants also acknowledged safety concerns with regard to those entering the homes to provide care. Providers might be required to work in isolated places without easy access to peers or other resources. Dangerous or uncomfortable situations can arise for providers as described by the following participant:

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

Participants described tensions related to relationships between providers, and the clients and their families, as a potential safety concern. On one hand, providers might struggle to preserve professional boundaries as friendships and intense emotional attachments develop with clients and families under circumstances of isolation:

> [Nurses] get very attached to these people … they get to really know these people. A lot of them [the clients] are lonely; they are shut in; they kind of cling to the social contact of the home care nurse coming in. It places a real emotional burden on the nurse that is different from what you get in acute care.

On the other hand, the ability to establish therapeutic relationships is impeded when different providers come and go.

Abuse. Clients may be victims of abuse from family members, which might not always be readily apparent to care providers:

> There may be things in the family that could definitely interfere with safety: things like abuse issues, neglect, violence. They may decide to withhold treatment. I mean, you don't know what goes on behind closed doors.

Detecting potential abuse issues was perceived to be more challenging when a myriad of providers are entering and leaving the home. Moreover, various caregivers can be unaware of isolated signs of abuse that collectively would alert providers to abuse. For example, family members might prevent providers' access to the home and client. Yet, unless one individual is carefully coordinating care and closely following a situation, subtle cues to potential or actual abuse can be missed. In some cases, imposters have posed as home care providers as way to gain access into a home:

> We've had experiences where people are posing as health care providers coming into people's home when they're really not – mocking up some ID. They're [clients] very trusting, so from a safety perspective, if they're [clients and families] not well informed, that could be a safety issue as well.

Erosion of the Home as Haven

Contemporary homes are not typically designed or envisioned as places where complex or long-term health care is provided. People consider their home to be a haven or a place where they are not exposed to the world. Yet, being a home care recipient means the arrival of numerous providers of care as well as a plethora of equipment. As one participant explained:

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

Participants suggested that while home modifications serve to address physical needs and safety, the introduction of equipment and other changes to the home environment could have emotional and social implications for the clients, family members, and caregivers. The home as a safe haven may be eroded:

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

Some participants noted that the "medicalization of personal space" might have a particularly strong impact on children in the home, a common challenge when younger clients with chronic needs are receiving home care. For example, one participant stated: "This is a new area where now the worker in the home will key into the fact that the four-year-old child is watching dad have painful dressing changes." The refrigerator, which at one time may have displayed favorite photos or the artwork of a child, has been re-deployed as a communication board.

> It [home] becomes the center of communication. So you could be having a treatment at home, and I could be coming for tea, and reading everything about you on your fridge. Providers and decision-makers were mindful of the invasion of the home space for the purposes of delivering home care. They were very aware of the fact that providers are guests in the home of the client and worked to respect how recipients wanted their spaces to look.

Incongruence between Care Demands and Capacity

The pattern of incongruence that emerged in this study was illustrated in three ways: (a) incongruence in the responsibility assigned to unregulated health care workers compared to the knowledge and skill provided in their training, (b) incongruence in the knowledge available to paid regulated professionals and access to this knowledge in a timely fashion, and (c) incongruence in the care expectations of families of clients and the level of support and resources available.

Unregulated health care workers. Incongruence in the responsibility assigned to unregulated health care workers compared to the knowledge and skill provided in their training was directly addressed by home care providers and researchers. These participants identified occasions when care demands or expectations exceeded the capacity of the home support workers, other health care professionals, and families or caregivers. The majority of participants noted that the "responsibility assigned to unregulated health care workers may transcend their knowledge and skill, with those with the least education doing the most intimate and isolated work". Yet, standards or regulations for many workers who provide personal care such as bathing and dressing are often absent. Standardizing training for unregulated care providers is a challenge and concern. As one participant noted: "Certainly the regulation of caregivers and what they know and how they're supported – and if they are supported – is certainly an issue".

Elements of workplace quality were also an issue as participants suggested that home care workers receive lower salaries in comparison to those in institutions and are not adequately compensated for travel time:

> I know in [town] we have a huge problem recruiting PSWs [personal support workers] because of the long-term care facilities in the area and the wages. There is a difference in what we pay and what the hospitals pay, especially when they have to work a few additional hours at home.

One participant specifically acknowledged system-level challenges for securing adequately prepared workers:

> A huge problem is getting the staff. When you are working in an environment where you are in competition with RFPs (requests for proposals) – how much you want to charge or price you want to give per visit – you have to look at the nurses you have on board. It becomes a problem when you are trying to be a successful organization and pay your staff accordingly so that you retain your staff.

Information access. Incongruence between the information or knowledge available to paid regulated professionals and access to this knowledge in a timely fashion represented a challenge, particularly from the provider's perspective. Participants suggested that health care professionals could find themselves in situations for which they are not adequately prepared to provide the necessary care. This is especially true for unexpected situations when health care providers only become aware of new or changed care regimes after arriving at a home: "You go in, you see something that you have never seen before and then you are on your own".

The capacity for health professionals to provide adequate care depends also on their ability to gain necessary knowledge and skills for the procedures and care they are expected to provide. Yet, health care professionals might be challenged to keep abreast of new, constantly evolving technologies and equipment, pharmaceuticals, and procedures and techniques that are introduced as part of care in the home setting. Finding the time to gain and sustain competencies is a significant challenge for those on the front lines, and the absence of easy access to evidence-based clinical information is reported in the literature as a barrier to maintaining professional competency (LeHoux et al., 2003).

Recipient care expectations. Incongruence between the care expectations of families of clients and the level of support and resources available to provide such care contributed, in our study, to a perceived inability of health care providers to meet client and family needs. Participants particularly noted that a lack of human resources limited the extent to which providers were able to spend time teaching and listening to families' and caregivers' concerns. Human and financial limitations contributed to wait lists for services:

> Let's start with the human resource constraint. It's not only that there are not enough people to send [to clients' homes], there is also not enough money to provide the [required] level of service. Or there is a waiting list: "you can get home care in three months from now".

The types or level of care family members or caregivers were expected to perform also surpassed their capacity at times. In a context of constrained resources, family members and caregivers with health-care-related education or experience were particularly relied upon:

> "Workload is high. I think that's a given reality. So if you're a clinician going in and you come across a caregiver – be it a daughter or someone who's capable – it's like you've hit the jackpot.

There is an expectation on the part of professional providers that family members will do almost as much, if not more, than the paid and trained workers, often without the necessary education or training. One participant summarized the complexity of care that caregivers assume because they are expected to:

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

Yet, the provision of standardized training to family caregivers faces a number of challenges, including adapting to the unique nature of each home and meeting the varied needs of the caregivers: "One of the biggest gaps in training in the community setting is that we do not have proper ways of training people … providing education to non-paid providers." Participants suggested that conviction for ensuring properly trained family caregivers could be lacking:

> I don't think there's the same effort to train the family members who have to do the same thing. So I think that's a big issue in terms of safety in terms of both them and to the individual they're caring for.

Additionally, caregivers might be unaware of or unable to access reliable, current, and relevant information that would enhance their ability to provide safe and adequate care.

Discussion

Participants in this study identified *fragmentation in services* as a potential compromise to safety in home care. The pattern of fragmentation was manifested in three ways: (a) a disconnect in approach to client involvement in the acute-care setting versus the home care setting, (b) the involvement of multiple agencies in the delivery of home care, and (c) communication breakdowns. Home care agencies and associated providers have a long tradition of working with families to assist them in the process of care delivery. Hospitals, on the other hand, traditionally have not involved clients and families in the care process until the client is going home: some type of care is then abruptly required of clients and families, and automatically involvement by the family and client begins. The study participants attested to this (Levine & Zukerman, 2000). Current hospital trends show promise in delivering patient-centered care and hold promise for enhancing the level of client involvement in hospital care (Reynolds, 2009).

Fragmentation of services through the use of multiple agencies in the delivery of home care caused considerable consternation for providers and managers interviewed in this study. They realized that this situation results in multiple client records and multiple providers entering homes, thereby creating the potential for breaks in continuity of care. It also increases responsibility on the part of the client and family for trying to keep track of who is coming when and doing what. This raises the question as to who is ultimately accountable in such a structure. This phenomenon of home care delivery by multiple agencies in one home has been documented as a source of risk for all involved (McGraw, Drennan, & Humphrey, 2008). Given such findings, it is a phenomenon worthy of consideration in the discussion of a national strategy on approaches to home care delivery.

Fragmentation also manifested itself in the form of communication breakdowns. A failure to consider home care as part of discharge planning and poorly timed initial home visits contributed to safety issues for clients and their families and caregivers. The safety issue most often encountered was a family in crisis when the services they needed and expected were not delivered in a timely manner. This finding supports other research that described how lack of discharge planning and waiting times for services negatively affected client rehabilitation and placed increased and unrealistic demands on caregivers (Ski & O'Connell, 2007). However, further information is needed regarding how to assess and determine the appropriate timing of initial home visits. Crucial services can be missed when there is inadequate or inconsistent communication among the many providers and agencies providing care in the home. Understanding is needed about the barriers that limit communication among the various providers, disciplines, and agencies in the home care setting. A shift from task- or service-focused care to client- and family-centered care will require knowledge about innovative ways to work cooperatively and collaboratively.

One example of a client-centered initiative in the delivery of home care is medication reconciliation. This means that at the time of admission to a home care program, all medications that a patient reports taking are verified against the hospital discharge medication list and the client's pharmacy list. This represents a form of communication that works to ensure the patient is receiving the medications intended and that everyone involved is also aware of the current medication list. Initiatives such as medication reconciliation can be expanded to address other areas where communication is inadequate in order to enhance patient-centered, safer health care.

A second pattern emerging from the study data is *vulnerability*, which manifests itself in four ways: (a) exposure to infection, (b) medication mismanagement, (c) isolation, and (d) abuse. A number of safety risks were identified for clients, family and caregivers, and health and support workers. Lack of in-home equipment and varying degrees of home hygienics were identified as particular sources of safety risks for clients. This lack supports research findings indicating that care recipients, including many who live on pensions or low incomes, often are neither able to afford nor accommodate the additional supplies and equipment required for their care. Moreover, the continuous (as opposed to intermittent) use of a home for care provision added to the debris and clutter in a home, and illness prevented or reduced the opportunity and ability for household members to clean (Angus, Kontos, Dyck, McKeever, & Poland, 2005). While equipment and cleanliness are identified as important aspects of safety, conundrums exist about what constitutes a safe level of care in the home care setting or what is an acceptable level of home hygiene.

Infections resulting from the care and treatment received, commonly referred to as health-care-associated infections, were described as safety risks. This concern has been raised by others as well. For example, drug-resistant infections that were once exclusively associated with institutional settings are increasingly found in community settings and pose risks for those receiving home care services (Gorwitz, Fridkin, & Worowski, 2008; Grossman & DeBartolomeo, 2008). These organisms have been shown to spread to clients' homes from nursing bags and improperly cleaned equipment. Practitioner practices and agency policies have also been linked to the varying transmission rates (Grossman & DeBartolomeo, 2008; Kenneley, 2010). However, understanding the sources of and ways to mitigate infections potentially attributable to care providers, and the treatments they provide, remains a challenge. Little baseline data exists about health-care-related infections in the home care setting, and few studies have explored health-care-associated infections in the home setting (Baumrucker et al., 2009; McGoldrick, 2008; Patte et al., 2005). The study results suggest that research be undertaken on acceptable levels of home hygiene, and the origins and transmission of infections in home care.

Unintentional and deliberate incorrect administration of medications by clients and family members was identified as a safety risk and a source of vulnerability. This concern aligns with that of others who have begun to identify contributory factors for medication mis-administration in the home including increased client and family autonomy, polypharmacy, lack of knowledge, and impaired cognitive status (Hall Ellenbecker, Frazier, & Verney, 2004). Recent attention has been given to interventions that can serve to reduce unintentional medication mis-administration including (a) medication reconciliation, (b) routine and comprehensive review of medications, (c) the use of registered pharmacies, (d) inclusion of pharmacists on the health care team (Ballestine, 2008), and (e) the use of blister calendar packs and cognitive supports (Banning, 2009). However, gaps remain in terms of the means for measuring adherence to regimes, and to address deliberate medication mis-administration. There is also an absence of theoretical frameworks to assess the complexities and sources of medication mis-administration, which means that important interventions can be overlooked.

Isolation was a form of vulnerability experienced by both caregivers and providers. Frequently, as family caregivers take on increasing responsibility for a client with complex needs, client and caregiver ties with family and community are gradually severed. This happens for several reasons,such as no longer having the time to socialize and the fact that those who used to visit no longer come around (Coughlin, Pope, & Leedle, 2006; Proot et al., 2003). Care providers, too, spoke about isolation in the sense that many visits are made to clients who live alone, and some treatments of a more intimate nature cause providers to feel a sense of isolation. Exposure to potentially dangerous and uncomfortable situations is a risk for providers who often work alone and without the protections commonly found in institutional settings. Similar findings have been reported by others who note that working in clients' homes puts one at substantial risk for exposure to violence or threats at work (Bussing & Hoge, 2004; Hogh, Sharipova, & Borgm, 2008). While researchers have also begun to address the safety of providers working in the home care sector with regard to risks such as percutaneous injuries (Gershon et al., 2009), exposure to blood (Leiss et al., 2009; Zanoni et al., 2007), and impacts to emotional well-being (feeling lonely, overwhelmed, and overburdened) (Denholm, 2009; Xanthopoulou et al., 2007), in general, research about provider safety in the home care sector remains limited. Further understanding is needed about the risks and ways to protect home care providers.

One intervention that is making a difference with respect to isolation is technology. Providers can remain in constant contact via telephone, with their service agencies to receive the support necessary. Clients and families who have the financial means can use technology to converse virtually with family and friends. For others, lack of financial resources will mean that a level of isolation will persist.

The final form of vulnerability our study participants identified was the potential for abuse, either client to caregiver, or vice versa. The risk for abuse (emotional, physical, sexual, financial, and abandonment) has been well documented and considered attributable to changes in family relationships and dynamics, increased caregiver burden, history of difficulties in family relationships, mental illness, alcohol and drug misuse, and differing personal and social expectations (Payne, 2007). However, in the absence of reporting standards across the country, the extent of abuse in Canada is not well understood. Research is required that examines how diverse client, family, and environmental factors interact to generate abuse and how interventions can prevent or mitigate abuse.

A third pattern identified in this study was the notion of "*home as haven*". Providers and managers were cognizant of the fact that the space clients call home is often transformed into a space that looks very much like a hospital room. This study confirmed findings in the literature acknowledging the fact that relocation of care to the home setting can fundamentally challenge the personal significance and relational meaning of the home for the client and caregiver (Angus et al., 2005; Exley & Allen, 2007). Odors, food, sounds, and furniture arrangements are important aesthetic features of a home environment that allow individuals to feel at home and are central to their comfort. Alterations in the home environment and an influx of providers can create tensions as a result of disruptions with what clients and families have come to expect from their homes.

Home is a space where clients and families expect that privacy will be maintained (Exley & Allen, 2007). This study identified compromises to privacy and confidentiality as safety concerns for clients. Privacy is the right of individuals to keep personal information from being disclosed, while confidentiality is concerned with how care providers treat the private information once it has been received (Erikson & Millar, 2005). Clients' and families' abilities to maintain their rights to privacy can be more difficult when the selection and control of who and when people enter the home are altered (Angus et al., 2005). To our knowledge, little research has explored the implications of home care service or client and family privacy. Recent research that has explored the challenges related to confidentiality supports concerns identified by our study participants (Tracey et al., 2004. Further research is needed that explores how clients and families conceptualize the space they call home, as well as confidentiality and privacy in relation to the care provided in the home. Research is also needed regarding the types of information that need to be protected, the conditions under which disclosure or exposure is considered appropriate, appropriate recipients of information (e.g., other health care providers, family members), and interventions that aim to protect clients and families.

The final pattern that emerged from this study data was *incongruence* which was manifested in three ways: (a) the level of responsibility expected from unregulated home care workers (UHWs) relative to their training, (b) information required by professionals to carry out home care versus access to needed information, and (c) care expectations of families versus the level of support and resources available. The presence of UHWs was a source of concern for all involved in this study. Similarly, health care professionals, nurses in particular have been expressing this concern for the past few years to the Canadian Nurses Association (CNA, 2009) The Canadian Nurses Association has convened interested parties on this matter over the years and, in 2009, initiated a Pan-Canadian planning committee on UHWs. This culminated in the identification of five priority issues a) clarity of roles and functions, b) competencies/standards of practice, c) delegation, liability, and accountability, d) education and training, and e) staff mix and outcomes. Included among these priorities is the development of common core competencies for UHWs to be used across jurisdictions and care settings.

Provider data in our study revealed the incongruence providers experienced in the need for timely, up-to-date information to deliver optimal care and a frustration over the lack of technology and learning opportunities that would permit this. Evidence abounds that "knowing the client" is key to quality care delivery and improved patient outcomes (Luker, Austin, Caress, & Hallett, 2000; Radwin, 1996; Tanner, Benner, Chesla, & Gordon, 1993). Research has also identified that time is necessary to get to know the client. Technology such as personal digital assistants for accessing electronic medication and procedure related documentation as well as the internet holds the promise of delivering time to the provider and should be considered a priority in care delivery systems (Macdonald, 2008). All jurisdictions are working on the concept of the e-health record, for example. These efforts, along with putting technology in the hands of providers, will begin to address this incongruence.

The capacity for health professionals to provide adequate care depends also on their ability to gain necessary knowledge and skills for the procedures and care they are expected to provide. Other studies have noted that the knowledge, skills, and know-how required by providers for complex home care procedures (e.g., peritoneal dialysis and parenteral feeding) is not well described, and the level and quality of training must be examined (Lehoux et al., 2003). An increase in specialized clinical and management skills will be required as the home care sector continues to expand. However, as suggested by Denholm (2009), "traditional approaches for orienting, training, supervising, and supporting clinical and support staff are not effective when staff are not contained within the same four walls" (p. 35). Further research is needed to identify innovative and effective ways for those on the front lines to obtain and sustain competencies to provide safe quality care in the home.

The final source of incongruence identified in our study was that what clients and families expected to receive in terms of home care services and support often did not match what was actually provided or available. Previous research has similarly reported that increased demand for services in the home has not been matched by increases in resources (Forbes et al., 2008). In the absence of resources, home care becomes narrowly defined as simply medical tasks, and there is less ability to serve those with long-term chronic care needs requiring fewer non-medical services but rather require increased daily living supports. Family members and caregivers take on roles which they do not necessarily want to assume or for which they are unprepared; accordingly, caregiver overburden was identified as a significant concern. This finding confirms earlier research (Carretero, Garce, Rodenas, & Sanjose, 2009; Exley & Allen, 2007). Moreover, policy trends may be leading to expectations and obligations for families and caregivers for which they are unprepared and which could compromise their roles as a spouse, child, or sibling. Research is needed to understand how types and levels of care influence family roles, how responsibilities for caregivers can be negotiated, and what strategies exist that can support caregivers within varying contexts.

Limitations

The study's key informants represented western, central, and eastern Canada and are experts in the field of home care. Although there were a variety of participants, it could be argued that additional representation from visible minority communities would provide additional insights. Representation from mental health providers was not obtained.

Conclusions

Given that the demand for the number and range of home care services is projected to continue to grow, learning how best to protect clients, family members, caregivers, and providers is paramount. Exploring the perceptions of researchers, health care providers, policy makers, and decision makers helps us to map several areas for future research related to safety in home care. The four patterns identified in the study, which illustrate safety-related concerns, all warrant further research. However, three of these patterns merit particular attention.

First, the *fragmentation in services* created when multiple agencies are involved in delivery of care in a single home is a top-priority area. Comparative studies of satisfaction and care outcomes where single- and multiple-agency services provide care are warranted.

Second, *vulnerability* can be addressed through research on acceptable levels of home hygiene, transmission of infections modes, and deliberate mismanagement of medications. Abuse is also a dimension of vulnerability and one that is presently being addressed in part by media messaging to raise public awareness. For example national television regularly uses ads targeted to seniors and their family members describing financial, physical, and psychological abuse. Organizations such as the Canadian Association of Retired Persons also works tirelessly to raise awareness regarding abuse.

Third, *the gap between the support provided and the support and resources* expected by clients and families warrants research priority. Research with clients and families eliciting their perceived roles in home care is one place to begin, and this understanding then needs to be translated into programs to support client and caregiver roles in home care .

Finally, with regard to *"home as haven"*, the fourth pattern of safety-related concern, research is needed that explores how clients and families conceptualize the space they call home. The work of caregiving makes a valuable contribution to the home care industry and to the quality of life of home care clients. Studies that contribute to furthering our understanding of how to advance home care while respecting the home as haven will make a valuable contribution to home care safety knowledge.

References

Angus, J., Kontos, P., Dyck, I., McKeever, P., & Poland, B. (2005). The personal significance of home: Habitus and the experience of receiving long-term home care. *Sociology of Health and Illness*, *27*(2), 161–187.

Ballestine, N. (2008). Polypharmacy in the elderly: Maximizing benefit, minimizing harm. *Critical Care Nursing Quarterly*, *31*(1), 40–45.

Banning, M. (2009). A review of interventions used to improve adherence to medication in older people. *International Journal of Nursing Studies*, *26*, 1505–1515.

Baumrucker, S., Sheldon, J., Stolick, M., Oertli, K., Harrington, D., Vandekeift, G., et al. (2009). Providing care in an unacceptable environment. *American Journal of Hospice and Palliative Medicine*, *26*(6), 493–499.

Bussing, A., & Hoge, T. (2004). Aggression and violence against home care workers. *Journal of Occupational Health Psychology*, *9*(3), 206–219.

Canadian Home Care Association (CHCA) (2008). *Home care the next essential service: Meeting the needs of our aging population*. Mississauga, ON: Canadian Home Care Association.

Canadian Nurses Association (2009). *Maximizing health human resources: Valuing unregulated health workers*. Ottawa, ON: Canadian Nurses Association. Retrieved from http://www.cna-nurses.ca/cna/documents/pdf/publications/UHW_Final_Report_e.pdf

Carretero, S., Garce, J., Rodenas, F., & Sanjose, V. (2009). The informal caregiver's burden of dependent people: Theory and empirical review. *Archives of Gerontology and Geriatrics*, *49*, 74–79.

Coughlin, J., Pope, J., & Leedle, B. (2006). Old age, new technology, and future innovations in disease management and home health care. *Home Health Care Management and Practice*, *18*(3), 196–207.

Denholm, E. (2009). What's so special about home care? *Nurse Leader*, *7*(4), 35–37.

Erikson, J., & Millar, S. (2005). Caring for patient while respecting their privacy: Renewing our commitment. *Online Journal of Issues in Nursing*, *10*(2), 1–13. Retrieved from www.nursingworld.org/ojin/topic27/tpc27_1.htm

Exley, C., & Allen, D. (2007). A critical examination of home care: End of life care as an illustrative case. *Social Science and Medicine*, *65*, 2317–2327.

Fiske, S. (2004). Developing a program of research. In C. Sansone, C. Morf, & A. Panter (Eds.). *Handbook of methods in social psychology* (4th ed.) (pp.71–90). Thousand Oaks, CA: Sage Publications.

Forbes, D., Markle-Reid, M., Hawranik, P., Peacock, S., Kingston, D., Morgan, D., et al. (2008). Availability and acceptability of Canadian home and community-based services: Perspectives of family caregivers of persons with dementia. *Health Care Services Quarterly*, *27*(2), 75–99.

Gershon, R., Pearson, J., Sherman, M., Samar, S., Canton, A., & Stone, P. (2009). The prevalence and risk factors for percutaneous injuries in registered nurses in the home health care sector. *American Journal of Infection Control*, *37*, 525–533.

Gorwitz, R., Fridkin, S., & Worowski, K. (2008). More challenges in the prevention and management of community-associated, methicillin-resistant staphylococcus aureus skin disease. *Annals of Internal Medicine*, *148*(4), 310–313.

Grossman, S., & DeBartolomeo, D. (2008). Managing the threat of methicillin-resistant staphylococcus aureus in home care. *Home Healthcare Nurse*, *26*(6), 356–364.

Hall Ellenbecker, C., Frazier, S., & Verney, S. (2004). Nurses' observations and experiences of problems and adverse effects of medication management in home care. *Geriatric Nursing*, *25*(3), 164–170.

Health Canada (2004). *Home and community care*. Ottawa, ON, Canada: Author. Retrieved from Health Canada website: http://www.hc-sc.gc.ca/hcs-sss/home-domicile/commun/index-eng.php

Hogh, A., Sharipova, M., & Borgm, V. (2008). Incidence and recurrent work-related violence towards healthcare workers and subsequent health effects. A one-year follow-up study. *Scandinavian Journal of Public Health*, *36*, 706–712.

Kenneley, I. (2010). Infection control and the home care environment. *Home Health Care Management and Practice*, *22*(3), 195–201.

Lang, A., & Edwards, N. (2006). *Safety in home care: Broadening the patient safety agenda to include home care services*. Edmonton, AB, Canada: Canadian Patient Safety Institute (CPSI).

Lehoux, P., Pineault, R., Richard, L., St. Arnaud, J., Law, S., & Rosendal, H. (2003). Issues in high-tech home care: Sources of information and staff training in Quebec primary care organizations and relationships with hospitals. *International Journal of Healthcare Quality Assurance*, *16*(1), 37–46.

Leiss, J., Lyden, J., Mathews, R., Sitzman, K., Vanderpuije, A., May, D., et al. (2009). Blood exposure incidence rates from the North Carolina study of home care and hospice nurses. *American Journal of Industrial Medicine*, *52*, 99–104.

Levine, C., & Zukerman, C. (2000). Hands on/hands off: Why health care professionals depend on families but keep them at arm's length. *Journal of Law, Medicine, and Ethics*, *28*(1), 5–18.

Luker, K.A., Austin, L., Caress, A., & Hallett, C.E. (2000). The importance of 'knowing the patient': Community nurses' constructions of quality in providing palliative care. *Journal of Advanced Nursing*, *31*(4), 775–782.

Macdonald, M. (2008). Technology and its effect on knowing the patient. *Clinical Nurse Specialist*, *22*(3), 149–155.

McGoldrick, M. (2008). Infection prevention and control: Achieving a culture of zero tolerance. *Home Healthcare Nurse*, *26*(1), 67–68.

McGraw, C., Drennan, V., & Humphrey, C. (2008). Understanding risk and safety in home health care: The limits of generic frameworks. *Quality in Primary Care*, *16*(4), 239–248.

Patte, R., Drouvot, V., Quenon, J.L., Denic, L., Briand, V., & Patris, B. (2005). Prevalence of hospital-acquired infections in a home care setting. *Journal of Hospital Infection*, *59*, 148–151.

Payne, M. (2007). Safeguarding adults at end of life: Audit and case analysis in a palliative care setting. *Journal of Social Work in End-Of-Life and Palliative Care*, *3*(4), 31–46.

Proot, I., Abu-Saad, H., Crebolder, H., Goldsteen, M., Luker, K., & Widdershoven, G. (2003). Vulnerability of family caregivers in terminal palliative care at home: Balancing between burden and capacity. *Scandinavian Journal of Caring Sciences*, *17*(2), 113–121.

Radwin, L.E. (1996). Knowing the patient: A review of research on an emerging concept. *Journal of Advanced Nursing*, *23*, 1142–1146.

Reynolds, A. (2009). Patient-centered care. *Radiologic Technology*, *81*(2), 133–147.

Ski, C., & O'Connell, B. (2007). Stroke: The increasing complexity of carer needs. *Journal of Neuroscience Nursing*, *39*(3), 172–179.

Tanner, C., Benner, P., Chesla, C. & Gordon, D. (1993). The phenomenology of knowing the patient. *Image: The Journal of Nursing Scholarship*, *25*, 273–280.

Thorne, S. (2008). *Interpretive description*. Walnut Creek, CA: Left Coast Press.

Thorne, S., Reimer Kirkham, S., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing and Health*, *20*, 169–177.

Tracey, S., Drummond, N., Ferris, L., Globerman, J., Hebert, P., Pringle, D., et al. (2004). To tell or not to tell? Professional and lay perspectives on the disclosure of personal health information in community-based dementia care. *Canadian Journal on Aging*, *23*(3), 203–215.

Xanthopoulou, D., Bakker, A., Dollard, M., Demerouti, E., Schaufeli, W., Taris, T., et al. (2007). When do job demands particularly predict burnout? *Journal of Managerial Psychology*, *22*(8), 766–786.

Zanoni, J., Kauffman, K., McPhaul, K., Nickels, L., Hayden, M., Glassman, M., et al. (2007). Personal care assistants and blood exposure in the home environment: Focus group findings. *Progress in Community Health Partnerships: Research, Education, and Action*, *1*(2), 125–131.