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Article

Researching Triads in Home Care: Perceptions of Safety From Home Care Clients, Their Caregivers, and Providers

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Abstract
Home care demand in Canada has more than doubled in recent years. While research related to safety in home care is growing, it lags behind that of patient safety in institutional settings. One of the gaps in the literature is the study of the perceptions of home care triads (clients, their unpaid caregivers, and paid providers). Thus, the objectives of this qualitative study were to describe the safety challenges of home care triads and to further understand the multiple dimensions of safety that contribute to or reduce safety concerns for these triads. Findings indicate that clients, unpaid caregivers, and providers struggle in the home care system. Home care models that are client centered need to be considered to provide seamless, quality, sustainable home care.

Keywords
homecare, home care, safety, clients, caregivers, providers, Canada

Introduction
Home care in Canada grew by 55% between 2008 and 2011; as of 2011, there were 1.4 million home care recipients and 5 million family caregivers in Canada.1 Although acute institutional care in Canada is an insured service under the Canada Health Act, and recipients receive the care required at no direct cost, home care is not part of the Canada Health Act.1 Canada is divided into 10 provinces and 3 territories, each of which manages its own health care system through its provincial or territorial governments. Consequently the services delivered across the country differ dramatically in terms of service models and funding structures.2 Home care in this study encompasses publicly funded professional and nonprofessional support services delivered to clients living with chronic illnesses in their own homes.

Patient safety has been a long-standing priority area in institutional settings. A focus on safety in the home care setting has been more recent including safety concerns from the perspectives of home care clients, unpaid caregivers, and paid providers.3-9 The contexts and services of home care compared with that of the institution are quite different, thus requiring different approaches to examining safety.10 A foundational report titled Safety in Home Care: Broadening the Patient Safety Agenda to Include Home Care Services11 cosponsored by the Canadian Patient Safety Institute (CPSI) and Victorian Order of Nurses (VON) Canada (a national not-for-profit home and community care organization), led the way in identifying that addressing home care safety presents unique challenges and requires a reevaluation of underlying assumptions and guiding frameworks that have been used to examine safety in the institutional setting. The report outlined the following unique challenges: (a) safety of the client, family, unpaid caregiver and paid provider are inextricably linked; (b) the client/patient home setting is unregulated and uncontrolled in contrast to the hospital setting; (c) there are multiple dimensions of safety in home care, including physical, emotional, social, and functional safety; (d)

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there is greater autonomy for clients, families, and caregivers than what is experienced in hospital settings; and (e) a large percentage of clients receiving home care support are elderly and live alone.11 These realities were central in conceptualizing this research. In particular, the four dimensions of safety (physical, emotional, social, and functional) are used as a conceptual framework in which to organize the findings of this study.

Baker and Norton’s ground-breaking study12 on adverse events in hospitals in 2004 opened Canadians’ eyes to the issue of patient safety. It also sparked action, including the launch of the CPSI. It was not long before concern mounted for the safety of another, growing group of vulnerable Canadian patients; those receiving care at home. In response, four leading Canadian research organizations, the CPSI, the Canadian Institutes for Health Research (CIHR), the Canadian Health Services Research Foundation and the Change Foundation formed a partnership to fund research on the issue. This study, Researching Triads in Homecare: Perceptions of safety from homecare clients, their caregivers and providers, is one of five projects in a Pan-Canadian Safety in Home Care study jointly funded by those partners. The pan-Canadian study in addition to the project outlined here consisted of a review of the international home care literature on adverse events; a database study in jurisdictions using the Resident Assessment Instrument for Home Care (RAI-HC) as well as hospital discharge databases; home care chart reviews in jurisdictions not using the RAI-HC; and analyses of sentinel events in home care in three jurisdictions. The overall aim of the pan-Canadian study was to provide valid estimates of safety problems among Canadian home care clients and help develop new methodology within home care research. The focus of this article is on the results of this study. ID is situated in the naturalistic paradigm that means researchers using this methodology do not ascribe to a singular objective truth; reality for study participants is multiple and constructed; a priori theory is not required; and the researcher is the instrument.14

Interpretive Description (ID) was the methodology used in this study. Id is commonly used in two of the three provinces involved in this study.

Objective

1. Describe the safety challenges or concerns of recipients (i.e., clients and unpaid caregivers) and paid providers of publicly funded home care services identify.

2. Further understand the multiple dimensions of safety that contribute to or reduce safety related concerns for home care triads.

This article highlights the safety issues identified in the data analysis of interviews with home care recipients and providers as well as focus group participants. Although home care research has revealed that those individuals who receive or provide home care services often describe positive aspects, strategies, and solutions in face of their safety concerns,4,6,7 the focus of this article, and the study which it was written, is about the safety implications of home care. In this article, we present the study methodology and methods, the results, a discussion of the results in relation to the conceptual framework informing the work, a conclusion, and further recommendations.

Method

Interpretive Description (ID) was the methodology used in this study. ID is situated in the naturalistic paradigm that means researchers using this methodology do not ascribe to a singular objective truth; reality for study participants is multiple and constructed; a priori theory is not required; and the researcher is the instrument.14

Recruitment

This multisite study had team members that facilitated the recruitment of potential participants living in their respective regions. Recruitment took place through health agencies where personnel could contact prospective participants to determine their interest in study participation. Those interested in participating were contacted by the researcher who explained the study, answered questions, and arranged an interview for those willing to participate. Consent was obtained prior to the interviews and focus groups.

Data collection

During 2011-2012 semistructured, face-to-face, audio-recorded interviews were conducted with providers, clients,
and caregivers. Client and caregiver interviews were conducted in the home and when possible separately, to allow for more freedom in speaking about their safety concerns. Provider interviews were scheduled at a time and place agreeable to the provider. A small number of provider interviews were conducted via telephone. Two focus groups in each province were conducted and audio-recorded; one with professional providers and a second with HSWs. Table 1 includes samples of interview and focus group questions.

Table 1. Examples of Interview and Focus Group Questions.

<table>
<thead>
<tr>
<th>Participants</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client</td>
<td>Do you feel like the people who are providing your care know you and your situation? Please give me an example. Safety can also include things such as your emotional well-being (e.g., your interactions with your family or caregivers). What are your experiences with these types of safety?</td>
</tr>
<tr>
<td>Caregiver</td>
<td>Would you please tell me about the person you are providing care for and how long you have been doing this? Tell me about your home and how you manage in it day to day. Are there things about your home that you would change if you could?</td>
</tr>
<tr>
<td>Client and caregiver</td>
<td>If you had a magic wand, what would you change, keep, or improve upon when it comes to your home care? You are the provider for Client X who we have interviewed: Describe who helps the client at home and what they need to do for the client. Do they have the help they need? Describe for me what you consider safety to mean. Describe what makes you feel safe about homes. Describe anything that makes you feel unsafe about homes. Describe for me the provider role in home care safety.</td>
</tr>
<tr>
<td>Provider (focus group)</td>
<td>Do you feel prepared for the work you are expected to do in home care? Tell me about the communication between the various people who provide home care. How do you find out who is involved in visiting the same client as you? Describe how the time allotted for your visits allows you to provide the care the client needs.</td>
</tr>
<tr>
<td>Provider (focus group)</td>
<td>What do you believe are the safety issues within home care? What are the top 3 safety priorities that need to be addressed? How has communication and coordination between you and other service providers impacted on safety in home care? How has communication and coordination between you and your client impacted on safety with your client(s)?</td>
</tr>
</tbody>
</table>

In this study, the photos were analyzed by Human Factors Engineers (HFEs). Human Factors (HF) is a branch of learning that considers “human capabilities and limitations in the design of interactive systems of people, tools, technology, and work environments to ensure their safety, effectiveness, and ease of use.”15(p. 229) In the case of home care, HFEs understand the need to examine all factors at play and the potential threats to quality and safety through the analysis of mismatches in provider/caregiver/client capabilities, care processes, medical devices and other equipment, and the physical environment in which care takes place.18 Utilizing visual methods and HF analysis in home care research requires further discussion that goes beyond the present article; as such the authors are in the process of creating a separate paper to report on this topic. However, the findings of the HF analysis were congruent with the narrative findings regarding the common safety challenges existing in the homes across all three provinces.

**Sample**

Clients who were actively receiving home care services in their own home for a chronic illness (mainly congestive heart failure [CHF] and/or chronic obstructive pulmonary disease [COPD]), their caregivers, and providers were eligible to participate. This ensured that the client, caregiver, and provider knew each other, as well as the client’s circumstances and could speak to the common contexts of the particular home care situation. Thus, in each of the three provinces six home care triads were interviewed, for a total of 56 interviews (in two triads an additional provider was interviewed). Most of the clients were women (72%) with a mean age of 71.6 (range = 28-96) while nearly half the caregivers (53%) were men with a mean age of 67.1 (range = 36-93). The providers were split evenly...
between professionals (mostly respiratory therapists and nurses) and HSWs all of whom were predominantly women (90%). The mean age for the professionals was 46.6 (range = 30-61) and 47.4 (range = 24-64) for the HSWs. In addition, 13 professional providers and 19 HSWs also participated in focus groups.

**Data Analysis**

Our intention is to present findings that link directly to the safety concerns that were identified by participants. To do this, we have used the four dimensions of safety as outlined by Lang and Edwards\(^1\) as a conceptual framework for the overarching organization of our patterns. Lang and Edwards called for “broadening of the conceptualization of client safety” to one that would “expand the definition of safety in home care beyond the physical to include the emotional, social and functional” dimensions of safety.\(^{11(p. 18)}\) These definitions can be found in Table 2.

The safety issues we present here represent not only client safety but also illustrate the interconnectedness of the safety of the client with that of their caregivers and providers. This interconnected safety perspective is what differentiates our study from other researchers who have reported findings that lack the perspectives and identified safety concerns of home care triads.\(^4,6\)

Analysis was iterative and concurrent with data collection in that we compared each interview with subsequent interviews for converging as well as diverging patterns. The interview and focus group recordings were transcribed verbatim and uploaded into a qualitative software program (NVivo). Two researchers coded the interview and focus group data, identified patterns, and the relationships among the patterns. The photo narrated data were coded in a similar fashion by two members of the team including a HFE. Each jurisdiction had a lead investigator who coordinated and participated in the local data collection, and analysis. The team convened regularly to identify recurring, converging, and opposing patterns in the data.

**Limitations**

Involving all Canadian jurisdictions would enhance confirmability and transferability of the findings of this study. However, as this project was one among five in this pan-Canadian study examining safety in home care, the triangulation of findings across projects will help to address this limitation.

**Ethical Considerations**

This study received ethical approval from two universities, three health authorities, and one home care agency.

**Results**

Six patterns related to safety concerns in home care were identified from the analysis of the data for the three provinces involved in this study of home care triads. These patterns were as follows: (a) Doing What It Takes to Stay at Home; (b) Rationing Oxygen, Rationing Living; (c) Duty Creep and Losses: How roles change; (d) The Unacknowledged Challenge: Taking care to the home; (e) The Shared Decay of Health at Home; and (f) System Design Issues: Built-in barriers to safe care. Direct quotes from participants are used to illustrate the patterns identified. To support participant anonymity speakers have been identified only as client, caregiver, provider, or professional provider and HSW when distinctions need to be made clear. While we have listed these patterns separately, it is important to recognize that patterns do overlap but not to the extent that we could collapse them any further than presented here.

**Functional Safety**

Doing what it takes to stay at home. Staying at home and maintaining some degree of independence, control, and normalcy was vitally important to clients and their caregivers, and they were willing to accept many challenges to make that possible. Clients in two provinces in particular spoke of their wish to have as normal a life as possible, to limit the number of “strangers” (health care providers, regulated and nonregulated) entering their homes, and to have enough time on their own. They were willing “to live at risk” beyond the point of safety for themselves, their caregivers, and providers to avoid moving into some type of residential care. Doing what it takes to stay at home was articulated by one caregiver who explained,
[Client] could probably use more (home care services) but she could only get that living elsewhere, and she doesn’t want to do that. So I think she’s getting everything that she can get under the system right now.

Further evidence of this pattern was exemplified by the existence of home care agency contracts that clients who were believed to require a move to assisted living were asked to sign if they declined the move. One provider explained to us that a client “had signed a letter stating that she totally understands the risk of what she’s doing and she wants to continue living in the community.”

Providers in these two provinces said clients and caregivers hid their difficulties in trying to manage at home, and some even limited access to providers for fear the client might have to move into an assisted living arrangement. At the same time, clients and caregivers were aware and worried about the caregiver’s declining health and its impact upon the clients’ independence. Clients recognized their need for help to remain independent would grow, as one client explained,

I know that there will be more help as I need it; that will be good, because I don’t want to have to go into a home. I don’t like it. Throw me down the river.

Doing what it takes to care for someone at home also means mutual acceptance of increased reliance by clients and increased responsibilities by caregivers. Clients told us they relied on caregivers for assistance with everything from personal hygiene and housework to transportation, managing medication, arranging home care, handling finances, and keeping up a social life.

A choice to stay in the home also required adapting the environment, from transforming a living or dining room into a bedroom to installing equipment (such as commodes, bath chairs, grab bars, ramps, oxygen concentrators, and alarm systems). Clients and caregivers bravely continued doing what it takes and assured providers they were managing. For instance, one caregiver reported,

It’s a little tough bathing her [client] at times for me because it’s hard on my back, I’m going on 83. I can’t last forever either. But we get along pretty good me and [Client].

In the course of doing what it takes to stay at home caregivers were mindful that what they were doing was courting some risk. Providers recognized the growing risk assumed by clients and caregivers; one provider reported “one of the things that I hear caregivers talk about certainly when I work with these populations is sort of how much risk can we or can I manage at home.” Providers stressed the importance of establishing good working relationships with caregivers and recognizing the pressures and hazards they face.

This pattern illustrates the functional dimension to home care safety. As a client’s health condition worsens, it can affect their ability to manage daily activities thus relying more heavily on their caregivers for assistance. If the home care model and care provision in place cannot meet their needs within the home, clients and their caregivers worry about having to leave home and move into long-term care facilities. This places the client and caregiver in situations where they are willing to live at risk placing their safety in jeopardy as they struggle to stay in their home.

Rationing oxygen, rationing living. In two of the provinces, the majority of clients were diagnosed with COPD and were prescribed oxygen therapy. All were provided with provincially funded home oxygen. However, while clients had as much oxygen as they needed at home, where the stationary oxygen concentrator was located, portable oxygen supplies were only partially paid for by home care services. In one province, home care provided two portable oxygen cylinders per month which was reported by participants as sufficient enough to get to medical appointments, but not much more. The situation was similar in the second province. This meant clients who wanted to remain physically and socially active required supplementary health insurance or the ability to pay out of pocket to get the oxygen they needed. One provider reported,

To go to a doctor’s appointment, to go out for dinner to their son’s for the evening, or to go for the day they need to be on oxygen, all those portable tanks cost them. And a lot of these people don’t have Blue Cross or Manulife Insurance coverage; some of them do, some of them don’t. But this is where a lot of the cost comes in.

Clients described feeling “tethered to a machine in the house” which increased their sense of isolation. Some clients resisted commencing oxygen therapy as one explained,

She [provider] wanted me to go on oxygen. I said “I can’t because I’m working.” I was trying to do some work, and working out. And I couldn’t go on oxygen now. But then when [new provider] came on, she said, there’s nothing we can do. You’ve got to go on oxygen.

Clients participated in outside activities, such as going for groceries, or mowing the lawn, without using their oxygen because they feared using up their portable cylinders. That placed them at risk of becoming breathless or losing consciousness, and the consequences could be even more serious if the client were driving.

Providers recognized the limitations placed on portable oxygen and the negative consequences for their clients. One provider explained that ending oxygen rationing would be good for clients:
Because if you can allow them to get out of the house and even just go for coffee or go to the grocery store that would just do so much to improve their mood and to make things easier for them.

The use of oxygen on an as needed basis also helps to maintain the functional abilities of the client longer.

This pattern is also an example of the functional dimension of safety. Certain health conditions, like COPD, require oxygen treatment and yet the present provision of care is organized to restrict that treatment to the home, thus affecting the daily activities of home care clients. Many home care clients wanted to be active and felt restricted by the limitations placed on portable oxygen. These restrictions caused safety concerns as some clients were continuing to be active without the use of oxygen risking exacerbations and endangering themselves and others, particularly if they were out driving or operating machinery for work or lawn care. In addition providers worried that clients who were bound to the home through oxygen therapy may be at risk for depression and anxiety. It should be noted that the functional dimension of safety interconnects with the emotional in this pattern, as there is a psychological impact on clients who are restricted to the home by their oxygen treatments.

**Emotional Safety**

*Duty creep and losses: How roles change.* Living with chronic illness brings a multitude of changes and transitions. Participants said those transitions resulted in an ever increasing number of tasks and responsibilities for caregivers as clients’ abilities, independence, and freedom declined. There was pressure for caregivers to take on new, and often more demanding roles to manage the changes. We called this “duty creep,” and caregivers told us that combined with the stress and worry of the illness they increasingly felt the pressure of all the responsibilities.

We heard that as a client’s illness progressed, caregivers’ new and mounting responsibilities included managing medications, equipment, home care visits, and medical appointments; giving baths and personal care; preparing meals; cleaning; doing dishes, laundry, and exterior household maintenance; getting groceries; handling banking and financial management; and keeping the client, family members, and providers up to date. All this was expected, regardless of the caregivers’ age, personal health, work obligations, or family situation.

Adapting to transitions coincided with experiencing a multitude of losses for both client and caregiver. Many clients felt housebound and had to rely on friends and family for outings and social activities. Many clients mourned their loss of independence and decline in social activities. For example, one client shared,

I used to go to line dancing twice a week. And I miss that. Nobody knows how much I miss it. And all my friends, I talk to them a lot. But I don’t get dancing anymore.

Clients also felt frustrated in not being able to complete simple tasks such as laundry, dishes, and other household chores. One client illustrated the limitations of advancing illness:

Well, the home care has just started the past month because it’s hard for me to do anything, to breathe and stuff. So like making the beds and stuff now, if I pull one sheet up then I’ve got to stop. And then take a few minutes and do it again. But floors and stuff like that, I can’t do.

Dependence on others was not easy for clients and was made clear by a caregiver who stated “she gets really stressed when it’s to do with her care because she can’t do anything. She’s at the mercy of anybody that comes in there.” Caregivers also experienced a loss of autonomy and freedom as their responsibilities increasingly made them feel they had to be available 24 hr a day. Many stopped working, or gave up favorite activities as the client’s illness progressed. One such caregiver shared feeling a loss of independence while also a sense of duty to the client:

I think I said a little while ago about being a free bird to do whatever I wanted for years and that has stopped. I don’t know how somebody else would handle it. But I myself right now am dealing with it and I haven’t had any difficulties yet. But it’s like almost like being tied . . . No, my duty is right here to do the best I can and that’s what I’m trying to do.

These losses and mounting responsibilities changed roles at home. Clients expressed hardship adapting to the sick role after having worked and been active, and even after being caregivers themselves. Caregivers said caring changed their relationship with the client. Some tasks just seemed wrong to caregivers, one of whom stated “I don’t think a daughter should have to help her mother have a bath or shower, she’s got to be entitled to her dignity.” Despite the mounting responsibilities, losses, and role changes, caregivers again felt a sense of duty or obligation and expressed this in saying “she has been a very special aunt to us. She looked after our youngest daughter right from when she was a baby. So it’s our turn to look after her.”

The sense of duty was both internal and external. Providers confirmed they often expected caregivers to take on tasks regardless of their age, health, or life situation, even when they knew the request caused stress, and potentially hurt their health:

I mean definitely, you know, just the managing medication sometimes, things like that, we’ll ask the caregiver, either the spouse or caregiver to sometimes ensure that they are taking their medications properly . . . So we’ll ask them to be involved.

Another provider explained,

I had one lady who said I’m so tired, and the doctor . . . She was in the hospital and said she wanted to stay. He said, “Your husband needs you.” And she’s 85.
Managing both a sense of duty and loss of freedom caused some distress for caregivers, but also the clients who recognized their increasing dependence on caregivers and felt they were becoming a burden. Clients felt increasingly more isolated and expressed a sense of anxiety as their health conditions worsened. The emotional dimension in coping with Duty Creep and Losses leads to negative health outcomes such as depression and anxiety for clients, and physical and emotional exhaustion for caregivers, which in turn can lead to errors in managing care at home.

**Physical and Social Safety**

The unacknowledged challenge: Taking care into the home. Many clients who were sick enough to need home care were not well enough to clean and maintain their house or apartment. This meant clients and their caregivers sometimes lived in surroundings that were less than pristine and deteriorating. At the same time, providers found themselves spending their workdays in conditions that would not be accepted in a hospital or nursing home. Unlike institutions, there are no standards to ensure homes meet specified cleanliness or maintenance standards for either a client or a professional. Our research found this unacknowledged challenge was important in all three provinces.

A well-kept house was perceived as important for clients in two provinces. Some said support with cleaning kept the dust down, resulting in fewer respiratory problems, while others said “keeping up the house” added to their health and well-being. Providers saw cleanliness differently, generally agreeing that clients and their families should assume some responsibility for maintenance and keeping the home clean. This was captured in the words of one provider who stated,

> I’ve been put in situations where things have been left un-cleaned for long periods of time, and it would be a reasonable expectation on the part of home care that the house be cleaned professionally by the clients or their families.

Providers had some specific safety concerns about working in peoples’ homes, including long-term exposure to cigarette smoke; clients smoking near oxygen; unrestrained dogs; the presence of drugs or guns; and the state of driveways, walkways, and stairs (particularly in winter). Two providers explained,

> It’s the unpredictability piece I guess that would be the most difficult to manage . . . even walking up to the entrance, is it shoveled, is there something sprinkled for the ice . . . is there somebody smoking in the home, have they stopped smoking for that period of time, you know, prior to us coming and going?

Even though we have a safe workplace agreement that every client must sign, the majority of patients do not put their pets in another room or tie them away from the door. They’ll say, “Oh, they don’t bite,” or, “They’re very friendly.”

Providers told us their challenges ranged from bedbug infestations to working in unsafe neighborhoods, so they felt little or no control in the homes where they worked. There was a consensus that providers needed to feel safe to deliver safe care.

In all three provinces, providers mentioned safety issues that affected clients and caregivers, including clutter, scatter rugs, and cramped spaces where clients had to move about:

> And I mean clutter you have a hard job maneuvering around things. And you’ve got seniors that some of them are very fragile and half the time their vision is poor. And you know, they’re wandering around sometimes in the middle of the night with not adequate lighting, no nightlights. You know, they’re tumbling.

There were also problems with equipment intended to assist clients with their health, mobility, or safety. We were told that long waits for funded equipment placed clients at risk as they continued on without the needed equipment or supplies. In other cases where clients had the means to purchase equipment privately, they also faced risks of buying equipment without an expert assessment to ensure the item was the correct choice and fit. One provider reported,

> And here they get their equipment from the local pharmacies but is staff trained? When someone comes in and they say they want a walker, when they want a cane even, it would be nice to have that staff say, “okay, you’re going to buy a cane for yourself, let’s see what’s the proper length.” You know, having that knowledge.

Equipment was also reported as a barrier to safety because it was not designed for the home environment. The HF analysis illustrated mismatches between people, tools and environments. One of the biggest unacknowledged challenges in home care was trying to fit equipment designed for institutional care into private homes. Wheelchairs needed space to maneuver, walkers did not work well on carpeting, oxygen tanks and their tubing took up space and were a tripping hazard. Electric scooters, intended for outdoor use, were stored in the home, leaving little space and one client explained “it’s difficult to get in and out the door. It’s difficult to get in the bloody elevator. It’s difficult. I’m just tired of it, you know.” Clients often did not know how to use equipment safely or avoided using it. HSWs also said they were not routinely trained? When someone comes in and they say they want a walker, when they want a cane even, it would be nice to have that staff say, “okay, you’re going to buy a cane for yourself, let’s see what’s the proper length.” You know, having that knowledge.

> The people that installed it [lift] didn’t install it very well and it ripped out of the ceiling . . . I just pretty much fell back in bed, and the motor and the bar came down on me, it also hit a [live-in worker] too.

Providers cautioned, however, that clients were in control of their own environment, which limited providers’ influence:
You know, I just find there’s so many things that are out of our control that’s difficult. You know, we have recommendations and we see the safety issues and we want to deal with them but the client doesn’t always necessarily agree with those concerns or they don’t necessarily feel that it is a concern.

This pattern of unacknowledged challenges for home care clients, caregivers, and providers has direct safety concerns to all those involved. Providers may find themselves in neighborhoods or homes they feel are unsafe either structurally (rotting steps, high degree of clutter), physically (smoking in the home, pets), or emotionally (abusive clients or family members, stress in not having control over working environment). At the same time, clients and caregivers are managing their health conditions, numerous providers coming into their home needing to know or learn from them about equipment, medications, and other required treatments in addition to maintaining their homes. The potential outcomes include physical harm (through trips and slips or medication and equipment errors), to emotional or psychological distress, anxiety, and exhaustion. This pattern thus encompasses both the physical and social dimensions of safety.

**Physical, Functional, and Emotional Safety**

The *shared decay of health at home*. As clients’ health declined and their ability to manage decreased, they relied more and more on their caregivers; often increasing demands to the point where the caregiver’s own health began to deteriorate. Shared decay of health was considered a safety issue in all three provinces. Clients with COPD and/or CHF talked about struggling to breathe and the difficulty they had relying on family caregivers or HSWs to assist them:

> It’s very hard to get short of breath, choking. You can’t breathe. But what should you do? So my daughter is helping me to dress up. But it’s too much work for her. She is retired and she has too much work cooking and washing.

Providers confirmed that anxiety often accompanied health decline in clients with shortness of breath and explained how a “client was getting more anxious which usually happened as the disease progressed because anxiety went along with the shortness of breath.”

Clients also expressed stress and worry regarding the health and well-being of their caregivers. They were fully aware of their ever-growing reliance on their caregivers, the added responsibility this caused and the potential for damaging caregiver health: “She [caregiver] has her own stuff and that’s a worry for me too because what’s going to take place if something happens to her first?”; “He’s [caregiver] 83 and he’s looking after me. I’m 76.”

Caregivers told us that illness and the inability to continue previously enjoyed activities played heavily on the minds of clients, affecting both the client’s and caregiver’s ability to appreciate the limited time they had left together. This shared decay was captured by a caregiver who observed the client is “not jolly anymore like she was before. She’s very serious, if I can call it that way. And that makes me that way too.”

The growing dependence and thus caring responsibilities, as well as witnessing decline in their loved ones’ positive outlook, weighed heavily on the shoulders of caregivers. As such, caregivers often experienced their own health issues in the decay of health at home while continuing to manage domestic duties and the health care responsibilities of their loved ones. As one caregiver explained,

> Oh, the thing is lately when I wash my . . . I don’t wash dishes every day. I wash dishes every other day. And lately I’ve been taking my walker and putting it next to the sink and sitting at the walker and washing the dishes because I can only stand so long.

The result is often a home involving not one home care client and a caregiver, but two potential home care clients struggling to manage home and health together. For instance, in illustrating the multiple health issues clients and caregivers manage together one caregiver reported,

> Now it’s my turn to look after [wife], I had a heart attack in 1981 and almost died. So she looked after me then and got me back to health. I had my prostate out in 2002. I had a triple by-pass in 2006, and I had radiation in 2008. So she’s taken care of me. Now it’s my turn.

Although caregivers, out of duty, obligation, or love as we saw in the previous pattern *Duty Creep*, take on the roles and responsibilities necessary for caring for their loved ones; the mounting cost to their health and their overall well-being is noteworthy. As the client’s health declined, and reliance on and responsibilities of caregivers increased, the caregiver may also face declining health. Thus, clients and caregivers run a risk of sharing the decay of health at home, consequently generating two home care clients within the health care system.

In the move toward increasing home care services, there is a risk that mounting levels of responsibility will fall to caregivers who may be aging and trying to manage their own health issues as well as those of the client. When a caregiver’s health declines, it causes safety concerns regarding potential errors in following the treatment and care plans of the client, which may lead to rehospitalization. In addition, the negative health outcomes experienced by caregivers could result in their own hospitalization, leaving the client wondering who will provide their care and assist in managing the home. Thus, there are implications within this pattern related to the physical, functional, and emotional safety of clients and caregivers.
Physical, Functional, Emotional, and Social Safety

System design issues: Built-in barriers to safe care. The way home care is designed and delivered can actually compromise safety. Delayed access to services, equipment, and medication was one issue. Others included scheduling home care visits, the certification and training of HSWs, and how well the home care organization communicated with staff and clients. The design issues varied across the three provinces.

Access to equipment. Home care recipients in all three provinces said their equipment needs were met to varying degrees in home care but, as we noted earlier, they reported challenges in accessing the equipment in a timely way. Sometimes getting equipment involved negotiating, filling out complicated forms, and/or long waits. One provider explained,

Maybe I’m just worried that sometimes he will just have a hard time to breathe. Because we already asked for a CPAP [continuous positive airway pressure machine] and we haven’t heard anything from them yet and it’s been almost three months.

In some cases, clients without supplementary medical insurance could not afford medication, portable oxygen, or other equipment. Providers explained that these delays could affect both the safety and well-being of clients and caregivers:

It’s not so much the commode or the little things but wheelchairs and things like that cost so much, they take so long. And the process of going through the funding is so great that while we’re going through that process of finding, procuring, getting the equipment, there’s skin breakdown. And that’s a huge safety issue.

Inconsistency in home care visits. Inconsistent scheduling of home visits and cuts in the time providers were allowed to spend with clients were cited in two provinces as contributing to safety issues. Clients and caregivers worried about inconsistency; one client reported,

[Home care] could send a different person every single day unless you stick up for yourself. If you don’t you have such a high risk of getting sick from bringing that many people into your house.

Providers also explained that poor scheduling resulted in many different staff entering the client’s home, which led to challenges including lack of continuity of care; clients and caregivers having to train providers over and over in terms of their unique situations and preferences and the risk that new providers would not realize when the client had a new health problem, or was declining. As one provider said,

Another problem is when they move you from clients, then you got new people in and they don’t see the changes in a client. They may have gone downhill in a week and now you got new workers . . . I lost all my clients and I had to start with all new clients, and all the clients have all new workers, so we don’t see the changes and we can literally lose our clients again overnight and we’re moved somewhere else.

Providers preferred to retain the same clients because of the importance of continuity in building relationships and knowledge which were essential to recognizing the pressures and hazards caregivers faced and how this affected the client. Providers said continuity was necessary for regular assessment and ongoing teaching so caregivers would recognize changes in the client’s condition:

So I find with caregivers that’s always a challenge for them and for us to try and help them, teach them sort of in your unique situation, you know sort of when do the flags go up or when is it more important to head for that Emergency Room versus waiting for the nurse to come later in the day, or calling the nurse or the doctor.

Certification and training of HSWs. Concerns were raised by professional providers, clients, caregivers, and HSWs in all three provinces regarding certification and lack of standardized training for HSWs. Variations in training meant HSWs often entered homes without adequate information or knowledge and this was made clear by a HSW who stated “I have to tell you the very first day I was called to do this shift we had absolutely no training. We had absolutely no idea what we were getting into.” Another HSW explained,

Many times they send people into cases that really shouldn’t be there. You know, if it involves using a lift, well, how do I use this thing? You know, you’ve got a lady in bed with MS and you’ve got a caregiver in here, “Oh, I’ve never used one of these things before.” So we need adequate training.

In participating provinces HSW training varied. In one province, some had training, while others learned on the job. In another, training offered by private colleges varied from 6 weeks to 6 months. One caregiver explained,

They [HSWs] all meant well. I have no complaints with that. But I think the training could be a lot better for them people. When you get privatization you know it’s just grab the money and run.

In the third province, HSWs had recently been told to seek their own certification to work in home care. HSWs without a certificate were limited in the hours and duties they could provide and described this by stating “they’ve downgraded our skills so badly that we need a nurse to train us to put a nitro patch on for every single client,” and “if a client buys something [medicated cream] off the shelf they
know they want it, and we can’t put that on them until the nurse trains us.”

Providers in all three provinces said clients faced long waits for services because HSWs were not adequately trained or certified and could not carry out certain aspects of care. Despite this, many HSWs went beyond their mandates to meet other needs such as applying nail polish, grocery shopping, or simply changing schedules to spend more time with clients.

**Organizational communication.** Communication between HSWs and their offices was a concern. In one province, HSWs had no standard format for documenting concerns and reported safety and client issues in conversation or by voice mail or fax. HSWs told us their calls were often not returned for 24 to 48 hr, which they felt was too long, considering how ill their clients were. HSWs referred to this as “calling the place that doesn’t answer.” In another province, there was a 1-800 line to call with concerns, but HSWs believed that nothing came of their calls, they joked that likely no one ever checked for messages.

HSWs also told us they were afraid to speak up too much about system issues or complain when clients ignored rules or policies, in case they had their hours cut, had clients taken away, or even lost their jobs. This often resulted in HSWs making their own adjustments to accommodate clients, or they remained silent to keep their jobs.

HSWs wanted policies and procedures for communication and documentation in homes and with their offices. They explained that documentation of care was not considered part of their work. Ultimately, the lack of communication and support they received from their offices left HSWs feeling unheard, discouraged, and helpless:

It’s like for example you have a client, you start a client, you voice his concerns like so many times in the beginning or whatever time it is and then six months down the road the CC [Case Coordinator] comes and does a visit, and why is this like this? And you’re thinking to yourself, well it’s been reported a long time ago (laughs).

HSWs in one focus group expressed feeling further exclusion because they were not invited to general team meetings or to case meetings involving the client and family members, although they were the ones in daily contact with clients and families:

They [supervisors/ agencies] have meetings, case meetings, and there’s never workers [HSWs] in those meetings, never the people who actually see these clients, never in a meeting, never make decisions for anything. Like we have no say in anything and yet we’re frontline.

Professional providers also reported communication and support problems with the organizations they worked for, and with physicians and clients as well. In two provinces, for instance, professional providers said office meetings tended to focus on procedures rather than staff support so opportunities to discuss health, safety, or cases in general were limited.

The system design issues presented here have direct and indirect safety links to home care triads. As we reported earlier, living without needed equipment and supplies due to issues around access can place clients and others at risk when clients continue to engage in activities or struggle to maintain some normalcy without the equipment. Inconsistency in home care can lead to missing changes in the client’s health condition, medication or treatment errors, as well as increased stress in having to manage multiple providers. In addition, the lack of standardized training of HSWs places clients at risk for poor quality care and also adds stress and anxiety to clients, caregivers, and HSWs who are trying to manage in settings they may know little about. HSWs who are afraid to speak up, or professional providers who feel there is a lack of communication, may not feel able to express their concerns about clients and caregivers and how they’re managing, or to speak of their own safety. This limits opportunities to avoid various hazards or mitigate safety concerns. System Design Issues encompass the four dimensions of safety; physical, functional, emotional, and social.

**Discussion**

In their foundational report Lang and Edwards\textsuperscript{11} pointed to the need for expanding the definition of patient safety to include the four dimensions of safety (physical, emotional, social, and functional). Although their focus was on patient safety, they also recognized that the safety of the patient, caregiver, and provider is inextricably linked. Using the Lang and Edwards\textsuperscript{11} framework of four safety dimensions we have organized our results gathered from home care triads to illustrate the multiple yet interconnecting patterns of safety concerns. We will now discuss the study findings in relation to the framework and to relevant literature.

**Framework: Four Dimensions of Safety**

Lang and Edwards\textsuperscript{11} identified from the outset that efforts to study safety in home care needed to be viewed through a lens that was different than that of the institutional setting. They recognized that clients are the masters’ of the home care workplace, but that safety could not be located uniquely with the client. In light of this, they advanced the four pronged framework of physical, emotional, social, and functional safety. Lang and her research team have subsequently directed their research efforts in safety in home care to study triads of those involved to respect the uniqueness of what they discovered in that very first study—that clients needed their family caregivers, family caregivers were struggling under the weight of increasing responsibilities, and providers were also struggling to provide seamless quality care. These


factors all contribute to the safety of the home care client and need to be examined within the triad unit of care.

The framework served to situate the patterns identified in the data analysis as well as to illustrate the overlap in patterns and how they related to the dimensions of the framework. Doing What It Takes to Stay at Home, and Rationing Oxygen, Rationing Living illustrated the safety concerns related to the functional abilities of study participants. Communicating to Canadians that supporting them to stay in their homes is a priority and scaling up home care resources to demonstrate this has the potential to address these patterns positively.

Duty Creep and Losses: How roles change illustrated how emotionally fragile participant triads may become as responsibilities mount. The dangers to physical and social safety were evident in The Unacknowledged Challenge: Taking care to the home whereby the home care triads are expected to make the delivery of home care work no matter how ill-suited the physical surroundings or the abilities of those involved. The Shared Decay of Health at Home captured how client and caregiver decline occurs and that it is not only physical but also functional and emotional. Considering an approach to home care in which optimal services are provided from the outset has the potential to slow client decline, maintain independence longer, slow duty creep, and to adequately support clients and caregivers to delay losses and to stay well much longer.

The pattern that was the most revealing and that cross cut all dimensions of the framework was that of System Design Issues: Built-in barriers to safe care. This is particularly instructive and a logical place to begin to make the most impact on safety in home care. These dimensions thus highlight that key elements such as equipment availability, continuity of care, training of personnel, communication, and home maintenance need to be standardized across programs and jurisdictions to mitigate safety concerns and provide environments for receiving and providing safe and quality home care services.

Findings Related to Relevant Literature

Three of six safety related patterns identified here parallel findings from earlier team work. The Unacknowledged Challenge: Taking Care to the Home highlighted the importance of the state of the home for care delivery and as a workplace for care providers. Findings from a pilot study of recipients of home care conducted in 2009\textsuperscript{19} also confirmed the importance of the home as a workplace, a care space, and the need to draw attention to helping recipients to keep up this space to be able to remain at home.

System problems such as equipment availability, continuity of care, training of HSWs, and communication difficulties were identified from the outset of the research conducted by this team\textsuperscript{11,20-21} and continue to surface in our research. It is important to note that these issues were also highlighted in the recent Health Council of Canada report on home care priorities for seniors in Canada\textsuperscript{22} as well as recent studies by the Nexus project\textsuperscript{3,5}. In addition, the Nexus project has published similar findings on the unpredictability of the care setting for HSWs and how these staff members often go beyond their mandates to personalize care for their clients.\textsuperscript{3,5} The other pattern that we have consistently found throughout our work to date and was also emphasized by the Health Council of Canada is that of the declining health of both client and caregiver.\textsuperscript{18,22-23} Although clients who have a chronic illness are expected to decline in health over time, the demands associated with their care often lead to the shared decay of the health of both the client and their caregiver. The pattern of duty creep and losses was not entirely new in findings of this study as Stajduhar\textsuperscript{24} in her research in palliative care reported the sense of duty that families feel in taking on the care of loved ones despite how extensive these responsibilities can be.

Two patterns identified in this study that represented new knowledge related to safety in home care were doing what it takes to stay at home, and rationing oxygen, rationing living. Although client and caregiver participants in two provinces reported doing what it takes to stay at home, this was not the case in the third province where home care recipients understood that the mandate of home care was to keep them in their homes as long as possible. This evidence points to the importance of policy related to the mandate of home care, resources channeled to home care, and the importance of communicating a commitment to providing care to maintain care recipients in their homes.

In two provinces, most of the care recipients suffered from either COPD or CHF and were oxygen dependent. Our previous work did not capture as many oxygen dependent clients. Knowledge generated in this study that client activity and socialization were restricted due to costs associated with portable oxygen is important and points to the need to lift restrictions on the amount of portable oxygen provided to clients. Permitting clients to fully benefit from access to oxygen at all times may well keep them stable longer.

The patterns identified were interrelated and therefore action will be important on all patterns simultaneously to address the safety concerns of home care recipients and providers. The dissemination of these findings will proceed through the Knowledge Translation plan that involved the larger pan-Canadian research team under the CPSI umbrella. In addition, the authors of this paper have applied for a Partnerships for Health System Improvement grant through the CIHR to move the findings into practice.

Conclusion

There are safety issues in home care. They include providing care in residential spaces not designed for it; waits for services, equipment, and providers; poor planning and communication by paid providers; heavy demands on family and friend caregivers; high turnover in HSWs; and failure to include home maintenance and repair in home care services.
The demands of looking after a chronically ill person can overwhelm family members or friends who provide the bulk of care. Sometimes their health declines too; sometimes they have to give up other activities in their lives. Home care organizations are struggling to coordinate and deliver seamless care within current models of care and resources, and need to include clients, their caregivers, and various types of providers as integral members of the care team. The identification of this set of safety related patterns, and in particular the pattern of System Design Issues, will give decision and policy makers areas on which to focus to meet the rising demand for home care, deliver the care clients expect, and to operate a safe and sustainable home care system.

Recommendations

We have made the following six recommendations in light of the research findings:

1. **Doing What It Takes to Stay at Home**: A “home first” policy is required to support people receiving care at home. This policy would include systems and resources that ensure prompt response to needs and concerns, effective communication, coordinated care, and a safe environment for clients, caregivers, and providers.

2. **Duty Creep and Losses: How Roles Change**: Offer caregiver training, educational resources, and ongoing support to provide care; create policies that ensure counseling for caregivers is part of home care services; and compensate caregivers for lost wages.

3. **Rationing Oxygen, Rationing Living**: Restrictions on portable oxygen must be lifted across health care models and expanded to include unlimited portable oxygen.

4. **Unacknowledged Challenge: Taking Care to the Home**: Policies and home care models are required that include the home in home care; meaning its security, cleanliness, and maintenance. These elements are integral parts of home care safety.

5. **System Design Issues: Built-in Barriers to Care**: There is a need to consider a model of care whereby each household has a professional primary care coordinator to ensure seamless care; better support for clients and caregivers; eliminate inefficient administration that delays care and puts safety at risk; increase access to programs, equipment, and different types of providers; and develop standard competencies for HSWs.

6. **Shared Decay of Health at Home**: Create routine assessments of caregiver’s health and well-being as part of home care; conduct ongoing reassessments of clients and caregivers that include updating and adapting care to their changing health needs.

Authors’ Contributions

AL and MTM contributed to the study proposal, ethics application reviews and revisions, data analysis, study report editing, and preparation of this manuscript; JS contributed to proposal development, ethics applications reviews, data collection, analysis, report writing, and review. LS contributed to proposal development, recruitment, data analysis, and findings review; TB, SR, LT, and CGC collected and coded data, participated in data analysis and report writing; MG in consultation with AE coded photographs and contributed to the HF analysis; DD and RB are the PIs on the overall study for which this project is one part and they have reviewed this manuscript; HL and SD provided feedback to the study team as they advanced in the data analysis process.

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