

Transitional Care for Seniors: What do Care Partners and Seniors Really Experience?

Veronique M Boscart¹ and Maryanne Brown²

¹CIHR/Schlegel Industrial Research Chair for Colleges in Senior's Care, Conestoga College Institute of Technology and Advanced Learning, Schlegel Centre for Advancing Seniors Care, 299 Doon Valley Drive, Kitchener, Ontario, Canada

²Clinical Leadership Services in Gerontology, Creating Gerontological Excellence, Warkworth, Box 29, Ontario, Canada

*Corresponding author: Veronique M. Boscart, CIHR/Schlegel Industrial Research Chair for Colleges in Senior's Care, Conestoga College Institute of Technology and Advanced Learning, Schlegel Centre for Advancing Seniors Care, 299 Doon Valley Drive, Kitchener, Ontario, Canada, Tel: + 519-748-5220 Extn: 2964; E-mail: VBoscart@conestogac.on.ca

Received date: Jul 25, 2018; Accepted date: Nov 27, 2018; Published date: Nov 30, 2018

Copyright: ©2018 Boscart VM, et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Abstract

Background: Current senior's care provided within the Canadian health care system is not often person-centred; nor is it always in accordance with gerontological best practices. Furthermore, gaps also exist in access to and continuity of care services, leading to poor quality of care and avoidable readmissions or setbacks in seniors' health or chronic care conditions. The impacts of these gaps are compounded when critical information is not transferred with seniors when they change care settings (i.e. transferring between hospital, home, retirement communities, etc.). Research suggests that seniors do not always receive resources required to support them through these transitions, and advocates for their needs.

Methods: This qualitative study's objective was to explore 35 seniors' and 25 care partners' care transition experiences in a suburban community, in Canada. This study is part of a larger project aimed at developing a better understanding of how to enhance care and transitions through identifying seniors' and care partners' perspectives of access to and continuity of quality care, and awareness and information availability during care transitions.

Results: A situational analysis revealed that several factors impede successful transitions for seniors, including not being listened to; needs being ignored; task-focused and splintered care; neglect of the care context; and absence of care continuity.

Conclusion: Transitional care is often not person-centred, does not follow best practices, and presents with several gaps in access to and continuity of health care services. These findings informed subsequent stages of the overall research project aimed at creating better transitions and care experiences for seniors.

Keywords: Transitional care; Seniors; Care partners; Continuity of care; Health systems; Person-centered care; Chronic disease

Introduction

Health care organizations, clinicians, researchers, and policy makers recognize a significant need to improve seniors and care partners' (i.e., families and/or friends) care transition experiences. Often, care and services provided before, during, and after seniors' transitions are not person-centred, lack chronic disease prevention and management (i.e., care standards in accordance with the latest evidence to support best outcomes) [1] and are not in accordance with gerontological best practices (i.e., care standards in accordance with the latest evidence to support best outcomes) [2,3]. In addition, several gaps exist in the continuity of seniors' health services. The impacts of these gaps are compounded when critical information does not transition with a senior when he/she moves to a different care setting [2]. Seniors and care partners' feedback suggests that their input and decisions are not always valued, and that they do not receive the resources required to support them through transitions and advocate for their needs [2]. In order to improve transitional care and promote person-centred transitions that are consistent with gerontological and chronic disease

prevention and management best practices [4], it was necessary to have a better understanding of seniors' transition experiences.

The overall goals of this three-year study were to increase positive transition experiences for seniors and care partners; improve seniors' access to and continuity of care; and increase information availability during care transitions. Study Phase one, presented in this manuscript, focused on exploring seniors and care partners' care transition experiences.

Background

Transitional care is often defined as the care provided when a patient is discharged from a specific care programme or location, or transferred from one care setting to another [5]. In reality however, discharge is not a single event; it is a stage in which health care professionals prepare a patient for relocation. Coleman defined transitional care as "A set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location" [2].

An economic trend to transfer patients rapidly from acute care to alternate levels of care requires all those involved to be informed about all aspects of the patient's care provision. As a result, policy makers have placed a strong emphasis on the transitioning process, and the preparation and education of patients and care partners [6].

Unfortunately, not all care transitions are supported by integrated care services. This lack of continuity can cause adverse outcomes, such as medication errors, infections, falls, or readmissions to acute care [6]. Seniors are at greater risk of experiencing poor transitional care because of frequent transfers, multiple co-morbidities, and a high number of health care professionals being involved in their care [7].

Research in this area is sparse. A systematic review of 17 studies on transitional care for dependent seniors discharged home from hospital found that most studies excluded patients who were frequently readmitted, such as those with dementia [8,9]. Seniors and care partners were not always involved in the transition and were left to their own devices to cope after the discharge had taken place [2]. Yet, most health care professionals did not consider discharge planning beyond their own care setting as part of their job [10]. Improving transitional care for seniors and care partners requires a good understanding of transition experiences, and facilitators of or obstacles to transitions.

Methods

This study employed a qualitative design to explore the transition experiences of seniors and care partners. To address this objective, data was collected from two groups: seniors residing in the community and their care partners. Prior to commencement of the study, a Research Ethics Board approved the study to protect confidentiality and participant rights.

Sample and recruitment

The sample was conveniently selected. Participants were invited from a local community by posting flyers in newspapers, community and senior centres, physicians' offices, home care agencies, hospitals, and retirement homes and communities (i.e., privately-owned residences that provide rental accommodation for seniors and makes at least two care services available). Investigators aimed to recruit 30 seniors who resided in the community; were 65 years of age or older; experienced one or more chronic conditions; had one or more healthcare transitions over the last 12 months; understood and spoke English; did not suffer from an acute medical condition or palliative illness; and had the cognitive ability to respond to questions as identified by scoring >2 on the Recall Score [11]. Investigators also aimed to recruit 15 care partners who resided in the community; provided care for a minimum of four hours a week to a senior; and understood and spoke English. Care partners were recruited in their own right. Interested seniors and care partners were invited to provide consent and participate in an individual semi-structured interview.

Data generation

All interviews were semi-structured and conducted by one investigator (MB) with extensive expertise in interviewing. Questions prompted for reason(s) for transitioning, transition experiences, support received, and successes and deterrents of transitions. Based on

participants' responses, the interviewer probed to further elicit clear, in-depth responses.

Data analysis

All interviews were transcribed verbatim. Identifying information was removed, and participants were assigned code numbers. Both investigators read the transcripts separately, using a situational analysis technique to identify phrases or concepts. This analysis aimed to understand a specific situation by exploring the social, cultural, and organizational context within which the phenomenon of interest was understood [12]. For this study, the analysis was organized under three main categories: transition experiences, factors that made transitions successful and factors that impeded transitions. Further analysis within each category produced key words and phrases indicative of factors influencing participants' perspectives. During team meetings, both investigators developed themes and subcategories, and compared data for similarities and differences.

Results

Demographic information

Twenty-six seniors and thirteen care partners were recruited. Seniors ranged in age from 65 to 70 years, equally balanced for gender. Seniors' number of transitions ranged from one to eight, with the majority reporting five or more within the last year. The majority of these transitions included home to hospital, hospital to retirement communities, or home with services. The seniors described their health as good or very good, yet reported at least two chronic conditions.

Care partners ranged in age from 60 to 70 years. The majority reporting seven or more transitions for the seniors they cared for. Most care partners described the seniors' health as good to excellent.

Transitional care experiences

Before discussing the qualitative themes, some patterns that were presented should be highlighted. Seniors and care partners described coping with different health care needs. Care partners' challenges were often ongoing and of long duration (i.e., years). Several care partners were also care recipients. Lastly, while the themes are reported as discrete groups or concepts, data suggests that these themes are not simple lists of recommendations but complex factors at interplay with each other.

Overview of themes

The analysis revealed several distinct themes (Table 1). Participants' feedback was categorized into six subthemes: Knowing what is needed and negotiating the health care professional's response; Being listened to (or not) when expressing care needs; Hoping for relational approaches as a framework for care; Experiencing the health care system as a limitation of care delivery; Recognizing chronic disease; and Understanding health care professionals' limited control. Care partners' experiences were grouped into the following subthemes: Dismissing partners in care; Care partners' health problems; and Financial and transportation barriers.

Seniors	Care Partners
1. Knowing what is needed and negotiating the HCPs response	1. Dismissing Partners in care
2. Being Listened to (or not) when Expressing Care Needs	2. Coping with Caregiving
3. Hoping for Relational Approaches as a Framework for Care	3. Managing Financial and Transportation Barriers
4. Experiencing the Health Care System as a Limitation of Care Delivery	
5. Recognizing Chronic Disease	
6. Understanding HCPs' Limited Control	

Table 1: Overview of themes in care transition experiences.

The following are the themes identified in seniors' and the care partners' interviews through the analytical process.

Theme 1: Knowing what is needed and negotiating the health care professional's response

This theme relates to seniors and care partners' clear articulation of their needs, and discussions had with health care professionals to convince them of those needs. During interviews, seniors and care partners described specific care issues they needed support with. Examples included physical care, depression, pain, and nutrition. Not only did seniors and care partners express their needs and the type of care or services they required, but the support they requested was often minimal. An older woman with Chronic Obstructive Pulmonary Disease (COPD) described her home situation, while caring for her husband who had experienced a stroke in the past year:

"I phoned the [Home care Agency] and just checked if I could get some help with the vacuuming... [Husband] used to do this for me as with the COPD, I find it hard. So I phoned to just check to see... If I could get some vacuuming. Nope, I'm not the patient. If you weren't the patient and you're not able to do it... Even if those were the things that [Husband] was doing previously" (Senior-35/Care Partner-36).

It was difficult and, at times, frustrating for participants to understand why requests for minimal help were refused.

Another finding is related to seniors and care partners' ongoing needs. Many seniors lived for several years with a gradual decline of health, sometimes interjected with acute events. They described it as a process of "taking stock" and making decisions about help that would be needed in the near future. Therefore, by the time they reached out to an organization or health care professional for help, they knew exactly what type of services they needed to continue living with chronic disease.

An 87-year old widow described her future needs clearly:

"All they have to do is either give me a bath or a shower, and make sure I get dressed. I prepare mostly on my own" (Senior-3).

An 88-year old lady who cared for her 84-year old husband at home stated:

"When the time comes, we will need some transportation, because of our age and also because my husband being the driver now, his time is limited. So I know there will be a need for transportation" (Care Provider-11).

This care partner had carefully thought about the future, and knew exactly what services would be required to continue living at home.

When health care professionals entered this precarious balance, a negotiation took place between the different players. Seniors and/or care partners expressed what they needed to health care professionals and health care professionals provided a response, outlining the help they could, or, in some situations, could not, provide. Given seniors' well-articulated needs, one would assume that it would be rather straightforward for health care professionals to decide on what the priorities were in these situations. Yet, participants indicated that health care professionals were often not responsive to the articulated needs. Seniors and care partners talked at length about health care professionals' responses to their questions. These responses seemed to fall in one of the following three 'categories.'

The first category encompasses responses given by health care professionals that left seniors and/or care partners with the perception that the need was not recognized as a "real need" and was subsequently dismissed by the health care professional. This left the senior with a feeling of despair. This 82-year old woman lived independently, had several comorbidities, and was diagnosed with severe clinical depression. She described the response of a health care professional when asking for help with groceries:

"I don't know what she was. I think she was a social worker. She gave me things that I could do to help myself. You know, "think positive" and I thought "For God's sake, lady, I've gone past that stage." I was in the depths, not talking to anybody, not leaving the house for weeks on end, crying if I met anybody, and you tell me just to pie it up [deal with it]?" (Senior-4).

A dismissal of one's needs by a health care professional was perceived as disrespectful and left the senior feeling misunderstood.

A second category of responses given by a health care professional when confronted with a senior and/or care partner's appeal for support fell into the category of health care professionals ignoring the need and proceeding to identify another, different need. This left the person who reached out for help frustrated, as not only was the call for help not perceived as valid; the actual issue was not resolved. This negotiation was in addition to the seniors or care partner having to explain to the health care professional that the other issue was well known and managed and not a priority at this time. This 81-year old husband, caring for his spouse with severe Alzheimer's disease at home, described this situation:

"She fell on her shoulder and she was really hurting...the ambulance came and took her away... I'm not allowed to go with her. So 8.30 pm, I phoned and got the doctor [ER] and he said: 'Come and get her, we can't do anything for her.' I said: 'What's going on?' 'Well,' he said, 'She doesn't know where she lives and she doesn't know what year it is.' I said, 'Well, what the hell does that have to do with pain?' He said, 'we can't do anything for her, she needs to get assessed for dementia, come and get her.' If I would have seen that doctor that day I would have punched him. I was so mad. So I drove to the ER and got her in my car...and I brought her home and I was taking Tylenol for something so I gave her Tylenol. She was in so much pain and her shoulder were swollen and blue" (Care Provider-26).

This man was confronted by health care professionals who did not recognize that his wife was in pain; the health care professionals informed him of his wife's confusion and need for a cognitive assessment, while she had been diagnosed with Alzheimer's disease many years before. This care partner was angry that the health care professionals did not value his concerns.

Lastly, there is a third category to capture health care professionals' responses to an expressed need. This category consists of responses where the health care professional recognized the expressed need; yet no services were delivered due to system issues. These issues were related to the limited availability of services needed, or to a lack of communication between the different healthcare services and agencies. For example, an older man, caring for his spouse with Alzheimer's disease at home, described:

"We encountered this a lot when [spouse] was slipping into severe anxiety and we were trying to find effective treatment. There was a case where the doctor referred us to [named local service]. We heard nothing for weeks. When we went back to the doctor, she said "Oh, they said [spouse] was too far gone for them to effectively intervene so they bounced it back to me". Well, nobody told us that. ... By the time we actually got an appointment, [spouse] had been to the ER twice" (Care Provider-31).

In this situation, lack of communication with the care partner led to a concerning delay in services.

Overall, this first theme demonstrated seniors' and care partners' strength in articulating needs and defining priority concerns they needed support with. Most care needs were the result of the seniors' decline because of chronic illness (es), so regular home-care support could be coordinated. Despite the clearly voiced needs, seniors and care partners described their requests as being ignored or not responded to. In some situations, care was delayed or withheld, or seniors and care partners received an inappropriate service.

Theme 2: Being listened to (or not) when expressing care needs

An overarching theme that emerged as seniors and care partners' described transition experiences was the perception of not being listened to. This theme has several subcategories.

Feeling ignored by health care professionals: Seniors and care partners described their experiences with health care professionals not listening to their experiences and symptoms, and how this made them feel. Seniors and care partners expressed feelings of sadness, rejection, frustration, and anger. A 78-year old woman described the experience of being ignored in a hospital, caring for her husband who suffered a major stroke that ended with his passing:

"Sometimes, you felt unimportant, you felt like you were just another body... You weren't at the head of the list of urgency today. There was times you felt really unimportant and there is always people worse off than you, for sure. But still, you should not be made to feel that way. You don't like to feel you are another number in the system" (Care Provider-35).

Although this experience had occurred several months before, the participant was emotional in recounting this story. She did not understand why health care professionals would not acknowledge her.

Participants also talked about not feeling listened to when trying to explain a specific issue to a health care professional. Seniors and care partners know their health status well and because of their familiarity with the chronic illness, were able to pinpoint a problem or single out a changing symptom. When the senior and/or the care partners decided to explain the situation to the health care professional, they hoped for a response demonstrating an acknowledgment and understanding of the issue. However, several participants described how health care professionals did not take the time to listen when they talked about a symptom or worsening situation.

One participant describes this:

"I was breathless. And I was puffing and panting and thought: "I don't know what this is." And I could not sleep at all. I was sitting up and I thought I better go and see someone. And our doctor has a complicated set-up. You can phone to set up an appointment but you can never get through. So, I went to the hospital and they had me do all kind of tests and then they sent me home. And I sat in that chair all night because I could not lie down to sleep. I knew something was wrong... and the respirologist said [4 weeks later]: "You have asthma," so he got me on inhalers and it is better now. But I wasn't impressed with being sent home. I'm 80-something, and I live alone, and I really thought I was going to die. It was scary" (Senior-4).

This participant knew something was not right, yet, in her opinion, she received inadequate care and support.

Knowing that more things will go wrong when not being listened to: At times, not being listened to generated negative consequences for seniors. These situations started out with seniors and care partners informing the health care professionals about a symptom or changed situation. Some health care professionals did not pick up on these changes or deemed the changes irrelevant so did not intervene. As a result, seniors and care partners felt obligated to repeatedly explain how that a small change could lead to an escalation and affect their quality of life. These explanations were received with mixed feelings by the health care professionals; some seemed to realize it was important to listen, others did not.

A senior described a situation where she had a fall 20 years ago in which she fractured her knee. At the time, surgery was performed and the senior had since managed well. Unfortunately, in the last year, she started to experience severe discomfort in this knee:

"How can you tell a surgeon, you know, like I'm falling all the time. My knee is buckling all the time, and him pointing to a picture of the X-ray and saying "Well, look, everything is where it should be". Well, if everything is where it should be, what is causing the buckling? Obviously something is not right. That's when he should have said "Let's find out what the problem is." See what I'm saying? It was like a nightmare for years. Every time I fell I hurt myself" (Senior-6).

When health care professionals do not listen to a senior describing a change, their situation might worsen and create excess disability, requiring far more complex intervention down the line.

A 77-year old lady described a situation in which her older husband got sick at home:

"He was so sick, my walls were full of faeces, and the floor, throwing up too. So we rushed him by ambulance to the ER. We went to the ER and the nurse said he's got food poisoning. I said "Well, how do you know? You did not test him for nothing?" The doctor said "Its food poisoning." And I said that I hate to see him sick like that. And you know what he [ER doctor], told me, "You married him"... Anyway, it was the wrong diagnosis; I took him back home and he ended up having a gall bladder infection and stones" (Care Provider-17).

This quote indicates that the health care professional discredited information presented and neglected to listen to the care partner's perspective. The health care professional consequently failed to recognize a more serious situation.

Seeking help elsewhere when health care professionals and the system fail to help: As a response to health care professionals ignoring needs during transitions, seniors and care partners have found creative ways to receive help somewhere else. Some rely on strangers to help them out. This care partner described her four-month struggle to find someone to put on her husband's elastic stockings after they had transitioned into a retirement community:

"The home care agency told me they don't do things like that. And then the lady that cleans the building; she was such a kind lady, and we were telling her about the stockings and ... she says "I'll put your stocking on." And in a matter of minutes. And she came in every day. And she did not want to take money, but we insisted she did. But she'd come in every morning. She was so kind" (Care Provider-1).

As one might suspect, there were situations in which unsuspecting seniors and care partners were sometimes taken advantage of when seeking help. One care partner described her husband being discharged from the ER:

"I said to the nurse, "I have a problem trying to get him [husband] back in the car." And she [ER nurse] said "I can't help you, but we have a list of services who can provide transportation". The first one I called would take five hours to get there. So the second one I called said "Well, we can be there in about an hour and a half" And I thought "Well, that is a little better." And he said it would be expensive, and I said "Like, how much"? And he said: \$500." We live 14 km from the hospital. So, I said, I think not". So I called the caregiver [Paid care partner by a home care agency], who was on duty that day anyway, and she lived in the area, and I asked if she could meet me at the ER. I am not supposed to ask her. But she helped me get him in the car" (Care Provider-2).

This care partner encountered a situation she needed help with. Some agencies charge large amounts of money to help out when the health care system fails to provide services.

Theme 3: Hoping for relational approaches as a framework for care

A third theme in this analysis captures seniors and care partners' perception that, overall, health care professionals and the system did not really know how to respond to seniors' needs. There was a variety of reasons for not responding to care needs (e.g., not listening and identifying other needs), but once there was a commitment to provide services, several care partners felt that health care professionals did not

understand that the approach to providing support was of utmost importance.

An example of this was provided by a daughter, caring for her mother with Alzheimer's disease at home. The daughter asked for help to provide a weekly bath to her mother. For a couple weeks, the health care professional attending the home, asked the mother one question upon arriving: "Would you like to take a bath?" The mother refused every time and the health care professional interpreted this response as a 'non-compliant' situation. Homecare services were withdrawn. During the interview, the daughter talked about the health care professional failing to recognize that her mother needed to feel at ease first, before the topic of a bath was brought up. This health care professional did not engage at a relational level with her mother, causing anxiety and confusion. As a result, the daughter did not receive the support she needed to keep her mother at home. Providing care and support to seniors and care partners at home requires a trusting relationship. Health care professionals can strengthen this relationship by demonstrating relational practices and building continuity of care. Some care partners had the impression that health care professionals were not interested in the relational aspect of care, which made it difficult to build a trusting relationship between seniors and health care professionals. This in turn had a negative impact on seniors' overall care.

An example of this was provided by a son who, joined by his family, provided over 20 years of homecare to both his parents. The father was in his 80's with Alzheimer's disease and the mother had suffered a stroke a couple of years earlier. Both parents were very private. The son stated:

"We are a very committed family and we are very involved in the care of our parents. And there are good nurses and support workers out there that could become acquainted with mom and dad and who get to know them and are willing to work with them. And when they ask to do something – if dad sometimes says "No, I don't want my meds, I don't want to do it," then they are patient and kind, chat for a little bit, and try again... But my frustration is that every day there was a different person. I was ending up having to wait each time to make sure they understood what was going to happen. I had to wait for them because I have to make sure mom and dad are ok with them coming in, to make sure they clicked, and then I left for work. So, if there are 10-12 people that were coming in, never basically in a row..., give me 3 or 4 people instead. If they provided more consistency, they could have connected with mom and dad" (Care Provider-9).

The above quote demonstrates a disregard for the importance of relational care and continuity, both from a system and individual health care professional level. Seniors with cognitive impairment require services within a relational framework, provided by consistent health care professionals who know the person well. The parents in the aforementioned story needed committed health care professionals who knew their personalities and routines, and therefore understood how to respond to their care needs. When several different health care professionals enter the house, seniors will experience anxiety and unmet needs. Some of these situations can even lead to preventable admissions to long-term care (LTC), as was the case in the aforementioned story.

Theme 4: Experiencing the health care system as a limitation of care delivery

A fourth theme relates to health care professionals' limited inability to provide care due to system barriers and limitations. Seniors and care

partners described a health care system that limits care delivery to certain locations, and has a lot of rules to provide (or withhold) care, system issues, and guidelines and policies. Seniors and care partners believe that the health care system is well-designed, and some rules and guidelines are needed to regulate when and to whom care is provided. Most participants recounting positive stories receiving care for one specific issue. However, when confronted with multiple needs and chronicity, the system acted as a barrier.

Countless examples were given to validate this issue; we will describe some to demonstrate the rigidity of the system resulting in the inability to provide services.

This senior talks about seeking help with nail care:

“The [home care agency] won’t cut your fingernails or toenails, you have to go to [named facility]... It costs \$40 each time you go. And if you don’t have transportation to go there, well... So who is to cut people’s fingernails if you don’t have family? It has nothing to do with being able to walk again, but the [home care agency] lady said when she first came here “Oh, we are not allowed to do this.” Well, what am I going to do?” (Senior-28).

This example describes a system that is not designed to respond to seniors with multiple needs, within the context of limited support and resources. An older woman described her experience of finding an appropriate wheelchair to help transport her husband from an acute care facility to their home. The therapist was unable to provide a wheelchair on the day of discharge, causing the discharge to be delayed twice.

“So at this point in time, [husband] was so desperate to go home... and he asked the therapist: ‘Why can’t you loan me this wheelchair, the one I’m sitting in now?’ He was the only guy in there that was that size. ‘Why can’t you loan me this wheelchair till tomorrow morning? My wife will bring it back.’ And she [therapist] said: ‘We can’t do that. I cannot let this wheelchair go.’ Then he [husband] said: ‘Well, you let me go home in this wheelchair for a home visit [previous week].’ So I [wife] said: ‘What if this new wheelchair can’t come now?’ She [therapist] said: ‘Then, he doesn’t go home.’ And [husband] said: ‘What if I give you a \$1000 dollars for that wheelchair?’ It was a manual old wheelchair and I’m not kidding. A donation to the hospital just to get him home. ‘No,’ she [therapist] said, ‘We don’t do that.’ They wouldn’t even consider it. I started to cry and [husband] started to cry too and he said: ‘I’m going to die here.’ And then I cried even harder” (Senior-7/ Care Provider-8).

The rules of this hospital allowed the man to use this wheelchair to be transported home for a weekend visit, but did not allow the use of that same wheelchair to support the discharge transportation. This story is an unfortunate example of care dictated by a rigid system.

Rules and regulations are sometimes difficult to understand or justify for seniors and care partners, considering the negative effect they have on the quality of life of those the system is designed for. This son described the tremendous difficulty in getting home care:

“She [mother] had a very mild stroke. She was in the hospital for maybe 6 weeks, but they were anxious to get her home. I guess, that’s where I was asking for help and that was sort of the beginning of the frustration I had with the system. Because I had trouble meeting with the lady that’s with [home care agency] in the hospital. We finally connected. I was asking for somebody for half a day, because I had mom and dad [both have Alzheimer’s disease, mobility and vision problems] to look after, but they wanted to give me like half an hour a

week for each. So I convinced them to give me an hour for both of them, so at least it was only one nurse coming in” (Care Provider-9).

In this story, the system was supportive in providing home care but its rules dictated that each one of the parents was to receive care from a separate health care professional, resulting in two different health care professionals coming to the home. The care partner needed to negotiate that one health care professional care for both parents so that care continuity was somewhat protected. Several participants described the altogether lack of health care services because of system barriers and poor communication between service providers. An older woman had been admitted to an urban acute care facility for elective surgery and suffered a stroke post-operative. She was transferred to a rehabilitation facility in that same city and the time for her discharge had come. The woman described how she was discharged to her home while unable to mobilize, toilet, or prepare food independently.

“After 2 months in [large rehab facility], you can’t stay any longer, so they ship you home. But before they ship you home, they want to have somebody out here that’s going to take over and look after you. They couldn’t find anyone. So, I came home with nothing. I called several agencies. But I could not get anyone; they did not service this area. After 6 weeks, I found someone from [home care agency] who came and gave me a shower. My first shower after getting home. And they did that for once a week for 10 weeks. But after 10 weeks, I was on my own again. I can’t even walk or open a door” (Senior-20).

Rules, regulations, and policies often form a deterrent to optimal transitional care. Seniors provided examples, such as being informed that electronic scooters were not allowed in a retirement community, and that some agencies charge up to \$200 monthly to rent a wheelchair. An older care partner described her experience of moving to a retirement community to care for her ailing husband:

“We rented a 2 bedroom apartment, it was very small and very expensive (\$3,500 a month). And with that we could have 5 breakfasts a week and 8 dinners a month. Well, we are not loaded with money, but we thought maybe this is the best way. But the only door that opened automatically was the front door and we could not bring our scooters in. The doors were so heavy, it took all your strength to hold them open...and I could not do the laundry myself, so we traded in our dinners for having our laundry done. So we had that..... So, [husband] had been putting on his elastic stockings but, as he went on with his illness, he couldn’t do it anymore. So they sent someone up in the morning and at night and charged us. After 3 weeks, we got a bill of \$357.00 and that was before they put the taxes on. So we traded in our breakfast in to get the stockings on” (Care Provider-1).

It was difficult for this care partner to understand how this retirement home rules lead to optimal care. Furthermore, some regulations and policies interfere with quality care, and can have serious consequences. One senior’s story described several examples of how rules hinder care, and of how none of the health care professionals seemed to understand this:

“I had a heart attack in February, and when I got to the hospital I got diagnosed immediately and put into ICU. I got excellent care. It was the time of Clostridium difficile [a hospital acquired infection] and they were checking and checking. They put me in isolation and then they discovered that I didn’t have it, but they could not transfer me to [academic hospital in large city] because Monday was a holiday and they did not accept any out-of-town patients on that day. So they kept me here and the next morning they were going to take me, transfer me to [academic hospital] for the heart surgery. My minister came in to

give me communion and they would not let her come in because of the isolation. I thought that a bit strange, but rules are rules, I guess. So then I was told that I would be leaving the hospital at 9 am and the ambulance took me up and we waited there [academic hospital] most of the day, but their shift was over before I could get admitted so we came home after being there all day and then another ambulance had to come and take me the next day” (Senior-37).

This person was caught in a web of organizational policies, protocols and procedures, and it is not until the individual brings the entire story together that one begins to understand the negative impact of a rule-driven health care system.

Theme 5: Recognizing chronic disease

A fifth theme that was apparent in most interviews was health care professionals’ limited recognition of chronic disease, and the importance of its management to prevent further decline. Health care professionals responded well to acute exacerbations of a disease, often leading to a stay in acute care, but once the issue was dealt with, the senior was transferred or discharged without supports. This story relays the experience of an older woman who suffered a stroke. She provides examples of how health care professionals and the system failed to deal with her chronic care needs.

“I had to call to organize and book the services and get information.... It would have been so helpful if there was somebody that could do some of that calling for me to find out about services. Have you ever tried to hold a phone and write with your left hand at the same time? I can’t use my right hand anymore. The phone was falling and I’m trying to write with my left hand and you are not used to that? Even that alone is... physically impossible” (Senior-20).

In this situation, health care professionals did not recognize the chronic nature of suffering a stroke. This person needed help with setting up the support services once she transitioned home.

Another woman described her older husbands’ situation when he had a stroke:

“At 11 am, the ambulance came and we went to [large community hospital] and they said it would be at least 48 hours before they really knew what was happening. So we waited, and that evening, 5pm, they transferred him to [community hospital, closer home]. And there we sat for a few hours in ER again. And I guess they did not know what to say, as no one had done any test yet. So that night at 10 pm, he gets admitted to a medical floor. And in the morning, a doctor passes by and says: ‘He is going to go to rehab.’ So he went down to rehab. And no one had done any test or assessments and he still had not come out of bed or walked. I stayed with him till 11 pm. And sometimes early in the morning, he wanted to go to the bathroom and no-one was there and he had this really bad fall and he had another bleed in his head” (Care Provider-35).

This description is an ill-fated example of a health care system and health care professionals failing to recognize the consequences of a traumatic event when one has multiple instabilities. The transfers between different wards and hospitals probably led to delayed information sharing, risks for further deterioration and decline, not recognizing the trajectory of chronic disease and the complexity that comes with this leads to negative outcomes.

Other participants provided stories of health care professionals ignoring dying and death during transitions. Care partners do not always know they have decision-making power over some transitions

and they assume that loved ones will be well taken care of. However, some health care professionals do not recognize symptoms of rapid decline or impending death, resulting in unnecessary transitions at a time when palliation and comfort care should be a priority. This lady recounted the story of her husband’s journey:

“It was getting more and more difficult to get [husband] out of his chair at home, and then it got to a stage where he just could not walk, and I could not help him up. He was a big man, you know. And I could not do it, so I decided he better go into the hospital, and he never came out, that was it. They had been discussing that they would send him home. But the day he was going to come home, they phoned me and said that he was too ill. ‘We just moved him to an inside ward and then tomorrow you can visit.’ So I stayed the night [at home], and I said I wanted to stay with him [in the hospital], and that is the night he passed... And I felt guilty, I felt guilty because I couldn’t do more for him” (Care Provider-2).

The decision to first discharge this man home, and then change the plan to transfer him to another ‘inside’ unit on the day of his passing suggested little recognition of his impending death. Health care professionals often focus on more immediate situations, and this perspective does not allow recognition of chronic disease progression or the need for palliation. Not only was the wife ignored as an involved decision maker, but she was denied the opportunity to be with her husband at the time of his passing.

Theme 6: Understanding health care professionals’ limited control

Despite these disappointing stories, seniors and care partners trusted health care professionals unconditionally. Seniors and care partners believed that health care professionals acted in their best interest, and provided the right care. They also understood that health care professionals could not do more beyond what they already do. This older woman was in treatment for liver cancer and received chemotherapy. She talked about the gaps in the system and the health care professionals’ care, but indicated an understanding of the health care professionals’ constraints within the system:

“So I was very, very sick, off to the ER I went. I waited 3 hours lying in a bed before seeing a doctor. The doctor said she was going to give me this antibiotic. This was now about 10 o’clock in the evening so the only place to fill it was [local pharmacy] so I went over there. The pharmacist said: ‘Well, you are not [name on the prescription], are you? And you are not 13 years old, and you don’t have a bladder infection?’ And I went: ‘No.’ [local pharmacy] was very nice about it, they said I would have to go back to the hospital and get a different prescription. I said that they had to call them [ER] and find out. Anyway, they called them and finally the doctor [ER Dr] called back and [local pharmacy] was really fuming at this point because it was past closing time. The ER doctor said: ‘Oh that is okay, it is the same antibiotic for her.’ So when I got home, I went on the email and wrote a letter to the administration of the hospital. They phoned me the next morning and said: ‘Can we send an ambulance out for you?’ I said: ‘No, I can drive in myself.’ And I did. So they ended up taking really good care of me. But you know, a little too late” (Care Provider-27).

The overall impression of stories where the health care system failed was that participants were hopeful. They held on to the belief that the system and the health care professionals were going to serve them well.

Additional themes identified by care partners

In addition to the six themes identified from the interviews with seniors, three additional themes emerged for care partners.

Theme 1: Dismissing partners in care

Care partners were not always invited to be involved in the decisions related to seniors' care. As a result, care partners were left feeling that their expertise and meaning was not valued. A care partner described her experiences with her ailing husband recurrently being admitted:

"Sometimes, you had a transfer from the ER to the acute care. Usually when they said that; and that was in the middle of the night; they would say to me: 'You might as well go home' (Care Provider-1).

This care partner felt dismissed and that her input was of no further value, so she was asked to leave.

The same participant talked about a dismissal at the time of an ER transfer:

"One time, he had fallen, a glass had broken and he had cut himself, and there was blood all over the kitchen floor. And when the guys [Paramedics] came over, one of them said to me, he said: 'Wash that floor right away because if you don't, that blood will get in the grout and you'll never get it out.' But, you know, that puts extra pressure on you, and when I do things like that I wheeze really badly, and with the arthritis, I have to do a bit and sit, and do a bit and sit, and all I want to do is go to the hospital" (Care Provider-1).

This care partner wanted to be involved in the care of her husband, but was not invited to do so. She did not feel acknowledged as a partner in care.

Theme 2: Coping with caregiving

Care partners' emotional and physical health challenges were frequently discussed during the interviews. Care partners are often spouses of seniors, similar in age, and the care that seniors required at home added an emotional and physical strain. Some transitions were the result of the care partner's inability to continue care at home because no services were available. This woman talked about providing physical care as the 'lifter' when transferring her husband from the bed to the wheelchair, and vice versa:

"I had to have physiotherapy ...the soreness here in the left lower back. And I went to about 3 months of physio and the pain was unbelievable. And I'd be up every night moaning and groaning. So I said if I could just stop moving him and easing up on that, then it will start to go away. But it didn't" (Care Provider-5).

Care partners tried to do the best they could, often with limited support or care equipment. This sometimes resulted in physical ailments, and in emotional stress and fatigue.

Another woman talked about the emotional strain of being a care partner for her 74-year old husband:

"There is no break. My husband is a very private man and as his wife, the things that I have had to do... I'm sure if he was well, it would break his heart. I do get out twice a week for half an hour to get groceries. And once a week I go to the bank for 15 minutes. That's it. There's no help. I wish there was something more they could do for caregivers. I have a sister who just lost her husband a year ago. And she was doing exactly what I am doing, caregiver for 2 years. She said: 'Do

you ever just all of a sudden stop and cry for no reason?' I said: 'Yeah, buckets' (Care Provider-34).

This woman did not receive any services or support in her role as a care partner and the stress of the care giving role was concerning. Care partners wanted to provide care but with limited or no services available, it took a toll on their emotional and physical health.

Theme 3: Managing financial and transportation barriers

The financial impact of caregiving should be underestimated. In each one of the interviews, care partners discussed the expenses and consequences of expenses incurred when providing care. This woman described caring for her husband at home:

"How somebody with limited means can do any of this is totally beyond me. I ended up putting in a request against the insurance company for his care – so the first one that went in included some of his medical equipment, meds, and a month of caregiving. The bill came to something like \$13,000. And I put it into the insurance company and oh, an age before I got an answer. Eventually they sent me a cheque for \$200. So I thought: 'You missed a few zeros, or the period is in the wrong spot.' So I phoned them and they said: 'We do not provide the funds for this.' ... I eventually got \$6,000 of that \$13,000 back with a letter saying this was a one-shot deal. So by the end, with close to 2-hour care per day, I needed \$18,000 a month. And I did this for close to a year" (Care Provider-5).

Many participants talked about financial pressures. Some participants did not have the resources to sustain caregiving at home.

Discussion

This part of a larger study aimed to explore the transitional experiences of seniors and their care partners in the healthcare system. Individual interviews were held with seniors and care partners to discuss reason(s) for transitioning, transition experiences, support provided, and successes and deterrents of experienced transitions. Overall, this study revealed several factors that impeded successful transitions from seniors and care partners' perspective. The authors distilled the findings of the analysis into four categories.

First, care provided before, during, and after transitions was not always person-centred; nor was the care incorporating principles of gerontological best practices, chronic disease management or end-of life approaches [3]. Despite seniors and care partners articulating well-defined symptoms with a clear request for help, some health care professionals failed to listen to the expressed concerns. This finding is consistent with McCloskey who described that nurses perceive to have little time to discuss transitional planning in response to other work pressures [13]. Knowing that most of seniors' needs are not sudden, better planning for care delivery or transitions should be possible.

Moreover, several gaps in health care professionals' knowledge of gerontology, Chronic disease prevention and management, and palliative care hinder successful transitions [3,14,15]. Some health care professionals failed to notice important symptoms of decline or impeding death. Others did not consider practice strategies to prevent exacerbations of acute diseases, falls, functional decline, or requests for transportation. The emphasis on addressing the one important, often acute, issue at hand leads to ignoring other underlying complexities. These findings are conformed by large studies in the United States [16] and Europe [17].

Secondly, several gaps existed in access to and continuity of health care services for seniors, including limited communication about and with other available services. Seniors and care partners had great difficulty navigating the health care system on their own. They were not aware of services or agencies, or could not locate or contact them. When services were available, there seemed to be several challenges with the continuity of care or services provided. Naylor and Keating discussed gaps within homecare services and how gaps are compounded when important patient information does not transition with the senior from one care setting to another [10,18].

A last theme under this category is the lack of health care professionals' awareness of care partners' physical and emotional stress. The health care professionals are only focused on seniors' health issue (s) and as soon as that is dealt with, the care provider perceives their job to be done. This statement was sadly confirmed by the story of the older woman trying to get her husband in the car, in the ER parking lot. None of the staff provided any help but when asked, provided a list with phone numbers for the care partner to call.

Thirdly, findings suggested that seniors do not receive the resources required to support them through transitions and advocate for their needs. Help requested at home or during a transition does not always need to be extensive. The findings of this study provided an interesting dichotomy between the care and services that seniors indicated they needed to maintain their status and the system deciding what type of care and services would be offered. Often, the needs expressed by senior and/or care partners were not the ones that were addressed by the system, further devaluing the seniors and care partners' voice. Despite these stories, seniors tend to trust professional care providers. Both seniors and care partners hold hope that health care professionals know what is best, even if there are serious breakdowns in trust, competency and accountability [19].

Lastly, several policy and funding models have created barriers to care access and/or sustainability. Seniors and care partners are willing to promote their own health, and prefer to remain at home. In spite of that, requests to receive support at home are difficult to complete and not well-organized, often resulting in bigger challenges and relocation. This study provides substantiation to the idea that providing care and services to seniors and care partners does not outweigh the implications of not receiving services; a structured economic study is needed to provide additional data.

Overall, this study highlights the fact that transition is not a one-time experience for seniors and their care partners. Health care professionals need to be knowledgeable about the components of effective, person-centred transitional care. Communication between sending and receiving care organizations (e.g. sharing of care plans) is essential [2] for health care professionals, as well as care agencies' awareness and understanding of seniors and care partners' individual stories and care trajectories [20].

Several initiatives to enhance transitional care are underway. In particular, there is a focus on avoiding rehospitalisation and this has led to several discharge initiatives in acute care facilities improving transitions care [21,22]. New and stronger home-based primary care models are finding their way through the health care system, and aim to create smoother transitions between care facilities. New roles, such as discharge specialist, transition coaches and care coordinators, aim to improve quality and safety of care transitions [23]. Rigorous research is needed to evaluate the impact of these roles on the care experiences of seniors and their care partners.

Conclusion and Practice Implications

There is significant room to improve seniors' care transitions in the Canadian health care system. Findings from this descriptive qualitative study indicate that transitional care is often not person-centred, not following best practices, and presents with several gaps in access to and the continuity of health care services. All participants had countless examples of the effect that poor transitional care has on their own and/or their care recipient's health and quality of life. Conclusions drawn from this study indicate that future research should also explore cultural, ethnical, and economic scopes to give a more in depth look at care transitions in the Canadian health care system for seniors. Findings of this study will inform subsequent stages of the project, aimed at creating better transitions and care experiences for seniors and their care partners.

Acknowledgement

The authors would like to acknowledge the support of the Change Foundation. The authors also acknowledge the contributions of other members of the PATH project team, and the participating seniors and care partners. Funding for this study was received by the Change Foundation during 2012-2015. This research project has received ethical approval by the Research Ethics Board of University of Ontario, Institute of Technology (REB file #12-019) and Conestoga College (REB file #155).

References

1. Smith SM, Soubhi H, Fortin M, Hudon C, O'Dowd T (2012) Managing patients with multimorbidity: Systematic review of interventions in primary care and community settings. *BMJ* 345: e5205.
2. Coleman EA (2003) Falling through the cracks: challenges and opportunities for improving transitional care for persons with continuous complex care needs. *J Am Geriatr Soc* 51: 549-555.
3. Manderson B, McMurray J, Piraino E, Stolee P (2012) Navigation roles support chronically ill older adults through healthcare transitions: A systematic review of the literature. *Health Soc Care Community* 20: 113-127.
4. Mezey M, Kabayashi M, Grossman S, Firpo A, Fulmer T, et al. (2004) Nurses improving care to health systems elders (NICHE): Implementation of best practice models. *J Nurs Adm* 34: 451-457.
5. Jewell S (1996) Elderly patients' participation in discharge decision making: 2. *Br J Nurs* 5: 1065-1071.
6. Naylor MD, Aiken LH, Kurtzman ET, Olds DM, Hirschman KB (2011) The importance of transitional care in achieving health reform. *Health Affairs* 30: 746-754.
7. Callahan CM, Arling G, Tu W, Rosenman MB, Counsell SR, et al. (2012) Transitions in care for older adults with and without dementia. *J Am Geriatr Soc* 60: 813-820.
8. Golden AG, Tewary S, Dang S, Roos BA (2010) Care management's challenges and opportunities to reduce the rapid rehospitalization of frail community-dwelling older adults. *Gerontologist* 50: 451-458.
9. Piraino E, Heckman G, Glennly C, Stolee P (2012) Transitional care programs: Who is left behind? A systematic review. *Int J Integr Care* 12: e132.
10. Coleman EA, Berenson RA (2004) Lost in transition: Challenges and opportunities for improving the quality of transitional care. *Ann Intern Med* 141: 533-536.
11. Chu L, Schnelle JF, Cadogan MP, Simmons SF (2004) Using the minimum data set to select nursing home residents for interview about pain. *J Am Geriatr Soc* 52: 2057-2061.
12. Clarke AE (2003) Situational analysis: Grounded theory mapping after the postmodern turn. *Symbolic Interaction* 26: 553-576.

13. McCloskey R (2011) A qualitative study on the transfer of residents between a nursing home and an emergency department J Am Geriatr Soc 59: 717-724.
14. Wyatt KD, Stuart LM, Brito JP, Leon BC, Domecq JP, et al. (2014) Out of context: Clinical practice guidelines and patients with multiple chronic conditions: a systematic review. Med Care 52: S92-S100.
15. Hempstead K, DeLia D, Cantor J, Nguyen T, Brenner J (2014) The fragmentation of hospital use among a cohort of high utilizers: implications for emerging care coordination strategies for patients with multiple chronic conditions. Med Care 52: S67-S74.
16. Wolff JL, Starfield B, Anderson G (2002) Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. Arch Intern Med 162: 2269-2276.
17. Thiem U, Klaaßen-Mielke R, Trampisch U, Moschny A, Pientka L, et al. (2014) Falls and EQ-5D rated quality of life in community-dwelling seniors with concurrent chronic diseases: a cross-sectional study. Health Qual Life Outcome 12: 1-7.
18. Naylor M, Keating SA (2008) Transitional care: Moving patients from one care setting to another. Am J Nurs 108: 58-63.
19. Ward-Griffin C, McKeever P (2000) Relationships between nurses and family caregivers: Partners in care? ANS Adv Nurs Sci 22: 89-103.
20. Toscan J, Mairs K, Hinton S, Stolee P, InfoRehab Team (2012) Integrated transitional care: patient, informal caregiver and health care provider perspectives on care transitions for older persons with hip fracture Int J Integr Care 12: e13.
21. Halasyamani L, Kripalani S, Coleman E, Schnipper J, Van Walraven C, et al. (2006) Transition of care for hospitalized elderly patients- Development of a discharge checklist for hospitals. J Hosp Med 1: 354-360.
22. Dahl U, Steinsbekk A, Jenssen S, Johnsen R (2014) Hospital discharge of elderly patients to primary health care, with and without an intermediate care hospital – A qualitative study of health professionals' experiences. Int J Integr Care 14: e011.
23. Coleman EA, Parry C, Chalmers S, Min SJ (2006) The care transitions intervention: Results of a randomized controlled trial. Arch Intern Med 166: 1822-1888.