Muscled by the System: Informal Caregivers' Experiences of Transitioning an Older Adult into Long-term Care*

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RÉSUMÉ

Cette étude a exploré les expériences des aidants devant s'occuper de la transition d'une personne âgée vers une institution de soins de longue durée (SLD). Une approche de description qualitative a été utilisée pour l'analyse d'entretiens semi-structurés effectués auprès de 13 aidants de personnes âgées hébergées en centres de soins de longue durée dans le sud de l'Ontario. Nos résultats illustrent que les aidants ressentent des soucis et un lourd fardeau de manière chronique lorsqu'il s'agit de prendre une décision sur l'hébergement ou de faire une demande pour un centre de soins de longue durée. Le sentiment de ne pas avoir le contrôle était un thème récurrent dans les entretiens, particulièrement dans les cas où les aidants requéraient une place en SLD. Les participants se sont sentis bousculés, sous pression et punis à travers le système de santé, mais soulagés et privilégiés après l'acceptation de l'offre de la place en CHSLD. Cette expérience tumultueuse a encouragé les aidants à anticiper les prochaines transitions. Il est recommandé que les aidants aient accès à une préparation et à un soutien ciblé pour mieux gérer les transitions. Une amélioration de la communication entre les professionnels de la santé est essentielle. Les amendes imposées lors du refus d'une place en SLD devraient être réexaminées, considérant l'impact négatif de celles-ci sur les aidants.

ABSTRACT

This study explored informal caregivers' experiences of transitioning an older adult into long-term care (LTC). Qualitative description guided our analysis of semi-structured interviews with 13 informal caregivers of older adults from three LTC homes in southern Ontario. Our findings illustrate that caregivers experience chronic worry and burden before deciding on, or requiring to apply for, LTC. A sense of lack of control was a prominent theme, especially when caregivers were applying for LTC beds. Participants perceived pushing, pressure, and punishment from the health care system and felt relieved and fortunate after they accepted a bed offer. This tumultuous experience stimulated caregivers to anticipate future transitions. It is recommended that caregivers receive preparation and targeted support to manage transition experiences. Improved communication among health professionals is essential. Penalties for declining an offer for a bed in LTC should be re-examined in relation to its negative influence on caregivers' experiences.

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In 2012, over 2.2 million Canadians provided unpaid eldercare to adults with age-related health conditions and physical limitations (Sinha, 2013). Nearly 115,000 older adults were admitted into residential care facilities from 2009 to 2010 (Statistics Canada, 2011). Researchers have found that 22 per cent of older adults continue to receive informal, unpaid care after they move into facilities such as assisted living or long-term care (LTC) homes (Cranswick & Dosman, 2008). Caregiving, therefore, does not end with institutionalization and can be a long journey alongside the older adult. Informal caregivers may co-experience multiple transitions as the older person requires more support at home, enters acute care, and transitions into LTC. In Ontario, Canada, care of older adults in the community and at home is mediated by Local Health Integration Networks (LHINs). LHIN care coordinators guide caregivers through the application and placement process into LTC (LHIN, 2017). The multiple care providers and services required in the care of older adults can lead to fragmented care with poor communication among clinicians and sectors.

Previous research strongly indicates that caregivers consider LTC as a final resort to meet the needs of their aging family members (Caldwell, Low, & Brodaty, 2014; Dellasega, Mastrian, & Weinert, 1995; Liken, 2001a; Liken, 2001b; Ryan, McKenna, & Slevin, 2012). Consequently, caregivers strive to keep the older adult in their own home for as long as possible (Caldwell et al., 2014; Ryan, 2002). These factors contribute to later transitions into LTC, which may result in a health crisis for the older adult or for the caregiver (Caldwell et al., 2014; Liken, 2001a; McLennon, Habermann, & Davis, 2010; Penrod, & Dellasega, 2001; Ryan, 2002; Strang, Koop, Dupuis-Blanchard, Nordstrom, & Thompson, 2006). When acute care is required following a crisis, caregivers find themselves under pressure from health care professionals (HCP) to make important decisions about the older adult's care (Caldwell et al., 2014; Cheek & Ballantyne, 2001; Cornes et al., 2008; Penrod & Dellasega, 2001).

It is evident that caring for older adults, particularly if their health physically or cognitively declines and they require institutionalization, can be challenging for informal caregivers. One study of caregivers' experiences of this transition presented findings across the journey to placement (Penrod & Dellasega, 2001). This study found six distinct phases of the caregiver experience, starting at the time after which caregivers realized continuing to care for the older adult at home was impossible. Before the decision to place the older adult into LTC was made, caregivers evaluated the new reality of caregiving and experienced conflict between this reality and their ideal vision of being a caregiver. Temporary relief following the decision to place was met with a new struggle to find a LTC bed with pressure, and without much assistance, from "the system". After the move, caregivers re-defined their role and wrestled with guilt and relief. In all phases, caregivers felt alone (Penrod & Dellasega, 2001). From a broader theoretical perspective, Meleis' middle-range nursing *transitions theory* (Meleis, 2010; Meleis, Sawyer, Im, Messias, & Schumacher, 2000) depicts transitions as having many facets including perception, movement, process, and time (Chick & Meleis, 1986).

Other studies explored the decision-making aspect of the caregiver experience (Caldwell et al., 2014; Caron, Ducharme, & Griffith, 2006; Dellasega et al., 1995; Lundh, Sandberg, & Nolan, 2000; McLennon et al., 2010; Penrod & Dellasega, 2001; Ryan et al., 2012) or the experiences of caregivers transitioning an older adult with dementia (Caldwell et al., 2014; Liken, 2001a, 2001b; McLennon et al., 2010; Strang et al., 2006). These more focused explorations of caregivers' experiences may be insufficient to capture the experience of caregivers throughout the transition to LTC and in a holistic way. Further research is needed to understand caregivers' interactions with the health care system throughout this type of transition in a Canadian context.

The purpose of this study was to describe informal caregivers' experiences of transitioning an older adult into LTC in order to identify better ways to support caregivers through healthy transitions. The following questions guided the study: What are informal caregivers' experiences before, during, and after their aging relative's or friend's transition into LTC? What are their perceptions of navigating and working with the health care system during this transition?

Methods

We used Sandelowski's (2000) approach to qualitative description to address the research questions. Qualitative description was chosen because of its proven strength for gathering firsthand knowledge of patients', relatives', or professionals' experiences with a particular phenomenon, as well as its ability to make new knowledge easily accessible to professionals of various clinical backgrounds (Neergaard, Olesen, Andersen, & Sondergaard, 2009). Our study sampled caregivers of recently transitioned older adults from three LTC homes in Southern Ontario. We selected these homes because of the co-location of a LTC facility with a supportive housing complex. The homes also had diverse characteristics including a range in number of beds (from 65 to 130 beds), religious affiliation, and funding models. We applied convenience and purposeful sampling to capture the experiences of participants who were willing and able to speak about transitioning an older adult into LTC. Administrative personnel (i.e., directors of care and managers) were contacted via email to assist with recruitment. They identified and made initial contact with caregivers of new residents. They also obtained verbal assent from caregivers so that research team members could contact them to share more information about the study and schedule interviews.

Potential participants were included if they facilitated the transition of an older adult into LTC within the past six months. We sought variation among the characteristics of caregivers, particularly as to their relationship to the older adult. We offered to meet participants at a place of their convenience and comfort, resulting in all interviews occurring at the respective LTC homes. Consenting caregivers were interviewed for 30–60 minutes, and a $10 gift card to a local coffee shop was sent to participants after the interview to thank them for their participation. Consent was obtained through a consent form process. Study approval was obtained from a university-based ethics review board.

We interviewed 13 participants from three LTC sites (n = 13). Directors of care pre-screened the participants, so all potential participants that our research staff approached did consent. Recruitment of participants through the directors of care stopped once data saturation or significant overlap in findings was reached within themes. We used a semi-structured interview guide (available upon request). Interviews were led by a master's-level nursing student and two other research staff. Nine female (n = 9) and four male (n = 4) caregivers were interviewed. Adult children (n = 4) and spousal caregivers (n = 3) had the highest representation. In addition to family friends, other family members such as siblings and a niece participated. Over 60% (n = 8) of participants were aged 45–65 years, and the remaining participants were over age 65 (see Table 1). Most participants transitioned an older adult who was previously at home and who came to LTC from an acute care or rehabilitation centre after a significant health or safety event such as stroke, exacerbation of heart failure, and fall with fracture. Others were unable to manage their activities of daily living despite community resources or caregiver support.

Interviews were recorded, transcribed verbatim, and uploaded into Dedoose, a web-based data management application. Three of our research team members inductively coded three early interviews to develop the initial coding scheme. This was followed by inductive analysis to label, categorize, and code emerging concepts into key themes. The remaining transcripts were systematically coded in Dedoose, a web application for mixed-methods research (https://www.dedoose.com/), and the team met regularly to discuss evolving codes and themes. When strong themes emerged relating to lack of control and struggling to move through the system, we adapted the interview guide to probe these aspects of the caregivers' experience with additional participants. As we continued to work with the data, we collapsed some codes together and created overarching themes to contain the new subthemes. This occurred throughout frequent discussions among the research team.

Analyst triangulation and member-checking were the key activities that we used to enhance the rigour of this study (Lincoln & Guba, 1985). Three qualitative researchers with nursing backgrounds analysed early transcripts followed by regular discussion among team members in order to achieve consensus in the original coding scheme and creation of themes and subthemes.

Table 1: Participant characteristics

	Total (n = 13)	
Characteristic	***n***	**%**
Age		
Less than 45 years	0	0
45–65	8	62
Greater than 65 years	5	38
Sex		
Male	4	31
Female	9	69
Relationship		
Spouse	3	23.1
Adult child	4	30.8
Sibling	2	15.4
Other family	2	15.4
Friend/neighbour	2	15.4

Two-page member check letters were sent to each participant following the interview to allow participants to review and verify that we had accurately captured their experiences. This also provided a forum for participants to add to or correct early interpretations. These approaches enhanced the credibility and trustworthiness of the study's findings (Lincoln & Guba, 1985; Patton, 2015). A diverse sample of caregivers, varying in age, gender, and relationship to the transitioning older adults (see Table 1) from multiple LTC settings increased the transferability of these findings to other informal caregivers from other settings.

Findings

We discovered key themes from the journey of caregivers across three phases of the LTC transition: before transition, during transition, and after transition (see Figure 1 for illustration of findings). This linear presentation is helpful for structuring and ordering the findings although it does not fully capture the complexity of the experience (Lundh et al., 2000). A fourth theme that characterizes caregivers' transitions experiences is the impact it had on their health and well-being.

An overarching finding that we perceived during interviews and solidified in analysis was caregivers' sense of lack of control as they interacted with the health care system. The caregivers were instrumental in the older adults' care, from sustaining them at home, to navigating them through community services, acute care, and into LTC. Despite the pivotal role played by caregivers, their sense of control was constantly threatened. The nature of this theme was particularly evident during transition, in which caregivers were faced with selecting and applying for LTC homes.

Caregivers' perceived absence of control, the changing nature of the experience over three phases, and the influence of the experience on their own health suggest that transitioning an older adult into LTC is a meaningful transition for the caregivers themselves. A glimpse into the reality of caregiving is captured by the following quote:

> It's my family and it's four people that we love. I'm not just going to abandon them for the system. I don't know what happens to people that don't have – like, for instance, if [he] didn't have us, what happens? Who looks after them? Who does the finances for them? Who makes the decisions? … maybe you know that; I don't know that. (Niece)

This quote speaks to the complex experience of caregivers when managing a transition of an older adult into LTC. It also demonstrates the sense of duty that caregivers feel to advocate for the older adult and brave the health care system on their behalf. Finally, it captures the roles that caregivers must assume as the health of the older adult declines.

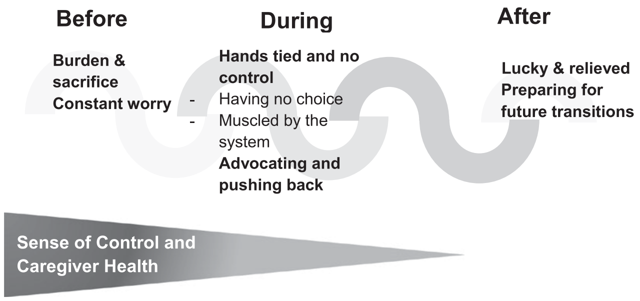

Figure 1: Caregivers' transition experience

Before Transition

In this study, the pre-transition period was considered the time when the older adult received care in their last residence prior to LTC (e.g., home or retirement). This period was often marked by significant health decline for the older adult, including progressing illness and/or a pattern of unsafe events such as falls. The informal caregivers assumed greater responsibility during this time and were instrumental in maintaining the older person in their home. For example, one caregiver described her commitment to caring for her family friend and the roles she fulfilled during this phase:

> I had vowed, I said that I would take care of her as long as I could, because … she was like a mom to me. As long as she was at home I would go over there once or twice a week. She did not drive so I took her for grocery shopping … When the Alzheimer's started, I more or less had to start taking all her payments and bills … and then she started putting me on bank accounts. (Friend)

In addition to expanding their caregiving scope and spending more time in the role of caregiver, they often enlisted additional services through the Local Health Integration Network (LHIN, formerly Community Care Access Centres), Meals on Wheels, and Veteran Affairs. Burden, sacrifice, and constant worry characterized the experiences of informal caregivers during the pre-transition period.

Burden and Sacrifice

Significant burden was placed on informal caregivers as they made personal sacrifices in order to maintain the older adult in their home for as long as possible. Participants fulfilled many roles outside of caregiving including parenting and sustaining full-time careers. Some participants were older themselves, and others were supporting more than one older adult.

The remarkable sacrifice of informal caregivers is illustrated through one participant's experience. The niece of a recently transitioned older adult and caregiver to her parents, uncle, and aunt explained:

> I already had to quit my job to look after the four of them. Between all the trips I had to Emerg [emergency department] with family and appointments and trying to supplement the care in their homes, I went to my aunt and uncle's for twice a week for fifteen years almost … I had to give up a lot to keep them in the system and just coping as best they can. (Niece)

A brother of a recently transitioned woman reflected on the time involved in caregiving and the burden of helping her maintain her home, particularly as she went in and out of hospital before moving to LTC:

> You know we were coming down to the house more often than ever because things were getting bad … I'm not being preachy or anything but I've run into guys that I work with that have got similar situations to mine and we say, "well, I don't know how we found the time to go to work." Because you know, right now we don't seem to have any spare time hardly at all. (Brother)

The physical care that some of the older adults required (e.g., bathing, toileting, and transfers) became physically overwhelming, particularly for older caregivers. One wife stated about the care of her husband, "I'm not a young person either anymore. I couldn't hardly do it you know … It's the interim time that I just couldn't manage it." It was clear that the burden carried by caregivers and their personal sacrifice was instrumental in sustaining the older adults in place, thus delaying their eventual entry into LTC.

Constant Worry

In parallel with mounting burden and sacrifice, this time was inordinately emotional and stressful for caregivers. With mounting care needs and instances of injury or health crises as the older adult's health declined further, caregivers experienced constant worry about their loved one:

> There was always a great fear that, you know, you were going to find him dead at the bottom of the stairs after two days or whatever. But he was fiercely independent that he was going to stay home. (Niece)

The participants gained awareness that the available services and amount of time they could spend caregiving could not guarantee the safety of their loved ones. This worry wore on the participants over time and compounded the stress associated with the pretransition period.

During Transition

Crisis commonly marked the beginning of the second phase. All transitioning older adults discussed in this study were admitted to an acute care setting after a health or safety crisis. They remained in the hospital, a rehabilitation program, or at home with supplemented community nursing and home-making support. During this period, caregivers actively searched for and applied for LTC beds. Significant interaction between informal caregivers and health care professionals (i.e., LHIN care coordinators, discharge planners, social workers) occurred during this phase. The caregivers strived to find LTC homes that were close to home and that they perceived to provide good care to residents. In contrast, their perceptions of the priorities of care coordinators and hospital staff were that they applied immediately to LTC homes with short waiting times (described by participants as shorter than six or three months). Caregivers often emphasized this aspect of their transition during the interviews, in which they were interacting chiefly with LHIN care coordinators and hospital staff. Caregivers' struggle to exert control over the transition was most pronounced in this phase.

Hands Are Tied and No Control

After managing their family member or friend at home for months to years, this period represented a serious loss of control over their loved one's care. They struggled to meet the needs of the older adult while trying to navigate the rigid and unforgiving acute care and LTC systems:

> Honestly, right from the beginning we knew it was happening and we knew it was coming. My sister and I were so stressed, I remember going home crying numerous times. Crying at night, the two of us, we would break down. And we would be like "what are we going to do?" … Very helpless … our hands were tied. Because we knew that mom can't go home, they're not willing to help us try and it's just like, "here's a list of homes; go look at them and let us know." (Daughter)

Two subthemes of "having no choice" and being "muscled by the system" elucidate this theme further.

Having No Choice

Early in the interviews, it was apparent that transitioning a family member or friend into LTC and choosing a LTC home did not feel like "choices" that were made by the caregiver or older adult. This feeling pervaded when it came to applying to specific homes. Several prominent quotes from participants across the study illustrated this point. For example:

> Truthfully, there's not a thing I could recommend [to a friend]. As I said before your hands are tied, you have to go through this big umbrella and they have the decision as to where he's made, as to where you go and stuff … I can't say I really

> learned anything from it, just the fact that you can't make the decision, somebody makes it for you. (Wife)

When asked about what made the move more difficult, one caregiver said that being told that "you have no choice" was one of the hardest parts of the experience.

Muscled by the System

Strong imagery was prominent in the participants' recollections of their interactions with "the system", including LHIN care coordinators and other HCPs (e.g., discharge planners and social workers). The system was found to be rigid and compassionless by informal caregivers striving to find the right home for their loved one. Participants commonly used words such as "pushing", "pressuring", and "punishing" to characterize these interactions. One participant described receiving a bed offer:

> The statement they give you is, you take, you don't look at. Here's the bed offer … 24 hours, this is the offer, this is the bed but if you don't take it then you get … and I said, "so it's really like putting the thumb screws on," like you're really punished if you say no, right? (Niece)

This pressure was more palpable when the older adult was "taking up" an acute care or rehabilitation bed that might otherwise be needed by another person. In this situation, they often felt pressured to submit applications to LTC homes with short waiting lists in order to clear room for incoming patients. Therefore, the caregivers felt forced into accepting a bed in their least preferred home or else decline it and face being removed from all waiting lists for three months. The relentless nature of coercion perceived by caregivers in this study is evidenced by the following quote:

> They were continually after us like calling us or emailing, saying like "this isn't good enough, we need something that's more of a quick entry." And I said, "they're usually that [quick entry] for a reason." Like we've gone through – my sister and I went through tons of them [LTC homes]. (Daughter)

Advocating and Pushing Back

In response to feeling "strong-armed" by the system, some participants assumed a greater advocacy role. Caregivers who did so were influenced both by their situation and their relationship to the older adult, as well as by their individual personality. Adult children most often took on, and were vocal about, this aspect of their role. For example, some family members and caregivers pushed back by delaying application to, or acceptance of, an LTC bed. This was done because the caregivers believed accepting the bed to be an act of settling. These beds were often deemed unacceptable because of facility cleanliness, a perception of the home providing less than "good care", as well as being located outside of the preferred distance for regular visitation.

One wife and caregiver to her husband and parents depicted vividly the task of advocating during the transition. Fighting for what was best for the older adult and their family took many forms, and advocating at times took the form of pleading:

> I begged them to keep him. I said, he's getting care that he needs here. I begged them to keep him and they wouldn't, couldn't … Your loved one can fall through the cracks if you're not there to advocate for them. You have to be there, you have to ask questions, you have to push, you have to get where you want to be because they can't do it for themselves. (Wife)

Advocating in this manner did not come without apprehension. Participants experienced tension between fighting for the right home for their loved one and a belief that care coordinators could choose for them. Another caregiver described it as follows:

> Some people had told us sometimes you don't have a choice. They said if you don't soon pick they may pick for you. And she could end up two hours away. And we're like "can they honestly do that?" (Daughter)

After Transition

The final phase of these caregivers' transitions commenced when an LTC bed offer was accepted and the older adult moved into the facility. After accepting a bed, the physical move to LTC was typically fast and described as smooth. The journey to this point seemed to suddenly end. The caregiver's feeling of relief and thinking about other transitions became apparent themes of this aspect of the transition trajectory.

Feeling Lucky and Relieved

A profound sense of relief was expressed by most caregivers, recognizing that their loved one would be safe and their struggle through the system was over. Beyond relief, the caregivers felt fortunate when an available bed in a home that was on their preferred list became available. One adult son with his wife commented, "He got to stay in his town … in our situation we were very, very fortunate to get placed where we did." The sense of relief and luck was enhanced when caregivers perceived that their loved one was adjusting well to their new home. For example, one wife stated, "He's settled in quite nicely, actually better than I've settled in at home." When caregivers were happy with the care from LTC staff, they were able to find some peace after the transition:

> Just the knowledge that they had caring individuals here … But just to know that the doctors and the nurses here are very good, they're doing their best and that helps to know that. (Wife)

Preparing for Future Transitions

This experience urged caregivers to think about and prepare for future transitions of other aged relatives and even for themselves. One caregiver spoke about her preparation for her father's impending transition:

> You know, I have my dad in assisted living with Alzheimer's and we know eventually he'll have to go into long-term care … I've been proactive and put him on the list because some of the lists I guess are … a couple of years long. (Niece)

One family member expressed worry about her children having to go through what she did with her mother:

> I told my girls 'Shoot me, shoot me.' If I have to go, honestly I don't even want to see my girls go through it. When I get old, I hope that it's better than it is now. Because I would never want to see my own children go through what my sister and I had to go through. The pain and to try and go through and with that lack of respect I think for … I would never want to see my kids go through that. (Daughter)

The challenge of this experience extended beyond the boundaries of the transition while also spurring thoughts, anxieties, and actions in anticipation of eventual transitions.

Caregiver Health

The health of the caregivers emerged as a common concern across the transition phases and speaks to the influence of the caregiving experience on personal health and well-being. All participants noted the stress and fatigue relating to seeing and protecting their loved one through this transition. Two participants had significant health events which they attributed to their caregiving role. A family friend of a recently transitioned older adult said:

> But she was there [home] as long as she could be and … We kept her there as long as we could, my father said … he said it's not good anymore … he could see that I was starting to go downhill and I did have a stroke … she was in the car with me when I had it. (Family friend)

The wife of one older gentleman particularly struggled after her husband moved into LTC from their longtime family home during and after the transition and observed, "It was stressful on me. I was having a few problems. You know I had to go to the doctor and get some medication to kind of calm me down; 'nerves' type of thing."

Another spousal caregiver of her husband and parents in LTC described the toll that caregiving had on her and how it continued to impact her health:

> Maybe I can, you know consider even going to work one or two days to help with the financial burden … But right now it's just been too much, you know? Mentally, physically, and emotionally, I'm not up to be working right now. (Wife)

The constant stress and worry associated with transitioning an older adult through different levels of community supports and care environments towards LTC negatively influenced the caregivers' health across their transition experience while also contributing to a sensed lack of control over themselves and the transition overall.

Discussion

The findings from this study advance current knowledge regarding transition experiences of caregivers when older adults enter LTC in three key areas: (1) caregivers' sense of control during the experience; (2) the applicability/validation of transitions theory to understanding caregivers' experiences; and (3) the influence of caregivers' experiences on future transitions.

In this study, the importance of control throughout informal caregivers' experiences was apparent. The language used by participants such as "our hands are tied" or "being muscled" during decision-making illustrated this struggle. Similar imagery was used by participants from previous studies of caregivers' transition experiences (e.g., feeling coerced and rushed; Caldwell et al., 2014; Cornes et al., 2008; Cheek & Ballantyne, 2001; Penrod & Dellasega, 2001). Other caregivers compared the experience to fighting a war (Cheek & Ballantyne, 2001) or to treachery (Lundh et al., 2000). This early finding urged the research team to dig further into the phenomenon of control with future participants.

Consensus among study participants and support from past literature demonstrates the perceptions of caregivers that there is "no decision" to be made or opportunity for "choice" when placing an older adult into LTC or when searching and applying to LTC homes (Cheek & Ballantyne, 2001; Lundh et al., 2000; McAuley, Travis, & Safewright, 1997; Penrod & Dellasega, 2001; Strang et al., 2006). This could reflect past findings that caregivers maintain older adults at home for as long as possible. Thus, when crisis or significant decline occurs, there truly are no other options (Caldwell et al., 2014; Dellasega & Mastrian, 1995; Ryan et al., 2012). This finding may also suggest a gap in community services and alternative care settings in meeting the care needs of older adults and their caregivers. Based on this finding, sensitivity of language is recommended in future research and when HCPs engage with caregivers surrounding decision-making, as it may not be perceived as a freely made decision.

The perceived powerlessness of caregivers increased once they were required to find and apply for beds in LTC homes. Lundh et al. (2000) found that Swedish spousal caregivers had no choice into which home their husband or wife went. The final home depended on local availability and on the community caseworker. This finding resonates with the experience of this study's participants. Despite their constant effort to research different homes in the local area, participants were continually confronted by barriers to choosing their preferred homes. In another study, American caregivers faced limited and suboptimal LTC home options (Penrod & Dellasega, 2001). Therefore, it appears that the sense of control in selecting homes of their choice projected by system processes onto caregivers is illusory.

Some caregivers tried to influence this dynamic by "pushing back". This advocacy was required to make the most of a challenging situation. In one study, spousal caregivers found that to exert any influence required an immense amount of assertiveness and persistence (Lundh et al., 2000). Some spouses in this study accepted homes with intentions to move the older adult when a more desirable bed became available or refused the offered home to wait for other offers. A fear of punishment from delaying bed acceptance was not described in this study. Although caregivers in the present study tried taking similar actions, there was a sense that they could be punished or sanctioned for doing so. The potential for punishment threatened the small amount of control that caregivers might have felt over choosing a home or accepting an offer.

This study's findings both align with and challenge the well-established transitions theory (TT) (Meleis, 2010; Meleis et al., 2000). Although we did not use TT as a framework to develop the study or to analyze participant experiences, it is useful to consider the study findings within the context of this theoretical model. According to TT, the nature of the caregivers' transition alongside the older adult in this study represented simultaneous developmental, situational, and health/illness transitions. The stressful interactions between caregivers and health care professionals during the transition led to what can be described as an unhealthy transition for the caregiver. This supports established relationships between TT concepts and the importance of therapeutic intervention by HCPs in promoting healthy transitions. Large-scale collaboration with informal caregivers, community supports, acute care systems, and LTC is pertinent to fill this gap and to support the health and well-being of informal caregivers. Findings from Davies (2005) are also echoed in this study, as the advocacy activities by caregivers in this study were not accurately depicted in the relationships of TT concepts.

This finding may also highlight that HCPs focus on the health of the older adult in transition rather than taking a relationship or family-centered approach. This spurs further questions, such as, who in this system is the appropriate person to provide a formalized, continuity of support to caregivers throughout the transition? Person-centered and interprofessional interventions such as those described by Coleman, Parry, Chalmers, and Min (2006) have potential to improve the caregiver experience and sense of control when tailored to health transitions into LTC.

The participants' discussion of preparing for future transitions was a novel finding. This perceived need to "start planning now" seemed to arise in relation to their recent challenging transition experience. Caregivers began anticipating future transitions, not only for other older adults in their lives but also their own eventual transitions. Preparation and knowledge are conditions of transitions and are factors which facilitate or inhibit successful and healthy transitions (Meleis et al., 2000; Schumacher & Meleis, 1994). TT predicts that anticipation of transitions by the caregivers can facilitate impending transition experiences (Meleis et al., 2000). This finding might be explained by current caregivers' not wanting to burden family members, such as children, when they age. This forward thinking may stem also from a lack of trust in the health care system. Caregivers may feel that if they do not prepare now, they and their family members will face similar challenges. Although this may be the case for some caregivers, it is important to recognize the multiple barriers and processes of the health care system that can inhibit smooth transitions for even the most prepared individual or family. This finding can broaden our perspective that transitions are not isolated events and carry implications for future transitions and life experiences.

Our study does have several limitations. Although the age and gender representation of caregivers was on par with national statistics, only one third of the sample was adult children compared to a national average of 48 per cent (Sinha, 2013). Further, all participants cared for older adults who recently transitioned into smaller Southern Ontario LTC homes and may not represent the experience of participants who transition in larger cities or LTC homes. The participants in our study were ultimately pleased by the care received in the LTC homes, which may have significantly influenced their willingness to participate in this study and their experience compared to caregivers who were unhappy with the LTC home conditions. The convenience sample in this study was more likely to capture caregivers who were highly involved in the older adult's life or who had a more positive experience in LTC homes. We also did not collect demographic data on culture and, therefore, could not explore how culture and background could influence transition experiences. Finally, despite efforts to flesh out the emerging themes with future participants by adapting the interview guide following the early interviews, the recruited participants often focused on the physical move into LTC rather than on their experience of the transition over time.

Implications for Research, Policy, and Practice

The understanding of this experience as a personal transition for caregivers themselves as well as the person transitioning demonstrates the importance of targeted caregiver support through the transition phases. Health promotion and transition preparation interventions may be required to sustain informal caregivers upon whom health care systems depend. Therefore, there is opportunity and necessity to enhance the role of HCPs in supporting caregivers.

In addition, this study may support the re-evaluation of policies which involve penalties that result in removing older adults from waiting lists when bed offers are declined, which as discussed previously can be a result of advocating for their family or the older adult in their care. Therefore, innovative policy solutions may prove to facilitate care transitions while maintaining the well-being of informal caregivers and older adults.

As populations age in Canada and around the world, a greater number of informal caregivers may be seeking support from HCPs and other types of health care services such as LTC to meet the care needs of older family members and friends. Considering the international phenomena of aging in parallel with the growing interconnectedness caused by globalization, qualitative approaches such as this, as well as others (Caron et al., 2006; Cheek & Ballantyne., 2001), remain vital to exploring issues related to caregivers and institutionalization across borders (Naleppa, 1996) as well as cultures (Caldwell et al., 2014) and race (Stevens et al., 2004). Given this context of international research, this study specifically highlights the perceived effects on informal caregivers regarding control, transition theory, and future transitions within the institutionalization process.

Further research into the perspectives of health care professionals such as discharge planners or care coordinators working in the public system or within private agencies who support transitions into LTC from hospitals and the community is required. Understanding the perceptions of both caregivers' experiences and their own perceptions of coping with the pressures of health care systems can help future HCPs to alleviate anxieties surrounding care transitions. Also, research into supportive behaviours that caregivers perceive as useful, whether informational or psychosocial, can also lead to concrete support recommendations to inform HCP practice.

Conclusion

The role of facilitating the transition of an older adult into LTC represents a significant transition experience for informal caregivers. Their experiences varied across different phases of the transition. Feeling out of control of the transition, for example, was common, and caregivers felt as though they had no choice in the decisions made to seek out LTC or to which homes to apply. Interactions with "the system" were disempowering resulting in some participants struggling to advocate and push back.

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