

# 'There was no preamble': Comparing the Transition from Hospital to Home in Different Care Settings\*

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#### RÉSUMÉ

Les personnes âgées doivent généralement faire face à davantage de transitions entre les structures de soins. Notre étude visait à comparer les expériences de transition vers le domicile vécues par des patients âgés provenant d'unités de soins de courte durée ou de réadaptation, ainsi que par leurs aidants. Étude descriptive qualitative. Les patients âgés de 65 ans ou plus et leurs aidants qui ont été recrutés pour les entretiens semi-structurés provenaient d'unités de soins aigus hospitaliers et d'établissements de réadaptation. Une analyse thématique a été utilisée pour cerner les thèmes émergents. Seize patients et quatre aidants ont participé. Le rôle majeur des aidants dans la facilitation de la transition, la préparation variable du congé, l'optimisation des transitions par les prestataires de soins, les soins manqués et les divergences liées aux médicaments sont des expériences communes vécues lors des transitions pour tous les milieux de soins. Les patients en orthopédie et en réadaptation ont plus souvent fait part de leurs expériences de transitions antérieures impliquant une préparation de congé, ainsi que d'éléments associés à l'imprévisibilité de la coordination et de l'attente pour des services ambulatoires. Les différences de réponses entre les soins de courte durée et les soins orthopédiques indiquent que les pratiques et les politiques de soins de transition doivent évoluer vers une approche individualisée qui tienne compte des expériences antérieures des patients, de leurs besoins et de leurs attentes en matière de soins.

#### **ABSTRACT**

Our qualitative descriptive study compared how older patients and their informal caregivers experienced the care transition from acute care or rehabilitation to home. We recruited patients 65 years of age or older, or their informal caregivers, from in-patient units within acute care hospitals and rehabilitation facilities to participate in semi-structured interviews. We identified emergent themes via thematic analysis. In all, 16 patients and four patient caregivers participated. Across all care settings, caregivers were integral in facilitating the transition as well as experiencing variable discharge preparation, health care providers' optimizing transitions, and missed care and medication discrepancies at transition points. Orthopedic and rehabilitation patients more commonly voiced prior transition experiences in discharge preparation, including having to unexpectedly coordinate and wait for outpatient services. Differing responses between acute care and orthopedic settings suggest that transitional care practices and policies favor an individualized approach that considers patients' previous experiences, needs, and care expectations.

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# Introduction

The time following a patient's being discharged from hospital to go home is a precarious period for the discharged patients and their caregivers. Notably, this transition point is considered to be a period of increased risk accompanied by gaps in communication, teaching, and information sharing (Backman & Cho-Young, 2019; Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011). Older adults are especially at risk for adverse outcomes related to multiple factors: the physical and emotional stress, as well as ineffective and/or mismanaged care transitions (Cheek, 2010). Approximately one-quarter of older patients have an adverse event post-discharge, and one in five will revisit the hospital within 30 days of discharge (Dharmarajan et al., 2017; Forster et al., 2004). Individuals aged 65 and older account for only 16 per cent of the Canadian population, yet they are considered high users of the health care system accounting for almost 46 per cent of public-sector health care spending (Canadian Institute for Health Information, 2017; Rotermann, 2017; Slade, Shrichand, & DiMillo, 2019). Chronicity also factors into health care use with older adults often seeing four or more physicians (Schoen, Osborn, How, Doty, & Peugh, 2009). Consequently, older adults tend to experience more transitions in care setting and health care providers (Naylor, 2002). Direct clinical evidence underscores the danger of older adults experiencing such events at the time of and immediately following discharge from a health care setting.

Discharge preparation is a strategy often used to increase discharge readiness and decrease readmission to hospital and Emergency Department visits (Bobay, Jerofke, Weiss, & Yakusheva, 2010). Considerable research evidence suggests successful discharge planning depends on comprehensive care plans, patient and caregiver assessments, and ongoing engagement of hospitalized older patients and their informal caregivers (Bauer, Fitzgerald, Haesler, & Manfrin, 2009). However, findings from previous studies of hospital discharge planning of older adults vary in the extent to which patients have been involved or request to be involved in decision-making (Foss & Hofoss, 2011;

Roberts, 2002). Many patients experience general dissatisfaction with the discharge process, particularly concerning inadequate explanation about medication and post-discharge care (Knight, Thompson, Mathie, & Dickinson, 2013).

Discharge planning gaps are evidenced in patients' not receiving written discharge instructions and not knowing when to seek follow-up care, underscoring inadequate care coordination for patients with complex needs (Schoen et al., 2011). Older adults and their informal caregivers often face challenges after discharge from acute care as breakdowns in communication, rushed discharge planning, and confusion over whom to contact post-discharge are common occurrences (Dossa, Bokhour, & Hoenig, 2012; Neiterman, Wodchis, & Bourgeault, 2015). More recently, efforts are being made at local and system levels to improve care transitions by optimizing communication at time of discharge (Hahn-Goldberg et al., 2016), care coordination (Evans, Grudniewics, Wodchis, & Baker, 2014), and post-discharge follow-up (Canadian Institute for Health Information, 2015). Authors of a recent report (Slade, Shrichand, & DiMillo, 2019) examined the physician workforce providing care to patients over 65 years of age. Medical specialties that yielded the highest percentage of total services were internal medicine and physical medicine or rehabilitation at 47.7 per cent and 39.0 per cent respectively. Relatedly, older patients receive five times more major surgical services (e.g., hip and knee replacement) and require 10 times more hospital care days when compared to those of the younger population.

Current care transition quality standards and best-practice guidelines fail to capture unique challenges across settings that may exist and which require different approaches (Health Quality Ontario, 2019b; Registered Nurses' Association of Ontario, 2014). In light of where older adults are receiving care coupled with inadequate practice standards, it is increasingly important to understand the factors, which may vary between care settings, to improve the transition home and ultimately impact the success of these very efforts. However,

absent from the literature is an analysis exploring the discharge and the post-hospitalization experience between different care settings. Accordingly, in this study we sought to understand the experiences – of patients aged 65 and older and their informal caregivers – leading up to, and returning home from, an in-patient acute care or rehabilitation setting including barriers and facilitators underpinning the patients' recovery.

#### Methods

# Study Design

This qualitative descriptive study used semi-structured interviews targeting patients and their informal caregivers. The chosen methodology facilitated a rich description of informants' care transition and post-discharge experience.

#### Recruitment and Sample

We recruited patients between October 2017 and July 2018 who were enrolled in a double-blinded, ongoing randomized control trial (RCT) of a discharge instruction intervention. Patients were discharged from one of six in-patient units across Ontario, Canada: three general medicine, one orthopedic, and two rehabilitation units. (ClinicalTrials.gov: NCT02673892, 2019). Research staff first approached all consecutive participants in the RCT about participating in a follow-up qualitative interview about their care transition experience. Consent for the interview was obtained and inputted into a database maintained by research personnel. The first author then used the database to identify potential participants for the qualitative study, with enrollment stopping once thematic saturation had been met.

Participants had an admission diagnosis of congestive heart failure, chronic obstructive pulmonary disease, pneumonia, hip fracture or hip replacement, knee replacement, or stroke (six quality-based diseases with transitional care metrics). The participants had a life expectancy of more than three months and were being discharged home (including retirement homes) (Health Quality Ontario, 2019a). Eligibility criteria for patients in our qualitative study included being aged 65 years and older and experiencing a transition to home; this did not include long-term care or other hospitals within the previous 30 days (i.e., discharge home from an in-patient unit). Informal caregivers acted as a proxy for patients either when required to as a substitute decision-maker for consent purposes or by patient and caregiver preference. A demographic questionnaire was administered to patients during the hospital stay by research staff. Recruitment for involvement in the qualitative interview occurred between October 2017 and July 2018 and was discontinued when data

saturation was reached. Saturation was observed when no new themes emerged, and the research team reached consensus. This study received Research Ethics Board approval at all five study sites.

#### Data Collection

The first author contacted patients or their informal caregivers who had consented to participate in a qualitative interview during recruitment into the RCT. A trained qualitative researcher conducted and recorded all interviews by telephone within 30 days of the patient's discharge from the in-patient unit. The authors developed two interview guides for participants – one for the patient, one for the caregiver – and framed questions according to the care transition trajectory (see online Supplementary File 1: Patient Interview Guide). A professional transcription company transcribed audio files verbatim. The average length of the telephone interviews was 24 minutes (range: 7 to 70 minutes).

# Qualitative Analysis

We used thematic analysis to interpret the data and to report on themes identified within the text that focused solely on the transition from in-patient unit to home (Braun & Clarke, 2006). Authors independently and repeatedly read interview transcripts to allow for familiarization of the data. Data collection and analysis occurred simultaneously, thus allowing the authors to compare similar and divergent experiences across the different care settings. The initial codes we generated were then categorized first according to broader level themes that centred on positive and negative experiences. To establish trustworthiness during this iterative process, authors met several times to refine codes (i.e., peer debriefing), and identified emergent themes within settings and across settings and which were vetted by the research team (Nowell, Norris, White, & Moules, 2017). While the data collection stage continued, and as new data were being gathered, themes became more apparent in the coded text. The study team reviewed the transcripts line by line, initially independently, and then the study team reached final agreement once a "coherent pattern" was identified in the narrative (Braun & Clarke, 2006). We noted divergent findings across study sites and highlighted them in the results.

The research team used several key strategies to ensure rigour was maintained throughout the research process. Techniques included transcript analysis by two qualified researchers who then developed a coding framework (Braun & Clarke, 2014; Mays & Pope, 1995). The coding framework enhanced the reliability of the analysis by providing a systematic approach for coding across the dataset and for identifying patterns in relation to the research objective. Lastly, the researchers

purposefully sought and included evidence of deviant or other such experiences that contradicted emerging themes (Mays & Pope, 1995).

#### Results

Sixteen of the 20 people interviewed for this study were patients aged 69 to 93 and mostly female (n = 9), and the remaining four people were caregivers of patients who underwent a transition in care. Most of the caregivers were female (n = 3), and each identified having a different relationship to the patients - spouse, daughter, daughterin-law, and niece. Of those discharged, six were from an acute care orthopedic unit (mean length of stay ± standard deviation [SD]  $4.1 \pm 2.1$ ); seven from an acute care internal medicine unit (10.85  $\pm$  6.79); and seven from an in-patient orthopedic rehabilitation unit ( $24 \pm 8.14$ ). Interviews took place, on average, 18.6 days after discharge (± 12.4 SD). Additional patient demographic characteristics are presented in Table 1. Our analysis identified universal themes spanning all care settings and several themes unique to the orthopedic surgical and rehabilitation care settings. Themes are presented below with associated illustrative quotes (see Table 2).

## Themes Span All Care Settings

The following four themes reflect common findings found in patient and caregiver narratives across all care settings.

Theme 1: Filling in the Gaps – Caregiver Presence and Support

Patients described informal caregivers, which included family, friends, and neighbours, as being instrumental

Table 1: Demographic characteristics of patients

Patients $n = 16$
9
75.6
44
25
19
6
6
10.85 ± 6.79
$4.1 \pm 2.1$
$24 \pm 8.14$
10
6

to the care transition experience. Informal-caregiver participants, referred herein below as "caregivers", described engaging in processes meant to optimize the care transition for their family member. Across all settings, caregivers were relied upon for simple duties like preparing meals as well as for more complicated tasks such as coordinating care services and making alternative living arrangements.

Both patient and caregiver informants reported a lack of a formal needs assessment by the health care team to evaluate caregiver capacity prior to patient discharge. For one patient who underwent surgery, her request for home care services was denied when her husband was considered capable of assisting his wife despite his own poor health, illustrated in the following quote:

She [social worker] looked at my husband who is 76. She said, "Can you look after your wife?" "Well," he said, "I guess I'll have to." He has had three hips, three backs, a knee, and he's still supposed to look after me. (Patient, Orthopedics)

Caregivers described being left to coordinate care post-discharge for their family member with inconstant support provided by the health care team. As one caregiver shared:

So, it was a bit of a mess in that sense. I just took it upon myself and I called CCAC [home care] myself, said "This is my uncle ... We now need a little bit of help with bathing ... " So, I took it on upon myself. But again, let's say I was elderly and I didn't know the system: I wouldn't have been able to do that. (Caregiver, Internal Medicine)

Caregivers also shared the impact of their role on employment when having to take time off or negotiate a flexible schedule. Many caregivers acknowledged the need to be present and needing to be a source of support for their family member while dismissing their own personal needs, illustrated in the following caregiver quote from an adult child caregiver:

For a family member who's worried to death ... who's very, very overwhelmed with elder care, because I'm not a young person, I'm old, I'm almost ready for elder care myself ... Where before I was going to the grocery store, I was cleaning his house, I was doing his laundry ... I was averaging a day a week because of all his medical appointments.... And that was interfering with my ability to earn a living. (Caregiver, Internal Medicine)

Theme 2: Experiencing Variable Discharge Preparation – 'There Was No Preamble'

Patients and caregivers described variable discharge practices ranging from suboptimal to satisfactory communication with their health care providers leading to, 286

Table 2: Patient and caregiver care transition experiences

Theme	Illustrative Quote
Filling in the gaps – caregiver presence and support	<ul> <li>I was hoping, because everyone else seems to be able to go to rehab and things like that after surgery. Like, my wife just died so I'm alone, you know? I thought I could go in rehab for at least a week, because I thought I'd be living alone. And my friends altered their plans and they came and just moved in, and I realized I probably could not have stayed alone. (Patient, Orthopedics)</li> <li>Basically, she [social worker] contacted a few of them and they indicated what services they provide And then left it up to me to contact them and talk to them and decide which one we were going to go to and so on. (Caregiver, Rehabilitation)</li> </ul>
Experiencing variable discharge preparation – 'There was no preamble'	<ul> <li>One person came up, which by the way I had to ask for, that was the social worker. Now she couldn't do anything for me and I understand I expected it to be all pre-set but I gather that the ones in Toronto or the ones in different territories. They have Ontario split up I gather into the same organization but different groups so they can't do anything with another area, which is a bit surprising. They could at least send my name and number I made all the calls. I had to call three different numbers to get to the right group. (Patient, Orthopedics)</li> <li>They said it to them [family friend], and somebody called me and then I thought, okay, I called my husband because we have to go get the car. And I was able to go in and I kind of approximately knew the time. (Caregiver, Internal Medicine)</li> </ul>
Feeling a connection with health care professionals	<ul> <li>Oh, I had a phone number and I was in touch with, I guess, the chief. I didn't actually meet her in person, I didn't have to. She would return my calls if I asked for a call, and we were in touch on the telephone a couple of times I found a respite facility. I will say that the person in charge of the floor, doctor was marvellous. She allowed me the time necessary to get the spot for my dad, and organized a medication review, and generally was very, very accommodating. (Caregiver, Internal Medicine)</li> <li>Well, it wouldn't be the OT, but you kind of had to ask to see them and then they would eventually come around. I don't know how busy their workload is, so I don't want to judge. But there really wasn't anybody else No, there was nothing really clear. It was sort of you learn as you went along. (Patient, Rehabilitation)</li> </ul>
Experiencing missed care and near misses	<ul> <li>It wasn't until the morning that I was leaving that physio came back and they said, okay, we need you to do therapy before we can discharge you. And that was the morning that I was leaving. (Patient, Orthopedics)</li> <li>The one medication he kept her on he doubled the dosage and he didn't tell me that it was the only one. I was reading this four-page medical discharge form. I said, that's strange. That's not what she's taking. So, then I went back and caught him doing his rounds. This was after she had been discharged So, that was corrected. But then the second thing was that – although the medications were changed – there's the discharge medication sheet that's sent to her pharmacist [that] for some reason was not sent. They never got it. (Caregiver, Rehabilitation)</li> </ul>
Knowing what to expect from a previous dis- charge experience	<ul> <li>I was prepared for what I was going to have to do, not because of what they told me. Because I've done it before; I was in Florida and had surgery on my hip and it was a four-and-a-hour drive. I think they gave me more information about what to expect and they said you will not be able to sit up for a long drive home. So, having the last two surgeries, because someone was nice enough to give a suggestion, What we did was, we had a three-inch piece of foam [that let us change the seat height so I could be comfortable on the drive]. (Patient, Orthopedics)</li> <li>Well, I had a knee operation one year ago and I was there three days. I was supposed to be there two days, but since I developed a fever, they kept me one more day. The operation of the knee was not that severe, so that was okay then. But, this operation was much more important, and I was not even [kept in the hospital] long enough No. No The doctor discharged [me too] early I had to leave, because they said that they needed the room I didn't have any choice to stay longer, no. They just dumped me out That was the worst thing that happened to me. We don't dump people on the street like this, 24 hours after surgery. (Patient, Orthopedics)</li> </ul>
Coordinating unexpectedly and waiting for ongoing care	<ul> <li>And then I'd always go home with CCAC [home care] coming in to do exercises with me. Nothing was mentioned about that this time, about anybody coming in. So, I figured I just do the exercises on my own. And they said, here's a list of people who are OHIP physiotherapists, so you can call them, maybe in about three weeks. And after three weeks, you'll be able to go out and go to a physiotherapist. (Patient, Orthopedics)</li> <li>At the time of the discharge, they acknowledged that she needed more rehab, that she could go to a day rehab, but that there was a huge backlog and that it would be for four weeks, six weeks. (Caregiver, Rehabilitation)</li> </ul>

and at the time of, discharge. Surprised and frustrated reactions were reported in several cases. Leading up to the time of discharge, participants spoke about not

having had the opportunity to engage in discussions about the eventual transition home, receiving little notice of their discharge date, experiencing missed care, and receiving complicated written discharge summaries resulting in feeling unprepared for the discharge home. Participant narrative supported the notion of patients "not really knowing" when they were going to be discharged or becoming aware of the discharge plan "as you went along", whereas for others their discharge experience was compared to being in a "big factory" with regards to how quickly patients were admitted and discharged. Many patients and caregivers were informed of their or their family member's discharge with little notice.

In an acute care narrative, a caregiver unexpectedly learned about the sudden discharge from a family friend visiting her uncle. In rehabilitation settings, despite a longer stay, patients had comparable experiences. A patient admitted to rehabilitation described the transition as "chugging along" and being surprised when she was informed of her discharge date in the absence of any preparation. Similar sentiments of insufficient information were shared by participants about their understanding of home care services and follow-up care. Written information was often reported as not being helpful and given to patients too late or at the wrong time during an admission, which was the case for a patient who received written material three days post-operation:

They told me someone from pre-admitting would come in and there would be a lot of discussion and instructions, but nobody showed up so I didn't get any pre-admitting. I got my book with exercises almost my third day of my operation. (Patient, Orthopedics)

Another story involved a complicated discharge summary given to an ill 87-year-old patient that made little sense to his caregiver daughter: "Basically, my dad was given 18 pieces of paper. ... he didn't read any of it ... he threw it in the corner" (Caregiver, Internal Medicine). Although their conditions might have been different, patients in rehabilitation settings described similar experiences regarding the discharge summary.

For some patients and caregivers, a satisfactory discharge experience stemmed from receiving information from providers in an understandable fashion. Generally, participants described this information as "thorough" and "informative", being "realistic" to the needs of the older patient and personalizing material to the patient rather than to a physician. Discharge information received in this way reinforced participants' sense of being informed and prepared for returning home. These patients and caregivers described receiving instructions, pamphlets, and discharge instructions that eased their discomfort. For example, one caregiver reported receiving a "package" prior to her mother-in-law's being released: "They quickly went through the package ... I felt very comfortable knowing what was happening the morning of, as well as what I can anticipate in the next couple of days" (Caregiver, Rehabilitation).

Theme 3: Feeling a Connection with Health Care Professionals

Establishing a connection with health care providers seemed to improve the care transition experience of both patients and caregivers. Many participants in all settings described having interactions throughout their stay with a consistent provider who seemed interested in the patients' progress. Physicians were often identified as filling this role, as noted in the following quote by a patient eventually discharged from rehabilitation: "He was really great. Even if he just came in the door and said, 'Anything that you need?' And then if I said, no, I was fine, he just said, 'Well, that's great, I'll see you tomorrow'" (Patient, Rehabilitation).

Several patients and caregivers identified key providers as being instrumental to the care transition. In some cases, this provider enhanced the transition home despite participants experiencing poor communication around discharge. While mostly satisfied with the quality of care received, several patients discharged from acute care noted the "revolving door" of nurses. This, they stated, contributed to being given varying advice. According to one participant on an orthopedic unit, he received "different advice from different nurses on how to get in and out of bed" (Patient, Orthopedics). For a caregiver whose wife was transitioned from acute care to a rehabilitation facility, a constant stream of nurses, physicians, and other staff was described as "disorienting", and which may have contributed to his wife's delirious state.

Theme 4: Experiencing Missed Care and Near Misses Participants across all care settings reported missing care, near misses, and medication discrepancies noticed, either leading up to or at the point of transition from hospital to home or once discharged back home. One example noted by a participant was not receiving any patient education before surgery. For another patient, an order for an X-ray of a knee was overlooked until the patient was "out the door": "Yeah, I don't think they look at the papers until you're ready to go home, and that's not right because if she had checked that paperwork in the beginning, I would have had that X-ray" (Patient, Orthopedics). Unclear medication instructions were commonly mentioned by patients. Such examples included not knowing when to end certain medications, challenges with taking pain medication, or not being informed of changes made to patients' medication regimen as noted in the following quote:

The one medication he kept her on – he doubled the dosage and he didn't tell me ... I was reading this four-page medical discharge form. I said, "That's strange. That's not what she's taking." So, then I went back to the [hospital name] and caught him doing his rounds. This was after she had been discharged. (Caregiver, Rehabilitation)

Themes More Prevalent in Orthopedic Acute and Rehabilitation Settings

The following two themes represent findings that seemed to be unique to patients and caregivers who experienced the transition home from orthopedic acute care and rehabilitation settings.

Theme 5: Knowing What to Expect from a Previous Discharge Experience

Participants often recounted and reflected upon past hospital admissions. In doing so, they acknowledged that these experiences provided them with knowledge of the system and prepared them for what to expect. This was a recurrent theme for orthopedic patients who had had prior surgeries, particularly in the context of a short length of stay and little preparation for the transition home. A patient who underwent a similar surgery in the past was able to independently devise a plan on how to manage the long car ride home post-operatively, which is evident from this remark:

I was prepared for what I was going to have to do, not because of what they told me ... I've found that, I've done it before: I was in Florida and had surgery on my hip and it was a four-and-a-half-hour drive [to get home]. I think they gave me more information about what to expect, and they said you will not be able to sit up for a long drive home. (Patient, Orthopedics)

Previous surgical in-patient stays enabled a resourceful approach to the patient's current hospital-to-home care transition. Participants reported their having already in possession certain equipment, or knowing how to coordinate outpatient rehabilitation upon discharge, and some had even fashioned a method to enter a car post-surgery. For one patient with an exceptionally short hospital stay of 24 hours, despite being aware of what to expect from previous surgical encounters, there was still a sense of pressure to be discharged: "That was the worst thing that happened to me. We don't dump people on the street like this, 24 hours after surgery" (Patient, Orthopedics). Although patients with shorter lengths of stay after an elective surgery also had access to an optional pre-op class to learn more about the surgery and what to expect, patients often leveraged previous experience that minimized their need for the pre-op care:

Because I had had the same surgery a year before in the United States, where I originally fell, I know, more or less ... because I did the rehab at [rehabilitation location], I knew, more or less what to expect, so there was maybe less need for that. (Patient, Orthopedics)

Theme 6: Coordinating Unexpectedly and Waiting for Ongoing Care

Some patients and caregivers described having to coordinate their own care, such as ongoing physical

rehabilitation and home care services, following discharge from the orthopedic unit. One patient, who was anticipating in-home physiotherapy based on a previous surgical experience, instead received a list of government-funded physiotherapists so that she could personally arrange outpatient physiotherapy. Other patients noted recent changes to home care service delivery whereby care that was previously covered by nursing personnel was now the responsibility of patients to manage. Having to self-administer daily injections post-op was an example given by one patient: "CCAC [home care] used to do it; apparently, no longer. But I guess when outside agencies change policies, you also have some changes, especially in a year when a patient has an expectation that is no longer offered" (Patient, Orthopedics).

Overall, patients making their own arrangements also spoke about variability in receipt of home care services, which seemed to reflect either the timing or their location. For example, although some patients received no additional home care services in their home, others in different parts of the province (Ontario) seemed to receive more assistance to help them with their personal care. One patient noted such variability when comparing a previous hospital experience:

I'm still taking needles daily, related to the post-op. And CCAC [home care] used to do it – apparently, they no longer [do]. But there was some fuzziness on do they, or don't they? But I guess when outside agencies change policies, you also have some changes, especially in a year when a patient has an expectation that is no longer offered. (Patient, Orthopedics)

Once home, these patients and caregivers often experienced waitlists for ongoing physical rehabilitation as evidenced in the following remark: "I would have appreciated having somebody come to the house and help me with that ... I'm not going out now because I'm still on the waiting list, so I have nobody" (Patient, Rehabilitation). Participants with previous experience transitioning from hospital to home appeared to better navigate the health care system once discharged so as to avoid waiting for care. For example, a patient who received outpatient therapy had previously requested to speak with a social worker prior to her discharge and thereby arranged to see a physiotherapist at a specific facility post-discharge. Likewise, a caregiver with superior knowledge of the health care system seemed to know whom to contact to request additional physiotherapy support for her uncle. Although most patients returned home, one patient transitioned from in-patient rehab to a retirement setting where she, too, continued to wait for more physical therapy.

#### **Discussion**

This study showed that many patients and caregivers had similar experiences when transitioning from an in-patient unit back to their homes, or to an alternate care setting, regardless of diagnosis or acute versus rehabilitation setting. However, for those returning home from an orthopedic or rehabilitation in-patient setting, the authors noted different themes. Commonly experienced across all care settings was the integral role of family/ informal caregivers; patients and caregivers not being prepared for what to expect; health care providers optimizing the transition experience; and, finally, missed care and medication discrepancies at transition points. Themes that were more strongly reflected in the acute care orthopedic and rehabilitation settings include the role of a prior transition experience in preparing a patient for discharge and managing their recovery, and unexpectedly having to simultaneously coordinate their own care and wait for outpatient services. Participants from the orthopedic and rehabilitation units seemed to draw on previous surgeries and encounters with the home care system and related services, which enabled a more positively perceived experience.

Themes observed to cut across all sampled care settings consist of both facilitators and barriers to effective transitions. Acting as enablers to patients' recovery, caregivers in our study were heavily involved in providing physical care and coordinating care for patients. This finding is consistent with the broader caregiver literature that underscores the many care processes facilitated by caregivers for older individuals, thereby demonstrating the importance of conducting family caregiver needs assessments (Byrne, Orange, & Ward-Griffin, 2011). This is similar to a recent study by Hahn-Goldberg, Jeffs, Troup, Kubba, and Okrainec (2018) who found that caregivers act at both granular and macro levels - completing necessary care tasks to navigating the system for patients with limited health literacy. Often mitigating negatively perceived transitions was the patient/caregiver-provider relationship, which speaks to care recipients' and carers' desire to connect with a clinician who is a consistent point person. Having one main contact has been found to be beneficial in supporting patients and families during the transition period by providing continuity of both point person and service (Sims-Gould, Byrne, Hicks, Franke, & Stolee, 2015).

Barriers to quality transitional care consist of inadequate discharge preparation of patients and caregivers, which was reflected in minimal notice of the discharge date and non-meaningful discharge summaries, a finding which has been reported in previous studies and is the focus of ongoing improvement initiatives (Foust, Vuckovic, & Henriquez, 2012; Graham, Ivey, & Neuhauser, 2009; Hahn-Goldberg et al., 2016). Our study also found that negative sentiments were expressed in missed care, medication discrepancies, and unmet care transition needs. Although for some

participants who underwent elective surgery, attending an optional pre-op class was perhaps meant to mitigate possible risks of having shorter lengths of stay. Elective orthopedic patients, however, continued to experience unmet needs and dissatisfaction with discharge planning efforts. This finding supports previous research of efficiency pressures in the in-patient setting for fast throughput, jeopardizing the quality of care coordination (Allen, Hutchinson, Brown, & Livingston, 2017; Dedhia et al., 2009). Targeted risk assessment interventions that support early discharge planning and patient/family engagement have shown a positive impact on quality and safety, and a reduced cost of patient care transitions (Ohta, Mola, Rosenfeld, & Ford, 2016).

Our findings contribute to the growing body of literature, including closely aligning with recent work by Stolee et al. (2019), who introduced a "Transition of Care" framework of factors to improve post-acute care transitions for older adults. Overlapping areas include fostering patient involvement, supporting the role of family caregivers, and strengthening health care provider-patient relationships. Although our results have elucidated a greater understanding of how care transition experiences vary between care settings and how contextual elements, such as having a previous admission to hospital or access to home care services, could influence the success of the care transition (Rennke et al., 2013). The themes of patient/caregiver unexpectedly coordinating their care post-discharge and experiencing delays in ongoing physical therapy represent care transition nuances to the orthopedic and rehabilitation patient population. Another study in Canada has also noted that patients and caregivers consistently prioritize funded and available home care services as a means of improving the transition from hospital to home (Kiran et al., 2020). Although in recent years there is more emphasis on patient participation in managing their own health care, research has shown that patients are not a uniform group; rather, they take on varying levels of involvement in their care when hospitalized (Lund, Tamm, & Bränholm, 2001). Our study highlights an opportunity for health care providers to consider patients' and caregivers' preferences for participation in transitional care planning.

This study comes with several limitations. First, participants were recruited from an RCT of a transitional care tool (Hahn-Goldberg et al., 2016), which may have influenced responses such that those randomized to the patient-oriented discharge summary had more caregiver involvement and discharge preparation. However, this potential limitation was minimized by design for data collection and analysis such that knowledge of randomization was unknown to the study team and patient, and interview guide questions were framed to gather experiential information from

respondents of the care transition event rather than the intervention or lack of the intervention (Turner III, 2010). Second, the 30-day follow-up time frame may have contributed to participants' recall bias of the discharge event. Third, we noted that caregiving continues to be a gendered profession in that most of the caregivers we interviewed identified as female. As we observed in previous research, care transitions are affected by complex dynamics, including the gender and relationship status of the primary caregiver (Allen, Lima, Goldscheider, & Roy, 2012). Our failure at applying a gendered lens to the results might have resulted in missing important insights of gender differences in caregiving during transitions in location.

# **Implications**

These findings underscore important practice implications. The common themes across all care settings demonstrate salient factors that should be considered when improving the hospital-to-home trajectory. Health care providers and teams should involve informal caregivers, provide timely discharge preparation to patients and caregivers, establish a relationship with patients and caregivers, and be vigilant regarding missed care or near misses at the point of discharge. Contextual factors operating at the patient, organizational, and healthcare-system level also play a significant role in determining the experiences of older adults and caregivers transitioning home from care settings (Rennke et al., 2013). Therefore, health care providers should consider practice changes that are contextualized to the unit of care and patient population, and are embedded in policy and practice, which may result in better outcomes (Allen et al., 2017). Our results place further emphasis on opportunities for improvement related to coordination and follow-up care, including home care and outpatient therapy, for orthopedic patients (Kiran et al., 2020). Further research is warranted for researchers to better understand contextual factors and processes that enable and constrain the care transition experience for the complex care needs of older adults.

# **Conclusion**

Older patients who are being discharged home share, along with their caregivers, similar care transition experiences despite care settings. Variability in the experience is attributed mostly to contextual differences and may be a marker of differences in care needs and discharge processes. Future work in support of improving the care transition of older adults, along with caregivers' needs, must not only include identifying key contextual factors and processes, but also determine how health care providers can be more aware of

patients' and caregivers' desire for participating in the planning. Transitional care practices and policies need to move towards a more individualized approach that considers patients' previous experiences, needs, and expectations of care.

# **Supplementary Materials**

To view supplementary material for this article, please visit http://dx.doi.org/10.1017/S0714980820000380.

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