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Exploring success in sub-acute hospital-to-home transitions for palliative patients: a descriptive qualitative study

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Abstract

Background Transitioning from a sub-acute hospital to home is highly desirable to some palliative and end-of-life individuals and their family caregivers, but the transition process itself is complex and can be logistically challenging. This formative assessment sought to better understand what constitutes a successful sub-acute hospital-to-home transition from the perspectives of health care providers connected to a sub-acute care facility in Ottawa, Canada, with reflections from a patient and a family caregiver.

Methods Our descriptive qualitative study involved 13 virtual interviews and one virtual focus group between February and May 2023. Our sample included health care providers involved in the sub-acute hospital-to-home transition for palliative patients from a sub-acute facility, as well as one patient and one family caregiver who had experienced a palliative transition in this context. We used reflexive thematic analysis to code the data, and we inductively developed themes based on participants' experiences.

Results We collected data from 14 health care providers, one patient, and one family caregiver who were involved in, or had experienced, a sub-acute hospital-to-home transition. We found three themes delineating participants' shared perceptions of the key foundations of a successful sub-acute hospital-to-home transition in the palliative context: meeting patient goals; sharing information to ensure informed decision-making; and having someone to coordinate the transition.

Conclusions Our study highlighted that a successful sub-acute hospital-to-home transition should be person-centred and requires effective communication and coordination, both within and across, hospital and home environments. These insights will help inform intervention co-design to improve palliative care transitions in the next phase of this project.

Keywords Palliative care, Qualitative research, Patient discharge, Hospital-to-home transitions

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Introduction

For some palliative patients and their families, leaving the hospital to return home at the end of life is highly desirable. Returning home can be a joyful experience. However, the process of transitioning from hospital to home as part of a palliative care journey can also be logistically challenging and frustrating. As part of a larger research project seeking to improve hospital-to-home transitions for patients receiving a palliative approach to care, this study's objective was to conduct a formative assessment to understand how care providers, patients, and family caregivers associated with Bruyère Health in Ottawa, Ontario, Canada viewed a successful transition in this context. These findings will inform intervention co-design in a future phase of the project.

Background

Sub-acute hospitals offer specialized care for patients who do not need the high level of care provided in acute settings. Many individuals receiving a palliative approach to care are hospitalized before death [1] and, despite some patients' desire to return home to die [2–6], this transition does not occur. This outcome is poorly aligned with a person-centred healthcare model, wherein patients work with their healthcare providers to make informed and empowering decisions about their care [7]. When hospital-to-home transitions are not centred around the patient and do not respect their goals of care, it can have significant negative effects on the physical, psychological, social, and spiritual well-being of patients and their family caregivers [8–16]. However, this topic remains underexplored in the context of sub-acute hospital-to-home transitions. In an earlier phase of this project, McCoy et al. found that common sub-acute hospital-to-home transition interventions included regular home visit follow-ups after discharge, individualized transitional care programs, palliative care consultation services, and an individualized interaction with an advanced practice nurse [17]. These interventions were associated with positive system- and individual-level outcomes such as reduced risk of hospital readmissions, reduced length of stay, and improved functional status [17].

In an international context, many countries and organizations have implemented structures and frameworks to enhance access to and delivery of palliative care, including addressing hospital-to-home transition processes at the end-of-life [18–21]. While healthcare systems vary globally, the Canadian context places significant emphasis on person-centered care as a cornerstone of palliative and end-of-life care [7]. This study adds to the large body of international literature on care transitions by addressing an existing gap in understanding sub-acute hospital-to-home transitions in the palliative care context in Canada from the perspectives of those most closely involved in the process, both on the hospital and community sides. Of the research available on this topic, most focuses on the impact of transitions on health care service delivery, rather than on improving the patient and family caregiver experience. With more countries adopting person-centered approaches to healthcare, there is a growing opportunity Canadian sub-acute hospital-to-home transition models to inform and inspire international reform.

Research on hospital-to-home interventions for palliative patients often fails to capture the elements most meaningful to patients and family caregivers [17]. Arias and García-Vivar conducted a narrative review that looked at the experiences of palliative patients and their family caregivers during care transitions by exploring negative experiences to identify areas for improvement [22]. This study responds to the call for additional work in this area to explore positive and successful transition experiences. The lack of emphasis on positive experiences points to a gap in understanding what constitutes a successful sub-acute hospital-to-home transition for palliative and end-of-life patients. Existing literature supporting the hospital-to-home transition for patients nearing the end-of-life suggests that successful processes could include effective collaboration and information sharing [23, 24]. However, the mechanisms through which fragmented communication and collaboration among healthcare providers in hospital and community settings remain poorly understood, especially when provider roles are unclear, impacting transition coordination [25]. There is significant value in better understanding the sub-acute hospital-to-home transition experience from patient, family caregiver, and healthcare provider perspectives as a means of better understanding the priorities of these groups and how reform initiatives targeted at improving transitions can make changes in areas of key importance to them [26]. Our study seeks to offer clarity on the key components of successful sub-acute hospital-to-home transitions from the perspectives of those most closely involved in the transition process.

Objective

Identify components of a successful sub-acute hospital-to-home transition for palliative and end-of-life patients at Bruyère Health from the perspectives of those most closely involved in the process.

Methods

This study took a subjectivist inductive approach to understanding the sub-acute hospital-to-home transition. Rooted in the constructionism paradigm [27], this involved working up from data collected from participants involved in the transition process and searching for patterns across the data to generate an understanding of

what components participants identified as being most salient to their transition experiences, specific to the Bruyère Health context. We used a team-based approach to code book development and data analysis to inductively develop, analyze, and interpret patterns across our qualitative dataset [28]. Engaging multiple researchers in the data analysis, guided by Church *et al.'s* (2020) approach, enabled us to leverage diverse interdisciplinary perspectives, helping us to identify pockets of success in narratives that were largely about gaps and challenges. While a comparison of positive and negative perspectives of participants could be valuable, this project instead takes a strengths-based approach and reports on what pockets of success look like in the context of palliative subacute hospital-to-home transitions in hopes of sharing promising practices and building on these in the future.

Setting

Bruyère Health's hospital programs encompass 450 beds that provide care for aging and medically complex patients, geriatric and stroke rehabilitation, and palliative care. During the year of study (2022–2023), complex continuing care had 743 admissions and 288 home discharges, geriatric rehabilitation had 699 admissions and 571 community discharges, and the palliative care unit had 460 admissions and only 21 community discharges. Bruyère Health does not engage a specific transition professional (e.g., discharge planner) for their palliative patients in the hospital setting beyond the multi-disciplinary palliative care team that includes physicians, social workers, nursing staff, and allied professionals (e.g., dietitian, pharmacist, chaplain).

Recruitment

The research team used convenience and snowball sampling to recruit participants, leveraging professional networks and patient rosters at Bruyère Health. Recruitment for this study was very challenging. To capture the transition experience from diverse perspectives, we sought three participant groups: (a) hospital- and community-based health care providers, (b) palliative patients, and (3) family caregivers. Eligibility criteria required participants to be above 19 years of age, fluent in English or French, have the capacity to consent, and have experienced a palliative hospital-to-home transition at Bruyère Health in some capacity. Given that only 21 palliative patients experienced a Bruyère Health transition within the study period and the limited life expectancy of the patients in this group, our recruitment pool of patients and family caregivers was extremely small and made recruitment of these participant types very difficult. Care providers were easier to recruit, though still challenging given the required connection to Bruyère Health specifically. Hospital and community care providers were recruited by clinician members of the research team who reached out to their colleagues in person and via email. Nurses and social workers in the hospital were emailed an invitation to participate by their managers. Physicians, nurses, and care coordinators who worked in the community and/or with the Regional Palliative Consultation Team were emailed an invitation to participate by their managers. We also posted recruitment materials on the Bruyère Health Palliative Care Unit, presented six times during care provider rounds in the hospital, and reached out to the patient and family advisory committees at Bruyère Health. Our one patient and one family caregiver participants were recruited with their consent by a member of their circle of care. To transfer their name and contact information from clinician to researcher, we used a consent-to-contact process approved by the Research Ethics Board (REB) requiring encrypted messaging. This study was approved by the Bruyère Health REB (# M16-22-047) on November 11, 2022. Participant consent was obtained via a verbal informed consent statement prior to data collection. In line with SPOR guidelines, participants were remunerated with a $25 gift card in reciprocity for their time [29].

Data collection

The research team consisted of two palliative care physicians (JR and SHB, both MDs), a clinical nurse specialist (GL, credential RN), a qualitative researcher and principal investigator of the study (SRI, credential PhD), a postdoctoral fellow (KKM, credential PhD), and research coordinators (TS and MM). The range of experience of the research team with palliative care transitions, both in research and clinical capacities, varied greatly with JR and SHB having decades of experience and KKM and TS having none. All members of the research team identified as Caucasian women, with GL being Francophone while the others had English as their mother tongue.

Team members collaborated to create two interview/focus group guides (see Supplementary File A), one for health care providers and the other for patients and family caregivers. Development of the guides were informed by findings from a scoping review conducted in a prior phase of the project [17]. SRI conducted the focus group. KKM conducted the interviews. Guide questions were refined after the focus group and the first two interviews to include two additional questions to formally solicit information that had been spontaneously brought up in the first few interviews. The guides focused on asking participants to share their experiences with hospital-to-home transitions in the context of Bruyère Health. For example, participants were asked to assess their transition experiences, how they would define a successful sub-acute hospital-to-home transition, and what parts (if any) of their most recent transition experience

they considered to have been successful. We also asked about the types of support patients could receive during the transition from hospital to home and if/where participants could identify areas for improvement in transitions. As part of data collection, participants were asked to complete an online questionnaire using Microsoft Forms to collect demographic information on our sample. Microsoft Teams was the virtual platform we used to conduct the interviews and focus group. Interviews lasted between 44 and 60 min and the focus group was one hour in duration. Interviews were audio recorded. Recordings were transcribed by the third-party transcription company, Playwrite. Transcripts were de-identified and all participants consented to the use of direct quotations in knowledge dissemination. All data about participants were stored in a password-protected server at Bruyère Health and accessible only to the core members of the research team.

Participant recruitment occurred from December 2022 to May 2023. The goal of this study was not to achieve data saturation but to complete an initial formal assessment of facilitators of a successful sub-acute to hospital transition at Bruyère Health to inform future phases of a larger research project. This aligns with the view that "data saturation is not a universally useful or meaningful concept for all types of thematic analysis research" [30]. Recruitment ceased after six months despite the small sample size due to a combination of pragmatic considerations associated with the one-year funded timeframe for the study and consensus among the research team that, from their concurrent analysis of interview transcripts, they had sufficient understanding of existing pockets of success in sub-acute to home transitions from the healthcare provider perspective to proceed with the next phase of the study which will involve additional data collection of patient and family caregiver perspectives. This decision meant that we did not capture a diversity of patient and family caregiver perspectives in this phase of the study; however, the team felt that there would be sufficient opportunity to explore this during future co-design workshops with patients and family caregivers.

Data analysis

We analyzed transcripts using an adapted version of the team-based approach outlined by Church et al. for use in multi-coder analysis [28]. Two coders (KKM and TS) familiarized themselves with the data by re-reading all the transcripts and considering the dominant categories that emerged from the interviews. We used these categories as our preliminary codes to develop a codebook in MAXQDA, a qualitative data management software. To establish inter-rater reliability, KKM, SRI and TS collaboratively - coded two transcripts, inductively adding codes to the code book until consensus was reached that we had captured all key categories. KKM and TS double-coded the remaining ten transcripts, coding individually and then meeting virtually to resolve all discrepancies in coding. Upon completion of coding, KKM and TS collaboratively reviewed the coded segments in order of code frequency and assigned weights to all the segments in the top five codes to rank exemplary quotations in each code. KKM then reviewed the coded segments holistically to interpret patterns associated with our lens of a successful transition. KKK, TS, SHB and SRI met to discuss key patterns and solidify these into themes. KKM reviewed the exemplary quotations and identified those that were the best illustration of each theme.

The research team applied Lincoln and Guba (1985)'s criteria for trustworthiness during each phase of the analysis [31]. To address credibility or the fit between participants' views and the research team's representation of their views, we engaged multiple researchers from both research and clinical backgrounds in the interpretation of our findings. KKM and TS led the analysis and engaged in regular peer debriefing with SRI and SHB (who possess research and/or clinical expertise in palliative care) for external checks on the research process to ensure themes and subthemes were vetted by team members. To ensure transferability, we sought to provide sufficient description of our findings to enable others to consider how they might be relevant to their own context. Throughout the project, the core research team was careful to document the research process to ensure transparency and dependability. For example, we used memos in MAXQDA to document considerations and self-reflexive notes about potential patterns and themes and stored raw data in well-organized, secure online archives. To ensure confirmability and reflexivity, our research team documented our methodological approach and analytical choices to provide transparency in decision making. Research team members involved in data collection made reflexive journal entries following each interview/focus group to record methodological decision points and rationales, their own personal reflections of their values and insights, and how these shaped their understanding of the data. We did not formally analyze these journals, but they were used to inform the interpretation of our themes to ensure that researchers interrogated how their own experiences and pre-existing knowledge influenced the analysis. This study meets the requirements of the COREQ reporting guidelines for interviews [32]. See attached checklist in Appendix A.

Results

This study included 14 healthcare providers, one patient, and one family caregiver. Healthcare provider types included: physician, nurse practitioner, coordinator, social worker, pharmacist, spiritual care providers, and

administrator. The average length of career was 15 years, and 70% of care providers were specifically trained in palliative care provision. Most providers were female, spoke English, and none identified as a member of a visible minority or Indigenous group. A summary of participant demographics can be found in Table 1. The participants were unknown to KKM (the interviewer), except in one case where a project co-investigator was interviewed as a study participant. To mitigate bias, they did not review or code any transcripts.

The team identified three themes describing what participants saw as success in palliative sub-acute hospital-to-home transitions derived from their experiences in the Bruyère Health context (see Fig. 1). These included: (1) meeting patient goals; (2) sharing information to ensure informed decision-making; and (3) having someone to coordinate the transition. The results presented here focus on delineating participants' shared perceptions of the key foundations of a successful sub-acute hospital-to-home transition; we do not present results on diverging perspectives of participants nor focus on the challenges and care gaps identified by participants, though these could offer valuable insight in a subsequent paper. The findings represent the voices of healthcare providers most strongly, as this participant type made up the majority of our study sample.

Table 1 Participants' demographic characteristics

Demographics	Patient and Family Caregiver	Healthcare providers
	(N = 2)	*(N = 14)*
Age range in years	1 (45–54) 1 (65–74)	N/A
Female sex, *n* (%)	1 (7)	13 (93)
Male sex, *n* (%)	1 (7)	1 (7)
Preferred language, n (%)		
English	2 (14)	13 (93)
French	0	1 (7)
Indigenous	0	N/A
Visible Minority	0	N/A
Type of Healthcare provider, n (%)	N/A	
Physician		3 (22)
Nurse Practitioner		1 (7)
Coordinator		3 (22)
Social Worker		2 (14)
Pharmacist		1 (7)
Spiritual Care Provider		1 (7)
Administrative Staff		3 (22)
Years in practice, mean (range)	N/A	14.89 (4–39)
Location of role, n (%)	N/A	
Inpatient		10 (71)
Community		4 (29)
Geographical Area of practice/living, n (%)		
Urban	2 (14)	13 (93)
Rural	0	1 (7)
Palliative Care Training, n (%)	N/A	
Yes		10 (71)
No		4 (29)

Theme 1: meeting patient goals

Participants described transitions from sub-acute hospital-to-home as most successful when they aligned with the patient's goal to go home. They juxtaposed "patient-initiated" transitions where the patient wanted to go home with "system-initiated" transitions, where the patient did not want to leave the hospital. Chronic palliative patients fit into the system-initiated transition category. These were patients that had initially been admitted to the palliative care unit because they required active symptom management as part of palliative care, but once their condition stabilized, they no longer met the criteria to stay on the unit or to qualify for support from a home palliative care team upon leaving the hospital. Many chronic palliative patients expressed hesitancy to leave the hospital with the limited supports being offered at home and saw a hospital-to-home transition as being contrary to their wish to remain on the palliative care unit.

Despite acknowledging that "the most successful [transitions] are the ones where a patient's goal is being achieved" (HCP12), health care providers explained that the reality of system-level resource constraints often made it impossible to prioritize patient goals, particularly when a patient's goal was *not* to transition home. A healthcare provider noted that:

> *We have underdiscussed the stress and strain put on the patients and families when they are in that category of it being a system-initiated discharge. I think having more training, more standardization, more resources available, more social work availability, like [a], collaborative effort to have good communication and emotional support around that time of initiating the discussion [about transitioning home] that is super stressful for those patients and families (HCP12).*

In summary, participants noted that meeting patient goals is an important component of a successful sub-acute hospital-to-home transition but that this can be challenging given resource constraints in both the hospital and community settings.

Theme 2: sharing information to ensure informed decision-making

The importance of sharing information among patients, family caregivers, and health care providers was discussed by participants throughout the interviews in the

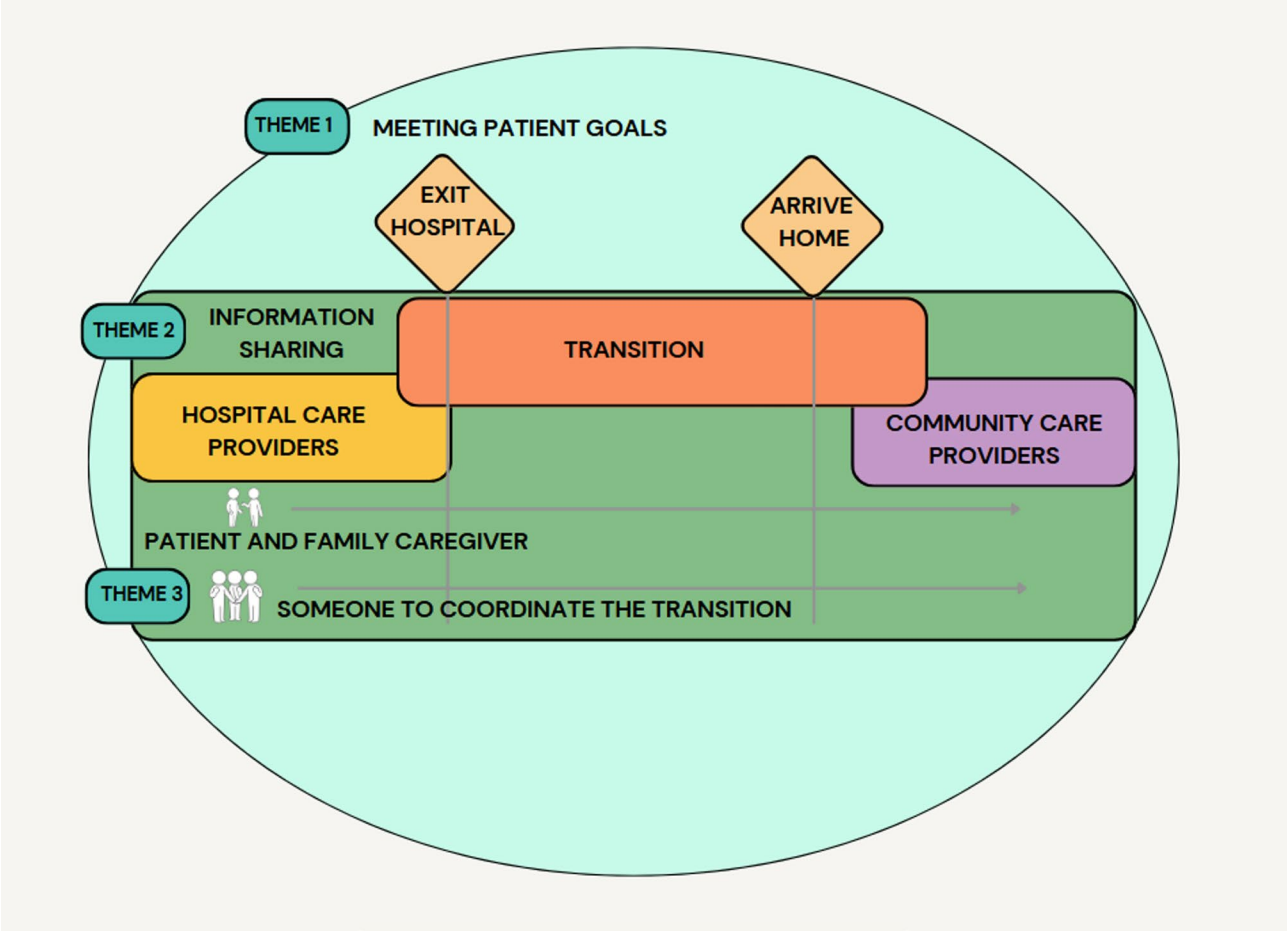

Fig. 1 Pockets of success in the context of a sub-acute hospital-to-home transition

context of improving knowledge sharing between various parties. Participants shared experiences where they saw patients and family caregivers struggle to access, understand, and process the information and educational resources they needed throughout the transition process. The family caregiver participant confirmed this, explaining how they experienced feelings of isolation and a lack of control over their situation: "I can't stress enough, I feel like we're on our own. And I find it hard to believe that others feel significantly more assisted" (FCG1). When discussing information that is helpful for patients and family caregivers as they prepare for a sub-acute hospital-to-home transition, a healthcare provider shared:

> *Ideally, the patients have an opportunity to meet with a physician, a social worker, and other relevant members of the care team to…discuss… programs that would be able to support them at discharge… here's your healthcare status, here's what we're looking at, we're going to give this to you in writing, then you're going to be able to think about it, then we're going to come back in a couple of days and answer any questions… – really making sure that we understand their goals of care, so that we can tailor the discharge support to their goals (HCP6).*

The same healthcare provider highlighted family conferences as a tool that is used to share information.

> *When the patient struggles to make [transition] decisions, or the information is very complex, or it changed from pre-admission, or they were struggling prior to admission, we will have a family conference, which is a wonderful tool that we use to make sure that information is disseminated accurately and holistically, and that patients really understand the information and have the capacity to ask questions and make informed decisions (HCP6).*

Yet, health care providers reflected that there is often a discrepancy between ideal practices that set patients and family caregivers up for success, and what often occurs in day-to-day practice. They explained that human resource shortages are often a constraint and that transition timing is particularly difficult in the palliative care context

where "things are always moving. Circumstances are always changing. And then of course, there is immense pressure in hospitals to discharge people, and you can't predict when all of the services will be ready, and all of the bare minimum things will come together at the right time, for that person to transition out of the hospital" (HCP1). This discrepancy between 'ideal' standards that enable successful sub-acute hospital-to-home transitions and what often happens was a dominant narrative in the healthcare provider interviews.

We also heard from participants that information sharing is fundamental to a successful sub-acute hospital-to-home transition. Health care providers working in the hospital explained that "we do a lot of preparing people for what it's going to be like at home… but once you leave our door, it's over, right? We've shared information and we just have to hope that they've received the information and do what's needed with that information" (HCP1). In-hospital health care providers also spoke about the challenge of balancing their limited capacity to follow up and with the importance of hearing about patient and family caregiver discharge satisfaction. As one provider explained, "I would love to call people three days after, see how they're doing, and help them problem-solve any issues that have arisen, because I guarantee you there are issues that have come up, but I don't have the capacity to do it." (HCP6). As a result, in-hospital health care providers who felt unsatisfied with the discharge process did not feel that they had the capacity to assist patients once they transitioned home.

Health care providers expanded on the importance of, and their shared desire for, frequent bi-directional information sharing across hospital and community settings. Health care providers aspired to creating a well-communicated, collaborative transition, but juxtaposed this with the reality of their daily work. The reality of gaps in communication among hospital and community health care providers was confirmed by multiple participants. For example, one community physician reported that:

> *There really is no collaboration…the information that I receive comes on an 8 by 10 referral… it's a cold handover on paper for me. For the nurses, it's probably even less…. They get essentially a nursing order, which probably just states "palliative nursing" literally (HCP16).*

From the hospital healthcare provider perspective, we heard "I would like more feedback regularly from [the community] team about how did our discharges go. We don't really get that kind of feedback" (HCP1). In sum, bi-directional information sharing was identified as a key component of a successful sub-acute hospital-to-home transition, though it could be difficult to operationalize given existing resource constraints in hospital and community settings.

Theme 3: someone to coordinate the transition

A final requirement noted by participants when asked to describe the components of a successful sub-acute hospital-to-home transition was the need for a single healthcare provider to be specifically responsible for coordinating the transition from beginning in the hospital to end in the home. Health care providers explained this type of coordination as fundamental to success:

> *All the checkmarks have to be ticked off. Things need to be organized with dates, times, and names of people who are coming. So, whether it's home care, knowing the number of hours that home care is coming in, which days they're coming in, having that in a nice list or some kind of calendar for the patient is always helpful. Having the equipment organized ahead of time. Having it delivered to the house so that it's unwrapped from the plastic, so that it's already set up to the correct height that the patient might need it at. Whether it's a backbench, a walker, or whatnot, having that organized with family there to receive it and have it already set up (HCP7).*

This was another example where this finding emerged from discussions wherein healthcare providers juxtaposed their ideal of a successful transition with their experience of what happens in the Bruyère Health context. Healthcare providers confirmed that Bruyère Health did not employ a dedicated transition professional for palliative patients, there was no transition checklist that was consistently used, and that uncertainty existed about which healthcare provider was responsible for the coordination of the hospital-to-home transition. As one healthcare provider explained, "I think part of the reason some of these transitions home are so difficult is that nobody is entirely sure who the leader [of the transition] is." (HCP16). Another suggested that on the hospital side the "social worker does a lot of the heavy lifting" (HCP13) and that the home care team coordinates the details once the patient is discharged into the community. As part of recounting their experience, the family caregiver shared, "Our bathroom doesn't work. We need to ramp into our house. This guy's not going to live very long if he doesn't have a hospital bed, all that kind of stuff…the hospital was sort of like, "okay, well, you figure it out or deal with it," once he's at home." (FCG1). The fact that the caregiver took on the responsibility of coordinating many of the transition details for their loved one corroborates the healthcare providers' perspectives that there is not a single healthcare provider who coordinates all the transition details from beginning to end. When asked to

think about the transition process holistically, participants expressed that "[what] is really lacking in our system across the board is our providers and people who are involved at bedside [in the] hospital and involved at bedside in the home. People who can carry that care forward, and who can provide patients and families with a bit of consistency [across care settings]. And so that is definitely lacking in end-of-life care at home as well" (HCP1). Despite the lack of clarity around who should coordinate the details, participants were clear that for a transition to be successful, someone must assume the leadership role and should oversee the transition from start to finish across multiple care settings.

Discussion

Our study gathered the perspectives of a variety of hospital- and community-based care providers, one patient, and one family caregiver with experience of a sub-acute hospital-to-home transition from Bruyère Health using a palliative approach to care. We identified three key foundations of a successful transition: meeting patient goals; sharing information to ensure informed decision-making; and having someone to coordinate the transition.

Our findings in the palliative care space support evidence from studies in acute care settings that show hospital-to-home transitions are most effective when the goal to go home is collaboratively established by the patient, family caregivers, and health care providers [33]. Hedqvist et al. (2023) found that to achieve a safe and secure transition from hospital to subsequent care at home, proactive work during the discharge planning process needs to be facilitated [34]. Our study suggests that it may be difficult to get patients and family caregivers to collaborate in this type of proactive planning in situations where patients (e.g., chronic palliative patients) are being discharged from the hospital against their wishes. In previous studies, notable system constraints affecting hospital discharge decisions have included bed pressures and staff shortages [35]. System-initiated discharges are a way for hospitals to cope with the ongoing challenge of balancing the demand for care with the available resources [36], yet they do not provide a context for a successful hospital-to-home transition wherein palliative patients and family caregivers feel that their needs are central to the decision-making and planning processes, especially given the highly emotionally charged context that often surrounds decisions about goals of care and preferences at the end-of-life and common knowledge of long wait times and gaps in access to care services and supports in the community. It is difficult to reconcile a person-centred model of palliative care with one that requires the system-initiated discharge of chronic palliative patients from hospital into resource-poor community settings where they will be offered limited supports.

For those patients for whom a hospital-to-home discharge is aligned with their care goals, the literature confirms our findings that patients may not be discharged to their homes often due to resource limitations [37] and limited timing windows specific to the palliative care trajectory. Hedqvist et al.. suggest promoting patient safety in care transitions requires "strategies [that] must go beyond interprofessional collaboration, incorporating adaptability and flexible resource planning" [38]. Our findings suggest that, in our context, this is unlikely due the rapidly changing physical condition of palliative patients coupled with little desire to adapt current ways of working in hospitals to be more patient-centred and no resource flexibility across care settings. For example, our participants shared cases where a sub-acute hospital-to-home transition was desired by a palliative patient, but the rotation schedule of physicians caused delays in care continuity and timeliness of discharge decision-making resulting in the window of opportunity for discharge to pass without the patient leaving the hospital. We also heard about significant resource shortages in the community causing delays in obtaining the home assessments and personal support and adaptive equipment needed to safely discharge a palliative patient home during the period where they were physically able to leave the hospital. For success transitions to become the norm, we need to grapple with the reality that ideal of a person-centred sub-acute hospital-to-home transition is often in tension with organizational barriers and resource constraints, even when patient and provider goals of care are aligned.

In their recent work, Ingvarsson, et al.. describe a disparity between the assumed central role of older adults in care transitions and their insight and involvement in planning and decision-making [39]. In our findings, this tension also exists. On one hand, participants noted a desire for person-centred care and decision-making, but, on the other hand, they described patients and family caregivers struggling with accessing, understanding, and processing the information they were provided with. This is consistent with results from acute care transition studies, where researchers noted that a lack of information sharing related to patient care resulted in patients and family caregivers struggling to adhere to discharge plans, experiencing overwhelming stress, and feeling deserted by their healthcare team [33]. Ingvarsson, et al.'s recommendation for healthcare professionals to actively involve older adults throughout the care transition process fits with our findings and could help to avoid situations where patients and family caregivers experience feelings of isolation and lack of control about and during the transition process [39]. However, questions remain about the best mechanisms to operationalize this. Our findings shed some light on the question of mechanisms, suggesting that having a single health care provider responsible

for the transition from beginning to end could help with patient and family caregiver communication and engagement. This supports findings from our prior work exploring patients' perspectives on quality of care in primary care, where we found that communication was an overarching theme that facilitated coordination of care between patients and healthcare providers, empowering patients to engage in shared decision-making about their care [40].

Yet, communication challenges were not isolated to patients and family caregivers in this study. Health care provider participants emphasized the need for improved knowledge sharing between hospital and community health care providers. This echoes research by Flierman et al. that describes incomplete and insufficient handovers among providers, and lack of leadership during transitions as key factors hindering information sharing in hospital contexts and during hospital-to-home transitions [41]. Our findings that siloed healthcare communication systems resulted in fragmented information sharing among hospital and community care highlights the many complexities in meaningful communication and engagement of care providers and patients/family caregivers, as well as among care providers both within and across hospital and community. In our past work exploring information sharing in the context of hospital-to-home transition care coordination, we found that optimized continuity of care required reliable information transfer and communication across health care providers [42]. More work on the specific mechanisms for this that would set both hospital-based and community healthcare providers up for success when coordinating sub-acute-to-hospital transitions across settings is needed.

Finally, a critical aspect of sub-acute hospital-to-home transitions is to identify a coordinator responsible for leading the transfer, who is equipped with the skillset to "liaise across clinical, organizational, and geographical boundaries" [43]. Given the current siloed state of healthcare provision in the Ontario health care system, this proposal for more integrated working continues to pose challenges in its requirement for healthcare providers to "perform tasks that go well beyond the typical responsibilities and regulations of their role" [44]. On one hand, patients and family caregivers have indicated that identifying a single healthcare provider to be responsible for managing their care plan and transition can foster trust and reassurance, and simultaneously mitigate stress and anxiety [33]. It can also help family caregivers to feel that they are not required to take on the burden of managing the transition details because they see someone clearly in that leadership role. On the other hand, a blurring of traditional or expected roles can have negative implications for role direction [45] and can create role conflict between providers [46]. There is a comprehensive literature on employing integrated care components in transitional care models from hospital-to-home for frail patients that may be modifiable for future work on palliative sub-acute hospital-to-home transitions [47].

Strengths and limitations

A notable strength of this work is that we have demonstrated that the themes previously observed in the acute care and hospital contexts are transferable to the sub-acute hospital context. To our knowledge, no studies have used a strengths-based approach to explore whether these core components were transferable. We have also completed a formative assessment of the experiences of sub-acute hospital-to-home transitions in the Bruyère Health context for use in developing co-design workshops with patients and family caregivers in the next phase of this research project.

This study faced several significant limitations that should be acknowledged to provide context for the findings. Despite extended efforts over several months, recruiting participants from populations experiencing significant health-related challenges proved extremely difficult. As a result, the sample size was notably small, with only one patient and one family caregiver participating in the study. The patient and family caregiver participants were the only ones who agreed to be interviewed by the research team despite significant efforts on the part of the research team, including our clinician partners, to engage more participants from this group. Patients and family caregivers at the end-of-life are a notoriously hard-to-reach population. We engaged with a variety of clinician partners, trying to recruit patients/family caregivers from their roster using the consent to contact process with minimal success. We decided to include the one patient and family caregiver in our analysis to honour the time they took to share their experiences with us and hope to have more success engaging additional patients and family caregivers in future phases of this project. We will not share the disease of the patient to ensure we can maintain confidentiality given the very small population from which we were recruiting.

While small sample sizes are common in qualitative research focused on individuals living with life-limiting illnesses and their family caregivers [48], this minimal representation poses challenges to the generalizability and diversity of the findings. Importantly, the aim of this study was not to achieve data saturation but rather to explore and obtain preliminary insights into the perspectives from each participant group. These challenges underscore the need for further research to expand on and validate the themes identified from a patient and family caregiver perspective [48].

A second challenge we faced was recruiting social workers to participate. Throughout the study, we heard

from participants that social workers were critical facilitators of sub-acute hospital discharges. However, we were only able to engage two social work providers, despite our various recruitment strategies that spanned over six months.

Conclusion

This paper describes how a successful transition in the sub-acute hospital-to-home context is understood from the perspectives of those involved in the transition. Findings highlight three critical elements: meeting patient goals, ensuring informed decision-making through effective information sharing, and the need for dedicated coordination of the transition process. These themes offer valuable insights into the complexities of these transitions in an emotionally charged and resource-constrained context where the ideal is often in tension with the reality of daily practice. Our findings reveal how gaps in communication, organizational policies and processes, and resource constraints can hinder timely, person-centred care transitions for palliative patients and their family caregivers. Findings from this formative needs assessment will inform a multi-year effort to co-design, implement, and evaluate an intervention to improve the coordination of sub-acute hospital-to-home transitions for individuals with palliative care needs across the Champlain region of Ontario.

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

Acknowledgements

One co-investigator on this project was interviewed as a study participant. To mitigate bias, they did not review or code any transcripts. The authors would like to thank all participants including patients, family caregivers, and healthcare providers who shared their experiences in the study.

Author contributions

KKM contributed to study design, data collection and analysis, project administration, and wrote and revised the manuscript. TS contributed to study design, analysis, project administration, and was a major contributor in drafting and reviewing the manuscript. MM contributed to study design, analysis, project administration, and contributed to drafting and reviewing the manuscript. SHB, GL, and JR contributed to study design, as well as reviewing and editing the manuscript. SRI contributed to study conception, analysis, funding acquisition, investigation, project administration, supervision, and was a major contributor in writing, reviewing, and editing the manuscript. All authors reviewed and approved the final version of the manuscript.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

In accordance with the Research Ethics Board at Bruyère Health Research Institute, this study was approved as study # (M16-22-047) on November 11, 2022. Participant consent was obtained via a verbal informed consent statement prior to data collection.

Consent for publication

Participants were informed that results of this study would be published, but the data would be presented so that it would not be possible to identify any individual. Participant consent was obtained via a verbal informed consent statement prior to data collection.

Competing interests

The authors declare no competing interests.

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