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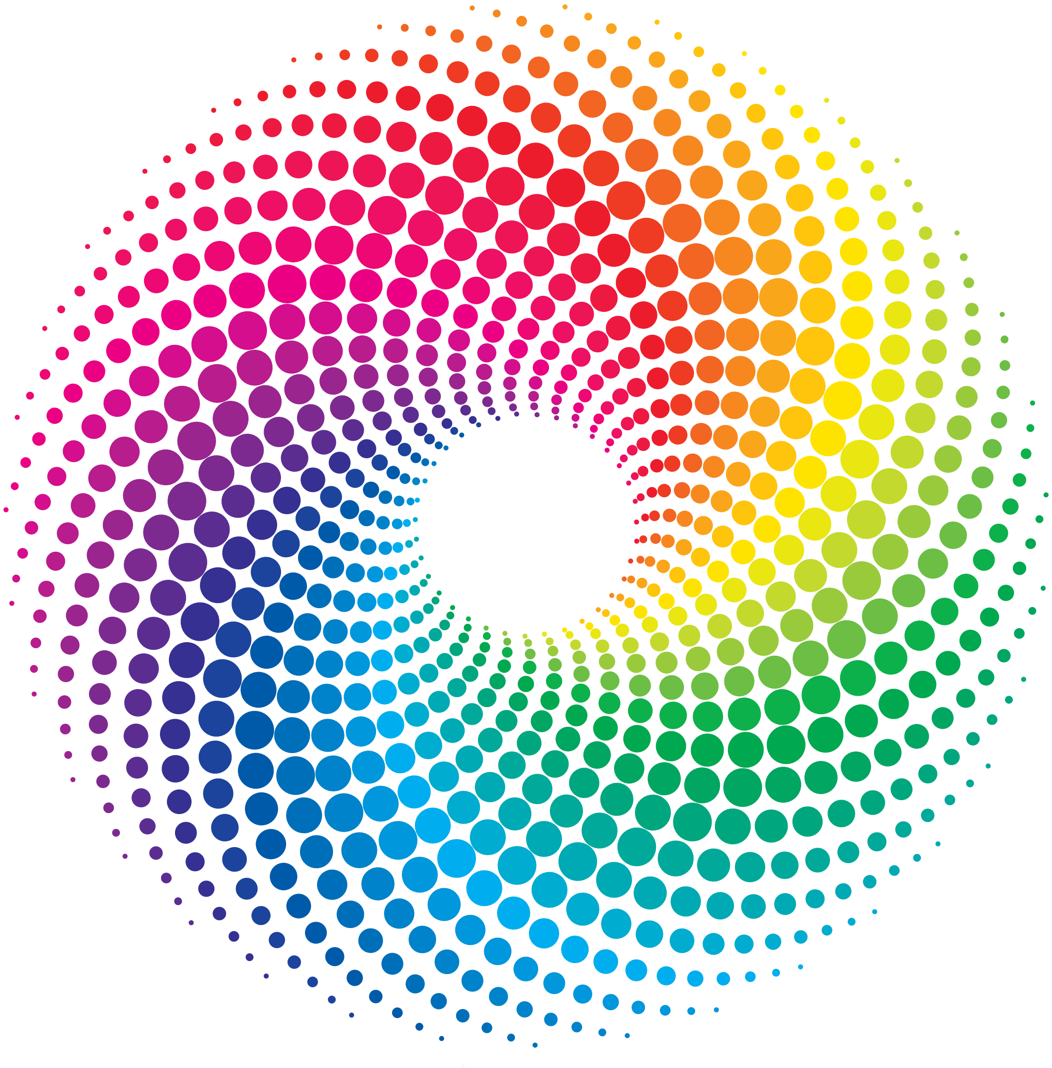

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A Patient-Centered Transitions Framework for Persons With Complex Chronic Conditions

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Hospitals are under increasing pressures by governing bodies to meet mandated performance standards and fiscal targets. As a result, hospitals are incentivized by funders to discharge patients efficiently and effectively. Gaining insight into the patient experience of discharge, as well as understanding patient needs and concerns, is prudent. Leveraging this knowledge may expedite patient discharge and potentially minimize hospital readmission rates. The purpose of this study was to better understand the discharge experiences and concerns of patients with multiple chronic diseases—a population currently understudied. In this study, qualitative survey data were analyzed from a large scale, mixed methods study that took place in 2011 at Bridgepoint Hospital, a complex continuing care and rehabilitation facility in Toronto, Canada. One hundred and sixteen patients were interviewed individually using a self-designed survey composed of open- and close-ended questions. All data pertaining to hospital discharge were extracted and examined using qualitative descriptive analysis. Key discharge concerns were related to process (next steps in the care plan, friction in the provider–patient relationship, premature discharge), consequences (relocation, impact on family, leaving the comforts and security of the hospital), and needs (availability of home care, managing daily activities, navigating the predisability home). Our findings are presented in a patient-centered framework that can be used as a guide for future discharge strategies for complex patient populations.

Keywords: patient experience; qualitative; discharge planning tool; multimorbidity

Advancements in medical research and improvements in public health over the last two centuries have decreased the societal impact of communicable diseases. However, the rate of noncommunicable (i.e., chronic) conditions is on the rise worldwide (World Health Organization, 2011). In 2008, 63% of global deaths were attributed to chronic conditions (World Health Organization, 2011). *Chronic disease* can be defined as a condition that lasts a year or more and requires ongoing care and/or limits activities of daily living (Benjamin, 2010). The number of people with multimorbidity, the presence of one or more conditions, is growing in prevalence worldwide. An analysis of 31 million U.S. Medicare patients found 67% of adults older than the age of 65 years had suffered from multiple conditions (Salive, 2013). Given this epidemiological shift, implementing new models of patient care that move away from provider-centered and disease-specific frameworks toward a more patient-centered approach is an instrumental direction of change for health care systems. Dr. Moira Stewart, a widely published author on patient-centered care, proposed a model of patient-centered care based on "an integrated understanding of the patients' world—that is, their whole person, emotional needs, and life issues" and "common ground on what the problem is and mutually agree on management" (Stewart, 2001, p. 445). This article provides evidence that in-hospital

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patients desire patient-centered care as defined by Stewart. Our research focused on the discharge concerns that persons with multiple chronic conditions reported before leaving hospital.

Being discharged from hospital is a vulnerable process for patients (Coleman, 2003; Kuluski et al., 2013; Naylor et al., 2013). This period, often referred to as *transitional care*, is defined by the American Geriatrics Society as a "set of actions to ensure the coordination and continuity of health care as patients transfer between locations or different levels of care within the same location" (Coleman, 2003, p. 549). A systematic literature review on transitional care models by Naylor and Keating (2008) demonstrated that poor transitional care led to adverse events, low satisfaction of care, and high rehospitalization rates in the older adult population. Multiple studies have examined provider-administered interventions, such as discharge checklists and questionnaires, and provider-to-provider hand-off tools designed to improve the quality of care transitions (Coleman, Parry, Chalmers, & Min, 2006; Doran et al., 2013; Graumlinch, Novotny, & Aldag, 2008; Halasyamani et al., 2006; Weiss & Piacentine, 2006). Despite a push by researchers to understand the causes and effects of poor transitions of care, gaps in knowledge currently exist about the patient experience, particularly the experience of patients with complex chronic conditions.

Previous studies have evaluated discharge concerns in hospital settings and cited that patients had concerns about lack of engagement, housing, home care, and self-management (Allen, 2001; Efraimsson, Sandman, & Rasmussen, 2006; Fairhurst et al., 1996; Foss & Askautrud, 2010; Fuji, Abbott, & Norris, 2013; Harrison & Verhoef, 2002; Huby, Stewart, Tierney, & Rogers, 2004; Johnson, Gaughwin, Moore, & Crane, 2005; Rydeman, Törnkvist, Agreus, & Dahlberg, 2012; Swinkels & Mitchell, 2009; Toscan, Mairs, Hinton, & Stolee, 2012). In a recent systematic review of transitional care interventions of hospitalized older adults, the authors concluded that those at greatest risk of rehospitalization are often excluded from such research (Piraino, Heckman, Glenny, & Stolee, 2012).

The objective of this study was to determine the discharge concerns reported by persons with *complex chronic conditions*, defined as one or more conditions that require intensive health care services. By virtue of their admission to complex continuing care (the site of the study), all patients met this operational definition. By addressing these concerns, we argue that the experience of care transitions can become more patient-centered.

Despite a push by researchers to understand the causes and effects of poor transitions of care, gaps in knowledge currently exist about the patient experience, particularly the experience of patients with complex chronic conditions.

METHODOLOGY

This study took place at Bridgepoint Hospital, a 404-bed urban rehabilitation and complex continuing care facility in Toronto, Canada. Bridgepoint's inpatient complex continuing care and rehabilitation program specializes in medical, musculoskeletal, and neurological rehabilitation. The Medical Rehabilitation program has 93 beds that serve frail elderly patients and patients with cardiopulmonary conditions and complex medical needs. The 69 musculoskeletal rehabilitation beds' focus is on patients recovering from complex orthopedic surgery, trauma or progressive bone and joint disorders. Patients with primary conditions such as stroke, brain injury, and neuromuscular conditions make up the Neurological Rehabilitation program. Bridgepoint's inpatient specialized Medical and Complex Care program has 167 beds and is designed to treat patients with significant health impairments, disability, or advanced stage disease.

This article describes an analysis of qualitative data obtained from a mixed methods cross-sectional study at Bridgepoint Hospital conducted in 2011 (Kuluski et al., 2013). Purposive sampling of the hospital's population was employed using the following criteria: the patient could give informed consent, had the cognitive capacity to answer questions, and could withstand sitting with an interviewer for at least 15 minutes at a time to respond to interview questions. This sampling strategy yielded a 116-person participant pool (Table 1). Experienced interviewers trained in qualitative research methods met with hospital inpatients one-on-one and asked a combination of open- and close-ended questions from a survey tool based on a framework created by the research team (Schaink, et al., 2012). The framework resulted from a scoping review of literature and is featured in an article previously published (Schaink et al., 2012). Depending on the preference and abilities of the patients, interviews took place over several occasions. The interviews were audiotaped and transcribed verbatim by an external source and checked for accuracy by the respective interviewer. One of the survey questions asked patients to share any concerns regarding hospital discharge, which is where this article focuses.

The original data were entered into NVivo software Version 9. A node report based on all comments in the entirety of the interview related to hospital discharge was generated for analysis. The bulk of the data were composed of responses to the interview questions "Do you have any concerns about discharge?" and "If yes, can you describe the concerns." Qualitative description, a content analysis method, was employed to provide a comprehensive summary of the data (Sandelowski, 2000).

TABLE 1. Patient Characteristics

Variable	*N*	%
Sex	116	
Male	49	42
Female	67	58
Age	111	
≤44	13	12
45–64	52	47
65+	46	41
Marital status	112	
Has a partner (married or living common law)	30	27
Does not have a partner (unmarried, divorced, widowed, single)	82	73
Education	109	
High school or less	47	43
More than high school	62	57
Ethnicity	111	
Caucasian	89	73
Other	22	27
Morbidities		$M = 5.00$ $Mdn = 5.00$ $Mo = 5.00$ $SD = 6.00$
Length of stay at time of interview (days)		$M = 162.27$ $Mdn = 66.50$ $Mo = 59.00$ $SD = 317.18$

Note. From "The Care Delivery Experience of Hospitalized Patients With Complex Chronic Disease" by K. Kuluski, S. N. Hoang, A. K. Schaink, C. Alvaro, R. F. Lyons, R. Tobias, and C. M. Bensimon, 2013, *Health Expectations*, *16*(4), e111–e123. Adapted with permission.

Themes were not predetermined; rather, they were identified inductively. Using one large sheet of paper, all the excerpts sharing the same code were noted along with the corresponding identifier. This technique is known as the *one sheet of paper* (OSOP) method and was developed by researchers at the University of Oxford, Health Experiences Research Group (Ziebland & McPherson, 2006). After multiple readings of the data, the text sections were categorized into themes that addressed the research question. This method of coding, known as *open coding*, organizes information into categories and allows for easy retrieval of data (Ziebland & McPherson, 2006). The next step was axial coding, which grouped the subthemes together and were further refined into broader themes (Ziebland & McPherson, 2006). Themes that emerged answered the research questions and were "exhaustive," "mutually exclusive," "sensitive," and "congruent" (Merriam, 2009). The lead author (JH) met with two other research team members on several occasions to verify the themes; one conducted a review of the same node report (AG), whereas the other (KK) was the lead investigator who coded the original set of interviews. The naming and grouping of the themes was an iterative process, and consensus was reached on the final themes. This multi-researcher-conducted systematic approach to analysis ensured descriptive validity of this study's results.

RESULTS

Three broad themes were identified: process, consequences, and needs. The theme *process* captured patient concerns prior to discharge. The theme *consequences* included patient comments related to the anticipated implications of their health condition postdischarge. Rounding out the trio of themes, *needs* describes how patients reported concerns about post-discharge condition management. Each theme had three or more subthemes and are depicted in Figure 1.

Of the 116 patients interviewed, 35 people stated they did not have concerns about discharge. Respondents in this group tended to be younger on average, had fewer health conditions, and had shorter lengths of stay at the time of interview. Some of the respondents in this cohort wanted to be discharged as soon as possible, and a few patients stated they were ready to go home but did not frame this as a concern per se. Although these characteristics are worth noting here, the primary focus of this study was to look at the key themes presented by individuals who had concerns about discharge to provide insight into any gaps in knowledge about transitions of care.

Process

Patients expressed concerns about the logistics and process of being discharged from the hospital. More specifically, patients were concerned about the next steps in their care plan, emerging friction in the provider–patient relationship, and the fear of premature discharge.

Next Steps in the Care Plan. Some patients cited a lack of clarity in their plan of care that provoked feelings of anxiety and fear. A 43-year-old patient who was receiving rehabilitation for a broken leg described her outlook on recovery:

> I'm scared of the fact that I don't know what I'm anticipating when I come home . . . Scared of the fact that just in general, that I honestly don't know what's going to happen to me after May 16 when this cast comes off.

Patients desired a concrete plan for their discharge. A 64-year-old female patient who had a stroke and was also diagnosed with diabetes and hypertension wanted more information from her health care providers about post-discharge resources:

> I mean they don't tell you anything or they don't say when you leave the outpatient services we'll provide you with supports in the community.

Friction in the Provider–Patient Relationship. Patients raised concerns about their interactions with care providers. Some patients described a misalignment of care plan goals. A 78-year-old patient who was in hospital recovering from a knee replacement described communicating with her occupational therapist about transferring into her home's bathtub as "frustrating" and "battle-like."

Some patients were presented with inconsistent messaging from care providers. A 68-year-old patient who was at the hospital for the third time because of knee replacement complications noted that her physicians had conflicting opinions regarding next steps: "This doctor is not on the same page as that doctor. And this doctor, he's kind of laying back saying we'll see how things are going to go." The same patient went on to say that she felt excluded in the treatment process and felt "in the dark as to how things are moving along."

In addition, patients commented on pressure from their care providers to accelerate their recovery at an uncomfortable pace. A 51-year-old patient who had arthritis and was recovering from postsurgical complications from her second hip replacement had concerns about the expectations of her physiotherapy providers:

> Just that, you know, the physio department seems to be a little bit too pushy . . . And what I was told was my own pace. To me, my own pace is my own pace. And that you were allowed to stay up to 3 months. And some people, I guess, do stay that long. But they really are pushing for people to get out at the 1 month.

Premature Discharge. Likewise, some patients were concerned about leaving before their "time" or "too early." Some patients characterized readiness for discharge as being "confident" when walking as well as not depending on assistive devices such as walkers to ambulate with. The expectation of ambulating independently was echoed by many patients. A 51-year-old patient recovering from a fractured hip and also suffering from lymphoma and Parkinson's disease commented on how it was reassuring to have care providers help him walk and was concerned about using assistive devices when he returned home:

> And I guess it's not going to be the same situation. So that's the one reservation. I do have, is that someone is not going to be standing beside me. I am going to have to rely on mechanical things such as sticks or walkers or poles, or whatever. And I'll put my faith in them more than anything else . . . And I think that's part of the game plan, is to try to buoy up my sense of self-reliance . . . And so I'm doing it on my own. But I still have the gnawing ambivalence that I'm not doing it on my own.

Likewise, a 28-year-old patient who had a history of leukemia and was recovering from a knee replacement expected to rehabilitate to the point of walking independently when he was first admitted into hospital, but during the course of his stay, he learned he would be discharged once he could ambulate with crutches.

In summary, patients expressed uneasy feelings with the trajectory of their care planning, and some had specific concerns about their interactions with care providers and readiness for discharge.

Consequences

The theme consequences encompass patient-reported implications about their health conditions post-hospital stay. The subthemes were leaving the comforts and security of the hospital, relocation, adverse events at home, and impact on family.

Leaving the Comforts and Security of the Hospital. Patients build relationships with fellow patients and health care providers while in hospital. Some patients noted how they would "miss" the people at the hospital. To that end, a consequence of being discharged from hospital would mean leaving behind social supports. Some patients described the hospital atmosphere as holiday-like and "fun." A 55-year-old man admitted for complications from multiple sclerosis described the importance of the in-hospital social circle:

> In the sense of having people to talk to all the time, yes. Because I talk to a lot of people around here, and I'm going to miss that. Of course, I prefer to be healthy and have a nice place to live, but the atmosphere here is pretty good, and I'm going to miss it.

In summary, patients expressed uneasy feelings with the trajectory of their care planning, and some had specific concerns about their interactions with care providers and readiness for discharge.

The hospital can be a secure space for patients where they feel supported by health care providers and receive around-the-clock care. Moreover, patients feel like it is “normal” to be sick in the hospital, whereas in the community, they feel ostracized by their illness. The hospital is also a sanctuary for some people because it is a space of routine and resources. A 58-year-old patient with multiple health concerns including cirrhosis of the liver, esophagitis, and pancreatitis described hospital life:

> Yes, I do have concerns because here, there’s a routine. Lunch is served at a certain time. Physio is at a certain time. You know, there’s a dental clinic here. And reintroducing structure on my own that would be my main concern.

When patients spoke about leaving the hospital, they expressed concerns about going home and living alone. An 84-year-old patient who was in hospital for pneumonia and internal bleeding in the leg commented on how the circumstance of living alone was a major concern:

> But I don’t think you cannot have concerns and worry when you go home on your own. I think it’s impossible. You’d have to be inhuman to not worry about some of that.

Adverse Events at Home. Many of the patients who said living alone was a concern also stated they had fears about slipping, falling, or fainting when they returned home. A 78-year-old patient who was in hospital recovering from a knee replacement and had other underlying health issues including arthritis, hypertension, and asthma conveyed her fears about having an accident at home alone:

> And the possibility of slipping, and because I live alone, nobody would even know I have fallen. So that is the big issue for me . . . I’m afraid of falling, yes.

Impact on Family. Some patients talked about the impact of their health condition on their family members. Patients were concerned about the capacity of their loved ones to care for them once they returned home. A 55-year-old patient with rheumatoid arthritis admitted with infection in his joints and bodily wounds was unsure if his partner could care for him and did not have any other family members he could call on for assistance:

> Very much so. I am not sure I’m going to manage at all. And I’m not sure my partner can cope with the strain of looking after me . . . My parents live 500 km away in a rural area. My brother lives a couple of miles from them. And they are the two people I would consider. My in-laws live in [city] and [city] but they couldn’t really do anything for me. The only one that could possibly is my brother-in-law. He has a nice place that’s all on one floor. And I could theoretically move in with them but we are not really that close. We are on friendly terms but not on the terms to say, “Hey, can I move in with you?”

Many of the patients who said living alone was a concern also stated they had fears about slipping, falling, or fainting when they returned home.

Relocation. Because of their health conditions, some patients were told that care in a long-term care facility was the only viable option. One patient had to leave behind a spouse while he moved into a care facility and was worried about how his spouse would cope financially. A 79-year-old patient with congestive heart failure and osteoarthritis remarked on the difficulty she would face in moving out of her home,

> And I do want to go to my own home because I’ve lived there for 44 years and I’ve got a lot of things to sort and get rid of. For both reasons. Which is hard. It’s really, really, hard.

Many patients cited major concerns about the living conditions of long-term care facilities. An 83-year-old patient hospitalized for a pinched sciatic nerve and edema had serious reservations about moving into a long-term care facility informed by a negative prior experience:

> But I don’t want to go in an old aged home because I have been there after I was out from the other rehab because I was weak. And they tried to put me somewhere until I regained more strength . . . and I went through this for 3 days and then my granddaughter came and took me home. And I said I’d rather die than go to a place . . . You know, if somebody wants to get sick, just go there and in no time, they’ll get sick.

When asked about her discharge planning, a younger patient with several health diagnoses including diabetes, arthritis, hypertension, depression, and anxiety did not feel that entering a care facility was the most appropriate setting for her:

Patient: “I was upset. I didn’t want to go to an old aged home. I mean who would? I don’t feel like I belong there. I don’t feel that’s the place I belong.”
Interviewer: “Remind me how old you are.”
Patient: “56”

In summary, this theme illustrates the fears that patients had when they envisioned their lives post-discharge. For some, stepping out the hospital doors represented leaving behind social supports and intensive health care services. For others, the impact their care needs would have on their family members, such as spouses, when they returned home were of primary concern. Finally, patients (midlife and older adults) were distressed about the possibility of relocating into long-term care homes.

Needs

The data captured in the *needs* theme encompasses patient concerns about their ability to manage their health condition and the availability of health care supports at home. The subthemes availability of home care, navigating the predisability home, and ability to manage daily activities comprises the final theme.

Availability of Home Care. Patients spoke about requiring formal supports upon returning home. A 78-year-old patient who was in hospital recovering from a knee replacement was not only concerned about whether she would qualify for home care but also commented on other seniors who might be struggling to obtain assistance:

> Well, I've had a tremendous amount of stress attempting to get one home service that's coming to bathe me once a week . . . And I'm not fighting for me so much as all the . . . there are so many elderly women who are on minimal income who couldn't, and who might try and do it themselves when they shouldn't.

Some patients, who received home care in the past, recounted their negative experiences. A 62-year-old patient with a rare neurological condition in addition to arthritis, hypertension, and asthma spoke about her family having to take over the procedure of giving her injections at home:

> Yes. They come because my [husband] can't make needles. He is very strong on everything but when he sees blood or a needle, he feels sick a little bit. And so the nurse comes because I needed a needle in my stomach because I couldn't move for a blood clot. And the nurse comes [and stated], "I come for a week but then somebody in the family has to learn because we can't come every day." I said, look, my hands then were shaking, otherwise I would do it myself. I couldn't do nothing. So my son had to come every morning before he was going to work. He came to give me a needle for 6 months before I went to the hospital.

Patients also commented on having to pay out of pocket for home care services. A 54-year-old patient with multiple injuries from a boating accident was told she had to pay for private home care to apply her ankle-foot orthotic (AFO) device daily:

> So nonetheless, what I'm sensing . . . Not just sensing, I'm being told is that I need to go. And I am saying, look, I am very happy to work with you here. Let's figure out how I can put this AFO independently so that I can go. I don't want to be here either. But basically what's happening now is that I am going to have to go, I think, from what I'm told right now, and I'm going to have to pay for people to come $20 an hour to do this.

Continuous communication between patients and providers throughout the hospital stay may alleviate patient fears, decrease levels of uncertainty, and facilitate mutual understanding.

Navigating the Pre-disability Home. As a result of impaired functional states, patients were worried about their transition home to environments where they had to navigate barriers such as climbing stairs, using the bathroom, and maneuvering around the existing layout of the home. Some patients spoke about how bathing would be impossible because their bathtubs were inaccessible. One patient detailed the need to rearrange the furniture in her living room to allow space for her walker. A 58-year-old patient who had cirrhosis of the liver, pancreatitis, and esophagitis said her main concern with returning home was managing the stairs:

> So there are a lot of stairs. So that was my main worry going home, is like can I do the stairs? Because I don't want to be in a situation where if I'm struggling with the stairs. Because you know, oh dear, I won't be able to manage the stairs coming back up.

Ability to Manage Daily Activities. Patients verbalized their concerns about their ability to manage daily activities. Some patients were concerned with activities of daily living including toileting and bathing, whereas others focused on instrumental activities such as being able to operate a car. An 83-year-old patient with sciatic nerve pain, diabetes, hypertension, and kidney problems commented on being fearful of going to the bathroom at night because of mobility limitations.

> And now, they are sending me home at the end of the month and I'm completely alone. And I don't know, the daytime I am not afraid but at night, how am I going to the bathroom? I am unable to stand, unable to walk.

In brief, this theme reflects patient anxiety about their ability to return to their regular routines and the availability of community supports. Some patients were doubtful they could manage daily activities, such as bathing and toileting, whereas other patients' primary fear was negotiating the stairs at home. The recognition of patients' concerns is of value to care providers and hospital administrators. Mitigating patient fears and anxieties will require unpacking the three themes—*process*, *consequences*, and *needs*.

DISCUSSION

Hospitals are under increasing pressure by governing bodies to meet mandated performance standards, fiscal targets, and lower the number of alternate level of care days (i.e., the number of patients that do not require hospital care but remain in a bed because of lack of care alternatives). As a result, hospitals are incentivized by funders to discharge patients efficiently and effectively. Gaining insight into the patient experience of discharge as well as understanding patient needs and concerns is prudent. Not only will leveraging this knowledge expedite patient discharges but it may also minimize hospital readmission rates. Using the themes (process, consequences, needs) gleaned from our study, we propose a discharge framework designed to address patient concerns grounded in patient-centered care principles (Figure 1).

Bespoke Discharge Planning

As stated in this article's introduction, a patient-centered approach to care means treating patients as individuals by understanding and responding to their specific needs and circumstances (Stewart, 2001). As the results from this study indicated, patients had concerns about the care planning process and in their communication with care providers. When patients are unclear or lack knowledge about their care plan, it is an indication that there is a breakdown in patient-centered care (Robinson, Callister, Berry, & Dearing, 2008). Patients in this study reported feelings of anxiety and fear about recovery milestones and discharge plans in part because of lack of information about their care plans. Continuous communication between patients and providers throughout the hospital stay may alleviate patient fears, decrease levels of uncertainty, and facilitate mutual understanding. More specifically, care teams should allow patients to articulate their care goals upon admission, and then a formalized process of review of milestones in achieving these goals should be embedded in the care planning process. For example, hospitals within the Anne Arundel Health Systems in Maryland, designed a discharge protocol for patients known as *SMART*. A key

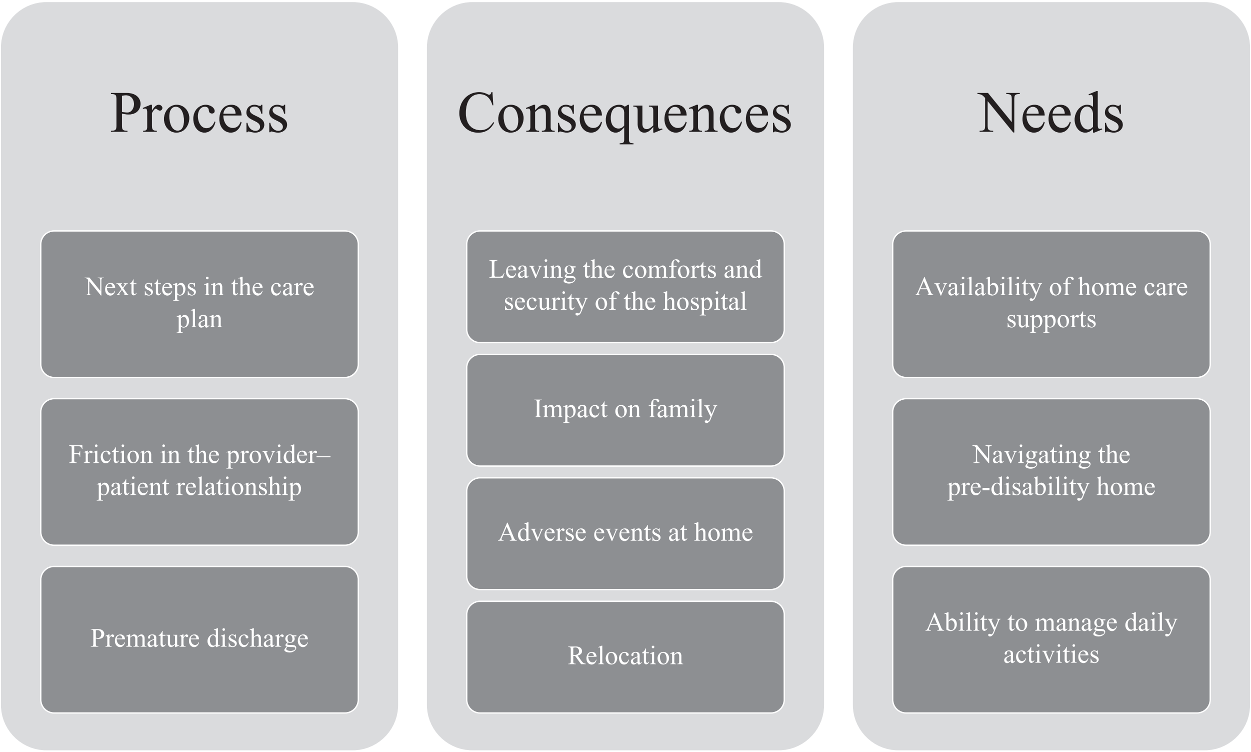

Figure 1. A patient-centered transitions of care framework.

piece in this model was the “Be SMART, Leave SMART” communication journal, given to patients upon admission to track questions and concerns for providers (Perkins, Schwartz, Andersen, & Ley, 2012). Although improving patient–provider communication is important in facilitating patient-centered care, integrating the framework proposed in this article (process, needs, consequences) overlaid on top of protocols such as the SMART will further individualize care planning. Employing a patient-centered perspective in discharge planning will aid hospitals to improve patient health outcomes and promote treatment efficiencies (Stewart et al., 2000).

Collaborative decision making between health care providers and patients is an important facet of patient-centered care (Robinson et al., 2008). Findings in this study revealed patients had concerns about their role in care planning. Historically, it has been suggested that health care providers, in particular physicians, have had paternalistic relationships with patients (Teutsch, 2003). Evidence of this power imbalance still persists in today’s health care environment as patients in this study commented on how they were “told” they were ready to be discharged and felt they were being “pushed out.” Some patients in this study reported distrust in their health care providers. Entwistle and Watt (2006) explored patient involvement in decision-making models and demonstrated that current practices present patients with a menu of options rather than enabling patients to articulate themselves fully in the decision-making process. Furthermore, patients’ thoughts and feelings about their providers directly influenced what they said and did with care providers; thus, we can argue that patients who trust their providers can better communicate their expectations in the care planning process (Entwistle & Watt, 2006). Health care administrators need to ensure policies support relational elements in patient-centered care such as patient engagement and trust building.

Care providers are under pressure to discharge patients efficiently and effectively. However, there appears to be a misalignment between provider practice guidelines and patient expectations when it comes to the clinical management of disease. Premature discharge was a dominant concern reported by patients in our study. Specifically, many patients cited their desire to rehabilitate to the point of walking independently before leaving the hospital. Patient expectation about staying in hospital until full recovery is in conflict with policies in our current health care system. Hospital administrators are mandated by the government to collect statistics on length of stay and are pressured to meet predefined targets. In many cases, these figures directly affect the financial remuneration the hospital receives. The message that hospitals aim to convey to patients is that a hospital admission is only one of the care settings along a continuum on a patient’s journey to recovery. After discharge, patients are expected to continue receiving care via home care, outpatient hospital clinics, specialist care, and primary care. Patients in our study reported they were not confident on how to access the next points of care and were concerned they would not qualify or receive adequate care post-hospital stay. If hospital care is to serve effectively as a site along a continuum of care, a health care system needs to provide comprehensive programming and services in all care settings. Our finding that some patients expected to be “fixed” before leaving the hospital does beg the question of what factors inform this belief by patients. Although this level of discourse is outside the scope of this article, health care administrators and policymakers should take this perception into consideration when reviewing program performance targets, such as the percentage of patients who lie outside expected length of stay periods. What some patients expect in their care provision (e.g., the length of stay in hospital) may be incongruent with current practices and policies.

If hospital care is to serve effectively as a site along a continuum of care, a health care system needs to provide comprehensive programming and services in all care settings.

Life After Discharge

Patients with complex chronic conditions are confronted with challenges related to their health conditions immediately upon discharge from hospital. Although the patients that we interviewed had not yet been discharged, they shared their anticipated concerns. Some patients in our study reported concerns about adverse events such as slips and falls when they return home. Initially, patients have to adjust to leaving the comforts and security of a sheltered hospital environment. While in the hospital, adverse events can presumably be addressed readily because there are health care providers available 24 hours a day. At home, some patients, especially those who live alone, do not feel the same sense of security. Many patients in a postacute or tertiary setting such as rehabilitation and complex continuing care have also been in hospital for a prolonged period, and returning home could mean a drastic decrease in the intensity and availability of health care support that they have become accustomed to. Once patients leave this protected sphere, they have to negotiate a myriad of daily living stressors such as managing finances, grocery shopping, housekeeping, and returning to work. For patients who have few friends and family, the contrast in support is particularly stark between hospital and home.

In addition to the loss of intensive health care supports upon hospital discharge, patients leave behind a social network of fellow patients and health care providers. An unexpected finding from our study revealed patients would “miss” the relationships developed while in the hospital. To our knowledge, patients in this study did not participate in formalized peer support groups while in hospital, and it was unclear whether they would participate in an outpatient or community-based support group to ease their transition. Peer support groups are frequently led by former patients who have experience managing their health conditions successfully (Morris & Morris, 2012). Researchers in the United Kingdom found peer support groups for hospital inpatients and their caregivers beneficial in the rehabilitation process (Morris & Morris, 2012). Stroke patients felt they learned new ways to cope, made new connections, and increased the awareness of their condition (Morris & Morris, 2012). As seen in the results of our study, patients desire and value the support of their peers. Capitalizing on this social network, via the integration of peer support groups into client care plans, in a hospital rehabilitation program and through outpatient programming could add therapeutic value in a relatively low-cost manner.

Patients contemplating long-term care placement after being discharged from hospital have serious reservations about the living conditions of and appropriateness of long-term care facilities. As indicated by our study and previous research, patients may associate their loss of independence with admission to long-term care facilities (Quine & Morrell, 2007). In addition, our current health care system, much like other industrialized countries, offers few options beyond facility-based long-term care for midlife to older adults who require around-the-clock care. Some patients in our study stated emphatically they did not want to be admitted into long-term care facilities, particularly if they were younger and had partners at home. Our study provides further evidence that patients prefer to manage their conditions at home with support so that they can continue to live with families and partners in familiar settings. Because of declining health or disability, some patients have little choice but to move from established homes and communities upon discharge from hospital. A patient in our study reported that she had lived in the same home for more than 80 years and could not fathom moving. Leaving familiar surroundings and communities is extremely worrisome for some patients and arguably misaligned with a patient-centered approach.

The consequences of hospital discharge are not isolated to the patient. Patients in this study were concerned about the impact on spouses and children. It has been estimated that informal caregivers (family, friends, and volunteers) provide 80% of home care (Baranek, Deber, & Williams, 2004). Research has shown the burden of caregiving can be deleterious on psychological and physical health on the informal caregiver (Pinquart & Sörensen, 2003). Furthermore, there is evidence to suggest that the health and well-being of the informal caregiver directly affects the well-being of the care receiver (Beach et al., 2005). In light of the potential harmful effects of caregiving on patient's family members, discharge planning should include an assessment of the abilities and capabilities of informal caregivers.

Supporting Patients in the Community

Patients were concerned about the availability of home care to support independent living in the community. Our current health care system is set up into silos of hospitals, home care services, primary care, and facility-based long-term care, and so forth. Transitioning and navigating through this disparate maze is challenging for health care users and their caregivers, particularly when managing medically complex conditions. Many patients in our study were troubled about not receiving sufficient assistance from home care or not qualifying for services at all. An article previously published on this study's data set reported some patients expressed the need for a system navigator to manage their care (Kuluski et al., 2013). An example of a patient navigator–driven program is the University of Pennsylvania's transitional care model (TCM), which has been in place for the past 18 years to treat high-risk, chronically ill older adults (Naylor et al., 2013). The TCM has demonstrated reduction in hospital readmission rates and a decreased overall cost of care per patient (Naylor et al., 2013). An advanced practice nurse (APN) acts as the primary care coordinator and follows the patient from admission to an average of 2 months posthospital stay. The APN conducts a comprehensive in-hospital assessment, and after hospital discharge, the APN provides regular home visits and daily telephone "check-ins" and accompanies patients to medical appointments. Another discharge model that supports continuity of care and facilitates therapeutic provider–patient relationships is Ontario, Canada's *transitional discharge model* (TDM). Patients discharged from hospital psychiatric care continue to be seen by inpatient care providers until a handoff is made to community providers; moreover, peer mentors who are mental health services consumers are matched with patients. A large-scale study of TDM found increased discharge rates, lower readmission rates, and cost savings (Forchuk, Reynolds, Sharkey, Martin, & Jensen, 2007). Although both the TCM and the TDM are merely band-aid solutions for a fragmented health care system, care navigation and peer support for complex patients with ongoing care needs are solutions

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that can be immediately implemented for the population of study as they move from hospital to home.

Given the discharge destination for most hospital patients is back home in the community, understanding the relationship between housing and health is important. Results from a multinational study of 1,918 individuals between the ages of 75 and 89 years, conducted by European researchers, revealed participants who lived in accessible homes, who perceived their homes as meaningful and useful, and who felt in control of their living circumstances were likely to be independent in daily activities, have better well-being, and have less depressive symptoms than participants who lived in inaccessible homes (Oswald et al., 2007). Findings from our study further highlight the importance of barrier-free home environments to support independent living for patients with mobility impediments. Oswald and colleagues' (2007) study also suggested that it was not the number of barriers in the home environment but the magnitude of the barriers that influenced accessibility and the ability to accomplish daily activities. This person–environment dynamic is important to note because a prescriptive approach to accessibility does not take into account an individual's preferences, abilities, and interactions with their environment. Although we recommend using a patient discharge framework that includes components that address accessibility in the home and the ability to manage activities, patient-defined needs and goals of care in the home should drive provider interventions.

This study offers a unique lens of understanding into the hospital discharge process and its implications on a neglected, high-needs population. Previous literature has examined best practices in transitions of care from a provider-centric perspective. Patient education, provider-to-provider handoffs, and discharge tools, although important elements in successful transitions of care, tend to exclude an understanding of the relational aspects of discharge including patient concerns. This article presents a framework (process, consequences, needs) based on complex patients' experiences of care transitions. A dominant concern expressed by patients was poor communication with care providers. Facilitating clear lines of communication at the outset of hospital admission until discharge is an essential step to improving care transitions. A novel finding from our study, not prominent in the literature, indicated that social networks are important to patients while in hospital. Bolstering social capital by offering resources such as peer support groups may improve quality of care and increase levels of patient satisfaction. Finally, embedding our transitions of care framework at a system level would make the most impact on patient care. Funding models and accountability frameworks, which incentivize discharge processes that place patients and their families at the center, are necessary to fully serve the complex needs of the chronic disease population.

REFERENCES

Allen, C. (2001). Back to the old house? 'Sick role' and biographical narratives of the housing needs of short-stay hospital patients. *Health and Place*, *7*(2), 81–92.

Baranek, P. M., Deber, R. B., & Williams, A. P. (2004). Introduction and overview. In *Almost home: Reforming home and community care in Ontario* (pp. 3–18). Toronto, Canada: University of Toronto Press.

Beach, S. R., Schulz, R., Williamson, G. M., Miller, L. S., Weiner, M. F., & Lance, C. E. (2005). Risk factors for potentially harmful informal caregiver behavior. *Journal of the American Geriatrics Society*, *53*(2), 255–261.

Benjamin, R. M. (2010). Multiple chronic conditions: A public health challenge. *Public Health Reports*, *125*(5), 626–627.

Coleman, E. A. (2003). Falling through the cracks: Challenges and opportunities for improving transitional care for persons with continuous complex care needs. *Journal of the American Geriatrics Society*, *51*(4), 549–555.

Coleman, E. A., Parry, C., Chalmers, S., & Min, S. J. (2006). The care transitions intervention: Results of a randomized controlled trial. *Archives of Internal Medicine, 166*(17), 1822–1828.

Doran, D., Hirdes, J. P., Blais, R., Baker, G. R., Poss, J. W., Li, X., . . . McIssac, C. (2013). Adverse events associated with hospitalization or detected through the RAI-HC assessment among Canadian home care clients. *Health Policy*, *9*(1), 76–88.

Efraimsson, E., Sandman, P., & Rasmussen, B. H. (2006). "They were talking about me"—Elderly women's experiences of taking part in a discharge planning conference. *Scandinavian Journal of Caring Sciences*, *20*(1), 68–78.

Entwistle, V. A., & Watt, I. S. (2006). Patient involvement in treatment decision-making: The case for a broader conceptual framework. *Patient Education and Counseling*, *63*, 268–278.

Fairhurst, K., Blair, M., Cutting, J., Featherstone, M., Hayes, B., Howarth, M., . . . Stanley, I. (1996). The quality of hospital discharge: A survey of discharge arrangements for the over-65s. *International Journal for Quality in Health Care*, *8*(2), 167–207.

Forchuk, C., Reynolds, W., Sharkey, S., Martin, M., & Jensen, E. (2007). Transitional discharge based on therapeutic relationships: State of the art. *Archives of Psychiatric Nursing*, *21*(2), 80–86.

Foss, C., & Askautrud, M. (2010). Measuring the participation of elderly patients in the discharge process from hospital: A critical review of existing instruments. *Scandinavian Journal of Caring Sciences*, *24*(Suppl. 1), 46–55.

Fuji, K. T., Abbott, A. A., & Norris, J. F. (2013). Exploring care transitions from patient, caregiver, and health-care provider perspectives. *Clinical Nursing Research*, *22*(3), 258–274.

Graumlich, J. F., Novotny, N. L., & Aldag, J. C. (2008). Brief scale measuring patient preparedness for hospital discharge to home: Psychometric properties. *Journal of Hospital Medicine, 3*(6), 446–454.

Halasyamani, L., Kripalani, S., Coleman, E., Schnipper, J., Van Walraven, C., Nagamine, J., . . . Manning, D. (2006). Transition of care for hospitalized elderly patients—Development of a discharge checklist for hospitalists. *Journal of Hospital Medicine, 1*(6), 354–360.

Harrison, A., & Verhoef, M. (2002). Understanding coordination of care from the consumer's perspective in a regional health system. *Health Services Research*, *37*, 1031–1054.

Huby, G., Stewart, J., Tierney, A., & Rogers, W. (2004). Planning older people's discharge from acute hospital care: Linking risk management and patient participation in decision-making. *Health, Risk & Society*, *6*(2), 115–132.

Johnson, A., Gaughwin, B., Moore, N., & Crane, R. (2005). Long-stay views from the hospital bed: Patient perspectives of organisation of care and impact of hospitalisation. *Australian Health Review*, *29*(2), 235–240.

Kuluski, K., Hoang, S. N., Schaink, A. K., Alvaro, C., Lyons, R. F., Tobias, R., & Bensimon, C. M. (2013). The care delivery experience of hospitalized patients with complex chronic disease. *Health Expectations*, *16*, e111–e123.

Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation*. San Francisco, CA: Jossey-Bass.

Morris, R., & Morris, P. (2012). Participants' experiences of hospital-based peer support groups for stroke patients and carers. *Disability and Rehabilitation*, *34*(4), 347–354.

Naylor, M. D., Bowles, K. H., McCauley, K. M., Maccoy, M. C., Maislin, G., Pauly, M. V., & Krakauer, R. (2013). High-value transitional care: Translation of research into practice. *Journal of Evaluation in Clinical Practice*, *19*(5), 727–733.

Naylor, M., & Keating, S. A. (2008). Transitional care: Moving patients from one care setting to another. *The American Journal of Nursing, 108*(9 Suppl), 58.

Oswald, F., Wahl, H. W., Schilling, O., Nygren, C., Fänge, A., Sixsmith, A., . . . Iwarsson, S. (2007). Relationships in housing and health aging in very old age. *The Gerontologist*, *47*(1), 96–107.

Perkins, S., Schwartz, M., Andersen, K., & Ley, C. (2012). *SMART discharge protocol: A pilot study to standardize the discharge process in an acute care hospital*. Retrieved from http://www.aahs.org/aamcnursing/wp-content/uploads/SMART-Discharge-Protocol.pdf

Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, *18*(2), 250–267.

Piraino, E., Heckman, G., Glenny, C., & Stolee, P. (2012). Transitional care programs: Who is left behind? A systematic review. *International Journal of Integrated Care*, *12*(5), e132. Retrieved from http://www.ijic.org/index.php/ijic/article/view/URN%3ANBN%3ANL%3AUI%3A10-1-113107

Quine, S., & Morrell, S. (2007). Fear of loss of independence and nursing home admission in older Australians. *Health & Social Care in the Community*, *15*(3), 212–220.

Robinson, J. H., Callister, L. C., Berry, J. A., & Dearing, K. A. (2008). Patient-centered care and adherence: Definitions and applications to improve outcomes. *Journal of the American Academy of Nurse Practitioners*, *20*(12), 600–607.

Rydeman, I., Törnkvist, L., Agreus, L., & Dahlberg, K. (2012). Being in-between and lost in the discharge process—An excursus of two empirical studies of older persons', their relatives', and care professionals' experience. *International Journal of Qualitative Studies on Health and Well-Being*, *7*, 1–9.

Salive, M. E. (2013). Multimorbidities in older adults. *Epidemiologic Review*, *35*, 75–83.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, *23*(4), 334–340.

Schaink, A. K., Kuluski, K., Lyons, R. F., Fortin, M., Jadad, A. R., Upshur, R., & Wodchis, W. P. (2012). A scoping review and thematic classification of patient complexity: Offering a unifying framework. *Journal of Comorbidity, 2*(1), 1–9.

Stewart, M. (2001). Towards a global definition of patient centred care: The patient should be the judge of patient centred care. *BMJ: British Medical Journal, 322*(7284), 444.

Stewart, M., Brown, J. B., Donner, A., McWhinney, I. R., Oates, J., Weston, W. W., & Jordan, J. (2000). The impact of patient-centered care on outcomes. *The Journal of Family Practice*, *49*(9), 796–804.

Swinkels, A., & Mitchell, T. (2009). Delayed transfer from hospital to community settings: The older person's perspective. *Health & Social Care in the Community*, *17*(1), 45–53.

Teutsch, C. (2003). Patient-doctor communication. *Medical Clinics of North America*, *87*, 1115–1145.

Toscan, J. F., Mairs, K. F., Hinton, S. F., & Stolee, P. (2012). Integrated transitional care: Patient, informal caregiver and health care provider perspectives on care transitions for older persons with hip fracture. *International Journal of Integrated Care*, *12*(2), e13. Retrieved from http://www.ijic.org/index.php/ijic/article/view/URN%3ANBN%3ANL%3AUI%3A10-1-112878/1530

Weiss, M. E., & Piacentine, L. B. (2006). Psychometric properties of the readiness for hospital discharge scale. *Journal of Nursing Measurement, 14*(3), 163–180.

World Health Organization. (2011). *Global status report on noncommunicable diseases 2010: Description of the global burden of NCDs, their risk factors and determinants*. Retrieved from http://whqlibdoc.who.int/publications/2011/9789240686458_eng.pdf

Ziebland, S., & McPherson, A. (2006). Making sense of qualitative data: Analysis: An introduction with illustrations from DIPEx (personal experiences of health and illness). *Medical Education*, *40*, 405–414.

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