

Experiences of Older Adults in Transition from Hospital to Community*

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RÉSUMÉ

Cette étude a examiné comment les patients éprouvent des transitions à la communauté des hôpitaux, y compris les problèmes de la vie quotidienne et les préoccupations médicales. Grâce à l'analyse de données qualitatives à partir d'entretiens avec 36 personnes, y compris 17 adultes âgées à haut risque avec des problèmes multiples de santé chroniques, récemment sortis de l'hôpital, et 19 membres de la famille qui ont fourni les patients avec des soins continus, nous avons demandé (1) quels sont les défis que les patients éprouvent dans la transition de l'hôpital, et (2) quelles sont les solutions de systèmes et politiques qui peuvent répondre aux défis que ces patients éprouvent? Nos résultats révèlent des défis à court et à long terme associés aux transitions à la maison. Les défis à court terme comprennent la préparation de l'habitation pour le patient et la compréhension de l'organisation des soins à la maison. Les défis à long terme sont associés à des problèmes pratiques et émotionnels. Réfléchissant sur nos résultats, nous suggérons que les besoins sociaux des patients peuvent être d'une importance égale à leurs besoins médicaux lors de la récupération post-décharge, et nous discutons les implications pour la politique.

ABSTRACT

This study examined how patients experience transitions to community from hospitals, inclusive of daily living problems and medical concerns. Analysing qualitative data from interviews with 36 individuals including 17 high-risk older adults with multiple chronic health conditions recently discharged from hospital, and 19 family members who provided the patients with ongoing care, we asked (1) What are the challenges that patients experience in transitioning home from the hospital, and (2) What are the system and policy solutions that can address the challenges these patients experience? Our findings reveal both short- and long-term challenges associated with transitions back home. Short-term challenges include preparing the dwelling for the patient and understanding the organization of care at home. Long-term challenges are associated with practical and emotional concerns. Reflecting on our findings, we suggest that patients' social needs may be equally important to their medical needs during post-discharge recovery, and we discuss implications for policy.

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The delivery of health services in Western health care systems has been described as fragmented and characterized by gaps in the provision of care (Coleman & Berenson, 2004; Dunnion & Kelly, 2005; McKenna, Keeney, Glenn, & Gordon, 2000). Shortened hospital stays have become a hallmark of many health care systems. In this context, the lack of continuity of care during the transition from hospital to community has been identified as a problem with serious negative implications for the well-being of individuals in many countries where this has been studied, including Canada, the United States, the United Kingdom, Australia, Sweden, and Japan (Borthwick, Newbrunner, & Stuttard, 2009; Boughton & Halliday, 2009; Efraimsson, Sandman, Hydén, & Rasmussen, 2006; Naylor, 2012; Tomura, Yamamoto-Mitani, Nagata, Murashima, & Suzuki, 2011).

Seeking to address the problem in *care transitions*, meaning the care provided during the transition from one health care site to another (Coleman, 2003), and to reduce the gaps in health services delivery, a number of different intervention models have been implemented, such as post-discharge planning in hospitals (Tomura et al., 2011) or the creation of intermediate post-acute care (Glasby, Martin, & Regen, 2008; Regen et al., 2008). The majority of proposed interventions, however, focus on the *medical needs* of the patients (see, for example Arbaje et al., 2008; Coleman, Parry, Chalmers, & Min, 2006; Howell, Silberberg, Quinn, & Lucas, 2007). Notably lesser attention is paid to the *social needs* of the patients in community, which are not necessarily related to medical complications, but, nevertheless, may negatively affect post-discharge recovery (Fabbre, Buffington, Altfeld, Shier, & Golden, 2011; Rockwell, 2010).

The goal of the study addressed in this article was to begin to fill this gap in the literature and explore how patients experience transitions from acute care hospitals to their day-to-day life in the community. Analysing qualitative interviews with 17 high-risk older adults with multiple chronic health conditions recently discharged from hospital, and 19 family members who provide the patients with ongoing care, we asked: (1) What are the challenges that patients experience in transitioning home from the hospital? and (2) What are the system and policy solutions that can address the challenges these patients experience? Our findings revealed both short- and long-term challenges associated with transitions back home. Short-term challenges included preparing the dwelling for the patient and understanding the organization of care at home. Long-term challenges were associated with practical and emotional concerns. Patients and caregivers themselves provided several useful solutions.

Challenges in Post-Discharge Recovery

Western health care systems are moving towards models of care in which individuals are discharged from hospitals sooner than before (Boughton & Halliday, 2009). This implies that they will have more needs, and will also require more sophisticated and prolonged care provided at home (Glasby et al., 2008; Regen et al., 2008). Currently, many health care systems face the problem of addressing gaps in the flow of information from hospital to community-based providers about patients' continuing care needs (Dunnion & Kelly, 2005; McKenna et al., 2000).

Fragmentation of care has serious implications. Patients and their caregivers may not recognize problems that necessitate professional care, or they may demand medical attention when it is not necessary. The uncertainty about what to expect during recovery may increase stress and cause anxiety among both patients and their caregivers (Boughton & Halliday, 2009). When care during the transition to community is poorly coordinated, it can also create mistakes in the management of care by health care professionals and community services. This outcome is especially alarming in older adults who may have multiple chronic conditions and multiple drug therapies (Garcia-Caballeros, Ramos-Diaz, Jimenez-Moleon, & Bueno-Cavanillas, 2010). In a fragmented health care system with a lack of centralized and shared health records, as is the case in Canada, health care teams working in the community may not be aware of the treatment and follow-up care requirements established in hospital.

A number of solutions have been sought to address these emerging concerns with the fragmented system of care. In the United Kingdom, a new policy of "intermediate care" was introduced which aims to provide a range of services including rehabilitation and integrated home care teams (Glasby et al., 2008; Regen et al., 2008). Some other models include in-hospital discharge conferences (Efraimsson et al., 2006; Tomura et al., 2011); follow-up in the community after hospital discharge (in person or by telephone); and the establishment of channels of communication between hospital and services provided in the community (such as with pharmacists and primary care services) (Altfeld et al., 2013; Henwood, 2006; LaMantia, Scheunemann, Viera, Busby-Whitehead, & Hanson, 2010). Many of these interventions have proved to be effective in reducing the number of hospital readmissions, but it has also become clear that these interventions cannot be delivered without consideration of specific needs of different population groups (Tomura et al., 2011).

Since the burden of and responsibility for organization and coordination of post-discharge care primarily falls on the shoulders of patients and their informal

caregivers, it is imperative that these individuals have the necessary information about what to expect after hospital discharge. An Australian study examining post-discharge experiences of seven dyads of surgery patients and their caregivers demonstrated that the post-discharge care was often not adequately conveyed to patients and their caregivers, who experienced a great deal of uncertainty and anxiety trying to manage care at home (Boughton & Halliday, 2009). Similar findings were reported in another Australian study inquiring into post-discharge experiences of 40 patients and their caregivers (Driscoll, 2000).

Although studies examining the experiences of patients and their informal caregivers provided valuable insights for our understanding of day-to-day experiences of individuals moving from hospital to community, they dealt mainly with medical issues and medical uncertainty. The social needs of the patients, such as the availability of supportive family environments, financial stability, and knowledge of community services, are implicitly present as a context for various interventions, but they rarely become a focus of analysis (Fabbre et al., 2011; Harrison & Verhoef, 2002; Perry et al., 2012). Yet the social needs of the patients cannot be separated from the physical recovery and, thus, should warrant our attention. Some researchers have observed that certain patient characteristics, such as poor socioeconomic status, living alone, or poor language proficiency, may negatively affect successful transition to community and thus require particular attention from health care delivery teams (Arbaje et al., 2008; Graham, Ivey, & Neuhauser, 2009). Fabbre et al. (2011) found that increased attention to social needs was helpful in post-discharge recovery. A study examining the meaning of the transition from hospital to community in Alberta showed that the success of transition was associated with the availability of social support, which could boost the confidence of the patients, improve the preparation for the transition, and improve functioning at home (Harrison & Verhoef, 2002). Attention to daily life needs was also evident in the findings of Rockwell (2010) for patients in British Columbia, who suggested that issues such as the lack of assistance with essential housework (cleaning or cooking) can negatively affect the well-being of the patients and ultimately worsen health outcomes.

Our study aimed to examine how the care transition was experienced, organized, and coordinated by patients and their informal caregivers at home. Rather than relying on a narrow definition of medical care, we focussed on organization and coordination of care ranging from medical needs to daily activities, such as walking, eating, or participating in community life. We sought to understand how patients and their caregivers experienced the transition to community and

which barriers and facilitators they identified on their way to recovery.

Methods

Participants for the present study were identified from a care transition intervention implemented in Southwestern Ontario for patients discharged from acute care hospital to home who were at high risk for acute care readmission. We used a risk screening tool (LACE) to select patients for the intervention. The tool identifies risk of readmission or death based on a hospital length of stay (L), acuity or urgency of admission (A), comorbid conditions (C) and recent emergency department utilization (E). Patients were selected based on a LACE score of 10 or higher from an overall potential score ranging from 0–18 (van Walraven et al., 2010). The intervention itself was based on the core elements of the Care Transition Intervention (Coleman et al., 2006) and included a visit from a nurse-practitioner (NP) in the hospital and another visit within 72 hours after discharge to the patient's home. The NP completed a personal health record with the patients that outlined their medications, upcoming laboratory tests and visits with physicians, and the patients' primary health concerns and goals.

The NP also either completed medication reconciliation during the home visit or ensured that one was completed by a community-based pharmacist within one week of discharge. Medication reconciliation included creating a complete list of the medications that the patient was taking, reviewing these and making changes to address any discrepancies including, for example, unsafe drug-disease and drug-drug interactions. While the intervention was implemented as a pilot program for all at-risk patients, consent was obtained from eligible patients to allow for follow-up telephone calls to complete survey tools and measure return visits and readmissions to hospital at 30, 60, and 90 days. Consent was also obtained from patients for in-home interviews at the same time. Ethical approval for the study was obtained from the Research Ethics Board of the University of Western Ontario.

Thirty-six interviews with patients ($n = 17$) and their primary caregivers ($n = 19$) were conducted in the 2010–2012 time frame. The patients were 70 to 89 years old with an average age of 79. The average stay in the hospital was 15 days with a minimum of six days and a maximum of 36 days. The most common diagnoses for hospitalization were cardiovascular conditions (congestive heart failure [CHF], stroke) and respiratory problems (chronic obstructive pulmonary disease [COPD], pneumonia). Other patients had a variety of health problems including diabetes, kidney disease, gastro-intestinal and neurological problems, and

cancer. On average, patients had 12 medications prescribed, and had a LACE score of 12.5 (LACE scores ranged from 10 to 18). Most patients ($n = 14$) needed partial assistance with personal care, 10 needed partial assistance in decision making, and six felt that they were competent to make decisions on their own. Three patients lived alone, nine lived with their spouses, and five with children or siblings. Only 12 patients reported their annual income and among those, most were in the \$10,000 to \$29,000 range. Three had identified their income range as \$30,000 to \$39,000 and only one patient had income of over \$40,000.

Caregivers for patients were defined as individuals who self-identified as being responsible for providing and coordinating the patient's care. Consent for caregiver interviews was obtained at the time of the in-home interview with patients. The majority of caregivers were women (spouses and daughters), and the majority of the patients were male (see Tables 1 and 2).

The interviews were semi-structured and lasted between 30 and 90 minutes. The interviews were scheduled over the phone, and the majority of patients preferred to have a caregiver present during the interview. The interviews were conducted in patients' homes in the presence and with the participation of an informal caregiver if one existed. Three patients did not have a caregiver and were interviewed alone. We also interviewed three caregivers without patients present. One interview, lasting more than two hours, was conducted with four people – a patient and three caregivers (husband, daughter, and son-in-law). With the consent of participants, the interviews were recorded and transcribed verbatim.¹

The interviews were conducted two to five weeks post-discharge and focused on coordination of care and adaptation to the community after hospital discharge. We had a number of questions pertaining to the experiences of patients and a separate but related set of questions for the caregivers, but during the interviews with both types of participants present, the interview flowed from one person to another, (e.g., a patient would answer the question and the caregiver would provide additional comments, or the caregiver would answer the question and the patient would add his/her perspective on the issue). During the interviews, caregivers were asked to comment on the experiences of patients and also on their experiences as caregivers. We anticipated that some of the caregivers might be less forthcoming, when the patients were in the room during the interview, about the difficulties that they had experienced. In the few instances when caregivers were interviewed alone (see Table 2), they spoke more openly about caregiver burden and the impact of care on their own well-being. There were no other identifiable differences pertaining to our topic of interest (transition to community after hospitalization) in separate versus combined interviews.

Interview transcripts were coded in QSR International's NVivo 8, software for qualitative data management, using Charmaz's (2006) guide for qualitative data analysis. First, we did line-by-line open coding to identify themes in the interview data. We then mapped the relationship between analytic themes and allowed for emergence of thematic categories. After performing thematic analysis of the whole set of interviews, the data were divided into caregivers' and patients' interviews to identify similarities and differences in the

Table 1: Profile of patients

| Name | Gender | Caregiver | Caregiver's Gender | Relation to Caregiver |
|--|--------|-----------------|--------------------|--|
| Barry | Male | No | n/a | No family support |
| Annie | Female | No | n/a | Lives alone; two children, not interviewed |
| James | Male | Yes | Female | Husband |
| Donald | Male | Yes | Male | Partner |
| Daniel | Male | Yes | Female | Husband |
| Janine | Female | Yes | Female | Sister |
| Barbara | Female | Yes ($n = 3$) | Male, Male, Female | Wife, mother, mother-in-law |
| Diana | Female | Yes | Female | Mother-in-law |
| Victoria | Female | Yes | Male | Wife |
| Sandra | Female | Yes | Female | Mother |
| Oliver | Male | Yes | Female | Father |
| Matthew | Male | Yes | Female | Husband |
| Jennifer | Female | Yes | Male | Wife |
| Michael | Male | Yes | Female | Wife |
| Andrew | Male | No | n/a | No family support |
| Marc | Male | Yes | Female | Husband |
| Richard | Male | Yes | Male | Son |
| Total Patients: $n = 17$ (10 Males; 7 Females) | | | | |

Table 2: Profile of caregivers

| Name | Gender | Relation to Patient |
|---|--------|---------------------|
| Betty | Female | Wife |
| Scott | Male | Partner |
| Michelle | Female | Wife |
| Janice | Female | Sister |
| Jacob | Male | Husband |
| John | Male | Son-in-law |
| Nancy | Female | Daughter |
| Agnes | Female | Daughter |
| Natalia | Female | Daughter-in-law |
| Tim | Male | Husband |
| Sandy | Female | Daughter |
| Gloria | Female | Daughter |
| Ricardo | Male | Husband |
| Claudia | Female | Wife |
| Doug | Male | Son |
| Christopher | Male | Husband |
| Esther | Female | Wife |
| Sharon | Female | Wife |
| Brian | Male | Son |
| Total Caregivers: n = 19 (11 Females; 8 Males) | | |

responses of these two groups of participants. Although there were some differences between the major themes emerging from the patients' and caregivers' interviews, we also identified a number of interrelated themes pertinent to organization and coordination of care. These included the following: (1) difficulties of adjusting to the transition back home; (2) confusion about organization of care and navigation through the health care system; and (3) facilitating factors improving the experience of transition. In what follows, we present our findings, first focusing on the challenges, and then outlining facilitators for successful recovery. Where the differences between patients' and caregivers' views were found, we draw on these differences in presenting our results.

Findings: Challenges and Confusion

Getting Back Home

Adaptation to daily life after the discharge from the hospital was seen by many of our respondents as a real challenge. Cooking, dressing, bathing, and other daily activities can become difficult to manage immediately after discharge. Some patients needed walkers and the assistance of other devices, and these arrangements had to be made by the caregiver prior to discharge. Often the caregivers felt that the news about the discharge came too fast, before they had a chance to prepare the home for the patient. A daughter, caregiver of her mother, recalled:

It was just a real rush ... like getting out of the hospital ... We had the team meeting at the hospital and then ... the lady from [the hospital] ... came

that afternoon after the meeting to look at mom's apartment and it was a disaster ... The lady ... says "Oh my god!". ... "You've got to get rid of that [furniture] ... So my husband and I are like "Huh?!" Not even a full day [for preparing the house]. ... So it's like ... a marathon.

Another respondent, a male caregiver, provided a similar account:

The problem was they wouldn't tell us what day they were discharging her because they didn't know until the day they discharged her. If I'd have known a couple days ahead, I could have called [home care] and said "Okay, she's coming home. Let's set this up." But all of a sudden bang, you're out of the hospital and you're home – which she was happy to be, but nothing had been arranged, you know ...

The "rush" of discharge planning was often reported by our respondents. Discussing their experiences of discharge, many caregivers and some patients suggested that it was often arranged suddenly. Three patients were brought home to their children. In these situations, arrangements had to be made to create new space for the patient to stay, and lack of time was often associated with a fear that chaotic preparations would jeopardize the safety of the patient.

Once the patient arrived home, the adjustment to daily living began. Although most of the patients received assistance from personal support workers during their first week at home and could rely on support of their family members, for those patients who lived alone and lacked family support, returning home from the hospital was often associated with unique challenges. One male patient, who lived alone, noted:

They [hospital] had a lady who drove the car and she brought me here [home] ... Everything was alright ... except that I did not have the food in my fridge because I emptied the fridge before the hospital because I knew that I would be so long so the food would get spoiled.

While such immediate needs as getting food or making arrangements for the laundry were not considered "medical" issues, the disruption in these daily routines was identified by many individuals as pivotal in making the transition to "normal" smoother. Those who had the support of their family members were more successful in adapting to the transition, but those who lived alone found this transition especially difficult. Both patients and their caregivers talked about this experience as "overwhelming", "chaotic", and "confusing".

Dealing with Medical Confusion

When the patients were discharged from the hospital, they received a schematic one-page summary of the

various health care providers that would participate in organizing their care. In addition to their usual health care providers, such as family physicians and specialists, that the patients were seeing on a regular basis, many patients also received one or more visits from the nurse practitioner, case manager from home care services, personal support workers, physiotherapist, and other health care workers. Although the scope of responsibilities of the family physician and the health care professionals who provided care prior to hospitalization was clear, post-discharge care was often presented in a rather disorganized way. It was not uncommon for patients to confuse nurse practitioners, personal support workers, and physiotherapist/occupational therapists and to have only approximate knowledge of “who is doing what”.

The transition from hospital to community inevitably resulted in many changes in one’s personal life – changes in physical conditions, living arrangement, organization of daily activities, and taking care of one’s body were all experienced at the same time, which brought forth the feelings of uncertainty, confusion, and chaos. For many patients and their caregivers, establishing a routine was seen as central for successful adaptation to a post-discharge life. Depending on the number of community services received after the discharge and their reliability and consistency, the establishment of routine could take just one or two weeks or a much longer period of time. When the services received by the patients were disturbed by changing health care personnel, the patients experienced even more confusion. One of our female patients noted:

If the same person is coming in all the time, like, the same nurse, you realize it. But if a different person – what’s happened here? Like when I got home from the hospital I think three hours [later] there was a nurse in here. That would be about four o’clock. And then all of a sudden another night nurse shows up at eight o’clock. Now I’ve not seen those two since, but I do know a nurse comes in every Tuesday morning and I’m satisfied now.

Another challenge experienced post-discharge was an adaptation to a new regimen of medications. A male patient, who was discharged one week before the interview, complained:

Well, I’ll show you what the pharmacy sent up. There were 19 little bottles of medication and I was kind of getting confused with some of the meds I don’t know. I used to know them but I don’t anymore ...

Having medications delivered directly home would help people obtain the medications, but some of our respondents complained that they could not remember to take them on time. While prior to hospitalization

the medications schedule was routinized and, therefore, easier to remember, post-discharge medication management was difficult because of the changes in the types of medications, the new schedule, and the disruption in the routine of daily life.

Organizing Transportation

Whereas the confusion of the first few days after the discharge would usually pass, one issue that would arise as a permanent problem related to daily living was the problem of transportation. This theme was reflected in the interviews with both groups of respondents but was especially salient in the interviews with caregivers. According to many caregivers, the issue of transportation was one of the major challenges associated with post-discharge recovery. For instance, one of our respondents, a male caregiver who lived with his wife and in-laws, described the difficulty of transporting his recently discharged mother-in-law to medical appointments:

We had to get mom into dad’s van to get her down because she can’t walk too well. We need a little ramp or something. I’ll have to build one. Dad was talking about that, trying to make something so that we can manoeuvre her in the van better ... It’s very hard for her to get in the van.

Usually, upon discharge from the hospital, patients would be required to book a follow-up appointment with their family physician to arrange for blood tests and other medical exams. It would not be uncommon for the participants in our sample to be seen by two to three doctors on a relatively permanent basis. The problem of getting the recovering family member out of the house, especially during the wintertime, was a constant issue of concern for the family members. After discharge from the hospital, patients would not be as mobile, some had problems getting up or down the stairs, and some found it difficult to put on winter boots or extra clothing. Since previously routinized actions would have now required considerable effort and learning new techniques, the trip to a family doctor or a bloodwork lab could become a daylong journey for many of our participants.

To summarize, the post-discharge experiences of our respondents suggested that a major barrier for successful recovery was organizing the care plan and overcoming confusion in coordination of care. These findings are consistent with the existing literature that points to the lack of effective paths for transferring care from hospital to community and the need to develop effective practices to facilitate this transition (Borthwick et al., 2009; Boughton & Halliday, 2009; Fabbre et al., 2011). What we find particularly interesting is that the majority of our respondents were overwhelmingly concerned

with trying to re-establish order and routine in their daily lives, and they talked less about their medical concerns. Even in the context of medical care, it was not so much concerns about the bloodwork *results*, as *getting to the lab* to have the blood drawn. Setting up a schedule was seen as a primary goal of the first few weeks after the discharge by many patients and their caregivers, and organizing food delivery or grocery shopping and getting to medical appointments were seen as pivotal for successfully completing the transition to community.

Facilitators for Recovery: Social Capital and Social Support

Through analysing the narratives of patients and their family members, it became apparent that personal networks and social support became a crucial factor for successful recovery. Family members took the patients to various medical appointments, made sure that the medications schedule was followed and that medical needs of the patients were addressed. Therefore, those individuals who did not have family members or other people who could help with daily care were at considerable disadvantage during the recovery. A male patient, living alone, noted:

Well, I don't have very much care in the first place ... [My personal support worker] is helping me out taking the shower and there is nobody else except I, I have to do it on my own. I don't know how I am going to do later if I would not be able to do it. I hope that Almighty Creator will take me away and that would be the end.

Being unable to rely on somebody that can notice emerging problems was a particularly fearful factor in the accounts of these individuals. One of the patients mentioned that he was hospitalized after his landlord found him passed out on the floor, and the patient was not sure for how long he was unconscious in his apartment. He said:

I'm quite lonely here in a way, but I have good friends and that's it ... It's just ... [pause] ... I'm getting older. The problem – it's difficult to comprehend, you know. I've always done things on my own since I lost my wife. She's really done everything, you know. Since then I've been on my own basically. I mean, I share my troubles with myself, you know, basically.

The patients who lived alone often reported being depressed and unable to deal with the responsibility of watching their health on their own. The majority of our respondents, however, did have family support and often relied on family members to get to medical appointments and receive moral support. This reliance on family members was perceived differently by the

patients and their families. The patients often suggested that they were satisfied with their family members' provision of care and would prefer to rely on their family members in coordinating necessary care. The patients also saw their family members as well-equipped and knowledgeable in assisting with medical needs. The caregivers, however, often reported being overwhelmed and exhausted due to the constant need to coordinate care and ensure that the patients' needs were met. Some caregivers also felt that they lacked the physical skills needed to provide the instrumental care, and sufficient knowledge of the health care system to assist the patients.

The gendered organization of care was evident in the narratives of our respondents. Daughters and wives were generally expected to provide care, even when they felt they were less equipped for this task than others. The children (primarily daughters) often felt that their own health deteriorated as a result of their care work as well as relations with their own families.

What made care more manageable and less demanding for the family members was the knowledge of how to navigate the health care system and community services. Individuals who had worked in the health care system as nurses or social workers, or who knew how the system worked, felt that they were "on top of things" because of their ability to handle the situation. When we asked one of the caregivers what she thought made the transition smoother for her mother-in-law, she said:

Actually, probably having someone like me to be able to coordinate it [care] ... There might be other people that would be a little intimidated in the hospital but I wasn't so, you know, so I think that if it wasn't me and it was somebody who didn't know anything about hospitals, it would be great to have a social worker or somebody who helps the family member.

However, the majority of caregivers did not have an advanced knowledge of community services and had difficulty understanding how the services are provided and where they could access services to meet their or the patients' needs.

Lack of familiarity with available community services not only affected the well-being of caregivers; it also impacted patients' experiences of recovery. This direct impact was evident in access to available services and the ability to receive the needed care. The indirect impact was associated with learning about the services and navigating the community services, which, for some patients and caregivers, was an emotionally and physically draining experience.

Targeted Nurse Practitioner Initiative

Upon discharge from hospital, the patients recruited for this study received a visit from a nurse-practitioner (NP). While many patients and some caregivers did not fully understand the role of the NP, the reasons for the visit, and the scope of the NP's responsibilities, they relied on NPs to oversee the management of medications, to coordinate the services provided by home care services, and to establish the process of medical follow-up. Many patients reported that the NP assisted them with medication management, that she would refer them to other services, and would "put everything on the right track".

Many patients and caregivers relied on the visit from the NP not only to assess the physical well-being of the patient but often, to organize the care provided at home. Moreover, since the visit from the NP was associated with the discharge from the hospital, many patients saw it as a reassurance that any newly emerged medical needs would be addressed and recognized under the regimen of care coordinated by the NP. Reflecting on the role of NP in providing post-discharge care, one of male caregivers said:

And [the NP] seems to have connection with the hospital to the point where she can look up records as well and make the connection which is very helpful. I mean, it gives some kind of continuity.

For many patients and caregivers, the NP's visit was the most valuable assistance received during the transition from hospital to community, and those patients who lacked the knowledge of the health care system or those who did not have family members assisting with care were especially grateful for having the NP available to organize their care. These visits, however, were scheduled to initiate the organization of care, not to coordinate it on a permanent basis. As we discuss next, more permanent solutions were offered by our respondents as potential facilitators in coordinating and organizing the patients' care.

One Person to Coordinate Care

Having one person in charge of care was seen by many caregivers as potential facilitator for successful organization of care. Even when the family members were willing to take on the coordination of care, having a case worker who would assist with advice, organization, or navigation was suggested as one of the most important facilitators. Describing the ongoing challenges of organizing care for her mother, a daughter, sharing caregiving with her sister, stated:

Well ... it would be nice [to have one person coordinating care], especially with my sister and I who don't always agree, it would be nice to have a third person in there maybe coordinating things

because, with my sister, sometimes they call her, sometimes they call me ...

When the care for the patients was organized by a number of individuals or care agencies, it could create additional barriers for coordinating care. The patients who coordinated care themselves usually managed relatively well in keeping track of their appointments schedule, but they lacked the knowledge of the system to know who to contact should a problem arise.

When care was provided by a number of informal caregivers, it also could complicate organization of care. Caregivers would bring their loved ones to the appointments that were cancelled, some appointments would be missed, some calls to community services would not be made, and some would be made more than once. Caregivers who had knowledge of the health care system usually took upon themselves the sole responsibility of organizing care for the patients, but the caregivers who lacked knowledge of the system often expressed their desire to have just one person to coordinate and organize care.

Meeting Daily Needs

One of the recurring themes in the narratives of our respondents was the difficulty that they faced in accommodating the daily needs of the patients. The major facilitating factors in this case seemed to be (a) knowledge of available services; (b) the ability to organize service delivery at home; and (c) financial security, in cases where services needed to be paid for privately. The desire for services to be provided at home was often mentioned by our caregivers. At the same time, not many actually pursued this strategy, mainly because of a lack of knowledge about the possibility to arrange such services. Those who did know how to proceed, such as the female caregiver of her mother-in-law quoted below, usually highlighted the benefits of such practice:

I've arranged for as many people to come in and provide services as I can so we don't have to go out ... Partially because when [name] was ill in December, taking her just to get her bloodwork done was a whole afternoon ... So now they're coming in to do the bloodwork ... I would love to have more people come in. It's just so much easier on them [patients].

In sum, having health care professionals coming to the patients, rather than transferring them to various medical appointments, was seen as a facilitator in organizing post-discharge care. Some caregivers arranged for medical laboratory technicians to come to the home; a few others had the advantage of receiving in-home visits from their family doctors. Some also had physiotherapist sessions scheduled at home. When these services were provided at home, the respondents often

expressed their gratitude and satisfaction with the in-home visits. When possible, the patients also received assistance with daily care, such as cooking, cleaning, dressing, and bathing from the local publicly provided home care or through privately purchased services.

Discussion and Recommendations

Table 3 summarizes our findings and highlights their practice and policy implications.

Our participants revealed a number of barriers for successful adaptation to daily life during the post-discharge period. Some of them were more immediate and short-term, such as getting the home ready for the transition from the hospital and getting used to new medical care routines. Other issues, such as transporting patients to medical appointments and providing social and emotional support, posed ongoing challenges for patients and their caregivers. Whereas some of the challenges faced by the patients during the post-discharge period may not have simple solutions, we contend that several changes in health care organization may ease the process of adaptation to community life.

Our findings indicate that the concerns raised in the literature regarding transitions of care resonated with the experiences of patients and their caregivers. Our study also showed that many of the aspects deemed to be of most concern to our respondents about their transition to the community were not rooted in medical uncertainty but, rather, in difficulty organizing day-to-day life after discharge from the hospital. Therefore, it can be argued that social needs must be given closer attention in managing care transition from hospital to community. Our findings did not suggest that medical concerns of individuals are unimportant for the successful

recovery, but that social needs may be equally – if not more – important for post-hospital transition.

Gaps in the provision of post-discharge care have been known to present a problem for health care delivery for some time, not only in Canada but elsewhere as well (Arbaje et al., 2008; Borthwick et al., 2009; Boughton & Halliday, 2009). The lack of effective transitional care after hospitalization has been linked to readmissions, especially among those with lower socioeconomic status and lack of social support (Arbaje et al., 2008). Poor knowledge of available services can further exacerbate the difficulties faced by individuals during the transition from hospital to community (Fabbre et al., 2011). Given that the majority of health care systems are moving towards a model of care that favours earlier discharge to home and community care from hospital, it is imperative to understand how care providers can improve the continuity of care during this transition and make this process smoother for patients and their caregivers. A standard component of hospital discharge should be simple assessment of patients' post-discharge needs for food, equipment, transportation to future medical appointments (or arrangement for in-home appointments), and coordination of follow-up medical and social care services. Use of Naylor's (2012) transitional care model (TCM), piloted in the United States, is one of the ways to provide such services. This model recognizes the importance of providing support to patients and their caregivers post-discharge. Trained nurses assist patients and their family members with adjustment to community life and navigation through community services. This model provides one solution for addressing the needs of patients in community and reducing the chaos and difficulty of post-discharge recovery. Using Naylor's model or a similar intervention to assess patients' needs and implement services

Table 3: Policy recommendations

| Area of Concern | Barriers and Challenges | Facilitators for Transition |
|--|---|--|
| Preparing residence | <ul style="list-style-type: none"> • Living space needs to be rearranged • Patients may need to move in with their family members • Patients may lack food and other necessities upon discharge | <ul style="list-style-type: none"> • Home safety assessment • Coordination of discharge planning with family members • Assessment of the availability of the basic necessities at home |
| In-home services provision | <ul style="list-style-type: none"> • Transportation • Challenges with accessing services in different locations • Restricted mobility may prevent patients to continue care with their usual health care providers | <ul style="list-style-type: none"> • Regular visits from Nurse Practitioners • Medical testing at home • Availability of health care teams including physicians working with the patients at home |
| Ongoing management and coordination of care | <ul style="list-style-type: none"> • Difficulties in navigating a system • Multiple community services and care providers • Lack of continuity of care | <ul style="list-style-type: none"> • Case management approach • Coordination between and across different community services and health care providers • Consistent care providers |

to meet those needs, would be a key improvement strategy.

Note

1 One couple did not consent to recording the interview but did allow taking notes. These notes were transcribed and added to the dataset.

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