ORIGINAL RESEARCH

Patient Experiences of Transitioning From Hospital to Home: An Ethnographic Quality Improvement Project

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BACKGROUND: Little is known about patient perspectives of the transition from hospital to home.

OBJECTIVE: To develop a richly detailed, patient-centered view of patient and caregiver needs in the hospital-to-home transition.

DESIGN: An ethnographic approach including participant observation and in-depth, semi-structured video recorded interviews.

SETTING: Kaiser Permanente's Southern California, Colorado, and Hawaii regions.

PATIENTS: Twenty-four adult inpatients hospitalized for a range of acute and chronic conditions and characterized by variety in diagnoses, illness severity, planned or unplanned hospitalization, age, and ability to self manage.

RESULTS: During the hospital-to-home transition, patients and caregivers expressed or demonstrated experiences in 6 domains: 1) translating knowledge into safe, health-promoting

The transition from hospital to home is a complex event offering multiple provider-identified opportunities to improve healthcare quality.^{1–8} Centering care delivery around patient needs and preferences is both inherently valuable and linked with better outcomes.⁹

The Care Transitions Measure (CTM) identifies 4 domains of patient experience related to hospital discharge: information transfer, patient and caregiver preparation, self-management support, and empowerment to assert preferences.¹⁰ It discriminates between patients who do or do not experience a subsequent readmission or emergency room visit and between levels of care coordination.¹¹ Quality indicators like the CTM are important tools for systematic healthcare improvement, but they provide a limited understanding of patient experiences, which can drive the transformation of systems.^{12,13}

With the exception of patients with a few specific clinical conditions, relatively little is known about

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2012 Society of Hospital Medicine DOI 10.1002/jhm.1918 Published online in Wiley Online Library (Wileyonlinelibrary.com). actions at home; 2) inclusion of caregivers at every step of the transition process; 3) having readily available problem-solving resources; 4) feeling connected to and trusting providers; 5) transitioning from illness-defined experience to "normal" life; and 6) anticipating needs after discharge and making arrangements to meet them. The work of transitioning occurs for patients and caregivers in the hours and days after they return home and is fraught with challenges.

CONCLUSIONS: Reducing readmissions will remain challenging without a broadened understanding of the types of support and coaching patients need after discharge. We are piloting strategies such as risk stratification and tailoring of care, a specialized phone number for recently discharged patients, standardized same-day discharge summaries to primary care providers, medication reconciliation, follow-up phone calls, and scheduling appointments before discharge. *Journal of Hospital Medicine* 2012;7:382–387 © 2012 Society of Hospital Medicine

how adult patients perceive the hospital-to-home transition.^{14–17} They recall receiving discharge instructions but lack details about what to do if problems arise.¹⁸ They may lack important information despite receiving instruction.¹⁹ Caregivers report problems related to emotional support, discharge planning, and family participation,²⁰ and patients and caregivers express anxiety, confusion, a sense of abandonment by the healthcare system, and the perception that their preferences are disregarded.²¹

As part of ongoing quality improvement activities, we sought to develop a richly detailed, patientcentered view of the hospital-to-home transition. Our purpose was to understand patient and caregiver experiences during this pivotal healthcare experience.

METHODS

We used an applied ethnographic approach,²² conducting participant observation and video recording in-depth, semi-structured interviews in Kaiser Permanente Southern California, Colorado, and Hawaii. The United States' largest, private, not-for-profit integrated healthcare delivery system, Kaiser Permanente addresses all health needs for more than 8.9 million members.

To balance the pragmatic imperatives of quality improvement with obtaining enough information to understand patient experiences, we planned a sample

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Additional Supporting Information may be found in the online version of this article.

TABLE 1. Key Observations Related to Patient and Caregiver Experiences During the Transition From
Hospital to Home

Need	Key Observations
Translating knowledge into safe, health-promoting actions at home	Even when patients and caregivers believe they have all needed information before discharge, they often find later that they are lacking knowledge or cannot translate it into contextually appropriate actions.
	Patients and caregivers may inaccurately perceive that they have successfully translated knowledge into safe, health-promoting actions.
	The day of discharge may not be the optimal time for learning.
Inclusion of caregivers at every step of the transition process	Caregivers are integrally involved in the care for many patients.
	Discharge teaching does not optimally include caregivers.
Having readily available problem-solving resources	Questions normally arise after the transition home as patients and caregivers engage in ongoing care activities.
	Even patients and caregivers successfully providing care at home may need help interpreting experiences.
Feeling connected to and trusting providers	Patients and caregivers highly value a feeling of being connected to providers, typically in the context of ongoing relationships.
	Providers sometimes miss opportunities to connect with patients.
	Although investing in building connections with patients is time-consuming for providers, patients may disregard communication unless it occurs.
Transitioning from illness-defined experience to "normal" life	Patients and caregivers want to return to a sense of normal life as quickly as possible.
	This desire may interfere with the ability to absorb information and translate it, to prioritize healthcare needs,
	or to accurately assess the risk in a situation.
Anticipating needs at home and making arrangements to meet them	Patients and caregivers require many types of help, but some may have trouble reconciling the need for
	assistance with the desire to return to a normal life.
	Patients and caregivers find it stressful when needed arrangements have not been made.
	Some needed arrangements do not pertain strictly to healthcare (eg, help at home, meals).

of 24 patients across 3 settings with a mix of resource-intensive and less-intensive healthcare needs. We defined resource-intensive needs as occurring among patients aged 65 or older with 3 or more chronic conditions. We asked hospital staff to identify patients by level of need and variety in diagnoses and illness severity, planned or unplanned hospitalizations, age, and ability to self manage. Reasons for admission included joint replacement, acute appendicitis, chronic illness exacerbation, complications of cancer chemotherapy, and others. We included patients who were inpatients or discharged no more than 3 weeks before interview. We excluded those under the age of 18 or discharged to non-home settings. The project took place between September and November of 2008; 24 patients, half of whom were male, gave written informed consent for video recordings and authorization to distribute protected health information throughout and beyond Kaiser Permanente for quality improvement and educational purposes. Participants took part in interviews and observations lasting 1 to 3 hours; caregivers and family members participated in 9 instances.

Two or 3 observers attended each interview, which took place in the hospital on discharge day, at postdischarge appointments, or in patients' homes. Openended questions prompted broad-ranging inquiry into patients' lives, medical history, hospitalization experience, medications, care network, challenges, personal goals, and inner experience. Some questions were adapted and expanded from the CTM; others were prompts to demonstrate activities (eg, "Can you show us how you organize your medications?"). In addition to interviewing patients and caregivers, we observed interactions between patients, families, and hospital staff before discharge. We also observed patients and caregivers at home and when interacting with outpatient primary care providers. The purpose of observation was to understand the context of patient and caregiver experiences and to identify consistencies or discrepancies with their descriptions of experiences. (see Supporting Information "In-Home Interview Guide" in the online version of this article)

Data included field notes and video recordings. In addition, observers summarized their strongest daily impressions as brief "team stories" that were shared with the observation team, local operations staff, and Kaiser Permanente national subject matter experts.²³ Consistent with a grounded theory approach, interviews were professionally transcribed and qualitatively analyzed by multiple observers in iterative stages to develop broad domains of patient experiences.²⁴ We clustered similar experiences and identified exemplar statements and behaviors. Team stories were analyzed separately, using a similar process. We reviewed recorded interviews to refine our emerging understanding of patient and caregiver experiences and discussed our observations and impressions about each domain. To maximize internal validity, an independent researcher who did not attend the interviews reviewed the transcripts and coding and participated in final qualitative analysis. Institutional review board approval was not required for this quality improvement project.

RESULTS

Patients and caregivers expressed or demonstrated 6 domains of experience as they transitioned from hospital to home (Table 1).

Translating Knowledge Into Safe, Health-Promoting Actions at Home

A primary activity on discharge day was patient education provided by hospital staff. Topics included health conditions, medications, resources, activity, diet, equipment, supplies, and procedures. A nurse typically reviewed written instructions with the patient; the process ranged from thoughtful conversations to cursory recitation of printed information. Teaching was often sandwiched between other activities, and some staff members appeared pressured to complete it.

Patients and caregivers generally reported having all the information they needed; however, when we observed them at home, we noted that translating knowledge into safe, health-promoting actions was a separate step. A common example was medication management. Patients or caregivers often rewrote the discharge medication list, grouping medications by purpose or creating charts of when to take each one. Patients and caregivers developed varying and somewhat complex systems for home medication management. For example, 1 patient taking 16 medications filled five 7-day pillboxes each week; from these, he filled a tiny mug 5 times a day, placing it where it would remind him to take his medications. Patients interviewed about their medications at home often expressed uncertainty about their understanding of the medications and about how and why they were taking them.

When procedures were involved, such as dressing changes or administering intravenous (IV) solutions, in-hospital teaching didn't always translate smoothly into safe action at home. A man who learned to administer total parenteral nutrition in the hospital found his first at-home session unexpectedly challenging: "I just got home and was behind schedule hooking up to the machine. I'm thinking, 'Which (tube) goes where?' and getting real tired. I looked at the sheets. They have all the information you need, but it's too much for a tired person. I didn't want to read, and the pictures weren't clear, and I thought, 'I'll just try to remember what they said.'" (Patient #9)

We directly observed patients and caregivers failing to translate knowledge into safe, health-promoting actions at home. Two days after discharge following a total knee replacement, a patient navigated a flight of stairs with a walker. In another instance, a caregiver hung an IV on a coat hanger hooked precariously to a mailbox as children raced around the room. An older man described strengthening and mobility exercises as instructed by his physical therapist but didn't perform them. Their reasoning was often unclear. For instance, after a nurse reviewed a list of discharge medications and left the room, despite verbal agreement with the instructions, the patient commented: "Eight pills are too many. I'll take 3 today and 3 tomorrow and see how I feel." (Patient #27)

Inclusion of caregivers at Every Step of the Transition Process

After discharge, caregivers helped with or took responsibility for managing medications, wound care, administering intravenous antibiotics, adjusting diets, filling prescriptions, obtaining medical supplies and equipment, taking vital signs, interpreting signs and symptoms, monitoring health indicators, deciding who and when to call, and advocating for patients. When patients required hands-on care tasks, such as dressing changes or intravenous medications, caregivers typically received instruction from hospital staff before discharge.

However, in many cases, including caregivers in discharge teaching appeared to be a low priority. In several instances, caregivers were unable to speak directly with a physician before the patient's discharge: "I was hoping I could do that before she came home. I know it's hard to get hold of the doctors, but I wanted to know what to expect." (Caregiver #24)

Even when a caregiver was present, hospital staff frequently directed teaching exclusively toward the patient. For example, a nurse and patient sat side-byside to review instructions; the highly motivated caregiver, seated across the room due to lack of space, was unable to see the written material. The integral role of caregivers in helping patients at home contrasted with their often peripheral role in in-hospital transition processes.

Having Readily Available Problem-Solving Resources

Patients and caregivers needed to know who and when to call for more information. They needed to discriminate between providers (eg, when to call a cardiologist vs a primary care provider), identify who to call in an urgent or emergent situation, and know how to access various resources. Some questions arose because patients lacked sufficient detail about what to expect. Even patients who successfully translated knowledge into safe, health-promoting actions might need help interpreting observations: "The wound is closed on top but not underneath, and the WoundVac is supposed to be working on the cells. I'm using the same amount of foam as when I started, so is it really healing? Shouldn't we be using less foam? We don't have anyone to answer the questions." (Patient #22)

Many patients with chronic conditions had "direct" numbers to their physicians' office; some had important numbers for a doctor or pharmacy on speed-dial. Many patients and caregivers expressed a sense of pride at knowing how to navigate the healthcare system: "I've learned how to get to him. I call downtown, and then they call out to his office." (Patient #8)

Other patients and caregivers gave conflicting messages; they said they knew who to call but provided few specifics: "If he needed a nurse, I'd ask for the nurse assistant. I'll just do that or something." (Caregiver #20)

Feeling Connected to and Trusting Providers

For patients and caregivers, a critical aspect of communications with providers was a sense of connection, typically with a particular healthcare provider as part of an ongoing, trusting relationship. Patients expressed feeling respected, that their individual concerns and needs mattered, and that providers appreciated their emotional experiences, listened carefully without seeming rushed, and valued their knowledge. Successful experiences of connection were clearly meaningful to patients: "The most important thing is how genuine the doctor is as a person. I pick up on that right away. It bothers me when they're not all there. It amazes me that they have the intellectual prowess to be a doctor, but there are other components that are not quite there yet. My doctor, he's got it all." (Patient #9)

This sense of connection often contrasted with what they may have experienced during short-term relationships with providers in the hospital. In addition, providers sometimes overlooked opportunities to connect with patients. For instance, a clinic nurse, busy with intake, did not acknowledge a patient's repeated requests for help modifying his diet.

Transitioning From Illness-Defined Experience to "Normal" Life

Patients and caregivers described or demonstrated a variety of ways of leaving—or wanting to leave—the experience of illness behind, including feeling independent, useful, motivated, confident, and in control; helping others, including other patients in similar circumstances; feeling hopeful about recovery; and maintaining a sense of perspective.

This desire to get back to normal life affected the amount of information patients and caregivers absorbed on discharge day: "I was so anxious to leave. I was like, 'Yeah, yeah, let's do this. I'm all packed. I've got one foot out the door.' At home, I got ready to take my medication; the discharge instructions didn't jibe with what the doctor wrote. It was as much my fault as anyone's, because I was rushing to get home." (Patient #16)

Resuming usual activities, sleeping in one's own bed, eating familiar foods, being among friends and neighbors, and intentionally limiting the impact of a health condition on activities were all attempts to quickly restore a sense of normal life. Any milestone on the path to recovery seemed to help: "I was so ecstatic in the car coming home. We were back on the road of real life." (Patient #22)

In some instances, the drive to feel a sense of normal life outweighed physical needs. For instance, a young woman with cancer delayed notifying her physician that she had cellulitis because she didn't want to interrupt her usual activities. After several days, she was taken to the emergency room by ambulance and admitted for IV antibiotics.

Anticipating Needs at Home and Making Arrangements to Meet Them

Patients and caregivers anticipated a variety of postdischarge needs. These included hands-on healthcare tasks, grocery shopping, food preparation, and the like, as well as household maintenance, assistance with pets, and other daily activities that were unrelated to healthcare: "I can't do it by myself. I can't just jump in the car and drive. So there are things that you need other people to help you with to get through the day." (Patient #9)

However many patients described a network of support including family members, neighbors, friends, clergy, and others. More than 1 helper was often required. However, patients sometimes found it difficult to reconcile the desire to return to normal life with needs for help. For example, an older woman refused a home health nursing visit for congestive heart failure because she felt it encroached on her independence. The same desire to return to normal life led patients to overestimate their ability to function independently. After a several-day hospital stay for back surgery, a patient asked a friend to drop him off at home. He then used his walker to get to his car to retrieve a cart for his belongings. He pushed the walker with 1 hand and dragged the cart behind him up 2 floors to his apartment. Once inside, he went to bed, exhausted. In addition, it was sometimes difficult for patients to accurately anticipate needs. For example, a man who returned home alone after surgery suddenly realized his bed was much lower than the hospital bed; he wasn't sure he could get out of it without help.

Transportation home from the hospital and to outpatient appointments after discharge was a frequently identified need, leaving patients making hasty and suboptimal arrangements for a ride home, worried about keeping scheduled appointments, or both.

Patients and caregivers found it stressful when arrangements had not been made: "First, we have to worry about getting home, and then I have to go to the medical supply store. What if she has to use the restroom? She has to wait until I get back." (Caregiver #8)

Patients and caregivers described experiences of making arrangements that were largely successful; however, they were also often time-consuming.

DISCUSSION

Using an ethnographic approach, we identified 6 domains of patient and caregiver experience during the hospital-to-home transition. Many needs in these domains arose in the hours and days after patients returned home, and patients and caregivers often found it challenging to meet them. Our project adds a detailed, patient-centered perspective on the transition from hospital to home.

The domains we identified share some conceptual territory with the dimensions of the Care Transition Measure and the Transitional Care Model,²⁵ but generate a more detailed understanding of patient and caregiver experiences. Key findings include the fact that patients can find it challenging to translate knowledge into contextually appropriate action at home. This confirms some published results. For

instance, estimates of outpatient adherence to complicated regimens range from 5% to 77%.26-29 Significant opportunities exist to improve the reliability of translating medication instructions into systems that work at home,³⁰ including aligning medication lists with physical aids (such as weekly pill boxes) and explaining medications in patient-friendly terms. We also found that same-day discharge teaching can be ineffective because patients are anxious to leave the hospital or staff members feel rushed. Emotion can interfere with cognition, and transferring information shortly before hospital discharge may overlook learning readiness, a fundamental principle of patient education.^{31,32} In addition, the desire to return to normal life, coupled with uncertainty about who to call for clarification, can lead patients to simply do the best they can with whatever information they recall.

The literature refers to "handoffs" of patients from one provider to another as an episode of care is completed, but our findings suggest patients perceive hospitalization as an event occurring within ongoing relationships with the healthcare providers to whom they feel most connected.^{33,34} Some patient and caregiver needs could be addressed by actively supporting these relationships during the hospital-to-home transition: explicitly acknowledging their importance to patients, ensuring that providers have discharge information, and framing discharge as a transition back to the care of trusted providers. Some of our findings require system-level changes. Patients and caregivers with unmet transportation needs expressed anxiety about how or if help would materialize. Partnerships with community organizations could enable healthcare organizations to address needs like transportation that fall outside traditional discharge activities but significantly impact patient experiences. In addition, healthcare organizations are rarely designed for straightforward navigation; patient-centered organizational designs could eliminate the need for patients and caregivers to learn how to navigate. For instance, a single point of contact for recently discharged patients might improve the process of finding help.

Strengths of our quality improvement project include the range of patients we interviewed and in-depth observations and interviews across settings. Ethnography is ideal for generating a rich understanding of patient experiences, allowing us to observe needs patients did not mention, as well as the physical and emotional context of the transition. Weaknesses of our approach include the fact that the experiences reflected in each category were determined, to some extent, by the questions we asked. This may have constrained the variety of experiences patients reported. In addition, Kaiser Permanente's integrated nature may have affected our findings, although we believe patients and caregivers reported experiences that are likely universal.

Our project occurred in a healthcare system with an integrated electronic health record (EHR). Interventions

to improve provider-identified gaps in the discharge process often rely on information technology.^{35–43} However, information technology does not eliminate continuity of care issues.⁴⁴ Our EHR is widely used, but available information did not consistently ensure strong enough care coordination or good communication.

Including the patient's primary caregiver in discharge teaching appeared to be a relatively low priority for hospital staff, unless there was a hands-on care task. Even when a primary caregiver was present, hospital staff frequently directed teaching exclusively toward the patient. The extent to which caregivers feel adequately prepared for their roles and responsibilities needs further exploration.

CONCLUSION

Our applied ethnographic approach reveals that patients experience several challenges while transitioning from hospital to home. Reducing readmissions is likely to remain challenging unless we broaden our understanding of the types of support and coaching required. We are translating our findings into quality improvement activities, conducting pilot projects focusing on risk stratification and tailoring of care, a specialized phone number for recently discharged patients, standardized same-day discharge summaries to primary care providers, medication reconciliation, follow-up phone calls, and scheduling appointments before discharge.

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