

**Understanding Rehospitalization Risk:
Can the Hospital Discharge be Modified to Impact Recurrent Hospitalization**

Running title: Rehospitalization risk and the discharge process

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Journal of Hospital Medicine. In Press.

ABSTRACT

Background: High rates of unnecessary rehospitalizations have been shown to be related to poorly managed discharge processes.

Objective: A qualitative study was conducted in order to understand the phenomenon of frequent rehospitalization from the perspective of the discharged patients and to determine if activities at the time of discharge could be designed to reduce adverse events and rehospitalizations.

Design: Semi-structured open-ended interviews were conducted with 21 patients during their hospital stay at Boston Medical Center. Interviews assessed continuity of care after discharge, need for and availability of social support, and ability to obtain follow-up medical care.

Results: Difficult life circumstances posed a greater barrier to recuperation than lack of medical knowledge. All participants were able to describe their medical condition, the reasons they were admitted to the hospital and the discharge instructions they received. All reported the types of medications being taken, or the conditions for which medications were prescribed. Recuperation was compromised by factors that contribute to undermining patient's ability to follow their doctor's recommendations including support for medical and basic needs, substance use, and limitations in the availability of transportation to medical appointments. Distress, particularly depression, further contributes to poor health and undermines the ability to follow doctors' recommendations and the discharge plan.

Conclusions: Discharge interventions that assess the need for social support and provide access and services have the potential to reduce chronic rehospitalization.

INTRODUCTION

The Institute of Medicine (IOM) reports^{1,2} have estimated that the number of deaths due to iatrogenic errors of omission and commission in hospitals is between 44,000 and 98,000 per year. More people die in a year from medical errors than from car accidents (43,458), breast cancer (42,297) or AIDS (16,515).³ The IOM report recommended a goal of 50 percent error reduction over the next five years.⁴ Since publication of these reports, a great deal of interest has been focused on how to make our hospitals safer.^{5,6} Times of transitions in care (e.g. from home to hospital, from emergency department to hospital, from the intensive care unit to the general ward) have been identified as opportune times to improve continuity and thus to decrease errors.

The hospital discharge process is often non-standardized and frequently marked with poor quality.⁷ One in five hospital discharges are complicated by adverse events within 30 days, many of which lead to visits to emergency departments (ED's) and rehospitalizations.^{8,9,10} Nationally, approximately 25 percent of hospitalized patients are readmitted within 90 days, often because of errors resulting from the discontinuity and fragmentation of care at discharge that exposes patients to iatrogenic risk and raises costs.^{11,12} Low health literacy rates, lack of coordination in the 'hand-off' from the hospital to community care, gaps in social supports, and the absence of physician follow-up after discharge limitations place patients at high risk of rehospitalization.^{13,14,15} Increasingly, as hospitalists provide more inpatient care, it is difficult for PCPs to be aware of all the complexities of a hospitalization.¹⁶

Studying the hospital discharge process provides an opportunity to learn more about its complexities¹⁷ that could then be used to standardize the process and focus on those interventions that reduce medical errors and the resulting adverse events. However, to date, few studies describe the essential components of the discharge process and there are no studies that focus on the discharge process from the point of view of the hospitalized patient. Therefore, a qualitative study was conducted in order to understand the phenomenon of frequent rehospitalization from the perspective of the discharged patient and to determine if activities at the time of discharge could be designed to reduce adverse events and rehospitalizations.

METHODS

The larger study of which this work is a part examined the transition from the inpatient service at a large inner-city hospital to community care in order to inform the development of an intervention to improve the discharge process. Qualitative research stresses the socially constructed nature of reality and qualitative researchers seek to answer questions that stress how social experience is created and given meaning.¹⁸

Qualitative interviewing permits the researcher to understand the world as seen by the respondent within the context of the respondent's everyday life.¹⁹ Learning from the experiences of patients hospitalized more than once in a six month period will help to identify their perceptions and beliefs about their disease and discharge instructions and inform additional interventions that could prevent rehospitalization.

Sample: Semi-structured open-ended interviews were conducted with 21 patients during their hospital stay at Boston Medical Center. In order to be eligible for the study, a patient had to receive medical care through a health center affiliated with Boston Health Net, a

network of community health centers serving primarily low-income patients, and had to have been hospitalized on at least one additional occasion in the previous six-months. Each day during the interview period the Boston Health Net Nurse identified all patients admitted within six months and contacted the interviewer with their names and room numbers. The interviewer (MS) approached potential participants in their hospital rooms and obtained informed consent at the time of the interview. If the patient agreed, the interview was conducted at that time. If the patient was not available at that time the interviewer made at least two attempts to visit the patient at a convenient time. The interviews were conducted over a four month period on 17 different days with no more than two interviews completed on any one day. The participants ranged in age from 18 to 79; 10 respondents were male, 11 were female. All were English speaking. The mean age of the 20 patients who provided demographic information was 45.55 and the median age was 47. Participants' self-reported racial or ethnic identities included nine White (five males, three female), three Black (two males, one female) four African-American (one male, three female); one Latina; one Hispanic (male), one Spanish (male), one mixed (female). One male and one female provided no race or ethnic identity. Two participants were excluded from the study because they did not speak English and two were excluded because they were unable to speak due to their medical conditions. Interviews were audio taped, but no full names were used on the tape. Only subject code numbers were used to identify respondents. The discharge records of each participant were reviewed for consistency with participant's descriptions of their condition. The study was approved by the Institutional Review Board of Boston University Medical Center.

Interview Guide: To help assure collection of comparable qualitative data, an interview guide listed specific questions and topics to be covered in a particular order in the interview. Questions were drawn in part from a pilot test of interviewing of patients on the inpatient service re-hospitalized within 90 days of a prior admission.¹⁷

Interviews assessed continuity of care after discharge, need for and availability of social support, and the participant's ability to obtain follow-up medical care. The interview script consisted of open-ended questions concerning events leading up to the current hospitalization, previous hospitalizations, the instructions they received the last time they were discharged, home situation, ability to attend medical appointments, and participant feedback on the discharge process. Follow-up questions were asked based on each subject's responses to the questions on the interview script. Interviews lasted between 20 and 45 minutes.

Analysis: The interview tapes were transcribed by a transcription subcontractor and the transcriptions were checked for accuracy by the interviewer. Each interview was evaluated by a set of thematic codes developed by two qualitative researchers (LS and MS). Codes represent a category or theme found in the data and the codes were put directly into the text by attaching to segments of text. To improve inter-rater reliability of coding, the two qualitative researchers coded three interviews, reviewed the codes and once it was clear that they both understood the coding scheme they coded the interviews. They resolved any problem cases and checked each other's work throughout the coding process to ensure that each interview was coded correctly. The findings were analyzed to explore whether or not linkages exist between and/or among particular themes.

Patients' discharge records were reviewed to compare discharge notes about patient's condition with the patient's description of their condition and treatment.

RESULTS

All the patients who participated in this study were able to describe their medical condition and the reasons they were admitted to the hospital. All participants were rehospitalized for the same primary diagnosis. The range of the previous hospitalization for 20 participants was 5-6 months (five participants - four diabetes control, one lupus erythematosis flare); 6 weeks-2 months (four participants - fall, seizures, hypertension, SOB), 3 weeks-1 month (eight participants – two kidney disease, two seizures, COPD, , sickle cell, PVD, alcoholic gastritis), and 1-2 weeks (three participants – abdominal pain, alcohol intoxication, lower GI bleed). The principal diagnosis in the discharge records matched that of the participant's description. Participants also described the discharge instructions they received. Although some did not report the "brand name" of medications they were taking, all reports of the types of medications being taken, or the conditions for which medications were prescribed, were consistent with discharge summaries. Although none of the participants incorrectly reported a medication or condition to the interviewer, a few did not provide information of every medication or condition. In one case the discharge summary noted medications for bipolar disorder and mental illness; in two cases medications were prescribed for depression. One patient, hospitalized with cirrhosis of the liver, talked about "stress and depression" but nothing was written about these issues in the discharge record.

For participants in this study, difficult life circumstances posed a greater barrier to recuperation than lack of medical knowledge. The interviews in this study illustrate the personal and social impact of disease that resulted in rehospitalization.

Discharge and Medical Knowledge

During discharge, transition care processes can fail at many points.²⁰ These include communication of the care plan, reconciliation of current and initial medication regimens, transportation of the patient, follow-up care with a provider, and preparation of patient and caregiver for maintaining the patient's regimen.^{20, 21, 4, 22} Participants in this study identified some of these factors, and additional factors, as constituting barriers to effective care transitions.

At discharge, seven participants were advised by physicians to change their diets or refrain from tobacco or alcohol use. Participants clearly understood the instructions and could give detailed accounts of diet changes they were supposed to make or explain the reasons tobacco or alcohol use caused or exacerbated their diseases. A diabetic whose discharge instructions included diet change listed *"Sweet ones, starchy ones... with a lot of carbohydrates"* as foods she is not supposed to eat while others described the links between alcohol use and adverse health, *"In my mind, I think that alcohol is a way out... But I know that it, that it's not...And so, the pancreatitis develops."*

Lack of understanding about their medical condition or knowledge about procedures to be followed were not evident in this population. Instead, recuperation was compromised by factors such as distress, substance use, support for medical and basic needs, and limitations in the availability of transportation to medical appointments.

Many participants reported not receiving necessary rest as a result of needing to work or care for young children.

Crises and Coping: Distress

Despite understanding of needed behavior changes, almost half of the participants explained how difficult life circumstances and gaps in ongoing care or support made it impossible for them to follow medical advice.

Almost half of the participants described themselves as being stressed, sad or depressed. Their explanations indicate a relationship between distress and subsequent behaviors that exacerbated their conditions.

Among three self-described alcoholics, one, a 52 year old white male re-hospitalized for alcohol related seizures, had relapsed after the deaths of both his mother and girlfriend. He explained, “Well, after my girlfriend died, I really started to hit the bottle.” Another, an unemployed 45 year old Black American female with chronic pancreatitis, lacked stable housing and at the time of the interview lived with a heavy drinker. She said that, “When I get stressed out, the first thing I want to do is go run to the [liquor] store.” And a third, a 62 year old white male with cirrhosis of the liver, reported drinking because of lack of regular treatment for chronic depression:

My problem is has to do with stress and depression, which is what I'm gonna try to deal with this time. 'Cause that's... contributed to me getting so depressed I just... just started drinking again. I just... next time it'll kill me. So. That's almost... a kind of a suicide wish, I guess. ... I know it's gonna kill me if I keep drinking... I think I need to get into something. But... there's... I don't know if you call it "substance abuse," but... I think it's

related to... deep depression, which is not necessarily substance abuse, but it can... I'm sure there's some relationship.

Similarly, the experiences of participants with diabetes illustrated clearly how depression contributes to undermining their ability to follow their doctor's recommendations. One, an 18 year old African American teenager re-hospitalized for diabetes control discussed her inability to maintain her physician recommended diet:

Like when I'm stressed out.... I get depressed and, um... I give up. Just don't wanna do it anymore. It's not I don't want to, I can't. I just can't do it... I, when I got home, I actually did good! I actually really did good. I was eating salads. I did go on a diet. I ate salads, grilled food, and things like that. I took my medicine. I started loggin', like writin' everything down in a book. I wrote down what I ate every day, what my blood sugar was, and how much medicine I took. I was doin' good. But then, I got depressed, and I stopped doin' it.

Continuity of Condition Management

Participants expressed a need for help at home after discharge although, in most cases, the help they reported needing did not require medical knowledge or technical skills.

Skilled care

Few participants reported needing and receiving visiting nurse services and even in these cases, some of the responsibility for care fell to family members. Lacking sufficient access to visiting nurse services or other needed support, their health suffered. A 42 year old Latina diabetic participant with kidney infection described a visiting nurse's unsuccessful attempt to teach her husband how to change the catheter:

They try to show, 'cause before? I don't got the catheter, they're comin' in my house, in the morning? You know, put the catheter into my bladder, and they come back before me go to sleep, they try to show my husband how to do it, but he can't (chuckles light), you know, he can't...So, the... the doctor decide to leave the catheter there.

Basic need care

The post-hospital assistance needed did not require medical expertise. During the time after their last hospitalization most participants needed assistance with daily chores such as cleaning, cooking, child care, and driving and turned to friends and family members to meet these needs. During recuperation, no family member was capable of providing full-time care, and, as a result some participants were unable to follow physician advice about resisting or refraining from certain activities. A 67 year old African American male, whose foot ulcers kept him from walking, explained about his

recuperation during which he had to stay in the same place for eight hours while his brother worked:

Oh, maybe if I had to go to the bathroom or something, I can't... but for the most part, I guess I had things set up... where I didn't, you know, where I didn't move... I just set my things up to keep me from movin' all day. I'd set my food up and everything else, little sandwich and all that. So, there wasn't anything about... you know, worrying about movin'... or, getting hungry, I guess.

None of the participants were able to pay for support services such as house cleaning or in-home care, and in all cases relied on busy friends and family members to meet their needs.

The experiences of three single mothers with health conditions characterized by debilitating chronic pain illustrated how very different access to supportive family members impacted their ability to seek care and follow medical instructions as well as how child care responsibilities compromised their recuperation. One, a 20 year old African American young woman hospitalized for polycystic kidney disease described situations during which the intensity of the pain did not permit her to do basic household chores. At those times she relied on her five-year-old son:

He... he actually knows how to sweep, he knows how to wash dishes. At five and a half, he surprised me, but... (Chuckles)... he can wash dishes, so. He has to get up on a chair, but he can wash 'em.

As a result of needing more care than was available, she traveled south to stay with her mother who was unable to leave work to come to Boston:

I took the bus, because my son has sickle cell trait, so, they told me from day one it's not really good for him to fly on a plane? So, I had to take him... it took like twenty hours... you know, stoppin' here, stoppin' there, like, pullin' my bags and stuff, so it put me in more pain than I was in. (213)

Another, a 24 year old of "mixed" background chronically hospitalized with sickle cell pain crises, delayed medical treatment because of lack of childcare:

There's been times that I have had to wait till I could find somebody to watch my kids, to even come to the hospital... There's been times that... uh, it'd be awhile before I could get anybody, so instead of me coming to the hospital, I have to wait at home, in a lot of pain... I would have to wait... any time between five hours to two days before I could find somebody to watch my kids. (N13)

This pattern of child care interfering with recovery continued after leaving the hospital:

The minute I get home it'd be nice to have somebody to watch the kids, so I could at least recuperate for like twenty-four hours before I have to take care of things... I would have to usually just go home and just get right to it.

The experience of a third, a 29 year old African American woman with systemic lupus erythematosus, illustrates the ways in which family support can ease the burden of illness. The participant relocated in order to be close to her mother, aunt and cousins, all of whom cared for her children when she is in the hospital:

When I was in [neighboring state] it was terrible... 'cause my, my kids wasn't goin' to school, 'cause I couldn't get up to get them dressed and wake them up. My daughter almost got kept back, and stuff. It was real hard... and it wasn't good, you know, that they could just... run through the house rampant, do whatever they want, and not be

supervised... So that was very dangerous, too. And then, it put like, it put a stain on my oldest, my daughter...

She contrasted this with her current situation in which family members cared for her children when she is in the hospital or sick at home:

Like, this morning... they took the kids to school for me and everything. Made 'em breakfast, made sure they was dressed right this morning...My mother picked them up from school this afternoon.

Transportation to appointments

Travel to follow-up appointments was difficult for many of the participants.

Almost half reported taking public transportation to appointments and others either drove themselves, were driven by relatives or friends or paid for taxis. Those relying on public transportation were more likely than others to miss appointments because of transportation issues if they did not feel well:

Depending how I feel. If I feel all right, I'll take the bus; if not, I'll get a taxi or I'll just won't show up.

I would borrow a bus pass or somethin', you know,. from -- his name

is Joe ... because I would make like evening appointments.

Um, because my sickle cell tends to act up if it's cold..So, if it's really cold, I don't go.

As one 55 year old white female who has seizures summed up the matter of traveling by bus when not feeling well, "you do what you have to do!"

CONCLUSION/DISCUSSION

The hospital discharge process has been identified as a time when sources of error occur that result in rehospitalization. A multiplicity of factors adversely affecting care transitions apply to the hospital discharge process including the preparation of the patient and caregiver, communication of the care plan, changes in the medication regimen, transportation of the patient, scheduling of follow-up care and the availability of advance care directives.²⁰ Patients with low socio-economic status have been found to be especially vulnerable after discharge. A 1989 telephone survey of 6,455 patients recently discharged from hospitals in the US found that low socioeconomic status and poor patient health were independent predictors of patient problem scores after discharge. A nationwide telephone survey of 1,800 recently discharged patients and their care partners also revealed that low socioeconomic status and poor patient health status were associated with care partner problem scores.²³

High rates of unnecessary rehospitalizations have been shown to be related to poorly managed discharge processes. Although some factors identified in other studies of care transition did influence the rehospitalization of participants in this study, others did not. Transportation and follow-up care greatly effected rehospitalization while health literacy had a minimal effect. Fifteen of 20 participants were readmitted within a period of weeks to two months for the same primary diagnosis but understood their medical conditions and knew the procedures to be followed. Having a chronic illness may have impacted their understanding of their disease because they had received teaching over time. However for the majority of participants in this study -- inner-city, minority, low income patients -- there are factors beyond the discharge process that impact their

rehospitalization. Difficult life circumstances and gaps in ongoing care or support resulted in distress and behavior that exacerbated their conditions. Participants lacked social and emotional support that would have enabled them to prioritize maintaining their health.

Although the concept of social support lacks a universally accepted definition, it is generally understood as involving emotional connection and caring²⁴ and occurring in a relationship in which the person providing the support is equipped to respond to a wide variety of needs—ranging from practical assistance to counseling and encouragement—based on the concerns or life circumstances of the patient. Qualitative studies of social support interventions demonstrate the ways in which having a dependable person to whom a patient can turn for encouragement, information, and practical assistance improves his/her ability to maintain health regimens and manage chronic pain. An intervention in which nurses made weekly telephone contact with low-income pregnant smokers helped them manage numerous stressors, and in some cases reduce their tobacco use²⁵ and a support group for women with chronic pain helped participants learn practical strategies for reducing pain and reduced isolation and emotional distress about their conditions.²⁶ A study of consumer experiences of transition care²⁷ found that the most valued institutions were those in which providers from one facility thoroughly communicated a patient’s medical and treatment history to providers they encountered in another. Also important was involving the consumer in medical decision making, preparing the consumer to actively participate in his/her own care, and attending to individual needs and preferences.

There are a number of limitations to the study including reliance on participants' reports of their conditions and experiences with medical staff at a time when they were rehospitalized. In the vulnerable position of being hospitalized, participants may have been reluctant to have complaints about the hospital experiences tape recorded. All participants reported positive experiences with hospital staff during the formal interview. In two cases two participants reported negative experiences with hospital staff after the audio recorder was turned off and the interview concluded,. Other limitations about the hospital setting include limited privacy. Either a roommate was present during the interview or the interview was interrupted by a visit from a hospital staff person or a telephone call. Participants were asked to recall events that for some occurred several months before the interview thus introducing the possibility of inaccurate recall of events.

To address these limitations we compared interview transcripts to discharge summaries in order to assess any inconsistencies that may have resulted from this lack of privacy. The differences between summaries and patient reports were two participants not reporting illicit substance use and two not reporting psychiatric conditions. Despite these limitations, conducting this study in a hospital setting allowed investigators access to a highly vulnerable population that would be most impacted by improvements in the discharge process. Given the difficulties many participants reported in getting to appointments it is unlikely that a study conducted outside the hospital setting would have effectively reached this population.

These results support the findings in this study that life circumstances outside the hospital can be as important to recovery as institutional coordination of medical care. Although the stresses described by the low-income patients in this study may not directly

cause subsequent illness, their experiences clearly demonstrate the ways in which stresses make it difficult or impossible to attain sufficient rest to heal, maintain behavior change necessary to improve health, and follow instructions given by clinicians at the time of discharge. Interventions targeting low-income patients are thus more likely to succeed if they include provision of social support and assist patients in easing the burden of daily responsibilities. Effective transition care includes support that may not be explicitly medical, but without which participants lack the stability to fully recuperate. Without the possibility of taking a break from household or parenting responsibilities it is difficult to rest enough to truly recover. The descriptions of extreme measures taken in order to obtain needed support illustrate how recuperation was compromised both by family responsibilities and lack of flexibility in caregiver work schedules. Distress, particularly depression, further contributed to poor health and undermined the ability to follow doctors' recommendations and the discharge plan.

Discharge interventions that explicitly assess requirements for social support needs and connect patients with agencies or volunteer groups that, for example, call or visit people recuperating from illnesses, provide meals on wheels, or offer other services such as light cleaning or shopping have the potential to address the complexities of life circumstances that result in poor health and chronic rehospitalization. This study has identified the crucial role social support plays in getting and staying well.

ACKNOWLEDGMENTS

This project was supported by grant numbers 1UC1HS014289-01 and 1U18HS015905-01 from the Agency for Healthcare Research and Quality (Dr. Jack). The authors thank Maria Rizzo DePaoli MSW and Cornelia Walsh RN for assistance with logistics of the study. .

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