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Hospital Self-Discharge Among Adults with Sickle Cell Disease: Associations with Trust and Interpersonal Experiences with Care

Carlton Haywood Jr., PhD, MA^{1,2}, Sophie Lanzkron, MD, MHS¹, Neda Ratanawongsa, MD, MPH³, Shawn M. Bediako, PhD⁴, Lakshmi Lattimer-Nelson, MD¹, and Mary Catherine Beach, MD, MPH^{1,2}

¹ The Johns Hopkins University School of Medicine, Baltimore, MD

² The Johns Hopkins Berman Institute of Bioethics, Baltimore, MD

³ The University of California, San Francisco

⁴ University of Maryland, Baltimore County, Baltimore, MD

Abstract

BACKGROUND—Patient self-discharge from hospitals has been associated with a number of negative clinical outcomes. Research suggests that low patient trust and poor quality interpersonal experiences with care may be associated with hospital self-discharge. Although adults with sickle cell disease (SCD) often report poorer quality healthcare experiences, research examining hospital self-discharge and its associations with both patient trust and quality of healthcare experiences is lacking for this patient population.

OBJECTIVE—To examine the association of interpersonal experiences with care and trust in the medical profession with hospital self-discharge history among patients with SCD.

DESIGN—Cross-sectional study.

SETTING—A large, urban academic medical center.

PATIENTS—Adults (age 18+) with SCD seeking outpatient or inpatient care.

MEASUREMENTS—We compared patient characteristics, patient perceptions of the quality of interpersonal experiences with care, and levels of trust between patients with and without a history of hospital self-discharge.

RESULTS—Adjusted analyses indicated that having a history of hospital self-discharge was associated with more negative interpersonal experiences and lower levels of trust.

CONCLUSIONS—Hospital self-discharge may be an important indicator of the quality of care received by adults with SCD. Further research is needed to better understand this phenomenon so that effective interventions can be designed to prevent its occurrence.

Keywords

Trust; Healthcare Quality; Sickle Cell Disease; Hospital Self-Discharge

Introduction

Patients who leave a hospital against medical advice (AMA) have increased risks of negative clinical outcomes. Leaving a hospital AMA has been associated with increased risks of emergency department and hospital readmission, longer lengths of stay upon hospital readmission, increased risk of morbidities, and increased mortality.^{1–3} Ibrahim et al. estimated that 1.44% of all hospitalizations for adults in the U.S. end with the patient leaving AMA.⁴ Prior research, however, has shown that specific patient populations may experience greater AMA discharge rates, as up to 4.9% of asthma-related hospitalizations,² 13% of HIV-related hospitalizations,¹ and 30% of psychiatric-related hospitalizations have been shown to end with the patient leaving AMA.⁵

A small body of research examines the reasons that patients leave AMA. In prior studies, dissatisfaction with care and conflicts with medical staff were among the most commonly cited reasons given by patients.^{2,6} In a study of healthcare provider reflections on recent patients who left AMA, providers identified patient mistrust, suboptimal physician-patient communication, and physician-patient conflict as important contributors to the patient leaving AMA.⁷

Sickle cell disease (SCD) is a painful genetic condition which in the U.S. affects mostly African-Americans and leads to frequent hospital utilization. Patients with SCD frequently report having poor quality interpersonal relations with healthcare providers when the patient seeks treatment for his or her pain.⁸ Patients often report that their healthcare providers do not believe the patient's reports of pain, providers do not involve the patient to his or her satisfaction in setting the course of care, and providers typically stigmatize the patient as having a substance abuse problem.^{8–17} Indeed, a recent systematic review has shown that there is a high level of evidence that negative healthcare provider attitudes serve as a barrier to appropriate pain management in SCD.¹⁸

To our knowledge, the only study to date of hospital self-discharge history among adults with SCD was conducted in the United Kingdom by Elander et al. These investigators found that 14% of their sample of patients reported ever having discharged themselves from a hospital.¹⁹ The most common reasons for this behavior given by these patients were that they grew tired of waiting for relief of their pain, there were other conflicts that occurred on the medical ward, and because they just simply wanted to go home.

Given the interpersonal conflicts and poor quality pain management often found in SCD care, additional examinations of hospital self-discharge in this population are warranted. We hypothesized that SCD patient reports of interpersonal conflict during previous healthcare encounters would have an independent association with the likelihood of the patient having ever self-discharged from a hospital. We also hypothesized that there would be an independent association between a patient's level of trust in the medical profession and their self-discharge history. The aim of this study was to test these hypotheses.

Methods

Study Design, Setting and Sample

We conducted a cross-sectional study of patients with SCD seeking care at a Mid-Atlantic, urban academic medical center, from September 2006 to June 2007. Eligible patients were adults aged 18 years or older with any sickle cell hemoglobinopathy (HbSS, HbSC, HbS/ α -thalassemia, or HbS/ β -thalassemia) who were seen at the medical center during the study period.

Data Collection Procedures

Eligible patients were recruited from the adult sickle cell and hematology outpatient clinics, the Emergency Department, the inpatient units, or within 5 days after discharge from an acute hospital visit. We collected data by patient interview and medical record abstraction. The interview assessed demographic characteristics (e.g., age, sex, educational attainment), patient-reported annual hospital utilization for pain, previous interpersonal healthcare experiences, and trust toward the medical profession. A trained interviewer conducted the patient interview, which lasted approximately 15 minutes. Patients received \$10 for completion of the interview. We abstracted from the patient's medical record their hemoglobinopathy type, their previous complications from SCD, and the presence of other comorbidities. The academic medical center's institutional review board reviewed and approved the study procedures. All participating patients gave informed consent.

Measures

Patient History of Hospital Self-Discharge—A patient's history of hospital self-discharge, the dependent variable, was assessed using a single, dichotomous (yes/no) item developed by Elander et al.¹⁹ which asks "Have you ever discharged yourself from a hospital, or left suddenly or unexpectedly?"

Previous Interpersonal Healthcare Experiences—Previous interpersonal healthcare experiences were assessed using a single, dichotomous (yes/no) item developed by Elander et al.¹⁹ which asks the patient to report whether or not they have ever had difficulty persuading medical staff about their sickle cell pain.

Trust in the Medical Profession—A patient's level of trust in the medical profession was assessed using the previously validated 5-item Wake Forest Trust in the Medical Profession scale.²⁰ There is evidence for the construct validity of this unidimensional scale through its positive associations with trust in a specific physician, general satisfaction with care, and following a doctor's recommendation, and its negative association with having had a prior dispute with a physician, having sought a second opinion, or having changed physicians. This measure uses 5-point Likert scaling (strongly disagree to strongly agree) to assess patient agreement with the following statements: 1) Sometimes doctors care more about what is convenient for them than about their patient's medical needs (reverse coded), 2) Doctors are extremely thorough and careful, 3) You completely trust doctors' decisions about which treatments are best, 4) A doctor would never mislead you about anything, and 5) All in all, you trust doctors completely. Scores on each of the items were summed to form a composite score, and then transformed onto a 0 to 100 scale. Higher scores indicated greater levels of trust toward the medical profession. The factorial validity of this measure in the current study was assessed using confirmatory factor analyses (data not shown) which supported the unidimensionality of the measure in our sample. This measure demonstrated good internal consistency in the current sample with a Cronbach's alpha of 0.80.

Covariates—We assessed a number of additional characteristics that could confound the relationship between previous interpersonal healthcare experiences, trust, and patient history of hospital self-discharge. We assessed demographic variables for patient age (continuous), sex, education (high school education or less vs. greater than a high school education), and annual household income (<\$10,000, \$10,000 to \$35,000, and \$35,000+). We used a categorical variable which examined the patient's self-report of their annual hospital utilization for treatment of vaso-occlusive crises (VOC) (≤ 3 per year vs. $3+$ per year). We assessed the patient's clinical characteristics (hemoglobinopathy type, and histories of acute chest syndrome, pulmonary hypertension, avascular necrosis, renal complications, hypertension, and hepatitis C). We also used an indicator variable to identify patients who

possessed a positive urine toxicology screen for cocaine or marijuana use upon a hospital admission at any time within the previous 5 years of the patient interview. We restricted the toxicology screen results to these two substances alone as the standard therapeutic regimen for pain relief for many patients in this population could lead to a positive toxicology screen for opioids. Finally, we included a categorical variable to represent whether or not the patient's interview occurred in the outpatient or inpatient setting to assess the potential that interview setting might be associated with hospital reported self-discharge history.

Analytic Methods

We restricted all analyses to those patient records that had complete data on all of the variables of interest. Bivariate relationships between the primary independent variables, the covariates, and the dependent variable were examined using t-tests and chi-square tests as appropriate. Due to sample size considerations, only variables related to the dependent variable at a p-value of ≤ 0.20 were retained for inclusion in subsequent regression models. We used exact logistic regression modeling to examine adjusted relationships between the primary independent variables of interest and the patient's history of hospital self-discharge, while controlling for any covariates retained from the bivariate analyses. Exact logistic regression modeling is preferred over the maximum likelihood estimation found in traditional logistic regression models for data with sample sizes of less than 100.^{21,22}

Results

Patient Characteristics

Ninety-five patients were enrolled into the study. Of these, 86 had complete data on all variables of interest and are thus the subjects of this analysis. Overall, 40 patients (46.5%) had a history of self-discharge. Table 1 summarizes the patient characteristics and provides the bivariate comparisons between patients with and without a history of hospital self-discharge. Patients with a history of hospital self-discharge were more likely to report experiencing 3 or more hospitalizations each year for treatment of their sickle cell pain (62.5% vs. 34.8%, $p = 0.01$). Patients with a history of hospital self-discharge were about twice as likely to have a positive toxicology screen in the past 5 years (27.5% vs. 13.0%, $p = 0.09$).

Associations Among Interpersonal Experiences, Trust, and Hospital Self-Discharge

In unadjusted analyses, having a history of hospital self-discharge was associated with a greater likelihood of reporting difficulty persuading medical staff about sickle cell pain (85% vs. 47.8%, $p < 0.001$) and with lower levels of trust in the medical profession (44.8 vs. 62.3, $p = 0.0001$).

Table 2 reports the results of a multivariate exact logistic regression analysis. Persons reporting difficulty persuading medical staff about sickle cell pain were more likely to report having ever self-discharged from a hospital, even after controlling for patient trust, hospital utilization, and 5-year toxicology screen history (Adjusted Odds Ratio [AOR] = 3.89, $p = 0.04$, 95% CI [1.05,16.26]). Patients with greater levels of trust in the medical profession were less likely to have ever self-discharged from a hospital, controlling for difficulty persuading staff about pain, hospital utilization, and 5-year positive toxicology screen history (AOR = 0.96, $p = 0.003$, 95% CI [0.93,0.99]). Independent associations between hospital utilization and self-discharge history, or between 5-year toxicology screen history and self-discharge history, were not observed in this study.

Discussion

In this study, we found a high proportion of patients with SCD had a history of hospital self-discharge. Patients with lower trust, and those who reported difficulty in persuading medical staff about sickle cell pain, were more likely to report having ever self-discharged from a hospital, even after controlling for self-reported hospital utilization for sickle cell pain, and the patient's 5-year toxicology screen history. Because hospital self-discharge is potentially dangerous,¹⁻³ our study reveals an understudied aspect of how low trust and poor healthcare experiences may put patients with SCD at risk for poor outcomes.

In our study, 46.5% of our sample reported ever having self-discharged from a hospital, a figure which is much higher than the 14% found by Elander et al. in their United Kingdom (London-based) sample. Other differences in our two patient populations may account for this discrepancy. Compared to the Elander sample, a much greater percentage of our patients reported ever having difficulty persuading medical staff about their pain (65% vs. 39%). As difficulty persuading about pain was independently associated with an increased hospital self-discharge history in our study, one might expect that our sample, which had a higher percentage of patients reporting difficulty, would also be found to have a higher percentage of patients reporting a history of hospital self-discharge. A second difference between the two patient samples is that our sample of patients experienced a greater number of hospital visits in the 12 months preceding the study compared to the Elander et al. sample. If this difference reflects an underlying difference in the overall hospital utilization experiences of the two groups, then our sample of adults would have greater opportunities, on average, than the Elander sample to experience hospital self-discharge. Other factors, such as patient behavioral or cultural differences between patients in the U.K. (with a national health system) and the U.S. (without a national health system), might be explored in future studies.

It is important to note that the wording of the hospital self-discharge item as used both in our study and by Elander et al. would not only capture AMA discharges, but additionally may capture other sudden decisions about hospital discharge made by patients. A national-level study of AMA discharges among adults with SCD in the U.S. which uses hospital records and/or chart review is needed in order to provide a more generalizable estimate of the prevalence of AMA discharge among this patient population in the U.S.

Elander et al. suggest that while hospital self-discharge among SCD patients may be interpreted by many as a sign that the patient engages in problematic use of opioids or other substances, it may be more appropriate to view this behavior as a sign that the patient has received inadequate management of their pain.¹⁹ In our study, hospital self-discharge tended to be associated with having a history of substance abuse as operationalized by a positive toxicology screen for cocaine or marijuana use during any admission in the previous 5 years. Elander et al. found that hospital self-discharge and other so-called "concern raising behaviors" such as use of illicit substances were found to be significantly associated with patient attempts to obtain relief from their pain, but were not significantly associated with symptoms of actual substance dependence or addiction.¹⁹ For example, each instance of illicit substance use reported by the patients in the Elander et al. study described patient attempts to use marijuana in efforts to manage pain, to relax, or as alternatives to prescribed analgesics. Clinicians in the U.S. who observe positive toxicology screen results for SCD patients may see these results as casting doubt upon the legitimacy of the patient's pain reports, thus causing a reduction in the amount of pain medicine provided to the patient, when in fact, a substantial percentage of these results may reflect SCD patients attempts to manage their pain outside of a hospital setting. This potential discrepancy between clinician interpretations of the meaning of positive toxicology screen results for SCD patients, and the actual significance of these results for many patients as reflecting attempts to manage pain,

could contribute to interpersonal conflicts between the clinicians and patients, and ultimately, patient self-discharge and decreases in patient trust in clinicians. Further, to the extent that SCD patient positive toxicology screen results reflect use of illicit substances for reasons other than attempts to manage pain, this should signal for clinicians a need to refer the patient for substance abuse treatment and counseling in addition to (and not instead of) efforts to manage the patient's pain.

Our study is among the first to show empirically that persons with a history of hospital self-discharge have lower levels of trust in the medical profession. Discharging oneself from a hospital could cause a patient to view future healthcare experiences in a more negative light, and cause the patient to have lower trust in the medical profession. Healthcare providers often label patients with a history of leaving AMA as challenging patients. Seeing in the medical record that a patient has left AMA before may bias the provider to view the patient in a more negative light, and consequently affect the quality of their communication with the patient, leading to lower patient trust. Alternatively, a patient could already possess lower trust in the medical profession due to poor quality interpersonal experiences, and thus be more likely to self-discharge from a hospital during a future acute care visit due to a heightened wariness or greater level of anxiety.

The most consistent and robust predictors of trust found across studies in the literature are the quality of previous interactions with medical care.²³ Poor physician communication, and experiences of conflict with staff have been associated with lower ratings of trust among a wide variety of patient populations.^{24–27} Interestingly, we found a relationship between trust and hospital self-discharge even after controlling for the quality of previous interpersonal experiences as measured by prior difficulty persuading staff about pain. Future studies should examine the relationship between trust and hospital self-discharge history while controlling for other measures of previous interpersonal healthcare experiences among this patient population.

There are limitations to the current study that must be considered. First, as a single institution study, these results may not be generalizable to patients with SCD seeking care at other institutions. Also, we did not assess the actual reasons why patients chose to self-discharge. Thus, while our data suggests that patient perceptions of poor quality care contributed to this behavior, we cannot state this definitively. The validity of a self-reported annual hospital utilization measure as used in this study may be limited by inaccurate patient recall. However, we compared our patient's self-report of annual hospital utilization with chart documented hospital utilization in the previous 12 months and found that the two measures were correlated in the appropriate direction, thereby giving us greater confidence in the validity of our self-reported measure. Finally, the cross-sectional nature of the data in this study makes it impossible to specify with certainty the causal directionality of the associations found here. Prospective research must be conducted to help tease apart the potentially complex relationships among trust, interpersonal experiences with care, and hospital self-discharge.

Adults with SCD who have ever self-discharged from a hospital have lower trust in the medical profession, and are more likely to report having had prior difficulty persuading medical staff about their sickle cell pain. The clinical consequences of hospital self-discharge in this patient population must be examined, and the specific reasons behind this behavior must be further elucidated, so that clinicians and researchers may be able to design interventions to mitigate the occurrence of this potentially dangerous phenomenon.

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Table 1

Bivariate Comparisons – Adult sickle cell patients with and without a prior history of sudden hospital self-discharge, from a cross-sectional study of patients seeking care at a Mid-Atlantic, urban academic medical center

Characteristic	History of Sudden Hospital Self-Discharge		
	No (n = 46)	Yes (n = 40)	p-value
Patient Characteristics			
Age, Mean (sd)	33.9(12.1)	31.8(8.4)	0.32
% Female	56.5	62.5	0.57
% with High School Education or Less	43.5	55.0	0.29
Household Income, %			0.51
<\$10,000	28.3	37.5	
\$10,000 to \$35,000	30.4	32.5	
\$35,000+	41.3	30.0	
% with 3+ Hospital Visits per year for vaso-occlusive crises	34.8	62.5	0.01
% with Positive Toxicology screen in past 5 years	13.0	27.5	0.09
Clinical Characteristics			
% with Hemoglobin SS disease	65.2	61.5	0.73
% with History of Acute Chest Syndrome	56.5	60.0	0.74
% with Avascular Necrosis	24.4	32.5	0.41
% with Pulmonary Hypertension	36.9	30.0	0.49
% with Renal Complications	13.3	20.5	0.38
% with History of Hypertension	21.7	17.5	0.62
% with History of Hepatitis C	10.9	15.0	0.58
Interview Location			
% Inpatient	43.5	55.0	0.29
Previous Interpersonal Experiences			
% Reporting Previous Difficulty Persuading Medical Staff About Pain	47.8	85.0	< 0.001
Trust			
Interpersonal Trust, Mean (sd)	62.3(19.8)	44.8(19.2)	0.0001

Table 2

Independent Correlates of a Prior History of Sudden Hospital Self-Discharge Among Adults with Sickle Cell Disease (Exact Logistic Regression)

	Adjusted Odds Ratio
Difficulty Persuading about Pain	3.89 * [1.05,16.26]
Trust in the Medical Profession	0.96 ** [0.93,0.99]
3+ Hospital Visits/year due to VOC	0.96 [0.26,3.36]
Positive toxicology screen in the past 5 years	4.29 [0.89,24.64]
<i>N</i>	86

*
p < 0.05

**
p < 0.01

95% confidence intervals in brackets