Return Visits to the Emergency Department: The Patient Perspective

Kristin L. Rising, MD, MS*; Kevin A. Padrez, BA; Meghan O'Brien, MD, MBE; Judd E. Hollander, MD; Brendan G. Carr, MD, MA; Judy A. Shea, PhD

*Corresponding Author. E-mail: kristin.rising@jefferson.edu.

Study objective: Reasons for recurrent emergency department (ED) visits have been examined primarily through administrative data review. Inclusion of patients' perspectives of reasons for ED return may help inform future initiatives aimed at reducing recurrent utilization. The objective of this study is to describe the personal experiences and challenges faced by patients transitioning home after an ED discharge.

Methods: We performed semistructured qualitative interviews of adult patients with an unscheduled return to the ED within 9 days of an index ED discharge. Questions focused on problems with the initial discharge process, medications, outpatient care access, social support, and health care decisionmaking. Themes were identified with a modified grounded theory approach.

Results: Sixty interviews were performed. Most patients were satisfied with the discharge process at the index discharge, but many had complaints about the clinical care delivered, including insufficient evaluation and treatment. The primary reason for returning to the ED was fear or uncertainty about their condition. Most patients had a primary care physician, but they rarely visited a physician before returning to the ED. Patients cited convenience and more expedited evaluations as primary reasons for seeking care in the ED versus the clinic.

Conclusion: Postdischarge factors, including perceived inability to access timely follow-up care and uncertainty and fear about disease progression, are primary motivators for return to the ED. Many patients prefer hospital-based care because of increased convenience and timely results. Further work is needed to develop alternative pathways for patients to ask questions and seek guidance when and where they want. [Ann Emerg Med. 2014;■:1-10.]

Please see page XX for the Editor's Capsule Summary of this article.

0196-0644/$-see front matter

http://dx.doi.org/10.1016/j.annemergmed.2014.07.015

INTRODUCTION

Background

Despite significant policy rhetoric about reducing "unnecessary" use of the hospital, very little is known about patients who repeatedly seek care within a short timeframe. Since the inception of financial disincentives for hospital readmissions, hospitals have focused on reducing 30-day readmissions with a number of interventions and initiatives.[1-3] Almost one third (28%) of all acute care visits in the United States and half of hospital admissions originate in the emergency department (ED),[4] but how repeated ED utilization fits into the overall conversation about hospital readmissions is not clear. Although limited, efforts to reduce the frequency of patients returning to the ED within a short period of ED discharge have emerged.

Coincident with this focus on reducing recurrent hospital use, implementation of the Patient Protection and Affordable Care Act and creation of the Patient-Centered Outcomes Research Institute have underscored the importance of including the patient voice in the design and delivery of health care. Reasons for patient returns to the ED and predictors of future return for both hospital readmissions and repeated ED visits have been investigated primarily through use of administrative data, and a number of factors associated with increased rate of ED return have been identified.[5-16] These factors include patient descriptors such as older age, lack of family support, nonambulatory status, and arrival to the ED by ambulance. It is not clear, however, whether any of these factors are actually in the causal pathway of patient returns and to what extent they represent modifiable risk factors for intervention. To better understand this causal pathway and to build a model of patient-centered care, we must include the patient perspective.

Importance

Inclusion of the patient perspective may identify factors contributing to recurrent ED visits not previously identified in administrative data. An improved understanding of risk factors and best practices may ultimately improve the patient experience during and after an ED visit and decrease ED revisits.

Editor's Capsule Summary

What is already known on this topic

Factors associated with return emergency department (ED) visits have been studied with retrospective administrative data sets. Such analyses cannot reveal motivations for these visits.

What question this study addressed

Patients' perspectives on the medical and social factors that lead to return ED visits.

What this study adds to our knowledge

In this qualitative study of 60 patients returning to a single ED, patients' uncertainty was the primary reason for return visits.

How this is relevant to clinical practice

By gaining an understanding of why patients choose to return to the ED, we can begin to design and implement interventions designed to reduce the number of unnecessary return ED visits.

Goals of This Investigation

The objective of this study is to describe the experiences of patients transitioning home after an ED discharge, with a focus on identifying medical and social challenges that patients perceive to have contributed to their return ED visit.

MATERIALS AND METHODS

Study Design and Setting

This is a qualitative study using individual semistructured interviews with patients returning to the ED within 9 days of a previous ED treat-and-release visit (index visit). Nine days was selected on the basis of previous retrospective work in which we assessed the occurrence and timing of ED return visits after a previous ED discharge for approximately 5 million index ED discharges. In this work, we used advanced modeling techniques to characterize the timing of returns, with results suggesting 9 days as the most reasonable cutoff for identification of acute ED revisits.[17]

The interview guide was designed with open-ended questions to elicit patients' personal experiences and perspectives for the following topics: clinical care, discharge process, and prescriptions received from index visit; health care use since index visit; transportation availability and use; social support; activities of daily living; employment; sources of health advice; factors influencing decision to return; general health care system use and beliefs; and overall impression of care received in the ED (Appendix E1, available online at http://www.annemergmed.com).

Questions were piloted on a group of 5 patients who met study criteria for enrollment but who were not enrolled in the study, and unclear questions were eliminated or revised for clarification. Interviews were audiorecorded to allow accurate transcription after the interview. There were 2 primary interviewers (K.A.P., M.O.) for this study, both of whom were trained by an expert in qualitative methods.

This study took place at 2 hospitals, the Hospital of the University of Pennsylvania and Penn Presbyterian Medical Center, both of which are within the same health system and have the same shared electronic medical record system. These institutions are teaching hospitals associated with an emergency medicine residency and staffed primarily by board-certified emergency physicians. Both are located in West Philadelphia, Pennsylvania.

Selection of Participants

Patients aged 18 years and older who were discharged from the ED at either study site and had a subsequent unscheduled return to the ED at either site within 9 days were potentially eligible for the study. An unscheduled return was defined as any visit for which the patient was not specifically instructed to return at that time for continued care, such as a laboratory test or wound check. These broad selection criteria were chosen to preclude restricting our population to certain clinical conditions, thus risking that we overlook possible important patient- or condition-specific characteristics.[18]

Patients with a scheduled return ED visit (such as a wound check) or who left the initial ED visit without a formal discharge (including left against medical advice, left without treatment complete, and left without being seen) were excluded. In addition, patients who were unable to participate in the interview because of the severity of their medical condition or who were otherwise unable to communicate were excluded. Patients who did not speak English fluently or who were deaf were also excluded. Finally, patients deemed unable to consent to participate were excluded, including those who were intoxicated. Patients who had multiple 9-day revisits within the study period were interviewed only once, though they could be reapproached on subsequent return visits if they declined participation at previous attempt(s) of enrollment.

All patients provided written informed consent. Patients received $20 as compensation for the time required to participate in the interview. Research approval was obtained from the university's institutional review board.

Data Collection and Processing

Patients were identified automatically by the electronic medical record system as potentially qualifying for the study at ED triage if an index ED visit within the past 9 days was identified, and an electronic alert was sent to the interview team. Patient eligibility was assessed and patients were enrolled and interviewed by the on-call interviewer as soon as possible after they arrived in the ED, with the timing and location of the interview determined on a case-by-case basis to ensure maximal privacy and minimal interruption to patient care. Interviewers

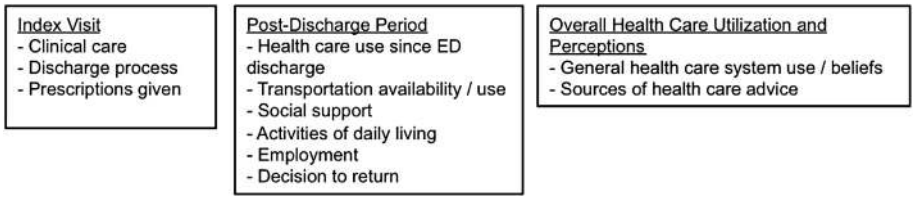

Figure. Conceptual model. *ED*, Emergency department.

were scheduled across all days and times of the week and were limited to enrolling a maximum of 2 patients during any one shift in an effort to minimize bias caused by enrolling patients only on certain days or within specific periods. Patients who were admitted on return visit were still eligible for enrollment as long as the interview was completed within 24 hours of arrival of the patient to the ED. Written informed consent was obtained before the interview.

Patients were also asked to complete a short demographic survey at the end of the interview, with the following questions: primary care physician name, number of children, number of adults in household, education level, primary language, ability to read discharge instructions written in English, and preference for having discharge instructions written in another language. The questions were read to them and recorded by the interviewer. In addition, data were extracted from the patients' electronic medical record. Information pertaining to both visits included chief complaint, discharge diagnoses, triage time and date, and discharge time and date. Patient information included age, sex, race, insurance status, and previous ED utilization.

Consistent with established qualitative research methods, interviews were continued until thematic saturation was achieved, in which no new themes emerged in the interviews. Customarily, this requires approximately 30 interviews.[19] We aimed to enroll an equal mix of patients who were admitted and discharged as a result of their return ED visit in case we discovered that these patients had different perspectives and experiences with their health care use. The goal of 20 to 30 patients per group occurred naturally during the study, and thus purposive sampling was not required to meet these numbers for the final interviews. Interviews took place during a 5-month period.

Primary Data Analysis

Recordings of the interviews were transcribed by an independent transcription agency. Transcripts were then checked for accuracy, stripped of identifying information, and imported into NVivo 10 (version 10; QSR International, Burlington, VT) for coding and analysis. The coding scheme was developed with a modified grounded theory approach. Codebook development started with the interviewers, who were not involved with the study design. They first identified broad themes based on the first 5 transcripts and then applied open codes to the transcripts. The initial set of codes was tested on each subsequent interview transcript to refine the codebook. After the interviewers made an initial comprehensive attempt at the codebook, it was refined and organized by the rest of the investigative team. Codes were further revised in an iterative manner with the constant comparison method between and within transcripts, and more content-driven axial codes were applied.[20] The final coding scheme was established and applied to all transcripts.

All interviews were coded by 2 of 3 reviewers. The median κ was 0.74, with a range of 0.19 to 1.00. Final coded transcripts were reviewed by all 3 reviewers and discrepancies were resolved by consensus.

We organized our analysis by developing a conceptual model that separated observations into 3 domains: initial ED treat-and-release visit (index visit), postdischarge period, and overall health care use and perceptions (Figure). Observations related to the index visit included those about the clinical care received, the discharge process itself, and prescriptions received. The prereturn period observations focused on issues with social resources and other social challenges, health care use since the index ED visit, and the factors influencing the actual decision to return to the ED. Non–time-dependent observations focused primarily on the patients' overall ideas and opinions about the medical system and their preferred means of accessing health care for various needs. After review of overall themes, responses were compared for patients admitted at the return ED visit and those who were discharged.

We use descriptive statistics to characterize the study population both overall and comparing patients according to disposition from the return ED visit, though formal statistical comparisons are not performed because of the small sample. Because interviews were semistructured, and because the primary goal of this work was to identify themes rather than to generate benchmarks, not all topics were discussed with all patients. Thus, although numbers of responses are presented below, ratios are presented only for those questions asked of all respondents and therefore having a known denominator.

RESULTS

We conducted a total of 60 interviews, 24 with patients who were admitted at their return ED visit (14 inpatient, 9 observation, and 1 transfer) and 36 with patients who were discharged from the return visit (1 against medical advice, 1 left without treatment complete, 34 routine discharge). The mean age of enrolled patients was 43 years (range 19 to 75 years), with 39 (65%) women. More than half of the patients (31/60) had only 1 or 2 previous ED visits in the year preceding their

enrollment in this study. At the other extreme, just over one third (21/60) of patients had been "high users" during the year before enrollment in this study, which we defined according to previous literature as patients with more than 4 index ED discharges during 1 year.[21,22]

Despite efforts to enroll patients equally across the days of the week, the majority of patients presented to the ED during the weekday for the index (90%) and return ED visits (73%). More than two thirds of patients (n=43; 70%) reported having a primary care physician. More than half (n=34; 56%) of patients had no children and 13 (21%) had 1 child. Time between the 2 visits was from 0 to 9 days, with close to half (47%) of patients enrolled returning within 72 hours and three quarters of the patients (75%) returning with 144 hours (Table 1). We present illustrative quotes for each of the major themes described below in Tables 2 through 4.

Most participants (41/60) did not have problems with the discharge instructions or process. Those who did express problems reported difficulty understanding the written discharge papers, not receiving the discharge papers before leaving the ED, or feeling rushed or unprepared for discharge. Most patients reported no problems with filling or receiving the medications prescribed during their first visit, though about one third of patients (19/60) thought they did not receive the medication they needed, with this medication most often being a pain medication.

More than one third of patients (24/60) expressed concerns about their clinical care. Some wanted more diagnostic tests or to be admitted on the first visit, whereas others thought their chief complaint was never addressed during the first visit. As one participant explained, "I told them that my stomach is hurting bad, and they just gave me the medicine that they use for, like, when you're pregnant to help you stop throwing up. It wasn't as much as me throwing up; it was my stomach. It's, like, a pain in my stomach that's hurting and I feel like they didn't address that issue. That's why I'm back today." In addition, participants commonly reported dissatisfaction with the discharge diagnosis provided or explanation of their chief complaint.

Patients rarely had difficulty with social resources (including transportation, access to and preparation of food, stable housing, and child and family care), drug or alcohol abuse, or mental health issues. The most common challenge identified was with general mobility, including problems moving around the house because of current illness. Patients did not generally report problems with transportation in their daily lives, though some desired a cab voucher home from the hospital or expressed difficulty getting home after visiting the ED. They often arrived to the ED by means of a ride from a family and friend, and most did not own a car but rather relied on public transportation. Of the patients who were currently employed, half (14/29) reported that their illness was interfering with their job.

Many patients believed they were not referred to an outpatient provider when discharged from their index visit, and only approximately 1 in 5 patients visited an outpatient clinic after the index discharge. Some did not try to make an outpatient appointment because of a perceived difficulty in making one (eg, never able to schedule an appointment soon enough) or lack of insurance, whereas one third of patients (21/60) contacted their outpatient providers to make a follow-up appointment but did not attend it before returning to the ED. When asked why they did not follow up as an outpatient, patients reported believing that their symptoms were too severe to wait until their scheduled appointment or being instructed to return to the ED by the outpatient provider they contacted.

Patients most frequently returned to the ED because of fear and uncertainty about their condition, with this fear driven by the belief that their condition was worsening or not improving in the timeframe they expected, as well as by a lack of explanation for what was causing their symptoms. One patient described, "I've already talked to my doctors…and they did have, like, a plan in place but it just.… I just don't know where the deterioration's coming from, and I'm so afraid, and that's been creating a lot of

Table 1. Characteristics of interviewed patients: entire sample and by disposition from return ED visit (admitted versus discharged).*

Characteristic	9-Day Revisits		
	All, N=60	Admitted, n=24	Discharged, n=36
Age, mean (range), y	43 (19–75)	47 (19–73)	40 (21–75)
Women	39 (65)	15 (63)	24 (67)
Visit 1, weekday	54 (90)	22 (92)	32 (89)
Visit 2, weekday	44 (73)	19 (79)	25 (69)
Visit 1, time			
Day (8 AM–3:59 PM)	30 (50)	12 (50)	18 (50)
Evening (4 PM–11:59 PM)	22 (37)	9 (37.5)	13 (36)
Night (midnight–7:59 PM)	8 (13)	3 (12.5)	5 (14)
Visit 2, time			
Day (8 AM–3:59 PM)	41 (68)	15 (63)	26 (72)
Evening (4 PM–11:59 PM)	15 (25)	6 (25)	9 (25)
Night (midnight–7:59 PM)	4 (7)	2 (13)	1 (3)
Has PCP	42 (70)	18 (75)	24 (67)
Lives with at least 1 other adult	41 (68)	15 (63)	26 (72)
Number of children in household			
0	33 (55)	15 (63)	18 (50)
1	13 (22)	4 (17)	9 (25)
≥2	14 (23)	5 (21)	9 (25)
Education			
No high school degree	15 (25)	5 (20)	10 (28)
High school deg/GED/some college	34 (57)	15 (63)	19 (53)
College degree	8 (13)	4 (17)	4 (11)
Postgraduate degree	3 (5)	0	3 (8)
Time to return visit, h			
0 (<24)	5 (8)	1 (4)	4 (11)
1 (24–<48)	10 (17)	5 (21)	5 (14)
2 (48–<72)	13 (22)	4 (17)	9 (25)
3 (72–<96)	9 (15)	3 (13)	6 (17)
4 (96–<120)	6 (10)	3 (13)	3 (8)
5 (120–<144)	2 (3)	0	2 (6)
6 (144–<168)	9 (15)	7 (29)	2 (6)
7 (168–<192)	3 (5)	0	3 (8)
8 (192–<216)	3 (5)	1 (4)	2 (6)

PCP, Primary care physician; *h*, hours.
*Data are presented as No. (%) unless otherwise indicated.

Table 2. Index visit.

Theme	Quote
Clinical care	
Wanted more tests	"I think they should have took blood work to see what it was and stuff in there that—because if they would have took blood, they would have found out, oh, you had a rash coming on. Because that could have been in my system already, but they probably didn't show to this point. The best they should have did ran tests and they didn't do it."
	"I know it's hard to arrange an MRI in the ER, but I feel like in the circumstance, I mean, with a young person presenting with severe, like, neurological deterioration, that might be something that's maybe a little bit more warranted than someone who comes in for a single headache. I mean if, like, if they're really concerned that—I mean, they can do a head CT for that but for—like I feel like—my stress has like really been downgraded."
Wanted admission	"I mean, not that I love staying here—I'm happy to get discharged whenever they discharge me, but it probably would have been better for me if they kept me over and just monitored that condition."
Complaint unaddressed	"I told them that my stomach is hurting bad, and they just gave me the medicine that they use for, like, when you're pregnant to help you stop throwing up. It wasn't as much as me throwing up; it was my stomach. It's like a pain in my stomach that's hurting and I feel like they didn't address that issue. That's why I'm back today."
	"I just really wish that they had addressed the problem that I came in with. They kind of like blew it off when they seen the CT scan, and seen that the ovary was huge."
Discharge process	
No problem	"Everything was fine, very professional. I understood all the procedures and I've been following through with it."
Problem understanding	"Because I don't—I don't understand English very well, so some sentences I don't understand. It is difficult for me. That's why I sometimes let something go."
Rushed out/unprepared	"Well, I felt like I was rushed out of there because they needed the room for someone else, and I was trying to tell them I still didn't feel too good, but after they didn't listen to me I got frustrated and said—just took the stuff and left."
	"Well I was told I was being admitted and then they came in suddenly and told me I was not being admitted; they had changed the course of events. They had not decided whether I could ingest liquids or solids; they just told me I was leaving and they discharged me, gave me the paperwork, and didn't explain anything."
	"I think they could've waited a little longer before they discharged me. Tried to get me to—I don't know—try something other than the IV to get me—to get the medicine that I needed to see if I would be able to keep it down or see if it would help or work before I left so I wouldn't have had to come back, I guess."
Limited explanation	"They just put chest pain and I'm just lost, like okay, well, what did they find? They just leave you lost. Like, they take care of you, but they leave what's wrong with you between them instead of sharing it with you."
Prescriptions	
Did not receive what was needed	"I didn't know that they wasn't going to give me any pain medicine when I left here. And that's what I was worried about, like why didn't they give me no pain medicine so that way it could have held me over until I went to my family doctor?"
	"They was, like, no, you don't need no pain medicine. You don't need nothing. So that's what made me come in here, because I'm in a…lot of pain."

COPD, Chronic obstructive pulmonary disease; *GI*, gastrointestinal.

anxiety for me." Patients sometimes made the decision to return to the ED without input from others, but more often they sought the advice of a spouse, friend, or family member, often selecting someone who had personal experience with the patient's illness or worked in the health care system. Some also sought the perspective of a health care provider known to them and were referred to the ED over the telephone or at an outpatient appointment. A number of patients also reported receiving unsolicited advice from friends or family instructing them to return to the ED. Though patients were not explicitly asked whether they were returning for a new or continued problem compared with their initial visit, the majority discussed continued problems related to the initial visit as a reason for return.

Many patients discussed their relationships with outpatient providers and issues related to seeking outpatient care. Although the majority of the patient sample reported having a primary care physician, patients varied in regard to how often they consulted their primary physicians and their perceptions of how helpful their physician was in serving their health needs. Some patients reported being well attended to by outpatient physicians, often already consulting multiple specialists. Others believed their extensive outpatient physician network caused problems because of difficulties coordinating care and constant referrals. Patients frequently reported problems with receiving needed outpatient care, including difficulties contacting providers, inability to make appointments when needed, and waiting too long at their actual appointments. Other prominent themes related to the limited use of outpatient care included problems accessing care because of lack of insurance, dissatisfaction with a primary care physician, and lack of trust in their primary physician.

Many patients preferred to receive general (nonemergency) health care in the outpatient clinic setting, though they identified a number of problems limiting their ability to receive sufficient outpatient care. These included problems with the clinic lacking resources needed to complete their evaluation or treatment (eg, no intravenous lines for hydration, limited blood and imaging tests on site), delays in diagnosis associated with outpatient testing, and inconvenience related to having multiple appointments on different days. In keeping with these findings, patients who preferred to receive their health care in the ED primarily reported reasons of convenience and more timely evaluations within the hospital setting.

Table 3. Postdischarge period.

Theme	Quote
Social resources	
Problems with mobility	"Well, I have to go from this first floor to the third floor, so with the COPD the breathing part trying to get up them steps all the time, and if I do laundry I have to go all the way to the basement, so 3 flights of steps for me is a lot. Some days it's not as bad as others, you know."
Need transport home from hospital	"So I know one time they used to give cab vouchers. They used to give you tokens. They didn't offer me…a way of getting home. How did you get here? Did you get here by ambulance? Did you get on a bus? Did somebody bring you? They didn't ask any of that."
Illness interfering with job	"The job that I'm working, I don't receive any benefits, so—and that was one of my main issues. I'm not getting paid for me being out, and that's another reason why I wanted this stuff to be expedited, because I'm losing income due to the situation, so yeah. That's the only thing, just not getting benefits for time off."
	"I can't get in to work and do what I have to do, so income is really impacted."
Health care use since index visit	
Difficulty making PCP appointment	"My doctor's office was today. I tried to go walk in so she could take me. But when I went there, they told me they cannot take me; she was packed. So I have to make an appointment for her to tomorrow. Then I come home, but I was feeling the symptoms and they was bothering me a lot. And I don't even know—I would lose my mind, so that's the reason why I say, okay, I got to go to the ER again, because if I can't see the doctor, to tell her what's going on, then I have to go to the ER, because this is really something for me; it's come to the way that I cannot take it."
Difficulty making specialist appointment	"Well, I called the neurologist because I felt I really need to come back. And they told me they wouldn't have a doctor until—they wouldn't have an appointment available until January. So I had to get here before then."
Did not attend appointment—symptoms too severe	"…my GI doctor, but I already had an appointment set up…, which was yesterday…. I was too sick. I couldn't make it."
Did not attend appointment—referred to ED	"… I spoke to the occupational health nurse and she asked about how I felt, and I told her I was fine. And then I had an episode last night, and then this morning, I spoke with, I believe it was the nurse at my doctor's office, and my doctor actually got on the phone and said that he felt I should come back to the emergency room, because he wanted me to see a neurologist."
Decision to return	
Fear/uncertainty	"I've already talked to my doctors…and they did have, like, a plan in place but it just…. I just don't know where the deterioration's coming from, and I'm so afraid, and that's been creating a lot of anxiety for me."
	"I know I'm going to be sick, I know I'm going to throw up, but where is this pain coming from? I just hope that they can find out today why I keep having this pain."
	"I don't know what's a stroke, but I know reading up on symptoms that you have or whatever, you know, so I said I would rather be safe than sorry, so that's why I wanted to come back to the emergency room."
	"I started bleeding so I got scared. I don't want to be home in the middle of the night and it pass through, be by myself."
Getting worse or not getting better	"Well, I came because symptoms have gotten worse and it was kind of a decision I had to make on my own, you know. So I just decided that it's really time to see what really was going on."
	"The pain is so severe I can't take it no more. I need somebody to find out what's going on with me. I can't keep going from hospital to hospital. I need to find out what's going on."
Made decision alone	"I came because symptoms have gotten worse and it was kind of a decision I had to make on my own."
Sought advice from friends/family—works in health care	"I have [a] cousin, like, she works at the hospital. I call her and ask her do you think this is this or…. I called her the other day and asked her, like, I told her what I was going through. She said, well, you need to get to the hospital and find out."
	"My baby sister is a critical care nurse, so if I talk to anybody about medical issues, it's my baby sister."
Sought advice from friends/family—personal experience with illness	"She got coronary heart disease. That's why I talked to her and see what she preferred, and she was, like, instead of waiting until tomorrow you might as well just call them and ask them what to do, and that's what I did."
	"Besides my doctors? You know what? My friend is a registered nurse. I talk to her but she's, like, crazy…. But she's, like—she listens to me. So I appreciate it. Whereas a lot of people would be, like, maybe you're just crazy. She, like, listens to my whatever. So she's cool."
Unsolicited advice to return	"My wife told me to come back because I wasn't going to really come back…. I said, no, I ain't going to go the emergency ward if I go to the hospital. They said, well, go ahead and take your butt to the hospital and find out exactly what's going on."
Referred by provider	"I had an appointment today, a regular appointment with the doctor's staff, and they decided to send me here."

Table 4. Overall health care use and perceptions.

Theme	Quote
Has PCP	
Multiple providers—no problem	"Starting in the beginning of this month, I've been seeing doctors every—like, every other day, maybe."
Multiple providers—hard to coordinate	"I really feel like I need an oncologist or somebody to coordinate all this at this point."
Multiple providers—too many referrals	"See, when I have whatever hurting me, the doctor tell me to go see my—at the dialysis center they say go see your primary doctor. Well, your primary doctor, you go see somebody else.… So whatever it is, I just go see that doctor, go see that doctor, go see that doctor, whatever."
Difficult to contact PCP	"I'm, like, well, I'm in and out the emergency room because when I do call my family doctor, sometimes I can't get through to them because they be so busy during the week, so I have to come to the emergency room and see what they could do for me."
Wait too long at PCP appointments	"Sometimes the same thing because other appointments run over or the doctors are running late, and so, I mean, the majority of the time for me it's automatically to just come to a hospital. I mean, I'll still have to wait, but I'll be seen within 2 or 3 hours and possibly be back home and rest and start caring for myself instead of sitting in the waiting area for 2 to 3 hours and then still have to be seen…."
Does not like PCP	"I was referred to my primary. Yeah, to my primary doctor, which I'm not—I don't go back to her for 4 months. And I really don't like her. I'm thinking about changing and getting my primary here because she—it's a health center for—and they're just—I just don't like it there."
Slow evaluation because of limited facilities at PCP	"And at primary care doctors' offices, their testing is limited because their facilities are smaller so they can't—they don't have right on hand the test—I would say all the tests that they need to complete their jobs. I mean, they can do them, but they're not fully complete if you get a patient that's ill with something that you now have to send off for this test or wait for this test to come back before you can fully know what's wrong with them. So I think I would have to say testing would be something to be improved for me anyway."
No PCP	
No insurance	"Well, I'd been trying to—well, I'm in a floating situation where I don't have health insurance at the moment, but it—I have health insurance, the—just the thing hasn't gone live yet. So I'm kind of in that buffer period and so I've been calling left and right. I called the clinic—the orthopedic specialist—the orthopedic specialist and they said, well, I have to call the clinic. So then I called the clinic—what was it [district health center]—and they were like, oh, yeah. We don't do any orthopedic stuff. And then I called 4 and then, like, yeah. We can't take care of you because your price bracket is too high. And it was—and then I—and I just went back to the ER and they were, like, yeah. We can't refuse you health care here so come back in, and then that's what the front desk lady told me, so that's why I'm here."
Unable to afford free clinics	"I don't have the money to pay them. And even free clinics cost $60, so I don't have it."
Preference for nonemergency care	
Prefers PCP	"I'd definitely rather try to, you know, go with my primary and my specialist first, versus just going to the ER. If they can definitely do something for me at the office, then please do."
	"I rather go right to my primary care, which is only like a half a block right on the corner block. So it's easy for me to get there and back and forth. They call me up and stuff like that, talk to me."
Prefers hospital: quicker answers	"I was referred to Frankford Clinic. And the only problem with the Frankford Clinic is they don't have the facility. They don't have the laboratory facility that can bring back the answer right away, like the hospital does. I had to wait 2 days. So, if I go to the clinic I have to wait 2 days and in 2 days' time I could be dead. So, that was the problem with the clinic."
Prefers hospital: more convenient	"I know that's one of the reasons why emergency rooms and hospitals are so overcrowded. I mean, a lot of us think the same way. Oh, I'm not gonna go sit 2, 3 hours here when I can go to the hospital and wait 2, 3 hours, be seen, cured, and be back home or back to work without being out for a week and 2 weeks at a time and things like that."
Prefers hospital: second opinion	"Well, I think I like the emergency room better because—I mean, and really at any hospital, honestly, because it's different than going to a facility where your primary care doctor is. If I get—I mean, with me, if I'm told something by one doctor then there's another doctor I can talk to if I want a second opinion if I think I don't—if I'm not comfortable with the result, then there is someone else I can get a second opinion. They could be more experienced or just maybe seen my situation or more than 1 case, so they would be better experienced at it."
Prefers hospital: more likely to feel better	"So if I'm not feeling my normal self and I go see my primary care doctor and what my primary care doctor does for me or says to me doesn't cure my ailment or make me feel any better, then after that visit now it's, like, okay, this is I guess starting to become a waste of time to keep coming here so I'll just keep going to the hospital. At the hospital, I'm guaranteed to be feeling better by the time they discharge me or I'm guaranteed to get the prescription that's going to work for me. I won't have to play around with my safety pretty much…."

Patients were similar in regard to their perceptions of previous clinical care, the discharge process, prescriptions, and social resources and challenges regardless of whether they were admitted or discharged from their return ED visit. The primary difference between the admitted and discharged populations was in reasons for return, with patients who were admitted from the return visit focusing more on clinical deterioration of what was often a chronic or preexisting condition as a primary reason for their return rather than fear and uncertainty about their medical condition. As one admitted asthmatic patient explained, "My asthma started to flare up real bad…. [I]t's a darn change in the weather. I get real bad during like cold weather…. I've been trying to take the nebulizer machines and the Albuterol inhalant myself at home, but it wasn't working." In addition, these patients more often indicated extensive and regular use of the health care system, including having a primary care physician, as well as 1 or more follow-up appointments in place after their initial visit. Related to this pattern of regular use of outpatient providers, this sample of admitted patients were more likely to report being referred to the ED by a provider, rather than relying on the advice of a friend or family.

LIMITATIONS

Our sample was limited to a convenience sample of 60 patients within a single health system, and thus the themes identified may not be generalizable to different patient populations. Although this was a heterogeneous sample, patients were not specifically enrolled by demographics, and thus we assumed no differences in response according to specific demographics.

Our sample intentionally has a key selection bias. Specifically, we did not enroll patients who had an ED visit and then had successful follow-up in the outpatient setting or did not seek any further follow-up. This population of patients who were able to successfully obtain needed services rather than return to the ED represents a different cohort than the population that we were interested in understanding.

In addition, as we have described briefly above, our semistructured interview format was not standardized enough to allow us to rank order patient concerns in a meaningful way or to delve into differences between subgroups such as those with acute conditions only compared with those with multiple complex chronic conditions.

Despite these limitations, our findings offer important insight into the experiences of a distinct population of patients who are not successfully transitioning to an outpatient care setting after ED use. We believe this work provides a valuable starting point from which researchers can develop future larger studies focused on 1) determining the proportion of all ED patients that struggle with post-ED transitions, and 2) testing the ability of strategic interventions to improve care.

DISCUSSION

Our findings offer rich insight into both the physical and emotional challenges that patients have on discharge from the ED. In their narratives, most participants discussed their decision to return to the ED being driven largely by fear and uncertainty about their medical conditions, as well as a lack of trust in the system to be responsive to their needs. They perceived having no other option about where to go to obtain answers or further reassurance because of actual or anticipated difficulties with accessing outpatient care services in their needed timeframe.

This work is an important step forward in actively engaging patients during an acute care episode in defining their challenges in staying healthy. To our knowledge, there have not been any similar comprehensive studies performed of ED patients from the patient perspective to assess factors potentially contributing to short-term return ED visits. Naughton et al[23] surveyed patients with a repeated ED visit, but they used a 6-month period for returns and limited the population to patients older than 65 years, which significantly limits the applicability of this work to answering the question of what causes patients to return to the ED within a few days of a previous visit. They did find an association between anxiety scores of patients and repeated use of health care resources, supporting our finding that fear and uncertainty drive patient decisions to return to the ED.

The majority of work in regard to improving discharge from the ED has focused on improving the actual discharge process itself,[24-36] and we find, perhaps as a result, that most patients do not report problems with this process. There is a small body of research exploring patient perspectives about inpatient readmissions. Most relevant is a study by Kangovi et al,[37] in which they performed a 36-item survey of patients with 30-day hospital readmissions to assess potential problems of care transition. They found that 45.5% of patients reported challenges on transition home, with only 1 of the top 5 factors identified by patients being something that occurred during the index hospitalization (lack of preparedness for discharge), with the other 4 pertaining to issues with social support, medications, and activities of daily living. Our study reinforces this finding that patients identify the majority of their struggles as occurring after leaving the hospital, and not being directly related to the discharge process.

We believe that there are 2 primary themes emerging from this work. First, patients need more reassurance during and after episodes of care, especially in times when there is not a clear explanation for the cause of their symptoms. Excellent care by clinical standards may not equate with excellent care by patient standards, especially when patients are discharged with few answers and an unclear plan of action. Though patients generally did not identify problems with their discharge process, they often went home still afraid and uncertain of next steps. This finding suggests that emergency providers should be more proactive in ensuring that patient concerns have been addressed before discharge, which may include better verbalizing their clinical thinking, ensuring communication of test results, and addressing uncertainty felt by many patients related to lack of clear diagnoses.

Second, patients do not have ready access to needed advice from providers in between their scheduled visits or inpatient

hospital stays. This is in part due to the "reactive nature" of US medicine, and experts have begun to focus on how to insert thinking about healthy choices into the 5,000 waking hours a year spent outside of a physician's office.[38] This theme has direct ties to key policy initiatives focused around increasing the value of health care delivery. Changes in delivery such as referral of patients to the ED from outpatient care offices by nonmedical personnel, the decreased availability of telephone advice, group practice models limiting patient access to providers who know them, the absence of home visits for patients with mobility problems, and fee-for-service models that provide incentive for the volume of care are all likely contributors to the divide between patients and providers. Regardless of how well informed patients are at discharge from the ED, it is inevitable that new questions will arise once they are in their home environment and initial treatment effects wear off. We suggest that development of a reliable means of contacting providers in the postdischarge period, perhaps through novel telemedicine methods, may help patients in managing their concerns without a return hospital visit.

In summary, we find that patients come back to the ED because they are anxious about symptoms, unsure of what else to do, and have lost trust in the health care system's interest in serving as their advocates. They see options as limited to calling a provider in the hope of a timely appointment or coming back to sit in the waiting room until they can be treated again in the ED. We suggest that to deliver patient-centered care, the medical community must learn to better meet patients when and where they want. In addition to efforts focused on preventing readmissions, attention should be focused on developing and facilitating pathways for patients to ask questions and seek guidance after leaving the ED, before their primary or subspecialist physician appointment and whenever they are unsure about how best to stay healthy. Technology used correctly may facilitate connectedness with care teams or improve access to the guidance and perspective that patients need to optimally care for themselves.

Supervising editor: Daniel A. Handel, MD, MPH

Author affiliations: From the Department of Emergency Medicine, Thomas Jefferson University, Philadelphia, PA (Rising, Hollander); the University of California San Francisco School of Medicine (Padrez), Department of Internal Medicine (O'Brien), San Francisco, CA; the Department of Emergency Medicine, University of Pennsylvania, Philadelphia, PA (Carr); and the Division of General Internal Medicine, Perelman School of Medicine at the University of Pennsylvania, Philadelphia, PA (Shea).

Author contributions: KLR and BGC conceived of the study. KLR, JEH, BGC, and JAS designed the study. KAP and MO conducted the data collection. KLR, KAP, and MO analyzed and interpreted the data. KLR drafted the article, and all authors contributed substantially to its revision. KLR takes responsibility for the paper as a whole.

Funding and support: By *Annals* policy, all authors are required to disclose any and all commercial, financial, and other relationships in any way related to the subject of this article as per ICMJE conflict of interest guidelines (see www.icmje.org). The authors have stated that no such relationships exist and provided the following details: Supported by the 2013 Emergency Medicine Foundation/ Emergency Nurses Association Foundation Directed Team Grant.

Publication dates: Received for publication June 9, 2014. Revision received July 6, 2014. Accepted for publication July 10, 2014.

Presented at the Society for Academic Emergency Annual Meeting, Dallas, TX, May 2014; and the Academy Health annual meeting, San Diego, CA, June 2014.

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APPENDIX E1.

Interview Questions (after consent has been completed)

I'd like to learn about the events that took place between your last discharge in the emergency room on _____ and your return visit today. My goal is to figure out whether there are things we can do to help you stay healthier at home.

Overall

Tell me the story of how/why you landed back here so soon.

Tell me about things you needed or were told to do once you left here.

Prompts

For example, were you told to see a physician or get medications?

Did you have a chance to do these things?

Do you think there is anything that could have been done differently the first time to keep you from landing back here?

General Health Care Use

What is your preferred place to get your health care? Why?

Prompts

Do you prefer to get regular health care in the ED or in an outpatient clinic?

How does the ED fit into your health seeking?

Prompts

For example, do you see the ED as a place to get your usual care, or is it a place you would rarely use for care?

Who do you turn to for health care advice?

Prompts

Why do you turn to them? Something special about the relationship?

Specific Questions (can omit if already discussed certain points above)

1. Let's go back to your last ED visit with the discharge instructions that you received. A lot of times, people have trouble with reading or understanding the medical information they are given, or they believe that instructions are not explained well enough. Tell me about your experience receiving your discharge instructions.

Prompts

For example, tell me about who explained your instructions and whether you had a chance to ask questions.

Can you tell me more about that?

What other problems did you have with the discharge process? (Repeat until none.)

2. Now let's talk about medications. I have a few questions about medications.

2a. Were you given any prescriptions when you were discharged?

IF YES: Tell me about any problems that you had filling the prescriptions or taking the medications.

Prompts

For example, did you have problems paying for your medications or getting to the pharmacy to fill your prescription?

Tell me more about that.

What other issues did you have with filling your prescriptions? (Repeat until none.)

IF NO: Skip to 2b.

2b. Tell me about any (other) medications that you think may have been helpful for you to receive when discharged.

Prompts

Tell me more about that.

Did you ask for that?

3. Now let's talk about outpatient physicians or other types of providers you may see or talk with.

3a. Were you referred to any physicians or clinics when you were discharged?

IF YES: Did you see, or try to see, that physician? Tell me about what happened?

IF NO: Skip to 3b.

3b. Did you see a (any other) physician, either in the clinic or another ED, since your last ED visit?

IF YES: Tell me about what happened at that physician visit and what instructions you were given by that physician. (Then skip question 4.)

Prompts

For example, your physician may have advised you to come back to the ED or to change your medications.

Tell me about your experiences with these issues.

Tell me more about that.

Tell me about any other advice or instructions you were given. (Repeat until none.)

IF NO: Skip to 3c.

3c. (Only if answer no to 3b) Did you talk to a physician or a nurse on the telephone or by e-mail since your last ED visit?

IF YES: Tell me about any advice or instructions you were given by the nurse or physician.

Prompts

For example, tell me about whether you were given advice to go to clinic or to come back to the ED.
Tell me more about that.
Tell me about any other advice or instructions you were given. (Repeat until none.)

4. Next let's talk about transportation. Some people have talked about issues with getting transportation to the physician or the pharmacy. Tell me about any problems getting to the pharmacy or the physician's office or getting other things you needed because of transportation issues.

Prompts

Tell me about how you got between places.
How often is transportation a problem for you?
Can you tell me more about that?
Were you well enough to drive?
What other problems do you have with transportation? (Repeat until none.)

5. Some people have mentioned problems with not having enough support, or the right kind of support, from friends and family at home. For example, some live with multiple people and feel completely unsupported, and others live alone but feel very well supported. Tell me about the people whom you are able to ask for help and whether you thought you needed more support at home after you were discharged.

Prompts

Tell me more about that.
What other things did you feel like you needed more support for? (Repeat until none.)

6. Tell me about your decision to come back to the ED today and who helped you make the decision about whether to come back to the ED.

Prompts

For example, are there specific family members or friends that you talked to?

7. Do you have a job outside of the home?
IF YES: Tell me about any work-related needs you had during the past few days that were difficult for you.

Prompts

Tell me about any work that you have had to miss because of your current health problems.

IF NO: Skip to 8.

8. Now I'm going to ask you about a few other things that some people have mentioned having problems with after leaving the ED. Think about how each of these affected you during the past few days.

8a. Tell me about any issues with getting or preparing enough food.
8b. How about any issues with your housing, such as not having housing or living on a high floor and having problems getting up the stairs?
8c. Tell me about any issues with child care or caring for other family members or friends.

9. I know this can be a sensitive issue, but sometimes people talk about issues with drugs or alcohol that make it hard to care for themselves. Tell me about any ways that drugs or alcohol made it harder for you to get healthy these past few days.

10. Finally, I have one last general question about your support in life in general, not just related to your return visit today. Tell me about whom you normally talk to aside from your physicians for health advice. This may include people such as certain family members, your partner, or other friends.
10a. What is special about this person that you turn to them for advice?
10b. Is there something special about their relationship to you?

11. We in the ED would like to figure out how to improve the discharge of patients, and I'd like to hear your ideas. Tell me about anything else that you think could have been given to you or done at your last discharge to make your return home easier or your return to health more successful.

Prompts

For example, a follow-up telephone call or help with setting up a visiting nurse.
Tell me about any other suggestions. (Repeat until none.)

12. That's all the questions I have for you. Is there anything else that you would like to add?

Before we wrap up, I have a short form to fill out with you.

13a. Who is your PCP?
Name _____Unsure_____ None_____
13b. How many children do you have? _____
13c. How may children do you live with? _____
13d. What other adults are you living with?
Living with spouse/partner _____ Living with other adults(s) _____
No other adults in household _____
13e. What is the highest level of education that you completed?
<8th grade _____ 8th grade _____ some high school _____

high school or GED _____ some college _____
4-year college degree _____ postgraduate degree _____

13f. What is your primary language: _____

13g. Are you comfortable reading discharge instructions written in English?
Yes _____ No _____

13h. ***Skip unless answer is NO to either 13f or 13g.***

Would it be better for you to have discharge instructions written in a language other than English?
Yes _____ No _____

Thank you so much for taking the time to talk with me today. I hope to use the information I've learned to improve the care of all our patients in the future.