Internal and Emergency Medicine (2019) 14:133–138
https://doi.org/10.1007/s11739-018-1943-6

EM - ORIGINAL

Barriers to compliance with emergency department discharge instructions: lessons learned from patients' perspectives

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Received: 16 May 2018 / Accepted: 31 August 2018 / Published online: 18 September 2018

Abstract
The objective of this study is to understand patients' perspectives about system-based barriers that may influence decision-making regarding following discharge instructions. In this qualitative study, subjects were interviewed by phone 1–4 weeks following being discharged to home from the emergency department (ED). We used a semi-structured interview guide to ask a series of open-ended questions about subjects' recent ED visit and subsequent course, including discharge instructions, whether or not they complied with those instructions, and reasoning behind their decisions to follow-up or not. All interviews were recorded and transcribed to identify themes among the transcripts, which were analyzed to identify barriers to compliance. While the majority of those interviewed expressed no specific concerns or challenges, four system-based themes did emerge regarding patient attitudes toward and experiences with discharge instructions. They were: (1) failure to ensure clarity about diagnosis at the time of discharge from the ED, (2) failure to identify patients' feelings of hopelessness regarding the utility of follow-up, (3) difficulty in scheduling follow-up appointments, and (4) the importance of a clear discharge process. This study finds several system-based barriers might influence compliance. The four identified themes suggest a recurring cycle of visiting the ED, being discharged to primary care or specialists, and ultimately returning to the ED. We propose that systems-based interventions may help to break this cycle.

Keywords Patient compliance · Emergency department · Qualitative study

Introduction

There are approximately 110 million emergency department (ED) visits in the United States every year, with 45% of patients being subsequently referred for outpatient follow-up. Unfortunately, it is estimated that only 26–56% of these patients actually follow up [1]. This low follow-up rate creates a number of issues that include premature discontinuation of treatment plans, lack of identification of misdiagnoses, and disjointed long-term management of chronic conditions [1]. Better compliance with follow-up may improve health outcomes, decrease return visits to the ED, and reduce malpractice risk [2]. Several studies have investigated interventions to improve outpatient follow-up rates, but there has been little work to understand the issue of follow-up from the patients' perspectives. We, therefore, conduct this study to describe the issues that have an impact upon whether or not patients decided to follow up for their recent ED visit. Our goal is to characterize patient-identified system-based barriers that may influence decision-making.

Methods

Study design

We conducted a qualitative study about discharge instructions and follow-up among patients who had recently visited

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a single ED. This study design was specifically chosen for its utility in identifying patient-identified issues, not limited by the a priori assumptions of the investigators. Following approval by the institutional review board, we identified study subjects through a weekly database query of patients presenting to the Hershey Medical Center ED from May 1, 2015 to September 30, 2016. Eligible subjects were contacted by phone between 1 and 4 weeks following their ED visit. If the phone call was unanswered, the next subject on the list was called. Phone calls were made at varying times of the day and week over the span of several months. Verbal consent to audio record was obtained at the beginning of the phone conversation. Using a semi-structured interview guide ("Appendix 1"), subjects were asked a series of open-ended questions about their recent ED visit and subsequent course, including discharge instructions, whether or not they complied with those instructions, and the reasoning behind their decisions to follow up or not. The audio recordings were transcribed by a single investigator. In accord with well-established principles of qualitative research [3], each interview was coded for themes and additional interviews were performed until thematic saturation was achieved. Based upon the existing research [4, 5], we anticipated reaching this endpoint with fewer than 24 subjects.

Selection of participants

Subjects were selected based on inclusion criteria, including: (a) being 18 years or older, (b) a presenting chief complaint related to the abdomen including abdominal pain, nausea or vomiting, and constipation or diarrhea, and (c) were discharged home after an ED evaluation and treatment. Abdominal complaints were chosen to narrow the scope of the study to a common complaint that has a historically variable level of follow-up, with fewer than half following up with a primary care provider [6]. Exclusion criteria included pregnancy, residence in a nursing home or other extended care facility, inability to consent, inability to speak English, incarceration, or previously having been included in the study.

Analysis

We began analysis, while interviews were being conducted and continued to recruit subjects for the study until thematic saturation was achieved; this occurred after 20 subjects had been recruited. We performed a thematic analysis of the content of the 20 transcripts using Atlas.ti software (atlasti.com) to aid in text management, coding, and retrieval. The following research questions were used to analyze the data: (i) how does the subject describe comprehension of the discharge instructions? (ii) what are subject-stated reasons for compliance and noncompliance? (iii) what barriers to compliance are identified by the subject? and (iv) what are the subject's perceptions of the health system following discharge? One investigator (ES) read through each transcript, identifying quotes from each subject. The same investigator then developed a code book of themes with conceptual definitions for each theme related to the research questions, which were then reviewed and discussed with the other investigators.

Results

We approached 253 patients to participate in the study. Twenty-two patients agreed to participate and twenty ultimately completed interviews after two patients reported they left the ED prior to being discharged. Of the patients who completed interviews, 7 were male and 13 were female. Average age was 47.6 years (range 28–79). 17 were Caucasian, 3 were African American, and 1 was Hispanic. All were insured (7 HMO, 8 Blue Cross, 3 Medicare, and 2 Commercial).

Four system-based themes regarding patient attitudes toward, and experiences with, discharge instructions emerged from the data. The four themes included: (i) a failure to ensure clarity about diagnosis at the time of discharge from the ED, (ii) failure to identify patients' feelings of hopelessness regarding the utility of follow-up, (iii) difficulty in scheduling follow-up appointments, and (iv) the importance of a clear discharge process.

Clarity about diagnosis

A consistent theme across patient stories was that the patient identified a lack of clarity about diagnosis after discharge. Rather than identifying a diagnosis or list of possible diagnoses, patients frequently reported that the healthcare staff "had no idea what was going on" (subject 1). Other specific examples of responses are below:

- "They pretty much said they saw the signs and symptoms of what I was having, but didn't know what was happening." (subject 1).
- "So yeah I didn't really have a set thing they could really say that they could find other than 'it was just irritated,' and they thought it was just my gastroparesis flared up or something. Like I said I had to go to a different [ED] to find the problem." (subject 4).
- "There was not a definitive diagnosis. I had a chest scan and various blood tests and so forth taken and there was no definitive reason given." (subject 11).

However, it was not always clear that the perception of a lack of knowledge of a diagnosis negatively influenced patients' willingness to comply with discharge instructions.

Some patients reported that they trusted the healthcare staff's recommendations, even though the diagnosis was not clear. For example, when subject 11 was asked what influenced a decision to follow a discharge instruction, the subject stated that "I would say trust." Subject 2 noted that: "Oh well I knew I would follow what they say… I wasn't just going to not follow up."

Patient hopelessness regarding follow up

Hopelessness was a relatively common theme across patient stories. Patients described being stuck in a cycle of visiting the ED, being discharged to follow up with their PCP, following up with their PCP, having their pain or symptoms return, and having to return to the ED, at which point that the cycle resumed again. This cycle influenced their willingness to follow up. Patients reported that the only way to stop the cycle was to stop following discharge instructions, which ironically would ultimately restart the cycle when they were forced to return to the ED. The hope for a diagnosis and treatment plan, therefore, seemed to influence patients' decisions whether to follow discharge instructions.

- "It's been a whole circus of one doctor sending me to another doctor. I went back and forth with the OB/Gyn and the other doctor, and they told me to go to the ED and the ED told me a couple times that if the doctors can't find it they don't know what they can do… They keep saying to come back when it gets worse and when I come back—because it's worse—they don't do anything for me anyway… And they told me to come back if I have more pain, but what's the point in coming back, because I'm taking so much time off work, and it's not doing anything for the situation?" (subject 1).
- "It wasn't until the 3rd hospital on the 4th visit that I went to anybody who even figured that out … they just blow it off and send you home because they say: "Its not an issue for the ED; it's a problem for the specialist", but the problem is you have to wait for a specialist until January, and I even asked my primary care doctor "What do I do if this keeps happening and flares up again?" All he says is if it flares up again to go to the ED because he can't treat it, and I'm already scheduled for the specialist and it's so far away that if it happens again I have no choice but to go to the ED." (subject 4).

Difficulty in scheduling follow-up appointments

Many patients described difficulty in scheduling follow-up appointments, particularly with specialists. Often, the first available appointment would be 1–6 months after the ED visit. While patients could be placed on a waiting list for cancellations, this, nevertheless, often led to delays in care, and in some cases, a return visit to the ED. Despite difficulty in scheduling the appointment and frustration with the healthcare system, patients prioritized attending specialist appointments above any other discharge instruction.

- "Just to make an appointment with the specialist which I did, but I can't get in until January. I kind of expected it. I went to get in with them years ago, but that's when they stopped taking the welfare insurances… I'm used to it with my insurance. They like to make it really hard. It's great to have when you only need minor medical care, but when you need specialists, it's a nightmare… If something happens between now and January I don't know how many ED visits I might have… It all depends on how my body wants to act. And it's very frustrating to know at the end of every ED visit no matter where I go it's going to be: 'Well make sure you follow up with the specialist.' I am, but not until then, so what am I supposed to do?" (subject 4).
- "Yeah, just temporary [medications] until I was put into pain management, but I have to call there because they told me that I had to be put on the cancellation list because I couldn't get scheduled to be there until January." (subject 9).
- "I'm like: 'As big as this hospital is, that's the only thing that you have available? A month later?' And I thought that with these appointments that… are so far out: It's ridiculous." (subject 13).

The importance of a clear discharge process

While some patients reported frustration with various aspects of the discharge process, others reported that they trusted the healthcare professionals' recommendations, and were able to completely follow the discharge instructions. These patients reported that good communication, written instructions, being contacted by their PCP following their visit, personal experience in the healthcare field, and having a friend or family member present during the ED visit all contributed to the ease of the following discharge instructions.

- "The directions were pretty easy; when I was discharged, I was discharged with medications, and I continue to take those, and I followed up with my family physician the very next day, so everything was really self-explanatory if you read the directions." (subject 7).
- "I was told that because it was going to be surgery, they would be contacting me within the next day or so to get everything scheduled for surgery. And by the time I got out of the ED and into the car, I already had a voicemail on my cell phone where they had called and said: 'We just wanted to follow up, and we will be scheduling you

for surgery… it looks like it will be a Monday, someone will call you on Thursday with the time and all that information.' And that's exactly what they did." (subject 8).

- "After my diagnosis on Sunday, the following day, I had an appointment with my doctor … where he (told me to go to) a gastroenterologist and now going to a colonoscopy later on. He did what he needed to do!" (subject 10).
- "I found the recommendations easy to follow. I was very glad that I had the printed out version to follow, because when I left the ED, I was feeling better than when I walked in, and I hadn't been eating and hadn't been getting a lot of fluid in my body, so I wasn't the most attentive human in the world. So, I did need to reference those directions a couple of times, so it was helpful to have them written down, but there wasn't anything confusing or any misunderstanding about what I needed to do; it was just a matter of how fast I needed to drink and what foods to start with. I was very pleased with the way I was treated in the ED and with the discharge instructions." (subject 17).

Discussion

The issues having an impact on compliance with discharge instructions are complex. Atzema and Maclagna [7], in a scoping review of the literature, found 38 studies that addressed follow-up compliance and its predictors. Of them, 12 investigated the association between insurance status and compliance, and 10 found a significant correlation. Other factors identified in their reviewed studies included age (increased compliance at both extremes of age), existence of a primary care provider (decreased compliance with lack of a PCP), a better patient understanding of the reason for following up (increased compliance), and increasing disease severity (increased compliance). Race as an independent variable was assessed in two studies with differing conclusions.

Several studies have attempted to characterize the factors that associated with compliance with discharge studies. Kyriacou [1] found that making a follow-up appointment for patients at the time of discharge improved compliance but did not find a statistically significant association with having a primary care physician, insurance status, or other sociodemographic characteristics. McCarthy [8] found that referring uninsured patients who lacked a PCP to a community health center did little to improve follow-up rates, concluding that lack of access was not the sole explanation for failures to follow-up. Qureshi [9] found, in addition to socioeconomic considerations, that patients' lack of understanding of the reason for follow-up or a belief that follow-up was not necessary was significantly associated with failure to follow up with their general practitioner. Gignon [10] found that adherence with discharge instructions was significantly correlated with a lack of understanding of those instructions, particularly in regard to medication prescriptions.

However, all of the studies mentioned above started with a priori hypotheses by the investigators about the factors related to noncompliance with discharge instructions. To our knowledge, no studies to date have interviewed patients to investigate what barriers that they perceived existed to following ED discharge instructions. This qualitative study explored patients' experiences with discharge instructions and their stated reasons for complying with, or not, to the recommendations made by the ED personnel.

A qualitative, as opposed to quantitative, study design was selected, because it is "an approach for exploring and understanding the meaning individuals or groups ascribed to a social or human problem" [11]. As such, it can be informed by a constructivist worldview with several underlying assumptions [12]:

1. Human beings construct meanings as they engage with the world that they are interpreting.
2. Humans engage with their world and make sense of it based on their historical and social perspectives.
3. The basic generation of meaning is always social, arising in and out of interaction with a human community.

Such a design is inductive, i.e., proceeds from observation towards the development of a theory or hypothesis (in contrast to a quantitative approach that starts with a hypothesis and then accumulates observations to support or refute it), and is particularly appropriate for this sort of inquiry.

Thematic saturation is a core-guiding principle to determine sample size in qualitative research [3, 13]. We reached this endpoint after 20 interviews. This number is consistent with that determined by Hennink [4] (who found that saturation was typically reached in 16–24 interviews) and Guest [5] (who found that saturation typically occurred within the first 12 interviews).

The four themes that we identified form a recurring cycle, as demonstrated in Fig. 1. While patients sometimes reported a clear understanding of their discharge instructions, at other times, they reported a lack of knowledge of a discharge diagnosis, which had downstream effects. As the cycle continued with a recommendation to follow up with a primary provider or specialist, a breakdown in the system occurred when patients were unable to make an appointment in a reasonable timeframe. For example, some patients found it unacceptable, given their symptoms, to be scheduled appointments weeks to months after their ED visit. Despite the waiting time, patients emphasized the importance of following through with the appointment and planned to attend, but reported that, if their pain or symptom was to return in

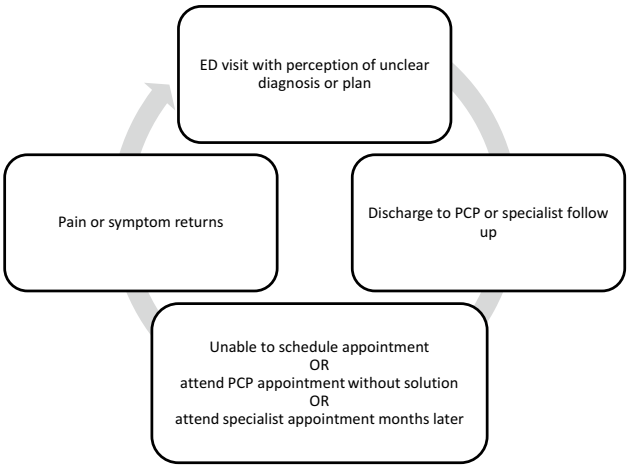

Fig. 1 Cycle identifying barriers to adherence with follow-up plans

the interim, they were forced to return to the ED. This contributed to a feeling of hopelessness and a longing for resolution. In an interesting reversal of the barrier to follow up, some subjects reported that they would continue to return to their healthcare providers in the hope that "someone might stumble upon what it is."

When patients did not enter this cycle, or were able to break it, this promoted compliance with discharge instructions. It is important to consider the system-based barriers that influence this cycle. These may include increasing availability of specialists, providing appointments directly from the ED, increasing communication between ED providers and PCPs, or improving clarity of communication and reducing uncertainty by formulating a plan about what to do if the symptoms recur. These may all lead to improvement in patient-centered care, prevent the feeling of hopelessness, and reduce overuse of the healthcare system.

Our study has several limitations. The study was performed in the setting of an academic teaching hospital in a suburban/rural setting. It is, therefore, subject to a population bias, i.e., it is characteristic of a particular geographic area and may not reflect other areas or healthcare systems. This study includes the stories of 20 patients with a single presenting symptom, and may not be comprehensive of a larger patient population presenting with a variety of other complaints. Selection bias is also a consideration, as it was necessary to approach 253 individuals to identify the 20 who ultimately completed the interview. There is no way to determine that these 20 had the same concerns as the larger group. However, having achieved thematic saturation suggests that the likelihood of having missed other issues is small. The issue of long-lag times in specialist referrals may be a phenomenon unique to an academic medical center; it would be instructive to gather similar data from a community-based ED.

In conclusion, we studied the perspectives of patients being discharged from the ED, and identified four common themes in patient narratives about compliance with discharge instructions. Future research is needed to further characterize these themes, identify themes in different populations, and explore the effects of potential interventions specifically tailored to overcome these barriers in the ED discharge process.

Acknowledgements The authors would like to thank Nancy Campbell, RN, and her research project team for the assistance in the planning and conduction of this study.

Compliance with ethical standards

Conflict of interest The authors have no potential conflicts of interest.

Human and animal rights statement All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

Appendix 1. Semi-structured interview guide

1. I would now like to begin asking you a few questions about your recent visit to the Emergency Department at Penn State Hershey Medical Center on ___(date)___.
2. When you left the emergency department, what was your diagnosis?
    a. Could you tell me more about your understanding of that diagnosis?
3. Tell me about the physician's or healthcare staff's recommendations for when you were discharged.
    a. Probing questions:
        i. What (if anything) was difficult to understand and why?
        ii. What (if anything) was easy to understand and why?
        iii. What people or things (that you or others did) helped you understand the recommendations?
        iv. Regardless of whether you agreed or not with the recommendations (we will get to that in a moment), describe how well you felt that you understood the recommendations when you left the ED?

4. Could you tell me about your experience in following those recommendations?
5. Talk about any medications that you were given prescriptions for.
    a. Probing questions (ask for each prescription).
        i. What were your thoughts about the prescription?
        ii. How well did you think it would work? Please explain.
        iii. What influenced your decision to fill or not fill the prescription?
        iv. What did you expect that the prescription would do? How well did it meet your expectations?
        v. What (if any) financial issues were there in getting the prescription?
        vi. What (if any) financial hardship did paying for the prescription cause?
6. Describe the plan, as you understood it, for following up with a doctor or other health provider after your ED visit.
    a. Probing Questions.
        i. What were your thoughts about this follow-up plan? (Probe whether they intended to follow it or not and why).
        ii. How well were you feeling at the time your follow-up was to occur? How if at all, did this influence your decision to attend the follow-up visit?
        iii. What (if any) financial issues influenced your decision to follow-up or not follow-up?
        iv. What (if any) barriers did you encounter to attending your follow-up appointment? (probe transportation, scheduling, etc).
7. We have talked about what the emergency physician thought was going on and what plan they recommended when you were discharged. What did you think was going on?
    a. How, if at all, was that different from what the doctors were thinking?
    b. What (if any) effect did that have on your decisions to follow the plan they suggested or not follow it?
    c. How much input did you feel that you had in making the plan?
    d. If you could have made up your OWN plan, what would it have been?
    e. What were you hoping the doctors would do when you decided to go to the ED? Did that happen? (Why or why not?)
8. This concludes the interview. Do you have any questions for me?

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