

## ORIGINAL RESEARCH

**A qualitative study of young women with high hospital utilization: Patient perceptions of the transition from pediatric to adult care**

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**ABSTRACT**

**Introduction:** Patients who are frequently admitted to the hospital are a highly vulnerable population. Our interdisciplinary STEP program works intensively with these patients on the inpatient general medicine service to improve care coordination, improve health, and decrease hospital utilization. Of enrollees in the first three years of the program, over half were 18-35 years old, and of these patients, over 80% were women. We explored perceived challenges faced at the time of transition from pediatric to adult care.

**Materials and Methods:** In depth, semi-structured interviews were carried out with 11 women ages 18-35 who were currently or previously enrolled in STEP. Interviews were audio recorded, transcribed, coded, and content analyzed.

**Results:** Of the patients interviewed, 64% had a primary diagnosis of sickle cell disease. Three primary themes emerged: lack of support in transition from pediatric to adult care, strained communication with providers as a barrier to care, and worsening health as patients entered adulthood. Over 70% of participants reported 2 or more Adverse Childhood Experiences (ACEs), with an average of 3.6.

**Conclusions:** The experiences of participants in this study suggest multiple avenues for patient-centered interventions that improve care in this population, all based on improving communication and shared decision making between patients and providers. One crucial area for improvement is the transition from pediatric to adult care. This transition represents a vulnerable time, during which many patients – and, in particular, individuals with ACEs – would likely benefit from additional support.

## INTRODUCTION

Patients who are frequently admitted to the hospital are a highly vulnerable population, often facing medical, social, and behavioral health challenges that are compounded by discontinuity between hospital admissions and care settings. While patients with frequent admissions represent a disproportionate percentage of hospital admissions and healthcare expenditures nationwide,<sup>1-3</sup> their needs are frequently not met by traditional care models.

At the Hospital of the University of Pennsylvania (HUP), the multidisciplinary STEP Program works specifically with patients with extreme hospital utilization (a minimum of five but often 10-30 admissions per year), with the aim of streamlining care, improving care coordination, improving health, and decreasing hospital utilization. Of program enrollees in the first three years of the program, over half were 18-35 years old, and of these, over 80 percent were women. Our extended work with these patients led us to hypothesize that challenges faced at the time of transition from pediatric to adult care may have played significant roles in many patients' experiences and utilization over time.

Prior research has identified many risk factors for high health care utilization,<sup>4,5</sup> and several studies have elicited patients' perceptions of factors contributing to high hospital use.<sup>1-3</sup> To our knowledge, however, no work has specifically focused on young women with high hospital utilization, either in general or specifically related to the transition from pediatric to adult care. This study aims to better understand the perceptions and experiences of this important subset of the high utilizer population.

## MATERIALS AND METHODS

### Setting, Study Design, and Participants

This study was carried out at the Hospital of the University of Pennsylvania, a 695-bed urban academic hospital located in Philadelphia, PA. Between September and December 2019, we recruited women ages 18-35 who were currently or previously enrolled in the STEP program. Eligible patients for the STEP program had a minimum of five, but often 10-30, inpatient admissions per year to general medicine and experienced at least one psychosocial barrier to care. After exclusion of patients who were deceased or had discontinued communication with the program, 17 patients were deemed eligible as of September 2019. This study was deemed exempt by the University of Pennsylvania Institutional Review Board.

### Participant Enrollment & Data Collection

We developed a semi-structured interview guide of open-ended questions, designed to identify drivers of frequent hospitalizations, patients' experiences with the transition from pediatric to adult care, and patients' perceptions of how their care could improve (see appendix). Participants self-reported demographic data including race, age, primary diagnosis, and number of hospital admissions in the past 12 months. Participants were asked to respond to a survey regarding adverse childhood experiences (ACE), which was adapted from the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System (BRFSS) ACE Module (see appendix).<sup>1</sup>

Interviews were conducted by two medical students (MS, GM) trained in qualitative interviewing. The medical students approached patients during hospital admission, explained the study, and asked if patients wanted to participate. Most interviews took place in-person during

admission. The remaining interviews were conducted over the phone.

### Analysis

Interview audio files were transcribed, de-identified, and entered into NVivo 12 for coding and analysis. Using content analysis, a codebook was developed to closely match common themes and ideas identified in the interviews. Two coders (RN, CK) established strong inter-rater reliability,  $\kappa = .85$  with four (36%) interviews. The remaining seven interviews were divided between reviewers and coded independently.

## RESULTS

### Overview

Interviews were carried out with 11 participants (Table 1). Of the 17 eligible patients, 14 were successfully contacted. Of the three patients who were contacted but not interviewed, two declined to be interviewed, and one could not be reached after an initial introduction. Among those interviewed, nine identified as Black or African American (82%), with a mean participant age of 25.9 (SD 2.6) years. Seven (64%) had a primary diagnosis of sickle cell disease (SCD), and the other participants had type I diabetes mellitus, end-stage renal disease, and systemic lupus nephritis. Over 50% reported more than 16 admissions in the past 12 months. Participants reported an average of 3.6 and median of 3.0 (SD 3.1) ACEs.

Three primary themes emerged in interviews: lack of support and decline in quality of care in the transition from pediatric to adult care, strained communication with providers as a barrier to care, and decompensation in illness as patients enter adulthood. Illustrative quotes are presented in Table 2.

**Table 1:** Patient Characteristics

Characteristics (n=11)	Value
Black or African American, n (%)	9 (82%)
Age, mean (SD)	25.9 (2.6)
Primary Diagnosis of Sickle Cell Disease, n (%)	7 (64%)
Adverse Childhood Experiences, mean (SD)	3.6 (3.1)
Hospital admissions in the past 12 months, n (%)	
0-5	0
6-10	5 (45%)
11-15	0
16-20	1 (9%)
20+	5 (45%)

**Theme 1:** Transition from pediatric to adult care was fragmented and difficult to navigate

#### 1a: Lack of organizational support

Seven patients reported being told with little notice that they would no longer receive care at their pediatric hospital and were given little to no information about how to successfully transition to an adult physician. This change often led to lapses in care, issues in transferring medical records, and moving between several physicians and hospitals in a short period of time. During the transition period, care was particularly erratic, as patients lacked a primary doctor and had no clear care plan. Patients felt overwhelmed and wished they had been provided with a referral for an adult physician to help them avoid a gap in care.

#### 1b: Shift in social support as parents step back from caregiver role

During childhood, patients primarily received support from their families in managing symptoms and coordinating healthcare. Seven participants specifically mentioned their parents as key supports in scheduling and attending appointments, organizing medications, and communicating

with providers. In contrast, as adults, interviewees felt that they had gone from being taken care of (either by their physicians, family members, or both) to having to navigate their care on their own. This shift in support meant scheduling appointments, remembering to take medications, and advocating for their own health.

**1c:** Loss of strong alliances with pediatric providers

Ten participants explicitly mentioned that they were more satisfied with their healthcare during childhood than adulthood. This preference was primarily attributed to the compassion their pediatricians offered them. Participants felt their childhood providers were more attentive to their needs, explained medical concepts in terms they understood, and made them feel comfortable during their hospital stay. They felt these relationships were lacking in adult settings.

**Theme 2:** Strained communication with care team

Participants noted significant barriers to developing a successful relationship with their providers, noting mistrust, lack of empathy, and communication failures.

**2a:** Lack of shared decision making and empathic communication

Interviewees felt that their physicians did not listen to them. A few patients noted that when they had a pre-established care plan in place that they liked, their physician often ignored it or declined to make changes when the patient felt it was necessary. Other patients noted that, even when a physician asked for their input, suggestions were not taken seriously. They felt that, as a result, their symptoms were not controlled during their hospitalization and that they were more likely to come back sooner with similar complaints.

**2b:** Breakdown in trust between patients and providers

A lack of empathy and communication issues led to distrust between patients and providers. Patients said that they did not trust their physicians to listen to them, noting that they felt as though their physicians judged them, often before even meeting them. In some cases, this perception led patients to give up on trying to advocate for their care because they felt it was pointless.

**2c:** Accusations of drug-seeking by providers

The most common complaint participants raised about their physicians was that physicians frequently dismissed reports of pain as attempts to obtain prescription medications for illicit use. Seven participants noted that they had been accused of drug-seeking behavior by their provider and, as a result, were denied care they needed. Interacting with these physicians was difficult for patients as they felt that their physicians had made up their minds as to what the patient wanted and were not amenable to changing their perspective. Notably, six of the seven participants who mentioned being accused of addiction to pain medications were African American.

**Theme 3:** Worsening of illness severity over time

Participants noted that their condition had changed significantly since they were children and, in many cases, had become more severe and harder to manage. Overall, patients perceived that admissions were less frequent on average prior to transition. When asked how many admissions they had in their last year at the children's hospital, 50% reported less than five, and all reported less than 20. When asked how many admissions they had over the previous 12 months, all reported above five, and 45% reported over 20.

**3a:** Destabilizing life events and mental health exacerbating illness

A bi-directional relationship between mental and physical health was noted as a significant challenge for interviewees. Stressful life situations such as experiencing grief, going through a significant break-up, or being exposed to anxiety triggers were noted as causes for physical symptoms of chronic diseases. These sentiments were exclusively raised by African American participants with SCD.

**DISCUSSION**

These semi-structured interviews provide important insight into how we may be able to improve care for this population of young women with frequent hospitalizations.

First, this study delves into the experience of transition from pediatric to adult care in this vulnerable population. Many of the challenges noted by the participants are consistent with existing literature on this topic, including changing relationships with providers, adjusting to an unfamiliar hospital culture, and establishing independence and responsibility.<sup>1,2</sup> This study adds to the literature by providing perspectives from a population of patients who are years removed from transition and who have had fragmented and inconsistent care since entering adulthood. While we do not know whether poor transition itself is directly causative of subsequent problems (versus reflective of underlying challenges that persist into adulthood), the fact that patients see this as a time when care deteriorated suggests a key role for supportive programs. At a minimum, such programs could serve to smooth the transition to an identified adult provider, manage expectations, and make recommendations to improve patients' early experiences in adult hospitals.

Second, this study reveals the high prevalence of ACEs in this population. Per the 2016 National Survey of Children's Health, one in ten children nationally has experienced three or more ACEs, placing them in a category of especially high risk.<sup>1</sup> Stress and psychosocial trauma early on in life have been associated with poor health into adulthood. Specifically, people who have four or more types of exposures to childhood adversity have a 4- to 12-fold increase in risk for alcoholism, drug abuse, depression, and suicide attempt and a 2- to 4-fold increase in poor, self-rated health.<sup>4, 5</sup> This study suggests that ACEs might be an important screening tool to identify patients who require additional care coordination as they transition.

The themes elicited in our study add to prior qualitative work addressing perceptions of patients with high healthcare utilization. In a recent study at Northwestern, work to elicit patients' perceptions of factors contributing to high hospital use identified several themes including the important role of psychological, social, and economic factors in course fluctuation, the perception of acute illness as uncontrollable and unpredictable, and a strong desire to avoid hospitalization. Prior qualitative work with complex, high-needs patients enrolled in the Camden Coalition of Healthcare Providers Care Management Team identified relationships with care provider teams, and a history of early life trauma, as factors related to current utilization. Our work highlights the importance of communication and establishing strong provider relationships and identifies the time of transition to adult care as one of particular vulnerability. Notably, as in the prior studies above, housing insecurity and substance abuse did not emerge as themes identified by our patients as proximal drivers of high hospital utilization.<sup>2-5</sup>

## LIMITATIONS

This study has several limitations. The number of eligible patients was small, reflecting the highly specific population. We were unable to contact all eligible patients, and it is unknown whether non-enrolled patients may differ in their perceptions from those who participated. This study was conducted in a single large urban academic hospital that is affiliated with an academic children's hospital, where most of these study participants received care as children. Participant experiences in this type of specialized well-resourced pediatric institution may have played a role in their experiences of transition, making their experiences specific to this setting. This study excluded male patients and those over the age of 35 to capture the experiences of a specific population that is overrepresented among extreme high utilizers enrolled in our hospital's STEP program. This population might not be representative of frequently admitted patients in other health systems.

## CONCLUSION

The experiences of young women in this study suggest multiple avenues for patient-centered interventions that may improve care, all based on improving communication between patients and providers. The experiences of these patients, and high utilizing populations in general, provide a window into the cracks in our systems of care. Identifying these cracks can help us understand where the system can be improved not only for this population, but also globally to the benefit of all patients. One crucial area for improvement is the transition from pediatric to adult care. This transition represents a vulnerable time, during which many patients – particularly those with a history of ACEs – would likely benefit from additional structure and support.

**Table 2:** Themes, Subthemes, and Representative Quotes

<b>Theme</b>	<b>Subtheme</b>	<b>Representative Quotes</b>
Transition from pediatric to adult care was fragmented and difficult to navigate	Lack of organizational support	<p><i>“And that’s honestly how I felt, like I just was thrown out to the wolves and figure it out.”</i> (Participant 4, African American, Lupus, 24 years old)</p> <p><i>“At [children’s hospital], they’re on top of you and take care of you. At the adult hospitals, it’s really just on you, and you have to be your own advocate.”</i> (Participant 1, white, End Stage Renal Disease, 27 years old)</p> <p><i>“You know how mom birds leave the nest when they feel like their kids are ready to try and get out there on their own. That’s how I feel like once you’re leaving [children’s hospital]. You pretty much get graduated and you’ve got to try it out on your own. You have to try and find a doctor. You have to try find like a hospital.”</i> (Participant 5, African American, Sickle Cell Disease, 25 years old)</p>
	Shift in social support as parents step back from caregiver role	<p><i>“Well, as a kid my mom really took care of me, so it was easier because I could-- it was easier because she was taking care of me and I didn’t have to worry about anything because she always had my back.”</i> (Participant 7, African American, Sickle Cell Disease, 22 years old)</p> <p><i>“It was just difficult to know where you were in the process, what you had to do next in the process. If you had to sign papers for the insurance, who had the insurance? And then I didn’t have my parents to guide me either, because they had gone back to regular working and everything. So it was like I was in the dark with a little match to light the way. And it wasn’t much.”</i> (Participant 2, African American, Sickle Cell Disease, 29 years old)</p>
	Loss of strong alliances with pediatric providers	<p><i>“The bedside manner, it still exists at those Children’s Hospitals. At the adult hospitals, the bedside manner, it doesn’t exist there anymore. The care just doesn’t exist anymore. They don’t even have a heart. They don’t care.”</i> (Participant 6, African American, Sickle Cell Disease, 26 years old)</p>
Strained communication with care team as barrier to care	Lack of shared decision making and empathic communication	<p><i>“I’m always in the hospital longer than a week, sometimes three weeks. And I hate it because nobody ever wants to listen to me, but they always ask me, ‘[Participant], how do you think we should take care of your pain?’ And then as soon as I say how I think they should do it, ‘Oh, well, you know we can’t do that.’”</i> (Participant 3, African American, Sickle Cell Disease, 32 years old)</p> <p><i>“I just felt like the doctors were rushing me out from the first day that I got there. The same day that I got there they were asking, ‘When do you think you will go home?’ And started to go down on my medication quick and stuff.”</i></p>

		<i>I just felt like I was rushed.</i> ” (Participant 10, African American, Sickle Cell Disease, 28 years old)
	Breakdown in trust between patients and providers	<p><i>“I do not wanna go to any appointments as an adult. But as a child, I wanted to do all of it. I was happy, excited to go see my doctors because I loved my team. They were great. But as an adult, I don't talk. I just go to my appointments, hear what they're saying, hear what they gotta say, get my prescriptions, and I go.”</i> (Participant 10, African American, Sickle Cell Disease, 28 years old)</p> <p><i>“I can't tell you how many doctors I've got that really seem as if they didn't care. And it makes me want to cry right now because it's like you guys are in this to care, why don't you care?”</i> (Participant 5, African American, Sickle Cell Disease, 25 years old)</p>
	Accusations of drug-seeking by providers	<p><i>“I'm just another black woman with sickle cell, a young black woman with sickle cell and they just think that it's for the drugs. It's not.”</i> (Participant 6, African American, Sickle Cell Disease, 26 years old)</p> <p><i>“When I'm in pain and I come in for pain medication, I've had doctors tell me they're not going to lose their license over treating me and getting me out of pain.”</i> (Participant 2, African American, Sickle Cell Disease, 29 years old)</p> <p><i>“Some people have a high tolerance for pain. I just don't, and you know, sometimes it scares me because I feel like, ‘Oh, I don't want the doctors and stuff to be thinking, Oh, I'm abusing drugs.’ No, I'm not abusing drugs. I'm just trying to keep myself out of the pain.”</i> (Participant 4, African American, lupus, 24 years old)</p>
Worsening of illness severity over time	Destabilizing life events and mental health exacerbating illness	<p><i>“Some people might think it's easy or, “Oh, you're just in pain, you okay.” No, that's just not it. It's not just the pain. It's meant to – it messes with your brain. It messes with your state of mind. It messes with everything. That's why I have depression. That's why I have anger issues. That's why I have anxiety and stuff like that [crying] because when you go through stuff like this, it's so scary.”</i> (Participant 7, African American, Sickle Cell Disease, 22 years old)</p> <p><i>“Well, for one thing, the stress can affect my blood sugar. And then I just stress even more because then my blood sugars aren't good. That's like a never-ending circle sometimes.”</i> (Participant 8, white, Type I diabetes, 28 years old)</p>



**Appendix:****Interview Question Guide****Let's first talk first about you and your health now:**

1. Please tell me about your disease and how it has affected your life.
2. Can you talk about the last time you were in the hospital (or if currently admitted, your current hospitalization)?
  - a. Why did you feel you needed to come to the hospital?

**Now let's go back in time and talk about your health as a child**

3. Tell me what it was like taking care of your disease as a child. (e.g. taking medications, going to appointments, hospitalizations)
4. About how old were you when you started needing more hospital stays?
  - a. Prompt: What happened at that time to cause you to need more hospitalizations?

**Let's talk about your transition from care as a child to care as an adult.**

5. How would you compare your disease management as a child versus as an adult, in terms of how sick you were from your disease?
  - a. Prompt: If things got better, why do you think that happened?
  - b. Prompt: If they got worse, why do you think that happened?
6. How would you compare your interactions with your doctors and hospital as a child versus as an adult?
7. What could have made your transition from pediatric to adult care easier?

**Now let's talk about how your medical care could improve now.**

8. What can your doctors and other care providers do now to help you feel healthier?
  - a. Prompt: Do you think there is anything that can help prevent you from needing to come into the hospital?
9. For my last question: many people with chronic diseases are impacted by stress and mental health, [which we haven't discussed yet.] How do you feel your disease is impacted by these factors?

## ACE Questionnaire

Prologue: I'd like to ask you some questions about events that happened during your childhood. This information will allow us to better understand problems that may occur early in life, and may help others in the future. This is a sensitive topic and some people may feel uncomfortable with these questions. Please keep in mind that you can ask me to skip any question you do not want to answer. All questions refer to the time period before you were 18 years of age. Now, looking back before you were 18 years of age---

1. Did you live with anyone who was a problem drinker or alcoholic?
2. Did you live with anyone who used street drugs or who abused prescription medications?
3. Did you live with anyone who was convicted of a crime and sentenced to serve time in a prison, jail, or other corrections facility?
4. Did you live with anyone who was depressed, mentally ill, or suicidal?
5. Did your parents or adults in your home ever hit, punch or beat each other up?
6. Were your parents ever separated or divorced because of marital problems?
7. Not including spanking, did a parent or adult in your home ever hit, beat, kick, or physically hurt you in any way?
8. Did a parent or adult in your home ever swear at you, insult you, or put you down?
9. Did an adult or anyone at least 5 years older than you try to make you touch them sexually?
10. Did an adult or anyone at least 5 years older than you ever touch you sexually?
11. Did an adult or anyone at least 5 years older than you force you to have sex?

Response options:

Yes

No

DK/NS

Refused

Additional option for question 6: Parents not married

Source: CDC BRFSS ACE Module

**Notes**

**Conflicts of Interest:** None declared.

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