

Homeless High Users of the Emergency Department: Understanding the Relationship Between  
Life Stress and Emergency Department Use

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**Abstract**

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**Background:** Patients who frequently use Emergency Department (ED) services are particularly vulnerable to poor health outcomes and have high healthcare costs. Homeless high users have particularly complex healthcare needs and increased difficulty in using and accessing healthcare. To determine modifiable targets for intervention, understanding patient perspectives on their healthcare service use must first occur; however, patient perspectives, especially those of homeless high users, have been absent from the literature.

**Aim:** To describe the views of homeless high users of the ED about the influence of life experiences on their ED use.

**Methods:** Researchers conducted in-depth, semi-structured interviews with 18 homeless persons with more than four ED visits in the six months prior to interview date. Interviews were audio

recorded and transcribed verbatim for analysis in Dedoose by three coders. Qualitative analysis was performed in three phases—open, axial, and selective—to illuminate final themes.

Quantitative data from medical records triangulated interview data and interviewer notes.

**Results:** In describing the pattern of use by homeless high users, four domains emerged: a (1) *crisis moment* leads to increased ED use, which warrants an (2) *intervention* that (3) *stabilizes* patients for a period; (4) *predisposing instability* impacts both whether a crisis moment will occur and the degree to which a crisis moment impacts ED use.

**Conclusions:** This work contributes to understanding the multitude of factors that impact ED use among the most vulnerable patients, which is the first step in elucidating promising interventions. Future interventions should consider expanding evidence-based case management programs. The next research step is to standardize a set of data socioeconomic data elements to determine which patients warrant intervention immediately after a crisis point rather than after ED use has drastically increased.

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# **Introduction**

## *Background*

The role of emergency departments (ED) is changing, especially in light of a transforming healthcare system. EDs were originally designed to provide high quality medical treatment to those in need of immediate care for traumatic injury, as well as to provide counseling and social interventions for those in need of care.<sup>1</sup> Today, the ED continues to serve that purpose but has expanded its role in the US healthcare system; ED providers are treating increasingly complex patients, providing triage for inpatient admission, diagnosing and testing for new disease, and conducting surveillance for disease and injury,<sup>2</sup> as well as treating acute episodes for chronic conditions<sup>3</sup> and providing social services. As patients face many barriers to access to timely primary care,<sup>4,5</sup> the ED's role as a healthcare safety net, providing care for some of the most vulnerable patients, becomes ever more imperative.<sup>6,7</sup> The Institute for Healthcare Improvement Triple Aim offers that the priorities of the healthcare system are to improve patient experiences and to improve the overall health of populations, while reducing the per capita cost of care.<sup>8</sup> EDs are often a costly means of care, between 2 to 5 times the cost of primary care,<sup>9</sup> and as such are under enormous pressure to reduce costs.<sup>9</sup> The transformation of the healthcare system is driving EDs to find ways to minimize costs while maintaining the health of the high needs populations they serve.

Reducing ED service use of high users benefits both high users themselves and the facilities from which they receive care. ED high users are particularly vulnerable to poor health outcomes due to a variety of factors, including lack of continuous care,<sup>5</sup> the increased likelihood

of unnecessary tests and procedures, and the episodic, rather than continuous, nature of ED use.<sup>10</sup> High ED users are also likely to have a greater burden of illness, more likely to have psychosocial problems, and are admitted to the hospital on a more frequent basis than patients with other care patterns.<sup>11-13</sup> These patients also impact the EDs they visit. A decade-long study conducted by the New England Healthcare Institute found that 30-50% of all ED visits are “avoidable,” meaning that they could be eliminated without reducing the quality of patient care, and that the elimination of these visits could result in yearly savings of up to \$38 billion for EDs.<sup>5</sup> These “avoidable” visits are deemed as such because they result either from patients seeking non-urgent care at the ED or, more often, patients who seek care for conditions that could have been prevented by regular primary care.<sup>5</sup> However, the structural and psychosocial barriers to accessing primary care for many patients often means that these “avoidable” visits are their only avenues to timely, effective care.<sup>14</sup> High users of the ED also contribute to overcrowding, which increases wait times and contributes to stress of staff and patients alike.<sup>5</sup> Finally, between 1-5% of overall ED patients account for as much as 21-28% of annual ED visits and costs.<sup>15</sup> Reducing the costs accrued by high users of ED services could reduce costs for all patients and payers.<sup>5</sup> Efforts should be made to increase access and linkage to outpatient and preventive care in order to reduce the use of the ED when possible.

High users of ED services have high-acuity conditions and a high burden of disease.<sup>16,17</sup> Two narratives dominate the conversation for why a subset of patients so frequently visit the ED. The first suggests that many high users misuse the ED in place of primary care or only to receive shelter, food or other services.<sup>5</sup> Several explanations for the preference of the ED over primary care exist, which vary by person and region due to differing structural contexts, such as public policy.<sup>12,18,19</sup> However, this narrative has been debunked through several studies; for example,

low-acuity visits account for only around 6% of ED visits, suggesting that many ED visits by high users are warranted and urgent.<sup>19</sup> Alternatively, the second narrative posits that high users of ED services instead represent rational use of the ED due to the presence of complex chronic conditions, often complicated by substance use and/or mental health disorders.<sup>19</sup> Although significant barriers to accessing better preventive or ongoing primary care exist, management of patients through these services may reduce or prevent these occurrences in numbers and/or severity.<sup>5</sup> Other reasons given for frequent ED use include: being refused care in a clinic before, the perception that an ED visit costs less than a regular visit,<sup>20</sup> poor communication with providers, lack of access to other care,<sup>2</sup> and lack of health insurance.<sup>21</sup> The complexity of the conditions faced by ED high users warrants a multi-faceted approach to reducing ED use.

Several methods have successfully reduced ED use among its most frequent users. Although ED physicians only make up 4% of the physician workforce, they treat 11% of acute care visits annually.<sup>4</sup> As emergency physicians are trained to diagnose and treat the immediate condition at hand, rather than guide long-term use and care coordination,<sup>9</sup> they rely on support from those more experienced in care coordination, such as social workers. A two-year randomized trial demonstrated that case management significantly reduces psychosocial problems among ED high users, including homelessness, alcohol use, lack of health insurance and social security income, and financial need, as well as reductions in ED use and cost.<sup>22</sup> In Washington state, emergency physicians partnered with Medicaid in a seven-step program that ultimately reduced Medicaid fee-for-service costs by ten percent in six months, primarily through inter-site care integration and care coordination.<sup>19</sup> Clinical case management represents a promising method of reducing ED use and improving quality of life for high users.

Socioeconomic status complicates the care of a subset of high users. Homeless patients in particular have complex healthcare needs and have increased difficulty in using and accessing health services.<sup>23</sup> Risk factors for high utilization of ED services among homeless patients include mental illness, drug misuse, violence, social isolation, comorbidities, and chronic illnesses.<sup>23</sup> Because of the chaotic nature of their life styles, these patients often experience barriers to recovery, as medication or care plan engagement may prove difficult. These patients also often visit the ED for psychiatric emergencies.<sup>24</sup> Patients who use psychiatric emergency services are then more likely to have developmental delays, to be uncooperative, to have unreliable social support, and to have a lifetime history of incarceration and substance use.<sup>24</sup> Patients whose care is complicated by unique social conditions warrant more tailored interventions.

### *Research Question*

An in-progress study is qualitatively exploring the specific life experiences affecting healthcare utilization amongst a group of homeless high users of the ED in Seattle. Results from this study will be used to describe the experiences of a group of homeless high users of the ED, potentially identifying some regional factors associated with high ED use and strategies to improve services for these patients. In accordance with other studies, these patients' ED use may exist in an identifiable pattern based on their interactions with the healthcare system and socioeconomic factors.<sup>25</sup> The primary aim of this descriptive, mixed methods thesis is to explore potential patterns of healthcare utilization through secondary analysis of the qualitative data collected in participant interviews with a focus on participants' life experiences and encounters with the medical system. Further, quantitative medical record data will be triangulated with the qualitative results to better understand the healthcare utilization patterns of these ED high users.

*Primary research questions: There are four components to the primary research question:*

- a. Is there an identifiable pattern of ED use for this group of homeless participants? If so, what is it?*
- b. Are there life experiences that impact ED use? If so, what are they?*
- c. Are there common experiences? If so what are they?*
- d. What might be points of intervention?*

Further, as a secondary aim, this study will analyze the quantitative data from medical records to describe ED use and potential contributors to high ED use. In addition to those patterns elicited from the qualitative analysis, some patterns not discussed in interviews nonetheless contribute to the story of increased ED use.

*Secondary research question: How do participants' medical records corroborate or contrast the themes elicited from interviews?*

## **Methods**

### *Study Setting*

The ED High User Case Management (HUCM) program offers short-term, intensive case management for individuals with four or more visits to the emergency department within three months. The program has reduced ED use of these patients by 55% and inpatient charges by 63%.<sup>26</sup> Further, a significant decline in ED charges from the patients saved the hospital an estimated \$2.2 to \$5.5 million in 2014. In partnership with this program at an urban, level 1 trauma center, researchers recruited and interviewed participants (n=18) at various stages in the program, including those eligible but not enrolled in the program, those enrolled within 30 days of interview, and those established in the program. Between June and November 2016,

researchers conducted semi-structured qualitative interviews with high users (defined as four visits in the last six months) of the HMC ED, as well as a corresponding medical record review.

### *Study Subjects*

Three case managers in the HUCM program referred participants for interviews. Although eligibility for the HUCM program includes four or more visits to any ED in the most recent six months, greater priority is given to patients with eight or more visits to an ED in the most recent six months. Participation in the study was incentivized with a \$25 gift card. Criteria for inclusion in the study included eligibility for or participation in the HUCM program, ability to speak English, ability to communicate orally, and cognitive ability to consent to participation as determined by the referring case manager.

### *Data Collection*

#### *Qualitative Instrumentation*

Two researchers conducted semi-structured qualitative interviews with high users of the HMC ED identified by the HUCM program. The questions were open-ended and guided participants to reflect on 1) stressors or challenges have faced, 2) overall impressions of interactions with providers, 3) communication with providers, 4) services needed or used, and 5) recommendations for how the healthcare system and HUCM could better meet their needs (see full interview guide in Appendix A). Participants could speak freely and raise their own topics during the interview. Interviews ranged in duration from a half-hour to ninety minutes and were audio-recorded, transcribed verbatim, and entered into Dedoose qualitative analytic software for analysis.

### Quantitative

The secondary research question aims to determine how participants' medical records corroborate or contrast the themes elicited from the qualitative interviews. To better understand the population we interviewed and to answer the secondary research question, researchers collected quantitative data from medical records after participants consented via HIPAA waiver. Basic demographic data from medical records included age, gender, race, and ethnicity. Housing status and existence of a relationship with a primary care provider was based on self-report from the patient. Although all participants were homeless either at the time of interview or two weeks before or after, three categories of housing status included: 1) homeless, 2) temporary (i.e., medical respite or inpatient chemical dependency unit), and 3) supported (i.e., subsidized housing). Status in the HCUM program was classified based on the length of time between entrance into the HUCM program and interview date: *established patients* had been involved in the program for more than thirty days, *newly enrolled patients* had been involved in the program for less than thirty days, and *eligible, not enrolled patients* had been identified by the HUCM program as eligible, but declined to enroll. (N.B. criteria for case management intervention by the HUCM program other than number of ED visits includes willingness to participate and cooperate.) Finally, the median duration in the program was calculated from the entrance and exit dates provided by the case managers.

Microsoft Amalga is a software program that aids health researchers by pulling specified data fields from Electronic Medical Records and displays that data in a unified platform.<sup>27</sup> After obtaining approval from the University of Washington Amalga Team, this platform was used to gather the following data from participant medical records, which was also used to answer the secondary research question. Data enumerating and describing encounters with the medical

system during the 2016 calendar year includes: number and dates of ED visits to HMC, number of outpatient clinic visits within the University of Washington Medical System, and number of inpatient days. (N.B. inpatient days are recorded in the format DD:HH:MM; the reported number of inpatient days consists of the total time elapsed rounded to the nearest day). Data reported from each unique ED visit (n=295) included self-reported pain status from the Numeric Rating Scale (0-10), and triage status from the Emergency Severity Index (1-5). The Numeric Rating Scale is a validated measure for measuring self-reported pain on a scale from 0 (no pain) to 10 (worst pain).<sup>28</sup> The Emergency Severity Index is a universal ED triage tool that stratifies patients into five groups, from level 1 (most urgent) to level 5 (least urgent).<sup>29</sup>

The International Classification of Diseases (ICD) is a set of mortality and morbidity codes used internationally to report diseases and health conditions.<sup>30</sup> ICD-10 billing codes were gathered for each visit. Finally, the EDIE® database collects data from all EDs visited by a patient in one state to deliver to ED practitioners.<sup>31</sup> This database, however, restricts data to one calendar year prior to access date. For this study, visits to any ED on dates between February 15, 2016 and February 15, 2017 were compared to visits to the study ED during the same time period.

## *Analysis*

### *Qualitative*

The primary research questions aimed to determine: a) if an identifiable pattern of ED use exists, b) if life experience impacts ED use, c) what common experiences exist across participants, and d) what potential points of intervention exist. To answer these questions, researchers performed qualitative analysis using Dedoose analytic software on verbatim interview transcripts using three phases of coding.<sup>32</sup> Phase one consisted of open coding to

determine categories of topics; phase two consisted of axial coding to interconnect these categories; and phase three consisted of selective coding to build these categories into more representative domains.<sup>33</sup> The final product of these three phases includes the themes surfaced from analysis of all data, both qualitative and quantitative. Three coders performed analysis, two of whom conducted the interviews, to generate codes. The research team double-coded all interviews and met to discuss the codes, categories, domains, and themes. Any disputes in these were discussed until unanimous consensus was reached.

### Quantitative

The secondary research question aimed to determine how the medical record compared to the findings from the qualitative interviews. To answer this question, several aspects of the medical record data was analyzed. Basic descriptive statistics were generated for participant demographics.

To determine how the most frequently reported reasons for ED visits by high users compared to the perceived reasons for visits by physicians, ICD-10 billing codes were analyzed. Most visits contained multiple diagnoses, but for the purposes of this study, the research team chose only to analyze the first diagnosis, as this would be more comparable to the reason for visiting the ED reported by the patient. These primary diagnoses were coded into categories based on the ICD-10. To account for single participants who may contribute to a disproportionate number of a diagnosis, the list of ICD codes was then narrowed to only include one participant within each diagnosis. Primary diagnoses that occurred in more than three patients are reported in Table 8.

## **Results**

The average age of the 18 participants was 52 years old (SD 9.50). Participants were mostly male (n=14) and White (n=7) or Native American (n=6), rather than Black (n=4) or Native Hawaiian (n=1). Ten of the participants were homeless at the time of interview, although some were in temporary (n=3) or supported housing (n=5). Those in temporary housing were either in medical respite care or inpatients at the time of interview, but were otherwise homeless. Those in supported housing only received this shelter less than two weeks prior to interview. Twelve of the participants had a primary care provider at time of interview, and most were established (n=12) patients of the HUCM program, rather than newly enrolled (n=5) or eligible but not enrolled (n=1). The median number of HMC ED visits in 2016 was 18 visits per participant (range 1-36). The median number of inpatient days was 26 days per participant (range 0-97), and the median number of outpatient visits was 7 (range 0-177). Finally, the median duration in the HUCM program was 169 days (range 54-377). The median proportion of HMC to all ED visits was .64 (range .13-1.00). Finally, the median duration in the program was determined to be 169 days (range 54-377).

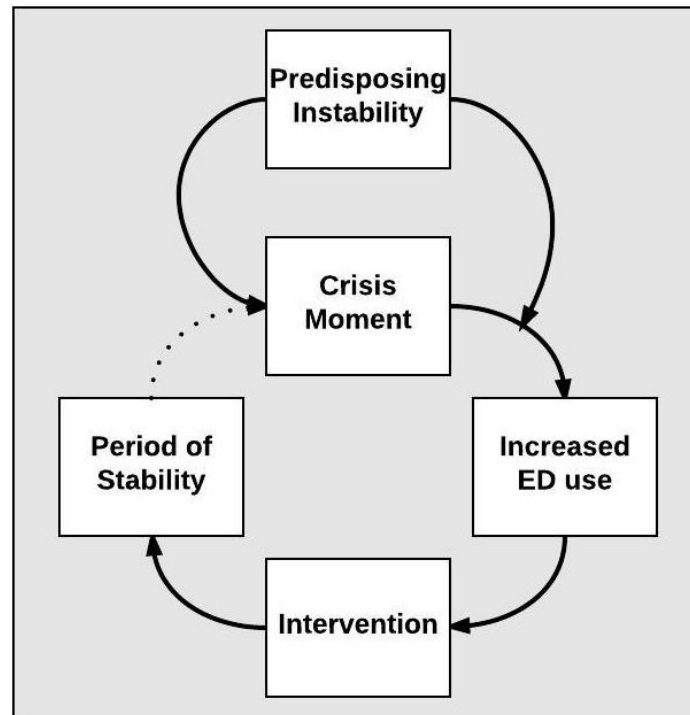
<b>Age</b>	<b>N</b>	<b>SD</b>
	51.89	9.50
<b>Gender</b>	<b>N</b>	<b>%</b>
Female	4	22%
Male	14	78%
<b>Race</b>	<b>N</b>	<b>%</b>
Black	4	22%
Native Hawaiian	1	6%
Native American	6	33%
White	7	39%
<b>Housing Status</b>	<b>N</b>	<b>%</b>
Homeless	10	56%
Temporary Housing	3	17%
Supported Housing	5	28%
<b>Primary Care Provider</b>	<b>N</b>	<b>%</b>
Yes	12	67%
No	6	33%
<b>Encounters with Healthcare System</b>	<b>Median</b>	<b>Range</b>
ED visits	18	1-36
Inpatient days	26	0-97
Outpatient visits	7	0-177
Proportion of HMC to all ED visits	.64	.13-1
<b>Status in HUCM Program</b>	<b>N</b>	<b>%</b>
Eligible, not enrolled	1	6%
Newly enrolled	4	22%
Established	12	67%
<b>Duration in HUCM Program</b>	<b>Median</b>	<b>Range</b>
	169	54-377

**Table 1.** Basic demographic characteristics of participants (n=18).

### Qualitative

The overarching theme elicited from the qualitative analysis is an identifiable pattern of ED use. The first and second parts of the primary research question ask: a) if an identifiable pattern of ED use exists and b) how life experiences impact ED use. Fourteen of the eighteen participants reported both stable and unstable periods in recent history that recur, indicating that a pattern of ED use does exist and is impacted by life events. From the interviews, we elicited four domains that support the theme of a pattern of ED use that can be represented by three distinct stages; a (1) *crisis moment* results in increased ED use. In many cases, (2) *intervention*

(intensive case management) steadies socioeconomic instability, thereby reducing ED use and introducing a (3) *period of stability*. A subsequent crisis moment sometimes, though not always, reoccurs, and the pattern begins again. A fourth domain, (4) *predisposing instability*, impacts whether a crisis moment occurs, as well as the degree to which a crisis moment impacts ED use.



**Figure 1.** Conceptual model of the pattern of ED use derived from the interviews.

<i>Phase</i>	<i>Illustrative Quotes</i>
<b>Crisis moment</b>	<i>“You know, cause this accident, it—it you know, changed my life.”</i>
<b>Increased ED use</b>	<i>“And I don’t want to go—I was going to go there today. I was going to go back today because this hurts so bad. It’s just so much pain. But I can’t just keep going there. Twenty-seven times since January. Twenty-seven times I’ve been there.”</i>
<b>Intervention stabilizes</b>	<i>“Each and every time, you know I was having a hard time and then I got [my case manager]. And I needed to. She was—I was lost, you know. Lost in my mind and they gave me a case manager. She helped me out. She helps me a lot.”</i>
<b>Period of stability</b>	<i>“When things were going good, I would go to yoga every day. And I’d stay at the Bread of Life mission for \$5 a night. And it was—it’s okay.”</i>

**Table 2.** Quotes that illustrate the phases of the pattern of ED use.

The third part of the primary research question asks if common experiences can be elicited across participants. Unsurprisingly, throughout the interviews, participants described most of their life events, such as homelessness, as having negative impacts on their quality of life. A *stressor* is “conditions of threat, challenge, demands, or structural constraints that, by the very fact of their occurrence or existence, call into question the operating integrity of the [person].”<sup>27</sup> For example constantly fearing victimization may be threatening, coping with a chronic illness may be a challenge, meeting excessive qualifications for housing may reflect an undue demand, and the absence of employment opportunities or persistent discrimination may result from structural constraints reflective of disadvantage. Example stressors elicited from participant interviews include unstable housing, lack of employment, substance use, chronic illnesses, mental health, and lack of social support. This definition was employed when determining what life experiences of the participants could be classified as a “stressor.” Participants described these stressors both when asked “the number one thing on [their] mind” and brought them up organically throughout the interview.

#### *Domain 1: Crisis Moment*

The second part of the primary research question aims to identify if particular life experiences impact ED use. One common experience across participants was the presence of stressor in the form of a crisis moment. Fourteen participants reported a specific crisis moment that resulted in extreme instability, and these were organized into three categories. The most common crisis reported involved a deterioration in health status, which includes acute flare-ups of chronic illnesses (e.g., arthritis), cancer diagnoses, and most commonly, trauma. Six of these participants were pedestrians struck by a motor vehicle, and others experienced severe falls (one of which resulted in a severe traumatic brain injury). The second most common crisis reported

was grief (three participants), specifically from the loss of a spouse. Finally, two participants reported that incarceration while battling a high-acuity chronic illness catapulted them into harsh socioeconomic conditions that significantly impacted their illnesses.

<i>Category of Crisis Moment</i>	<i>Illustrative Quote</i>
Health deterioration	<p><i>“Yeah, I got hit by a car back in June in a crosswalk and that’s what started all of this.”</i></p> <p><i>“My day-to-day life, now, well, I was working day labor. But since my health has gotten so bad, I just take it easy. I take my medications, and then usually just sit in the park, talk to my case managers.”</i></p>
Grief	<i>“I went to [chemical rehabilitation center], it was last year and I went in for detox and the rehab in general. After I got out, it was like the anniversary of the day my wife died and I just went back down the spiral hill.”</i>
Incarceration	<i>“Well, I lost [my housing], you know? Because of what happened, going to jail and stuff. But I didn’t care, you know? And then, I got hit by a car and because of it—a couple months later. And I got hit by a car and it broke my foot, but I had a concussion for two days.”</i>

**Table 3.** Quotes that illustrate the three categories of crisis moments: health deterioration, grief, and incarceration.

### *Domain 2: Intervention*

The fourth part of the primary research question aims to determine if any potential points of intervention may exist. The intervention currently in place, the High User Case Management (HUCM) program, was universally praised by all participants. These participants lauded their case managers’ impact on their well-being through the organization of both their personal life and their healthcare. Most often, having one person to help organize all aspects of the participants’ life offered a stability not found elsewhere.

<i>Category of HUCM program impact</i>	<i>Illustrative quote</i>
Personal life	<i>“I use [my case manager] as a sounding board. I'm not good right now in the early stages of recovery. I'm still toxic in the relationship to unsupervised thinking. So I'm likely to call him about any number of things to see whether he thinks what I think is a good thing to do.”</i>
Healthcare	<i>“And so [my case manager] showed up real early to talk to the doctor. Or to talk to the Security guard that were – ‘Cuz she – at that point she didn’t know I had filed a complaint. That was good and so she was there when I got there and then she – and I went and saw the doctor and she was in the room, too. We got everything squared away and the – the pain medication did start working [...] - finally. And I was able to get a little bit of sleep that night. And then it’s just gotten better and better.”</i>

**Table 4.** Quotes illustrative of impact HUCM program had on participants’ personal lives and their healthcare.

### *Domain 3: Stability*

The first part of the primary research question aims to determine if an identifiable pattern of ED use exists. Intervention by the HUCM program often led to a period of stability, the third domain. One participant described a period of stability, even in the face of homelessness:

“When things were going good, I would go to Yoga every day. And I’d stay at the Bread of Life mission for \$5 a night. And it was – it’s OK. It’s better than, you know, the shelters that you don’t pay anything.”

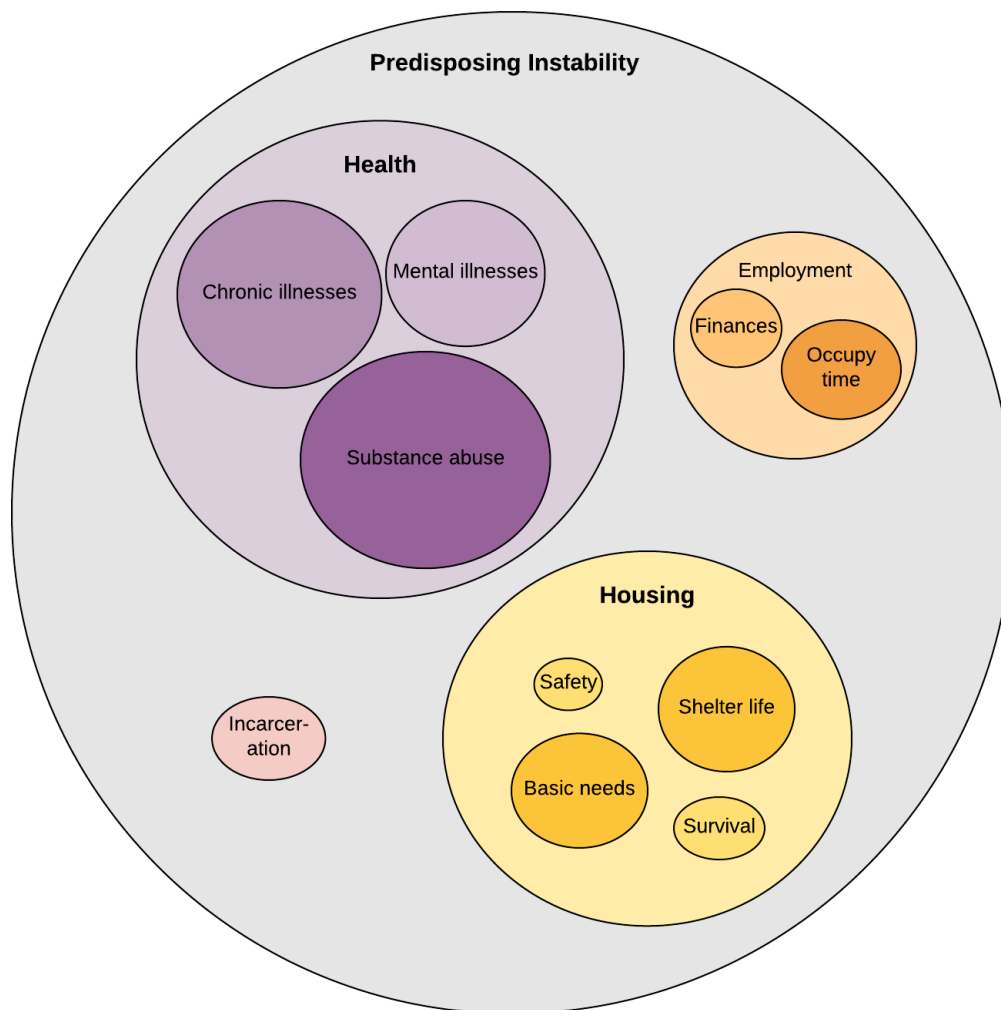
However, the socioeconomic circumstances of these patients often resulted in a fear or reality of being catapulted back into a state where they are particularly vulnerable to a crisis moment.

Another participant described the stability he felt in the hospital compared to after discharge:

“Being in a protracted state, like, you know, where I can really work on stuff, and I can be -- and not be rushed or not be taken care of, dumped back into an environment that's, you know, running counter to what we just tried to fix.”

#### Domain 4: Predisposing Instability

The second part of the primary research question aims to determine if life experiences impact patients' ED use, and the third part aims to determine common experiences across participants. What differentiates extremely high users from other patients who may experience similar crises is the fourth domain, *predisposing instability*, which impacts both the likelihood of experiencing a crisis moment and the degree to which that crisis moment impacts subsequent ED use. (refer to Figure 1).



**Figure 2.** Stressors that contribute to predisposing instability, which affects occurrence and intensity of crisis moment, as well as the degree to which the crisis moment affects ED use. The size of each bubble corresponds to the frequency with which participants reported that stressor.

The two categories of most commonly reported stressors included those related to health and housing. Within the category of health, fourteen participants discussed how their substance abuse impacted their health and healthcare. Participants also frequently discussed the penetrating impact their chronic illnesses had on their lives and healthcare use, as well as the cyclical impact of stress and mental health.

<i>Category of Health Stressor</i>	<i>Illustrative quote</i>
Substance abuse	<p><i>“Walk around, trying to get high. That’s my typical day. You know, but I’m hoping something gets better for me eventually. That’s one of the reasons why I’m up here with [my case manager], you know. So things can get right. I lost my eye sight partially. If it wasn’t for [my case manager], there’s no telling where I’d be at right now.”</i></p> <p><i>Interviewer: “So when you come in here, do you feel like you usually get your needs met?”</i></p> <p><i>Participant: “Yeah, as long as you don’t blow too high.”</i></p> <p><i>Interviewer: “As long as what?”</i></p> <p><i>Participant: “As long as you don’t blow too high because they got a Breathalyzer. And if they’re really concerned about how much you’ve been drinking, they’ll breathalyze you.”</i></p> <p><i>Interviewer: “What happens if you blow too high?”</i></p> <p><i>Participant: “They’ll put a tube inside you.”</i></p>
Chronic illness	<p><i>“Right now I’m on a schedule and what I do is on Monday through Wednesday, I get up at about four in the morning and I eat a light breakfast because I have to work out at seven. And because of my colostomy bag, it has to be empty. And that’s the only way I can do it.”</i></p>
Mental health	<p><i>“When like when my mind starts racing and I can’t concentrate, then it’s time to just try—time to go to the hospital. Because then my mind—I have Afib and my heart will start complicating and I could have a heart attack or a stroke.”</i></p>

**Table 5.** Illustrative quotes describing the stressors related to health.

Housing status and the subsequent stressors that arise from lack of housing were also mentioned by every participant. Most commonly mentioned, besides the extreme difficulty of finding housing, was the problematic culture and conditions of shelters. Participants frequently reported fear for their personal safety and for that of their belongings. Beyond safety concerns, most participants avoided shelters because of the culture; one participant described the residents:

*“And you just see so many people comfortable in that state of mind. They’re gonna be there the rest of their life because something died in them. I don’t think they’ll ever get it back.”*

Commonly, the lack of shelter complicated their health condition. One participant with a chronic seizure condition described his worsening condition due to medication that caused drowsiness:

*“You know, I’m fighting sleep and everything. And they’re telling me, okay, well, it’s bad to stay awake because it’s called sleep deprivation, and it raises your risk even higher to have a seizure. And so they’re giving me all these risk factors and they’re like this is maybe why you’re continuing to keep having them.”*

Finally, many participants described the difficulty of meeting basic needs, such as hygiene and elimination needs, and the impact of constantly being in “survival mode.” When asked the biggest day-to-day stressor, one participant responded, “Finding a place to pee.” Another participant described how survival consumed her life when responding to the same question.

*Interviewer: “What’s the number one thing on your mind?”*

*Participant: “To live. That’s the only thing. I don’t want to die now. I’m 43, I got four kids. Just trying to survive here. Get well. So there is one stressful thing, and I’m just gonna take that and that’s it. That is all. I just want to live.”*

<i>Category of Housing Status Stressor</i>	<i>Illustrative Quote</i>
Housing	<i>“I was involved with two different housing programs. The first one was the Salvation Army and I was shocked that I got in so fast, when they told me about it, you know? I signed up and went to their intake –just like a week or two later, they would call me up and said, ‘Yeah, you can move on in.’ I was like, ‘What?!’ So I moved into there—and I was there for about three or four months. And, you know, it’s okay but you still feel like you’re in a jail without the bars. Because your whole life, from the minute you walk through that door, you have to go through a Breathalyzer and then if you bring anything in, they check what it is.”</i>
Shelter life	<i>“When I’ve been to some of those shelters...they’re...you never know what’s gonna happen. That’s all I can say. Sometimes there’s fights, Sometimes people steal things. And then as far as sanitary conditions, you know, I don’t care how clean those guys get the place, when you got 50 or 60 homeless people that haven’t taken a bath in some of ‘em over two or three weeks and you don’t know what they’re carryin’ in their packs and – and you just—you don’t know.”</i>
Meeting basic needs	<i>“It was freezing cold and I was out here on the street. There was a heater in the alley, blowing heat up. And we stand on that. Sometimes stand on it all night, dry our clothes off.”</i>  <i>“I wish I could have [a pet], but I know I can’t take care of it cause I’m sick and I can barely take care of myself.”</i>
Survival	<i>“I quit going to yoga, you know? I was still working on my own. But it was just...it was just like everything fell apart, you know? And I just became homeless and just surviving. And that’s what I did for all these months.</i>
Safety	<i>Interviewer: “What’s the number one thing on your mind?”</i> <i>Participant: “Basically, it’s just safety. You know, I—safety out there. And make sure that, you know that I don’t get hurt. Because, you know, my brain surgeries—I had three brain surgeries—so I get nervous about that.”</i>

**Table 6.** Quotes illustrative of housing status-related stressor.

Several other factors also impacted quality of life and ED use, including the categories of employment, finances, difficulty occupying time, and incarceration. Lack of employment for many participants impacted both financial stability and mental health. In most cases, some health factor, such as debilitating chronic illness or substance abuse, rendered the participant unable to work. Lack of work compounded with limitation due to physical and mental ailments often led to

stress in occupying participants' time. One participant reported that the only time he was not "bored" was when he had doctor's appointments:

*"It's just, like, it's boring because now I find myself with, like, it seems like the whole 24 hours in a day is, like, not really wasted, but -- I mean, if you have appointments, I'm going to make those. But then after appointments it's just, like, okay. I don't have no plans. So it's, like, I'm just sitting there. You know, just bored. Just, like, it's, like, a forced bored, you know? And I don't like the way it makes me feel. And so it causes me to, like, be kind of, like, depressed a little bit. You know, I'm, like, wow, man, I want to go do this. I want to go do this. And then I think to myself, man, what if this happens if I do this?"*

<i>Other categories</i>	<i>Illustrative Quote</i>
Employment	<i>"Well, usually I work. But my health has been so bad that I haven't been able to work since May 31<sup>st</sup>."</i>
Finances	<i>"I tried every avenue I could to get out of this town. And I just couldn't do it. There are so many people at the bank, you have to have good credit. Because of all the trips to ER, whatever, whatever. The doctors have sent them bills. Right? And so, I couldn't pay them. So, my credit just went to hell; right?"</i>
Occupying time	<i>"Have breakfast and coffee, and you know take showers. And right now, you know because of the situation I'm in right now, you know, kind of, fill in my time."</i>
Incarceration	<i>"Well, anger management and the -- for the most part, that's really it, really. And -- and I got -- I got some PTSD, we talk about that a little bit too. Yeah. I got that from being in prison. I got that bad. So, you know, I kind of -- kind of like deal with that too."</i>

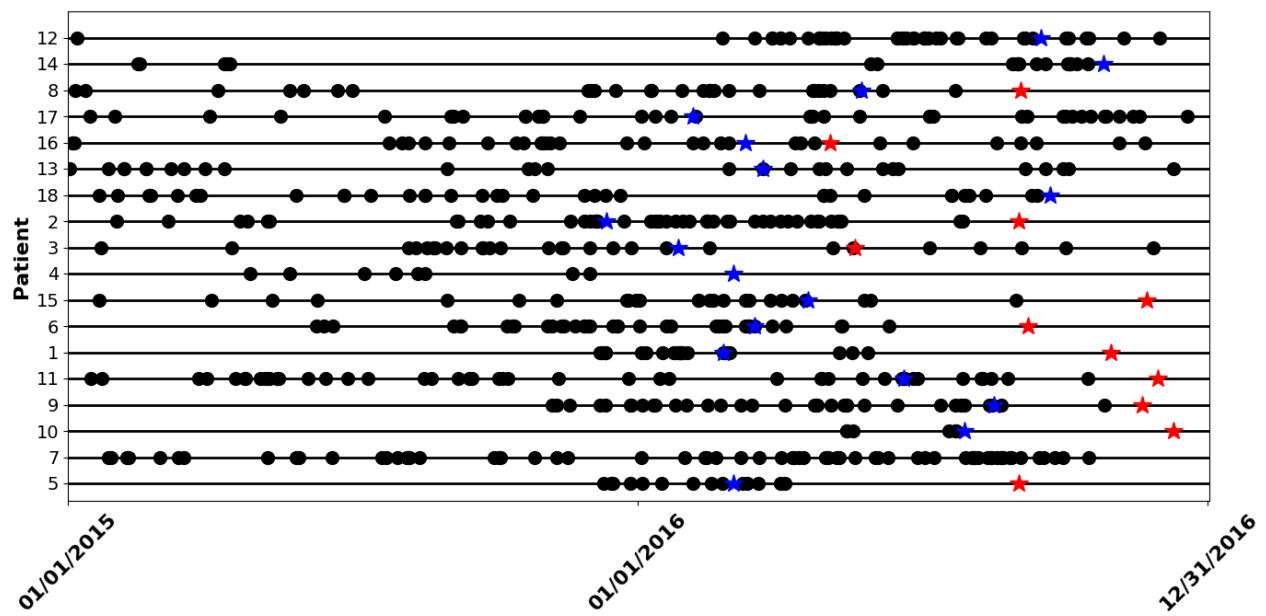
**Table 7.** Quotes illustrative of other factors that contribute to increased ED use and life stress.

Many of the factors described affect each other, and synergistically impact ED use. For example, one participant described how a miscommunication with a case manager while on parole led to incarceration. After his release, he was unable to access his Social Security funds, which rendered him unable to afford shelter. Because of his fear for safety and sanitary conditions in a shelter, he slept on the streets and did not properly care for his colostomy bag

wound site. The wound became infected and he reported to the ED for care. This type of compounding destabilizing factors leading to increased ED use was a common finding.

### Quantitative

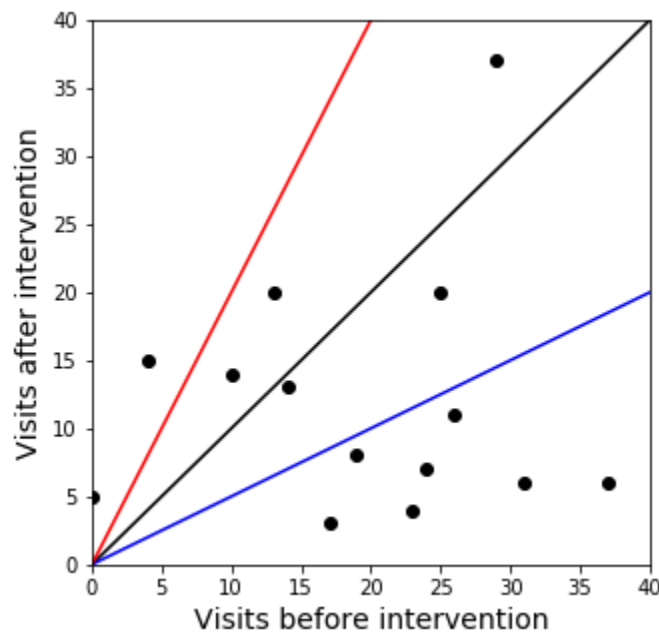
To visually answer the first part of the primary research question, which aimed to identify a pattern of use, ED visits from the 2015-2016 calendar years were graphed. The y-axis denotes original participant number and is ordered by greatest distance between ED visits (top) to least distance between ED visits (bottom) to visually display clustering of visits. This grouping demonstrates a clustering of ED visits in some participants consistent with the pattern of ED use described in the qualitative findings. Figure 3 also includes entrance and exit dates from the HUCM program.



**Figure 3.** Timeline of ED visits among participants (n=18) in the 2015-2016 calendar years, ordered by time between ED visits (greatest time between visits at the top). Blue stars represent entrance dates into the HUCM program, and red stars represent exit from the program.

To further illustrate the impact of the HUCM program on participants' ED use discussed in participant interviews, researchers generated Figure 4. In this figure, the x-axis refers to the

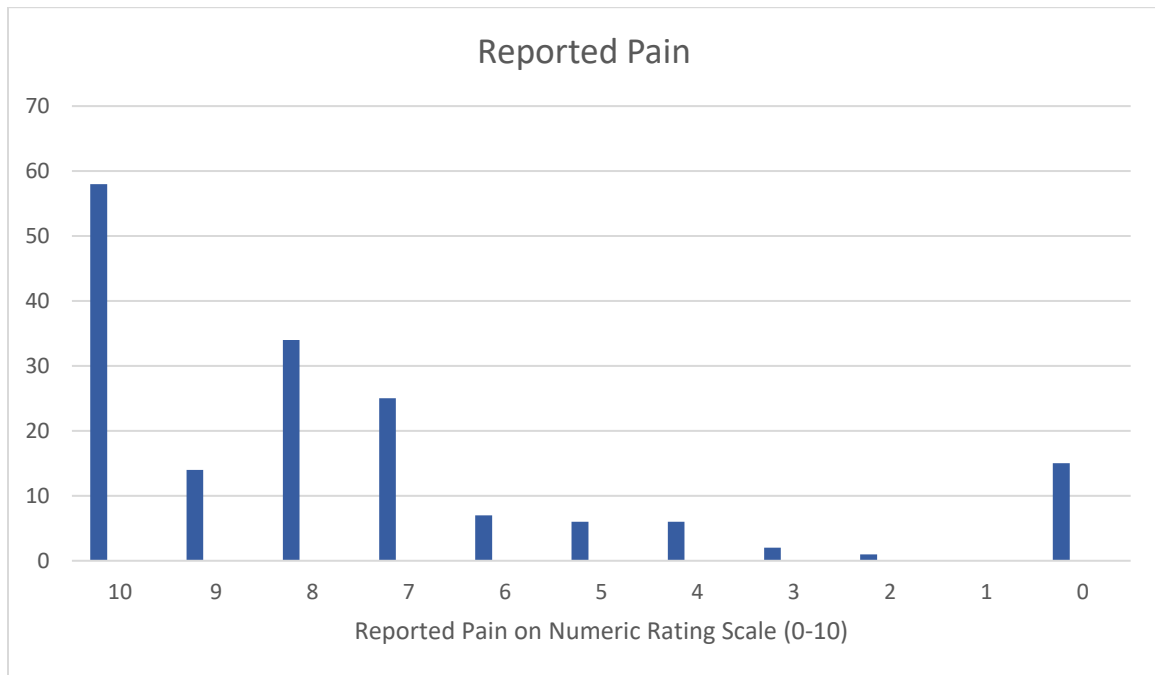
number of visits before HUCM intervention, and the y-axis refers to the number of ED visits after HUCM intervention. The black line denotes a 1:1 ratio (i.e., no change in number of ED use pre/post intervention); the red line denotes a 2:1 ratio (i.e., twice as many visits post-intervention as pre-intervention); and the blue line denotes a 1:2 ratio (i.e., half as many visits post-intervention as pre-intervention). This graph indicates that the intervention reduced more than half of the participants' ED use by more than half of their visits pre-intervention.



**Figure 4.** Change in ED visits after HUCM program intervention. Black line denotes a 1:1 ratio (no change), the red line denotes a 2:1 ratio (twice as many visits), and the blue line denotes a 1:2 ratio (half as many visits). This graph indicates the impact of the HUCM program on reducing ED use.

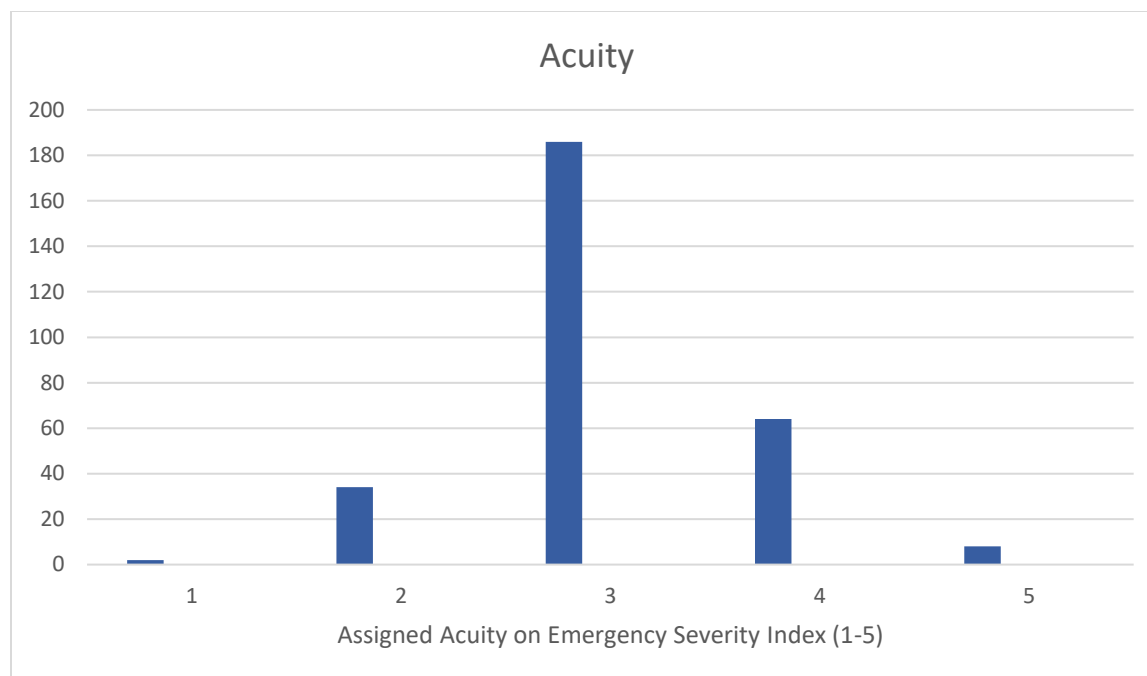
In the qualitative interviews, many participants discussed pain as a core factor driving them to the ED. To determine how this report compares to the pain reported at each visit, researchers analyzed data from the Numeric Rating Scale (0-10). More than half of the 295 visits had a corresponding reported perceived pain (n=152, 52%). The most common reported pain

intensity on the scale was 10 (n=58, 38%), 8 (n=34, 22%), and 7 (n=25,16%). The average reported pain was 7.48 (SD 2.94).



**Figure 5.** Patient-reported pain among visits in the ED (n=152).

To further compare the severity of illness reported by participants with a standardized assessment by health professionals, researchers gathered data from the Emergency Severity Index. All visits (n=295) had a corresponding acuity based on this scale (summarized in Figure 6). The most common assignment was 3 (urgent), and the visits averaged a 3.15 assignment (SD 0.67).



**Figure 6.** Summary of visit acuities based on the Emergency Severity Index (1=most urgent, 5=not urgent).

Finally, to compare the most common reasons for visits and crises reported by participants with diagnoses from physicians, ICD-10 billing codes were analyzed. These results and other common ICD diagnoses are summarized in Table 8. Overwhelmingly, the most common reason for visit, both within a select few participants, and across participants were related to substance use. “Alcohol related disorders” accounted for 31% of visits (n=91 visits) and were present in ten of the participants (61%). More broadly, visits related to any kind of substance use accounted for 35% of all visits (n=103 visits) and were present in 14 of all participants (78%). Because of the common report of pain, trauma, and mental illness in the interviews, we also looked for these themes in the ICD-10 billing codes. “Pain” in some way was reported in 14 participants (78%), and these diagnoses accounted for 18% of visits (n=54 visits). Trauma diagnoses were also common, consistent with crisis moments elicited from participant interviews. Eleven of the participants (61%) had trauma diagnoses, accounting for 8% of visits

(n=25 visits), and the most common of these was trauma to the head, which occurred in 7 participants (39%) and accounted for 4.5% of visits (n=13 visits). Finally, mental illness excluding that related to substance use accounted for 7% of all visits (n=22 visits) in six participants (33%).

ICD-10 Billing Code	N of participants	N of visits	% of visits
Alcohol related disorders	10	91	31%
Abdominal and pelvic pain	6	19	6%
Other and unspecified soft tissue disorders, not elsewhere classified	6	8	3%
Chest pain	5	14	5%
Nausea and vomiting	5	7	2%
Major depressive disorder, single episode	4	5	2%

**Table 8.** ICD-10 codes occurring in more than three participants.

## **Discussion**

These findings offer an insight into the complexity of factors that contribute to high ED use, while also providing the often overlooked perspective of the patients. In their narratives, most participants talked about the intersection of their socioeconomic stressors and their health—chronic conditions, mental health, and substance use. Many participants also described a point of crisis that catapulted their stark increase in ED use. Established participants praised the HUCM program for its influence on returning stability to their lives. Finally, the story illustrated by the medical records provides further support for the themes elicited from participant interviews regarding the pattern of ED use.

This work is a major step forward in understanding the factors that impact ED use among the most vulnerable patients and is the first step in elucidating promising interventions. Much of the research to date on the contributing factors of high ED use has relied on quantitative analysis

rather than engaging patients themselves. Even studies that do employ qualitative methods to understand service use by these high users often exclude the homeless. Describing the views of homeless high users on how their stressors impact their patterns of service access and utilization can highlight methods for improving services and points of intervention.

Two primary points of interventions emerged from themes of this secondary analysis. First, the impact of a crisis point on patients' pattern of ED use warrants attention. Preventing crises such as trauma or homelessness in the state of the U.S.'s underfunding of social services may prove difficult. However, enumerating all of the factors that contribute to post-crisis ED use may indicate earlier points for intervention. A standardized set of common data elements for understanding, and ultimately predicting, the pattern of use may allow for intervention before ED use escalates. The categories of stressors described in this study provide a starting point for such a set of elements to be developed.

Second, regardless of efforts to categorize ED visits by high users as "appropriate" or "inappropriate," these participants unequivocally view their conditions as urgent and warranted. However, these participants also demonstrate that case management, when applied in a specific manner, can ameliorate high ED use. While all established participants praised the HUCM program's methods, many also described the frustration of communicating with several different case managers. These participants described the frustrations of not knowing which case manager should address which problem and frequently being referred to other case managers multiple times before a stressor could be addressed. The HUCM program remedies this issue by ensuring a central communicator for all concerns. As evidenced by the HUCM program's success at reducing ED use and cost while stabilizing participants' social situations, as well as high praise

from participants themselves, expansion and further funding of the HUCM program represents perhaps the most promising solution to addressing service use by ED high users.

The study does have several limitations. First, a key selection bias exists. Patients who were the most unstable were either not referred or unable to complete the interview. These patients likely represent a unique perspective that may differ from those of participants able to participate. Secondly, the quantitative data suffers from a small sample size. Although qualitative interviews were performed until we reached saturation, the small sample size and even smaller sizes of categories (e.g. only one participant eligible, but not enrolled) rendered any efforts of correlation amongst demographics unusable. Finally, when asked about experiences at other EDs in the city, many participants detailed the difference in services compared to the ED from which they were recruited. However, we did only recruit high users from one ED which could represent another key selection bias. Despite these limitations, this study still represents an important step in informing future interventions aimed at reducing ED use.

In summary, these results support the hypothesis that a pattern of use does exist among homeless high users of the ED, as well as that common life experiences, like stressors, do exist among high users and impact the pattern of ED use. The information from the medical records corroborate both the notable impact of common stressors and the high acuity of the participants. The expansion of the HUCM program may be one potential point of intervention that reaches more patients. Further, since earlier intervention may prove promising, a standardized set of data elements describing socioeconomic stressors should be developed and used for predicting which warrant early intervention.

## References

1. Moore, M., Ekman, E. & Shumway, M. Understanding the critical role of social work in safety net medical settings: framework for research and practice in the emergency department. *Soc. Work Health Care* **51**, 140–148 (2012).
2. Hsia, R. Y., Nath, J. B. & Baker, L. C. California Emergency Department Visit Rates For Medical Conditions Increased While Visit Rates For Injuries Fell, 2005–11. *Health Aff.* **34**, 621–626 (2015).
3. Tinker, A. How to improve patient outcomes for chronic diseases and comorbidities. *Health Catalyst* 1–5 (2014).
4. Pitts, S. R., Carrier, E. R., Rich, E. C. & Kellermann, A. L. Where Americans get acute care: increasingly, it's not at their doctor's office. *Health Aff.* **29**, 1620–1629 (2010).
5. A Matter of Urgency: Reducing Emergency Department Overuse - NEHI.
6. Hsia, R. Y., Brownell, J., Wilson, S., Gordon, N. & Baker, L. C. Trends in adult emergency department visits in California by insurance status, 2005-2010. *JAMA* **310**, 1181–1183 (2013).
7. Tang, N., Stein, J., Hsia, R. Y., Maselli, J. H. & Gonzales, R. Trends and characteristics of US emergency department visits, 1997-2007. *JAMA* **304**, 664–670 (2010).
8. The IHI Triple Aim. Available at: <http://www.ihl.org/engage/initiatives/tripleaim/pages/default.aspx>. (Accessed: 15th January 2017)
9. Adams, J. G. Emergency department overuse: perceptions and solutions. *JAMA* **309**, 1173–1174 (2013).
10. Gill, J. M. Nonurgent use of the emergency department: appropriate or not? *Ann. Emerg. Med.* **24**, 953–957 (1994).
11. Williams, R. M. Frequent emergency department use in Sweden: implications for emergency medicine in the United States. *Ann. Emerg. Med.* **37**, 627–629 (2001).
12. Hansagi, H., Olsson, M., Sjöberg, S., Tomson, Y. & Göransson, S. Frequent use of the hospital emergency department is indicative of high use of other health care services. *Ann. Emerg. Med.* **37**, 561–567 (2001).
13. Schaulis, M. D. & Snoey, E. R. Three years, a thousand visits: a case study of the ultimate frequent flyer. *Ann. Emerg. Med.* **38**, 87–89 (2001).
14. Durand, A.-C. *et al.* ED patients: how nonurgent are they? Systematic review of the emergency medicine literature. *Am. J. Emerg. Med.* **29**, 333–345 (2011/3).
15. Soril, L. J. J., Leggett, L. E., Lorenzetti, D. L., Noseworthy, T. W. & Clement, F. M. Characteristics of frequent users of the emergency department in the general adult population: A systematic review of international healthcare systems. *Health Policy* **120**, 452–461 (2016).
16. Pines, J. M. *et al.* Frequent users of emergency department services: gaps in knowledge and a proposed research agenda. *Acad. Emerg. Med.* **18**, e64–e69 (2011).
17. Billings, J. & Raven, M. C. Dispelling an urban legend: frequent emergency department users have substantial burden of disease. *Health Aff.* **32**, 2099–2108 (2013).
18. Lang, T. *et al.* Non-urgent care in the hospital medical emergency department in France: how much and which health needs does it reflect? *J. Epidemiol. Community Health* **50**, 456–462 (1996).
19. Sommers, A. S., Boukus, E. R. & Carrier, E. Dispelling myths about emergency department use: majority of Medicaid visits are for urgent or more serious symptoms. *Res. Brief* 1–10, 1–3 (2012).
20. O'Brien, G. M. *et al.* Use of the ED as a regular source of care: associated factors beyond lack of health insurance. *Ann. Emerg. Med.* **30**, 286–291 (1997).
21. Lang, T. *et al.* Using the hospital emergency department as a regular source of care. *Eur. J. Epidemiol.* **13**, 223–228 (1997).
22. Shumway, M., Boccillari, A., O'Brien, K. & Okin, R. L. Cost-effectiveness of clinical case management for ED frequent users: results of a randomized trial\*. *The American journal of* (2008).

23. Moore, G., Gerdzt, M. & Manias, E. Homelessness, health status and emergency department use: An integrated review of the literature. *Australas. Emerg. Nurs. J.* **10**, 178–185 (2007).
24. Pasic, J., Russo, J. & Roy-Byrne, P. High utilizers of psychiatric emergency services. *Psychiatr. Serv.* **56**, 678–684 (2005).
25. Rising, K. L. *et al.* Return visits to the emergency department: the patient perspective. *Ann. Emerg. Med.* **65**, 377–386.e3 (2015).
26. Avenue, 401 Fifth & Seattle, S. 500. King County Department of Community and Human Services.
27. What is Amalga? - Definition from WhatIs.com. *SearchHealthIT* Available at: <http://searchhealthit.techtarget.com/definition/Amalga>. (Accessed: 13th February 2017)
28. McCaffrey Initial Pain Assessment Tool (PDF, 111KB).
29. Emergency Severity Index (ESI): A Triage Tool for Emergency ..
30. WHO | International Classification of Diseases. (2017).
31. Collective Medical Technologies » EDIE. Available at: <http://collectivemedicaltech.com/what-we-do-2/edie-option-2/>. (Accessed: 14th May 2017)
32. Home | Dedoose. Available at: <http://www.dedoose.com/>. (Accessed: 30th November 2016)
33. Creswell, J. W. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. (SAGE Publications, 2012).
34. A Handbook for the Study of Mental Health: Social Contexts, Theories, and Systems, Second Edition.

# Appendix A: Interview Guide

## Consent procedure completed

### Introduction

*(Tape recorder is turned on.)*

We began recording this interview to make sure we hear everything you are telling us.  
This is Participant X.

Welcome and thank you for your participation today. My name is \_\_\_\_\_ and I am a researcher (assistant) at \_\_\_\_\_.

The purpose of this interview is to explore your experiences using health care and other services. In particular, we are interested in your

- Stressors or challenges that you are facing or have faced in the past
- **overall impressions** of your interactions with previous doctors and nurses
- **communication** between you and your medical providers
- what, if any, **services** you typically need or use
- **your recommendations for how we can better meet your needs**

Just a few logistics, and then we'll get started.

- Please feel free to speak openly and honestly.
- This interview will last approximately 1 hour. If you need to use a restroom or take a break, please feel free to do so at any time.
- There is no "right answer" to any of the questions or one "right experience." We are here to learn from all of you.

## QUESTIONS/PROMPTS

### Past and Current Experiences

1. **Tell us about your day-to-day life. What do you do on a typical day?**
2. **Where did you sleep last night?**
3. **Tell us how you feel on a typical day?**  
*Probes: emotional, physical, other*
4. **Tell us about the #1 thing on your mind.**  
**What is the most stressful problem you are facing right now?**
5. **What brings you joy? Or has brought you joy in the past?**

**Medical Service Use**

- 1. Do you have a regular doctor or primary care provider or clinic? Who/where is that?**
- 2. Can you talk to me about your decision making process about getting medical care?**
- 3. Tell us about the last time you saw a doctor. Why did you go? Where did you go? What happened?**  
*Probing questions:*
  - a. Do you feel you were treated fairly?
  - b. Were services satisfactory/were your needs met?
- 4. In the past, how do you think communication has gone with providers? Tell us about a time you remember talking with a doctor/nurse.**
- 5. What brings you in to the Harborview Emergency Department most of the time? How do you usually get there?**
- 6. Do you think your needs get met at the Harborview Emergency Department? Tell us about that.**
- 7. When you went to the Harborview Emergency Department last time or a memorable time, what brought you there?**  
*Probing questions:*
  - a. How did you get there?
  - b. How did you decide to go to Harborview ED vs. other site?
  - c. **What did you expect would happen at the Harborview Emergency Department? What were you hoping for?**
  - d. **Did that happen?**
  - e. **What was recommended to you after your visit?**
  - f. **How was communication?**
- 8. What is the hardest part about going to the HMC Emergency Department?**
- 9. Is there anything you like about going to the HMC Emergency Department?**
- 10. What is the hardest part about getting medical care outside of the Emergency Department?**
- 11. Is there anything you like about getting medical care outside the HMC ED?**

**12. Part of the HU program is to help you decide where you are going to get your medical care. What do you think about that? Will it be hard? Why or why not?**

**13. What are you working on with your HU case manager right now?**

**14. What advice or recommendations do you have for HU program to best meet your needs?**

Ask patient to graph quality of life over last 6 months and explain changes. Ask about medical care during changes. Assist as needed.

**Final question:** Our goal today was learn about your experiences in the healthcare system and other stressors you are facing. You have all shared a lot of valuable information. **Is there anything else you want to say that you didn't get a chance to say yet? Is there anything we missed?**

*Do you have questions for us? Answer any specific questions, etc.*

Thank you all very much for your time. Your responses are very valuable and will help us improve services to families.



Stop here and turn off recorder.