The Hardships Of Healthcare Among People With Lived Experiences Of Homelessness In New Haven, Ct

Brandon James Hudik

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The Hardships of Healthcare Among People With Lived Experiences of Homelessness in New Haven, CT

A Thesis Submitted to the Yale University School of Medicine in Partial Fulfillment of the Requirements for the Degree of Doctor of Medicine

by

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Abstract

Objectives: People with lived experiences of homelessness encounter barriers to accessing and maintaining appropriate healthcare. This project aims to: 1) identify how these barriers manifest in New Haven, CT; 2) examine the negative health and healthcare impacts such barriers may incur, including when people adapt to or try to overcome them; 3) examine the characteristics of positive experiences in accessing healthcare in order to inform future approaches to healthcare for this vulnerable population.

Methods: This study is a subanalysis of the Justice, Health, and Housing Study (JustHouHS) and draws on longitudinal, qualitative interviews with low-income New Haven residents who experienced homelessness (N=36) at any point during the study. Parts of interviews that discussed healthcare were coded using an open-coding technique until themes could be identified and analyzed.

Results: Our participants described a healthcare system with many barriers to accessing and maintaining care, as well as a lack of effective help in navigating them despite the need. They described having limited agency as well as assumptive, uncaring, and impersonal experiences that led to harm, mistrust, and a lack of engagement. This was most pronounced in regard to substance use, which disproportionately impacts this population. Prioritizing healthcare often came at the cost of other basic needs and vice versa, and economic precarity had a notable impact on healthcare engagement. Participants adapted or coped with healthcare barriers through available, creative,
deceptive, or desperate ways. Finally, the study elicits how resources and providers that encourage, empower, meet them where they are, and step “outside” or go beyond the expectations of current systems positively impact their health and engagement with healthcare.

**Conclusions:** This study supports the idea that until the many barriers to accessing and maintaining care for unhoused populations are dismantled, healthcare systems and related resources have a responsibility for providing proactive, sufficient, and effective help in navigating them. Also, healthcare providers should consider how current approaches to care may have negative impacts specific to their unhoused patients, and make concerted efforts to listen, empathize, and understand their needs, being prepared to go above and beyond to provide equitable care. This can create environments of trust and support, which is especially important in addressing substance use and its disproportionate impact on our participants and this population. The study also argues for healthcare systems that are more flexible, forgiving, and which attempt to meet patients who are unhoused where they are, both literally and figuratively. It also supports the idea that basic needs, like housing, and social safety nets should be viewed as critical elements of one’s health and healthcare, not merely adjacent factors, and should be redundantly addressed. Finally, it highlights the importance many in this population place on their health, emphasizing the potential for healthcare engagement should the system improve its ability to embrace them.
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Introduction

Health Consequences of Homelessness

People experiencing homelessness are individuals without permanent or stable housing. They may live in one place, or transiently in many places: on the street, in a shelter, abandoned building, or vehicle, or in the houses of a series of acquaintances, friends, or family members. Chronic homelessness is defined as having experienced homelessness for at least a year, or repeatedly, while struggling with a disabling condition such as a serious mental illness, substance use disorder, or physical disability.\(^1\) In the United States, over 3 million people experience homelessness each year, with over 568,000 on any given night. A third of these people stay in unsheltered locations, such as on the street.\(^2\) Many intersecting individual and structural factors lead to and are compounded by homelessness. Individual factors include criminal justice system involvement, unstable employment, poverty, substance use disorders, domestic violence, sexual abuse, childhood trauma, disability, and mental and physical illness. Structural factors include mass incarceration, income inequality, declining public assistance, psychiatric deinstitutionalization, shortage of affordable housing, and unaffordable healthcare.\(^3,4\)

Many people experiencing homelessness lack access to the basic means of maintaining one’s health. Besides adequate and stable shelter, they may lack access to appropriate clothing, healthy foods, phones, transportation, toilets, showers, laundry machines, refrigerators, stoves and storage, including medicine cabinets.\(^5\) Compared to
their housed counterparts, those experiencing chronic homelessness are up to six times more likely to become chronically ill, four times more likely to be hospitalized, and three to four times more likely to die at a younger age.\textsuperscript{6-8} Causes of excess illness burden, hospitalization and mortality include mental illness, infections (including hepatitis C, human immunodeficiency virus, tuberculosis, and respiratory infections), cardiovascular disease, substance use, malnutrition and resulting vitamin deficiencies, traumatic injuries (due to falls, lacerations, sprains, and fractures), exposures (such as hypothermia and frostbite),\textsuperscript{9} suicide, homicide, and poisoning (from both medications and substance use).\textsuperscript{10,11} Common chronic medical conditions among this population include hypertension, peripheral vascular disease, poor dentition, gastrointestinal illness, and neurological disease.\textsuperscript{11} Commonly, some degree of disability results from these conditions, further perpetuating the cycle of homelessness by decreasing one’s functionality.\textsuperscript{12}

Additionally, those experiencing homelessness often have other unmet health-related needs that are important not only to their health but also to a sense of dignity and autonomy, such as access to hygienic products, sexually transmitted disease education and prevention, dermatological, dental, foot, and vision care. Given that these needs are often cumulative, and given the complexities of homelessness itself, healthcare providers must have more time, patience, compassion, and persistence to engage effectively with this population.\textsuperscript{13}
Barriers to Accessing and Engaging with Healthcare

Despite their increased healthcare needs, people experiencing homelessness have fewer encounters with healthcare in the ambulatory setting than their housed counterparts. This is often because healthcare competes with needs that are more salient, such as obtaining adequate food, shelter, or safety. In fact, people experiencing homelessness describe their understanding of “health” as being closely related to their conception of “survival.” Additionally, their ability to longitudinally engage with ambulatory care is impacted by a lack of reliable access to transportation, money, and insurance – a lack of access compounded by repeated experiences of homelessness. Ultimately, delays in diagnosis due to lack of regular preventative ambulatory care and care fragmentation negatively impacts mortality.

The shortcomings of current models of ambulatory healthcare for this population are particularly visible in the context of self-management of chronic conditions, like diabetes and cardiovascular disease. Such conditions often progress unchecked until these patients become severely ill, forcing them to rely on acute healthcare settings such as the emergency department. This progression is not only due to the hardships of scheduling, getting to, and affording appointments and subsequent medical interventions, but also due to the difficulty in performing the self-care routines expected for chronic conditions. For example, if one suffers from heart failure, they may need to measure their weight daily to determine the need for diuretics, which help prevent an exacerbation of their disease. However, those in this
community rarely have access to a scale.¹⁶ These factors all culminate in the progression of chronic diseases, often rapidly.

More broadly, for people experiencing homelessness it can be more challenging, to impossible, to adhere to strict diets and medication regimens. Adherence to dietary recommendations such as low carbohydrate intake in diabetes or low sodium in heart failure, is near impossible without reliable access to food in general, let alone healthy foods. Adhering to complex medication regimes is also difficult, as many lack reliable access to pharmacies, insurance coverage, consistent meals to take medications with, or secure, transportable storage. In addition, side effects of medication regimens for chronic diseases, such as increased urinary frequency related to diuretic usage and hypoglycemia due to diabetes medications, are also more difficult to manage or tolerate for people without reliable access to bathrooms or food. Many chronic health conditions – such as hypertension, heart failure, and diabetes – develop slowly over the course of many years and the benefits of medications used to treat them are not readily apparent to the user.¹⁶ Thus, the increased challenges of following daily medication regimens in this population may outweigh the importance of continuing self-management of their conditions, especially when factoring in medication side effects and disconnection from sources of health education and encouragement.

Even after overcoming barriers to engaging with the healthcare system, the literature describes additional barriers individuals experiencing homelessness have to confront. During interactions with healthcare systems, these individuals consistently describe overwhelming experiences of stigma and shame related to their circumstances
that make disclosing current or past health concerns and traumas difficult. This is most pronounced when it comes to substance use, which is stigmatized, implicitly or explicitly, by many providers. Notably, the literature consistently shows that substance use among those experiencing homelessness is greater than in the general population, and that it not only increases emergency room visits (independently of homelessness itself), but is also the leading cause of death among this population. Additionally, many experiencing homelessness feel as if their providers view substance use as a moral failure instead of a health issue, thereby making them less worthy of dignified care and less valuable as a human being. Thus, many with lived experiences of homelessness fear that such a history may lead their provider to not take their concerns seriously and/or to provide inadequate care. Other examples of negative experiences include feeling like the thoroughness and quality of one’s care is being triaged based on an assumed ability to pay, feeling invisible to providers and systems alike, and feeling blatantly disrespected due to their circumstance. Over time, negative experiences with healthcare due to stigma colors future interactions leading individuals to anticipate being mistreated in healthcare settings, contributing to feelings of medical mistrust and, ultimately, a poor understanding of one’s medical conditions.

On top of the stigma and biases that affect patient care, healthcare providers and systems often lack an understanding of the issues faced by those experiencing homelessness. In the rare cases in which they do have an understanding, they often fail to apply it towards improving their clinical practices. Put another way, systems and providers often fail to fully appreciate the impact of social determinants of health,
trauma, and past adversities on the health and clinical presentation of individual’s experiencing homelessness. This concept is illustrated by healthcare clinic policies that lead to patients being asked to leave because of the way they dress or smell, or not being offered harm reduction resources to meet them where they are. When they are seen in clinic, patients experiencing homelessness often feel that the time, empathy, and compassion afforded to them is inadequate relative to the difficulties they face. In addition, there is perceived lack of accountability for these inadequacies.22

In a perfect world, healthcare systems would do their best to tailor care to the unique needs, wants, and challenges of each patient. In reality, systems are often inflexible and expect conformity from those they serve. One example is a lack of flexibility and understanding for patients showing up late or missing appointments due to a lack of access to reliable transportation or dealing with more salient needs, as discussed earlier. In a study in Canada, which has a more robust social safety net than in the United States, healthcare and social service providers noted that housing is required by hospital policies before initiating treatment for substance use disorders. Such experiences contribute to negative perceptions of traditional healthcare systems and, by extension, the providers who work within them.22

Beyond those described above, people experiencing homelessness also perceive other shortcomings in the healthcare system. For instance, many share the perception that their providers prioritize their own status, job security, and finances over the needs of their patients. Many also feel that healthcare systems lack representation and input from the unhoused community.22 They describe systems full of “red tape,” or
administrative hurdles, that effectively turn people away from seeking care in the future. As an example, the amount of paperwork, number of phone calls, and level of care coordination that increase in proportion to one’s level of need are often put on the shoulders of the patient and require an unrealistic degree of health literacy. Existing literature suggests that administrative burdens and hurdles reduce participation in social welfare programs, and it is likely that similar burdens and hurdles reduce participation in healthcare. In fact, some scholars argue that these burdens, as they apply to government-funded programs, are a hidden and more politically attractive way to reduce participation in and use of these programs and therefore reduce public spending.

**Adaptations to Healthcare Barriers**

The literature describes some ways in which people experiencing homelessness adapt to barriers that exist in the healthcare systems. For example, Diane Martins’ qualitative study describes strategies of “underground resourcefulness” that marginalized persons rely on to survive. These strategies include sharing medications or modifying doses to make them last, as well as volunteering for research studies or feigning unconsciousness in order to be seen by a medical professional. In that and similar studies, participants described resorting to measures considered to be unethical or even illegal, such as stealing a relative’s credit card to pay for treatment, or intentionally committing a crime to become incarcerated, therefore obtaining access to
healthcare, shelter, and food. Finally, when these or other attempts fail, some described resorting to substance use to cope with the difficulties of their physical and mental health, or to “numb the pain of their existence.” For these people, substance use disorder often ensues, which can lead to a cycle of criminalized behaviors such as engaging in sex work or theft in order to afford continued use.5

Barriers Outside of Healthcare Affecting One’s Health

Outside of the healthcare setting, there are additional barriers accessing resources for those experiencing homelessness that may have consequences on their health. In 1996, the United States’ “welfare” system, which functions as a social safety net to provide direct financial benefits to individuals in need, was overhauled to include strict eligibility requirements for receipt of benefits, including workforce participation or a qualifying disabling condition that did not include substance use disorders.28 Following these reforms, the number of individuals receiving financial benefits from the government via programs like Temporary Assistance for Needy Families (TANF) or Social Security Disability Insurance (SSDI) in the United States decreased precipitously. As a result of this systemic change, obtaining a mental illness diagnosis became one of the only ways for impoverished individuals, including those experiencing homelessness, to qualify for these benefits. This is a phenomenon that Hansen describes as “pathologizing poverty.”29
While these now-needed mental illness diagnoses were sometimes appropriate, they came at a physical and mental cost as patients had to take potent psychoactive medications with significant side effects - such as sedation, obesity, diabetes, and elevated cholesterol - in order to stay eligible for benefits like disability pay and permanent housing. Similarly, other people sought disability-qualifying chronic pain diagnoses, leading to a domino effect of opioid prescriptions, substance use disorders, and overdoses. In both approaches, individuals were unable to legally work even part-time or else they’d disqualify themselves for benefits and/or be branded as “cheaters” or “underserving poor” by society at large.

Similarly, scholars have noted that some people experiencing homelessness report staying in shelters instead of accepting temporary living arrangements with others, such as family or friends, in order to qualify for priority housing programs. While intended to prioritize those with the greatest need, these scholars argue that such programs actually participate in creating need itself by requiring people to reach desperation - homelessness - before becoming eligible for assistance. Unfortunately, as previously discussed, experiences of homelessness have many adverse effects on one’s health, which may be prevented if housing needs were met at an earlier stage.

Additionally, use of emergency housing shelters themselves has potentially adverse effects on one’s health. Many emergency shelters are first-come, first-served, shared spaces with minimal security. Thus, personal belongings, including medications, can be easily stolen. Additionally, many shelters employ strict, sometimes punitive policies around the hours one may come and go, as well as around “missing”
nights once assigned a bed. For instance, one may have to line up hours before the shelter opens just to get a bed and may lose their spot if they violate any policies. This ultimately affects one’s ability to work and make appointments, both medical and not. Rosenberg et al. argues that policies that hinder one’s ability to assert control over their own life and develop a sense of ontological security, or feelings of home and belonging, have a serious impact on one’s identity and well-being.\textsuperscript{36}

The identification of barriers that impact access to healthcare and other resources that impact health for those experiencing homelessness is understandably incomplete, as each city’s and healthcare system’s approach to, stance on, and resources addressing homelessness are unique. Nonetheless, the consequences of these barriers are real, as they may play a role in perpetuating homelessness and the medical and social conditions associated with it, as well as lead to potentially harmful adaptations to get around them. Thus, a greater understanding of the strengths and weaknesses of local healthcare for those experiencing homelessness may lead to changes that are more equitable, applicable, and effective.

**Impact of COVID-19**

Considering the health and healthcare challenges that people experiencing homelessness face, it comes as no surprise that this population is at increased risk of contracting, spreading, and suffering from the coronavirus disease 2019 (COVID-19).\textsuperscript{37} For instance, many who are unsheltered lack ready access to sanitary facilities and
supplies. For those staying in shelters, conditions may be crowded and the guests unable to follow CDC safety guidelines around regular testing, mask wearing, social distancing, indoor gathering, etc. Additionally, there are concerns that as the pandemic continues or comes to pass, there will be an economic and eviction reckoning that will burgeon the number of people experiencing homelessness and thus competing for already limited resources. Also, because of the precautions taken to mitigate risk of COVID-19 infection, the services that these people rely on - including shelters, soup kitchens, food pantries, and drop-in centers - are struggling to obtain the resources, space, and volunteers, including retirees and students, that they rely on to meet the current demand, let alone the anticipated increased need to come.37

The Coronavirus Aid, Relief, and Economic Security (CARES) Act of 2020 allocated funds specifically to those experiencing homelessness. It also funded state and local programs aimed at those at risk of losing their housing due to an inability to pay rent. Efforts were made to make other resources available to at-risk populations, such as stimulus checks, eviction moratoriums, temporary housing in hotels, etc.37 While well-intentioned, it is nonetheless important to understand the lived experiences of obtaining these resources by intended recipients in order to evaluate their effectiveness.
Innovative Models for Providing Primary Care

Purkey and MacKenzie suggest that in order for healthcare providers to live up to the standard of “curing sometimes, relieving often, and comforting always” for patients, especially the most vulnerable, there must be a cultural shift away from “one-size fits all” models of care. Instead, they promote team-based care models that exhibit more understanding, versatility, creativity, and compassion than the status quo.22 To that end, research within the Veterans Health Administration (VHA) has shown evidence that primary care models that provide comprehensive, well-coordinated, patient-centered care that also addresses social determinants of health improve patient experiences amongst veterans experiencing homelessness. In turn, these positive experiences have been linked to increased primary and ambulatory care visits, reduced acute service usage, and better medication and recommendation adherence.21,38-40

The VHA approach includes a focus on the mission to reduce homelessness, providing access accommodations to patients, training providers specifically in healthcare delivery for those experiencing homelessness, and coordinating primary care with mental health, addiction medicine, and social work services. They refer to this patient-centered, medical home model as Homeless Patient Aligned Care Teams (HPACT). Notably, a major component of this model and those like it is the input of team members who themselves have faced or are facing challenges like those of the population they aim to serve.41 It is pertinent to note the large financial commitment from the U.S. Department of Veterans Affairs to this cause. For example, programs such
as the U.S. Department of Housing and Urban Development-Veterans Affairs Supportive Housing (HUD-VASH) play a large role in supporting housing for veterans.42

Nevertheless, medical home models like HPACT’s recognize that traditional care models are neither flexible nor comprehensive enough for those experiencing homelessness. Therefore, they often have multiple sites with ready access to secondary (i.e., specialist care), tertiary (i.e., specialized care in a capable facility, like dialysis), and respite care (i.e., post-acute, recovery care) as well as teams dedicated to outreach. They also integrate local agencies and resources for housing, employment, and legal assistance. This allows for an increased ability to address medical and health-related social needs in one place, which is important for a population facing barriers to care on many fronts, particularly transportation and care fragmentation. These models also emphasize the principle of “Housing First,” the idea that one must have a decent, permanent, and safe place to live before their health and socioeconomic status can improve. Ultimately, evidence shows that models of care exhibiting these characteristics are both more effective and better received and should therefore become the status quo for those experiencing homelessness.43-46

Background Specific to Thesis

The U.S Department of Housing and Urban Development’s Continuum of Care (CoC) Program was designed with the goal of ending homelessness by providing funding for efforts by nonprofits, states, and local governments to quickly rehouse homeless and
other vulnerable individuals, minimizing their trauma, promoting their access to and effective utilization of mainstream programs, and optimizing self-sufficiency. CoC Program funding recipients are required to conduct Point-in-Time (PIT) counts of those experiencing homelessness at least every other year and to collect and report certain metrics. New Haven, Connecticut is a mid-sized city in the Northeastern United States. Like most places in the country, it has a shortage of affordable housing and, as a result, a large subpopulation experiencing homelessness as well as programs receiving CoC funding to address it. Based on a 2019 PIT count, the city had 503 people experiencing homelessness, a rate of 9.39 per 1000 people, of which around 100 were unsheltered, 370 were staying in emergency shelters and the rest were living in transitional housing. Of the 503 people surveyed, 66 disclosed having mental health diagnoses, 24 disclosed having substance use disorders, 13 disclosed having HIV, and 64 disclosed fleeing domestic violence. Finally, 35 individuals disclosed experiencing chronic homelessness. Those who performed the PIT also made a note that those under age 25 were significantly undercounted.

Like many other cities, New Haven provides resources for its subpopulation experiencing homelessness, including long-term rental assistance, community and outreach healthcare programs, clothing closets, soup kitchens, food pantries, shelters, warming centers, substance use treatment and rehabilitation programs, as well as a 211 phone helpline to direct those in need. Nonetheless, as in most jurisdictions, there are shortcomings in who these resources reach. Researchers have often argued that a critical part of evaluating the effectiveness of policies, as well as their potential
unintended consequences, is understanding how the people they’re aimed at experience and respond to them.50

Statement of Purpose

The aim of this project is to analyze transcripts from qualitative interviews from participants in the Justice, Housing, and Health Study (JustHouHS) with lived experiences of homelessness in New Haven in order to: 1) identify barriers that limit access to local healthcare systems, resources, and providers; 2) examine potential health implications these barriers may incur, including when participants adapt and attempt to overcome them; 3) examine characteristics common among positive experiences in obtaining healthcare and the implications these characteristics may have in improving future approaches to care for this population.

Based on the literature presented in the introduction, the following hypotheses regarding this project were made: 1) the approaches of healthcare systems, resources, and providers in New Haven pose barriers limiting access to those experiencing homelessness. They may be assumptive, unwelcoming, or do not provide adequate assistance, ultimately leading to suboptimal accessibility, quality, or coordination. This negatively impacts the physical and mental health of the individual they intend to help; 2) those experiencing homelessness navigate these barriers in a variety of creative ways. Some strategies lead to successful access to services. Other times these strategies are unsuccessful with implications for health; 3) those experiencing homelessness will view
more positively the resources that are convenient, that meet them where they are, and that make a point to act in their best interests. These resources will also have more positive impacts on their health.

Methods

This thesis project is a secondary analysis of the qualitative interviews conducted during the Justice, Housing, and Health Study (JustHouHS) of participants with lived experiences of homelessness. For more details on the methodology of the JustHouHS study summarized below, see the references for the study’s website or the paper by Keene et al.34,51

Overview of the Justice, Housing, and Health Study (JustHouHS)

JustHouHS was a longitudinal study funded by the National Institute of Mental Health (R01MH110192) designed to examine the intersections of the criminal justice system, housing, and health, with a particular focus on sexual health and HIV risk. Low-income New Haven residents - defined for the project as those who were unhoused, receiving food assistance or Medicaid, or residing in census tracts with greater than 20% poverty - were recruited using a combination of flyers posted throughout the New Haven community, outreach from service providers, and snow-ball sampling. The low-income population of New Haven was being studied because it is the population most at
risk for criminal justice involvement, housing instability, and HIV. Given the study’s interest in the intersection of mass incarceration and health, the sample was stratified to include 200 individuals released from prison or jail in the prior year and 200 who were not, for a total of 400 recruited participants. JustHouHS participants took a baseline survey in the fall of 2017 and returned to take a follow-up survey every six months for a total of five surveys. A subset of JustHouHS participants (N=54) also completed qualitative interviews every six months. For each survey and interview completed, a $50 debit card was given to the participant.

**Recruitment in Qualitative Arm**

Participants were randomly selected from among those enrolled in the survey and who answered “yes” to interest in the interview arm of the study in a survey question. 54 participants were selected: 27 were from the low income (LI) arm and 27 were from the criminal justice (CJ) arm. Random selection among participants interested in the qualitative component took place within both the LI and CJ arm. Once selected, research assistants called the participant to describe the qualitative interview process and ask if they were still interested. If still interested, the research assistant would schedule an appointment. If not interested, they were removed from the list and another random selection was made. After about three quarters of participants were selected, the team reviewed gender and race representation in the qualitative cohort and ensured that the qualitative cohort was similar in representation to the survey
cohort for race and gender. This was done through random selection of participants within the underrepresented race or gender. Two additional participants were recruited for one time only interviews due to their unique circumstances.

Overview of Interviews

The interviews were semi-structured and varied in length. Interviews lasted between 13 and 155 minutes with an average of 54 minutes (excluding one-time interviews). Participants were invited to take part in an interview every six months for two years, for a total of four interviews each. Three team members conducted the interviews, with the same interviewer across waves for participants. An interview guide covered the following topics: housing, criminal justice involvement, economic situation, sexual relationships, condom use, HIV testing, health, relationships with family, friends and partners, family background, and the participant’s community connections. To allow for unanticipated insights, interviewers followed the natural flow of the conversation and probed on domains of interest. The baseline interviews captured both current and historic information on the topics of interest, while follow-up interviews focused on changes to these domains as well as allowing for further probing on information shared at baseline and a deeper understanding of the issues discussed. The fourth interview focused on issues of HIV, condoms, and sexual risk. An additional interview occurred outside of the anticipated study period that focused on experiences with the COVID-19 pandemic. Data from the qualitative interview transcripts were coded using the
software program NVivo 12 and analysis began by indexing interviews for major topics of interest for the project with the 54 enrolled in the interview cohort.

**Student Contribution**

For this thesis project, this author performed a secondary analysis of qualitative interviews from the JustHouHS study. This study was chosen because it includes and follows participants experiencing homelessness in New Haven over a period of years, including when the COVID-19 pandemic began. This longitudinal design provides the potential to analyze the evolution of peoples’ perspectives, experiences, and adaptations related to their health and interactions with healthcare.

For this analysis, this author focused on participants in JustHouHS’s qualitative arm who met the following sample subset criteria: identifying as living in a hotel/motel, homeless shelter, or as homeless at any wave of the study or in the 6 months prior. Of the 54 participants interviewed, 36 met these criteria. Then, this author used the software program NVIVO 12 to query for and export excerpts of transcripts of interviews with these participants tagged under the parent nodes of “health,” “substance use,” and/or the child node of “social service provision” (parent node: “relationships”).

Next, these excerpts were coded in the software program Dedoose using an open-coding technique. A draft codebook was then developed, centering on the experiences of, responses to, and health consequences of services, systems, and people
that provide or connect to healthcare. The codes also identified potential health consequences related to homelessness. This codebook was then applied to an excerpt sample by this author to discuss and further evolve the codes with the JustHouHS team (see ‘Appendix A’ for codebook). Afterwards, the codes were applied to all the excerpts from the broader NVIVO query and emerging themes were analyzed by this author. Finally, these themes and their analyses were situated in the context of existing literature and discussed.

Comprehensive summaries of participant data at each wave in the study, known as matrices, were generated previously by the JustHouHS team and provided snapshots of what was discussed in each interview. This allowed the research team to capture the participants’ data across time and quickly see how their data fit within the JustHouHS study’s domains. Similarly, these matrices were used to remind this author of participants’ situations with regards to housing, economic status, health, criminal justice involvement, and substance use, and how they changed over time. This was particularly relevant in the analysis of each participant longitudinally. There was also invaluable input from members of the JustHouHS team and academic advisors throughout all stages.

Human Subjects Research

Because the JustHouHS study was designed to look at the impact of mass incarceration on HIV/AIDS, some study participants had a history of criminal justice
involvement, and some became incarcerated over the course of the study. Research was not conducted with anyone while they were incarcerated. However, research was conducted with individuals mandated to live in halfway houses, or serving on probation or parole and therefore, under the jurisdiction of the criminal justice system. It was critical to include their perspectives to achieve study goals. The study did not involve any extra risk to these groups.

The JustHouHS study received a Confidentiality Certificate by the Department of Health and Human Services as well as institutional IRB approval from Yale University. The protocol was determined to present minimal risk to subjects. Informed consent was obtained from all participants and documented with a signed, written consent form. All participants in the study indicated a pseudonym by which they were identified. Additionally, in keeping with NIH and Yale HIC policy, there was a representative on the IRB representing the interests of individuals with criminal justice involvement.

Results

Summary

The themes that emerged from this subanalysis depict a healthcare system with numerous barriers to accessing and maintaining care without adequate, accessible, or effective resources to navigate them. Many of our participants describe the struggle to navigate these barriers on their own, further weighing down their already overburdened shoulders and leaving them with little agency over their care. They also depict
healthcare experiences full of assumptions based on biases and stigma, particularly around substance use – which is often intertwined with the experience of homelessness – leaving them feeling unheard and unsatisfied with their care, with some even being directly harmed as a result. Others describe healthcare that is personally or systematically uncaring: treating them unkindly, impersonally, inferiorly, or exploitatively. It follows that their experiences reflect a systemically perpetuating lack of healthcare engagement and trust by a population that has been historically disenfranchised.

The themes also illustrate not only the cost of prioritizing certain basic needs over healthcare, but also the cost of prioritizing healthcare over other basic needs. Additionally, the economic precarity of participants leaves many without the ability to absorb the direct and indirect financial costs of a healthcare event, leaving many to live in fear of such an event happening and leading others to avoid engaging in care completely. They also show how our participants adapted to or coped with the healthcare barriers they faced, employing creative, available, deceptive, and sometimes desperate measures. Others gave up trying and employed coping mechanisms, like substance use or prayer.

Finally, the themes highlight aspects of the healthcare system that patients experiencing homelessness view positively. They appreciated resources and providers that encouraged and empowered them in accessing healthcare and making positive changes for their health. Such empowerment often came from providers who created an environment of trust; trust that was often developed with providers who were kind,
went above and beyond expectations, or acted “outside” the system. Our participants emphasized the positive health impact from systems and providers that made the effort to meet them where they were, from their physical location to the issues most important to them, such as pain management to help their daily function and nonjudgmental, harm reductive approaches to substance use. Finally, participants touched on some of the conveniences brought about by the COVID-19 pandemic that helped them engage with care, such as flexible methadone treatment options, prescription deliveries, and phone appointments.

**Shortcomings in healthcare**

*Inadequate help in navigating healthcare barriers*

A major theme that came up across interviews is the notion that there is insufficient or ineffective assistance provided for navigating barriers within the healthcare system. These barriers take many forms - scheduling, insurance policies, provider bandwidth, transportation, and care coordination - but all impede healthcare access and negatively impact the health of those seeking help. In many cases, those experiencing homelessness ended up shouldering the burden of the administrative barriers around accessing and maintaining healthcare. Unfortunately, our participants are not only among those most in need for help in navigating the healthcare system and its barriers but are also those who are most harmed when hindered by them.
One participant, Evan, notes that despite efforts to see his epilepsy specialist regularly, he has been told by scheduling staff that “the doctor is extremely busy” and is hence only able to get in once per year. He further notes that he was hoping to use his epilepsy diagnosis as the basis to apply for disability benefits. Regarding the disability application, he says, “yeah it’s-it’s a pain in the butt. But you gotta do what you gotta do... But I – I mean I talked to my doctor and he said, ‘hopefully you get it.’ He said, ‘your case looks good so...’ And I don’t have a lawyer... I’m doing this all on my own.” Even though the provider is verbalizing hope that Evan gets these benefits, it’s clear that his surface-level inquiry is not helping resolve the difficulties Evan is having trying to apply.

Brandon, another participant, also shares his frustration with scheduling appointments. He says, “... they [are] slow. Then they take months to get in. I got an ailment – I say, I’m hurting now and you telling me to come back next month.” However, to switch to a different primary care program, he had to make a plea to the program coordinator to help him or else it would’ve taken over a year. What’s more, he expresses fear over being cut off from this new program due to a recently missed appointment. Ultimately, both Evan and Brandon are ultimately left disappointed with the level of service they received.

Cora shares how the limited bandwidth of some providers, whether due to busy schedules or a large patient-to-provider ratio, negatively impacts basic healthcare. She notes how the doctor at her temporary housing program was spread thin managing the complex medical needs of over 40 people there. Due to this, she felt there were long
delays in her receiving even medication refills, such as a nasal spray to help with her troublesome allergies.

Jordan, another participant, shared an experience described commonly in the literature of how abrupt deprescribing policies for opioid medications led to his illicit use and subsequent substance use disorder52:

*I-I was in [town name] homeless. I had a hectic couple years. Um, I got hurt on my job and then they-they – uh, my doctor, um, got me addicted to Percocets and oxyContin ‘cause my leg was broke in two places. It’s still broke now, actually. And, uh, they put me on those pills heavily and next thing you know they said they can’t give me no more, so I buy – start buying them on the street. Then I couldn’t afford them on the street so I started using heroin [slurps drink] ‘cause it was cheaper, and that’s my story.

Other participants described insurance policies that posed barriers to their healthcare access that they wish they had more help in navigating. Maya shares that while her state insurance covers methadone, a medication that is typically dispensed daily in a physical clinic for the treatment of opioid use disorder, she’d prefer to try Suboxone, a different medication which can be conveniently taken anywhere. However, since she doesn’t have access to a car, she can’t get to the few providers covered by her insurance who could prescribe Suboxone, leaving her feeling “stuck.” Cora also shares her frustration that she has limited options for mental health providers due to restrictions placed by her state insurance. She doesn’t feel like her current provider listens very well and would like to find a new one but is unsure who she can ask to see if she can.

Another barrier to healthcare described by participants is transportation. For example, Trinity describes the challenges of getting to the methadone clinic daily while
balancing work and illness. One time, she describes being so sick that she had to have a friend drive her to the clinic, feeling the whole time like she was going to faint. She shares that this burden is why she stopped her treatment in the past, significantly impacting her health.

Participants also noted frequent administrative burdens. For instance, Evan shares that he prefers to continue working through his chronic back issues and epilepsy rather than reapply for disability, as the previous application has already been pending for five years. He notes that applying is “a pain in the butt” and that you must see certain doctors, making the process more challenging. Trinity notes not only the difficulty she has had in coordinating between a lawyer and her doctor to get a letter stating that her injury from decades ago was job-related and thus entitling her to compensation, but also the impact it has had on her feelings towards her provider:

*He would give me papers that my diagnosis – like I was stupid or something and it’s – it doesn’t say – I need it to say “job-related injury” and he never gave me that, and me and him had, you know, a little conflict about it. And I don’t feel comfortable with him cutting on me now [for surgery].*

Like Trinity, Jayden too shares having to take the lead in coordinating paperwork between a lawyer and doctor to help him get money from a pending lawsuit. Addison shares her frustration towards her husband’s pending case for VA benefits after suffering a gunshot wound while on active duty as well as for supplemental security income for chronic back pain after being stabbed: “…there’s just a process for everything…but we both have faith.” Finally, Michael describes being required to get a tuberculosis test before being allowed into a drop-in center for those experiencing
homelessness. When he was finally able to get the test done, he lost his printed test result so had to struggle to find a provider again to get another test.

**Approaches to healthcare that are assumptive**

Another theme that arose was that healthcare providers are often perceived as acting assumptively towards their unhoused patients. These assumptions, often based on biases and stigma, guide providers away from appreciating what their vulnerable patients are saying or seeking a more accurate understanding of their situations, behaviors, and needs. The resulting disconnect in understanding between provider and patient inevitably leads not only to a lack of satisfaction in the therapeutic relationship, but sometimes directly to harm. In either scenario, the experiences perpetuate a lack of engagement with healthcare by a population that has historically been disenfranchised. Additionally, such assumptions are particularly pronounced in regard to substance use which, as discussed previously, disproportionately affects those experiencing homelessness and is the leading cause of death among them. As our participants highlight, substance use and homelessness, as well as the assumptions associated with each, act to complicate and reinforce each other.

Jordan, who originally developed an opioid use disorder after being prescribed opioids for a workplace injury, expresses frustration over how hard he now must push for his provider to take his pain seriously due to his assumption that he is seeking opioids. He states:
...He’s nervous about giving me something, another narcotic... But he gives me 2 milligrams. [Sighs] It is what it is. It helps I guess ‘cause it’s not hurting as much, but it’s still hurting. But like I asked him, "Why do I have to, you know, go through the pain? Why do I have to do that?" ‘Cause when I get tired of getting – being in pain I’m gonna use. That’s what happened. So I’m gonna use when it’s – when I’m really tired of struggling with the pain. He don’t get it.”

Jordan feels like his provider is not only failing to appreciate his pain, but also how it ties into his lived experiences of substance use disorder.

Similar to Jordan’s experience, Carter had a provider set him on the path towards opioid use disorder by abruptly stopping prescription opioids without consideration of the potential consequences. As Carter puts it, “then the doctor’s like, ‘alright, I think you’ve had enough [Percocet pills]. You don’t need no more.’ Now I go home and get sick all that. I’m buying ‘em from people on the street.” As Carter puts it, things went “haywire” from there. In this case, an inaccurate assumption of what his pain level and degree of opioid dependency were by his provider led Carter to disengage from healthcare and seek pain management elsewhere, notably through nonprescription substance use.

Carter also expressed frustration when his provider did not believe he returned to alcohol use while taking disulfiram (also known as Antabuse), a medication that deters one from drinking by causing them to feel very ill. Instead, the provider assumed that Carter had simply stopped taking the disulfiram, reasoning that if Carter had still been taking it then his reaction to drinking alcohol would’ve been much more severe. This is despite the administration of Carter’s disulfiram being directly observed. By assuming Carter was being nonadherent and then anchoring on this assumption despite
evidence to the contrary, the provider failed to consider discussing or trialing a different approach to treating alcohol use disorder that may have been more effective for Carter. As Carter has had legal trouble in the past due at least in part to his alcohol use, the stakes of ineffective treatment assistance for him were higher. What’s more, the provider’s clinical reasoning for putting Carter on disulfiram was not a shared decision but rather based on an assumption of what he needs, evidenced by Carter’s statement, “I feel like I’m taking [the Antabuse] for no reason but my clinician want me to stay on it, so I stay on it.”

In a different interview, Jordan shares that his doctor once became “mad” at him for missing appointments, assuming he was being negligent. However, on further questioning, he recounts having to take three different busses to get to the office due to his lack of a vehicle and suspended license. In addition, he was simultaneously facing legal and financial challenges that competed for his time, energy, and resources - a situation described by many of our participants.

Isaiah recounts his experience of doctors assuming his acute mental illness was drug-induced:

...but then I would have other manic episodes and I would end back up in the hospital, and the in New York [sniffs] their thing was [sniffs] – excuse me – their thing was, "Oh, it's drug induced." I said, "It's not drug induced." And then they start taking my urine and seeing that the only thing that he had, if that, was the marijuana. You understand? I said, "I'm having a manic episode. This has absolutely nothing to do with drugs." You understand? And actually, when I was having manic episodes I didn't even want to use drugs. You understand? I was trying to get my mind together. [Laughs]
Cora recounts an experience of coming to the emergency room with a migraine and being treated differently because of her charted history of substance use. Even after she denied any current use, they assumed she was lying and told her, “with an attitude,” to take ibuprofen, a nonprescription medication for pain relief. She describes her perception of this assumption and attitude further: “…[they assume] you got aches and pains ‘cause you’re a drug user all your life.” She adds, “…Don't say all addicts do this - you can say most maybe, most people in the world drink coffee, most whatever, but you can't say all. You just can't.”

Cora also emphasizes the feeling of not being heard by her provider when they make assumptions about her needs. She recounts:

…but when I was meeting [the APRN] for the initial, like, consultation or whatever I don't feel like she listened to nothing I said. She was just like, "Okay, like I'll continue [your sleep medication] 'cause you've been on it and you need that and we're not gonna, like, stop that." But when I was telling her about, like, how – my feelings and, like, what I've been going through, she was like, "Oh, you'll be okay," like she...

Ryan, another participant, had a similar experience of his provider assuming his needs to the effect of not hearing what Ryan was actually concerned over:

…the doctor told me, everything good but – you don’t got AIDs, you don’t got STDs, you don’t got nothing. The only thing you need to do is get sun. I say "That is keeping me skinny?" He say, "No, no, I don’t care about that." I want to know why I getting more skinny. The first time I was 185 – 190 [pounds]. And then now I am 140. So how that happen? He say, I don’t know. I say, man, you’re a doctor, you don’t know? Get the fuck out of here, you just taking my money – my insurance card. Shit.

Addison describes being bit by a neighbor’s dog and, despite the throbbing pain she was in, she was sent home from the hospital without any pain medication. At the time of her interview, she planned to return to the ED to get help relieving it. These examples -
Cora’s hope for an empathetic ear, Ryan’s concern over his weight loss, Addison’s pain - highlight providers’ assumptions that their patients’ needs are different from what they are being told. All cases resulted in distasteful healthcare experiences.

Cora also shares an episode where she felt as if her pain management providers assumed she wasn’t in pain any longer because she declined to use the methadone they recommended, a medication which she doesn’t like to take. When asked by the interviewer if she was ever offered a different option, she says:

Nope… and the conversation just stopped after that. They didn’t ask me never again like how’s your back, your neck or your knees hurting today or anything like that, so…

For someone like Cora who’s experiencing homelessness and whose chronic pain is at least in part due to a past injury at the hands of the police, there is a high likelihood of trauma present alongside her medical concerns. However, such information never comes to light with the closed-ended, assumptive discussion she had with her provider. As Cora puts it:

I want one person that knows me, that we-we gain a track record, that she knows what I’m saying for years or whatever and that’s it and they could, you know, see the severity of my issue.

Finally, participants described assumptive security policies within healthcare facilities that play a role in preventing unhoused participants from getting the services they need. For example, Isaiah was arrested after he recognized he was acutely manic and sought help at the emergency room - an effort to be promptly seen suggested by a provider of his. However, in the process of seeking help, he got caught up in a verbal argument with a security guard after the guard assumed he was starting trouble or
under the influence of substances instead of genuinely seeking medical assistance. This episode was directly related to Isaiah’s housing status as he was not taking his psychiatric medications because they make him sedated, thus exposing him to the risks of theft and assault while sleeping outdoors or in shelters. Unfortunately, taking these medications is vital to reducing or preventing manic episodes.

**Approaches to healthcare that are lacking in care**

Another theme to emerge from the interviews with JustHouHS participants with lived experiences of homelessness is the uncaring nature of the healthcare services they’ve interacted with, from both provider and system levels. Some felt they were treated inferiorly due to their perceived economic or social status, while others shared episodes of trust being broken and fears of being taken advantage of. Many described a healthcare system that felt impersonal and unkind. Finally, despite the presence of risk factors and contrary to a core tenet of primary care, many shared stories of having to initiate preventative care discussions with their providers themselves.

Participants described healthcare providers as quick to treat them inferiorly to other patients, be it due to stigma, biases, or their perceived socioeconomic status. Isaiah describes a personal belief that the hospital treats people who have low-income insurance poorly, an opinion formed by multiple health scares where he felt like providers didn’t listen to him nor acknowledge that he knows his body better than they do:
I don’t know this to be a fact, but I believe that at [university hospital], I believe that they probably have some animosity having to deal with the low-income insurance as much as they do....And it’s just not as professional as what it should be, and a lot of more people fall through the cracks. You understand. And then it’s easier for a little cover it up because these individuals don’t have the money to pay for a lawyer to rectify the situation.

Bently, who admits to using the emergency room as somewhere safe to sleep, notes that once staff and security began to recognize him, they were not so nice and made him leave the lobby and sit outside. He states:

Um...yeah, [phone ringing] but after going a few times like they'll-they'll rec – they [security] recognize you and, um, they, uh, they're not so nice. Like they're...they just know that you're just there 'cause you need somewhere to stay or you just want to be warm for a little bit and they'll just tell you – sometimes like – even like towards the end, like they'll just tell me to just sit outside, like tell me to leave the lobby and go sit outside.

Others share experiences of their trust in healthcare being broken down and tales of feeling taken advantage of by their providers. Pete and Brandon share that they’ve had multiple experiences of dentists who accept his Medicaid insurance trying to pull more of his teeth than necessary because they make more money doing so. Kaylee shares her trepidation over seeing “independent” doctors, preferring to see “established” ones, such as those working for the university hospital or community health centers, that she views as more trustworthy. Addison shares a belief that doctors or nurses at hospitals can give a “black needle” to those patients who are causing problems, stopping their heart – this is what she believes happened to her grandfather. However misled this belief may be, the fear of being taken advantage of by healthcare providers still rings true. Brandon shares a similar fear:

Yeah, he – I forgot them shots, what they call them. But see, it’s like you said about the dentist. That’s how it is with the doctors. That’s how they get paid, by
you and me – you and I doing experimental drugs to see if this stuff work or – yeah, let's see how this work. [Laughs].

Other examples include Brandon also sharing a perception of his trust being violated when a provider tried to order additional, unscheduled, “sneaky” urine drug tests. Trinity shared her story of delaying medically necessary surgery for her back for a long time because she didn’t trust the surgeon after feeling like he inappropriately refused to sign her disability paperwork. Isaiah shares how medication side effects affected his trust in healthcare and fears of being taken advantage of, leading to a cycle of repeat manic episodes that had a large impact on his life:

...I'm 47 now – I've been dealing with mental illness since I was probably around 21. So, um...they didn't have such a variety of medications... So I'm having these terrible side effects from the medication, and when you're experiencing stuff like that it turns you off. You understand what I'm saying? And-and you start thinking like, "Oh, well I'm sure you've heard that's all – they're trying to use me as a guinea pig, and I felt that way for a period of time, so I stayed away – you understand? – but then I would have other manic episodes and I would end back up in the hospital.

Brooklyn shares a story of being told she has HIV for the first time over the phone:

My heart just dropped 'cause the first thing I thought I was gonna die ...She didn't – "Oh, well you're positive." Like, why would you tell it over the phone? It messed my whole day up, like...

Finally, Maya shares experiences of doctors trying to scare her into making healthier choices:

...doctors always tell you, "If you don't stop smoking, you're going to get cancer. You're going to get COPD." They try and scare you out of smoking, which never works with anyone, by the way. I wish they'd – I hope they know that. And so I've been vaping.

Participants also described aspects of the healthcare system that are impersonal or unkind. Maya shares how she prefers the smaller, community-based hospital in New
Haven because it is “more interactive with their patients on a personal like caring level,” compared to the university hospital that is “straight up and down black tie, like straight and narrow business-like doctor patient.” Others describe more explicitly how the design of the healthcare system itself is unkind. Brandon shares how it feels like every time he goes to his primary care office there’s a new resident (trainee) taking care of him. As he puts it:

Then I go in, I gotta tell them, oh, you somebody new. Now I gotta tell you my whole story all over again and you got it right there on the computer. So. They do good though.

Another aspect of uncaring service described by participants was having to initiate certain preventative care conversations pertinent to risk factors common among their population. For example, Ahmad, Michael, and Kennedy all noted that they’ve requested to be tested for HIV at their primary care office and not the other way around. In Kennedy’s case, she had been with the same provider for about 15 years. Leah too notes having to initiate discussions around pre-exposure prophylaxis (PrEP) medications for human immunodeficiency virus (HIV), as well as HIV and sexually transmitted infection screening. Isaiah notes initiating conversations around HIV screening in the past after noting he’d never been offered it. Eventually, he initiated a discussion around PrEP, which was eventually prescribed to him.
Reactions to shortcomings in healthcare

Costs of engaging with healthcare

The next theme to emerge from the study is the cost of healthcare engagement among those with lived experiences of homelessness. Repeatedly, participants described how the lack of basic needs, such as housing, sleep, safety, and healthcare, detrimentally impacts their health. These impacts include environmental exposures, chronic exhaustion, assault, and chronic illness exacerbations, respectively, as well as the many others discussed previously. These basic needs are often multiple and overlapping, hence there is a constant juggling act as prioritizing some may come at the cost of others, especially healthcare. The corollary is also true, that prioritizing healthcare comes at the cost of other basic needs. Additionally, the economic precarity of many participants weighs heavily when considering the financial cost of healthcare, with many expressing their fear that such a cost may tip them over the edge. However, despite the tricky balance between needs and costs, time and again participants demonstrated great resilience.

Participants note how the requirements imposed by their daily needs are sometimes in direct conflict with what they know to be best for their health and, in these examples, their healthcare. Lee shares that because he must return to the shelter by early afternoon in order to secure a bed for the night, he must carefully pick and choose what he wants to deal with each day, including healthcare appointments. He notes he hasn’t been able to see an eye doctor for a long time to get new glasses, which make a big difference in his daily life. Leah, who intermittently experiences
homelessness, describes the pressure she felt to not lose her job working at a shelter to seek emergency healthcare:

...I had a miscarriage December 2nd because I was having a Crohn's flareup [at the shelter], and you can't leave the shelter unattended and I was calling people to come in for me, come in for me. Nobody would come...I lost the baby in the shelter and the ambulance had to come and get me. And she didn't fire me. I left the shelter unattended for 30 minutes because, yeah, oh, okay, and that was a liability. I was supposed to get fired because there was 30 people there, but you let me have a miscarriage, so how are you gonna explain that? So she let me keep my job. It was shitty.

She similarly shares that despite her doctors not wanting her to work due to the severity of her Crohn’s disease, she continues to take on “little jobs here and there” in order to provide food, clothes, and toys for her children.

Isaiah shares how prioritizing safety over his medication regimen has impacted his healthcare. As he notes, the psychiatric medications he is prescribed for bipolar disorder have sedating side effects. As a result, he often does not take them while experiencing homelessness because they make him vulnerable to being assaulted or having things stolen. Unfortunately, being off of these medications in the past has greatly impacted his life by contributing to recurrent manic episodes, arrests by police, and hospitalizations. Healthcare providers have even incorrectly attributed these episodes to substance use.

While many discussed how the needs of daily life limit their ability to engage in healthcare, others described an important corollary: the impact of the cost of healthcare on their daily life. For example, Mark had to give up a stable job in order to have surgery to fix a bone in his face that was broken during an assault. Pete shared a
similar story of giving up his job due to an unexpected illness and hospitalization. They describe their precarious economic positions, noting how devastating the cost of a major healthcare event would be. As Jackson bluntly acknowledges, “...let's say my foot fell off tomorrow what would I do? That would suck. I wouldn't be able to work. I'd just be tubbed. My situation would be fucked. I don't know what I would do.” Leah, who cannot find an accessible primary care provider or an outpatient gastroenterologist, relies on the emergency room and subsequent hospitalizations to address her frequent Crohn’s flares. However, this avenue for healthcare poses a major dilemma, as she notes, “...I can't afford to be in the hospital for a week and I can't afford to come down [to hospital]...”

*Adaptations to healthcare barriers*

Throughout the interviews, participants with lived experiences of homelessness shared many ways they adapted to shortcoming in their healthcare. Some stepped outside of the standard healthcare system, using creativity, available healthcare access points, personal appeals, or deception to obtain the care they needed. Nonetheless, due to the cumulative stressors of their health and often complex situations, many participants reached a point of despair, with some abandoning their healthcare altogether, some resorting to hope and prayer, and others employing coping mechanisms. However, regardless of how our participants adapted to or coped with barriers, they often described helping or providing advice to those in similar circumstances as themselves.
Due to the challenges of daily life, many with lived experiences of homelessness utilize creative, albeit sometimes burdensome, means to maintain their health and access healthcare. For instance, when asked how she managed her insulin, which must be refrigerated, while unhoused, Addison replied:

*I was losing 'em [insulin syringes] constantly, and once you lose 'em, it's hard to get back. You gotta wait 30 days before the state will refill your medications, so what we did do was we bought a cooler, which it got a radio on it with an antenna, and it's a cooler. We would take all the stuff that needed to be refrigerated inside the cooler, and we knew an ice... They would give us free ice so we could pack my insulin in it and take the cooler with us, 'cause it was on wheels.*

Brooklyn, who has HIV, noted instances of other people stealing or shelters losing her HIV medications until she consistently carried them on her person. Brandon notes that instead of calling to schedule doctor appointments, which is difficult without reliable access to a phone or a stable address, he just walks into his primary care office:

*It's like I just walk in – I just won't be seen that day. I walk in – Hi, I'm Brandon, I'm trying to set up an appointment as soon as possible, the first available one you have – she, "Well, we got one tomorrow." I'll take it. Or she'll say, um, "Well, your doctor's available next week." I'll take it. Or sometimes she'll say, "Well, it's booked up until next month." I'll take it. But if it's an emergency I'll see somebody then, just make a plan for... [going to the emergency room].*

Pete, another participant, rode his bike over 60 miles outside of New Haven to get to a free clinic to have a painful tooth pulled.

Other participants described overcoming barriers to their healthcare by utilizing system access points that are readily available, often the emergency room, even if their concerns do not meet the “appropriate” acuity. In almost all cases, participants decided what was feasible given their challenges. For example, Mark, who has a chronically sore back due to long days of manual labor, frequents the emergency department for
lidocaine patches, acetaminophen, and/or ibuprofen – treatments that are typically accessible through primary care providers or without a prescription at local pharmacies. Similarly, Addison describes having been admitted to the hospital for a dog bite but being sent home without prescription pain medication, with the assumption being that she could afford over-the-counter pain relief options. Without the financial means or reliable access to a primary provider to make that possible, she returned to the emergency department for relief for her now severe pain. For Evan, it’s inconvenient enough to get to his primary care provider that he also uses the emergency room when he’s sick.

Another strategy to circumnavigate healthcare barriers described by participants is appealing to specific individuals to aid them in accessing care. In his interview, Bently acknowledges that while he shouldn’t be going to the emergency room for his prescription refills, the waitlists for getting in to see primary care and mental health doctors are prohibitively long - often many months. He expresses interest when the JustHouHS study interviewer offers to help him find a provider.

Other participants shared stories of omitting information or lying to providers to get the healthcare they feel they need. Cora, who has chronic back pain, doesn’t always disclose her history of substance use when she goes to the emergency room because she feels she will be treated inferiorly. Specifically, providers will often only prescribe her ibuprofen or acetaminophen for her pain, one of which she has an allergy to, instead of more potent medications like opioids that are often avoided in those with a history of substance use due to the potential for misuse.
Participants also shared stories of the role hope and prayer played when the support they received from healthcare systems fell short. Jordan shared his story of returning to using intravenous opioid use after 11 years of abstinence. Although his doctor sent him to the hospital to facilitate getting him into an inpatient detoxification program, he ended up not being accepted due to a policy prohibiting fentanyl use, which was found in his system. Once discharged from the hospital, he then found out that his provider was uncomfortable with increasing his methadone dosage to help prevent further opioid misuse. Jordan states, “...So I just went back home and I prayed on it and I haven't used” and “...no matter, like, what adversity I face, I always get around it. You know, and I been, like - I had three roommates that were really testing me.” Similarly, Brandon notes the vital role that bible study and prayer at a local church played in giving him the strength to resist continued substance misuse.

Some participants shared tales of being overwhelmed by the barriers presented by the healthcare system, foregoing care out of frustration or desperation. Damian shares his stories of repeatedly leaving the VA hospital treatment program for substance misuse because he felt he was not receiving adequate medical help in alleviating the symptoms of opioid withdrawal, such as anxiety, nausea, vomiting, and diarrhea.

The study findings also highlighted potentially detrimental mechanisms by which some participants adapted to shortcomings or barriers to their or their family’s healthcare. For example, Jordan and Carter both adapted to providers abruptly cutting them off from prescription opioids by buying opioids off the streets. Cora describes the
desperation leading to committing a crime in order to afford healthcare for her grandchild:

...I mean I do a crime when I see no other outlet and no options, so that's all I know. You know what I mean? ...If I can't get the job at McDonald's and I know what to do tonight to make $100, unfortunately that's what I gotta do, because at 36 years old I'm telling you right now I can't even afford a bus ride or a water – a bottle of water? ...Like my kid's calling me like – she could call me right now and tell me her – my baby need, uh, ear infection medication and maybe medical don't cover and I gots to say I don't have it. And, you know, that doesn't make me feel great, you know, when...

Participants also shared encouraging tales of how they try to help others navigate similar healthcare barriers. Pete informs those he sees “on the streets” of certain dentists who take advantage of low-income individuals, pulling more teeth than they need to in order to make more money. When Pete finds out when and where the annual free dental clinic that he trusts will be, usually outside of New Haven, he spreads the word among the unhoused community. Lee spreads the word about a day program where one can access healthcare providers or a phone to schedule healthcare appointments, among other resources.

Aspects of healthcare that work well

Approaches to healthcare that encourage and empower

Although participants shared experiences highlighting many of the gaps in the healthcare system that those who are vulnerable often fall through, they also shared positive aspects working to close said gaps. Many emphasized not only the value they placed on their own health and healthcare, but also the pride they felt in making even
small positive health changes given the inherently challenging nature of their situation. To that end, they noted an appreciation of accessible healthcare resources that empowered them to make these changes.

Throughout the interviews, participants emphasized the value they place on good health and, consequently, their healthcare. Isaiah shared that seeing his mental health therapist weekly added more structure to his life, keeping him away from the temptation of substance misuse. He also notes how diligent he is in following his psychiatric medication regimen to prevent recurrent manic episodes, which he recognizes negatively impact his life, as well as following up with all his healthcare providers. The latter he notes is especially important for those in the unhoused community given the many health-related challenges they face. Maya shares that she tries to be “brutally honest” with herself, noting how returning to substance use leads to her becoming so thin she looks like a “hangman figure.” Instead, she reminds herself of all the good things that could follow her abstinence: a good job, house, and car. This motivates her to stick with her methadone treatment. The downside to these examples is that they highlight how many of our participants see themselves as personally responsible for achieving “good health” and, as a result, sometimes feel like it’s their own failure when they are not healthy.

Additionally, while not all participants felt the agency to do so, some shared stories of advocating for the healthcare they needed or felt they deserve. Additionally, a common thread among those who did advocate for themselves was that they had a provider who fostered a trusting environment. For example, Brandon advocated for
himself not to get his tooth pulled by his dentist since it wasn’t currently causing him any problems, and his primary doctor agreed with and supported him in doing so.

Kennedy shares why she decided to be honest with her primary care provider instead of just telling them what she thought they wanted to hear:

Because a lot of times my health was affected by my drinking, um, and also my personal life and my environment. And I think, had I gone to somebody that I had trusted, like this woman, in advance of my relapses, they may have been prevented or been slightly altered in some way... [Now] I’m proactive about it so I go to her, too, if I feel I’m overwhelmed and she adjusts my medication for me, like, my antidepressant. She increases it or something like that.

Similarly, Cora notes that she wants to gain a track record with a mental health provider, someone who really gets to know her and takes her issues seriously.

Michael notes that there are many widely known, accessible healthcare resources embedded in the community, including a healthcare bus that provides HIV testing, amongst other services. Cora shares her belief that many in the community know they can go to the community health van or community health clinic for preventative care, such as condoms to protect themselves from sexually transmitted infections. Kennedy shares that at the food banks and soup kitchens, where people congregate, there’s often healthcare providers screening for high blood pressure and blood sugar. Finally, Brandon notes how empowering it is having the bus pass given to him through a Medicaid program to get to and from healthcare appointments and programs.
Healthcare providers who abundantly care

In addition to valuing and advocating for their healthcare, as well as appreciating resources that empower them to do so, participants highlighted many instances where they felt healthcare providers themselves were welcoming. This welcoming approach took many forms, from providers who fostered a trusting environment, as in the case of Brandon and Kennedy, to providers who were genuinely kind. There were also those who went above and beyond expectations or stepped “outside” of what healthcare systems traditionally regard as appropriate. Participants showed appreciation for these encounters, which increased their trust in the system - some even establishing new connections to healthcare.

Some participants shared stories of providers exceeding the expectations of what traditional doctor-patient relationships entail. Jordan told of how one provider gave him a ride in his own vehicle to the hospital to get his swollen leg checked out. This act had unintended downstream benefits, as the hospitalization led to him getting connected to an outpatient hematologist who could manage his sickle cell anemia in the future, the root cause of his swollen leg. This doctor, who he describes as “amazing,” subsequently arranged for a visiting nurse to come every morning to help Jordan with medications, including his methadone. This meant he no longer had to go to clinic daily to get it, a major barrier to methadone treatment for some people. Jordan describes both the doctor and nurse as “good people that, like, really care.” In another example, Brandon notes how a provider at his substance use treatment program wrote a letter of support to his primary care doctor to benefit his medical care. They sent the doctor a fax
and also a hard copy with Brandon in case the fax wasn’t received, a small act of redundancy that can be seen as going above and beyond to make sure the support is effective. Jayden shares a story of a provider who almost immediately called his insurance company to advocate for him to get coverage of his gout medication after that coverage had abruptly stopped and left him at risk of a painful gout flare.

Others shared acts of kindness by their providers and the impressions these acts left. Maya shares appreciation for how her provider makes her feel comfortable and how “very nice” she is. Brooklyn notes fondly how, during the COVID-19 pandemic, her provider would often check in on her to see how she is doing. Pete shares the story of a dental student giving him his personal phone number in case he needed to see a dentist sooner than the annual free clinic they organize. Finally, Mark notes the great care he received when hospitalized for a surgery to fix a broken bone, emphasizing how many people constantly asked him how he was doing.

**Approaches to healthcare that better address the needs of those experiencing homelessness**

Given the daily challenges, medical complexities, and mistrust of healthcare prevalent amongst those with lived experiences of homelessness, it comes as no surprise that our participants conveyed an appreciation towards healthcare that met them where they were - literally, in terms of geographic location and timing, and figuratively, in terms of the issues most important to them. Maya’s provider encourages
her switching from cigarettes to nicotine replacement through a vaping device, an act of harm reduction that she notes has been effective and saving her a lot of money. Isaiah notes that healthcare providers at a substance use treatment program he entered respected his wish to stop using crack cocaine but not marijuana, stating simply: “okay, then we’ll work with you on that.” Michael appreciates the flexibility and breadth of available services at the community health clinic, noting he’s able to just show up when they open and get seen by “whoever’s available first.” In the midst of the pandemic, Maya and Jordan appreciate the convenience of being able to get a two-week supply of methadone without having to come to the clinic daily. Many also describe having their medications delivered directly to them, another convenience. Finally, Maya and Addison appreciate the convenience of being able to have appointments with providers over the phone.

The impact of meeting this population where they are geographically also shouldn’t be understated, as evidenced by the impact of even a single provider in New Haven. Jim, one of our participants, appreciates the convenience of a provider who visits the soup kitchen where he gets breakfast to offer a variety of healthcare services and follow-ups. Pete also expresses appreciation for the same provider, calling him a “good guy” that he has a good rapport with and who always comes out into the community to check on people. In Pete’s case, this provider checks on his blisters and sets him up with any testing he may need, be it for sexually transmitted infections or routine bloodwork. Henry shares a story of this same provider finding him on the New Haven green to follow up after he had missed his scheduled appointment the day prior. For Michael,
this provider’s presence and accessibility in the community allows him to find him when he needs even small things - for example, a tuberculosis test to get into a day program for those experiencing homelessness. For Isaiah, this provider had frequently checked in on him regarding side effects after starting a new diabetes medication, prioritizing Isaiah’s wishes and concerns by directly and repeatedly addressing them and deciding together to discontinue the medication as soon as his bloodwork results improved. The following quote from Isaiah nicely summarizes the impact of this provider and of his approach to care:

[Provider] is who I see for my asthma. You know, he comes out to the homeless community. If he feels that I need to come into the office he’ll let me know, but I see him pretty much – when he comes into [the breakfast soup kitchen] on Thursdays I’ll see him. You know, he’ll come and check in with me – are you all right, how’s your asthma medications, do you have enough, do you need some refills? You know, and he has this computer where all he has to do is get on a computer and send that, um, prescription right to the pharmacy, you know, so I’m never – it’s-it’s a blessing. I’m never without support in reference to my health, you understand? The support is there but you have to want it.

Discussion

The implications of this analysis are many, reflecting and building upon those described by the current literature and the hypotheses outlined by this author. First, this analysis highlights the many barriers to accessing and maintaining healthcare faced by the most vulnerable of society, particularly those experiencing homelessness. As it stands, many healthcare system efforts fail to make these barriers navigable, as reflected in the experiences of our participants. Additionally, research suggests that the
benefit from system navigation interventions may be minimal with respect to healthcare utilization, quality of care, health-related quality of life, health behaviors, as well as caregiver, cost-related, or social care outcomes.\textsuperscript{53} Thus, these barriers – be it issues with scheduling, cost, transportation, policy, and many others – must be addressed directly or removed, which cannot happen until healthcare systems and policymakers acknowledge and take responsibility for their presence and institute needed, potentially radical, changes. In the interim, healthcare systems and related resources must be accountable for providing sufficient help in navigating them for the most vulnerable individuals instead of the status quo where those most in need of offloading of these burdens end up shouldering more of them. Nevertheless, as long as these barriers remain, vulnerable populations will continue to confront them, be knocked down by them, and fall through the gaps of the system.

Another point highlighted by our participants is how often substance use is intertwined with their experiences of homelessness. For example, many describe how beliefs about people experiencing homelessness and their use of substances adds to the stigma from providers. Others describe how providers assume that because they are homeless, they are using substances, furthering feelings of mistrust towards healthcare. Some describe how given all the social hardships they face in experiencing homelessness, they resort to substance use as a coping mechanism. It comes as no surprise that substance use is greater amongst this population than the general public and that it is the leading cause of death.\textsuperscript{23} Given their lack of engagement to healthcare at baseline, the mutually-reinforcing stigma of homelessness and substance use, and
approaches to healthcare that do not meet the unhoused where they are, it is also likely that substance use disorders are an underrecognized and undertreated medical condition.

Additionally, while many providers justifiably weigh the health risks and legal ramifications of potentially overprescribing opioids, the negative consequences of deprescribing them are rarely given the same weight. This can lead to a predisposition for providers to deprescribe opioids without acknowledging the risks or taking a patient-centered approach, leading many providers to do so with a clear conscience. Often, they are unaware of how precarious patients’ lives may be, especially vulnerable ones like Jordan, due at least in part to their inability to give voice to their concerns, stressors, and substance use. Such lack of agency often stems from a fear of being stigmatized, not taken seriously, or from general mistrust in the system based on past experiences. In turn, providers may never even realize that the medical decisions they made sent these patients over the edge - especially if they hold beliefs that they were simply following policies around good” opioid prescription stewardship. This argument likely has merit beyond opioid deprescribing by emphasizing the importance of trying to build trust and rapport in order to understand one’s circumstances and needs before sound clinical decisions can be made.

Regarding the assumptive practices of healthcare systems and providers, this study highlights some areas of actionable change. For example, instead of expressing frustration over missed appointments that are assumed to be due to a patient’s negligence, providers should meet these unique challenges with the understanding and
flexibility they deserve. With respect to both Isaiah and Cora, the reasoning behind the assumptions of active substance use made by providers is less detrimental than the act of assuming itself. Even if the assumption had proven correct, the act itself breeds mistrust. What’s more, the one-size fits-all approach to those like Isaiah and Cora with even a chart history of substance use is a slippery slope. For one thing, most healthcare workers are aware of how long outdated or inaccurate information can linger in a patient’s medical chart, potentially introducing stigma and clinical bias in perpetuity. More fundamentally, however, such approaches fail to appreciate the nuance unique to each patient’s lived experiences, expressed needs, and current situation. Also, in both cases, the actual clinical issue was not being addressed – mental health for Isaiah and headache for Cora – furthering their distance from and disappointment in a system that does not embrace them. Finally, for those experiencing homelessness, who are disproportionately affected by substance use, the reach and impact of such stigma is much greater and, therefore, any changes to reduce it will likely go further.

In Jordan’s case, by taking an approach that assumed opioid-seeking behavior instead of prioritizing his concern of pain, the provider may have perpetuated the very substance use that he was wary of facilitating. This is because Jordan found himself desperate for pain relief and resorted to illicit substance use. Additionally, Cora’s provider’s assumptions of her needs led to her not feeling heard, which ironically was her biggest need of them all. She had traumatic past and was looking for a provider to connect and share this burden with. However, such information never came to light
without the trust fostered by an empathetic approach to care that minimized assumptions.

Beyond provider assumptions – which may come from a place of care, even if misguided – the experiences described by many of our participants revealed examples of providers being uncaring and of the healthcare system being impersonal. Many lost trust when providers didn’t recognize their struggles, treated them inferiorly to others, or tried to take advantage of them. Others felt dismayed by the impersonal nature of provider turnover in academic hospital systems. Or, as in Cora’s experience, they felt resigned to limited healthcare options that may not meet the quality or convenience they sought due to the fact that choice and agency are oftentimes a luxury, whether due to a lack of health literacy, or of resources such as housing, insurance, time, money, and support. Unfortunately, the stories shared by participants are evidence these negative experiences linger and affect their perception and engagement with the healthcare system going forward.

Participants having to initiate relevant preventative care conversations with their primary care providers is a role reversal that stands in contradiction to central role that preventative care plays in primary care. The reason for this phenomenon is unclear. It may be a result of uncaring providers, as was perceived by our participants, but the reality is likely more nuanced. It’s possible that providers do not want to make assumptions about certain stigmatized behaviors of their patients (although they should be asking all patients these questions), or that there is not enough time to address these topics given short patient appointments and often complex medical and social issues, or
that there is inadequate education of providers around topics pertinent to this population, particularly substance use, HIV treatment and prophylaxis, etc. Regardless of the reason, it highlights how the experience of healthcare can reinforce mistrust and experiences of mistreatment in people experiencing homelessness, leading to avoidance of healthcare, and again argues for healthcare delivery that better meets the needs of this population.

This analysis also highlights the many competing basic needs that patients with lived experiences of homelessness must often prioritize over their healthcare, such as sleep, employment, safety, and shelter. Making a more concerted effort to address these needs simultaneously with their health will not only better their overall situation but may also increase their engagement with healthcare. These elements should be viewed as critical elements of their healthcare, not merely adjacent factors. The fact that many of this study’s participants recognized the importance of their healthcare despite all the competing factors in their lives highlights the potential for engagement, even if it must come from outside of traditional approaches to care. These traditional approaches include system-based aspects such as office-based clinics, limited clinic hours and appointment times, behavioral and social support services separated from the medical clinic, as well as provider-based aspects such as understanding, flexibility, adaptability, and advocacy towards the population’s complex experiences and needs.

The economic precarity of many of this study’s participants, as well as people with lived experiences of homelessness more broadly, should also be emphasized. As Jackson and Leah note, many in this population are one economic hit away from losing
their health, or one healthcare hit away from losing any socioeconomic foothold. Such precarity argues for a Swiss cheese model to social safety nets at large, of which the healthcare system should be a part of. Such models recognize that even with the best efforts to close the “holes” in the system, there will always be some that remain open and others that are yet unseen. This necessitates a level of redundancy in safety nets, care, and resource delivery that come from many angles and form many layers in an attempt to minimize the chances that these “holes” align for people to fall through.

To emphasize this point, consider the case of Bently, who was desperate enough to find shelter and food that he made up medical concerns in order to be able to sleep and eat in the emergency room. Although he was medically cleared before being discharged back out into the streets, and while acknowledging that hospital resources are limited, there is still an argument to be made that sleeping on the street is in and of itself a medical emergency warranting acute intervention beyond an offer to speak to social worker. What those acute interventions could be are varied and resource-dependent, but a paradigm shift towards healthcare systems caring about and taking responsibility for the downstream health impacts of homelessness is a good first step – especially considering that the social safety nets currently in place are evidently not enough. This also lends to the argument that providing safe, affordable housing is itself a form of healthcare.

During the COVID-19 pandemic, many participants also shared their stress over becoming disconnected from healthcare, a phenomenon that is not unique to the unhoused population but is especially impactful to them and other vulnerable
populations already struggling to access and engage with adequate care. This again argues for more robust methods of maintaining healthcare engagement with them, especially during times of public health emergencies. Such methods must dismantle or at least minimize the healthcare barriers described, likely reflecting and building upon those already employed by the VA HPACT medical homes and outreach teams. The positive healthcare experiences described by our participants as a result of some of the pandemic-related changes implemented, such as telehealth, more options for receiving and taking methadone, delivered prescriptions, and free public transportation, argue for their continuance after the pandemic ends.

This study also highlights examples of how healthcare delivery that is caring, flexible, and understanding towards its patients experiencing homelessness could look. Besides direct examples of providers treating them with care, many of our participants highlighted acts of kindness by providers that operated “outside” the current healthcare system, such as personally driving them to the emergency room, meeting them at a soup kitchen, or checking in outside of business hours. Perhaps these examples are exceptions that prove the rule: that the design of most healthcare systems are inherently unkind to those experiencing homelessness. Participants also repeatedly appreciated care and resources that were empowering and iteratively attempted to meet them where they are. This fact, in addition to the VA’s research on their HPACT’s model discussed previously, highlight the potential downstream benefits of this approach, from less usage of acute care to greater satisfaction and engagement in primary care.39,41 As a prime example, the single provider in this study noted to
repeatedly adopt this approach had a large positive impact on our participants. Learning from his example, and what systems are or could be put in place to support this type of care provision, should provide a basic framework of the characteristics all providers should endeavor to emulate.

Finally, our participants who felt the agency to advocate for themselves often described providers who were trusted or created a trusting environment for them to do so, emphasizing the importance of longitudinal provider-patient relationships for those experiencing homelessness. Additionally, providers should foster the value that patients already place on their health while emphasizing that any illness or disease is not a result of a moral failure, which many of our participants described as a reason for feeling hopeless, giving up on their healthcare, or using substances.

Limitations

The JustHouHS study, and this subanalysis, have important limitations to consider. First, the number of participants interviewed represent a small sample of low-income residents from New Haven, Connecticut. The resources, healthcare systems, and policies described by our participants may not accurately reflect those in other areas, or even those still in practice. Also, while participants included in the subanalysis met the criteria of “homelessness” as outlined in the methods section, their experiences, the severity of their situations, and the degree of social support varied greatly from each other and over time. For example, one participant may have experienced an eviction
and been staying in a shelter or a friend’s basement for a few days, while others have been living on the streets and in shelters for many years. Thus, it is difficult to generalize findings to a unified experience of homelessness since it varies much from person to person, place to place, and moment to moment. Additionally, the interactions between healthcare and homelessness were not the main focus of the JustHouHS study or its design, which may have led to relevant experiences not being fully elicited during interviews and a smaller sample of unhoused participants. Finally, since this is a qualitative subanalysis, these findings cannot be extrapolated to represent the beliefs and perceptions of the entire community.

Conclusion

Those with lived experiences of homelessness face many barriers in accessing and maintaining healthcare. Additionally, the negative health and healthcare impacts of experiences unique to this population argue for a broader view of and accountability for what constitutes healthcare, including basic needs such as housing, safety, and food. Until these barriers can be dismantled, flexible and redundant approaches that extend beyond traditional models of healthcare to meet these patients where they are should be implemented.
Dissemination

Preliminary findings from this work were orally presented by this author during the summer of 2021 to the Yale SEICHE Center for Health and Justice.

Disclosures

The author declares that he has no relevant or material financial interests that relate to the research described in this paper.

Disclaimer

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References


44. Goyer C. Key elements of integrated care for persons experiencing homelessness: a guide for health care for the homeless providers. National Health Care for the


Appendix A

Codebook used during analysis of JustHouHS interview transcripts

*Examples of services that people experiencing homelessness interact with*

**Health services:** traditional healthcare settings (clinic, ER), outreach services providing primary care

*Note: not focusing directly on mental health and substance use services and programs, but rather more traditional healthcare provider-patient interactions*

**Health-connecting services:** can be anything that facilitates connections to healthcare, such as shelters, 211, 911, soup kitchens, drop-in centers, case management, parole officers

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*Exclusionary service dynamics*

*Note: focus is on “services” that provide or connect to healthcare services*

**Paternalistic:** participant expresses that a provider is assumptive of their needs and restricts their freedoms in their “best interest,” particularly with a negative connotation. E.g.: prescribing a medication despite participant not wanting to use it because of past experiences
**Punititive:** participant expresses the experience of disciplinary result(s) from behaviors perceived as “deviant” by a provider. E.g.: being kicked out of an ER because of an altercation that may stem from frustration over unmet medical need.

**“Red tape”:** participant expresses that a provider’s requirements are demanding, tedious, burdensome and/or prohibitive. E.g.: long waiting times; not feeling kept in the loop; internal politics; feeling “passed along” between providers; lack of continuity; feels as if the burden is on them.

**“Cold servicing”:** participant expresses an impression or an experience of a provider as being unwelcoming, non-embracing, stigmatizing, that they felt they were treated as not deserving of the service or taken advantage of.

**Discrimination:** participant expresses an impression or experience of a provider treating them differently because of their race, disability, sexual orientation, etc. Can be either implicit or explicit.

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**Inclusionary service dynamics**

*Note: focus is on “services” that provide or connect to health services*

**Continuity:** participant expresses continuity between providers or services.

**Empowerment:** participant expresses that a provider has given them tools to be empowered to take care of themselves health-wise or for handling stressors, such as
homelessness; a service or provider that they feel has given them agency; provider or service acknowledges the importance of appearance.

“Warm servicing”: participant describes a service or provider that is convenient, proactive, connecting, welcoming, non-judgmental, and embracing through their policies, culture, demeanor, or by meeting our participant where they are at in terms of needs and desires or geographically. E.g.: “one-stop shopping” models, forgiving and flexible policies; provider advocates who stand by them; services not easily lost to a mistake; health providers coming out to a soup kitchen to provide care there.

Potentially health-negative responses/results from service dynamics

Avoidance or self-removal: avoidance of or self-removal from services that provide or connect to healthcare. Include context, motivation and/or thought process of why they did so

Generalizing: generalizing or extrapolating the quality and/or experience of one provider or service into another, such as between different healthcare providers or from health-related into non-health-related provision (and vice-versa)

Exclusion: explicit exclusion (direct) from, banishment from or loss of a service that may provide or connect with healthcare; expressing intimidation by, lack of awareness of, or uncertainty of how to access a service that provides or connects to healthcare, for e.g. not going to the ER because they feel like they already can predict an undesirable
outcome (*indirect*); expresses that provision of or connection to healthcare services are easily lost, for e.g. missing a phone call back, missing an appointment, failing a drug test, a provider “disappearing” (*fragility*)

**Dismay:** Expressed or implied dissatisfaction towards provider or service; implied or explicit acceptance of or resignation towards current health, health-related status (“homeless”, “drug-user,” “crazy person”) or quality of health-related servicing despite indications that it is not everything they need or want (*settling*); expressed futility in pursuing better services; expressing directly or indirectly that they don’t fully engage with, trust, like or believe in a service or provider due to experiences with it or through word-of-mouth (*toe-dipping*); feelings of not having many/any options when it comes to the provision of or connection to healthcare services; feeling like obligations/requirements of services are restricting them at some cost, particularly to their health or well-being; expressed repetitiveness and/or lack of progression or meaningful change in interactions with services (*trapping*).

**Fragility:** participant expresses that the provision of or connection to healthcare services are easily lost; include examples, such as missing a phone call back, missing an appointment, failing a drug test, a provider “disappearing,” etc

**Exacerbation:** participant expresses persistence, worsening, or addition of burdens of health related to acquiring, receiving, maintaining, or losing health-providing or -connecting services; examples include feelings of worry, depression, exhaustion or worsening of physical state/ailments as one tries to get (re)connected to a provider
**Survival coping:** activities participants engage in to help deal with the stress, frustration, desperation, or expectations of acquiring, maintaining, or losing a healthcare-providing or -connecting service that may hurt their health or treatment E.g.: anger/frustration, substance use, returning to the street, sex work, other “less-than-ideal” situations, opting for unproven health remedies

**Prioritization:** participant expressing an aspect of their health needs must come secondary to other need(s) more salient, or some other need(s) must come secondary to health, e.g.: can’t focus on making and getting to an appointment to see a provider if must work for an income to afford housing or shelter bed.

**Misinterpretation:** participant expresses a misinterpreted or misguided understanding of their health or health conditions from interactions with a service or provider

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*Potentially health-positive responses/results*

**Giving back:** participant expresses desire to “give back” to and/or support others in similar circumstances or health-providing or -connecting services that have helped them; E.g.: becoming a counselor/mentor to help others who are homelessness issues; sharing successful paths to health service access, including effective people and resources; feelings of solidarity and support with others; assisting outreach services; advising services on shortcomings and possible improvements
Well-being focused coping: activities participants engage in and/or have access to help deal with the stress, frustration, desperation, or expectations of acquiring, maintaining, or losing a service that may help mitigate health consequences, or even benefit their health. E.g.: exercising, attempting to stay sober

Network support: participant expresses that a service or a provider led to or facilitated developing health-positive relationships, such as advocates and/or social supports. E.g.: feeling able to call a provider or service when needed and that they will be supported; a provider facilitating a connection to a caseworker

Trust, engagement and satisfaction: expressed feelings of trust in a provider/service; feelings of engagement, or willingness to comply; feeling that they’re being “heard”; feelings of satisfaction and/or gratitude in the quality of care from a service or provider; feeling like they have had their needs met and health burdens decreased

Hope: feeling hopeful or optimistic about the healthcare services they’re receiving and/or potentially will receive

Potentially health-positive, -negative and/or -neutral responses/results

Adaptation: participants engaging in activities to attempt to gain access to healthcare-providing or -connecting resources. E.g.: anger; lying, such as claiming to be suicidal to get mental health treatment in the ED; persistent attempts to access resources; monitoring of resource status; telling people what “they want to hear” or appearing as
“deserving” of aid; trying to appeal to personal kindnesses outside system such as strangers; using resources not as intended, such as calling 911 to get ride to hospital; remaining homeless, unemployed, using substances, etc. to have better chance at resources | include the ways these activities may change their treatment by service providers

**Agency:** participant expressing that they’re sticking up for themselves and their needs; include reasons they’re doing so and provider’s and/or service’s reaction to it; expressing pride in “little” accomplishments

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**Longitudinal**

**Lasting impact:** this code is to flag any experiences of healthcare that are affected by previous experiences or beliefs that came out in interviews, including once an individual is no longer homeless.