

MEDICAL MISTRUST AMONG INDIVIDUALS EXPERIENCING HOMELESSNESS

A Thesis
Submitted to
the Temple University Graduate Board

In Partial Fulfillment
of the Requirements for the Degree
MASTER OF ARTS

by
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Diploma Date: May 2021

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ABSTRACT

Meeting the healthcare needs of the homeless continues to be a significant challenge in the United States. Homeless individuals suffer a disproportionately high burden of both communicable and non-communicable diseases and are at increased risk of dying prematurely. Additionally, this population faces barriers to receiving healthcare that are less prevalent for non-homeless persons. These include difficulties physically accessing care, underinsurance, and highly comorbid mental health and substance use disorders, all of which contribute to nonadherence and loss to follow-up. As such, homeless individuals report unmet needs across multiple types of healthcare services.

Homeless people's perceptions and attitudes towards healthcare also affect their propensity to utilize services. As with all patients, homeless individuals articulate a desire for compassionate, person-centered care involving meaningful engagement and trust. Yet, this is often not the case. Stigma and perceived discrimination from healthcare providers on the basis of poverty, race, mental illness or substance use have made the homeless feel unwelcome in many healthcare settings. Homeless people often describe being treated less compassionately by providers, feeling invisible, dehumanized, or reduced to objects. Perceived prejudice may contribute to poorer adherence and more frequent utilization of acute care or emergency services compared to routine ambulatory care.

In this thesis, I explore homeless individuals' attitudes of trust or mistrust towards the healthcare system using qualitative methods. I interviewed participants who identified as homeless at Philadelphia FIGHT and Broad Street Ministry, two healthcare and social service organizations that serve the homeless community in Philadelphia. I conducted interviews using a semi-structured interview guide. Below, I discuss my rationale for doing this study, my study

methods, and results through five participant narratives elucidating key themes that arose during interviews. In the last chapter, I discuss why these results matter and how they can be used to inform future practice and policy aimed at reducing healthcare disparities for the homeless.

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CHAPTER 1: INTRODUCTION

My interest in working with the homeless population began as an undergraduate student at Penn. It was my first time living in a major U.S. city and, like any other U.S. city, Philadelphia is a place of marked inequality. While people residing in Center City's expensive luxury apartments and homes have a life expectancy of over 85 years, others living in a zip code just four miles up the road lack basic necessities and have a life expectancy of under 70 years.¹ This inequality was easy to appreciate with my own two eyes as a college student. I volunteered at a free health clinic in West Philadelphia, where all the patients were African American, uninsured and unhealthy. The segregated nature of the Philadelphia neighborhoods was striking. I could immediately tell when I was crossing from University City into West Philadelphia, or from Center City into North Philadelphia. The demographics would shift, landscapes became more barren, and long stretches of old row homes were punctuated by dilapidated buildings that intervened.

Even in the setting of this widespread inequality, rooted in historically racist institutional practices and structures, I always felt that there was a special indignity to homelessness—the kind of indignity where social suffering is exacerbated by material deprivation and the lack of the most basic of necessities: a roof over one's head. I would always feel wrenched with guilt when I passed a homeless person sitting on the sidewalk corners, with bleak smiles and cardboard signs asking for money or smiles or simple human acknowledgement. There was such a profound silence and anonymity to this suffering, to the extent that the invisibility of homelessness was perhaps worse than the homelessness itself.

As I tried to uncover where my guilt stemmed from, I realized that it was a perceived moral culpability on my part; that, far from homelessness being the sole product of individual failures and shortcomings, I was complicit in a system that allowed homelessness to occur, much like it allowed racism and other forms of injustice to occur. My studies in history, medical anthropology and social sciences at Penn provided a conceptual framework for me to understand my place in the world. I discovered that I was an oppressor. Through historic inequality in the distribution of economic and social goods, I was a beneficiary of a social structure that prioritized some lives over others, along lines of race, gender and class. I was given resources and opportunities that many others lack. Introspection taught me that this was not inherently my fault, and that my moral worth would rather be determined by what I decided to do with my privilege.

In one of my courses, I learned about a physician, anthropologist and sociologist named Rudolf Virchow. Widely known for his contributions to cell theory and pathology, Virchow is less known as a founder of social medicine. He strongly believed that social inequality was a driver of disease, and that physicians were in a unique position to press for social reform. Virchow once stated, “Medicine is a social science, and politics is nothing else but medicine on a large scale...If Medicine is to fulfill her great task, then she must enter the political and social life...The physicians are the natural attorneys of the poor, and the social problems should largely be solved by them.”² I was struck by Virchow’s worldview. It rejected biomedicine’s “separateness” from political and social institutions and its ostensible “objectivity.” I resonated with Virchow’s writings and felt moral clarity in the idea of leveraging my future profession as a physician to advocate on behalf of the poor. Being a physician represented not only an incredible

opportunity to impact individual lives, but also to solve some of society's most pressing problems.

I chose to do this thesis on medical mistrust among homeless individuals because it aligns with my professional interest in working with urban, underserved communities, and because homeless people deserve to have their stories heard. Homeless individuals suffer a disproportionately high burden of both communicable and non-communicable diseases and are at increased risk of dying prematurely.³⁻⁶ They also have numerous social barriers to care such as difficulty physically accessing care, underinsurance and comorbid mental health and substance use disorders, which all contribute to poor health outcomes.⁷⁻¹¹ With these challenges, I was interested in learning about how homeless people perceive their healthcare, both on the individual provider level and the institutional level. My interests are in qualitative research, as I believe that stories are central to medicine and understanding lived experience is a core task in doctoring. Furthermore, giving voice to people whose voices are often not heard is valuable.

I first performed a literature search to find out what studies have already been published on the subject of homeless people's experiences with healthcare. Unsurprisingly, homeless patients express a desire for compassionate, person-centered care involving meaningful engagement and trust.¹² Yet, numerous studies indicate that homeless people are treated less compassionately by providers, feeling invisible, dehumanized, or reduced to objects. Stigma and perceived discrimination from healthcare providers on the basis of poverty, race, mental illness and substance use have made the homeless feel unwelcome in many healthcare settings.¹³⁻¹⁵ One study by Wen et al. found that participants characterized unwelcoming experiences in healthcare as dehumanizing. The authors subsequently used the philosophical writings of Martin Buber's *I and Thou* (1923) as a conceptual framework, with "I-It" representing the way a person relates to

a thing or object without the power to define its own essence or purpose, and “I-You” representing the way a person relates to a dynamic being who has the ability to define his or her own essence. In the study, participants’ descriptions of unwelcoming healthcare encounters were associated with “I-It” ways of relating in that they felt dehumanized, whereas welcoming encounters were consistent with “I-You” ways of relating, in that they felt valued and listened to.¹³

I deeply resonated with Wen et al.’s interpretation of homeless patients’ unwelcoming healthcare encounters. Buber’s conceptual framework of “I-It” and “I-You” elegantly captures the discrimination and dehumanization that homeless patients often experience in the healthcare system. I knew this to be the case, unfortunately, because I witnessed such discrimination perpetuated towards homeless patients on my medical clerkships at Temple Hospital—whether it was the patient with infective endocarditis who was denied life-saving surgical replacement of his damaged heart valve because of his continued IV drug use, or the patient who was called “smelly” and “gross” when he came to the hospital with a leg infection. For my thesis, I wanted to explore many of the same concepts that Wen et al. did, with a particular emphasis on trust and mistrust. I also wanted to expand beyond individual provider-patient encounters to include interactions with and perceptions of the larger healthcare system: Do homeless patients trust the healthcare system? What do they think about pharmaceutical and insurance companies? What about hospitals? How do they think they are treated by the healthcare system relative to other patients? And how do those considerations affect their trust and willingness to seek care?

These questions are important not only because they provide an intimate perspective of homeless individuals’ lived experiences, but also because they say something about medicine and society. Many participants I interviewed felt that they were treated poorly by the healthcare

system compared to non-homeless patients. Several people pointed out inequities, including underinsurance and uninsurance, that disproportionately affect homeless patients and their ability to afford medications and medical services. It was frequently pointed out that homeless patients suffer from more illnesses and die faster because of these inequalities in care. There was also a profound mistrust of insurance and pharmaceutical companies. Participants commonly claimed these are profit-driven businesses that do not care about the welfare of patients. They were also articulate in tying their inequitable healthcare to society's treatment of the homeless at large, reflecting on homeless people's marginalization and disenfranchisement within society. All of these forces influenced their trust in the system.

These participants' experiences illustrate some important perspectives offered by the discipline of urban bioethics. For one, patients are human beings with unique contexts and stories. Medicine has long sought to objectify the patient's account of their illness using the lens of scientific reductionism. What the patient perceives as important details in their story, including the social aspects of suffering, are filtered out by the physician. Patients' stories then become condensed and packaged to fit a preformed set of illness scripts with which the physician is more familiar. Using this paradigm, the physician is able to narrow the diagnosis down and orders labs and imaging to arrive at a conclusion. But, in reality, patients are not rational beings devoid of context. A homeless patient with no insurance will not be able to afford their medications; a patient with a history of traumatic childhood abuse might have pervasive mistrust and not follow their provider's recommendations, even if a diagnosis is reached. The participants I interviewed all had unique backgrounds that influenced their ability to access care, to trust the care they received, and to be healthy. For many, having limited resources constrained their agency in managing their health. Healthcare providers must strive to understand their patients'

contexts in order to provide better care. Second, medicine as an institution is intertwined with history, politics and society. As Virchow stated, “Medicine is a social science, and politics is nothing else but medicine on a large scale.” My interviews demonstrated that homeless patients’ care is affected by political and structural forces, including discrimination and a profit-driven healthcare system in which corporate interests take precedence over patients’ health. Homeless and other marginalized communities are the most disproportionately affected by this inequitable system. Physicians, then, have an obligation to help the marginalized and to combat the entrenched power structures that perpetuate inequality.

CHAPTER 2: DATA COLLECTION

Participants for this study were recruited from Broad Street Ministry and Philadelphia FIGHT, two healthcare and social service agencies in the Philadelphia area that provide outreach to the homeless population. I first approached the board of directors for both sites to obtain study approval. Prospective participants were approached during service hours at Broad Street Ministry and given information about the study. The inclusion criteria were that participants be at least 18 years old, speak English, be able to give written informed consent, and have been homeless at least once in the past 6 months. My definition of homelessness is broad and includes living on the street, in a shelter, in a hotel, or at a friend's or family member's residence. If eligible, I would either schedule a future interview date or complete an interview with the participant on-the-spot in a private space with a closed door.

Participants completed audio-taped, in-depth semi-structured interviews. I developed and used a semi-structured interview guide with questions that explored the nature and meaning of trust or mistrust towards the healthcare system. Interview questions solicited information about where participants go for healthcare, what they like and dislike about providers they see, what is important when it comes to trusting their providers and the healthcare system, whether trust issues have helped or prevented them from seeking care, and what challenges homeless individuals experience when trying to seek healthcare. **Table 1** (appendix) shows the semi-structured interview guide questions. Before beginning interviews, I first obtained written informed consent from all participants. Interviews lasted between 25-60 minutes and were audio-recorded with participants' permission. Each participant also completed a demographic questionnaire after the interview. Interviewees were compensated with a \$25 Visa prepaid debit

card for their participation. I obtained approval from the University of Pennsylvania Institutional Review Board (IRB) for all study procedures.

I interviewed a total of 18 participants at Broad Street Ministry. **Table 2** (appendix) shows the demographic characteristics of the study participants. The majority of participants were male and had either Social Security Disability (SSD) or Supplemental Security Income (SSI) for their income. Most participants also had Medicare or Medicaid insurance, and some were uninsured. Slightly over half of participants reported having a mental health condition and a third of participants reported having a substance use disorder including alcohol or other drug use.

I recorded and transcribed all interview transcripts verbatim, and read each transcript line-by-line to identify which participant narratives would be most compelling to include in this thesis. For further research and publication, I intend to later analyze these transcripts for themes using a grounded theory approach with the qualitative data analysis software, NVivo. However, for the purposes of this thesis, I selected five key informant narratives that highlighted prevalent themes and ideas discussed by participants. These narratives are included below. To protect participant anonymity, I use pseudonyms for the interviewees, and de-identify specific medical centers, hospitals, social services agencies, and providers.

CHAPTER 3: SELECTED NARRATIVES

Part 1—John: Mistrust and its effects on healthcare utilization

John is a young man in his 30s with numerous health and social issues, including homelessness, untreated hepatitis C, seizures, and substance use disorder. Due to prior traumatic interactions with the healthcare system and his experiences of discrimination towards the homeless, John has a pervasive mistrust of the medical system that extends from primary care physicians, to hospitals, to pharmaceutical and insurance industries. He used to attend a Philadelphia-based wellness center for primary care to check up on his health issues. However, he grew progressively more frustrated with the fragmented care he received, or what he describes as “getting the runaround.” This was particularly challenging for getting his hepatitis C under control, as he needed referrals to outside specialists who could prescribe hepatitis C medications:

That’s why as of now, I’m still untreated. Because [the wellness center] were the ones giving me the runaround, like ‘oh you have to go here, and then all the way to this place, and then come back to this place, and then we have to approve this medication.’ Well, I got 30 years before it [hepatitis C] kills me if it’s untreated, before I end up getting cirrhosis.

As a homeless individual with transportation barriers and limited resources, John found it cumbersome to navigate seeing different providers in disparate locations. He now opts to visit the emergency room because he feels that his medical issues are not being addressed properly as an outpatient. He stated he utilizes the ER quite frequently due to alcohol intoxication or seizures. Although flawed in its own ways, he finds that the emergency room “gets things done a lot faster,” saying:

You know, as opposed to going to a private [outpatient] doctor, [where] they send you all over the place, and maybe missing something along the way...in the ED, they screen for all that stuff ahead of time when you come in, and once you see the doctor, they do the lab work, the blood tests, they screen for whatever you come in for. And within a few hours, they can generally determine what's wrong with you and what to treat you with.

However, John has also encountered inefficiencies at hospitals. He described an incident where he was admitted to the hospital for an infection and later discharged with two antibiotics that worked synergistically, meaning both medications had to be taken together to effectively fight his infection. When he went to the pharmacy to pick up his medications, he discovered his insurance covered one antibiotic, but not the other. John took just the one antibiotic that was covered by his insurance, which only kept the infection slightly at bay before it returned and worsened, prompting him to return to the hospital: "So then they had to prescribe me a whole different set of medications; and then I had to worry about whether *those* two medications were covered."

John's suboptimal care has been compounded by homelessness and the subsequent discrimination he faces in various healthcare settings. "I don't think they [homeless patients] get quite the same treatment, that they get treated the same way as 'normal society,'" he stated. He described a time when he was physically hit in the chest and face by Emergency Medical Services staff picking him up in an ambulance. He thought that this was "all due to being homeless." He has also experienced stigma and discriminatory treatment inside hospitals:

I've actually overheard the nurse one time saying she'd refuse to treat me...[because] I was homeless. And they had to have another nurse come in and take over, and she was like 'I'm going to be taking over for the other person.' And I'm like, 'I know...I heard the conversation in the hallway from here.' She was just like 'Oh, you weren't supposed to hear

that.' I'm like, 'Yeah. I never asked to be homeless.' But now that you know that I'm homeless, that doesn't give you the right to judge me or treat me any different. I expect to be treated the same.

He also dislikes having medical students evaluate him in the hospital, stating: "I feel like when I'm in the hospital, I wake up and it's like 'oh we have 50 med students!' And I don't want to be poked and prodded like a guinea pig...what happens if they mess up?" John expressed that homeless people are more likely to receive experimental therapy, which has eroded his faith in the healthcare industry at large:

I don't want to be poked and prodded, and they're like 'oh we'll give him experimental drugs, and see if this works or if this doesn't work.' Because they do that too, especially if they know that you're homeless, or you're lower class. 'Cause it's a multi-trillion-dollar industry, the pharmaceutical companies. They make money off of basically keeping people sick, which is messed up to say. They give you enough just to feel good, but not actually get better...But you're still going to need it, so that you gotta keep coming back so they can keep making money off of you.

On the subject of trust, John acknowledged that trust is "definitely a key thing...[especially] amongst the homeless people." He felt that physicians have "got to establish a trust pattern with [patients] you're working with... 'cause if they feel they don't trust you, especially when it comes to their health or their psychological or whatever they've got going on, then they're not going to talk to you." However, his negative interactions with medical providers have made him reluctant to disclose personal information—especially regarding his hepatitis C, drug and alcohol use—for fear of stigma and judgement. Consequently, his health has declined despite his young age. He stated, "I'm nowhere near as healthy as I should be, considering I drink way more than I should. I use street drugs, I smoke cigarettes and I eat junk food...and I

got hep C on top of it...I'll live until I live and when I die, I'll be with my mother; she died from liver failure." When asked about what healthcare providers could do to better meet the needs of the homeless, he stated:

People like that, personally I think they should find another profession. Because if you've got somebody like that, you might try to kill them or hurt them in some type of way, because you have access to medications and equipment and skilled knowledge about human anatomy. You can mess a person up especially if you don't like homeless people, or if you have a grudge or feel some type of way about homeless people. When I come across nurses or doctors like that, I don't want you working with me.

John felt that if he were to find a trustworthy provider, he would be more proactive in managing his health and taking medications. To establish trust, he expects an in-depth discussion about treatment options and possible side effects of medications, and wants to be attentively listened to if he has any questions or concerns. Most providers, however, have not taken the time to establish rapport with him and have not earned his trust. Thus, like many other homeless patients, he is frequently lost to follow-up and resorts to using the emergency room instead.

Part 2—Tabitha: Therapeutic and non-therapeutic doctor-patient relationships

Tabitha is a woman in her mid-40s with homelessness, PTSD, substance use disorder and multiple sclerosis (MS). She shared her lengthy story about battling MS after a delayed diagnosis and treatment, at which point her disease had already progressed significantly. Her symptoms first began at the age of 16, when she called her then-primary care provider (PCP) concerned about recurrent dizziness and falls. "Every time I stand up, I fall back down," she told him at the time. He prescribed her medication for vertigo, which relieved her symptoms temporarily. At age

22, her vertigo became worse, and an MRI showed four lesions on her brain, suggesting a diagnosis of multiple sclerosis. Her PCP then referred her to a neurologist to further discuss the next steps in treating her disease:

And I went to that doctor and walked into his office. At that time, I was 370-375 pounds.

And I walked into his office and I had 25 pages of research that I'd done proving that I had MS...And he looks me dead in the face and said 'you don't have MS, you're just fat. Go on a brown rice and water diet and see me in 6 months.' I said, 'but I only eat once a day.' He said, 'well I guess that one meal a day is going to have to be brown rice and water. So see me in 6 months.'

She left the office upset, and never returned to see a neurologist until she was 29 years old, a full seven years after her initial diagnosis at age 22. Tabitha cites the poor treatment from the neurologist as the reason she avoided following up: "Because I was turned off. It left a really bad taste in my mouth. I wanted nothing to do with anything related to neurology. I just went on about life as it was, and when I had little symptoms, I chalked it up to one thing or another." When she was 29, however, she developed blurry vision. When she drove, "I couldn't tell if it was one car with its break lights on, or two cars in front of me really close together." She began to lose her balance and fall more frequently. At her mother's urging, she went to the hospital and received two lumbar punctures that confirmed what she already knew: Her MS had progressed significantly. She recounted her doctors stating that in 9-12 months, "you'll either be dead or a complete vegetable."

Despite the devastating news, Tabitha was determined to slow the further progression of her disease and decided to try seeing a different neurologist, Dr. T. She established a more trusting relationship with Dr. T, who put her on a medication regimen that slowed the progression of MS, and eliminated other unnecessary medications from her regimen. After

several years working with Dr. T, he retired and referred her to yet another neurologist, Dr. G, who would become her most trusted physician and confidant. “I’ve been with Dr. G for a couple of years now, maybe 2 or 3 years, and he has gone above and beyond the call of duty,” she stated. Around the time she began seeing him, a new medication for MS—Ocrevus—had been approved for use in the U.S. Dr. G submitted the request for Ocrevus to Medicare on her behalf, but Medicare denied the medication on the grounds that it was “too expensive” for her. Tabitha recalled how Dr. G subsequently advocated for her and other MS patients who were denied the medication:

Dr. G was like ‘looking you’re going to get it, and here’s why. I have 14 patients that desperately need this medication. So you’re going to get it.’ So he took a whole team of not just himself, but a bunch of other neurologists to Washington to fight Medicare. He took it to the top, and he fought for us. And I’m like ‘well what if Medicare doesn’t approve it?’ He’s like ‘don’t worry, you’re going to get it. Look, if I have to sell my home, put my family out in the streets and live out of my car and pay for it out of my own pocket, you and the 13 others are going to get this drug, because you need it.’ What other doctor is going to do that? What other doctor is going to put their own finances on the line for 14 patients? No one! But he’s a doctor that cares. You know, he legitimately cares.

Dr. G ended up not having to pay out of pocket for his patients, instead convincing Medicare to pay for the medication, which cost approximately \$360,000 every six months according to Tabitha. Despite Dr. G’s individual heroic efforts, Tabitha’s faith in the larger healthcare system was undermined by this experience:

It sucks, the insurance companies run this country. Medicine runs this country. You know, they’re always shooting commercials about medications. ‘Just swallow this pill to fix your problems.’ It won’t. What it’ll do is create another problem...The system as a whole is a

huge farce. It's all about making money. I'm still trying to figure out why it costs more than a quarter million dollars for a medicine that you're only taking once every 6 months. Why? Nevertheless, her trusting relationship with Dr. G keeps her motivated to stay healthy. She delved into some of the reasons why Dr. G is so worthy of her trust, stating:

It's not just a doctor-patient thing; it's almost like a family. Whenever I talk to him or see him, I ask him about his kids. And he always gives me honest updates, and he always asks me about my daughter, who's going on 12. And he's seen her a number of times, he loves her.

During the interview, she also disclosed having been through traumatic experiences that have caused mental health and substance use challenges throughout her adult life:

In all honesty, I'm a crack addict. I'm addicted to crack cocaine. Trying to get over it, but it's going to be a long process because it's...triple faceted. It's the addiction, MS, and trauma. Psychological trauma. The addiction is just a symptom of the trauma. So I won't be able to get rid of the addiction until I get rid of the trauma, just like I can't get rid of the trauma until I get rid of the addiction. They're twin sisters, feeding off of each other...So I'm in the process of trying to get trauma therapy. They get me set up to go to rape counseling.

She felt comfortable disclosing these personal struggles to Dr. G, who is aware of her addiction. However, Tabitha reported feeling guilty about her continual cocaine use, because "crack definitely screws up your brain...but so does MS. So I'm really making my own disease worse every time I use." Although she knows that Dr. G is her advocate, she fears that she is letting him down, stating:

He's trying to keep me from progressing. And I'm shooting holes in all of the work that he's been doing every time I take a hit. I'm basically giving him the middle finger, you know? I don't want to do that, because I like him too much...and I'm really scared that at one point,

he's going to say 'I don't want to be your doctor any more. I'm going to let you go.' I don't want that to happen. But it's going to at some point; I can feel it coming.

Nevertheless, her therapeutic relationship with Dr. G, and his fierce advocacy on her behalf, has made all the difference in delaying the progression of her illness and enhancing her quality of life. Were it not for the first neurologist's egregious comments about Tabitha's weight when she was younger, she might have even been treated at an earlier stage of her disease. Tabitha's story thus powerfully illustrates how trust or mistrust can make an impactful difference in receiving care.

Part 3—David: Homelessness and mental health

David is a middle-aged man who has been in and out of housing over the last several years. Prior to 2014, he had been homeless and “deep in the streets” without an income, and unable to find work. A close friend then connected him with a social services agency that provided housing assistance. He started sleeping at a church and later moved to a safe haven for a couple of years, before getting his own apartment through Section 8, where he paid a small percentage of the rent with his Social Security Disability income. The agency not only helped him with housing, but also provided a team of counselors including case managers and a psychiatrist to address his mental health diagnoses of depression and anxiety. David discussed how the housing agency helped turn his life around during this time:

They're compassionate. They care about the homeless. They got me off the street. Got myself back my pride and dignity. So good to have a bed and lay in bed, and wash up real good. It brought my dignity and pride back; it gave me hope. 'Cause my hope had been lost and I don't wanna lose hope.

It was also easier for him to routinely see his PCP, Dr. J, during the time he lived in an apartment, compared to when he was homeless:

When I was housed, I went to see my doctor. I had everything—
transportation...everything was in place. ‘Cause I had a home, so I could go see my doctor. It
was no problem at all. I didn’t have a lot on my mind. I had a *home*. I felt good, the
depression wasn’t there no more. Everything was in place.

However, his housing lease fell through the cracks in 2018, and he landed back in the streets of Philadelphia. Being homeless again has made it considerably more difficult to see his PCP. He stated it has been almost a year since he last saw Dr. J, due to “being in the streets and moving a lot.” He has also struggled more with his mental health since losing his apartment:

Yeah, [the] depression came back. It’s like an on and off switch. [I have] depression and
anxiety. I get worried and sometimes get a little paranoid...you know what I mean? I get into
a shell with anxiety...I isolate and I don’t feel loved and stuff like that. That’s another reason
I didn’t go to the doctor; my depression. It’s real bad.

Despite not being able to see his PCP for the last several months, David does have a trusting relationship with Dr. J. He described Dr. J as an “all-around-doctor,” as well as a friend, counselor and story-teller with a sharp sense of humor: “He sits back and makes me feel good, man. He’s down-to-earth, sits down and talks to me. He shows that he cares. That’s the profession, man; you show that you *care*, and it goes a long way.” However, his experiences with hospitals have been largely negative. He shared about a time that he went to the psychiatric ward at a Philadelphia hospital when his “depression kicked in real bad,” and was treated poorly:

They evaluated me, but the staff workers were rude; real rude. And they were just laughing,
and it just didn’t make me feel good. I explained everything; I said I don’t wanna harm
myself or harm nobody, so I wanted to admit myself to get some treatment...They made me

sit up all night, I didn't get a bed...But I could hear the laughing, the talking; it was directed at me. They were acting kind of weird. It was a joke. They treated me like a bum off the street.

David also expressed frustration with health insurance companies. He talked about times when his insurance didn't cover a hospital stay and he had to receive assistance from case managers to help pay out-of-pocket. He said, "yes, they're out to make money; they have to. The care is secondary, but the main thing is money." When asked about how homelessness affects the care he receives, he stated:

With homeless [people], they say 'he doesn't have healthcare [insurance] so he can't pay for the treatment. We have to get paid, too.' So the homeless can be overlooked. If the insurance is not right, that's going to have an effect as far as my treatment and stay at the facility. Yeah, homeless [people]...we're the ones that are going to get overlooked. We might get treated, but deep down inside, you're a homeless person. You're an outcast. Nobody wants to deal with you.

When it comes to trust, David trusts his individual physician, but not the system at large. When asked why this was the case, he replied:

See, the primary care doctor is the one you trust, I mean really trust. Because you're putting your life in his or her hands. But that's the difference between the primary care doctor and the system...I know and trust my doctor; I know him personally. And I trust him more than anything. But I don't trust the system.

Like many other participants, David's marginalization within the healthcare system made him feel unwelcome. Furthermore, his story illustrates the important connection between homelessness and mental health. While he was housed, his mental health significantly improved;

when he became homeless again, he was once more depressed and experienced more barriers seeking healthcare.

Part 4—Lamar: Discrimination and disparities

Lamar is a man in his 40s who spoke at length about the discrimination and disparities faced by homeless patients within the healthcare system, particularly patients of color. The unwelcoming atmosphere has discouraged him from seeking further care, both in the office and the hospital alike. Consequently, it has been several months since he has seen a provider:

I feel like there's a lack of [participation]...the urgency wasn't there. The seriousness, the actual welcoming, the admiration that I would expect from healthcare providers. As far as me...being homeless. Trying to get care when I need it. I feel as a person dealing with the medical industry, I feel that it's not as urgent—or not a necessity—for people in my situation [to be] given the same attention as with people that can financially be taken care of. I feel it's discouraging. And by the same token, it's discrimination. People, they can't afford certain medical bills or commodities. And when we do try to get it, it's a hassle...As opposed to somebody who has funds, middle class...the dude that can go in and get standard treatment. I find that that's very upsetting and very discouraging.

There were several times when he went for primary care checkups or was admitted to the hospital, and experienced an environment of stigma or was rushed by medical staff. He described one such incident where he sought help for a migraine in the emergency room, but was not treated seriously and immediately discharged without treatment. “I just stopped going because I didn't feel that welcoming atmosphere. I didn't feel that they were actually treating me as a patient. I felt like I was treated more like an animal, for lack of a better word,” he stated. Lamar

has thus had a difficult time finding a trustworthy doctor with whom he can open up and share his medical concerns. He said:

I'm having a hard time really trusting doctors. I'm still searching for that doctor that I actually feel comfortable enough to go to. Where I'm getting the treatment and answers that I need to back up what he's saying. I don't want a backdoor answer, I don't want to feel like I'm just being given answers just to get me out of the office or hospital. As far as my interactions with the providers that I've had thus far, being that I've been homeless for so long, and being that I haven't really been getting the actual service that I deserve as a human being when I go into places, is one of the main reasons why I'm so adamant in not going to hospitals. Because of the treatment and reactions that I get when I walk into the doors.

In addition to the disparities in care he has experienced as a homeless individual, Lamar felt there was an added layer of inequality in being a patient of color. He stated:

And being that I'm a minority... we as the minority are guinea pigs. That to me is another reason why I feel some kind of way when it comes to dealing with doctors, because if you're working class... you're not going to have someone making six figures who doctors are just throwing random medications at... they're not going to say 'here we're going to give you this, try this [experimental] drug, see how you do with it.' I'm pretty sure you're going to have the best service they offer. As opposed to somebody that doesn't have that kind of money, you're not. That's why I don't like to deal with a lot of hospitals, that's why I don't trust a lot of hospitals. Especially being that I'm a minority and I'm black. I feel like that's where a lot of this type of treatment is being geared towards. The black community.

He also expressed frustration over what he described as the profit-driven nature of the healthcare system, saying, "at the end of the day, it's like the prison systems... it's not the [only] type of

organizations or companies that are like billion-dollar companies.” When asked how this profit-driven system affects homeless patients in particular, he replied:

By keeping us homeless. Because we can't afford high-cost insurance bills, medical bills, we can't afford that. And by that being the situation, a lot of homeless people are getting sick and dying. Just from the fact that they can't afford the insurance, we've just been having a hell of a deal even trying to go and take care of the smallest situations. And not getting the proper care we need just for that.

Lamar said that a lot more needs to be done to help the homeless population get proper medical care and feel comfortable enough going to the doctor's office or hospital. To accomplish this, he suggested:

Basically, just treat us like we're people, not like we're scum of the earth. And that's what a lot of people do. Like any major hospitals, organizations you come across. They see a homeless person and they're automatically like 'oh you're a drug addict, you're a drunk, you're this or that.' It's that label that's automatically thrown on you. It's just the whole stipulation, the whole process of 'okay, he's got to be homeless because he looks a certain way or he dresses a certain way.' These are the stipulations that people put on us...these organizations, these hospitals.

Lamar's insights capture the intersectionality of his experiences within the healthcare system, as both a homeless individual and a person of color. His mistrust is thus rooted not only in the stigma faced by homeless people on the basis of class, but also in the real historical mistreatment of African Americans in the United States.

Part 5—Mark: Agency and resilience

Mark is a man in his late 50s who offered a different perspective from many of the other participants. Despite struggling with homelessness and addiction, he has a strong trust in the medical system and has had largely positive experiences with providers. He sees his PCP at a health clinic tailored mostly towards care of the homeless community. “It’s a warm atmosphere,” he said. “Everyone is cordial, everyone is nice. And they treat you with respect. Everyone from the front desk staff to the security guard.” Speaking further about his relationship with his PCP, he said:

She was more intimate than most doctors that I had because she wanted to know my family life, if I was in a relationship, if I was in recovery, if I was using, what she could do to help. But she didn’t treat me no better or no lesser than what I should’ve been treated. And she had a family and she would show me pictures of her kids, their ages, what they were doing and stuff like that...And I mean, she followed me even when I wasn’t there. I would tell her when I was on the outside; when I was on the streets, when I was in my homelessness. And she would ask me, ‘Where do you go? What do you eat? Where are you staying at?’ And I would tell her.

Besides having asthma and hypertension, Mark shared about his struggles with on-and-off crack cocaine use:

Okay, I’m gonna be honest with you. I’ve had housing twice, and I screwed it up because I went back to using, and that’s why I’m here now. So I’m going to work on my housing again, but what I can say is that I’m 30 days’ clean. And I guess I’m tired of losing, when I could be winning, you know?

His substance use and homelessness have often made it challenging to follow up with his PCP. However, he is grateful that the health center and his physician still welcome him with open arms whenever he is able to make it for appointments, stating:

Yeah, sure. Sometimes I was in active addiction, [and] I missed appointments. But they didn't turn me away. If I showed up, they brought me in. She [the PCP] didn't change her point of view on anything. She always gave me the advice that I needed to have if I was in my addiction. Yeah, she told me 'this'll happen, but everything comes back to you. Nothing changes if you don't change.' That's how it works.

Mark has also had positive experiences getting treated at hospitals. He shared about a time that he went to the hospital when he had swelling and edema from acute renal failure. "They set me up to get dialysis, but it never happened because my kidneys healed. So I was blessed. But that whole situation about going to the hospital and stuff like that, I never had a bad episode with nobody." He acknowledged that other homeless patients may feel differently about hospitals, but offered a different perspective on seeking medical care as a homeless patient:

If you've been on the streets for 3, 4, 5 years and you haven't been to a hospital, you're not gonna go in there with glass slippers on talking about 'oh! I'm ready.' It's not gonna work like that. They already *see*. If anything, you need to take your guard down if you're homeless. Put your pride to the side, and let them do what they got to do. Because you need to help. Help can't show the help how to help. And a lot of homeless people are like that, they think they know what they need. When in reality they don't know what they need, and they need to just be quiet and let the people who have the professionalism do what they have to do to get them where they need to go.

Mark acknowledged that previously, he had trust issues and didn't take care of his health, stating, "sometimes I didn't care; I didn't care left, right, front or back." However, he later changed his

mind-set and discovered the importance of agency in taking control of his own health. When asked about why other homeless people might feel the healthcare system is inequitable, he replied:

It's easy to be on the outside looking in. Maybe just change your position. That's all I can say. Like I'm coming to some epiphanies in my life. I'm at a point now where, it's like, either you're going to be a part of it, or you're going to stand around and talk about it...Because if you're a complainer—I'm not a complainer—if you're a complainer, you're always going to complain. You won't see nothing except things to complain about.

He also discussed resiliency in overcoming his long battle with substance use:

I have to look past what you think, I have to look past how I feel about what happened yesterday. And I gotta push forward to what I want tomorrow. That's if there's a tomorrow for me. So I still have to push forward to it...I mean, I fell a couple of times. I got up; I can do it again. Maybe I need to find something a little bit different this time that's going to keep me on my feet. Because I'm an addict. I know I love to do drugs, but I have to learn to put something else I love in front of that, that has nothing to do with drugs.

Despite the challenges he faces, Mark attributed many of his health improvements to his medical providers, saying, “I think I owe them a lot, and I owe them more sometimes.” He strongly believes that the medical system exists to make patients feel better, and that for homeless patients experiencing trust issues, being “open-minded” to receiving care is important. Speaking about how the medical system has helped him, he stated:

Well, they showed me that it's not about subterfuge. They're not trying to trick me into anything. They just want me to be better health-wise. Look: the bottom line is, pharmaceuticals are going to make money; the healthcare system has to put out the pharmaceuticals, and you have people who might need the medication to get better. I can't

change none of that other stuff. They gonna make money. I need to get *me* better. I'm dealing with me! People be into that 'but the pharmaceuticals are making money, [and] health insurances.' Yeah well, that's what that's designed for! I surrender! I don't have time for that no more; it's time to get *me* well.

Mark's story, while different from most other participants, is important in illustrating the variety of perspectives homeless individuals have regarding healthcare. His feelings of trust towards his physician, the welcoming environment he experiences at his health center, and the genuine help he has received from hospitals are all encouraging anecdotes. His gradual shift towards increasing agency and ownership over his health also made him feel more empowered to navigate the healthcare system.

CHAPTER 4: ANALYSIS AND NEXT STEPS

This thesis has examined homeless individuals' trust in the healthcare system, exploring not only the physician-patient relationship, but interactions with and perceptions of the health care sector at large. Although participants varied in their experiences and degree of trust towards medicine, a common theme was feeling unwelcome in healthcare settings that perpetuated stigma towards homeless patients. Several participants noted feeling discouraged from seeking help because they were treated poorly compared to non-homeless patients. In some cases, this mistrust led to a loss of follow-up care or delays in diagnosis and treatment of illness, to the detriment of health outcomes. Furthermore, their trust frameworks expanded beyond individual provider-patient encounters to include systemic factors in the healthcare industry, notably pharmaceutical and insurance companies. Participants provided nuanced discussions about the structural inequities in a profit-driven system that predispose homeless and otherwise marginalized individuals towards poorer health outcomes.

Participants reported both positive and negative experiences in the interpersonal dimensions of care they received. Negative experiences were associated with perceptions of stigma and discrimination from healthcare providers on the basis of their homelessness or associated issues including mental health or substance use disorders. Homeless patients express a desire to be treated compassionately, and yet they report being neglected, mistreated, or dehumanized.¹³⁻¹⁵ One participant from this study felt traumatized after being physically assaulted by Emergency Medical Services; others have overheard demeaning conversations about them amongst medical staff conversing outside of their hospital rooms. These dehumanizing experiences are rooted in inequities in care and the hegemonic relations of power

that assume the homeless patient to be deviant.¹⁷ Ideologies of difference and deviance have long been implicit in biomedicine's relationship with the patient, and historically have shaped providers' practices in ways that exacerbate inequities for marginalized communities. Those experiencing homelessness thus have to navigate not only fragmented healthcare services using limited resources, but also the unequal power dynamics that serve to further disenfranchise them. In a population with already high rates of comorbid mental health and substance use, mistrust is a natural byproduct of these oppressive processes. The burden then falls on the patient to find the best care in a system that largely does not care about them. Subsequently, healthcare utilization and adherence to treatment may be adversely affected. Some studies have demonstrated that homeless individuals utilize hospital emergency rooms or other acute care services more frequently than the general population.¹⁸ This may stem from perceived discrimination in healthcare settings, which results in deferring and delaying care.¹⁹⁻²⁰ Many participants in this study expressed a reluctance to attempt engaging further with primary care physicians or hospitals due to prior negative experiences. Some even stopped taking their medications or received delayed treatment due to mistrust. Conversely, positive experiences with providers were viewed as fundamental to establishing a trusting physician-patient relationship and receiving proper care.²¹ Participants who had therapeutic relationships found that support from their provider was both validating and healing, restoring a sense of humanity.¹² Furthermore, those who felt that their physician genuinely cared for their well-being were more motivated to improve their health and follow up on their provider's recommendations.

Besides interpersonal interactions, participants also highlighted systemic barriers to care as an important domain of trust. While many participants felt that they could trust an individual provider, "the system" was a more elusive entity and therefore more difficult to trust. Two

closely related themes emerged from these discussions: Structural inequities and the notion of the medical-industrial complex. It is well documented that the homeless population suffers from many unmet health needs due to structural inequities ranging from food insecurity, to lack of transportation, to underinsurance or uninsurance.^{16,22-24} Participants in this study reported their lived experience of such inequity. Being uninsured or on public insurance—such as Medicare or Medicaid—was a key determinant of suboptimal health outcomes. Experiences like being denied insurance coverage for certain medications, or receiving a large bill after a prolonged hospital stay, were common. Many felt that there was a “non-system” for the homeless, which provided excellent treatment for the average citizen and the rich, but suboptimal care for the poor. Furthermore, participants shared largely negative perceptions of the United States’ profit-driven medical-industrial complex. Two participants whose narratives are included in this study claimed that insurance and pharmaceutical companies profit off of the poor, while simultaneously keeping them sick and poor. Mistrust was especially profound in participants of color, who believed that minorities are the targets of research studies and experimental treatments. Such mistrust is embedded in a broader history of unethical treatment and medical abuse of minorities, which has disenfranchised African American communities in particular.²⁵⁻²⁶ Much work is needed to dismantle the power structures—including systemic racism and discrimination—that have engendered mistrust in homeless communities, especially those of color.

These findings are important because systemic mistrust represents an added barrier to engaging in care for a population that is already marginalized and at-risk. To foster greater trust in homeless patients, both individual providers and institutions should find ways to eliminate stigma and discrimination against the homeless. The medical profession is imbued with the ideals of humanism and compassion for all, and healthcare professionals have a moral obligation

to provide the highest standard of care to anyone who seeks it. Training in cultural humility and competency, and particularly education in unconscious bias, represent one step that institutions can take to eliminating racist and other discriminatory behaviors towards disenfranchised populations.²⁷⁻²⁹ For example, one participant in this study felt that healthcare providers automatically label homeless patients as “drug users” and “alcoholics.” As a medical student, I have personally witnessed this language being used about homeless patients by healthcare providers. I have seen homeless people who inject drugs go undertreated or untreated for opioid withdrawal, and subsequently leave the hospital against medical advice because of their withdrawal and the stigma they experienced surrounding their drug use. The unfortunate reality is that this discrimination tangibly affects patients’ health. If certain medical providers lack the compassion that is needed to understand their patients’ social circumstances and provide the best care possible, then perhaps they should consider other professions. However, no healthcare worker is perfect. Each provider has unconscious biases, and education in bias may be helpful in mitigating the negative effects of discrimination in healthcare. One such effort at Temple University Hospital, called “Words Matter,” aims to eliminate stigmatizing language in the healthcare setting. The initiative encourages person-centered language among providers, such as saying “person who injects drugs” (PWID) instead of “substance abuser” or “injection drug user.” These initiatives are another important way that providers can increase their mindfulness around the language they use to think about and describe patients.

Additionally, the idea of creating healthcare practices specifically tailored towards the homeless population has been proposed, with some studies demonstrating improved outcomes.³⁰⁻

³² Many of the participants I interviewed sought routine primary care at two healthcare centers in Philadelphia that provide services predominantly for the homeless population. Several people

reported positive experiences, noting that their providers and other medical staff at the centers were compassionate and helpful. They also felt that since the other patients were homeless, and the providers had expertise in working with the homeless population, these centers were safe spaces for them to seek care in a judgement-free environment. However, not all participants supported the idea of healthcare for the homeless. One participant felt that by dividing care between homeless and non-homeless patients, inequality was perpetuated even further, and that truly equal care would involve integrating care for both homeless and non-homeless patients under one roof. In the future, I would be curious to find out more about homeless patients' perspectives of tailored versus integrated care, as both sides have valid points that raise more questions than answers about which approach is ultimately better.

Furthermore, it is essential to provide better social support to homeless patients, who experience the added burden of navigating a complex healthcare and social services system without the financial or social capital that others have. Case managers, community health workers and patient navigators are vital support personnel that have been shown to help homeless individuals better adhere to treatment, access insurance and community benefits, and navigate the system.³³⁻³⁴ These patient navigators often bridge a critical gap between patient and provider, taking on tasks that physicians and nurses are unequipped to handle and facilitating greater trust between patient and system.³⁵ Before medical school, I worked as a Health Coach for a healthcare nonprofit. Two of the patients I worked with were homeless, and both needed the support and advocacy that I had to offer as a Health Coach. One patient had uncontrolled diabetes because she did not have a refrigerator in which to store her insulin, and being on the street meant that she could not adhere to a healthy diet. I called several housing agencies and, after three months, was able to find her housing through Section 8. After becoming housed, her

diabetes was well-controlled and she did not have any further hospitalizations. My other homeless patient used crack cocaine and had trust issues with healthcare providers. He was scheduled to have his thyroid surgically removed because of unchecked Graves' disease, but kept missing his appointments due to substance use and mistrust. After gaining his trust over several months, I acted as a bridge between the patient and his surgeon, and he eventually completed his thyroidectomy and was disease-free. These two examples demonstrate how patient navigators can help homeless patients with limited resources and social support. In practice, community health workers and patient navigators tend to be from the same ethnic and community background as their patients, which facilitates even greater trust. This is an incredibly promising way for homeless and other marginalized, under-resourced patients to have greater access to and trust in the system.

Finally, it is crucial to recognize that medicine as an institution cannot by itself remediate the social policies that are at the root of poverty and inequality in the United States. Health policy experts and law-makers must address the underlying structural inequities that predispose homeless patients towards worse health outcomes. For homeless patients, homelessness is a significant driver of illness and suboptimal management of health. Ensuring housing is the only true remedy for homelessness. While many participants I spoke to wished that medicine could do more to solve the housing crisis, ensuring fair and adequate housing is ultimately the responsibility of policymakers. The same applies for health insurance, which should be universal as is the case for all other industrialized nations. Unfortunately, due to entrenched political ideologies and fears of "socialism" or "socialized medicine," the U.S. is the only industrialized nation without universal healthcare. The rejection of a single-payer system, along with the rise of a two-tiered healthcare system that relegates the poor to public insurance, has created a vast

chasm in care between rich and poor.³⁶ Until policy is passed that creates equitable care for all and eliminates insurance status as a proxy for moral worth, our institutions will continue to operate on unjust ethical principles. Many aspects of U.S. healthcare are simply inhumane. It is ethically and morally reprehensible that health is not viewed as a human right, but a privilege; that profit takes precedence over human life; and that some people remain ill and die without treatment while others have access to the best medical care. Virchow's words resonate: Politics is nothing but medicine on a large scale. In the future, I plan to become involved in health policy and advocacy to address many of the fundamental issues at the heart of our healthcare system. I am hopeful that more and more physicians will begin to leverage the power of medicine to advocate for social justice.

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APPENDIX

Table 1. Semi-structured interview guide

- Describe where you go (and who you see) for your healthcare.
 - Probe: Do you have a usual place of care that you think of as your primary care provider?
 - Probe: Where do you go for preventive care?
 - Probe: How about for managing any chronic conditions you may have?
 - Probe: How about when you are feeling sick? How do you decide when to see your primary vs. going to the ED?
- How often do you seek care in an average month? An average year?
- What do you like about the doctors/nurses you see for your care? What don't you like?
- What motivates you to see your doctor/nurse? What gets in the way?
- Tell me about how you think about trust when it comes to your care providers. What has been important in terms of you trusting your care providers? What has been important in terms of not trusting your care providers?
- Is there anything related to trust that affects your decision to seek care?
 - Probe: To take medications?
 - Probe: To follow up on treatment recommendations that have been made by your care providers?
- Describe a situation where trust helped you when getting healthcare.
- Describe a situation where trust issues kept you from getting the care you needed.
- What are the challenges that people experiencing homelessness face when seeking healthcare?
 - Probe: What do care providers do well for patients experiencing homelessness?
 - Probe: What could they do better at for patients experiencing homelessness?
- What part of navigating the healthcare system has been hardest for you? How has homelessness affected that?

Table 2. Participant demographics

Characteristic	N	%
Gender		
Male	15	83.3
Female	3	16.7
Race		
Black/African American	11	61.1
White	3	16.7
Biracial or multiracial	2	11.1
Something else	2	11.1
Public Benefits		
SSI or SSD	12	66.7
SNAP	9	50.0
None	2	11.1
Health Insurance		
Medicare or Medicaid	14	77.8
Uninsured	4	22.2
Mental health condition		
Yes	10	55.6

No	8	44.4
Substance use disorder		
Yes	6	33.36
No	12	66.7