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## Exploring Quality of Primary Care for Patients Who Experience Homelessness and the Clinicians who Serve Them: What Are Their Aspirations?

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### Abstract

To develop and evaluate an effective model of patient-centered, high quality, homeless-focused primary care, our team explored key domains of primary care that may be important to patients. We anchored our conceptual framework in two reports from the Institute of Medicine (IOM) that defined components of primary care and quality of care. Using questions developed from this framework, we conducted semi-structured interviews with 36 homeless-experienced individuals with past-year primary care engagement and 24 healthcare professionals (clinicians and researchers) that serve homeless-experienced patients in the primary care setting. Template analysis revealed factors important to this population. These included stigma, respect, and perspectives on patient control of medical decision-making in regard to both pain and addiction. For patients experiencing homelessness, the results suggest that quality primary care may have different meanings for patients and professionals, and that services should be tailored to meet homeless-specific needs.

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Conflict of Interest

The Authors declare that there is no conflict of interest.

## Keywords

homelessness; primary care; quality; access; trust; qualitative methods

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## Introduction

On a single night in 2018, there were 53,000 individuals in the US that reported being homeless (Henry, Watt, Rosenthal, & Shivji, 2018). Studies have demonstrated that experiencing homelessness is associated with higher mortality, increased hospital utilization, and poorer overall health (Baggett et al., 2013; Baggett, O'Connell, Singer, & Rigotti, 2010; Kushel, Vittingoff, & Haas, 2001; Moore & Rosenheck, 2016; Roncarati et al., 2018; Zhang et al., 2018). Individuals experiencing homelessness are increasingly older in age and have multiple, often longstanding, medical, psychological, and symptom-related needs (Beijer, Wolf, & Fazel, 2012; Patanwala et al., 2017). Moreover, access to primary healthcare for this population is poor (Kertesz, McNeil, et al., 2014; O'Toole et al., 2011).

Individuals experiencing homelessness face unique challenges in obtaining appropriate primary care: perceived stigma, lack of trust, negative experiences with care coordination, as well as logistic barriers such as ability to pay, lack of transportation, and pressure from competing priorities (Gelberg, Gallagher, Andersen, & Koegel, 1997; Gruenewald, Doan, Poppe, Jones, & Hutt, 2018; A. L. Jones et al., 2017; Ramsay, Hossain, Moore, Milo, & Brown, 2019; Wen, Hudak, & Hwang, 2007). Over the last four decades, federal and non-federal programs have sought to deliver primary care that is more responsive to their needs (S. Gabrielian et al., 2017; Jones et al., 2018; O'Toole et al., 2011). The United States Department of Health and Human Services funds approximately 300 clinical programs to deliver primary care to individuals who are homeless, and approximately 55 comparable clinics operate under the Department of Veterans Affairs (VA) (Gabrielian et al., 2014; Jones et al., 2019; National Association of Community Health Centers, 2019). Many such efforts emerge from the long-term experiences of health care providers who work closely with the people they wish to serve and from consensus established through consultation of patients (McGuire, Gelberg, Blue-Howells, & Rosenheck, 2009; National Health Care for the Homeless Council, 2016; O'Connell et al., 2010; O'Toole, Johnson, Redihan, Borgia, & Rose, 2015).

Despite these numerous efforts at addressing access to primary care, reports suggest that persons experiencing homelessness continue to have serious problems accessing primary care and that they have inferior experiences even when care is obtained (Baggett et al., 2010; A. L. Jones et al., 2017; Kertesz, McNeil, et al., 2014). Efforts to improve the design and delivery of primary care for persons who are homeless could be enhanced by a better understanding of what indicates quality in primary care, from the viewpoints of patients who are homeless and experts who have focused their careers on this population. Several studies have assessed perceptions of health care in general, or of mental health care, among patients who are homeless. In one, 17 homeless interviewees highlighted commitment, respect, trust, and inclusion as important to their overall satisfaction (McCabe, Macnee, & Anderson, 2001). Other qualitative work has typically assessed perceptions of health care in

general, or mental health services, without focus specifically on primary care, even though targeted investments in primary care for homeless populations date to 1984 and include both the United States Departments of Health and Human Services and Veterans Affairs (McCallum et al., 2019; Moore-Nadler, Clanton, & Roussel, 2019; Pahwa, Smith, Yuan, & Padgett, 2019; Zlotnick, Zerger, & Wolfe, 2013). To inform the development and evaluation of an effective model of homeless-focused primary care, our team conducted an in-depth, qualitative exploration of key domains of primary care that may be important to patients, guided by landmark reports from the Institute of Medicine (IOM) that sought to define key components of primary care and quality of care (Committee on the Future of Primary Care for the Institute of Medicine, 1996; Institute of Medicine Committee on Quality of Health Care in America, 2001). Our research questions were: What meanings, aspirations and understandings do homeless-experienced patients assign to general concepts of primary care quality laid out by the IOM? What meanings, aspirations and understandings do leaders and clinicians involving in delivery health care to homeless-experienced patients assign to general concepts of primary care quality laid out by the IOM?

## Methods

The study was overseen and approved by the Birmingham Veterans Affairs Medical Center Institutional Review Board. Interviews were conducted primarily in 2009, as part of a larger study to develop and validate a primary care experience survey for homeless individuals (Kertesz et al., 2014).

### Interview Guide Development

Domains were derived from two IOM reports that identified components of quality in primary care: *Primary Care: America's Health in a New Era* from 1996, and the 2001 *Crossing the Quality Chasm*, in particular its 10 rules for quality (IOM, 1996; IOM, 2001). Of a preliminary list of sixteen potential domains of interest, we prioritized eight for this qualitative study based on a card sort by patients and providers described elsewhere: Accessibility, Shared Knowledge and Free Flow of Information, Patient as a Source of Control, Continuity of Relationships, Accountability, Evidence-Based Decision Making, Coordination, and Cooperation (Steward et al., 2016). Based on these results, the study team developed and refined interview guides for both clinicians and patients. The interview guide for patients introduced the concept of primary care by soliciting from patients the place that most closely approximated a regular source of care for the individual.

### Participants

The present study employed a purposive approach to recruit a balanced sample of patients (persons receiving care from VA providers and persons receiving care from non-VA providers in a US federally-funded Health Care for the Homeless Program) and healthcare professionals with a breadth of knowledge and professional commitment in homeless-focused primary care (HPHs) (Creswell, 2007). Our inclusion of patients from a VA and non-VA primary care reflected our intention to later develop a survey tool for both settings, and awareness that VA and non-VA Health Care for the Homeless Programs were established under different legislation, with distinct expectations from their

respective federal funders. Our inclusion of both patients and HPHs sought to clarify how interpretations of primary care quality differ by stakeholder status, recognizing that both homeless-experienced patients and individuals with professional commitment to their care could have different but valid insights into how best to operationalize and measure quality in care.

The research team sought currently or previously homeless patients (hereafter, “homeless-experienced”) in primary care, with purposeful balancing with respect to gender, housing, and veteran status. Participants were recruited in Birmingham, Alabama (VA-based clinics) and Boston, Massachusetts (non-VA clinics). Clinic staff helped identify potential patient participants and gave them a flyer containing the study contact information.

A modified snowball approach was employed to identify HPHs (clinicians, administrators, and researchers) across the United States and Canada with experience in direct care, management, or published work on homeless health care (Goodman, 1961). First, HPHs (VA and non-VA) known to the investigative team who either advocated for or organized homeless health care nationally were contacted via email. Then, these individuals were asked to identify other potential HPH participants.

## Procedures

All interviewers were trained in qualitative interviewing by two experienced qualitative researchers, including video-recorded practice interviews subject to group and expert feedback. Staff working in two sites— Birmingham VA Medical Center and Boston Health Care for the Homeless Program (BHCHP)—conducted interviews. Patient interviews were conducted in person, while HPHs were conducted in-person and over the phone. Patients were compensated \$20, while professionals were given textbooks for their participation. Written consent was obtained from patients. Oral consent, with waiver of requirements for written documentation, was obtained from HPHs. Interviews were audio recorded and then transcribed verbatim. Transcripts were reviewed and modified for accuracy.

The team used an iterative mix of both inductive and deductive approaches to develop a codebook to guide the analyses of transcripts. First, we derived overarching domains from the IOM reports, and then conducted an iterative review of the first 4 interviews to devise heuristics that helped indicate the types of words, phrases, and concepts typically invoked in each IOM-derived domain. These heuristics then guided a template analysis approach to coding all interview data into themes aligned with each predetermined domain, while allowing for new domains to emerge (King, 2012). Text that did not fit within an IOM domain were organized into new domains and themes. Domains were added when the analytic team in a consensus felt that there was repeated attention to this issue. Upon review and consensus, themes and codes within the domains were merged when it was determined they had similar meanings. Thus, coding involved assigning 1–2 domain headings to every quote, based on whether the content referenced concepts from the codebook. After reaching an inter-rater reliability of 75% transcripts were coded independently. The analysis team consisted of: a graduate student in health professions; a physician with experience in delivering primary care for persons experiencing homelessness; a social work scholar who had previously worked as a homeless service provider; a nurse; an individual with a masters

degree in public health who coordinated research for a homeless health care agency; a college graduate who had volunteered in homeless service settings; a college student. This team met regularly to review all coding. Table 1 outlines each domain, its corresponding interview question, and emergent themes.

## Results

Tables 2 and 3 describe the demographic characteristics of the sample. Thirty-six patients and twenty-five HPHs completed semi-structured interviews. Patients were predominantly male and African American. Overall, HPHs were mostly white, female, and dedicated at least 60% of their professional effort to service or policy responses to homelessness. Birmingham, Alabama patients are noted as (VA) and Boston Healthcare for the Homeless non-VA patients are noted as (non-VA). The following sections summarize the eight domains queried in the interviews, as well as three emergent domains. Illustrative quotes are included to describe the themes within each domain.

### Accessibility

This domain refers to the idea that primary care should be easy to obtain. Many of the patients described the importance of accessibility of location and transportation. For example,

I had appointments to him, but I don't drive. I had problems where I wasn't making any money, I couldn't take taxis to get up to his office. It's on the other side of town. I couldn't walk that far. So, I figured, 'Well, I'm feeling ok. Heck, I won't even go.' (non-VA patient)

HPHs detailed similar transportation concerns. One described the challenge of getting a patient from primary care to a podiatry specialist in the event of an urgent need,

*Podiatry is a half a mile down the way some place and nobody's providing the little wheel chair how to get you there. I've seen some guys with canes stumping along; they're a mile from the freaking parking lot to get to where they got to go. (HPH)*

Other patient participants, however, felt their clinics were helpful in providing assistance with transportation. For example, some patients recounted experiences where their clinic assisted them in transportation by providing bus tickets.

Financial barriers and resource commitments to overcome them consistently emerged. One patient noted that he was turned away from a clinic when he didn't have insurance, but another patient came behind him and, "flipped out that insurance card" and the clinic staff said, "Be right with you" (VA Patient).

Clinicians and patients also described frustration with procedural and policy barriers that put care out of reach, such as systems-level reliance on mailed medication and telephone confirmation for appointments. For example

*We have a system, the only way you can get your medications would be if we mail it to you. Well that's a great freaking idea if I had a mailing address, Jack. I don't have a mailing address or "We're going to contact you by phone about your*

*appointment.” “Oh, good, I’ll be sure and get my new cell phone contract hooked up so you boys can get a hold of me.” (HPH)*

Patients noted other barriers, like knowledge of services and initiatives to access services. For example, “being a Veteran, you should have a primary care doctor. If you’re homeless or not. But a lot of people don’t even know. That’s the biggest thing, is getting people to know that they have those benefits.”(VA Patient) Patients had suggestions for improving knowledge of services. For example, one recommended that patients have, “something handed to them when they come in,” because, “it is good to see the services” (non-VA Patient) available to them.

HPHs detailed how reports of cumbersome primary care access experiences can dissuade service seeking. A report of policies mandating intake evaluation at a VA Medical Center prior to using outlying clinics, was seen as a barrier:

*If you’re at a Community Based Outpatient Clinic and you walk in and you not in an emergent situation, you’re broke, you’re hurting to go in there. They say, “well we really can’t help you until you have a primary care physician. You have to go to this hospital over here to be seen by them” that’s 120 miles away. How many of those people are just walking away or, the word on the street, “Don’t even waste your time man... They sent me over to this place. I don’t know how the hell to get there. To hell with them, man.” (HPH)*

Outreach and the ability to contact or locate patients was a frequently discussed aspect of quality, homeless-focused primary care. Some patients had engaged with mobile outreach teams, with one patient noting they had “actually saved a lot of people’s lives.” (non-VA Patient) Other patients had not engaged with any type of outreach program, but felt that such services would help get people into care.

The ability to access a specific provider emerged as an important aspect of primary care for homeless patients. For example, one participant described their ability to see the same doctor in different locations as enabling their access to care, noting that, “I have an option of what location I go to see her.” (non-VA Patient) Another patient described difficulty accessing their preferred provider, “Due to the staffing, there were periods of time where I felt like I was being barred from the doctor. You had to go to the extreme, seem like to me, to talk to a physician.” (VA Patient)

Appointments and wait time were commonly discussed as well. One patient described a need for appointments to be scheduled close together, “When I was on Suboxone, they’d set up the appointment so that I’d get to see everybody that same day. So, I wouldn’t have to come four or five different times a month. They made it convenient.” (non-VA Patient). Patients also felt that appointments should be timely and, “should happen within a week.” (VA Patient)

### **Continuous healing relationships or continuity of relationships**

This domain refers to the patients’ ability to receive care whenever they need it including over the phone or internet. A frequently discussed theme within this domain was having the

same provider or team over time and flexibility of location over time. One patient recounted an experience that highlighted the importance of the relationship with their provider over time,

She's worked with me. She's the one that even helped me, stayed with me, holding my hands go and everything. I went from being a bad alcoholic to what you see now, fixing to go on and get my own apartment and everything. (VA Patient)

Whereas another patient described the frustration of seeing a new provider,

"I seen a new doctor. That kind of upsets me, though, because then I have to go through the process of explaining to my new primary care physician what I went through, all the things I was going through. Because he can read the notes but unless you talk to someone and get to know someone, you don't really know what's going on with that person." (VA Patient)

Patients detailed how their capacity to reach or contact a provider they knew frequently influenced their primary care experience. For example, one patient described their frustration over "talking to computers" (non-VA Patient) instead of a real person. Participants described the feeling of being known and understood through significant interactions over time as an important aspect of their primary care experience. One patient noted that they felt confident speaking to their provider because they had, "worked with them for years." (non-VA Patient) However, not all patients have shared the same experience. Others expressed frustration over a lack of rapport with their provider, "There's no sense in having a primary care doctor if every time you go in it's just like the first time he's seen you. I mean, then what's the point?" (VA Patient) HPHs also saw the importance of their patients feeling understood; one clinician explained that this takes time and, "Sometimes you do it in 5 minutes and sometimes it takes 5 years." (HPH)

### Shared Knowledge and Free Flow of Information

This domain refers to the patients' ability to have access to their medical information and clinical knowledge. One theme within this domain was how others (like clinic staff, family members, or other patients) use the patients' charts to get information. Several of the patient participants expressed concerns about the security of electronic versus paper medical records. Patients feared that carrying paper records from the hospital to a shelter could result in misuse of the information, if stolen. Conversely, other patients expressed concern about the safety of the information in the electronic health record:

I had a batterer that comes to this clinic, and because I'd been abused so much by the guy I was just afraid to be here. I just felt like that he was getting my information through them but I was wrong. I just felt like everybody was against me and that they were trying to give him the information so he could find me but I thought wrong. Once I see [name of clinician] and she helped me, she's like, 'We don't give people's y'all's information, that's confidential. What goes on in this office stays in this office.' (non-VA Patient)

Participants felt the ability to access or obtain medical records influenced the satisfaction in their primary care experience. Specifically, patients frequently noted the importance of ease



and timely access to their records. For example, a patient stated, “I think that everybody should have access to their medical records to see what’s being written down and see whether or not it matches with your recollection of [what] the facts are.”(VA Patient) The HPHs agreed that patients should be well informed and have access to their records. One clinician noted a novel method to address barriers to care-related information stating that, of their patients, homeless individuals were the most frequent users of the online patient portal, My HealtheVet.

Patients described situations where they investigated the chart and had concerns about the content. One patient detailed prejudicial use of information from the medical record itself,

The other side of that is having somebody that looks at your records and using them in a punitive way as not to treat you but to cure you of something that you may not need to be cured of. In my case, I had already kicked my drug habit and I was trying to deal with my problems that was part of the wreck as a result of my drug use. And rather than her address those needs, she took a different attack in dealing with me. (VA Patient)

Further discussion of matters related to trust/respect and substance use is offered in separately marked sections below.

Some patients noted they had discovered inaccuracies when investigating the content of their chart. A patient stated, “I’ve had instances where they didn’t write what they saw. They wouldn’t write it. They would tell me, but now, I looked in my medical records it’s not there.”(VA Patient)

The manner or demeanor of communication was also highlighted as an important aspect of knowledge sharing. Patients expressed a desire for real communication with their primary care provider. Many participants provided anecdotes of two-way communication that left the patient feeling disconnected or neglected. However, other patients expressed appreciation for exchanges marked by candor from the clinician as opposed to telling them what they wanted to hear. One patient explained,

She confided in me when I was strung out. She doesn’t bite her tongue. She tells me what I need to hear... opposed to what I want to hear. She won’t let me sugar coat nothing. She’ll tell you listen, ‘I think you’re making a mistake, but it’s your decision. If this what you want to do, outside of the office, then that’s what you do.’ One time I came in to see her after I had relapsed and she said, “I really think you should go to detox.” I was like huh? I didn’t realize that it really had shown that much. I had lost maybe 50 pounds and she was like, “Man you’re not looking that good,” then she asked me, “Are you using?” (non-VA Patient)

Introduction of stigmatizing language by the provider was reported by patients as substantially influencing the free flow of information in their care. When seeking medication for pain, in some situations, communication fell apart entirely as a result. For example, one patient described a lack of communication when obtaining pain medication,

He actually called me a pill head. What are you talking about? How can you make that diagnosis on me and we haven’t even had a conversation about it? You just

looked at the drug screen and come up with your own conclusion. You didn't come here and say 'Well, what's going on witcha? You came up positive on this drug screen. What's the problem?' None of that conversation took place. I come in, he decided I was a pill head, gave me some Tylenol and told me to go home." (VA Patient)

Ways in which provider assumptions can adversely impact the care relationship are further discussed under "Substance Use and Mental Health" below.

Separately, participants also showed interest in, and concern about, whether there was unfettered information flow between physicians and other providers. For example, some declared appreciation for sharing of information through the health record. One noted, "At least, they're going back and seeing what the last doctor had to say before they make a suggestion or prescribing any medication." (non-VA Patient)

### Patient as a Source of Control

This domain reflects the idea that patients should be given the necessary information to exercise control over their medical decisions. Patients and clinicians valued control, but had somewhat different perspectives. Clinicians expressed that patients should, "have the same choice irrespective of whether they are homeless or not." (HPH) Patients reported the same and placed a lot of value on being in control of their medical decision making. However, some patients expressed a degree of ambivalence on how matters of control apply, especially regarding pain and controlled substances. They described situations where they felt they were not in control when they wanted to be. Many of these situations involved the patients' belief that they needed a specific type of medication:

My main problem is getting the medication that I need for my back. Because the pharmacies here won't let her write the medicine that. It is the pharmacist here that will not do it. That is a kink in it. They won't take the red flag off. Hell with them! If we actually need it and the doctor prescribed it, who is the pharmacist to say the doctor can't prescribe that damn medicine for you? Who is he? (VA Patient)

Some patients disavowed the need for control or preferred limited control. For example:

Control means to mean like he would be a puppet on a string. If I had control of anybody when I was drinking I wouldn't be here today. I'd be dead. I think a primary care doctor should be a give and take if I have any questions he's going to give me the answers. If he has any questions I should be willing to give him the answers; I should be straightforward with him, honest with him. Not try to connive different medications from him and if I do that, I hope that he would see through me and, and act the way he should act with my best interest. (non-VA Patient)

And:

I'm an addict! I'm a recovering addict, but I'm still an addict. And addicts want what they want and they want it yesterday. See if I had total control of what my doctor did and I went out there and relapsed it would be ugly. Because I'd be here every other week and I want oxycodone, I want the percs, I want the vics and 85% of them I'm not going to be taking anyway because it's not my drug of choice.

Cocaine's my drug of choice. Get money and go buy some crack. That's what I would do. (non-VA Patient)

HPHs discussed the importance of shared decision-making. For example, "You get far better results for better adherence to treatment plans if the clients or patients are involved in the development of those treatment plans or invested in it from the beginning."(HPH)

### Coordination of Care

This domain refers to a primary care practice's capacity to ensure a patient can get all the services they need even if it is from more than one person. Referrals were a common overarching theme within the coordination of care domain. Both patients and HPHs felt that there should be adequate access to outside providers, as primary care providers do not have the knowledge and resources to treat everything. A patient explained, "I think the quality of care would be better if as soon as your primary care physician sees something that's out of the norm or out of his scope to go ahead and refer you to another clinic." (VA Patient)

Referrals being available in a timely and convenient fashion were described as important to care coordination. An HPH explained,

*Say we make an appointment for a person at a hospital to see a specialist and we can't get that appointment made right when they're there it's a huge problem, because we may not be able to find the patient until they come back to us again.* (HPH)

While referrals were available, individuals also reported barriers to obtaining such services:

A lot of times they, oh say, 'I put in a computer for you to get a follow up with neurology and an appointment with neurology.' They put it in the system, it's dropped from them and it could take months before I get another appointment. (VA Patient)

Active coordination amongst providers was described as an important aspect of care coordination. Clinicians described the importance of patients being able to get care when they were not in the clinic. One clinician noted the importance of having other staff (like RNs) available, "to get the ball rolling or to get started,"(HPH) working up patients in their absence. Participants also highlighted the importance of external coordination. For example, patients felt that providers should be "helping to arrange and make it easier for the patient to" (non-VA Patient) receive specialized care outside of the clinic.

Last, participants (both patients and HPHs) frequently described their preference for co-location of services. A clinician explained,

*One of the things we do in our clinic is, it's a wrap-around service model, so we provide lunch, clothing, bus tickets and as well as having a housing counselor and a benefits counselor all on-site, as well as an integrated mental health all onsite so that the patient can really have some of their social needs at the same time they're getting their health care needs addressed.* (HPH)

## Accountability

This domain refers to the primary care provider's ability to address the majority of the patients' health needs. Indeed, patients believed their provider should be capable of responding to most of their needs. Patients also felt that an important part of accountability was taking their needs outside of the clinic into consideration when creating a treatment plan. For example, a patient described getting help obtaining better housing:

There was a time not too long ago that I needed a place. Housing put me back and wanted me to go 5 more years, but I asked [my doctor] could she help me on finding out housing and if I did get the housing could she sign the papers for me. (non-VA patient)

An emergent theme in this domain was the implication of preventive care and chronic disease management for meeting patients' needs. Clinicians asserted that their role includes making sure patients are receiving services like appropriate screenings, colonoscopies, pelvic exams, and mammograms. Patients felt that providing these services were a necessity for quality primary care as well.

Participants also discussed situations that could potentially limit accountability. For example, a major barrier described by participants is when there is a lack of shared decision-making. Indeed, a clinician explained that providing care is "much easier" when the patient and provider are on the "same page".

## Cooperation

This domain refers to the idea that providers should work as a team and communicate with each other. Patients described communication among providers as a critical aspect of cooperation; patients emphasized the importance of real communication, not just communication via the electronic health record. Both patients and HPHs described the importance of teamwork among providers. For example, an HPH explained that care teams should, "talk about your treatment plan. Potential treatment, past treatment, and how it correlates or how, what could benefit off certain treatment." (HPH) Patients and clinicians both agreed that the team should, "be competent with all areas of treatment" (VA patient), while also working closely with specialists. One patient noted:

Some doctors catch things that other doctors don't catch or some are focusing on one point and the other one might be focusing on another area and it's just better. Team work is always better 'cause people's focus goes in different areas. Doctors are real smart but everybody's not perfect and someone could have missed something that the other didn't miss. It's always good with more than one brain to put together. (non-VA Patient)

## Evidence-Based Decision-Making

This domain referred to the idea that primary care should be based on the best medical knowledge. Patients described different approaches to assessing whether their care was evidence-based. Some tried to assess whether what they heard from their clinicians aligned with information they could gather from external sources. One patient explained,

*There's one medication I'm on and I didn't even know it, you're not supposed to have grapefruit juice. I was never told that. It's not on the labels either on the vials, but it was on the literature that I read. Now if I didn't read the literature I wouldn't have known.* (non-VA Patient)

Other patients referenced the experience, reputation, expertise and training of the provider as guiding their perspective. Specifically, adequate medical training and experience influences the patient's confidence in the provider's abilities. Many discussed, at length, experiences with younger providers and students in training. For example,

Because of his youth, he's more susceptible to the knowledge that would provide the necessary care for me. And I think that's a good thing and being young is a plus in that. But also, as time goes on, because of the knowledge that he has gained, he's going to get the necessary experience to apply it even more so. (VA Patient)

HPHs often endorsed evidence-based decision making and also described situations where standard recommendations had to be tailored to patients' homeless-specific context.

I think that what happens is there is always going to be some unique populations and so then care needs to be tailored in a way that will meet those individuals' needs. (HPH)

In addition to the 8 domains planned for query based on the IOM constructs, the following 3 domains were emergent:

### **Homeless-Specific Needs**

A frequent emergent theme was needs specific to individuals experiencing homelessness. Within this domain was a discussion of self-esteem/self-worth related to the patient's experience of homelessness and how it affects participation in health care. Participants described fear that they would be "treated differently or discriminated against" (VA Patient) because they are homeless. HPHs provided examples of ways in which these feelings could be addressed. For example, "Awareness of the living conditions of the homeless patients allows the providers to be more sensitive and provide a little bit more dignity to their actions which generally makes a big difference." (HPH)

Patients described frustration with how security and other personnel treated them, noting that they were "treated differently" at some clinics and "were made to be uncomfortable because [they] were homeless" (non-VA Patient). Many patients shared similar stories of feeling stigmatized:

'Cause you're homeless, they all consider you as a drunk and a dope addict...All they have to do is find out that you don't have an address and you're plagued right then. Your health is limited to what you're going to get. (VA Patient)

HPHs described the necessity of training providers related to homelessness to address/prevent stigmatizing patients. One provider stressed the necessity of openness to "stepping out of the medical model and being very open minded." (HPH)

Many of the participants discussed how hygiene can influence the care experience. Absent any query on the matter, “smell” was mentioned 12 times (7 of 60 interviewees, including both patients and HPHs). Participants noted that appropriate homeless-focused care should provide services, like showers, as many patients do not have access to such amenities regularly. They also described situations where shelter had been provided and influenced their overall experience with care: “I’ve had a lot of nurses that would just say “Hey look, it’s too cold for you to be out there. Behave, stay in here tonight. You ain’t staying out in the cold weather.” (VA Patient)

Both patients and clinicians highlighted the influence of competing priorities when someone is homeless. A patient explained, “Generally most people don’t really care about their health when they’re out on the streets. They’re more concerned about getting their first drink or just trying to make it through the day.” (non-VA Patient) The technical implications of how homelessness affects medical care were also detailed. A clinician explained,

The endocrinologist put him on a 5 day—5 injections a day— regimen of his Insulin, and it was obviously not a regimen that was compliant with or consistent with the demands of his lifestyle but it didn’t reflect: 1. His food insecurity, nor did it necessarily reflect the fact that he couldn’t inject himself 5 times a day, and so we put him on a twice a day regimen and have actually gotten very good blood sugar control by incorporating the competing demands with the treatment decisions. (HPH)

### Substance Use and Mental Health

Substance use and mental health were emergent domains that we combined as they were often discussed together. One recurrent theme discussed by patients was the awareness and training of their provider to jointly handle behavioral and medical issues. Participants described the provider’s ability to have comfortable conversations with the patient about substance use. Specifically, participants expressed concerns about stigma toward substance use and mental illness. Experiences of either prejudice or welcomeness in relation to behavioral issues were described by patients. For example,

I don’t know if doctors look at people that has suffered from substance abuse as being unworthy or less than or ignorant, but it’s far from the truth, because I feel like we should be treated with dignity and respect. But from my experience, I, doctors look down upon people that has suffered from substance abuse or alcoholism. (VA Patient)

Patients felt that provider knowledge of their current or previous substance use could potentially result in different or worse care. They also described feeling separate or stigmatized by virtue of the particular clinic used. For example, a patient described being sent to a substance use/mental health provider outside of their primary care clinic as “discriminatory.” (VA Patient)

### Trust and Respect

Mutual trust and respect between the patient and provider was an emergent theme in this analysis, since those particular concepts did not form part of our a priori framework. And

yet, success and failure in fostering trust and respect permeated much of the interviews, including quotes associated with almost every other theme in the analysis, as should be evident in examples noted above in relation to Shared Knowledge and Free Flow of Information, as well as Substance Use and Mental Health.

Both patients and HPHs felt a relationship with trust and respect is built over time. HPHs also asserted that, “relationship building is the most important thing. It fosters trust over time.”(HPH) The first step in this process is an understanding that the provider is putting the patients’ interest first. Patients valued respect, compassion, and caring from their provider. For example, one patient described this relationship like,

He goes a little bit beyond medical care. He’s a morale booster, always encouraging. Spirits get pretty much uplifted after a visit with him. He’s never said anything negative to me. Always real - shows what I call genuine concern. (VA patient)

Another theme within this domain was confidentiality. Patients expressed the importance of physicians keeping information secret and abiding by their confidentiality agreements. This allows for patients to have what they describe as a comfortable relationship with their provider.

## Discussion

In this study we explored perceptions of quality in the primary care experience for patients, drawing on reflections of both patients who had experienced homelessness and HPHs in homeless care. The data highlight ways in which primary care delivery and the systems set up to measure, compensate, and credential patient-centered medical homes may need to be tailored when serving patients experiencing homelessness.

We focused on eight domains pulled from two key IOM reports which we prioritized for qualitative study using a card sort exercise, which is more fully described elsewhere (Steward et al., 2016). Three additional concepts emerged: Homeless-Specific Needs, Trust and Respect, and Substance Use and Mental Health. The results of this study underscore that each of the components of successful primary care commonly cited in books, quality of care initiatives, and survey metrics hold particular, powerful, and often unique implications for persons experiencing homelessness.

Conventional notions of quality that guided our study were often seen in unique ways by these patients and their healthcare providers. For example, the idea that primary care should be easy to access is found in nearly all primary care scholarship (Starfield, 1998). But the notion of access, for this population, ranged far wider than matters of payment, office hours, and physical location. It involved overlooked matters of knowing where and how care was available and whether care could be taken to the streets and shelters in some instances. It also included bureaucratic barriers and feeling welcome or unwelcome (O’Toole et al., 2015; Wen et al., 2007).

Similarly, the *Crossing the Chasm* report highlighted shared knowledge and free flow of information (IOM, 2001). In this sample, that construct included the subjective state of

feeling known and understood, as well as being comfortable that one's abusive partner would not be able to intrude on the care environment. It includes worries about the accuracy of the medical chart, and the spirit and manner in which communication took place. Nearly every element of our analysis has been described separately in the literature (physical safety, concerns about record accuracy, and patient-centeredness of communication) (Bullock, McFarlane, Bateman, & Miller, 1989; Roter, Hall, & Katz, 1988; Verheij, Curcin, Delaney, & McGilchrist, 2018). But to our knowledge, they have not typically been collectively examined as important elements of homeless health care as we did in this study.

Among the other six prespecified constructs, we note the somewhat discordant views, between patients and HPHs, in regard to "control." HPHs asserted robust support for patients having control in care; it may be inferred that professionals who seek work with marginalized populations place special value on seeing their clients gain agency in life and in their care. Conversely, patients reacted in contradictory ways, often referencing their pain and issues of medical treatment for it. Some cautioned that their own history of addiction rendered them problematic agents to entrust with control of their health care. Others referenced frustration that they could not receive pain medication. With the US now revisiting its own history in regard to opioid prescriptions, these divergent reflections may be particularly relevant today (Kertesz & Gordon, 2018). However, on whole, the discourse thematically encapsulates prior studies that have hinted that for patients, actual control is a double-edged sword and that negotiation of shared understandings may be more important (Ende, Kazis, Ash, & Moskowitz, 1989; Levinson, Kao, Kuby, & Thisted, 2005).

Additionally, the emergent domains of Homeless-Specific Needs, Trust and Respect, and Substance Use and Mental Health each stand out in part because of longstanding efforts to address these issues (McMurray-Avila, 2011). The need for providers to convince homeless patients that they were respected emerged with particular force, reinforcing what others have also found. For example, patients who are homeless often find themselves feeling dehumanized and convinced that they are not welcome or respected, both situations that hinder care (Moore-Nadler et al., 2019). It is particularly important that clinicians communicate both trust and respect, especially when caring for patients who are highly stigmatized in settings where mistrust by clinicians is often part of the culture (Merrill, Rhodes, Deyo, Marlatt, & Bradley, 2002).

One case for setting up homeless-specialized primary care programs could be that it may be essential to recruit, reward, and support clinicians who already have the desire to serve this population since that desire may not be entirely teachable. That said, there is some evidence that curricular attention to homelessness can moderately improve attitudes toward patients experiencing homelessness among trainees (Buchanan, Rohr, Kehoe, Glick, & Jain, 2004). And other work suggests that patient-level peers can have positive impacts on behavioral health, and on primary care in VA's Homeless Patient Aligned Care Teams (Barker & Maguire, 2017; Resnik, Ekerholm, Johnson, Ellison, & O'Toole, 2017).

One insight from this study is that themes emerged repeatedly across domains. For example, some perceptions of access depended on whether clinics addressed homeless-specific needs such as showers and clothing. Explorations of the free flow of information (i.e.,



communication) inevitably invoked respect, stigma, and substance use issues. Concepts of pain (mentioned 162 times by 27 of the participants), pain care, and opioid receipt emerged in multiple domains (6 of 11). While co-location of primary medical and specialty or behavioral health services featured prominently as favorable to coordination, the co-location of behavioral services resonated in quotes that we had flagged as relevant to accessibility and substance use and mental health.

Conceptually, it remains possible that a different analytic approach could have yielded firmer delineation of mutually exclusive constructs. Beginning with IOM-derived constructs, however, the blurry margins between elements of quality for this population may tell a larger tale. At some level, perhaps for all patients but notably for homeless patients, there is a degree of interdependency of the elements of good care. Free flow of information is not easy to achieve unless both parties are convinced that respect and trust are present. Accessibility depends in part on where services are located, and also on how they are connected to others (i.e. Coordination). A clinic with a shower (Homeless-Specific Needs) provides patients a potential means to feel less embarrassed and reduces their fear of disrespect when accessing care. In effect, while we assign value to assessing these elements individually, the actual high-quality primary care experience functions as a whole in which its elements are likely interdependent. Efforts to incorporate scholarship focused on complexity could help in future scholarship seeking to understand quality of care in which key components may be interdependent (Lich, Ginexi, Osgood, & Mabry, 2013; Luke & Stamatakis, 2012).

It should be underscored that this is not the first study to obtain insights from patients regarding homeless health care. For example, McCabe (2001) qualitatively assessed “satisfaction” (a somewhat different concept from patient-perceived quality) and highlighted patients’ value of respectful engagement, trust, and assumption-free care. Wen (2007), using qualitative methods, found that patient perceptions of unwelcomeness were due to perceptions of discrimination. O’Toole (2015), using survey data found trust, stigma and organizational obstacles play a major role. Our report provides a framework for understanding what these concepts mean to homeless-experienced patients and their providers.

This study has limitations. Patient-level respondents were drawn from two geographic locations, Birmingham, Alabama and Boston, Massachusetts. However, including Veterans and non-Veterans may add a measure of generalizability. Additionally, patient interviews came from two settings where financial access to care was assured: a VA medical center, and a Health Care for the Homeless Program in a state that had expanded Medicaid eligibility a decade prior to our data collection. Thus, the results could be less applicable in US states that have declined to expand financial eligibility for homeless single adults. But concerns such as respect and communication are likely to be important regardless of financial coverage.

Also, the choice of analytic approach reflected a particular study-related task: the development of a valid patient experience survey that aligned with the types of constructs sought by other patient experience surveys (Kertesz et al., 2014). This original task led to a template coding approach, one that imposes upon the data collection and analytic exercises

a number of pre-established interests of the investigative team. A more inductive analytic approach (such as grounded theory) could well have yielded novel insights not obtained in the present exercise.

In conclusion, this qualitative study strongly suggests that elements of primary care quality as laid out by the IOM resonate meaningfully for patients who have been homeless and their clinicians. At the same time, these analyses highlight numerous ways that seemingly self-evident constructs such as “care should be accessible” has specific meaning in the context of homeless health care. Institutions seeking to optimize care for this population include numerous charitable clinics, the Bureau of Primary Health Care, which manages funding for approximately 300 Health Care for the Homeless Programs, and the US Department of Veterans Affairs. These endeavors have lengthy histories of attempting to assure high quality care through application of standard metrics and tools, including credentialing programs for Patient Centered Medical Homes. How, and in what way, these endeavors should be tailored for this population remains a topic ripe for continued research and innovation.

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**Table 1.**

Domains, Questions, and Themes

| <b>Domain</b>  | <b>Question and Themes</b>   |
|--|--|
| <i>Accessibility</i>                                 | Question: What do you think about the idea that your primary care should be easy to get?<br>1) Accessibility of location & transportation to care<br>2) Patient knowledge of services and initiative to access services<br>3) Availability of systemic resources (ex: beds, funding, finances, insurance)<br>4) Outreach- ease of contact while homeless<br>5) Appointments  |
| <i>Continuity of Relationships</i>                   | Question: What do you think about the idea that you should be able to get your primary care any time or any place you need it?<br>1) Same provider/team over time- flexibility of location over time<br>2) Capacity to reach/contact the provider who knows me and vice versa<br>3) Feeling of being known and understood thru significant interactions over time  |
| <i>Shared Knowledge and Free Flow of Information</i> | Question: What do you think about the idea that information about your primary care as well as your medical chart should be easy to get?<br>1) Reference to how others use the chart to get information<br>2) Ability to access or obtain the chart for the patient<br>3) Manner or demeanor of communication<br>4) Description of whether health conditions, care, treatment were well or poorly explained<br>5) Sharing knowledge should mean sharing knowledge between physicians and/or other providers includes medical records and other forms of communication<br>6) Respect for privacy and confidentiality<br>7) Situation where patient investigates chart and asserts concern over whether contents are inaccurate, incomplete, unhelpful, or damaging in some capacity |
| <i>Patient as a Source of Control</i>                | Question: What do you think about the idea that you should have control in your primary care?<br>1) Patient values control/ disappointed at the lack of it (listening, scheduling, therapeutic decisions)<br>2) Patient disavows needing control, or recommends limitations<br>3) Patient asserts control  |
| <i>Accountability</i>                                | What do you think about the idea that your primary care should be able to meet most of your health needs, most of the time?<br>1) Health needs that are met or not met<br>2) How caregiver assumes or falls short of accountability  |
| <i>Evidence-Based Decision Making</i>                | What do you think about the idea that your primary care should be based on the best medical knowledge?<br>1) Sound clinical decision-making<br>2) Collecting data to allow evidence-based decision-making<br>3) Training and expertise of provider<br>4) System changes and housing change may be key to health  |
| <i>Coordination</i>                                  | What do you think about the idea that your primary care should make sure you get all the services you need, even when there is more than one person providing the service?<br>1) Referral<br>2) Active coordination/integration among providers<br>3) Adequacy and accessibility of multiple services  |
| <i>Cooperation</i>                                   | What do you think about the idea that your primary care should mean all of those who take care of you work as a team and talk to each other?<br>1) Communication among providers<br>2) Working as a team   |
| <b>Emergent Domains</b>                              |  |
| <i>Homeless Specific Needs</i>                       | 1) Self-esteem related to patient's homelessness, affects care participation and negative stigma (staff, organization)<br>v. how welcoming the organization is towards homeless patients<br>2) Training/ aptitudes for providers on homelessness<br>3) Special requirement to meet nonmedical needs<br>4) Priorities when you're homeless<br>5) The technical implications of how homelessness affects medical care  |
| <i>Substance Use and Mental Health</i>               | 1) Awareness/knowledge of behavioral issues with patients and the impact on primary care<br>2) Negative stigma towards substance abuse/ mental illness<br>3) Substance abuse limits use or changes dynamics of health care<br>4) Challenges to receiving medical care in a unique/specialized clinic   |
| <i>Trust and Respect</i>                             | 1) Physicians abide by confidentiality and are responsible for keeping information secret<br>2) Comfortable relationship with primary care physician (language of family, friends, raw interpersonal comfort)<br>3) Putting patient's best interest first - fiduciary aspect of trust.   |

| Domain | Question and Themes  |
|--------|--|
|        | 4) How patient and physician view each other (trusted, discriminated against, disrespected)<br>5) Issues related to providers having respect, compassion, awareness of dignity, and caring for the patient |

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**Table 2.**

Patient Characteristics N=36

|  | N (%)         |
|--|---------------|
| <b>Gender</b>                              |               |
| <i>Male</i>                                | 28 (77%)      |
| <i>Female</i>                              | 8 (23%)       |
| <b>Age, Mean (SD)</b>                      | 48.25 (14.92) |
| <b>Race</b>                                |               |
| <i>White</i>                               | 12 (33%)      |
| <i>African American</i>                    | 22 (61%)      |
| <i>Other</i>                               | 2 (6%)        |
| <b>Marital Status</b>                      |               |
| <i>Single</i>                              | 11 (30%)      |
| <i>Married</i>                             | 6 (17%)       |
| <i>Divorced/ Separated</i>                 | 19 (53%)      |
| <b>Employment</b>                          |               |
| <i>Unemployed</i>                          | 19 (53%)      |
| <i>Part-Time</i>                           | 7 (19%)       |
| <i>Full-Time</i>                           | 9 (25%)       |
| <i>Disabled</i>                            | 1 (3%)        |
| <b>Episodes of Homelessness, lifetime</b>  |               |
| <i>None</i>                                | 1 (3%)        |
| <i>One</i>                                 | 8 (22%)       |
| <i>Two or More</i>                         | 27 (75%)      |
| <b>Longest Spell of Homelessness</b>       |               |
| <i>None</i>                                | 1 (3%)        |
| <i>Less than a Month</i>                   | 1 (3%)        |
| <i>1 to 6 Months</i>                       | 7 (19%)       |
| <i>6 Months to 1 Year</i>                  | 6 (17%)       |
| <i>Over a Year</i>                         | 21 (58%)      |
| <b>General Self-Reported Health Status</b> |               |
| <i>Poor</i>                                | 2 (6%)        |
| <i>Fair</i>                                | 8 (22%)       |
| <i>Good</i>                                | 19 (52%)      |
| <i>Very Good</i>                           | 5 (14%)       |
| <i>Excellent</i>                           | 2 (6%)        |

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**Table 3.**

Healthcare Professional Characteristics N= 24

|  | N (%)    |
|--|----------|
| <b>Gender</b>  |          |
| <i>Male</i>  | 9 (40%)  |
| <i>Female</i>  | 15 (60%) |
| <b>Location</b>  |          |
| <i>Northeast</i>   | 11 (46%) |
| <i>Midwest</i>   | 2 (8%)   |
| <i>West</i>  | 7 (29%)  |
| <i>Southeast</i>   | 3 (13%)  |
| <i>Southwest</i>   | 1 (4%)   |
| <b>Race</b>  |          |
| <i>White</i>   | 21 (88%) |
| <i>African American</i>  | 1 (4%)   |
| <i>Asian/Pacific Islander or Native American</i>               | 2 (8%)   |
| <b>Professional Training</b>                                   |          |
| <i>Nurse (RN or NP)</i>  | 7 (29%)  |
| <i>Physician</i>   | 8 (34%)  |
| <i>Social Work</i>   | 5 (20%)  |
| <i>Other (Physician Assistant, Psychology)</i>                 | 4 (17%)  |
| <b>Job Category</b>  |          |
| <i>Direct Client Service</i>                                   | 8 (34%)  |
| <i>Administration</i>  | 10 (41%) |
| <i>Supervision</i>   | 1 (4%)   |
| <i>Research</i>  | 3 (13%)  |
| <i>Executive Leadership</i>                                    | 1 (4%)   |
| <i>Retired</i>   | 1 (4%)   |
| <b>Professional effort focused on homelessness, percentage</b> |          |
| <i>1–30%</i>   | 2 (8%)   |
| <i>31–59%</i>  | 4 (17%)  |
| <i>60–100%</i>   | 18 (75%) |
| <b>Ever Been Homeless?</b>                                     |          |
| <i>No</i>  | 20 (83%) |
| <i>Yes</i>   | 4 (17%)  |

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