

Patient Experience Journal

Volume 5 | Issue 3 Article 16

2018

A photo-elicitation study of homeless and marginally housed Veterans' experiences with patient-centered care

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Recommended Citation

Sestito, Samuel F.; Rodriguez, Keri L.; Hruska, Kristina L.; Conley, James W.; Mitchell, Michael A.; and Gordon, Adam J. (2018) "A photo-elicitation study of homeless and marginally housed Veterans' experiences with patient-centered care," Patient Experience Journal: Vol. 5: Iss. 3, Article 16.

Available at: https://pxjournal.org/journal/vol5/iss3/16

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Cover Page Footnote

Disclaimer: The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States Government. Acknowledgements: We would like to express our gratitude to the Veterans who participated in this study for sharing their stories, photographs, and insights, and to the clinical and administrative staff of the Homeless Patient Aligned Care Team (HPACT) at the VA Pittsburgh Healthcare System, where this study was conducted. Funding: This work was supported by a pilot research grant from VISN 4 Mental Illness Research, Education, and Clinical Center, VA Pittsburgh Healthcare System (PIs: Michael A. Mitchell, Lauren M. Broyles). This work was also supported by Department of Veterans Affairs, Health Services Research & Development (HSR&D) Service, locally initiated research funding (PI: Michael A. Mitchell; 72-079). Finally, this work was supported by the Department of Veterans Affairs, Office of Academic Affiliations Advanced Fellowship Program in Addiction Treatment (Michael A. Mitchell), a Career Development Award (CDA 10-014) from the Department of Veterans Affairs, Health Services Research & Development service (Lauren M. Broyles) and with resources and facilities at the VA Pittsburgh Healthcare System, Pittsburgh, PA. The funding organizations had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication. Author Contributions: Mr. Sestito, Dr. Rodriguez, Mr. Conley, Mr. Mitchell, and Dr. Gordon contributed to the study concept and design. Mr. Mitchell and Dr. Rodriguez conducted the interviews. Mr. Sestito and Mr. Conley coded the interviews, overseen by Dr. Rodriguez. Ms. Hruska and Dr. Rodriguez completed the analysis. All authors contributed substantially to the manuscript preparation and review. Conflict of Interest: All manuscript authors declare that there are no conflicts of interest (i.e., financial and personal relationships between themselves and others that might bias their work).

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Research

A photo-elicitation study of homeless and marginally housed Veterans' experiences with patient-centered care

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Abstract

As part of a qualitatively-driven mixed-methods study, this analysis aimed to describe Veterans Affairs (VA) Homeless Patient Aligned Care Team patients' experiences with patient-centered care. Veterans participated in audio-recorded, semi-structured photo-elicitation interviews about their health and VA health care. Transcripts were analyzed by two coders using template analysis. In 31/36 interviews, 19/20 participants discussed patient-centered care. Veterans noted Picker's *Patient-Centered Care* Principles; 1) access to care, 2) respect for patient-centered values, preference and expressed needs, 3) information, communication, and education, and 4) coordination and care integration were most commonly discussed, followed by 5) physical comfort, 6) transition and continuity, 7) emotional support and alleviation of fear/anxiety, and 8) family and friend involvement. They also identified 1) quality care and 2) being present with patient as central to patient-centered care. Improvement suggestions included the patient-provider relationship, VA services, and transportation. Photo-elicitation may be useful in understanding patient preferences, needs, and values to ensure patient-centered care delivery.

Keywords

Veterans, vulnerable populations, patient experience, patient-centered care, primary health care, qualitative research, photo-elicitation

Introduction

The Veterans Health Administration (VHA) serves more than five million Veterans at nearly one thousand locations throughout the United States (US). In 2010, VHA began to implement a patient-centered medical home model into all of its facilities. This initiative, known as Patient Aligned Care Teams (PACTs), focuses on improving patients' experiences with continuity of care, access to care, care management and coordination, and partnership with primary care physicians. The PACT initiative has addressed these aims by hiring more primary care staff, reorganizing the staff to facilitate a team-based approach, and implementing quality assurance technology and programming. I

Expanding the scope of the PACT model, specialized Homeless PACTs (HPACTs) are an integrated, "one-stop program" to address the varied and complex needs of homeless Veterans, such as access to health care, support for continued engagement in treatment, access to housing, and psychosocial needs.²⁻⁵ Specialized HPACTs are needed because, although the number of homeless Veterans in the

US has markedly declined since 2009 when the US Department of Veterans Affairs (VA) announced its commitment to end homelessness among Veterans, Veterans remain at increased risk for homelessness.^{6,7} Veterans continue to be overrepresented in the homeless population compared to civilians, with approximately 40,000 Veterans identified as experiencing homelessness on one night in January 2017.7 Approximately 25,000 Veterans used HPACT's services in 2016, with over 96 percent of those Veterans enrolled in HPACT and receiving VA homeless services.^{3,8} While research has shown that the HPACT model has had a variety of positive effects on the Veterans' overall health care and housing situations,9 there is somewhat limited information from HPACT patients about their experiences with the program and their care. It is imperative to examine patients' experiences with HPACT to determine if the initiative is being implemented in a patient-centered fashion. The purpose of this analysis was to describe HPACT Veterans' experiences with patient-centered care. We decided that photo-elicitation was the most appropriate method to guide the interview process and encourage patients to discuss their experiences with

HPACT because visual-based research methods, including photovoice, have been shown to be useful tools in health care and with varied types of patients, including Veterans and those who are homeless or marginally housed.⁷⁻¹⁵ Photovoice has been found to enable individuals to communicate issues of importance to them and "to reach policy makers and the broader public about issues of concern to the homeless."^{19,20} Photo-elicitation has been shown to produce rich data (including but not limited to feelings/emotions, memories, abstract ideas) by encouraging reflection, facilitating communication, and enhancing rapport in the researcher-participant relationship.^{21,22}

Methods

Setting and Participants

We recruited participants from the HPACT at the VAPHS, an urban academic medical center. For the purposes of this study, the term "homeless individual" was operationally defined more broadly as an individual who lack fixed housing and/or someone at risk of losing their housing in the near future. 23,24 Eligibility criteria required that each Veteran had an HPACT visit between March and August 2015, had plans for at least five months to remain in the Pittsburgh area, and understood and read English. Exclusion criteria included lack of willingness to be audio-recorded during interviews or sensory impairment preventing communication during the study. Clinical staff members approached potential participants prior to their HPACT visits. Veterans who were interested in participating were referred to a member of the research staff for informed consent procedures and further study details. In addition, one of the interviewers for the study was also in charge of recruiting participants. Our final sample size of 20 participants was chosen to meet established qualitative standards for minimum sample size based on theoretical saturation.²⁵

This qualitative analysis was part of a qualitatively-driven, mixed-methods photo-elicitation interview (PEI) research study. The logistical lessons learned from designing and executing our study,²⁶ qualitative results describing Veteran experiences with substance use, substance use recovery, and substance use treatment,²⁷ and quantitative results from the exit survey of Veteran experiences with PEI study participation²⁸ are outlined in previously published works. The Institutional Review Board and the Research and Development Office at the VA Pittsburgh Healthcare System (VAPHS) approved this project.

Data Collection

Participants completed a sociodemographic survey and participated in an orientation session about photo-elicitation during their first research visit. Digital cameras and memory cards were also distributed to the participants to use during the research. The orientation provided an

overview of photo-elicitation research and ethical and safety considerations, as well as camera instructions and strategies for take pictures. They received the following questions to focus on when taking 15-20 photographs over the next two weeks: "How do you think about 'health'?"; "What do you do to stay healthy?"; "What helps, what gets in the way?"; and "How does housing play a role in taking care of your health?". During their second research visit, participants completed a 30-60 minutes audio-recorded interview using their photos as points of focus about health and wellness, as well as facilitators of and barriers to health and wellness, including housing. At the end of the visit, they received a new set of questions to focus on when taking 15-20 photographs over the next two weeks. They were as follows: "What is good health care?"; "What has helped you get to your VA primary care appointments and any other healthcare services?"; "What kind of barriers do you face getting to your VA primary care appointments and any other healthcare services?"; and "What was your life like before and after you started receiving services from primary care?". During their third and final research visit, participants completed a 30-60 minutes audio-recorded interview using their photos as points of focus about health care quality and access. The participants then completed an exit survey about participation in the study. The interview questions discussed above were drafted by the principal investigator based on a literature review of relevant topics and finalized with input from the multidisciplinary study team, including a peer support specialist from HPACT.

Data Analysis

Participants' sociodemographic and health characteristic data were managed using REDCap.²⁹ Microsoft Word was used to transcribe the audio-recorded interviews verbatim and by the two coders to identify categories across interviews. We had a total of 20 study participants, with 20 completing the first interview and 16 completing the second interview, for a total of 36 interviews. The coders used template analysis, which involves deductive and inductive strategies.^{30,31} We coded segments of talk where participants discussed their VA care. In part, thematic analysis was guided by deductive coding using The Picker Institute's Eight Principles of Patient-Centered Care with a-priori categories of patient-centered care. 32,33 These eight primary dimensions of patient-centered care include 1) respect for patients' values, preferences and expressed needs, 2) coordination and integration of care, 3) information, communication, and education, 4) physical comfort, 5) emotional support and alleviation of fear and anxiety, 6) involvement of family and friends, 7) transition and continuity, and 8) access to care. 32,33 We coded along these dimensions because they align with HPACT's intent to provide personalized, proactive, patient-driven care, with long term goals of care coordination, access to primary care, and a patient-centered culture. 1,2,5 Thematic analysis was also inductive, using the grounded theory

approach of constant comparison, to identify any additional emergent categories beyond the aforementioned eight primary dimensions of patient-centered care.³⁴ We also assigned a positive or negative valance or evaluation to each deductively and inductively coded text segment. The two coders met with a study team member who served as an adjudicator to ensure codebook development consistency and resolve any conflicts that arose throughout the process. The a-priori eight dimensions of patient-centered care and additional emergent categories were independently applied by two coders to all transcripts, with coding differences resolved using negotiated consensus.³⁵

Results

For this analysis, our sample size was 19 participants, with 15 transcripts from the first round of interviews and 16 transcripts from the second round, for a total of 31 coded interviews. The 19 participants whose data are included in this analysis were predominantly male (95%), African-American (58%), single (47%), had at least some college or vocational school education (63%), lived in rented or owned property (32%) at the time of consent, and self-classified their health status as "fair" (53%) (Table 1). The mean age was 54.5 years (SD=8.5). The mean number of months as a patient at the VAPHS HPACT at the time of consent was 17.9, with a standard deviation of 9.4 months.

These 19 participants took a total of 306 photographs. The largest number of pictures taken by a participant for a

Table 1. Sociodemographic and Health Characteristics of the 19 Study Participants whose data were analyzed*

Characteristic	
Age in years, mean (SD)	54.5 (8.5)
Number of Months as a Homeless Patient Aligned Care Team (H-PACT)	
Patient at Time of Consent, mean (SD)	17.9 (9.4)
` , ,	n (%)
Sex	, ,
Male	18 (95)
Female	1 (5)
Race	
White	7 (37)
African American	11 (58)
American Indian	1 (5)
Education	
High school or lower	7 (37)
Some secondary education (no degree)	9 (47)
Associates Degree or higher	3 (16)
Marital Status	
Single	9 (47)
Married/Coupled	4 (21)
Separated/Divorced	5 (26)
Widowed	1 (5)
Housing at Time of Consent	
Transitional housing	5 (26)
Staying with friends or family	5 (26)
Rented/owned property	6 (32)
Residential treatment	2 (11)
Unsheltered/street	1 (5)
Self-Assessed Health Status	
Excellent	0 (0)
Very Good	1 (5)
Good	8 (42)
Fair	10 (53)
Poor	0 (0)

^{*}Because of rounding, not all percentages add to 100.

single interview was 27 and the smallest number was 2. The mean number of photographs per interview was 9.9, with a standard deviation of 5.6 photographs. The mean number of photographs per participant was 16.1, with a standard deviation of 10.5 photographs. The longest interview was 1 hour, eight minutes, 25 seconds, whereas the shortest was 12 minutes, 10 seconds. The mean interview time for all 31 interviews was 35 minutes 28 seconds, with a standard deviation of 11 minutes 19 seconds.

All eight of The Picker Institute's Eight Principles of Patient-Centered Care emerged as topics of discussion. The median number of dimensions mentioned by each participant was 6, with a range of 1 to 8. Most commonly, participants discussed access to care (n=17), respect for patient's values, preference and expressed needs (n=17), information, communication, and education (n=14), and coordination and integration of care (n=14) (Table 2). Less commonly, physical comfort (n=11), transition and continuity (n=10), emotional support and alleviation of fear and anxiety (n=5), and involvement of family and friends (n=1) were discussed (Table 2).

Further iterative analysis of the data showed that these participants noted 2 additional dimensions of patient-centered care provision, including quality care (n=16) and being present with patient (n=6) (Table 2). Also, participants shared suggestions for improving care to make it more patient-centered (n=9), focusing on the patient-provider relationship, VA services, and transportation (Table 2). Each of these emergent categories and suggestions, as well as the eight dimensions of patient-centered care, are discussed in greater detail below.

Picker Institute Dimensions of Patient-Centered Care

Access to care. A dimension of patient-centered care often discussed by participants was access to care (n=17). This dimension involved "attention to time spent waiting for admission or time between admission and placement in a room in the inpatient setting, and waiting time for an appointment or visit in the outpatient setting." Most participants focused on appointment scheduling and availability and transportation; some also talked about costs, patient-provider communication, lack of familiarity with VA services, and lack of access to services other than primary care (e.g., mental health care, dental care).

Positive talk of appointment scheduling and availability included ease of scheduling appointments by phone, email, or in person. There was also discussion of short wait times between scheduling and having the appointment, as well as flexibility/availability of appointment; many participants specified that VA access has greatly improved but that they experienced some site-level variation (e.g., current VA hospital is more efficient than their previous one). In addition, although there was negative talk about having to

wait for their prescriptions, most focused on the ease of getting and managing their prescriptions, such as in-person at the VA pharmacy or remotely through MY HealtheVet. As one person said about their PCP:

He's taken real good care of me, keeping my prescriptions up to date. Me and him will even email back and forth on MY HealtheVet. So, in a timely manner, within hours, boom, I have an answer. Or, I'll need to see you in the clinic, and set that up.

Negative talk also included long waits for appointments (at another VA site), wait lists or not being able to get an appointment due to high volume influx of patients, difficulty making appointment due to 2 separate local VA locations, appointment running behind, and lack of a streamlined check in processes for scheduled appointments (i.e., multiple redundant check ins when a patient arrives at the hospital and in clinic areas). Someone also said that they were sent to the emergency room during hours when the clinic was operational.

Most talk about transportation was negative and included means of transportation, travel costs, traffic/road conditions, and the weather (Figure 1). Some said they did not have a vehicle, which led many to utilize public transportation. They noted high costs of public transportation (e.g., no VA reimbursement for bus fare, inadequate bus tickets provided by VA, inability of postal service to get bus tickets to a patient), the high time investment of public transport (e.g., having to coordinate shuttle/bus times), and negative psychological effects of public transportation (e.g., relying on and riding the bus stresses them out). For VA transportation, it was said that patients must sometimes wait for transportation to VA, or wait for shuttle back from the VA. There were also conflicts with a person's work schedule and availability times of VA transportation. It was noted that travel was particularly problematic for those that lived at a further distance from the VA facility. One person who did not have a vehicle said they rely on their mother for transportation and are uncomfortable with her driving. The traffic/road conditions and weather were also said to be problematic. Examples included road construction, not having assistance to get to their VA appointment when the weather is bad, and being at the mercy of the weather when they do not have a vehicle and have to take public transportation. Positive talk of transportation focused on having means of transportation to get to the VA (e.g., personal/family/friend's vehicle; public transportation; VA shuttle; Disabled American Veterans [DAV] van).

Positive talk of costs focused on VA care being affordable or cost free. For example, one person noted the benefit of VA health care after becoming unemployed and losing their insurance. Although some negatively focused on

Table 2. Summary of patient-centered care (PCC) dimensions and improvement suggestions from 19 participants during 31 interviews

	# of	# of	
Categories	Participants	Interviews	Quotation Examples
Picker PCC	19	31	•
dimensions			
Access to care	17	21	They brought it all out on the news, some of the guys died. It's hard to get appointments. It's hard to get a good doctor. I had a doctor when I first started out in Aspinwall and I've never seen the doctor.
Respect for patient- centered values, preference and expressed needs	17	21	The attitude of their PCP or whoever they're dealing with. Everybody got different techniques, philosophies, theories how to handle, how to deal with a person. But they also got to realize it's a person you're dealing with. Yes, you could be dealing with this here aspect of his life, this situation [they are] going through, but it's the person you're dealing with. So, if you relate to that person as a person, instead of this number, or here is this disease, or here is this alcoholic. Not first thing, 'He is Mr. such and such who uses alcohol to abundance.'
Information, communication, and education	14	21	You should know your body a whole lot better than the doctor does, even though he has a medical degree If he pinches you with a pin, he doesn't know if the stick is going to hurt you or not. You've got to give him feedback. And this kind of relates topain medicine, he needs to understand how much pain he can tolerate. What's the threshold of comfortable versus this is way beyond, this is too uncomfortable, medically necessary.
Coordination and integration of care	14	19	I like the pharmacy here at the VA because, once you see your doctor, you're going right there You see your doctor, he prescribes something, you get the medicine there before you leave. If they don't give you all of it, they will give you a partial and mail you the rest. That's pretty good because it covers what you need and gets you started on your medication right away. You don't have to leave here and go to a pharmacy, wait for a pharmacy to get it, and then go home. You can all go, one shop, one stop shop. It's under that umbrella thing, everything under one roof.
Physical comfort	11	18	Well, prior to this a few years ago, I was incarcerated and spent 4 years in the Federal penitentiary. So, throughout the VAs help I was able to go through the training program and it uplifted me, it gave me some more reasons to be. It changed my life too. First of all, I don't want to go back to prison. They showed that there is some help for us Veterans, healthwise even in trying to find you a place, that's one of the things, my house, my housing was because of the Veterans Association.
Transition and continuity	10	14	Inpatient [care] is good, but when you're starting to get discharged they have problems with medications. I was getting discharged on the 1st, it took me 3 hours to get out of the unit. That's a little bit taxing. It could be done the night before,but they take their time getting you out of here. I'm ready to go after 30 days and especially 21 days where I was at I'm ready to bring the walls down. I know the nurses, and most of them are pretty good people and it's not them Bureaucracy takes forever It's a test in patience and it feels like you're getting out of Shawshank.
Emotional support and alleviation of fear and anxiety	5	5	I like to have a lot of emotional support because I have a mental illness, so I need financially to be supported I'm a disabled Veteran and I need the support of the VA as well to help me with my mental illness and different goals that I want to set. I have a case manager and she helps me a lot to keep my life together emotionally.

Table 2. Continued: Summary of patient-centered care (PCC) dimensions and improvement suggestions from 19 participants during 31 interviews

	# of	# of	
Categories	Participants	Interviews	Quotation Examples
Involvement of family and friends	1	1	Sometimes too much knowledge is dangerous because you get in the habit of being too healthy and checking your fever, blood sugar, and temperature every single day So I gave it to my wife and let he be in charge. So, if she says OK, it's time to take it now, OK, I'll take it now. Oh, not so bad. So then she'll look at me like I know what you're thinking. Nope, can't have it. Then why's it in the refrigerator? Well, it's not there to eat all the time.
Iterative PCC dimensions	18	25	
Quality care Being present with	16	23	I think good quality health care is when you have a doctor that understands you, and all my doctors understand me. I see a resident doctor now for my mental health under Dr. J I can tell by her body language and what she has to sayshe's worried about things that I may have to fix. She always shakes my hand when I see her and shakes my hand after the doctor's appointment. She had told me at the last doctor's appointment that she trusts me and she told me to make sure I get better and fix the problems that I'm having now I was on Thorazine and I was sleeping from 11 o'clock til 11 o'clock. Now I'm tapering off the Thorazine and I go to bed at 10:30, 11 o'clock and sometimes I'm up at 8, 9 o'clock. Changing the medication has given me a lot more energy. [My primary care provider] sees me once every 3 months 'Come in,
patient	0	0	how's it going?' T'm alright' The whole time they are looking at your chart. If there was something in [the chart] they would tell me There's a lack of information, which shows me a lack of interest. I mean, you wouldn't tell me that I should have an interest, especially if I had a non-caring attitude You didn't make me care either You didn't tell me why I should care. I didn't have enough information.
Suggestions for improving care	9	10	
Patient-provider relationship	6	6	Knowing what medication I am taking and expecting certain result from it. Give me a head up of what I am taking for the reason why I am taking it. What I am taking, and what's going to happen when I am taking it.
VA services	5	5	The VA needs to make sure and check up on these combat Vets that are coming back to make sure that they are OK in their head, that they have a roof over their head, that they have food. They need to be put back on track and some guys respond quickly to it and some people don't. Some people still have PTSD issues and I'd like to see the VA pay a little bit closer attention to the combat vets The kind of combat Veterans that we have right now are different than the ones before them.
Transportation	2	2	I'd like to have more access to get [to the VA hospital]. I am not a senior citizen. I can't get [ACCESS] on a senior citizen pass [I'd like] maybe a half pass, half-fare pass. That's not bad.



Figure 1. Photograph of quote about access to care

"I bought a Grand Cherokee on Memorial Day. The engine blew out, extremely upsetting... I don't have my own transportation right now, so that's a big hindrance in itself. Where I'm staying at right now and where I was staying at before, both places don't have a lot of public transportation. It's pretty rural and just to get somewhere to get on a public transportation is difficult... Last week, van didn't come in because of the roads... I work down here and I go to the methadone clinic daily. So, that's kind of like a big deal. We have a van from our center that comes down daily, sometimes two, it depends on the people. Last Monday they cancelled the van. We have a DAV driver and we're just down four days a week, usually Fridays. It's a volunteer driver because the center don't want to pay a guy overtime, so and that can be real hairy with the one driver. If there's more than 5 people, we have to take the big van and he don't want to have to take the big van. That Saturday, we were supposed to have a van to go to the store, we do a mall run. The guy that was supposed to drive was the guy that won't drive a big van and there was like 7, 8 guys on the list. So, he opted out and if the other guy wouldn't have volunteered to take us, we would have been stuck there all weekend... It's not even just health care, it's personal care and needs all around. Things...like the time, the availability to get to resources when you don't have transportation...is a big deal."

VA care being affordable or cost free. For example, one person noted the benefit of VA health care after becoming unemployed and losing their insurance. Although some negatively focused on having to pay transportation fees to get to the VA, some positively noted a lack of cost for transportation (e.g., VA travel pay reimbursement, such as bus fare; cost-free VA transportation, such as the VA shuttle and DAV van). As one person stated:

The beneficiary area for travel pay, every 3 days a week when I go to groups, I go over there, and they give me a little slip and you take it to one of the windows and they

pay you. Where can you go that you get paid to get well? They pay you to get well... This helps me. I don't have a car. I catch the bus and this pays my bus fare. It's like \$3.50, I have to catch two buses, so that's \$3.50 so that's \$7.00 a day. That's a lot of money. It really adds up if that's \$24 or \$28 a week.

Negative talk of costs benefits also included the high cost of care, such as prescription medications (e.g., human immunodeficiency virus [HIV] pharmaceuticals) and appointment copays for some patients.

Positive talk of patient-provider communication included ease of contacting their primary care provider (PCP) outside of their visit, such as direct communication with the patient via phone, email, or through MY HealtheVet. For example, one person said that their health care provider gave them their direct phone number so they can call if they need anything. Others noted that their PCP is available to return their phone calls or emails to answer questions or arrange appointments. Someone talked negatively about messages not being given correctly to their provider and loss of medical records.

There was negative talk focusing on lack of familiarity with VA services, including patients not knowing about services offered by the VA or a lack of understanding about process and services available. One person discussed not knowing about available VA services while homeless, except for emergency services, and a couple people said they only learned about VA services through word of mouth (e.g., a neighbor). As one person stated:

I used to take care of this older lady down the street from where my house was... She would always talk about her husband being in the service.... And she's like, 'Why don't you ever ask the VA for anything?' And I was like, 'Huh? Why don't I ask the VA for anything?' Because it never struck me to do that. And, I started looking around.

Some negative talk focused on access to care other than primary care. One patient noted not being able access dental care in a timely manner, which resulted in having a tooth extracted. Others focused on mental health care issues, such as difficulty accessing services and a long, redundant process. For example, one person said that patients with substance use disorders have to be in recovery before they can access mental health care.

Respect for patient's values, preference and expressed needs. Another frequently mentioned aspect was respect for patient's values, preferences, and expressed needs (n=17). This dimension involved "an awareness of quality-of-life issues, involvement in decision making, dignity, and attention to patient needs and autonomy." Most participants focused on the patient-provider relationship (i.e., communication, patient needs, trust, respect); some also discussed VA system-level support and coordination of care.

Talk of communication (in the patient-provider relationship) was mostly positive. This included VA providers and staff who were described as nice and friendly. Providers were described as showing genuine concern and were said to care about the patient and their overall well-being. Participants said they could talk to their provider and they would listen, have resources available, and were very helpful. One person explained how a

provider's personality can help the patient to relax, be truthful, and engage in a collaborative relationship:

The provider's personality. Take Dr. Y, beautiful personality. And when you have a beautiful personality, you get more cooperation. You get more with honey-you get more bees with honey.... The patient gets relaxed with you. Once they relax with you, then they open up with you, then they become truthful with you. Then you got this open book. So now you can proceed to accomplish what your goal is. Patient accomplishes what his goal is, the doctor accomplishes what his goal is, because they are all working together. For anyone to have that collaboration, they have got to have that type of communication and their communication comes from simple personality.

Communication (in the patient-provider relationship) was negatively talked about in relation to providers rushing through the appointment with no eye contact, patients feeling slighted during interactions with providers, and providers having a communication technique, style, or personality that did not "click" with the patient. Such interactions were not conducive to shared decision making and sometimes led patients to change provider. Forxample, one patient shared the following about their experience asking their PCP for a colonoscopy appointment that was suggested through MY HealtheVet because he is over 50 years of age:

He actually raked me over the coals... he was a little bit gruffer... He was like, 'You don't need one... Why do you keep coming here asking me for one?'... I'm arguing with my doctor about something I don't want to get... That conversation should not have had to happen like that. And I switched my primary care physician.

Another person said:

This doctor, we just didn't click. We didn't click... I think I got with Dr. Z after that. That doctor's technique for me, wasn't conducive... We didn't click, we didn't talk, we didn't communicate. It was like, I walked in as a number and I just see her as, I see the doctor as decision X. I am here for this, you're here for this. Give me this. Bye.

Importantly, it was noted that the VA system was open to acquiescing patient requests for provider changes.

Discussions of patient needs (in the patient-provider relationship) were largely positive and focused on the provider paying attention to and meeting patient needs, including health and non-medical issues (e.g., housing, financial) (Figure 2). They also appreciated when a provider related to them as a person with individualized needs. As one person said:



Figure 2. Photograph of quote about respect for patient's values, preference and expressed needs

"Well, when you come in for your meetings with the health care provider, [they ask] how you've been doing, where you've been going, what you've been doing. So that dialogue, through that conversation, through them conversations, through them meetings [I can] express. I mean, there's so many variations of what's talked about. It can be like these pictures, they could be your housing situation, your financial situation, your medical situation, your physical situation, your health situation because everything networks off of everything else. Everything is inter-connected."

When I am with Dr. X, we go through different topics. We bring up different issues. Yes, they could be dealing with this here aspect of his life, this situation going through, but it's the person you're dealing with... Relate to that person as a person, instead of this number or this disease, or here is this alcoholic.

One person succinctly said they are "intuitive to your needs" and another said providers learn what the patient's goals and needs are, then help the patient to achieve them. Health-related talk focused on when patient asks for mental health care (e.g., psychiatric treatment) and providers who will work with a patient (e.g., a patient who has an initial negative reaction to being prescribed medications). They also focused on providers who remember the patient, "watch out for them," are supportive, and are attentive and knowledgeable about the disease. Such things were said to create rapport and a sense of belonging. Some said that having rapport can also

lead to increased patient autonomy, particularly in taking a central role in care decisions. For example, one person with acid reflux said that they were referred to a dietician and attended educational classes, which helped them with self-care and make healthier food choices, such as eating more fish. They stated, "They give you a list of what's good for you. I eat a lot of fish now. People say, 'Why do you like them sardines?' But they have something called Omega-3, which is very good for me." Someone also appreciated that patients can request and be reassigned to a new PCP. Non-medical assistance and programs include the needed support required for an individual patient's situational needs. For example, one person explained that providers understand the patient and work with them on quality of life issues (e.g., excess sleeping due to medication). Another said that they address patient needs for food and shelter, which can help some patients with sobriety (e.g., "They helped me.... When I first started [at VA],...they sent me to a shelter for almost 2 weeks until I

was clean."). Another noted that providers help get patients into a work program. Negative talk of patient needs focused on addiction care, which put his mental health needs on hold, "I'm in recovery... I've had some other issues that I wanted to address, like some mental health issues, and those can't be addressed while being in active addiction. And I understand that, but it's such a long process and it gets a little frustrating sometimes."

Trust (in the patient-provider relationship) was negatively talked about in relation to providers making assumptions about patients and being suspicious of them using illicit drugs. This led patients to feel like they were being judged and subsequently lack trust in the provider. For example, one person said they were suspected of a drug-related injury:

He started making me come weekly... because they thought I was high or something. I told them, I said I fell getting off the bus, which is why I'm late. That's what I told them, and they thought I said I fell because you know, drugs or something... I started arguing with them about it.

Another person shared an experience of broken trust related to an allergic reaction to new medications, which led to the need for a patient advocate:

We were exploring Abilify and Haldol... The psychological [team] wouldn't pay attention. I told them I was hurting, I was in pain and I was having a bad allergic reaction to it. Wound up in the emergency room... The trust broke down. Because they were trying to say, 'Well, you didn't tell us, you went over our head.' And I'm like, 'No I told you first... I was like, 'They had directly to do with the influence of this medicine. I wound up having to get the patient advocate involved and a medical doctor to tell them, 'Look, he's having that much of an allergic reaction to it. He can't take it.'

Trust (in the patient-provider relationship) was positively talked about in terms of listening to the patient while not making assumptions.

Respect (in the patient-provider relationship) was negatively talked about in regards to communication. When communication breaks down, it was said to lead to loss of respect and patient's shutting down. As one person explained:

You got to be able to communicate with that individual that you're working with and as positive you can keep it, as positive it can be. If negative factors are coming in, there's going to be a break down. If there's a breakdown there's no communication. There's no communication or lack of communication, anyway it goes, the respect factor has been diminished.

One person who said they shut down after feeling disrespected by their PCP and changed providers stated, "I don't want to talk to you at that point. 'How you doing?' 'I'm fine.' 'Any problems?' 'No, I'm fine.' So communication broke down at that point. Get me out of here, do what you can to get me out of here and I'm going." Respect (in patient-provider relationship) was positively discussed in terms of how providers address patients:

You tell them to call you by your first name and they still address you, in my case Mr. [last name]. I'm like. 'Call me [first name].' But there's that respect there, and I think, in general, there should be respect given. Be it to the elderly, be it to someone in a higher position, be it to a service member. And I think a lot of people appreciate that.

Discussions of VA system-level support were largely negative and focused on the following: lack of variation in appointment times (e.g., only morning group therapy appointments), lack of concern about patients' time (e.g., have other places to be), lack of information regarding available services, dissatisfaction with VA protocol for handling patient medical records, lack of sensitivity to individual patients' needs (e.g., quality of life concerns), and treatments being "one size fits all." Positive talk of VA system-level support focused on the VA addressing an individual patient's mental health needs, Veterans receiving appointment reminder letters, and accommodating patients when they need to reschedule appointments.

Coordination of care was positively talked about in relation to coordinating appointments. For example, coordination of PCP and VA support services assisted patients with housing and getting bus tickets that allowed them to get to their VA appointments. It was also said that providers have a holistic view of patient well-being, such as your "housing situation, your financial situation, your medical situation, your physical situation, your health situation."

Information, communication, and education. Another common element was information, communication, and education (n=14). This dimension involved "clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care, and health promotion."³⁶

Positive talk of communication and information exchange largely focused on clinic visits. Providers were said to discuss health issues (e.g., "discussing various medications, him refilling my prescriptions") and non-medical issues (e.g., housing, financial). As one person said, their provider starts their visits by asking them, "How you've been doing? Where you've been going? What you've been doing?" Providers also get to know their patients better by asking more in-depth questions during visits, which can

benefit care. For example, one person said that providers who review patient/family health information (e.g., family history of cancer diagnoses) and ask for added information during the visit led patients toward thinking/talking about their health and pursuing provider recommendations (e.g., testing, treatment). One person even said, "They ask you almost too many questions. In other words, they want to make sure that they're not missing something. So it's not like. 'OK, next. Ok, next.' You know, this isn't a fast food line. And I appreciate that about them." Indeed, some said it was important for patients to share updates or new information with their providers during clinic visits, such as concerns (e.g., symptoms), so that they can collaborate and accomplish their care goals. As one person said about clinic visits:

That one-on-one sit-down talk is about the most important thing, because you're sitting there talking to him, he's talking to you. If you have any pertinent questions you want to ask him... That's your window, that window is going to close very rapidly... So, if there's anything that you think that you're being dealt with that... you are worried about, or you have questions about, that's the time to do so... You having the responsibility to voice those concerns. You should know your body a whole lot better than the doctor does,

even though he has a medical degree... You've got to communicate.

Providers updating patients on their health status and progress, as well as what they can expect in the future (e.g., conditions, prognosis), was said to benefit care, including self-care such as instructions for medication taking. For example, one person said, "One of the doctors told me that no matter what happens continue to take you medications, you know what I'm saying, so I continue to do that." Some providers were also said to inform patients of potential future recommendations if poor self-care choices continued, such as not being mindful of their diet. For example, a person who gained weight from eating too many desserts said their provider, "Stays on me, watching what I am eating... Saying, 'Hey. You keep eating like that, we're going to put you on a diet." Also noted were providers who had a supportive response to patient improvements. For example, one person who had been sticking to a "stringent discipline" for eating appreciated that their provider conveyed, "Being happy that I've lost 10 pounds" (Figure 3). Some wanted to be told their prognosis, even if it meant hearing bad news. As one person said, "If it looks like I'm dying, tell me because I can handle it, because I've got God."



Figure 3. Photograph of and quote about information, communication, and education

"[My primary care provider and I] talk, a lot, 'Hey doc, check me out I am not feeling good.' But I have been feeling ok. And he stays on me. Watching what I am eating. I gained some weight... About six months or so ago I only weighed about hundred-and twenty-five pounds. Now, I weigh hundred-and-two pounds. Oh man. He saying, 'Hey. You keep eating like that, we're going to put you on a diet.' Too much, put too much weight on me. I ain't never been on no diet man... That's why I tried to leave the sweets, leave that stuff alone. But cherry pies, oh man. Chocolate. Doughnuts. Cupcakes. All the time. Plus, I gotta eat to take my pills. That's one thing."

Negative talk of communication and information exchange focused on patients being given inadequate information from their providers about test results and how to interpret them (e.g., blood work) and not being informed about why they should follow their provider's recommendations (e.g., about self-care, testing, treatment). Lack of information from the provider caused patient frustration and was interpreted as lack of interest in the patient. It also led to a lack of understanding of the rationale behind recommendations and patients ignoring provider suggestions (e.g., getting an injection, quitting smoking). Also mentioned was a lack of information being provided to Veterans about available VA services and resources.

Education was talked about positively in relation to patients who were open to listening to what their providers have to say and learning during their visits (e.g., PCP, case manager). Providers helped patients learn more about their diagnoses. For example, one person said that, through the VA, they came to a greater understanding of their mental illnesses as a chronic disease (i.e., bipolar and depression diagnoses). Another person said their PCP taught them about the history of HIV discovery, different HIV strains, and appropriate medications for the patient's HIV strain. When providers taught patients about obstacles to staying healthy and why care recommendations were being made (e.g., self-care, testing, treatments), patients were more willing to pursue such care and followed provider suggestions. One person discussed becoming more open to getting vaccines:

He's talking about my health you know, and he's talking about every time that you come in [for a visit]. I used to duck shots, you know different shots, and it's all types of different vaccines... Just being open and listening to him, I think it was...informative. And I was impressed with that.

In relation to self-care, one person said the following about their PCP:

Dr. K keeps me on my toes, very good doctor. Very well respected. Just gotta be mindful of all the things he tells me to do. He keeps me from making bad choices with my health. He's pretty important in my lifestyle. He's a mentor, I'm his, I can't say protégé, I guess he's like a tutor and I'm a disciple of his brilliance, put it that way.

Another person discussed a conversation they had with their PCP and coming to an understanding that drinking alcohol may be considered "normal" by some, but it is not healthy:

He said, 'That's normal, that's norm. What about your health? Well, you know that's tearing your liver up or that you can't drink. Maybe that's the problem, that little

pain you had on the side. You know, have you ever thought about that?'... Boom! That's normal but it wasn't healthy. Wow, the light bulb went off, dang... Everybody I'm associating with, yeah that's normal...but it's not healthy.

In relation to self-care, someone else said, "The more you learn about how to take care of yourself, the better off you are. And there are some things that I don't know. So, I'm hoping to pick up something that will help me continue the path that I'm on, as far as maintaining as good a health as I can." Some even pursued additional learning opportunities by enrolling in VA programs or classes (e.g., class with dietician; groups that address different weekly topics, such as health, anger). Positive outcomes were discussed in relation to learning and taking advice, particularly from providers. One person said they "don't have much of a problem" with their mental illness because they "learned the tools and what to do like breathing, relaxation, problem solving" from nurses and other providers in the Psychosocial Residential Rehabilitation Treatment Program. Another person said they are no longer taking prescription medications for diabetes because their provider taught them how to improve their diet (e.g., "It's totally controlled with my diet.") and another discussed the importance of, "being informed about what will help should [my blood sugar] go low and how to deal with it. Through water and balancing this medication versus the heart and blood pressure medication" In addition, some people noted a connection between taking care of themselves and doing well in other areas of their life (e.g., housing, financial), as "everything is inter-connected." It was said that people who are do not fully understand the importance of maintaining one's health, and are not interested in learning, may not change their behavior (e.g., lifestyle modification). As one person explained, "Maybe a combination of me not showing any interest and not having the full knowledge of the magnitude of the necessity of good health. Maintaining good health."

Coordination and integration of care. Another dimension frequently talked about was coordination and integration of care (n=14). This dimension involved care "across clinical, ancillary, and support services and in the context of receiving 'frontline' care."³⁶

Positive talk focused on the VA helping them to get the varying types of assistance they need in their lives, including health-related (e.g., dental) and non-medical issues (e.g., housing, financial). Most said their PCP was the point person at the center of their care, who refers them to available services and helps to resolve emergent problems in their health and care (Figure 4). For example, one patient had said, "When you go to different providers, you have different opinions about things. And it's nice to have a primary care [provider]... If [the medication] is no



Figure 4. Photograph of and quote about coordination and integration of care

"Health care is like the engine, but you also need the bridge and [to] keep that kind of balance to where that bridge is stable and that engine is able to pass... I feel it's important to be a part of my health care because it makes it easier... When you go to different providers, you have different opinions about things. It's nice to have a primary care provider... They can either stop them or they can call the doctor that's associated with [the medication] and get it tweaked or stopped. In Mississippi, I had a bad experience with it because the psychologist wanted a medication, but they had a nurse practitioner prescribe the medications. When I had an allergic reaction to one of the medications, the nurse practitioner in their wisdom stopped it... The psychologist in their wisdom wanted me to be taking something, they really couldn't see me not taking anything, but what they kept recommending to him was something I couldn't take."

good, [the PCP] can either stop them or they can call the doctor that's associated with it and get it tweaked or stopped." They also said PCPs are in the best position to help patients because they have built a relationship (e.g., "You have a history, you have a rapport with them. He knows you best."). There was also some discussion of care coordination through social workers, case managers, and counselors.

People used a variety of outpatient care (e.g., home health nurse) and inpatient health-related services, including primary and specialty care (e.g., psychiatric care). There was emphasis placed on additional recovery support, such as the Center for Treatment of Addictive Disorders (CTAD) and its Opioid Substitution Therapy Clinic (OSTC) (e.g. motivational meetings), as well as various support groups (e.g., on-site Narcotics Anonymous and Alcoholics Anonymous meetings with all Veteran participants). VA assistance options for homeless and

jobless Veterans were said to be especially helpful, such as the Domiciliary Care for Homeless Veterans (DCHV) program, US Department of Housing and Urban Development-VA Supportive Housing (HUD-VASH) Veterans Recovery Center, and Community Transition Center.

Transportation assistance, such as cost-free VA transportation (e.g., VA shuttle, DAV van) and travel reimbursement, was useful as well. Many said it was beneficial that the VA offered such a wide range of services, many times out of the same location. One person described their experience of going directly from their PCP appointment to the pharmacy in the same VA hospital as, "One spot, one shot treatment... You can all go, one shop, one stop shop. It's under that umbrella thing, everything under one roof." Further, they said the following about the VA:

I look at the umbrella not as an umbrella but overall care... Whether it be out in a clinic, or whatever, but it's all connected to the hospital, comprehensive. Your medical, your prescriptions, anything else you need. For medical aid or emotional aid you get, it's all under one umbrella through the hospital and through the VA for us... It's all encompassed into one.

Some also said it was beneficial that the VA is national, explaining that they were able to continue VA care in a different state when they moved. Others appreciated that they are able to go to another VA facility or non-VA facility if needed. For example, one person said:

VA and [local non-VA hospital] interwork with doctors and care that, if the VA doesn't have something as a specialty or you're really bad, the ambulance will take you to [local non-VA hospital] and they'll take care of you. And, when you get stabilized and everything, they'll bring you to VA and the VA takes care of the bill. Which is great.

Of particular importance was that providers and staff work together and communicate with each other and the patient. For example, one person described their VA care as, "A group of people working together, because you almost need a team in the health profession. And everyone has to work. Like, you have to work with me as much as I have to work with you... To me, it's like a team effort. The patient, the doctors." In regard to care for "chronic conditions" one person said, "You have different doctors at different ways and, of course, different specialties, so they all intermix and, hopefully, they all interwork." This cross-communication was said to help to create a more seamless transition for patients between services, such as coordination of appointments and information sharing. There was some negative talk about what happens when this process breaks down, including care delays and extra effort on the patient's part to solve the problem. As one person shared the following about not being contacted to schedule their endoscopy appointment:

Same day surgery was supposed to call me and they haven't called me. I have to go in and have and endoscopy... They were supposed to get in touch with me and they haven't gotten in touch with me. And what I'm going to do, after I get out of here, is I'm going to go over to same day surgery and see about scheduling.

They were going ask their primary care provider for assistance, but they were not in clinic at that time.

Physical comfort. A somewhat less frequent aspect was physical comfort (n=11). This dimension involved "pain management, help with activities of daily living, and clean and comfortable surroundings." There was positive discussion of pain management for a variety of health

problems, such as gout and a knee problem, using alternatives to narcotics due to provider concern about addiction. For example, one person shared the following about their experience about seeking treatment when unable to walk from gout:

Being I was an addict, they wouldn't give me the real strong [medications]. But I had to stay there for about 2-3 hours. My medication worked, they give you that shot and the pills and it worked.

Another person stated:

I do have a doctor that I do depend on. I had a blownout knee from previous service activities. I have been in several car wrecks and I have had concussions, couple bad scars on my head, and things of that nature. I did need some type of pain medication at one time for my knee, but he was very strong with his way of handling it by not giving me anything that was narcotic-wise, or that's going to get me addicted to narcotic drugs or things of that nature. And telling me to deal with the pain best as I can because he needed me to work out through it. Work through it in order to get a better idea of how much pain I can take and how much pain it's going to give me. At first, I didn't want to listen to him, being that I was in pain. But as it gradually worked out, it did work out for the better because I really didn't need any strong pain pills at the time. I just wanted to get rid of the pain temporarily, not wanting to really deal with

Timely and effective pain management was described as especially important, because the patient is hurting and wants it to stop as soon as possible. As one person said:

If you're hurting or something's wrong with you and you know it, seeing someone about it and getting it taken care of is real important to you. You don't care what anyone else is going through, you got to worry about you. You're just thinking, 'OK, why are they making me wait?'... When you're hurting, not feeling good or whatever, you want to be seeing someone. You don't want to say, 'Hey I got an appointment 2 weeks from now.'

In terms of housing, most talk was positive and focused on the importance of having their own "nice" physical space in a good location that is safe, stable, peaceful, and protects them and their belongings. There was an appreciation of certain freedoms they had in their own space. As one person said, it is somewhere to go, "where I feel like I can be myself. I can relate to my thoughts, relate to my feelings without having to have conscientious concerns with others." Many were happy that the VA helped them to get housing, sometimes with additional financial assistance. For example, one person said, "They

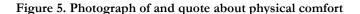
got me a nice apartment... We got the voucher to pick up some more furniture, furnishings for the kitchen, and stuff." Many used VA and Veteran housing assistance, such as the DCHV program and HUD-VASH, as a stepping stones that assists Veterans in improving many aspects of their life, such as their health, meals, job search assistance, and addition recovery (Figure 5). For example, one person discussed his experience with a Veteran's Home, a shelter for the homeless that provides short- and long-term shelter, permanent housing support, and other services (e.g., employment assistance, life skills training):

I never asked anyone for anything. Until recently, I needed that assistance. I realized you know I'm losing more ground than I'm gaining here, and I asked this facility. It's for Veterans, to give me that assistance. It's a homeless Veteran type of thing, also people that have addictions. And what this facility does is, it gives you some place to stay, a place to eat, a place to go to sleep at night, you know you're not out on the streets or something like that, and it has implementations of teaching you about your addiction... You are or may be homeless, and it also has opportunities. It helps you to get yourself back into society, helping you find a job.

They make sure that you take care of your health there, 'cause it is affiliated with the VA. It's a place for Veterans transitioning to a regular housing and stuff like that and they also make sure you maintain your health and everything. They watch out for you, plus it gives you a safe secure place for your stuff and for you to be able to relax. And they feed you. They always have lunchmeat or something in the refrigerator and then one cooked meal every day.

Also, another person said the following about living in a Veteran's Center and how it fosters active engagement in self-management:

I am cooking with myself, I am in my own space, and definitely a plus zone... as far as self-management goes. Stable environment, open environment where I am free to be myself, free to cook what I want, to cook according to my taste and ingredients... I'm there because I'm basically homeless. My addiction and the way I was living my life was very detrimental to all the things in my life and me and my ex-girlfriend had a trailer that we ended up losing... It's kind of like a shelter.





[&]quot;That's a picture of the sign out front of the Veteran's Center where I live now, where I'm staying. My thinking was that take a picture of something that pertains to the road you're taking to make yourself better... I have a roof over my head, meals, I don't have to worry about taking my meds because they give them to me."

Negative talk of housing focused on problems with unsanitary conditions, as well as and problems with other occupants in group settings. For example, one person said the following about a place where they stayed:

They put me, to clean the restrooms on the chore list... I go to the chemical closet to get the mop bucket out and there's no chemicals in there. So I walked into the office and I said, 'There's no chemicals in there at all, I mean there was nothing in there.' And they were like, 'Oh, just wipe it down with some water.' And I said, 'Excuse me?' I said, 'I... inspected the showers and there's black mold... Black mold is deadly. I said, 'You have homeless Veterans here that have all different kinds of health problems.

They said the following about another place where they stayed:

When I was there I was productive. A lot of those guys just lay in their rooms and sleep all day and not work on getting out of there. It's like a free motel. So, you know, when a lot of those guys would come down on me, I'd just let them have it with both barrels.

Transition and continuity. Less commonly mentioned was transition and continuity (n=10). This dimension involved "information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transitions."³⁶ Talk of transition and continuity was largely positive, with discussions of various inpatient/outpatient medical services, as well as non-medical assistance and programs (Figure 6). For example,

Figure 6. Photograph of and quote about transition and continuity



"I utilize [VA] programs. I was in the CTAD. I was in the domiciliary program, not only here but the one in Aspinwall. I was in the VA in Coatesville and I was in VA in Lebanon... I've been out here in Western Pennsylvania since '09, I came out here in '09 after completing a 6-month program in Lebanon, PA. After in 2000 going through Coatesville I would get out and disregard my health things like that. I kept refocusing on some help I was getting and, it makes you think. And you start [thinking], 'Why it would be nice to take full the plunge and decide to get healthy, mentally, physically, spiritually, socially, and also financial?' All the benefits that the VA has and, as a Veteran, utilizing my benefits. So, I been dealing with them, going through the VA system since about 2000."

one person who said they have been sober for a little over a year shared the following about CTAD and DCHV:

I went through a CTAD program... That's, that's a mental health and CTAD drug and alcohol abuse program they have over there. It's one of the best in the nation... I came to learn about this program, basically by accident. And I took advantage of it. And it tremendously helped me, to the max. I came in the program because I was about to be homeless. I needed some help with my drug and alcohol problem. I accompanied and went to the outpatient programs, and then I got into the in-house program.... I went to [an inpatient unit | first... I was coming off a binge. When I checked myself in, I was under the influence... Then you have the option of going home, or going to a shelter, or going to an extended program, which is [DCHV]... By that time, I had a clear enough head to know what I really wanted to do. I had a clear enough head to know that I didn't want to go back to alcohol and drugs.

Some focused on the resources provided during the transition from inpatient to outpatient, such as information, added providers and staff, and home-based treatment to keep them healthy. As one person succinctly stated, "You have everything you need when you leave... They want to get you out of here healthy and you have to understand that." More specifically, one person said they were given self-care exercises when discharged, which they described as, "Things that I need to do to keep a healthy body." Another person said they have a "machine the VA gave me for my psoriasis" that they use three times a week for home-based treatment. Providers and staff such as VA case manager, a dietician, a social worker, and a home health nurse were also provided during the transition from inpatient to outpatient. PCPs were also discussed as helpful after discharge from inpatient to outpatient care, giving patients added information to help them stay healthy. As one person stated about their PCP:

The things he tells me to do, he keeps me from making bad choices with my health. He's pretty important in my lifestyle. I was in the hospital for 30 days so he didn't know where I was at. I contacted him when I got out and um, now we're back at it. He's a good guy. It's helping me out what I'm learning about my obstacles and what I gotta do to stay healthy.

MY HealtheVet was also discussed as a useful resource to manage their prescriptions and other care. There was also negative talk of transition and continuity focusing on problems and delays with inpatient care discharge, such as problems with medications and bureaucracy that tests one's patience. There was also discussion of delays in transitioning from inpatient to outpatient services, requiring extra effort on the patient's part to expedite the process:

I chose to go over to [DCHV]. They had to put me on the waiting list. Now this is how determined I was. I was on the waiting list for about 4 or 5 days. During that time...I came back up [to the VA], to do outpatient classes, letting them know I was serious about my sobriety... Once they saw that, they initiated me to be put on the waiting list, and I got in to [the DCHV], which was housing, food, shelter, clothing. All the necessities... During that time, it was in the winter time. So, this is during the time we had a bad winter... The winter last year was really, really terrible. So I was really blessed, and took full advantage of it.

Emotional support and alleviation of fear and anxiety. Less emphasis was put on emotional support and alleviation of fear and anxiety (n=5). This dimension involved "such issues as clinical status, prognosis, and the impact of illness on patients, their families and their finances."36 Discussions of patient needs (in the patient-provider relationship) were largely positive and focused on supportive providers that show they are concerned and care about the patients by providing mental comfort, support, and guidance about their health and health care, such as when giving a patient "bad news" (Figure 7). For example, one person said that "this whole team of nurses" consoled them after positive HIV test results. Another person discussed a stuffed bear they received from providers as a symbol of caring about their health and well-being:

The bear is like a health aid. They gave me the bear, and the bear is like it lets you know there's somebody out there thinking about you... As long as I keep the bear with me, and the bear is considered in a safe place, then it mirrors that I am in a safe place... It's an effective tool because the VA passes them out... They let you know there's somebody out there that cares about your health, that cares whether or not you are in a safe place.

Providers showing concern for the patient was also said to help them feel understood.

Negative talk of patient needs focused on lack of healthrelated information provision during visits. This was viewed as a lack of provider support, which led patients to care less about their health and not pursue recommended treatments. For example, one person said a provider did not share pertinent information from their medical chart during their visit, which would have helped them to understand why they needed a shot:

There's a lack of information, which shows me a lack of interest. You wouldn't tell me that I should [care about my health], especially if I had a non-caring attitude... But you didn't make me care either. You didn't tell me why I should care. I didn't have enough information. I feel I didn't need that. I don't need no shots.



Figure 7. Photograph of and quote about emotional support and alleviation of fear and anxiety

"A doctor will stand sturdy and strong and hold up to you, tell you the truth if you want to hear it or not. The reinforcement of this wall, which is also part of that bridge that's even a sturdier, these sort of pillars that are holding it up here... This wall is the foundation making sure everything holds together, such as you holding yourself together. Your doctor is making sure you hold it together whenever he gives you the good news or bad news... So, it's kind of like a mutual-relationship then... The wall is there to let you know that sometimes you might break down and crumble, but you can also stay sturdy and stay strong. They might get some bad news about their health and they may crumble a little bit, but they can still stand strong and bear through it and deal with the situation and move on, not fold up, or crumble up, and just go to dust."

Involvement of family and friends. An infrequent aspect of patient-centered care was involvement of family and friends (n=1). This dimension involved "decision making and awareness and accommodation of their needs as caregivers." They positively discussed their spouse's (i.e., wife) central role in their self-care management, such as diet and home health tests (e.g., blood sugar, temperature, blood pressure) (Figure 8).

Iterative Dimensions of Patient-Centered Care

Quality care. A frequently highlighted dimension of patientcentered care that emerged through iterative analysis was quality care (n=16). Many participants remarked on how they felt about the quality of care they were receiving from the VA and it was evident that receiving "quality care" was important to them. This dimension focused on the patient-provider relationship and VA services, as well as affordable or cost-free care.

Quality care positively focused on "having good doctors in the health system" who "do a good job." One person succinctly noted they receive good quality health care, "basically all the time. I don't have any complaints about [my PCP]." Providers were described as accessible, dependable, caring, respectful providers who trust and understand their patients. They were also dependable, helped patients maintain their health, and met their care



Figure 8. Photograph of and quote about involvement of family and friends

"Too much knowledge is dangerous. Because you get in the habit of being too healthy. And checking your fever, and checking your blood sugar, and your temperature every single day, your blood pressure every single day. And just going through all that give-and-take of taking care of yourself, not taking care of yourself. So, I gave it to my wife and let he be in charge. So, if she says. 'OK, it's time to take it now,' OK, I'll take it now. So, then she'll look at me like, 'I know what you're thinking. Nope, can't [eat that].'"

needs (Figure 9). For example, one person described their mental health provider visits as follows:

I can tell by her body language, and what she has to say, what she's worried about and things that I may have to fix. She always shakes my hand when I see her, and shakes my hand after the doctor's appointment. She had told me the last doctor's appointment we had that she trusts me. And she told me to make sure I get better and fix the problems that I'm having now. And by her smile, and by her helping me change my medications to where I want them to be. I was on Thorazine and I was sleeping from 11:00 'til 11:00. And now I'm tapering off the Thorazine and I go to bed at 10:30, 11:00, and sometimes I'm up at 8, 9:00. So changing the medication has given me a lot more energy than what I was on before.

Providers were also said to be knowledgeable about relevant topics, share truthful information with patients, and educate patients (e.g., "A doctor that can explain to me by my blood work, how I'm progressing. If things are getting better, or if they're getting worse, if they see some conditions coming up."). They also provided accurate diagnoses, as well as appropriate testing (e.g., colonoscopy, blood tests) and treatments (e.g., medication to treat high

blood pressure), and made appropriate referrals to other departments and clinics (e.g., oncology). Providers also helped patients meet their care goals, including achieving desired short- and long- term goals and outcomes for their health, such as sobriety. For example, one person said that good quality health care means:

A good doctor and good nurse, nurse aide. They've taken me this far. He's been taking care of me. About four of five years ago I was kind of in bad shape. I had that stroke. I told you, it was put on by drugs [alcohol and crack addiction]. Yeah, they took care of me. I told him, 'I want to know what's wrong with me. And I want to live.' Yeah, they take care of me. I have good [VA] doctor.

Quality care also positively focused on the VA system, including departments and clinics. For example, one person succinctly said, "I think the VA gives the best care... I think the VA is the best health care for me." Another person said, "I'm not dissatisfied with the quality of the health care I'm receiving right now at all." Someone else said, "The care I get [in primary care] is good, it's excellent." More specifically, the VA was described as a place that treats Veterans with respect. Patients could also relate to providers and other patients and because of their

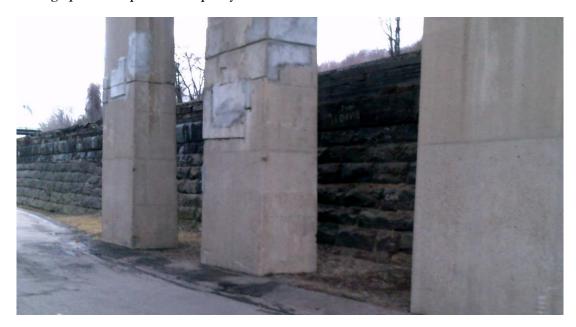


Figure 9. Photograph of and quote about quality care

"Good quality health care to me is having something that you really can depend on, as far as going to your doctors... You want to go to someone who is going to be able to help you and satisfy the needs that you have with your health care. Someone that you can depend on when you are having problems, where if they can't help you they'll try to get some way or somehow, someone who can help you. [This] picture, it's a bridge and these are the pillars that are holding up the bridge as it's standing as something strong, something sturdy that will hold up. As so, such as a doctor will stand sturdy and strong and hold up to you, tell you the truth if you want to hear it or not."

common military service, which makes them feel comfortable and secure. The VA also provides access to a variety of available VA services, including medical and non-medical assistance (e.g., housing, financial). As one person succinctly stated, "When I first started to engage in [my] health... I was homeless... A turning point was VA care, having access." VA services were said to help a patient with, "the road you're taking to make yourself better." Examples focused on medical procedures and tests (e.g., blood work, colonoscopy), as well as treatments (e.g., surgery, prescribed medications, devices [pacemaker]). As one person said, "Good quality? I guess I'm getting the best medicines I can get. The one doctor tells me, he said, 'Well, the medicine you're getting is, they consider it the Cadillac line.'." One person shared the following about DCHV:

I was drinking pretty hard, so I had that problem... I come across...the Domiciliary [at the VA] and it helps you get back on your feet. It helps you get through your sobriety, if you have mental issues or if you're homeless. And your health, they make sure that they take care of your health.

Some said that VA services helped them gain perspective and make a decision about what they want in life. For

example, a person shared the following about their experience with the CTAD:

It's an excellent program. That really helped me get myself back on track, gave me little bit more perspective about life, what I want out of life. If I want to go back to drugs and alcohol and waste my life away, or do I want to get my life together, get back on the right track, and go the right path. That was the opportunity that was thrust upon me and I think I took the right path, I took advantage of it.

Others described the VA as a "good support system" that provides "productive" and "fruitful" care. The VA was said to help patients achieve desired changes to better their lives in many different areas; this was said to be particularly important for those who are homeless and have substance use disorders. Some specified that the VA played a large role in helping them to achieve their short-and long- term goals, such as sobriety, stable housing and meals, employment, and not being incarcerated. For example, someone shared the following about CTAD and its OSTC:

This is CTAD. That's where the program for drug abuse is. OSTC is methadone maintenance. I belong to that. I

didn't have a life. I was a drug addict for 40 years. 40 years. And this hospital here has saved my life, changed my life... I come up here 3 days a week...for my methadone. And I go to the [motivational] meetings... I attend them 3 times a week too. I have been clean for 8 years. All through this VA hospital and these program that they have here.

Another person shared the following:

A few years ago, I was incarcerated and spent 4 years in the federal penitentiary. So, through the VA's help, I was able to go through the training program and it uplifted me... It changed my life too. First of all I don't want to go back to prison. They showed that there is some help for us Veterans, health-wise, even in trying to find you a place. That's one of the things. My housing was because of the Veterans Association, so everything that the VA represents has been a quality experience for me.

Positive talk of quality care also focused on affordable or cost-free VA care, such as reasonable or non-existent appointment copays (e.g., "Good service for an affordable price."). There was talk of not being able to afford care if they did not have VA coverage. For example, one person shared the following:

Without the VA right now, my health care would be terrible. I was in a car accident. Without it, I would have been in a whole lot extra cost that I wouldn't be able to afford it. So, this has been an enabler but a definite plus in my life as far as where my health has gone.

Another person explained their experience before getting VA care:

I had a job that gave me medical care... But, then I lost...my job and, with that, the health care that goes along with that job.... I didn't think about the VA because I had been out of the military since 1992. I wasn't getting medication that I should be taking, like high blood pressure medication and stuff like that, because I couldn't afford it. I had to choose between this and that, and [medication] lost.

Some also noted cost-free entertainment, social events, and food provided by the VA, such local trips. As one person said:

Hero's Hall, where they have the TV and give you coffee and they have the pool table, old movies. There's a lady there who comes around once a month, sometimes twice a month, and takes us to different places to eat, like the American Legions.... We go to different places and we eat and play Bingo and win different things.... Hoodies, one is for the Wounded

Warriors program. I got a lot of stuff for Vietnam, MIA/POW. And they give you a lot of stuff [at Hero's Hall]. Like, they have a lot of these little tiny things of lotions, oils, and soaps and stuff. They have a big box of them, you just take whatever you want. They give you shirts and everything, clothes.

Being present with patient. Emphasis on being present with the patient included time allotted during appointments and provider interest in the patient (n=6) (Figure 10). Time allotted during appointments meant not feeling the visit was rushed and having one-on-one patient-provider time. Provider interest in the patient meant "custom care" by engaging and listening to the patient, such as taking a thorough history and showing concern. Being present with patient also meant getting to know the patient in a comfortable atmosphere, such as not staring at the patient's chart through the encounter. Participants who discussed this dimension showed a genuine appreciation for health care providers who exemplified this trait.

Suggestions for Improvement of Care

Suggestions for improving care focused on the patientprovider relationship, VA services, and transportation (n=9). Suggestions about the patient-provider relationship emphasized the importance of shared decision making (e.g., collaboration and communication of information) and interpersonal skills (e.g., not rushing, having dedicated one-on-one patient-provider time, showing interest in the patient, communicating positively, seeing patients as having individual needs). Suggestions about VA services included aiding patients in navigation of the system (e.g., add patient liaison, VA reaching out to potential patients to inform them of available services, adding services (e.g., for combat Veterans, posttraumatic stress disorder [PTSD], homelessness), more group therapies, greater support for patients who use complementary and alternative medicine (CAM) (e.g., homeopathic remedies) or educate patients on why standard medical care is needed (e.g., prescription medications/treatments), and having flexible/additional hours of operation (e.g., weekday evening, weekend). Transportation suggestions focused on cost assistance (e.g., half-fare or cost-free bus passes).

Discussion

The Institute of Medicine considers patient-centered care a key area of quality improvement.^{37,38} In recent years, there have been several US initiatives focused on advancing patient-centered primary care for those who are homeless.^{39,40} The VA set a goal of high-quality health care that engages patients, is personalized, and improves the experience of Veterans.⁴¹ More specifically, the VHA used patient-centered medical home principles as the basis for PACTs.⁴² One of the nine principles that establish the foundation of HPACT care for Veterans is patient-



Figure 10. Photograph of and quote about being present with patient

"When I sat down with Dr. P and she went through my whole medical history in detail, nobody had ever asked me such in depth questions. She [said], 'From birth until today, we're going to cover everything that's wrong'. She even covered my, the family history, which made me think... I called my cousin, 'cause I had mentioned my cousin who has colorectal cancer... He was like, 'Yeah, you need to get [testing] done too because another cousin had it.' He's a first cousin and we're directly boy cousins. It's genetic. So, that helped in the health care, opening my eyes to a lot of things."

centered care.⁴³ Although patient-centered care has become central to discussions of quality, there remains a lack of consensus on what constitutes patient-centered care and the operational definition continues to change.^{44,45} A suggested solution has been that patients, as well as their families, health care providers, and health systems, be involved in determining "what counts as patient-centered care and how it should be accomplished" through surveys, patient assessments, and direct observation.⁴⁴

Using photo-elicitation methods, our qualitative analysis aimed to describe HPACT Veterans' experiences with patient-centered care. Our analysis of 31 audio-recorded interviews from 19 participants showed that homeless and marginally housed Veteran discussions of patient-centered care focused on The Picker Institute's Eight Principles of Patient-Centered Care: 1) access to care, 2) respect for patient-centered values, preference and expressed needs, 3)

information, communication, and education, and 4) coordination and integration of care were most commonly discussed, followed by 5) physical comfort, 6) transition and continuity, 7) emotional support and alleviation of fear and anxiety, and 8) involvement of family and friends. Further iterative analysis of the data identified quality care and being present with patient as central to patient-centered care; being present with the patient is also part of Planetree's patient-centered care model.³⁸ Suggestions for improvement focused on the patient-provider relationship, VA services, and transportation.

HPACTs may be an ideal primary care model for homeless Veterans who have been shown to experience a myriad of complex and prevalent barriers to health care (e.g., lack of transportation and social isolation/lack of support). 3,46,47 Homeless Veterans require a "coordinated effort that provides secure housing, nutritional meals, basic physical health care, substance abuse care and aftercare, mental

health counseling, personal development and empowerment" as well as "job assessment, training and placement assistance."49 The essential elements of the PACT are 1) Veteran-centric, 2) comprehensive teambased care where tasks and relationships are defined, and providers work at the top of their competency, 3) access to providers, 4) care management that includes seamless integration with specialty care, 5) improved coordination of all care transitions, 6) technology improvements, and 7) delivering health care in addition to "disease" care. 1-5,9 Like other patient-centered "medical home" initiatives, including those in homeless settings,49 the VA PACT model is designed to be a patient-driven, team-based, efficient, comprehensive, continuous, and coordinated, with excellent communication between the primary care team and the Veteran. 1-5,9 A PACT teamlet provides this patient-centric care. The teamlet consists of the Veteran patient along with the necessary clinical and administrative staff to promote the wellbeing of the Veteran. The PACT can be described as two parts: the core team and the expanded team. The core team of the Veteran patient, his/her provider (typically a physician, physician-assistant, or nurse practitioner), nurse care manager, clinical staff assistant, and administrative/clerical staff member are responsible for the Veteran's health care. Expanded team members (e.g., social work, mental health liaisons, pharmacists) are onsite seeing patients episodically, while consultants may work remotely from the core team. In the PACT, if a Veteran has a mental health or alcohol and other drug dependence health care need that PACT members cannot address, the teamlet would coordinate this care with one or more of the expanded team and/or coordinate with the Primary Care-Mental Health Integration integrated behavioral health care manager. Thus, both Primary Care-Mental Health Integration and PACT implementation should improve the access to and quality of mental health and alcohol and other drug dependence treatment within PACTs and improve collaborative care and referral to treatment processes.

In the past, patient-centered care typically centered on the patient-provider relationship.³⁹ More recently there have been varied conceptualizations of patient-centered care that include a broader set of attributes. Our study results are consistent with existing patient-centered care models (e.g., The Picker Institute, Planetree) that support multidimensional conceptualizations of patient-centered care. We found a multidimensional conceptualization of patient-centered care that included clinical, structural, and interpersonal factors. Clinical factors identified in our study included 1) respect for patient-centered values, preference and expressed needs, 2) transition and continuity, and 3) physical comfort. Structural factors identified in our study included 1) coordination and integration of care, 2) access to care and 3) quality care. Interpersonal factors identified in our study included 1) information, communication, and education, 2) emotional support and alleviation of fear and anxiety, 3) involvement of family and friends, and 4) being present with patient. It is likely that certain interpersonal factors (i.e., emotional support and alleviation of fear and anxiety; involvement of family and friends; being present with patient) were least discussed because homeless patients, including Veterans, often lack family and social support (e.g., social isolation), as well as social functioning.^{50,51} Further, the suggested care improvements from our study dovetail with previously identified barriers to care related to homelessness, such as transportation and support needs.^{3,46,47}

Our results are also consistent with existing research that supports multidimensional conceptualizations of patientcentered care. A scoping review of patient-centered health care found that approaches had three core elements, including "communication, partnership, and health promotion."52 A conceptual and empirical literature review found five conceptual dimensions, including "biopsychosocial perspective; 'patient-as-person'; sharing power and responsibility; therapeutic alliance; and 'doctoras-person"'.53 VA specific research has also shown multidimensional patient-centered care conceptualizations. For example, a qualitative study of patients from Veteran and non-Veteran-focused homeless health care programs found that accessibility, evidence-based care, coordination, and cooperation were priority areas for homeless patients.³⁸ A photovoice study of Veterans found different contextual factors to patient-centered care, including, "patient-provider communication and relationships, physical and social environments of care, and accessibility of care."11 Another photovoice study of racially diverse women Veterans of satisfaction with VA care "along dimensions in line with PACT priorities" found a focus on access to care in a timely manner, provider communication, and care coordination.⁵⁴ VA health care employees in a photovoice study also discussed their role in patient-centered care, with system and employee attributes seen as essential to a patient-centered care environment.55

Limitations

Our study has certain limitations. Generalizability is limited due to a non-probability sampling technique and somewhat small and homogeneous sample (e.g., gender, race, single VA site). We aimed to describe HPACT Veterans' experiences with patient-centered care, not generalize, so our results may best describe the experiences of more stable homeless and marginally housed Veterans (particularly due to our use of a somewhat broader definition of homeless individuals and a focus on HPACT users). ^{23,34,56}

Conclusions

Photo-elicitation may be a useful tool to study and understand patient-centered care from the perspective of participants in care. Photovoice has been shown to be effective in engaging marginalized groups (e.g., those who are homeless) in research.^{57,58} Our exit survey showed that, overall, participants had positive, favorable experiences with few drawbacks; they appreciated photography, as well as their interview experiences and connection with study staff.²⁸ In terms of participation barriers, the most common were issues with transportation, photography, and abstract study concepts.²⁸ Many participants also experienced unexpected or intense emotions.²⁸ Future photovoice studies with homeless individuals should prepare for participant emotionality and address the aforementioned barriers.

Patient-centered care is particularly important because it has been linked to improved patient-provider relationships (e.g., communication), processes of care (e.g., continuity and integration of care, efficiency of care), and outcomes (e.g., patient and health care provider satisfaction with care, improved patient health status and survival). 39,45,59 Our study identified key areas of patient-centered care for HPACT patients, as well as suggestions for improvement. Our results suggest that homeless and marginally housed Veterans require multidimensional support, as well as added assistance with particular interpersonal care factors, VA services, and transportation. Future studies with a larger, more diverse sample of patients as well as their families, health care providers, and health systems are needed to further understand preferences, needs, and values to ensure care is being delivered in accordance with patient-centered initiatives. 37-39

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