

Barriers and Facilitators to Care for Transgender Patients Experiencing Low Socioeconomic Status and Homelessness

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Abstract:

Purpose: Discrimination and disparity including increased rates of poverty, homelessness, and lack of access to healthcare, are well-documented in the transgender community. Despite high prevalence of low socioeconomic status (SES), limited health research focuses on this subset of the trans patient population. This study seeks to explore barriers and facilitators to care specific to low SES and homeless trans patients.

Methods: Using a semistructured interview format, transgender patients ($n=5$) were asked about their experiences accessing care at an urban federally qualified health center. Using a directed content data analysis methodology, interview transcripts were coded using preidentified category labels and novel themes were also identified and coded.

Results: Emerging barriers to care include lack of primary care and post-operative care, miscommunication within the care team, misinformation of Medicaid benefits, referrals to non-affirming healthcare environments, and lack of trans community building. Emerging facilitators include intentional patient panel assignment, a feeling of “moving forward” in transition, and access to health insurance and coverage for transition related care.

Conclusion: These interviews elucidate the unique clinical experiences of homeless and low SES transgender patients and offer insight for systems-level process modifications that could improve patient experience of healthcare and care coordination.

Keywords: transgender healthcare; barriers and facilitators to care; homelessness; qualitative inquiry

Introduction

Transgender (trans) people are subject to significant health disparities and forms of discrimination. The most recent U.S. Transgender Survey conducted in 2015 reveals significant rates of unemployment, poverty, and homelessness amongst this population.¹ Discrimination is strikingly present in the healthcare setting, and a third of 27,715 respondents report negative healthcare experiences and nearly a quarter report postponing necessary medical care.¹ In response to the initial Trans Health Survey in 2011, myriad reputable healthcare organizations declared improving transgender health a priority.²⁻⁷ However, discrimination, avoidance of care, and inconsistent identification of trans patients pose challenges to understanding the needs of transgender patients and how to engage them in care.⁸⁻¹³

Research that enhances understanding of barriers and facilitators to care has the potential to impact health disparities amongst the trans community. Much of the literature discussing trans healthcare experiences is comprised of studies with relatively privileged study samples despite high rates of low socioeconomic status and homelessness amongst transgender people.^{8,9} In several recently published articles, a limitation is the overrepresentation of racially or economically privileged participants.^{8,9,11-15} There is a gap in understanding of the unique needs of lower SES, non-white, and homeless trans patients.

Background

There is a burgeoning collection of research that identifies commonly encountered barriers to care for transgender patients in the U.S. Trans health studies are heterogeneous in format and design, and there is no consistent way of identifying trans patients in the clinical setting, posing challenges for researchers.¹⁶⁻¹⁹ Select barriers that prevent trans patients from approaching the healthcare setting include: lack of health insurance, inability to afford care, privacy concerns, and

lack of trust of healthcare providers.^{1, 8-11, 20, 21} Other barriers that compromise the integrity and quality of healthcare include: discrimination by staff/refusal of care, patient reluctance to disclose gender identity, paucity of knowledgeable healthcare providers, binary medical record systems/clinic use of inaccurate name and gender, and physical environment barriers.^{3,10,15,19,22,24,25}

Leading organizations and researchers in trans health offer insight on potential facilitators to care for trans patients. Facilitators are identified through exploratory and descriptive studies and on-going research by entities including the World Professional Association for Transgender Health, University of California, San Francisco Center of Excellence for Transgender Health, and Fenway Health Center.^{3,7,22-31} Facilitating practices are thought to create a *positive space* for trans patients, a space that is equitable and accessible to persons of all sexual and gender diversities.²⁹ Systems-level facilitators include training staff on best practices in working with trans patients and educating medical providers on transition-related care,^{10,29-31} integrating sexual orientation and gender identity information into electronic medical records,²⁵⁻²⁸ increasing trans visibility within the organizational culture,^{7,29,20} and altering the physical environment to be more accessible to trans patients.^{3,22,30} Micro-level facilitators include patient independence, persistence, and having a “do-it-yourself” approach to transition.¹⁴ The aim of this study is to raise the voice of low SES, non-white, and homeless trans patients within the healthcare literature and illuminate the barriers and facilitators to care for this unique subset of trans patients.

Methods

Study setting

Old Town Clinic (OTC) is a federally qualified health center (FQHC) in Portland, Oregon housed within a non-profit organization, Central City Concern (CCC), that delivers integrated health and social services. Services offered by CCC include housing, employment, education, and health services including inpatient and outpatient addiction services. OTC serves approximately five thousand patients per year, of whom forty-four were identified as transgender using a variety of ICD-10 codes and chart review. According to OTC's associate medical director, this is likely an underestimate (E. Rieke, April, 2016). OTC is committed to becoming a "trans-affirming organization" and utilizing patient engagement to inform improvements in its processes and service delivery.

Study population

We interviewed $n=5$ patients who self-identified as transgender, were currently receiving care at OTC, and were over eighteen years of age. Patients were initially recruited by fliers posted in the OTC lobbies and exam rooms. Subsequent patients were recruited by initial interviewees and OTC staff using snowball and convenience sampling methodologies. Patients were screened to confirm inclusion criteria via telephone by the interviewer prior to scheduling the interview. Ten eligible patients were recruited over a three-month time-period and five were lost due to scheduling difficulties, inclement weather, or declined to participate.

Interviews

In-person and phone interviews were conducted to illuminate the barriers and facilitators to care for this subset of transgender patients and how practices can be modified to improve services.

We utilized a qualitative descriptive design to explore patient experiences in the clinic environment. This qualitative inquiry is timely as OTC is amid a multifaceted quality improvement initiative to become a more trans-inclusive and affirming clinic. The interview

guide was developed using a collaborative approach including input and feedback from the clinic community (patients and staff) and refined by local trans health researchers. Interviews followed a semistructured script with open-ended questions and specific follow-up probes based on the national and international trans healthcare literature (Table 1).

Interviews lasted ~20-60 minutes with an introduction including the purpose and procedures of the interviews and time for participants to ask questions before giving informed verbal consent. The Oregon Health & Science University Institutional Review Board approved the project. Interviews followed a format of (1) collection of de-identified demographic information (2) semistructured, open-ended questions with specific follow-up probes, (3) summarization of answers by interviewer to confirm understanding of patient responses, and (5) optional feedback form about the interview process. The questions addressed three domains: (1) description of trans healthcare experiences at OTC, (2) key components of positive patient experiences and affirming clinical interactions, and (3) opportunities for improvement in OTC practices and environment. All patients were offered the opportunity to be contacted with the results of the study and consented to secure storage of contact information until completion of the project. Interviews were digitally audio recorded and transcribed verbatim to ensure that all details were accurately recorded.

Data analysis

Interview data were analyzed using a directed content analysis approach.³² All transcripts were carefully reviewed. Text that described a barrier or facilitator was highlighted. Next, all highlighted text was coded using a preidentified category based on the current literature (Table 2). Text that could not be coded into one of these categories was later analyzed to determine if it

represented a new category. If it represented a new category or subcategory of an existing code it was coded with a new label that captured the nature of the barrier or facilitator.

Results

Sociodemographic characteristics

Among the participants 40% identified as women, 20% as a woman and transgender, 20% as non-binary, and 20% as male. The average age was ~43 years (range 29-54) and the majority (60%) were multi-racial or African American. Ninety percent of participants obtained a high school education, were unemployed, and had an annual income of less than \$10,000. Sixty percent reported experiencing homelessness although based on the clinic setting this percentage is likely higher. One hundred percent of participants were receiving hormone therapy and 60% had received gender affirming surgery, 20% were interested and 20% were uninterested in pursuing surgical transition.

Barriers to care

The interviews revealed a broad range of barriers to care for transgender patients, some of which were not previously identified in the literature. Participant-reported barriers to care that are consistent with existing literature include paucity of knowledgeable mental health providers and concerns regarding the physical clinical environment (e.g. bathroom signage). Emerging barriers to care include inconsistent or lack of primary care and post-operative care, miscommunication within the care team, being uninformed of Medicaid coverage benefits, referrals to non-affirming healthcare environments, and lack of trans community building.

Lack of primary care and post-operative care. Participants expressed a need for information regarding preventive primary care/health maintenance and post-operative care for gender affirming surgery, particularly genital surgery. In the context of dysphoria, participants

expressed a desire for more information about their anatomy and physiology including menopause and fluctuation of hormones across the lifespan. Participants described the need for healthcare providers in promoting primary care health maintenance activities including routine cancer screening (e.g. pap smears). For example, one participant shared:

I think it's important that the clinic encourage us to do things for our bodies that are necessary... We're trying to run from our bodies, from the dysphoric parts, and be who we are and live as certain people and then neglect the natural parts... it's very difficult when we don't have someone saying, 'hey ____, you haven't had a pelvic in ten years.'

Similarly, another participant stated:

You might have some issues with your body that you're afraid to look at or have somebody look at because you're uncomfortable or ashamed but your doctor should be welcoming and gentle about these things.

Participants desired increased guidance during the post-operative period. According to one participant:

For trans females it's one thing to want a vagina all your life and it's another thing to have one and not know what to do with it. There aren't a lot of doctors right now who can tell you that... like cleaning your body and keeping it free from infections... [with] Medicaid dropping their ban, more and more people are having surgeries which means more and more trans women will need to know what to do with their bodies after they have surgery.

Miscommunication within the care team. Many primary care clinics offer integrated mental health care, as is the case at OTC. Such integrated care has the potential to facilitate progress in gender transition care, however participants described situations in which their primary care providers (PCPs) were unaware of the patient's level of involvement with mental health providers. Lack of care coordination amongst the team members led to postponement of medical and surgical treatments. Participants also noted a lack of trans knowledgeable mental health providers on the care team.

Misinformation of Medicaid benefits. In Oregon, medical and surgical therapies for gender transition are covered by state Medicaid. While this benefit had been in effect for two years at the time of this study, participants expressed lack of understanding of the Medicaid benefit and navigating the processes for coverage. Three participant responses illuminate this lack of

understanding: “I can’t get my electrolysis covered because I haven’t had the surgery, and I need electrolysis to get the surgery.”

My counselor and I had been working together for several months for a letter, my understanding was that you needed one, and then she (PCP) was talking about needing two! People have different ideas and the knowledge of what it fully takes [to get surgery].

For the safety of my body I was given an ultrasound and I was told the government wasn’t going to pay for it because my gender didn't match my genitalia...it’s hard not having someone say, ‘did you know that the state is now paying for this?’

Participant responses demonstrate confusion regarding Medicaid coverage and processes to access primary care and surgical therapies and lack of consensus amongst their care team.

Referrals to non-affirming healthcare environments. Although the participants expressed many positive attributes of the care they received at OTC, participants described instances of being referred for specialty care or procedures/imaging and the outside healthcare environments were not affirming. One participant stated:

I’ve been sent out for x-rays, cat scans, and MRIs. The place that’s closest to me, I have issues with them. They are not very respectful of my gender identity, I correct them every time I go in there. Next time I get x-rays ordered I’m going to request a different place.

Lack of trans community building. Participants identified gaps in opportunities for building trans community in the clinic setting. Examples to enhance trans community identified by participants include support groups that are available on a drop-in basis, groups that include psycho and health education, peer support programs, and trans affirming activities and events. With inconsistent access to cellular phones and internet/social media, participants expressed a need for alternate ways of disseminating information about groups and community events.

Emerging facilitators to care

The interviews also revealed several facilitators to care for transgender patients, some already represented in the literature and others that are emergent. Known facilitators expressed by participants include trans-competent and affirming staff, affirming information collection

processes and integration into the electronic health record, patient agency and patient-provider collaboration. Novel facilitators involve intentional patient panel assignment, a feeling of “moving forward” in transition, and having health insurance.

Intentional patient panel assignment. Patients expressed satisfaction with the attitudes, language, and approach of their primary care providers. They describe valuing a spirit of collaboration and recognition of their knowledge and agency:

I'm always with the best doctors who know about trans stuff, they're very particular about who I see...they're usually willing to educate themselves and find out information. My doctor might not know all the answers but she's very particular about her speech and what she can tell you.

People are educated and still wanting to learn, we're able to do that together...It's nice to be given some credit for what I do know about my own self.

A feeling of “moving forward” in transition. On multiple occasions participants concluded their remarks with “at least things are moving forward,” and “I feel like I'm moving forward.” This sentiment often followed a participant's description of experiencing a barrier/interruption in their gender transition journey. Working with a provider to keep the process going facilitated continued engagement and hopefulness in transition-related care.

Access to health insurance and coverage for transition related care. One hundred percent of the participants were low-income and had access to gender-affirming hormone therapy. As determined by follow-up questions, every person in this project had coverage for gender dysphoria treatment offered by the Oregon Health Plan (Medicaid), greatly increasing the affordability and access to care.

Discussion

Many of the barriers and facilitators to care reported by the interviewees were consistent with those represented in the literature, however important differences illuminate opportunities for changes in clinical practice that can benefit this patient population. Of note are increased rates of

insurance, access, and need for health provider guidance regarding hormonal and surgical therapy, and opportunities for advocacy when making patient referrals.

Although most the participants in this study were unemployed, they were insured at much higher rates than the current body of literature because of an inclusive Medicaid program. With increased access to care, participants expressed a desire for more guidance and information about their transition and health maintenance activities. Contrary to a previously identified facilitator of “self-management” of transition,¹⁴ participants in this study were encouraged by a feeling of “moving forward” but there was confusion about their healthcare coverage and difficulty in navigating the next steps in their transition goals. One implication is to utilize a gender transition care coordination template outlining patient transition goals and the necessary steps to achieve them (Table 3). Answers to patient’s questions about primary care and health maintenance activities could be addressed using the recommended anatomy inventory^{25,26} and trauma-informed discussions regarding health maintenance activities that could exacerbate one’s gender dysphoria.

An emerging theme in this study is the lack of healthcare providers who are knowledgeable about gendering affirming surgeries, particularly the mental health implications and post-operative care aspects. This is partially consistent with previous research findings in which patients must educate their providers about their healthcare needs,^{1,8,9,13} however participants in this study expressed not feeling equipped to educate their healthcare providers on these aspects of their care. If the gains in healthcare coverage for transition related care continue throughout the current U.S. government administration,³³ providers will continue to care for an increasing number of patients accessing medical and surgical therapies. There is a need for mental health providers to better understand the impact of gender affirming surgery on gender

dysphoria (e.g. process of hair removal, long wait lists, surgical outcomes). Primary care providers will also require more training on the post-operative period, including complications, and questions regarding routine health maintenance and preventive medicine. As patients and providers alike gain experience in these areas, reflecting this knowledge in the psychoeducation and health groups is necessary. Relatedly, participants' have a desire to share their knowledge and experience with the trans patient through groups and peer support. While informal networks are widely used amongst trans patients, formal peer support models are under-studied in the trans patient population and represents an area in which more research is needed.

A refreshing finding in this study, that patients felt respected by healthcare staff, gives rise to a new challenge for trans-affirming clinics: to advocate for trans inclusivity when referring patients to outside providers. As competency in providing care for trans patients is gained, the focus can go from inward clinic policies and practices to outward advocacy within the larger healthcare community. An implication of this finding is for clinicians to consider each referral for trans patients an opportunity to exhibit trans-affirming care. To preserve trust and patient agency, this should be done in the context of shared-decision making with the patient. When a referral is required, the provider and patient can review the medical record together and address inconsistencies in name, gender marker, or anatomy and discuss how to discuss these when making referrals with the goal of advocating for affirming care and improving the patient experience at outside agencies.

Limitations of this study include the small number of patients interviewed. Transgender patients represent a hard to reach research population, as previously noted.^{16-19, 34} Working with low SES patients who have inconsistent access to cell phones, e-mail, and transportation pose further challenges to recruiting a robust sample size. Given the paucity of information about low

SES, homeless, and non-white trans patients, this study contributes the voice of a marginalized patient population to the growing body of trans health literature.

Conclusion

This qualitative inquiry offers novel insight on the unique barriers and facilitators to care for trans patients accessing care from a homeless-serving organization. Despite the challenges inherent in their societal positionality, the participants exhibited high rates of insurance and access to medical and surgical treatment. With improved access to care through state Medicaid, patients expressed a need for increased guidance and information about their coverage, sequencing of their transition, and primary care activities. Implications for clinicians are to deepen their understanding of the healthcare needs of trans patients through the lifespan and broaden offerings of health and psychoeducation groups. As clinics demonstrate success in providing trans-affirming care it is imperative they role model inclusive care delivery practices to others in the healthcare community.

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Author Disclosure Statement

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Table 1. Semistructured Interview Guide with Follow-Up Probes

<p>1. Thinking about when you come to OTC, what do you like best about coming here? <i>Potential follow-up questions:</i> -What about the clinic environment makes you feel welcome, related to your gender identity? -For example the waiting room, offices, lab, group meetings, yoga classes, staff interactions</p>
<p>2. What do you like least about coming to OTC for an appointment? <i>Potential follow-up questions:</i> -Are there any parts of your time at OTC that feel hard because of your gender identity? -What about the clinic environment makes you feel unwelcome related to your gender identity?</p>
<p>3. Take a moment to think about your experiences at OTC, related to your gender identity. What do you think can be done to make OTC more safe or supportive for you?</p>
<p>4. What issues do you have at OTC getting the care you need related to your gender identity? <i>Potential follow-up questions:</i> -What rules, interactions, people, or other barriers do you face getting the care you need?</p>
<p>5. At OTC, are there kinds of care or medicines related to your gender identity that are harder to get? <i>Potential follow-up questions:</i> -How do you think this could be made easier for you?</p>
<p>6. Has OTC connected you to resources for things other than healthcare? If so, did the resources have good options for you, as someone with your gender identity? <i>Potential follow-up questions:</i> -How accepting/safe/comfortable were the resources? -What would have made the resources or referral to resources more helpful?</p>
<p>7. Can you think of an appointment with a healthcare provider related to your gender identity that went well, and made you feel good? What did that person or clinic do to create a positive experience for you?</p>
<p>8. If you could create an ideal health care experience related to your gender identity, what would that look like? Can you walk me through the experience, from the waiting room through the end of your appointment?</p>
<p>9. If OTC could do one thing that would make the clinic more welcoming and comfortable for you related to your gender identity, what would it be?</p>

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Table 2. Preidentified coding categories for directed content analysis

Barriers	Facilitators
Paucity of knowledgeable providers	Educated/trained staff and clinicians
Lack of trust, reluctance to disclose identity	Sexual orientation and gender identity information integrated into electronic health record
Structural barriers e.g. physical environment, bathroom accessibility	Trans visibility within the organizational culture and clinic setting
Lack of health insurance	Accessible physical environment
Inability to afford care	

Table 3. Components of Gender Transition Care Coordination Template

Date/Age of Social Transition
Community Connections/Social Support (Names, Contacts, ROIs)
Mental Health Provider (Name, Contact, ROI signed)
Goals for medical transition
Goals for surgical transition
Fertility Preservation and Options Considerations
Significant Mental Health Co-Morbidities & Mgmt
Significant Physical Health Co-Morbidities & Mgmt
Hormone Prescriber
Obtained Written Informed Consent
Date of Hormone Initiation
Current Hormone and Dose
Current lab monitoring schedule (Q3,6,or 12 months)
Health Maintenance Considerations (eg pap, a1c, DEXA) *ideally linked to anatomy inventory
2 Letters for surgery (Name and Credentials)
Referral for Surgery (Date and Location/Surgeon)
Referral for Hair Removal (Date and Location)
Mental Health Supports During Hair Removal
Aftercare Plan for Surgery Post-Op Period