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A QUALITATIVE EVALUATION OF  
TRANSGENDER PATIENT EXPERIENCES IN THE INLAND EMPIRE

By

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A capstone project submitted for  
Graduation with University Honors

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## Abstract

Transgender individuals face many economic and cultural forms of discrimination that add complex barriers to their access to high-quality healthcare services. In 2017, a survey conducted by the Riverside University Health Systems Public Health Department quantitatively evaluated the needs of the Inland Empire (IE) transgender community and found that 21.4% reported that they were refused care. However, the study sample did not represent the diversity of the IE, as half of participants identified as White. Our empirical study aimed to bridge the gap by conducting community-based research with racially and ethnically diverse IE transgender participants to better understand the healthcare practices that contribute to positive and negative experiences. We conducted focus groups in Riverside and the Coachella Valley in which participants completed an 8 – item demographic survey where 60% of participants identified as Non-White. The focus group questions explored general experiences like primary health issues affecting the IE transgender community, their individual positive and negative healthcare experiences, and their recommendations for educating providers. The data analysis revealed that there is a lack of correct medical information pertinent to the transgender community and that providers had low levels of cultural competency about the transgender experience. An important implication of this work is that it brings to the forefront the IE transgender narrative and their specific needs to reduce stigma and discrimination faced in healthcare settings. Future directions are to publish our findings and to present them to IE healthcare practitioners to inform them about the unmet needs that the community continues to experience.

## **Acknowledgements**

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## Introduction

It is estimated that transgender and gender non-conforming (GNC) people make up about 0.6% of the adult population in the United States.<sup>1</sup> Although this seems like a small percentage, it equates to roughly 1.4 million people and children. Due to the social structures that exist in the US, transgender and GNC (TGNC) individuals are often isolated because they do not align their gender expression and identity with traditional ideas of how gender should be performed. This results in them facing structural (e.g, laws, policies and economic inequalities) and interpersonal (e.g, physical and sexual abuse) stigmas that affect their ability to access basic resources such as employment, housing, and healthcare<sup>2,3</sup> This discrimination can present itself in healthcare in a variety of different ways such as the refusal of care, use of non-inclusive language, or lack of understanding about transgender health issues.<sup>2</sup> Consequently, the healthcare services are inadequate compared to the standard of care that their cisgender (i.e., a person whose gender identity and expression match the gender they were assigned at birth) counterparts receive. One of the major reasons why this disparity exists is that the education provided to physicians on transgender health, if provided at all, is often not competent enough to create an understanding of the community.<sup>2-4</sup>

As a result of this education gap, various researchers have attempted to study what is currently taught in medical school and residency curricula. In 2017, a study published in the American Journal of Sexuality Education examined the curricula of thirteen different medical schools across the U.S. and found that most schools only dedicated 1-2 hours to the topic of LGBT healthcare.<sup>5,6</sup> Furthermore, among these thirteen schools, only three of the programs focused separately on transgender healthcare and only one of them included information about intersex individuals.<sup>7</sup> Although intersectionality can be beneficial, there is a fine line between the

intersectionality of LGBT identities in curricula and the erasure of distinct identities and their experiences.<sup>8</sup>

In fact, a study done by Lambda Legal (a national organization dedicated to progressing civil rights for LGBT people and those with HIV through public policy and education) showed that transgender individuals are often the ones most impacted by non-inclusive healthcare practices like refusing care, using abusive language or being physically abusive. This study asked over 4,000 LGBT participants to report receiving inadequate care because of their identities and transgender individuals reported higher rates than their LGB and HIV+ counterparts in four out of the six criteria.<sup>9</sup> Nearly twenty-seven percent of transgender respondents reported being refused medical care and about twenty-eight percent reported being physically or verbally abused by healthcare professionals. This report also found that if other factors like income and ethnicity were included, the rate of experiencing discrimination was higher. This is concerning considering a 2015 report done by the National Center for Transgender Equality which found that transgender individuals are three times more likely to be unemployed (15%) than the general U.S. population (5%).<sup>10</sup> As a result of not being able to secure stable employment, transgender and GNC individuals often turn to sex work to support themselves and to pay for medical services that aid their transition (e.g, hormone replacement therapy and gender-affirming surgery).<sup>11-14</sup> One study on sexual risk behaviors of transgender and GNC youth in the U.S. found that nearly half of respondents reported engaging in sex work at least once.<sup>15</sup> Resorting to sex work as an occupation becomes a health concern because it puts those individuals at a greater risk of experiencing sexual violence and being exposed to STIs. In fact, the study also discovered that if participants have engaged in sex work before, the likelihood of having been diagnosed with an STI increased three-fold.<sup>15</sup> These studies

aforementioned tell us that there is a need to approach the health concerns of this population from a holistic viewpoint that not only considers the cultural barriers between patients and their providers but also considers the structural barriers that impact patients` health behavior decisions.

Although a considerable amount of data about the experiences of transgender and GNC people has been published within the last few years, there are a few limitations to the way these studies were conducted. Articles that discuss the implementation of TGNC related curriculum in medical schools focus on the way that medical educators and students conceptualize their own discrimination. While there is value in self-reflection, in order to make impactful action there is a need to understand how the TGNC community feels about the way their health needs are expressed in medical school curricula. Furthermore, in studies that do focus on gathering feedback from the TGNC community, most are quantitative which provides limited context behind the responses of individuals and how it impacts the health behavior decisions they make.

### **Challenges with Transgender Health**

As a result of the social stigmas around transgender and GNC identities, there are many challenges with transgender health and wellness. One of the most notable issues is that transgender individuals face exponentially higher rates of depression, anxiety, suicide ideation, and substance abuse than their cisgender counterparts.<sup>16</sup> Even in comparison to their LGB peers, trans people are twice as likely to think about and attempt suicide.<sup>17</sup> Specifically, in the Inland Empire 75% of transgender individuals surveyed responded that they had seriously considered committing suicide<sup>18,19</sup>. To put this statistic into perspective, 4.3% of the U.S. general population reported thoughts of suicide in a national survey conducted by the Substance Abuse and Mental

Health Services Administration.<sup>20</sup> Another notable issue with transgender health is that while it is illegal under federal law for health plans to exclude transgender-related care, the complexities of insurance and health benefit plans mean that it can still be difficult for transgender individuals to access care. This is especially concerning considering that medical and social transition can be a costly process and transgender Americans are four times more likely to have a household income under \$10,000 than the general population.<sup>21</sup> Due to these complications, transgender people sometimes turn to unsafe means to desired physical changes such as non-prescribed hormones or injectable silicone administered by non-medical persons.<sup>22-24</sup> Overall, there are a multitude of factors that contribute to the challenges transgender people face regarding health and wellness.

### **Setting**

We know little about how the discrimination described above impacts our local Inland Empire (IE) communities. The IE is a large region inland of and adjacent to Los Angeles which is broadly defined as Riverside and San Bernardino counties. It covers more than 27,000 square miles including cities such as Riverside, San Bernardino, and Ontario as well as rural communities like the Coachella Valley and the Hi-Desert. Due to the large size coupled with the variety of communities present in the Inland Empire, it can be difficult to assess health needs. What is known, is that living in the IE comes with a multitude of health barriers that lead to poor health outcomes. One of these barriers is a lack of providers in the region, especially providers that understand the unique challenges of the region. People living in the IE also experience poverty at extreme rates, especially in more rural areas such as the eastern Coachella Valley and Hi-Desert.<sup>25</sup> Industrial factors in metropolitan areas like Riverside and San Bernardino cause concerns such as poor air and water quality. Among the 57 counties in California, Riverside county ranks 49<sup>th</sup> in physical environment and 48<sup>th</sup> in clinical care which emphasizes the need for



public health interventions. <sup>26</sup>Considering the poor health of the IE population as a whole and the fact that transgender Americans are already more likely to have barriers to care and poor health outcomes, the need for understanding the intersections between the two factors becomes even more prevalent.

A report done by the Riverside University Health System`s Public Health Department in 2015 titled the “Inland Empire Transgender Health and Wellness Profile” (THWP) attempted to fill this gap by conducting a survey of 140 people across Riverside and San Bernardino counties to gather information about specific health needs of transgender and GNC people in the region.<sup>18,19</sup> It contributed a great deal of knowledge about discrimination and access to vital resources like health insurance and behavioral health services, but it was limited in its ability to provide context to the survey questions due to its mostly quantitative methodology. It also was limited in its ability to gather participants from diverse ethnic backgrounds with over fifty percent of respondents identifying as white.<sup>18</sup>

To fill these gaps, this project uses qualitative methods to provide more context to the statistics reported in the THWP. It also focused on recruiting participants that represent the diverse ethnic backgrounds of the Inland Empire. It employs a community-based participatory methodology to engage the community in the research process which adds value to the data collection while also ensuring that the vulnerabilities of the community are considered.<sup>27,28</sup>

## **Methods**

We utilized focus groups as a primary data collection procedure because it provides a platform for participants to share and unpack various perspectives. From November 2019 to March 2020, we conducted three focus groups comprised of at least 6 stakeholders each; one in the Coachella Valley at the Transgender Health and Wellness Center (THAWC) and two in

Riverside at the Center for Healthy Communities (CHC). Focus groups were conducted by a four-member research team that was trained with a physical one-day training as well as the CITI training required for conducting research under the Institutional Review Board (IRB).

Stakeholders were self-identified members of the TGNC community who reside in the Inland Empire and are least 18-years old. Prior to the start of each focus group, we handed out a short demographic survey to collect information that may impact qualitative data (e.g, race/ethnicity, age, gender identity, etc.). Focus groups facilitated discussions with three key areas in mind: (a) experiences of the community as a collective, (b) experiences of individual participants, and (c) priorities for educating providers. These key areas were vital towards gaining an understanding of the positive and negative experiences participants are having as to better comprehend what practices are being used and how they can be improved. Focus groups were approximately 2 hours long and audio recorded for later analysis. Due to a grant received by the Undergraduate Education`s Mini-grant Program, we were able to compensate participants with \$30 Walmart gift cards for their time and emotional and physical labor on the day of the focus groups.

Compensating participants was especially important given the fact that poverty disproportionately affects the transgender population, and community leaders mentioned the community was improperly compensated in past research studies.

To further address the distrust that the transgender community has for providers and researchers this project created a collaborative relationship where bidirectional learning and support takes place. To foster this relationship, we included prominent community members, like the CEO of the Transgender Community Coalition and THAWC, Thomi Clinton, and other staff from THAWC in important research decisions. More specifically, they were heavily involved in the formation of focus group questions and deciding how to compensate participants. These

practices align with the community-based participatory research (CBPR) technique, which challenges the shortcomings of traditional socio-behavioral health research. CBPR does this by shifting power to the community through bidirectional learning, collective decision making, and broadening the discourse to include cultural and social meanings.<sup>29</sup> This strategy is a solution to overcome the various challenges to conducting qualitative focus groups (e.g, recruiting participants and conducting groups across geographically dispersed areas).<sup>30</sup> In this study, utilization of the CBPR method served two purposes: (1) to create a research environment that encourages participants to be authentic in sharing their experiences without fear of judgement and (2) to maximize recruitment of transgender individuals in the region who have valuable input, but are hesitant to participate because of past experiences with research.

### **Qualitative Analysis**

Lastly, this project utilized a qualitative analysis strategy called rigorous and accelerated data reduction (RADaR) as its primary way of examining the data collected from focus groups. RADaR introduces a quick and comprehensive way of analyzing data so that the conclusions drawn from the study can be used to create practical solutions to complex social barriers faster than traditional data analysis techniques.<sup>31</sup> This technique consists of five steps to organize, analyze, and reduce data to bring forth exemplary quotes and themes. Using these quotes and themes, we can then develop project deliverables to be shared with the community, educators, researchers, and healthcare professionals. This analysis was completed by the primary researcher, Angela Olivares, and two other researchers who were recruited for their expertise. Kodiak Ly is a second year Sociology major who was recruited because of their attention to detail, their knowledge of qualitative research techniques from their sociology background, and their relationship to the community as a GNC identifying researcher. The second research team

member, Justino Flores, is a UCLA alum who worked on the UCR campus as a lab manager for the Laboratory of Aging Neurocognitive Imaging. He was recruited for his experience conducting qualitative research within his psychology lab, his work with LGBTQ+ populations as former director of the San Bernardino LGBTQ+ center, and his formal public health training from UCLA.

As with most qualitative data analysis strategies RADaR started with transcribing audio recordings from focus groups verbatim. Transcripts were then stripped of all identifiable information and audio files were deleted from recording devices for anonymity. These transcripts were double-checked for any identifiable information and formatted consistently to streamline the data for the reduction phases to follow. Phases consisted first of adding all transcriptions to an all-inclusive table that was organized by transcript, key area, question number, and region. This table was then reviewed individually by three analysts, including myself, with the overarching question in mind: “What factors are contributing to the negative and positive experiences participants are having when seeking care?”. Considering this question, irrelevant data was removed. Remaining data was then coded and reviewed to see if remaining quotes answered the overarching research question. After final review codes and quotes were analyzed to produce themes that emphasize recurring patterns in the qualitative data. Lastly, quotes were organized by theme to streamline data and combined with demographic data for later interpretation.

### **Ethics Approval**

We received expedited approval from the University of California, Riverside Institutional Review Board on 08/19/2019 (HS-19-126). All participants provided verbal consent to participate to prevent a paper trail that could link their identities to their responses.

## Results

### Participant Demographics

A total 20 people participated in focus groups: 13 people from the two Riverside groups, and 7 from the Coachella Valley group. The average age of participants was 27 years old (range 18-56 years). Most participants identified as a man (65%) with 4 identifying as a woman (20%) and 4 identifying as Non-binary or GNC (20%). The majority (60%) of participants also identified as non-white with 30% identifying as Hispanic, 25% identifying as Multi-racial and 10% identifying as Asian. Given that participants from the Riverside group were largely recruited from the UC Riverside campus, the majority (60%) also had some college with the rest having completed high school or post-secondary degrees.

### Major Focus Group Themes

Five major focus group themes were identified during analysis, these were: (a) Shortcomings of healthcare provider training, (b), Interpersonal barriers to healthcare, (c) Systematic barriers to healthcare, (d) Effects of improper care on transgender patients, (e) Positive healthcare experiences. Codes used to identify themes included redirecting conversations and services, insensitivity to transition, access to reliable information, resistance to care, limited insurance coverage, conflating gender and sexuality, genuine interaction with the trans community, and diversity amongst medical staff. Table 2 at end of this capstone includes exemplary quotes picked to represent each theme.

*Shortcomings of healthcare provider training.* This theme highlights the different ways that participants felt their quality of care was diminished by ineffective provider training.

Participants mentioned feeling as though providers had a rigid idea of what it means to be transgender. They reported that providers do not understand the difference between gender and sexuality and have expectations around how transgender people should engage sexually. As one 20-year-old Hispanic GNC participant shared, *“It is weird, my doctor told me. ‘There’s my other patient, a trans guy who only likes being penetrated.’ I’m like why are you f\*cking telling me this? Now I’m definitely not going to tell you anything. It’s like they have one idea of what a trans man or a trans woman looks like and that’s not what it is.”* As this quote illustrates, these perceptions are harmful to the patient-provider connection because patients feel as though they cannot trust their provider to keep their information confidential and not push these stereotypes into them. Gender non-conforming participants also reported feeling as though they had to educate providers on how transgender identities expand beyond the binary of male-to-female (MTF) and female-to-male (FTM). One 26-year-old multi-racial GNC participant explained, *“You have to travel down the rabbit hole of “what is gender?” and so there’s so much to educate. I feel like I’m always constantly educating people just to say who I am. I use they/them pronouns [and people are] like what do you mean? The whole system needs to be reeducated, it’s not the burden to be placed on our community to claim that we exist.”* This quote exemplifies the general feeling participants had where they felt the need to prove their trans identity to their provider. Participants also shared that providers often redirected the conversation to other topics or services. This was especially found in mental health providers who focused more on past diagnoses or finding new ones rather than gender-specific issues such as gender dysphoria. Overall, participants expressed that a lack of understanding about the diversity of the trans experience lead to misunderstandings between patients and providers that made interactions uncomfortable.

In addition to identifying the shortcomings provider trainings, participants also provided recommendations for improving trainings such as having providers volunteer or outreach for the community, requiring letters of recommendation and certificates for those identifying as trans safe practices, and increasing representation of diverse trans perspectives in trainings. One 38-year old trans woman voiced, *“Volunteering, outreach and [being] active in awareness and training. A lot of doctors stop when their clock hits stop. They're not actually being a part of our community [and are] treating us as an outside community. Having that trust in doctors that are active in our community can go a long way.”*

*Interpersonal barriers to healthcare.* This theme further addresses the ways that explicit forms of ignorance from providers can be barriers to care. Participants shared their experiences with providers misgendering them, calling them by their deadname (i.e., using their name given at birth) refusing to treat them, and making degrading remarks. One 38-year-old multi-racial trans woman shared, *“I got referred to an ear nose throat (ENT) doctor for something and they were really expedient about everything up to when I got there and it went [from being] expedient to misnaming, misgendering and then they started pushing back my appointments. They're like ‘Oh no we're going to cancel your appointment today; you can't come in.’ Then they stopped calling altogether and I had to reach back to my primary [so] I could get referred to someone that would actually see somebody that was trans.”* Participants also shared that there was a negative power differential between them and their providers. This was especially the case when participants shared what they knew about the transition process with their provider, which is concerning considering how uneducated some providers are about the trans experience. A 22-year-old white GNC participant shared their experience with this when asked what makes for good healthcare experiences, *“Being empathetic and treating us as normal people and not like*

*their weird science project. I've had a lot of providers talk down on me and I would like for that to stop. When I [saw] a gender therapist to fill out the forms to start testosterone, he was like 'well it seems like you already know a lot, but we'll see about that'.*"

Systematic barriers to healthcare. Participants also shared how systematic barriers such as limited insurance coverage and knowledge of benefits, transportation issues, and lack of expedient care contributed to the negative experiences they were having when seeking care. There was an emphasis on how lack of expedient care proved to be a significant barrier to participants being able to live their authentic lives and move forward in the transition process. According to one 19-year-old trans man, *"You have to see three separate therapists. One to start T, I guess in some cases not all. Then, two separate ones just to get top surgery and you probably have to see a different one to get bottom surgery. It's so many people and it draws out. You're taking years and gaps out of your life that you're trying to dedicate to your health just so you can start living it comfortably [and] it seems incredibly counterintuitive."* Another 20-year-old GNC participant described how this round-around with healthcare providers made them feel erased: *"I've been waiting and waiting for referrals. I've called, I've visited. I'm supposed to be having my top surgery, it's accepted by my insurance, but I keep waiting for their letters. I'm waiting for them to do their stuff and I'm calling and calling, and it feels like I'm just being forgotten. It feels like everyone kind of has that experience within therapy not getting the letters you need in time. I feel like trans people are being erased. I feel like we are constantly being forgotten. I don't know if it's like things take time but like you[ll] call "oh I forgot". I've had that happen to me so many times."* Another systematic barrier that was a significant struggle for participants was a lack of competent providers in the area that resulted in participants having to



travel far to seek care. This was especially the case for participants from the Coachella Valley focus group and participants who do not have their own cars.

Effects of improper care on transgender patients. This theme encompasses how participants responded to the negative healthcare experiences they had. Typically, instances of improper care resulted in participants avoiding care or looking for alternative, and sometimes unsafe, forms of care. In response to the lack of expedient care prevalent in the community, one 38-year-old trans woman described, “*Community members going three weeks plus without having their normal dosages and they start getting wigged out, so they start ordering from abroad and injecting animal estradiol and stuff.*” This same participant later expanded on how the inconsistencies in care result in participants self-dosing for fear of regressing in the transition process: “*I’m thinking [about how] we’re self-dosing all the time or not listening to how things should be because there isn’t a standard care practice for the trans community. One doctor you see is going to give you one dosage and the next doctor you see for continuity of care is going to give you a different dosage.*”

Other participants elected to just avoid seeking care because of the uncomfortable experiences they had previously. As one 26-year old GNC participant described, “*Especially when [you`re being] misgender[ed]. It’s not the worst thing but it just add[s] to the list. Honestly, it makes me not deal with health people often, I don’t want to. I put off a lot of things because of how bad it is. I hate [that] I get such anxiety just trying to call to make an appointment.*”

Positive Healthcare Experiences. While participants had negative experiences that hindered their access to quality care, participants also shared a plethora of factors that contributed to positive experiences. These factors included diversity amongst healthcare staff,

genuine interaction in the trans community, educating patients about the transition process, and holding emotional space for patients. Regarding one local provider a 28-year-old transmasculine participant said, “[She] is phenomenal. She knows the Trans experience. She dated a Trans man for a while. She knows what that’s like and I think that personal [and] upfront knowledge with Trans people is so vital and important for healthcare providers. Because if you never met a Trans person, how can you provide healthcare for them? If you don’t know how they live their lives, what HRT entails, how can you be a healthcare provider for them?”

Other participants shared that having a provider who cared about their emotional well-being, even outside the practitioner’s office contributed to a positive experience. One 19-year-old transmasculine participant shared an experience he had with a mental health provider saying, “When he gave me my letters and I saw my surgeon for the first time, he was like did you like the guy? Because if you don’t like him, don’t settle for somebody that you don’t feel comfortable with. You need to meet somebody and like them. In the community you want to get everything done, you don’t want to wait. He said trans people feel like they have to settle, they have to take what they’re given, they’re never going to be given anything else. He said, I want you to feel comfortable with the person, I want you to feel like you actually have somebody [who] is worth seeing.” Overall, these different experiences emphasize how taking the extra steps as a provider to be well educated, well connected, and empathetic towards transgender patients can have a significant impact on rebuilding patient-provider trust.

## **Discussion**

Employing a community-based qualitative methodology, this study aimed to better understand factors that contribute to positive and negative experiences of the Inland Empire transgender community. A central challenge highlighted by participants was that providers have

little to no understanding about the ways that trans individuals authentically live. Much of providers' understandings comes from stereotypes perpetuated by research and media or from trainings that may not have included trans leaders. Participants emphasized that these inadequacies led to providers having misconceptions about the community which strained patient-provider relationships. A significant misconception emphasized was that providers often conflate gender and sexuality. This resulted in participants experiencing situations where providers asked unnecessary and uncomfortable questions around their sexual behaviors (e.g., whether they enjoyed penetrative sex vaginally or anally, what kinds of body parts they thought about when sexually aroused, and what genders they engaged with sexually). This resulted in participants feeling a though they had to meet certain expectations around sexuality, sexual behavior, and their bodies in relation to these behaviors to get the referrals for trans related services that they desired. Participants also shared that providers were ill-informed about trans identities beyond the MTF and FTM binaries. This was especially significant to gender non-conforming participants who felt pressured by providers to have the desire "to pass" to gain access to tools of transition (e.g., HRT, surgeries, laser hair removal, etc.) when many participants felt most comfortable with an androgynous or non-binary aesthetic. Research also highlights that the inadequacies of provider trainings result in community feeling pressured to conform to normative gender ideals and to educate providers to get desired care.<sup>32,33</sup>

Participants were also asked to share recommendations for improving quality of care and patient-provider relationships. One suggestion that emerged was the desire for genuine interactions with the community. Many participants felt that providers who had a personal connection to the trans community were better at providing care. Thus, participants had a desire for providers who focus on trans care to engage more with the community through volunteering

and other community events. Research suggests that this alongside requiring more rigorous trans health trainings has the potential to significantly build provider-patient trust.<sup>34</sup>

Redirecting conversations also proved to be a challenge for participants, especially when seeking mental health services. Participants shared that mental health providers often treated trans identity as something to be corrected, which is possibly rooted in the historical pathologization of these identities by the psychiatric community. Until 2013, the American Psychiatric Association (APA) classified diagnoses around gender and sexual disorders in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) as Gender Identity Disorder (GID). This diagnosis was then changed from GID to Gender Dysphoria in the DSM-5 because of a workgroup, but the criteria around the diagnosis was largely unchanged.<sup>35,36</sup> As a result, many of the stigmas the workgroup attempted to eradicate remained. Participants also shared that many mental health providers focused on trauma or family relationships rather than gender dysphoria during gender counseling sessions. Some providers went as far to even focus on other mental health diagnoses such as ADD or PTSD as a motivating factor for participants` identifying as transgender. This idea that transgender identities are rooted in trauma is relic from early Freudian psychoanalytic thinking that believed incongruent gender presentation was a consequence of trauma, poor parenting, attachment disruptions, and trauma.<sup>37</sup> Unfortunately, these misconceptions around trans identities and adverse childhood experiences left participants feeling pressured to tell mental health providers what they wanted to hear to receive referrals for HRT, surgeries, etc. Participants described feeling as though mental health providers had a checklist, they expected participants to fulfill to receive referrals. Other research supports that this pathologization of trans identities leads to patients feeling silenced into only sharing

experiences that conform to normative ideas around gender.<sup>38</sup> Ultimately, this inability to understand gender as a complex and fluid concept tarnished the patient-provider connection.

Another prevalent challenge reported by participants were the systematic barriers that compromised continuity of care for participants. These included inconsistencies with provider`s processing time for paperwork, limited insurance coverage, limited providers, and transportation issues. Many participants reported they had experiences where providers forgot to file the necessary paperwork for participants to receive timely referrals for surgeries and other trans-related care. With regard to limited insurance coverage, participants shared that it left them with restricted options of what providers they were able to see and what prescriptions for HRT were covered (e.g, patches versus injections and needles needed for injections). Restricted options for providers also left participants with no choice but to seek care with inadequate providers or to travel far (sometimes up to 2.5 hours) to get care. These systemic barriers, especially those that cause delays in medical care, result in community members feeling unseen and unheard. This finding supports other research that shows the negative impact of these barriers, especially on rural communities.<sup>38,39</sup> Still, more research needs to be done how these systemic factors interact with other systemic factors such as racism, transphobia, homophobia, and sexism.<sup>40</sup>

Although participants reported a high volume of negative experiences, many still had positive experiences with providers that have the potential to serve as comprehensive models for care. One of the biggest factors that contributed to participants positive experiences was when providers broke down the power differentials between themselves and the participant. Participants reported that while they were expected to be educated on the transition process enough to fill in provider`s educational gaps, when they shared this knowledge with providers they were met with unsettling and combative remarks (e.g., “we`ll see about that”, “are you

sure?") that questioned participants role in their health plan. In positive experiences, these combative remarks were opposed when providers sought to learn from participants by asking clarifying questions about participant`s plans for medical transition. This is consistent with other research that suggests active listening is an important factor for cultivating positive relationships between patients and their providers.<sup>41-43</sup> Research also suggests having providers who take the time to educate themselves so they can educate their parents also contributes to positive patient experiences.<sup>32,34</sup> Lastly, it was emphasized by participants that seeing diversity among medical staff increased their comfortability around providers. This is consistent with other studies that suggest diversity among medical professionals leads to improved experiences and compliance with vulnerable populations (e.g., LGBTQ, people of color).<sup>44,45</sup> Given the experiences shared by participants, it is evident that the main priority of the community is to improve provider-patient interactions so that quality of care can also improve. Further research should employ CBPR methods to continue to explore positive experiences that have the potential to rebuild connections between transgender patients and their providers.

### **Study Limitations**

This study has several limitations. First, while most participants identified as non-white there was limited representation of Asian trans individuals and no reported representation of black trans individuals. Additionally, the majority of participants were either in college or had some higher education which points to a certain level of privilege. Thus, findings from this data may not be generalizable to these racial/ethnic populations and trans identifying individuals who do not have experience with higher education. Another demographic point to make is that most (65%) participants identified as transmasculine. Thus, it should still be noted that findings from this study may be more representative of transmasculine identities. Increasing advertising to

those outside of the college sphere and to more community centers than the THAWC may increase diversity amongst participants. Finally, a significant limitation to point out is that this study had a relatively small sample size of 20 participants, with only 7 being from the Coachella Valley region, thus findings from this study may not be representative of the entire Inland Empire.

### **Conclusions**

Although this study contributes to the limited pool of research available about the Inland Empire transgender community, more research still needs to be done to understand the complexities of this diverse population. Additionally, it is pertinent that future research employs a community-based methodology to continue to build connections between researchers, educators, and the community. This study highlighted that negative experiences of the community were influenced by a multitude of factors including lack of competent training, interpersonal barriers (e.g., refusal of care, intrusive questions from providers, pathologization of trans identities), and systematic barriers (e.g., limited insurance coverage, lack of providers in area, lack of expedient care). It also highlighted how these negative experiences have adverse effects on the provider-patient relationship that can diminish continuity of care and patient compliance. While these negative experiences were problematic and persistent, participants still shared factors that contributed to positive experiences (e.g., being consistent with and considering patient`s pronouns, being able to educate patients on transition process, diversity amongst healthcare staff) and provided recommendations for how care can be improved (e.g., actively engaging with the community through volunteering and outreach, increasing diversity of trans perspectives in trainings, creating a more standardized training or certificate program). Understanding these lived experiences and acquiring recommendations from the community are

vital to improving interventions, equipping healthcare providers with knowledge to provide better care and to redefining what needs to be met to qualify as a trans specialist.

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**Table 1. Focus group questions**

<p>Question Set A: General Experiences</p>	<ol style="list-style-type: none"> <li>1. What would you say are the top 3 health issues affecting transgender people in the IE?</li> <li>2. What would you say is the biggest barrier to accessing healthcare in the IE as a transgender/GNC person?</li> <li>3. How would you rate the cultural competency of healthcare professionals (primary care and/or specialty care) in the IE?</li> </ol>
<p>Question Set B: Individual Experiences</p>	<ol style="list-style-type: none"> <li>1. What is a positive healthcare experience you have had?             <ol style="list-style-type: none"> <li>a. Probe: What about this experience contributed to it being positive?</li> </ol> </li> <li>2. What is a negative healthcare experience you have had?             <ol style="list-style-type: none"> <li>a. Probe: What about this experience contributed to it being negative?</li> </ol> </li> <li>3. Have you ever felt that you were not receiving the correct medical care?             <ol style="list-style-type: none"> <li>a. Probe: What made you feel that way? (overly invasive questions, “botched surgeries”, discriminatory language, etc.)</li> </ol> </li> <li>4. If you were recommending a provider (primary care and/or specialty care) to a friend, what three criteria would you recommend them on?             <ol style="list-style-type: none"> <li>a. Probe: criteria can be things like knowledge of trans health issues, affordability, accessibility, etc.</li> </ol> </li> </ol>
<p>Question Set C: Educating Providers</p>	<ol style="list-style-type: none"> <li>1. How do you think educators can increase healthcare provider’s (primary care and/or specialty care) cultural competency about transgender/GNC people in the IE?             <ol style="list-style-type: none"> <li>a. Probe: For example, bringing people from the community to panel, bringing people from the community to be mock patients at medical schools, or putting information on board exams</li> </ol> </li> <li>2. What is something you wish your healthcare providers (primary care and/or specialty care) were more educated on about treating the trans community?             <ol style="list-style-type: none"> <li>a. Probe: this can include more education about preferred pronouns, preferred language around anatomy, more information about how to provide for specific trans healthcare needs like hormones, surgery, etc.</li> </ol> </li> <li>3. What do you believe qualifies a healthcare professional as a “transgender health specialist”?             <ol style="list-style-type: none"> <li>a. Probe: For example, providing services associated with trans healthcare (like HRT, aesthetic services (facial fillers, hair removal, etc.), and linkage to services like gender affirming surgery), knowledge of trans health issues, knowledge of trans specific vocabulary (pronouns, binders, etc.) or other criteria</li> </ol> </li> </ol>

**Table 2. Exemplary quotes from participants around five major focus group themes**

Theme	Exemplar Quotes
Shortcomings of healthcare provider training	<p><i>I had a therapist who said one of [their] patients is a transgender man [that] can only be sexually pleased by thinking of anal sex and I'm like why would you tell me this? Why would you make me feel bad if I don't think that way? That I should probably be thinking that instead of like two men or what if someone likes two women?</i></p> <ul style="list-style-type: none"> <li>- 19-year-old white trans man</li> </ul> <p><i>It is weird, my doctor told me. 'There's my other patient, a trans guy who only likes being penetrated.' I'm like why are you fucking telling me this? Now I'm definitely not going to tell you anything. It's like they have one idea of what a trans man or a trans woman looks like and that's not what it is.</i></p> <ul style="list-style-type: none"> <li>- 20-year-old Hispanic GNC person</li> </ul> <p><i>I feel like I had to explain that to everyone, you have to travel down the rabbit hole of "what is gender?" and so there's so much to educate. I feel like I'm always constantly educating people just to say who I am. I use they/them pronouns [and people are] like what do you mean? The whole system needs to be reeducated, it's not the burden to be placed on our community to claim that we exist.</i></p> <ul style="list-style-type: none"> <li>- 26-year-old multi-racial GNC person</li> </ul> <p><i>Since they don't know anything. [All they know] is the garbage that's put on the limelight about our community and they don't actually know anything about our community or how it works. Then they get over excited or freaked out. Both spectrums are just crushing [and] they don't know how to function as a normal doctor.</i></p> <ul style="list-style-type: none"> <li>- 38-year-old multi-racial trans female</li> </ul> <p><i>Consistency is bad. Some doctors are on it and you go to another doctor and they have zero idea.</i></p> <ul style="list-style-type: none"> <li>- 19-year-old white trans man</li> </ul> <p><i>They'd always talk me out of it. [They'd say] 'oh you're going to get masculine' and I'm like that's the point and they're like 'oh but you're going to get acne' and it's like I've [had] acne and 'oh well you might not be fertile' and it's like but I don't want to have kids. They always come up with new and more reasons why [I] shouldn't start and it's getting annoying at this point.</i></p> <ul style="list-style-type: none"> <li>- 18-year-old white GNC person</li> </ul> <p><i>The first gender therapist that I saw opened with that she was a PTSD therapist and she only ever wanted to talk about that. I'm not here to talk about my PTSD and she's like no let's talk about it. Every time I went in , which was once a week, like dude I came here to get a referral for T not to talk about my past and they're always like what came up in your past that made you think this and that. Nothing made me think this or that. They're looking at your past</i></p> <ul style="list-style-type: none"> <li>- 19-year-old white trans man</li> </ul>

When I went there [they were] focusing on ADD and ADHD. When I went there I [said] “Hey I just need my anti-depressants refilled before I do anything because I literally just moved [and] I ha[ve] new insurance and I don’t want to stop that”. But the person I went to had me take all these ADD tests because they were like “oh maybe this is what’s causing it”. I was like yeah perhaps, but at the same time I’m really not looking for [a] diagnosis. I just need something stable. They didn’t even ask about any of my gender issues. I know this is not the reason I have chronic depression [and] you never asked about the trauma that I’ve had. The [therapist was] like “oh it is this and we’re going to cure it and like you’re not going to need anti-depressants right now”. I was like ok, I just need these pills real quick.

- 26-year-old multi-racial GNC person

For gender therapy, it feels like they have this checklist in front of them and when you say something they’re like ‘oh check’. It feels like you’re trying to meet their criteria and that’s not how it should be.

- 19-year-old white trans man

It’s like quite literally they want you to be suffering. Like ‘please I want to be a cis man’. Like bitch I don’t want to be a cis man. I’m going in there and being like [I had an] okay childhood as a girl, I grew up as a girl. That was okay and they quite literally sat me down and told me you can’t say that if you want to get this, you need to say this. I’m doing this because I want this. It’s constantly lying to them, it’s never talk[ing] about being dysphoric and let’s fix that. It’s always let’s talk about your family.

- 20-year-old Hispanic GNC person

#### SUGGESTED SOLUTIONS

I feel like [the term] trans specialist shouldn’t necessarily be a doctor but more like a counselor that knows the process and can tell you what to do and maybe can recommend doctor’s they’ve heard in the past that are good with trans people. Kinda like a social worker they get assigned if you told your healthcare provider that you were trans . . . someone to help you through the process of making decisions.

- 50-year-old Hispanic trans man

I think like actual patient feedback. [People say] ‘good experience with this one’, ‘She doesn’t know what she’s talking about so don’t go there’. So that’s good in figuring out from other people how their experience was with the professional and I think if the provider goes to trans health conferences and things where they’re actually involved in the community,[then it] is a good way to gauge they know up-to-date stuff.

- 21-year-old multi-racial trans man

Maybe having to have references or letters of recommendation from past trans patients would be a way to formalize the way [we] access care by talking to each other.

- 29-year-old white trans male

Volunteering, outreach and [being] active in awareness and training. A lot of doctors stop when their clock hits stop. They’re not actually being a part of our community [and are] treating us as an outside community. Having that trust in doctors that are active in

	<p><i>our community can go a long way. I think that can definitely help with someone being a specialist.</i></p> <ul style="list-style-type: none"> <li>- 38-year-old multi-racial trans woman</li> </ul>
<p>Interpersonal barriers to healthcare</p>	<p><i>I once had a pharmacist that accused me of doing heroin. She said “ well, you know you only need one set of needles” but I need another set to draw the medication. That’s just how it works so I’m not shooting myself with dull needles and she’s like “we can’t give you more than a needle. If you need help [there’s] drug counseling”. I straight up told her I’m not doing heroin. I’ve been on this prescription for several years and you’re giving me a hard time and the other pharmacists were laughing in the back.</i></p> <ul style="list-style-type: none"> <li>- 28-year-old white trans man</li> </ul> <p><i>I had so much trouble finding therapists to write letters. They simply don’t know what it is, what guidelines to follow, [and] they’re afraid they’ll screw it up and I won’t get the care.</i></p> <ul style="list-style-type: none"> <li>- 56-year-old multi-racial trans man</li> </ul> <p><i>I got referred to an ear nose throat (ENT) doctor for something and they were really expedient about everything up to when I got there and it went [from being] expedient to misnaming, misgendering and then they started pushing back my appointments. They’re like “Oh no we’re going to cancel your appointment today, you can’t come in”. Then they stopped calling altogether and I had to reach back to my primary [so] I could get referred to someone that would actually see somebody that was trans.</i></p> <ul style="list-style-type: none"> <li>- 38-year-old multi-racial trans woman</li> </ul> <p><i>4 out of 10, I had some good experiences with [a ] therapist I used to go to in Fontana. When I went to the OBGYN I got misgendered a lot. My preferred name and pronouns were on my medical record, I’m wearing a pronoun pin and I am still getting misgendered.</i></p> <ul style="list-style-type: none"> <li>- 18-year-old white GNC person</li> </ul> <p><i>I don’t think I’ve had a positive experience especially regarding the health care in the city [of] Riverside. Part of it is always anxiety inducing for me. The way it gets brought up [is] always so clinical. They’d be like “oh are you sure?”. I already have issues knowing my own gender identity, so when someone is asking me those questions, depending on the context, I take it like it’s attacking. I [already] have issues doubting myself [and] I don’t need an outside person doubting me.</i></p> <ul style="list-style-type: none"> <li>- 26-year-old multi-racial GNC person</li> </ul> <p><i>I think a lot of medical professionals still focus on being transgender as a disorder. Like something that can be fixed but not like “let’s put you through HRT and like make you who you want to be” as in let’s see if we can reverse this you know?</i></p> <ul style="list-style-type: none"> <li>- 28-year-old white trans man</li> </ul> <p><i>I have to address that my bad experiences are little things like, discomfort basically, just a little misgender, the wrong name. It’s like a complete accident I understand but you know that feeling of dysphoria and to me that’s where the bad experience is. There’s just a lack of understanding and empathy. That’s what a bad experience is to me. Just not being understood and how quick it is to be erased, that’s what I’m scared about.</i></p> <ul style="list-style-type: none"> <li>- 20-year-old Hispanic GNC person</li> </ul> <p><i>Being empathetic and treating us as normal people and not like their weird science project. I’ve had a lot of providers talk down on me and I would like for that to stop. When I [saw] a gender therapist to fill out the forms to start testosterone, he was like ‘well it seems like you already know a lot but we’ll see about that’.</i></p> <ul style="list-style-type: none"> <li>- 18-year-old white GNC person</li> </ul>

	<p><i>I started going to a person that was closer at a clinic in Redlands, but he was just the worst. Everyone that's gone to him has had uncomfortable experiences with him. I just wanted the testosterone prescription, but he would do all kinds of things. Before I got top surgery, he wanted to know what like about my binding and stuff and he wanted to see what/ how my scars were healing and he would even go and look at my crotch area. He would [also] make unwarranted comments [like] 'you might pass better if you lost weight'.</i></p> <ul style="list-style-type: none"> <li>- 18-year-old white GNC person</li> </ul> <p><i>Oh! "Which genitals do you have now?" That's always a don't ask question I feel. Or they invert[ently] say "Okay, what surgeries do you wanna have?" "What are you going to have?" I'm [just] meeting you, why do you need to know this off the bat?</i></p> <ul style="list-style-type: none"> <li>- 38-year-old multi-racial trans woman</li> </ul> <p><i>When they ask 'Why do you think you're trans?' It's like Idk . . . I just am.</i></p> <ul style="list-style-type: none"> <li>- 25-year-old Hispanic trans man</li> </ul>
<p>Systematic barriers to healthcare</p>	<p><i>You have to see three separate therapists. One to start T, I guess in some cases not all. Then, two separate ones just to get top surgery and you probably have to see a different one to get bottom surgery. It's so many people and it draws out. You're taking years and gaps out of your life that you're trying to dedicate to your health just so you can start living it comfortably [and] it seems incredibly counterintuitive.</i></p> <ul style="list-style-type: none"> <li>- 19-year-old white trans man</li> </ul> <p><i>I've been waiting and waiting for referrals. I've called, I've visited. I'm supposed to be having my top surgery, it's accepted by my insurance, but I keep waiting for their letters. I'm waiting for them to do their stuff and I'm calling and calling, and it feels like I'm just being forgotten. It feels like everyone kind of has that experience within therapy not getting the letters you need in time. I feel like trans people are being erased. I feel like we are constantly being forgotten. I don't know if it's like things take time but like you[ 'll] call "oh I forgot". I've had that happen to me so many times.</i></p> <ul style="list-style-type: none"> <li>- 20-year-old Hispanic GNC person</li> </ul> <p><i>I go to a different site. They are not all queer there, but I think what roots my good experience is that they're all Latinx. That's a big factor for me cause I literally go there and they're like "Oh my God mijo". I feel like that's what makes me feel safe. The fact [that] I go there [for] my actual doctor really helps me.</i></p> <ul style="list-style-type: none"> <li>- 20-year-old Hispanic GNC person</li> </ul> <p><i>The first thing that made me feel comfortable with her was she said, "I've got two daughters and me and my wife are planning on adopting again" and I was like I already love you. Just makes you feel comfortable when you come in and they talk to you and they make you feel like you're friendly with them. It makes you feel comfortable and willing to tell them stuff.</i></p> <ul style="list-style-type: none"> <li>- 19-year-old white trans man</li> </ul> <p><i>I think to educate the community because they don't know [what] insurance they have available for them. Because they don't know, they end up doing stuff that's not right to do, like self-dosing and things like that.</i></p> <ul style="list-style-type: none"> <li>- 38-year-old multi-racial trans woman</li> </ul>



	<p><i>I have to travel from Joshua tree to here every time I have to see a doctor, which is an hour to an hour and half. Twice a month sometimes and surgery in Colton, which is two hours away</i></p> <ul style="list-style-type: none"> <li>- 22-year-old white trans man</li> </ul> <p><i>I have revision coming up and it's out in Los Angeles, so we'll have to drive the 2.5 hours there, have surgery, and drive the 2.5 hours back.</i></p> <ul style="list-style-type: none"> <li>- 38-year-old multi-racial trans woman</li> </ul>
<p>Effects of improper care on transgender patients</p>	<p><i>Community members going three weeks plus without having their normal dosages and they start getting wigged out, so they start ordering from abroad and injecting animal estradiol and stuff.</i></p> <ul style="list-style-type: none"> <li>- 38-year-old multi-racial trans woman</li> </ul> <p><i>I'm thinking [about how] we're self-dosing all the time or not listening to how things should be because there isn't a standard care practice for the trans community. One doctor you see is going to give you one dosage and the next doctor you see for continuity of care is going to give you a different dosage.</i></p> <ul style="list-style-type: none"> <li>- 38-year-old multi-racial trans woman</li> </ul> <p><i>Especially when [you're being] misgender[ed]. It's not the worst thing but it just add[s] to the list. Honestly, it makes me not deal with health people often, I don't want to. I put off a lot of things because of how bad it is. I hate [that] I get such anxiety just trying to call to make an appointment.</i></p> <ul style="list-style-type: none"> <li>- 26-year-old multi-racial GNC person</li> </ul> <p><i>I was like 'Is there any way you can call me by my legal name now?' 'cus I showed them my ID and they were like 'No'. And I was like 'I'm going to stop coming here'. I stop[ped] going [and] I haven't been to the dentist in a while 'cus I don't want to go, so that's an issue.</i></p> <ul style="list-style-type: none"> <li>- 19-year-old white trans man</li> </ul> <p><i>I told you guys about the dentist issue. I stopped going because I was so uncomfortable because for one second, they had to call out the wrong name. I was like I'm not going back there, and we have to dodge shit we shouldn't have to dodge. You shouldn't have to not be going to certain things because people are not taking the time to be considerate of you. So, it's like you're not taking your health all the way that you should be taking it. If you have high blood pressure and your cardiologist is being an asshole and you just stopped going, that's an issue.</i></p> <ul style="list-style-type: none"> <li>- 19-year-old white trans man</li> </ul>
<p>Positive healthcare experiences</p>	<p><i>She knows the Trans experience. She dated a Trans man for a while. She knows what that's like and I think that personal [and] upfront knowledge with Trans people is so vital and important for healthcare providers. Because if you never met a Trans person, how can you provide healthcare for them? If you don't know how they live their lives, what HRT entails, how can you be a healthcare provider for them?</i></p> <ul style="list-style-type: none"> <li>- 28-year-old white trans man</li> </ul>

*My person that prescribes the T is a PA, but he figured out a way for me to get T so I [don't pay] for it out of pocket because my insurance isn't going to take care of it if I'm trans. The PA has [it] figured out. I appreciate the fact that he mentioned a way for me to get what I wanted [even] if that meant he had to finagle the explanation. I appreciated that [and] everyone in the clinic is really sweet to me. . . they just treat me like a person.*

- 50-year-old Hispanic trans man

*I've only had good experiences with the nurses and receptionist. They treat me like a human and not like a science experiment. They didn't talk down to me they just talked to me as if we're having a casual conversation. They tend to be more relaxed or happier.*

- 18-year-old white GNC person

*I go to the Desert Aids Project and I see \_\_\_\_ over there and they always impress me because if I'm looking for something over there, they have a presentation for that. Right before my top surgery he had a presentation MTF just for top surgery. My other partner had to have one as well for FTM surgery, so he had presentations for both. It was super cool to see that he was so educat[ed]. When I went to the surgeon, I actually knew what was going on and was really informed about it.*

- 38-year-old multi-racial trans woman

*When I first went to Plan Parenthood to get prescribed T they were really good. They were upfront about what pronouns I wanted to use and even when asking about my anatomy. They would phrase it in such a way that it was coming from a gender-neutral place. S[uch as] '[have] you had the possibility of getting pregnant, yes or no? There was just clear communication between the receptionist, the people leading me to the hall, the people doing everything they needed to do before [and] after when the doctor sees you. They all seem nice [and] the topic of my pronouns came out once [they] know the reason [why] I am there.*

- 20-year-old Hispanic trans man

*They just treat you like a regular person. Their doctors come in and they [don't] start treating you like the only thing that you are is a trans person. They just come in like hey I saw your chart how you are doing? They don't have to ask you [and] if they ask you questions it's brief. All that makes you up is not your gender identity and they just kind of like talk to all the encompassing parts of you.*

- 19-year-old white trans man

*When he gave me my letters and I saw my surgeon for the first time, he was like did you like the guy? Because if you don't like him, don't settle for somebody that you don't feel comfortable with. You need to meet somebody and like them. In the community you want to get everything done, you don't want to wait. He said trans people feel like they have to settle, they have to take what they're given, they're never going to be given anything else. He said, I want you to feel comfortable with the person, I want you to feel like you actually have somebody [who] is worth seeing. He's pretty good, you should see him.*

- 19-year-old white trans man