

The Quality of Care of Transgender and Gender Nonconforming Patients: The Provider Perspective

Suma Vupputuri, PhD, MPH¹; Stacie Daugherty, MD, MPH²; Calvin Yu, MD³; Christine Truong, MPH¹; Ayanna Wells, MS, CHES⁴; E W Emanuel, MD⁴

Perm J 2020;25:19.227

E-pub: 12/16/2020

<https://doi.org/10.7812/TPP/19.227>

ABSTRACT

Background: Transgender and gender-nonconforming (TGNC) patients have inadequate quality of care. Few studies have examined the issues related to quality of care from the perspective of providers. The purpose of this pilot study was to understand the barriers and facilitators of quality TGNC care and develop recommendations for health systems.

Methods: We used phenomenological methods in the form of qualitative semistructured interviews to allow provider participants to elaborate about issues not covered in the script questions. Audio files from 11 provider interviews were transcribed and summarized by common themes. Thematic analysis was conducted in an iterative process to extract insights from the data.

Results: Six main subthemes resulted from our qualitative review regarding “barriers to quality care”: 1) provider training and knowledge of TGNC care, 2) provider and staff interactions with TGNC patients, 3) case management, 4) misgendering, 5) access and continuity of care, and 6) bias and discrimination. Four subthemes were identified as “facilitators of quality care” for TGNC patients: 1) skilled staff, 2) continuity of care and electronic health records, 3) organizational support, and 4) provider-patient interactions. Additional needs were also suggested.

Conclusions: Findings were distilled into 3 recommendations to improve the quality of TGNC care: 1) establish a dedicated case-management team; 2) provide access to more in-depth and meaningful training for providers, clinic staff, and administrative staff (and mandate certain basic training); and 3) allocate financial resources and enforce a policy of nondiscrimination.

INTRODUCTION

Transgender and gender nonconforming (TGNC) are umbrella terms for persons whose gender identity is different from the sex they were assigned at birth. The term TGNC is used within this manuscript as an inclusive description of all identities within the gender identity spectrum (other than cis-gender individuals). TGNC persons may or may not choose to seek medical transition. However, treatments such as hormone therapy, facial hair removal, speech modification therapy, surgery, or any combination of these procedures have been deemed medically necessary (if so chosen) by the World Professional Association for Transgender Health (WPATH), the organization that publishes the evidence-based Standards of Care and Ethical Guidelines for transgender persons.¹

TGNC individuals are arguably among the most marginalized populations in the US and continue to experience

discrimination, particularly in the health care setting. Approximately 30% of transgender persons delay or fail to seek medical care when it is needed.^{2,3} In addition to discrimination, reasons for not seeking care include the provider’s lack of knowledge and training on transgender care,⁴⁻⁷ inappropriate interactions/communication with providers,² and the provider’s lack of familiarity with the TGNC community in general.^{2,3,8} Further health system barriers for TGNC patients seeking care include a lack of TGNC-friendly spaces, a lack of gender-neutral bathrooms, electronic health records that do not clearly document gender identity,^{6, 9-11} and other medical and health system forms that do not provide the option to indicate gender identity. These barriers contribute to serious health disparities and inadequate care for TGNC patients.

Primary care services for TGNC patients include general episodic care, chronic care management, preventive care/screening, medically supervised transition procedures or treatment, and counseling. TGNC patients who are seeking medical transition (including those only seeking hormone therapy) are required in some health systems to be treated by behavioral health specialists and to have a diagnosis of gender dysphoria. Further, TGNC patients are often referred to specialty areas for transition care, including endocrinology, obstetrics/gynecology, urology, infectious disease, and surgery. Few studies have assessed how a diverse group of providers perceives the quality of care of their TGNC patients. We conducted a pilot study to answer the following question: At a health system with a young, developing Transgender Health Services program, what are the provider-perceived barriers and facilitators to improving the quality of TGNC care throughout the health system?

METHODS

The study was conducted at Kaiser Permanente (KP) Mid-Atlantic States, a group-model health system that provides comprehensive, prepaid health care to almost

Author Affiliations

- ¹ Kaiser Permanente Mid-Atlantic States, Mid-Atlantic Permanente Research Institute, Rockville, MD
- ² Department of Medicine, University of Colorado at Denver, Aurora, CO
- ³ Kaiser Permanente Southern California, Southern California Permanente Medical Group, Pasadena, CA
- ⁴ Kaiser Permanente Mid-Atlantic States, Transgender Health Services Program, Rockville, MD

Corresponding Author

Suma Vupputuri, PhD, MPH (Suma.Vupputuri@kp.org)

Keywords: Barriers to care, gender identity, qualitative methods, transgender, quality of care

800,000 members in Maryland, Virginia, and the District of Columbia. KP Mid-Atlantic States is composed of the Kaiser Foundation Health Plan and the Permanente Medical Group, a multispecialty group practice that provides health care for members of the health plan. Based on the growing TGNC population and the desire to improve care for a vulnerable patient population, leadership at KP Mid-Atlantic States has identified TGNC care as an area of focus and has encouraged the development of the Transgender Health Services program by designating a director and providing resources to support a small team. The Transgender Health Services program is a group of dedicated staff members who are committed to helping TGNC patients live their authentic life. The program coordinates clinicians and therapists experienced in TGNC healthcare and facilitates council, treatment, monitoring, and response to the challenges of navigating the healthcare system as a TGNC person.

A comprehensive literature review of issues related to the quality of care of TGNC individuals was conducted to develop a semistructured interview script with broad themes. Providers were encouraged to elaborate and offer thoughts on other barriers and facilitators of quality care and additional needs to improve the quality of care. Provider interview scripts were reviewed and approved by the Director and Program Manager of the Transgender Health Services program at KP Mid-Atlantic States.

We aimed to recruit 10 participants for this qualitative study: both preferred and nonpreferred providers, including specialty physicians, primary care physicians, and behavioral health therapists. Preferred providers are those who undergo additional training related to TGNC patient care and have requested to have more TGNC members on their patient panel. Preferred providers also have relevant prior experience and may have a professional and/or personal interest treating this patient population. This was a convenience sample of providers who were either on the preferred provider list or who had at least 2 TGNC patients from the Transgender Registry on their panel.

Of the 5 preferred providers whom we contacted, 4 agreed to participate. Of the 42 nonpreferred providers whom we contacted, 7 agreed to participate. Interviews were conducted by the same study Project Manager (author CT) for all 11 provider participants. We used phenomenological methods in the form of qualitative semistructured interviews to allow participants to elaborate about issues not covered in the script questions. Analysis was conducted using transcriptions of the 11 interviews (anonymized) and by listening to the audio files. Thematic analysis at the semantic level was conducted by a single researcher (SV) in an immersive, iterative process¹² to reflect on and extract insights from the data. Semantic themes examine the explicit

meaning of the data, not going beyond what the providers have said. Direct evidence (ie, quotes) was extracted and organized within a spreadsheet where the data were moved, grouped, and sorted into various themes. The themes and recommendations that were developed reflect the providers' thoughts and opinions, not those of the researchers.

Coding was done using a deductive strategy using thematically grounded *a priori* codes. The 5 deductive codes (training, relationships with patients, access to care, trust, and implicit bias) were developed *a priori* based on published literature on the quality of TGNC care in the US.

This study was reviewed and approved by the Institutional Review Board at Kaiser Permanente Mid-Atlantic States.

RESULTS

Provider participants included 2 (18%) from urology, 1 (9%) from infectious disease, 1 (9%) from behavioral health, and 7 (64%) from internal medicine. Of the 11 participants, 36% were preferred providers; 45% were white. The physician interview results are grouped according to the 3 main themes (and subthemes): 1) barriers to quality TGNC care (providers' knowledge/experience in TGNC health care issues, patient-provider/patient-staff interactions, case management, misgendering, organizational support, and implicit bias); 2) facilitators of quality TGNC care (skilled staff, electronic medical records [EMR]/continuity of care, organizational support); and 3) additional needs to improve the quality of TGNC care.

Barriers to Quality TGNC Care

Knowledge/Experience in TGNC Health Care Issues

Virtually none of the providers interviewed had formal training in providing medical care to TGNC patients (such as in medical school or residency). Most of the providers completed at least 1 continuing medical education credit on transgender care and/or cultural competency training and had participated in sessions on transgender medicine offered at conferences. Two providers had undergone in-depth trainings at the WPATH, Whitman Walker (a community-based health services provider specializing in LGBTQ health), or Human Rights Campaign. However, when asked about the standards of care for TGNC persons or the WPATH treatment guidelines, the nonpreferred providers were largely unfamiliar with the current recommendations for the treatment of TGNC patients. Many of the providers described learning about treating TGNC patients on the job.

A sentiment that was expressed numerous times was the need for more in-depth education, training, and workshops above and beyond the regular continuing medical education lectures on TGNC health. There was a desire for more meaningful training in smaller, more dynamic group

settings with more engagement and participation of TGNC persons. Participants also expressed interest in learning more about gender affirmation surgeries by observing actual procedures. The underlying caveat for more training was the need for protected time to attend these training events.

Specific training recommendations for nonpreferred providers, particularly in primary care, were voiced repeatedly. Some of the providers interviewed felt that many of their primary care colleagues felt unsure and uncomfortable treating TGNC patients. They felt that their colleagues were uncertain about the specific medical needs of TGNC patients and that they questioned potential differential therapies needed for TGNC patients. Participants also expressed that TGNC patients did not necessarily need an endocrinology referral for hormone therapy and could have their hormones prescribed and monitored in primary care if these providers are trained.

In addition, many of the providers stressed the need for in-depth cultural competency training of all staff, including clinical, intake (eg, front desk staff and medical assistants), and administrative (eg, member services and benefits staff). Many of the comments about this type of training stemmed from patient-staff interactions covered in the next section.

I think if [our health system] is serious about having high-quality transgender care...then they have to insist that everybody is expected to be culturally sensitive with transgender people and actually put training and consequences behind it because...I don't think that is the message that some of the support staff is receiving. And that's a huge barrier; if trans people don't feel safe they're not going to feel like they receive high-quality care no matter how much surgery you'll perform.

Another issue that providers described was the availability of resources to help them to treat TGNC patients. This included access to patient education materials (including the health system policies), information on how to manage a patient's transition process, access to the list of preferred providers, and where to look to learn more about TGNC care. A simple list of online resources that can be easily accessed especially in a busy clinic was suggested. These gaps overlapped with issues voiced regarding case management.

So one of the barriers that I have is information on how to make surgeries happen.

We don't have a lot of resources here...in the clinic. I don't know if it's because we don't have a lot of patients that needs them, but [it would be] good to have some more information, you know, to hand out to patients.

Maybe if there was something smaller and quick and easier to read to digest—like a pamphlet and a book that touches on all the aspects with recommendations or advice on how to handle or deal with that situation.

Patient-Provider and Patient-Staff Interactions

Some physicians felt perfectly comfortable with their relationships with TGNC patients, expressing that there were no trust issues that they were aware of and that their provider-patient relationships were not any different whether their patient was TGNC or cis-gender. However, there was acknowledgement among most of the providers that maintaining trust with TGNC patients is an important issue that is often difficult to achieve or maintain.

In comparing the way providers provide care for TGNC versus cis-gender patients, there seem to be discernable differences. TGNC patients may require support from their providers that goes beyond routine health care and treatment, depending on (among other things) their stage of transition. The providers we interviewed had numerous stories from their patients about mistreatment in other areas of the health system, including other providers, front desk staff, and administrative staff. Provider participants explained that when they refer a TGNC patient to another provider and that patient is mistreated, they feel responsible because it was their referral; this poor interaction also affects the trust between provider and patient. To minimize this risk, some provider participants reported calling the department/clinic that they were referring a patient to in order to inform them that their TGNC patient had an appointment and how to address them appropriately. Participants described common descriptors of an effective provider, including being patient, sincere, empathetic, respectful, open-minded, a good listener, and compassionate. These were expressed as being applicable for treating all patients but perhaps more important when treating TGNC patients.

Transgender [patients] have experienced a lot of bad treatment from doctors...so it can be hard to gain trust... [but] in general, when people find out that I know what I'm doing and I'm experienced and I'm culturally competent they are relieved and they are happy to have someone like that.

I think that none of us would have been aware that our staff was not open to trans patients. We had a session about 4 years ago...where we actually had someone in the room say that they didn't accept trans patients.

Patients tell you... "I'm not sure—I don't know where to go. I don't know what to do. They called me by the wrong name. People stare at me. Staff makes me feel weird." Those are things that they will usually reference. And those are things that we have control over.

Case Management

Providers consistently pointed to case management as one of the major barriers to quality health care for TGNC patients. According to many of the providers we interviewed, case management (specific to TGNC care) should be one of the most important components of a transgender

health program because it is the link between the TGNC patient and critical resources. There are unique aspects of transgender case management, including (but not limited to) finding culturally competent care, verifying and explaining benefit coverage and network requirements for services, and addressing social determinants of health.

I think that with the system, our case management could be significantly improved so that patients felt like there was someone who's going to help them navigate this path...

[Transgender patients] need...the case manager. You do need to have better identified who your specialists are going to be for this; there needs to be a better explanation of benefits, what is covered, what is not covered, and be very upfront about that. I think there needs to be things that need to be streamlined...For a lot of conditions, we do that, and we've now learned that you can do that. For HIV we need to do a lot of outreach—diabetes we need to do a lot of outreach. This is another case where we should be doing outreach.

Case management provides not only essential support to patients but also much-needed support to the health care providers. TGNC patients frequently do not have access to the information they need to navigate the health system and their health care, so when they find a provider whom they trust, often their unanswered questions fall to this individual. Without case management support, providers tend to manage things like scheduling surgeries and coordinating with surgical staff because they do not want their patients to suffer from mismanagement of care.

As a physician, I should help navigate the medical part but not figure out what paperwork goes where and when is travel going to be set up. Trying to make sure almost like a guidance counselor that XYZ is set up for them. I wish there was better case management.

My role really truly is clearly defined, but I feel like I'm playing a lot of different roles especially talking about benefits. Oh my gosh. That's not what I'm supposed to do

Trying to coordinate with [the external surgeons], time change[s], their operative schedule, it was not easy. So, it definitely required more of my time...

Adding to the complexity of treating TGNC patients is that some gender affirmation surgeries need to be contracted out to providers outside the health system; raising issues such as the coordination of travel, accommodations, communication about the surgery, presurgery instructions, postsurgery instructions, follow-up, and reimbursement. Providers are not always kept in the loop about these procedures and are forced to take extra time to proactively search for the status of their patients. Case management could be key in improving continuity of care and follow-up care after surgeries for TGNC patients who choose to undergo gender-confirming

procedures. A case management team might also be improved by including a TGNC patient navigator.

I just didn't feel that there was a good point person who was well acquainted with the folks that were [having] the surgery. So that made it more difficult for us to manage postoperatively, I think, and for the patient to communicate. They didn't really know who their point person was, whether or not they have a case manager.

One of the major gaps in care with respect to case management is the lack of information about the availability of case managers. As part of any transgender health program, the case manager will play a principal and meaningful role because they will be a source of or liaison to information and resources. These individuals need to be promoted and visible to patients, providers, and staff.

I don't know if we have a case manager. Do we? I'm not sure. So maybe there should be, right?

Another issue that providers described was the availability of resources available to them to help them to treat TGNC patients. This included access to patient education materials (including the health system policies), information on how to manage a patient's transition process, access to the list of preferred providers, and where to look to learn more about TGNC care. A simple list of online resources that can be easily accessed especially in a busy clinic was suggested.

So one of the barriers that I have is information on how to make surgeries happen.

We don't have a lot of resources here...in the clinic. I don't know if it's because we don't have a lot of patients that needs them, but [it would be] good to have some more information, you know, to hand out to patients.

Maybe if there was something smaller and quick and easier to read to digest—like a pamphlet and a book that touches on all the aspects with recommendations or advice on how to handle or deal with that situation.

Misgendering

There was full consensus among participating providers that misgendering and inappropriate language was a very important issue related to the quality of TGNC care. Some providers, who had more experience treating TGNC patients, believed this to be a basic and fundamental requirement for providers and staff who are interacting with TGNC patients.

I mean obviously, it's the most important thing you can do...it's a sign of respect and it's a sign of honoring their identity. I mean, it's a basic kind of right and privilege.

Other providers admitted that, despite their best efforts, they sometimes slip up and accidentally misgender a patient. The majority of providers had stories of their patients being inappropriately addressed within the health system,

whether by other providers, clinical staff, administrative staff, or member services.

I think it's extremely important. I find myself slipping, but I do work hard to at least address [transgender patients] the way they want to be called.

[Transgender patients] have some bad experiences with staff calling them the wrong name and then once they tell them, "Well, this is not my name" the staff insisting, "No, it's your name, it's in the computer and this is your gender, it's the gender in the computer."

Culturally competent training for all health system employees is needed to emphasize the importance of appropriate language in interactions with TGNC patients and to improve communication. Further, system-level supports to aid these efforts should be implemented, such as improving the EMR system, so it accurately reflects a patient's preferred name, pronouns, and gender identity.

...make sure that all the staff genders and names people appropriately and make sure that EPIC supports that...Even if you try you can make mistakes so EPIC would have to support that, people would have to be trained. And, again, make sure that it's clear for all who work for Kaiser that not treating transgender people appropriately is a big no-no and so that people are motivated to actually do it, however [they] feel about the issue.

As pointed out by several of the providers, misgendering TGNC patients can lead to serious adverse health consequences due to the exacerbation of patients' gender dysphoria.

Healthcare Access and Continuity of Care

Many participating providers pointed to issues of health care access for TGNC patients, especially difficulties in finding a preferred provider (ie, a provider who has experience and extra training in treating TGNC patients) and the limited availability of preferred providers because their patient panels are full. There is a need not only to expand the list of preferred providers but also to train all providers so they can confidently deliver treatment to TGNC patients.

[The health system] wants every patient to have access to any physician they want. But then once that physician is then closed out, even if that physician has a particular interest or expertise more than another, a new patient may not be able to access that.

Additional issues regarding the availability of surgeons who are internal to the health system were mentioned with the recognition that budget constraints may prevent this from happening at this stage. One of the reasons that external surgeons are an issue is that it creates a break in the continuity of care because providers are not updated about the status of surgeries, which in turn makes it difficult to provide appropriate follow-up care.

The continuity of care wasn't there...the base barrier for me is that I feel like once they've had their surgery they get lost, and unfortunately there are patients that seem to get lost in this bad follow-up.

Bias and Discrimination

We asked providers about implicit bias and whether they thought that it affected the quality of care of TGNC patients. We received mixed responses. There were several providers who believed that, by virtue of being a health care provider or being a provider who treats TGNC patients, implicit bias did not apply to them. Perhaps this was a function of some of the providers misinterpreting the question and not distinguishing between implicit and explicit bias. Regardless, there was a sentiment that bias among providers should not exist (in any form) with respect to any minority group and that, in general, providers treat all patients the same.

I would hope that we've come to a point in our professional lives where that shouldn't make a difference.

Even if you have some biases, it shouldn't come into the four corners of your medical management. So, I doubt it if there would be any doctor that would have any bias which would, you know, interfere with their management of this patient. I doubt it. I don't think so.

One provider who seemed to have much stronger views on the subject was well versed on what implicit bias is and how it affects behaviors. This provider noted that everyone has some form of unconscious bias depending on an individual's history and experience but that the key to dealing with unconscious bias was to recognize that a bias may be present and then to actively think about how their actions might be affected by it.

Of course. I think...everyone has unconscious bias. I try to work on my unconscious bias. But I know I have an unconscious bias specifically to age. And I try to be conscious of that or at least try to be conscious when I'm speaking to someone or explaining something and not just [thinking], "It's because you're old or you're young."

Moreover, it was remarked that not only is implicit bias an issue, but overt bias and discrimination may affect the care that TGNC patients receive. One provider remarked quite passionately that the system-level policy that allows providers to refuse to treat TGNC patients in and of itself reinforces discrimination when it occurs. There is no other group of patients that this applies to, and, considering that the TGNC population is particularly vulnerable to discrimination, the policy evoked frank disappointment.

...you already have providers here who said, "I'm not treating transgender patients." That's difficult for me to understand how those individuals are still working here. And

that sounds harsh and very controversial, but I don't see how they're still working here because we're here to provide care. I equate that to saying, "Well, you know what? I don't want to treat black people. I don't want to treat people who are of Asian descent." Then you shouldn't be working for [this health system]... They need to be able to see any doctor in our company and get excellent care that everyone else would get.

The area of medical ethics pertaining to the discrimination of TGNC patients by providers is a serious issue that deserves more attention and study.

Facilitators of Quality Transgender Care

Skilled Staff

The providers who were interviewed also described facilitators to quality transgender care in their health system. Although responses were inconsistent, providers pointed to clinical staff who they worked with who were particularly thoughtful and helpful when treating TGNC patients.

I'm blessed to have a very good clinical assistant. I have a good clinical assistant who's very thoughtful and is appropriating her use of pronouns, or she doesn't use them at all. She doesn't try to suggest pap smears in my trans males. She's aware of these things.

Communication/EMR/Continuity of Care

Providers also frequently pointed out the advantages of having an advanced EMR system with which to see patients' comprehensive medical management and to communicate with other providers. The EMR greatly facilitates the care for TGNC patients because it identifies the patient as TGNC, what stage they are at with their transitions, and any care they receive by other health system providers (such as endocrinology, obstetrics, or urology). Also, a new EMR module was recently rolled out to systematically document patients' sexual orientation and gender identity, including an organ inventory. Although still new, there seems to be hope that the sexual orientation and gender identity data will help in the identification and treatment of LGBTQ patients.

They're really good about trying to communicate and make sure we know this person's coming in or they're about to transition or they've just transitioned, or etcetera. So, I feel like that's a strength in terms of just communication in general with [this health system] we're lucky with the electronic medical record. I think in the end, things are kind of covered and for lack of a better word, so I think the resources are there, I don't know how much people know about them though.

Organizational/System Support

When providers were asked about system-level support for providing care to TGNC patients, the most frequent response was the Transgender Health Program and the

team that runs it. The Transgender Health Services program is a health system initiative that was developed to address health care issues specific to TGNC patients and to support patients as they navigate the health system.

I think now that we have a transgender team, I know who I need to reach out to when I need help or support. So that's really helpful.

Many providers pointed to the commitment of the organization to address TGNC health as a facilitator to improving to quality of care for TGNC patients. This was discussed in terms of patient health care and the preferred providers who are dedicated to TGNC health as well as support for the larger TGNC community. However, there was an acknowledgement that there were many resources still lacking and issues that remain unaddressed, and they expressed hope that the organizational commitment would translate into measurable improvements.

I think the fact that [the health system has] tried to have a presence in the transgender community in this area. We just went to a [community] transgender pride [celebration]—so that was helpful to be there and be with the community.

I think that it's wonderful that [the health system] does try to say that all patients deserve to be healthy and happy and they acknowledge that gender identity is part of that.

Provider-Patient Interactions

We questioned providers about their interactions with TGNC persons in the community as well as their patients and discovered that some providers took great pride in their community work with the TGNC population and were driven to improve their understanding of the TGNC community and patient-provider interactions:

I've taken that initiative to really work with this population. I'm not at the level that I would like to be. There are still things that I'm learning. I'm still developing my strategy of optimizing that relationship.

Some providers noted that, because of the nature of their specialty, the large number of TGNC patients that they see, and/or their personal situation, they are able to provide a more comfortable and safe space for TGNC patients to speak openly. One provider who was interviewed contemplated disclosing personal aspects of their personal life to their TGNC patients, recognizing that it might put patients more at ease.

I think that with them knowing that I am gay, that might be helpful to think, "Oh, this is someone who at least may be more understanding"...

Some providers go above and beyond clinical treatment to provide high-level support to TGNC patients.

I've counseled after gender-confirmation surgery getting them to have their birth certificate changed—that's really big

for a lot of them. And then also just trying to identify resources for them outside of [the health system] in terms of support groups, things like that.

Additional Needs to Improve the Quality of Transgender Care

Finally, providers were asked about additional opportunities or action that could be taken by the health system that could improve the quality of TGNC care. A topic that came up with both support and caution was to potentially develop a TGNC clinic. Such a clinic would include providers from different specialties, such as internal medicine, endocrinology, behavioral health, urology, and obstetrics/gynecology (all preferred providers), who are colocated in the same medical center. It was suggested that, in doing so, TGNC patients would have a safe environment to seek treatment and have confidence that all the providers participating in the clinic are knowledgeable, trained, and experienced at treating TGNC patients. In addition, this type of care model would likely improve the coordination and continuity of care. However, one provider pointed to a counter argument against a TGNC clinic, stating that patients might find such a clinic stigmatizing or make them feel that they are being segregated. Further, patients who do not openly disclose their TGNC status would not want to seek care at a TGNC clinic.

Another need that was mentioned to improve care for TGNC patients was a TGNC patient advocate. This would be a patient who has experience navigating the health system but who is also active in the larger TGNC community. A patient advocate such as this could have a big impact on patients who are trying to navigate stressful processes. Having peer support from someone who understands the challenges of the health care system and could share personal experiences and advice on how to overcome the challenges could be of enormous value to the TGNC patient population.

...it's one thing to just have this little checklist saying, well this is how you should talk to these people, but if we...had a trans advocate...a transgender patient and just let them be a point person for these patients to kind of latch onto, to help them navigate through. That's going to just take our service to that excellent level that we're striving towards.

Also, on the issue of social support, one provider suggested that organizing a patient event that invites TGNC patients to attend and interact with one another as well as health care professionals would be not only a source of needed information for patients but also a distinct and visible indication from the health system that they support trans health and TGNC patients. (Currently the health system has similar events for patient groups such as cancer survivors and patients with diabetes.)

I know the regional office has these things called Diabetic Day and Cancer Survivorship Day and that's actually for the

patients, not for the physicians and stuff. And so I don't know if there could be a Transgender Day and then those patients could feel comfortable to go to the location or region and there could be some doctors there to answer questions and resources and pamphlets. That's an option.

An event such as this could build trust between the health system and the TGNC patient population, combat misinformation, and offer the opportunity for TGNC patients to interact with one another.

DISCUSSION

In this qualitative study exploring the quality of care of TGNC patients from the perspective of providers, we identified several themes that we translate into recommendations for health systems who are interested in developing or improving a TGNC health services program. Overall, the quality of TGNC care at the health system we studied was perceived as average to most of the providers; however, it was acknowledged that the scale and the size of the health system poses challenges to implementing a comprehensive transgender health program. Although organizational endorsement of TGNC care appears to be present, providers agreed that this verbal support needs to be backed up with resources and policies to improve significant gaps in quality of care for TGNC patients. Although there was one provider who participated in our study who believed there were no barriers to the quality of care received by TGNC patients, the remaining providers offered insightful observations on current TGNC care at their health system. In our qualitative assessment, we identified several key themes. We have filtered and translated these observations into 3 discrete and feasible recommendations to health systems interested in improving or developing a transgender health program.

Recommendation 1: Case Management

A systematic case management model of care delivery should be established with case managers who are trained on the unique and comprehensive needs of the TGNC population, including requirements for treatment, therapy options, benefits and coverage, social determinants of health, finding culturally competent care, and serving as a liaison for out-of-network care. The need for improved case management is not solely to help patients but also to relieve the burden of providers. The TGNC case management team needs to be visible and available to providers to help work with their patients and for information and resources on transgender care.

Recommendation 2: Training

A comprehensive training program should be developed not only for health care providers but also for staff in the

clinic, health plan, and member services. These trainings need to be appropriate and specific to staff roles and presented in a way that is impactful to the intended audience. It is especially important that staff in any role understand the impact of misgendering TGNC patients and that the health system is clear that it does not accept intentional misgendering or refusal to address patients with preferred names and pronouns. For providers, additional in-person training to complement the continuing medical education courses should be made available and should potentially include simulated patients and role-play scenarios to improve the comfort level of providers who have not interacted with TGNC persons. The opportunity to view gender affirmation surgeries is also an educational strategy to help providers understand what TGNC patients undergo surgically in order to improve follow-up care of their patients.

Recommendation 3: Leadership Support

Leadership support is essential for developing a TGNC health program, and health systems should demonstrate support in terms of financial resources to address gaps in quality TGNC care, such as training and case management. Further, it is essential that health systems abide by a written policy of nondiscrimination regarding TGNC patients. At the core of quality health care for TGNC (and all) patients is the extent to which health care systems are successful at treating patients with respect, providing equitable medical treatment, serving the well-being of patients, and doing no harm. Thus, a policy mandating formal implicit bias and cultural competency training for all health system leaders, providers, and staff should be instituted, and, importantly, any policy that allows providers the option to refuse to treat TGNC patients should be eliminated.

The need for a multidisciplinary TGNC clinic received mixed opinions from providers and is not specifically part of the recommendations within, although it is worth careful thought because similar clinics have been effective in areas such as HIV and diabetes care.^{13,14} Although such a clinic may provide more visibility for a TGNC health program and facilitate centralized care for patients, addressing the 3 above recommendations as the first steps before considering such a clinic may be judicious. Also, another opportunity for the health system to build trust with TGNC patients would be to support a TGNC event where patients could receive information about TGNC care and benefits; interact with providers, researchers, and other patients; and feel like a visible patient population that is championed by the health system.

There are obvious limitations of the current study, including the small sample of providers and an analysis with no quantified measure to coding. Without codes, subsequent studies are not able to build on the codes that would

have been generated by this study. However, these study results (along with a companion analysis among TGNC patients) will be presented directly to the executive leadership in order to inform the direction of the Transgender Health Services program and establish priority areas for addressing gaps in quality care. These results may also inform similar programs at other health systems. Future directions to further the preliminary pilot study findings will include conducting structured surveys on a much larger sample of providers. A survey study such as this would allow the health system to monitor the progress of the Transgender Health Services program and assess comparisons between preferred and nonpreferred providers as well as by provider specialty. One of the aims of a repeated provider survey would be to establish and track discrete quality metrics across time.

In conclusion, this qualitative study of 11 providers within an integrated health system revealed many insights on how to improve the quality of care for TGNC patients. Although all of the providers were from a single health system, the experiences, comments, and suggestions they offered seemed worth taking note of regardless of health system. Dissemination of these study results to health system leaders will provide valuable input into the decision-making process of resource allocation. ❖

Disclosure Statement

The author(s) have no conflicts of interest to disclose.

Acknowledgments

We thank the Kaiser Permanente providers who participated in this study.

Authors' Contributions

Suma Vupputuri, PhD, MPH, participated in the study design, data collection, data analysis, and drafting, revising, and submitting the final manuscript. Stacie Daugherty, MD, MPH, participated in the design and revising the final manuscript. Kalvin Yu, MD, participated in the design and revising the final manuscript. Christine Truong, MPH, participated in the design and collection of data. Ayanna Wells, MS, CHES, participated in the design and revising the final manuscript. E.W. Emanuel, MD, participated in the design and revising the final manuscript. All authors have given final approval to the manuscript.

Funding

This research was supported by the KP Garfield Memorial Fund. The sponsor had no other role in this study other than funding.

How to Cite this Article

Vupputuri S, Daugherty S, Yu K, Truong C, Wells A, Emanuel EW. The quality of care of transgender and gender nonconforming patients: The provider perspective. *Perm J* 2020;25:19.227. DOI: <https://doi.org/10.7812/TPP/19.227>

References

1. World Professional Association for Transgender Health. Standards of care for the health of transsexual, transgender, and gender-nonconforming people, Version 7. *Int J Transgend* 2011 Aug;13(4):165-232. DOI: <https://doi.org/10.1080/15532739.2011.700873>

2. Bauer GR, Zong X, Scheim AI, Hammond R, Thind A. Factors impacting transgender patients' discomfort with their family physicians: a respondent-driven sampling survey. *PLoS One* 2015 Dec;10(12):e0145046. DOI: <https://doi.org/10.1371/journal.pone.0145046>. PubMed PMID: 26678997; PubMed Central PMCID: PMC4683012.
3. James SE, Herman, JL, Rankin S, Keisling M, Mottet L, Anafi M. The report of the 2015 Washington, DC: US Transgender Survey; 2016.
4. Cruz TM. Assessing access to care for transgender and gender nonconforming people: a consideration of diversity in combating discrimination. *Soc Sci Med* 2014 Jun;110: 65-73. DOI: <https://doi.org/10.1016/j.socscimed.2014.03.032>. PubMed PMID: 24727533.
5. Gardner IH, Safer JD. Progress on the road to better medical care for transgender patients. *Curr Opin Endocrinol Diabetes Obes* 2013 Dec;20(6):553-8. DOI: <https://doi.org/10.1097/01.med.0000436188.95351.4d>. PubMed PMID: 24468757.
6. Roberts TK, Fantz CR. Barriers to quality health care for the transgender population. *Clin Biochem* 2014 Jul;47(10-11):983-7. PMID:24560655. DOI: <https://doi.org/10.1016/j.clinbiochem.2014.02.009>. PubMed PMID: 24560655.
7. Sanchez NF, Sanchez JP, Danoff A. Health care utilization, barriers to care, and hormone usage among male-to-female transgender persons in New York City. *Am J Public Health* 2009 Apr;99(4):713-9. DOI: <https://doi.org/10.2105/AJPH.2007.132035>. PubMed PMID: 19150911; PubMed Central PMCID: PMC2661470.
8. Edelman EA, Corado R, Lumby EC, et al. Access denied: Washington, DC trans needs assessment report; 2015.
9. Bauer GR, Hammond R, Travers R, Kaay M, Hohenadel KM, Boyce M. "I don't think this is theoretical; this is our lives": how erasure impacts health care for transgender people. *J Assoc Nurses AIDS Care* 2009 Sep-Oct;20(5):348-61. DOI: <https://doi.org/10.1016/j.jana.2009.07.004>. PubMed PMID: 19732694.
10. Markwick L. Male, female, other: transgender and the impact in primary care. *J Nurse Pract* 2016 May;12(5):330-8. DOI: <https://doi.org/10.1016/j.nurpra.2015.11.028>
11. Ziegler E, Valaitis R, Yost J, Carter N, Risdon C. "Primary care is primary care": use of normalization process theory to explore the implementation of primary care services for transgender individuals in Ontario. *PLoS One* 2019;14(4):e0215873. DOI: <https://doi.org/10.1371/journal.pone.0215873>. PubMed PMID: 31009508; PubMed Central PMCID: PMC6476519.
12. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3(2): 77-101. DOI: <https://doi.org/10.1191/1478088706qp063oa>.
13. Kielly J, Kelly DV, Asghari S, Burt K, Biggin J. Patient satisfaction with chronic HIV care provided through an innovative pharmacist/nurse-managed clinic and a multidisciplinary clinic. *Can Pharm J* 2017 Nov;150(6):397-406. DOI: <https://doi.org/10.1177/1715163517734236>. PubMed PMID: 29123599.
14. Chaddha A, Smith MA, Patta M, Johnson HM. Hypertension control after an initial cardiac event among Medicare patients with diabetes mellitus: a multidisciplinary group practice observational study. *J Clin Hypertens* 2018 May;20(5):891-901. DOI: <https://doi.org/10.1111/jch.13282>. PubMed PMID: 29683249; PubMed Central PMCID: PMC6109367.