

Variations of Pediatric Transgender Care in the Midwest



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Abstract

The number of pediatric transgender patients seeking treatment is growing rapidly. As a result of this growth, there has been an increase in the number of clinics offering treatment; though there is variability across clinics in terms of resources and services accessible, due to various barriers. This project examines this variation in pediatric transgender care by clinic or provider location across areas of varying population density in the Midwest. Qualitative interviews were conducted with providers from Midwestern states who work with the population of interest. Interviews were transcribed and responses were organized by geographic region and similarity of responses. Major themes were identified based on commonly agreed upon topics or ones that varied by location of practice. Themes discussed in interviews included restricted access for patients, a lack of education among providers, and misinformation about the transgender population within the community. The only differences noted between providers by geographic region were patient demographics and number of providers working in their state. Providers reported that the future of transgender care is moving in a positive direction, despite the presence of significant barriers. Issues regarding pediatric transgender care transcend geographic differences. Better education about the transgender population for both providers and the community is necessary to improve care for this patient population. Democratization of care would also protect patients' access to care, as it would be more difficult to restrict through legislation.

Background

In the United States (U.S.), the transgender population is growing [1]. There are an estimated 150,000 transgender youth ages 13—17 in the U.S., and that number is expected to continue to grow [1, 2]. Many transgender youth experience gender dysphoria (GD), which the American Psychiatric Association defines as “conflict between a person’s physical or assigned gender, and the gender that he/she/they identify” [3, 4].

Treating gender dysphoria is complex and individualized. It generally calls for a combination of therapies that could include talk therapies, gonadotropin—releasing hormone (GnRH) agonists to block hormones, hormone replacement therapies (HRT) such as testosterone or estrogen, fertility consults, or surgical consults and interventions [2, 4]. For those who receive gender affirming services, not only does their GD resolve, but their psychological function improves as well, such that they have similar or better overall well-being compared to the general population [4, 5, 6, 7]. All but talk therapy are known as transition services, as they allow patients to transition to the gender they identify as. These treatments require an interdisciplinary effort with multiple providers including pediatricians, obstetricians/gynecologists, surgeons, psychologists, therapists, social workers, and nurses [4, 5].

Given the growth in the population seeking care, it’s thought there will be an uptick of specialized clinics in the

U.S. where children and youth can receive these gender affirming services. Clinics vary in support and resources available due to their geographic locations, causing disparities and forcing patients to travel for transition services [7, 8].

Providers spearheading these clinics have a passion for transgender health, but do not always receive clinical training, as the specialized programs available have only been recently developed. To compensate for the lack of education, multiple groups like the World Professional Association for Transgender Health (WPATH), the American Academy for Pediatrics (AAP), University of California San Francisco (UCSF), and others, have presented guidelines on standards of care and methods of treatment for children and adolescents with GD. These guidelines include how to address the topic with the patient and family, properly assessing the patient, and recommended ages for HRT as well as proper dosage [2, 9, 10]. Providers use these guidelines as a foundation for their practice or clinic when addressing the topic of gender dysphoria with their patients [2, 9, 10].

Barriers to addressing the health of trans youth can be traced to inability to access care due to the location of the patient, insurance gaps, lack of competent providers to treat the population, and discriminatory legislation [1, 2, 5]. Services accessible to patients can vary by geographic location and the insurance coverage varies by geographic location as well [1]. Competent providers are not widely

available since topics like gender dysphoria and being transgender are not taught to all incoming medical providers [1, 2, 11]. Discriminatory legislation was defined as legislation that restricts access to care or criminalizes it, and is an barrier frequently faced by trans youth [2, 5, 6]. These are just a few barriers directly related to transgender care, and are detrimental to the health of trans youth. The American Academy of Pediatrics reports “56% of youth who identified as transgender reported previous suicidal ideation, and 31% reported a previous suicide attempt, compared with 20% and 11% among matched youth who identified as cisgender, respectively” [2]. Gender affirming services help to resolve GD and improve psychological function, so that trans youth have similar or better overall well-being when compared to the general population [4, 5, 6, 7].

This project aims to assess variations in pediatric transgender care across the Midwest by looking at the similarities and differences between pediatric transgender care in large cities versus small cities/large towns. Additionally, this project will identify barriers and gaps to pediatric transgender care from the provider’s perspective, creating recommendations for the state legislature, residency programs, and health professional programs to close gaps and improve access to services [12].

Methods

The study population included providers working with pediatric transgender patients. Providers included therapists, psychologists, physicians (e.g. pediatricians, surgeons, psychiatrists, etc.), nurse practitioners, and physician assistants.

To create a sampling frame, providers need to meet the inclusion criteria of (1) working with a pediatric transgender population at least 1 day per week, (2) providing at least 1 treatment option for gender dysphoria (talk therapy, GnRH agonist prescription, HRT, fertility treatments, or performs gender affirming surgeries), (3) location of their practice was in the Midwest (North Dakota, South Dakota, Nebraska, Minnesota, Iowa, Missouri, Wisconsin, Illinois, Kansas, Michigan, Indiana, and Ohio), and (4) in either a Large City (LC) or a small city/large town (SC). A large city was defined as a population of 200,000 residents or more, a small city was defined as having greater than 100,000 but less than 200,000 people, and a large town was defined as having a population of 100,000 people or less (Figure 1).

A random sampling frame of 80 providers was compiled based on the inclusion criteria. A convenience sample size

of ten providers in large cities (LCP) and ten providers in small cities/large towns (SCP) were chosen based on provider background, location of practice, indication of guidelines followed pertaining to standard of care, and interest in the transgender population. Providers were contacted via email or phone call to participate in the project.

Qualitative interviews were conducted with providers in person, over the phone, and through video conferencing. Interviews were 30 minutes long on average. Questions revolved around the provider’s clinic, the services they offer, treatment philosophy, standard of care, practice limitations, additional barriers, and the future of transgender care.

Interviews were transcribed manually, and a content analysis was performed to categorize the information collected by geographic location of provider and themes/subthemes based on similarities and differences in responses. Gaps in care were identified and used as the foundations for recommendations.

Results

Provider Characteristics

Of the twenty providers invited, ten providers responded and completed the qualitative interview. Four met the small city/large town criteria and six met the large city criteria. States that providers worked in included South Dakota, Minnesota, Iowa, Indiana, Illinois, and Wisconsin. Providers included pediatricians, medicine/pediatrics physicians, psychologists, psychiatrists, therapists, gynecologists, and endocrinologists. Half of the providers interviewed worked in mental health (Table 1).

Nine providers worked in a gender medicine or transgender clinic, while one worked with the population within their individual practice. Services provided by interviewees included diagnostic assessments, mental health services, fertility consults, surgical consults, gynecological services, GnRH agonists prescriptions, HRT (estrogen or testosterone), and primary care services. The clinics that providers worked in also had surgical services, speech therapy, nutritional services, family education resources, school support, and legal support. Providers also described other services available in the community, including safe exercise spaces, play groups, vocal coaching, facial feminization, school-based supports, parent support groups, and legal services, to support the child and their family during and after transition. These networks were still present in the small

cities, though the network of resources were smaller than in the large cities.

All providers were aware of guidelines created by AAP, WPATH, University of California San Francisco, and The Endocrine Society. Both mental health and medical health providers noted following WPATH guidelines, while only medical providers followed guidelines presented by AAP and the Endocrine Society. Two LCPs mentioned they prefer the Australian guidelines as they were written with a “youth focus” and less of a gate—keeping model compared to other guidelines. An LCP mentioned they actually wrote their own guidelines, utilizing pieces of others to create ones that are “rooted in science”, while an SCP didn’t follow any guidelines directly, instead using their own discretion and knowledge to treat patients.

Patient Demographics

All providers reported having at least 40 transgender patients on their panel, with clinic panels ranging from 120—1300 patients. The age range of patients was 3 to 25 years. In five established clinics, providers reported seeing new patients through 18 years, but would continue to see established patients through ‘young adulthood’. Three providers (one LCP, two SCPs) reported being trained to treat adults as well, so they continue to see their patients through adulthood. Multiple providers noted that their clinic or location is the only location in the state or surrounding area with these services, forcing patients to travel for appointments. The longest distance traveled was 6 hours, while the average travel time was 3.5 hours. All providers noted that patients come from multiple states. SCP 2 noted that distance has been less of an issue with the integration of telehealth into their practice. LCP 6 noted there had not been a strong telehealth structure until the COVID—19 pandemic, which has forced many clinics to utilize virtual visits.

All providers reported that transfers of care occurred on rare occasion. Transfers were typically due to a move, transition to the adult clinic, or no longer requiring specific services when the patient moved on or was considered “well—adjusted.” At times, transfers would occur when the patient was seen for an initial visit, but the patient wanted to have a follow—up closer to home. SCP 2 reported “I can treat all ages, and they spent all this time looking for someone that is competent on the issue that they can trust, it's unlikely they will leave until they are ready.”

Limitations and Barriers in Pediatric Transgender Care

Themes discussed in regard to limitations and barriers of pediatric transgender care included restrictions in access to

care, inconsistencies in recommendations, inadequate education, and general misinformation in the community regarding transgender care.

Restricted Access to Care

Restricted access to care was defined as a barrier for either the provider, the patient, or both, that prevents the patient from accessing health services. Many providers reported frustrations with different aspects of care, specifically limitations they had or the barriers their patients had in receiving care.

An issue mentioned by all providers interviewed was difficulties with insurance and lack of coverage for pediatric transgender services. While some states had more inclusive language toward gender affirming services, commercial insurance providers required pre—authorizations and appeals to obtain coverage for some services, especially HRT and GnRH agonists. One provider noted they had to hire support staff for the sole purpose of handling pre—authorizations and paperwork because it took up “most of their time.”

Operational logistics was another concern, as providers noted issues with staffing and clinic space. They reported having minimal support staff to help run the clinic, which has forced staff to become overworked, along with additional pressure due to paperwork for insurance, including filing pre—authorizations. All of the gender health clinics were within a specialty (e.g. endocrine or adolescent medicine), so they were only able to use clinic space on a biweekly, weekly, or monthly basis. One LCP noted they were currently trying to expand their clinic times but were “fighting other departments for the space.” With limited clinic space, not one provider interviewed spent all of their time with transgender patients. Nine providers had designated clinic days, while only five of those providers had transgender patients interwoven into their clinic schedule, limiting transgender patient access to that provider.

For clinic and panel capacity, providers reported waitlists for an intake appointment with themselves or their clinics that were 1 to 9 months long. Two LCPs circumnavigated the waiting list by providing a questionnaire for the patient to complete and submit, so they were able to ‘triage the patient’ to prevent self—harming or suicide completion while on the waiting list. All providers noted a significant need for more providers to work in transgender care in order to decrease wait times. Mental health providers especially felt there was a bottleneck in attaining services, as other mental health providers did not feel qualified to address GD in their practice. This leaves some mental

health providers feeling as if they are the only ones in their state addressing the issue, which in some cases was accurate. A bottleneck effect was also noted by two medical providers due to a lack of education on the topic of pediatric transgender care.

Services available within the clinic was another restriction. Only two clinics were able to provide all gender affirming services, including surgical procedures. Two LCPs reported not having both mental health and medical components within their clinic, leading to increased travel to receive care at multiple locations. All providers mentioned having a network of clinics and providers available by referral to fill in these gaps.

Finally, providers felt that clinics were not reaching the vulnerable transgender population. All providers interviewed reported that a child needs at least one adult in their life to provide consent to receive treatment. Two providers noted that their patient population was predominantly of a higher socioeconomic status because of this requirement, as they have the familial support and financial means to obtain treatment. They shared, “we are missing the ones that are already kicked out of the house because their parents were not supportive or those that are unable to come out due to fear of their disapproval.” This is concerning as those who do not receive care are likely to live a lower quality life and be at higher risk for depression, anxiety, and suicide [2, 6, 7].

Inconsistencies in Transgender Care

A major theme throughout was the differences between providers when it came to guidelines followed. There are multiple guidelines a provider can follow, which has led to providers choosing a set of guidelines that they feel best fits their philosophy of care. This variation has led to inconsistencies in care. For example, an LCP noted that the two clinics they worked in had significantly different approaches, with one clinic being more conservative than the other and the guidelines they followed reflected those differences. This included variation between the clinics and even within provider panels on the appropriate ages for receiving HRT, GnRH agonists, or surgical referral.

There was some discourse surrounding the concept of gatekeeping in pediatric transgender care. Gatekeeping was defined by a provider as a way to “verify the concerns presented by the patient are valid and gender affirming treatments are appropriate.” Some providers thought it was necessary, especially as this field of practice is more controversial than others. Others felt it was too much and prevented patients from receiving care as it required patients to receive treatment for a long period of time and

obtain letters of support from providers before receiving certain treatments. One provider mentioned the informed consent model, which is commonly used in treating adults with gender dysphoria. Informed consent occurs when the provider reviews the risks and benefits of a treatment or procedure, but allows the patient to make the decision rather than the provider requiring letters of support or patients being treated for a set period of time. The provider felt informed consent would be more beneficial and allow patients to receive the care they needed as it posed fewer obstacles for the patient to overcome.

Education About Transgender Care

Pediatric transgender care is not typically part of the core curriculum when studying to be a healthcare provider. There are some fellowships and residencies that include education on gender affirming care, but this is usually included within LGBT care. All providers reported fielding calls from primary care providers, pediatricians, or mental health providers who felt uncomfortable talking about this topic or prescribing medications. One provider even mentioned that their patients teach them at times and share upcoming research and treatments available. Multiple providers mentioned they work to educate current and incoming providers on the topic of transgender care, by providing lectures and seminars so those providers can feel more knowledgeable and comfortable discussing the topic when practicing [13].

Misinformation about Transgender Care

Community misinformation about the transgender population is a major barrier to care. All providers mentioned families’ lack of understanding of being transgender as a huge barrier to addressing pediatric patient needs. For many, simply providing education and “demystifying” the transgender population had a positive impact and decreased stigma. An LCP reported that pediatricians working in their clinic spend time “counseling the parents on how to be a good parent,” where they covered the importance of listening to the child and how to affirm and encourage them during this time of questioning and identifying their gender.

Providers from both small and large cities spoke to the public (e.g. schools, companies, and other groups) about being transgender in order to educate and encourage the community to create a safer environment for this population.

An SCP reported that misinformation and fear have led to proposed legislation that would be detrimental to the transgender population. One example is South Dakota’s HB 1057, which aims to make prescribing HRT and GnRH

agonists to minors illegal and make it a class four felony for healthcare providers to prescribe these treatments. An SCP observed that misinformation about treatments for gender dysphoria and fear of the population were the driving forces behind this proposed legislation, and that it will take community education to stop the bill from progressing [14]. Misinformation and the mentality toward the transgender population, “especially in this social climate,” were talked about frequently by all providers. Providers also discussed HB 1057, or Arizona’s version of South Dakota’s HB 2706, which would prohibit transgender youth from playing in the sports of their identified gender, as another example of the pushback that the pediatric transgender population is facing [15].

Future of Transgender Care

When talking about the future of transgender care, all providers noted that care has improved throughout their careers, and they expect it to continue improving. They expressed excitement that clinics are expanding, and that progress is being made. The final discussion revolved around what they hoped to see change in the short and long term when it comes to pediatric transgender care.

One major hope was to see more gender clinics and knowledgeable providers all over the U.S., and especially in rural areas. SCPs and LCPs alike hoped to see an increase in primary providers comfortable talking about GD. SCP 1 wanted to see injection clinics for patients that have trouble with administering their treatments. These clinics are already common in adult care settings but are not widely available in the pediatric setting. With increased infrastructure for telehealth due to COVID—19, LCP 6 hoped that this infrastructure would remain in use after the pandemic, as it would increase access to care. Two providers discussed the idea of working in tandem with the primary clinics, where specialized clinics would conduct the assessment and diagnosis and create the treatment plan for other providers to implement, which could limit costs and travel.

All providers reported a need for improved education for providers but were split on whether continuing medical education (CME) or training during school and residency would be more beneficial. Some believed this topic should be taught to all health professional students, with LCP 1 stating, “like how all providers have some knowledge of HIV.” LCP 4 agreed with this sentiment but felt it would be difficult, as pediatric transgender care could fall under the definition of “controversial care,” making it difficult for institutions to integrate into the curriculum. They equated this with the current climate surrounding abortion care and stated that care should be “democratized” (i.e. the

majority of pediatric providers should be able to address GD across the U.S.), as there is strength in numbers and discriminatory legislation would be less likely to succeed [16]. “Groups and policies are able to attack providers and transgender care because there are so few [clinics to begin with]. It’s much easier in a small state where there are one to two providers that can be targeted versus if everyone practiced some form of transgender care.”

Three providers mentioned the need for guidelines that are evidence—based. SCP 1 reported that the abundance of research is promising, but only evidence—based interventions will move care forward. SCP 2 pointed out that WPATH is working on the 8th version of their guidelines and International Classifications of Diseases (ICD), which will be updated in 2022 to version 11. The new versions of these guidelines and classifications will change the terminology for gender dysphoria to gender incongruence. They expect that with this new terminology for GD diagnosis, there will be less difficulty in obtaining insurance approval.

During the discussions, all providers mentioned the safety of their patients, and the need to make sure that future changes keep patients’ well—being in mind. This is because of increased rates of harassment and bullying, both from individuals and policy makers in the form of discriminatory laws. Multiple providers hope that with increased understanding within the population, society will become more accepting, resulting in fewer legislative and insurance—related restrictions.

Discussion and Greater Significance

Results indicate that providers treating transgender patients in small cities and towns have similar experiences to those in large cities. Both groups of providers saw a large number of pediatric patients across the Midwest. SC providers indicated that transfers rarely resulted from clinic limitations, rather all transfers occurred due to the patient aging out of the pediatric clinic, moving out of state, or moving on and not needing care. This final reason was most common for mental health services.

The limitations and barriers present for LC providers were similar to those faced by SC providers. Limitations included lack of time, insufficient resources, and too few providers to properly treat the population. The only difference in limitations noted between LCPs and SCPs was the number of providers available to treat the pediatric transgender patients; this number was greater among LC providers. SC providers noted they were either the only one providing these services, or that they were one of very

few. Barriers to care present for both LCPs and SCPs included self—selecting of patient populations (i.e. those who had fiscal and social support to begin transition were more likely to seek care) and accessibility of care (i.e. insurance coverage, costs, and travel time). All providers, regardless of geographic location, felt the future of transgender care was slowly moving in a positive direction. They believed it would continue to improve with improved provider and community education and the democratization of care.

The results of this study indicate that providers who regularly work with the pediatric transgender population have similar experiences and desires regarding how to provide care to their patients. Geographic location did not play a critical role in limiting their ability to provide care or their knowledge of transgender care.

Comparison to Current Literature

The results of this study differed from the existing literature, which noted fewer resources and education available for providers in smaller cities. This variance is likely due to differences in the study populations. Primarily, research on transgender patients in smaller populations has focused on primary care providers, pediatricians, or mental health providers, who do not work regularly with the transgender population [1, 8, 17]. Transgender patient research is also performed in tandem with the LGBTQIA+ community as a whole, rather than just focusing on transgender patients alone. Transgender care has only recently been considered on its own in research studies [17].

Strengths and Limitations

This study was unique as it included providers of both mental health and medical practice, while focusing solely on patient care. Looking toward the future by asking how care for pediatric transgender patients can be improved was also a novel approach in the emerging field of transgender healthcare research. The sample size in this study was small, with only 10 participants from the Midwest region. Additionally, non—random sampling techniques were used, which limits the study’s generalizability to the U.S. as a whole. Future research that either looks at other regions of the U.S. or the U.S. as a whole should be conducted. Recall bias was likely as providers might not remember accurate numbers for panel size and travel time in the moment. Selection bias was also present, as providers who responded to the inquiry were more willing to discuss the topic. This was noted by a participant during the interview, who explained that SCPs might have ignored the request to protect their practice and

patients. Fewer SCPs responded to the interview inquiry, and those who were willing to respond may have been more vocal about transgender issues or lived in an area where they felt comfortable discussing their pediatric transgender practice.

Recommendations

The goal for healthcare workers is to implement a gold standard for transgender patient care, which removes disparities in care among transgender patients when compared to their cisgender counterparts. This calls for education for medical and mental health providers on the topic of transgender health and gender dysphoria among youth, so that a greater number of providers feel comfortable addressing this issue, rather than simply referring to a specialist. One potential solution is to develop a specialized team of at least one mental health provider and one medical doctor who are considered experts to assess and diagnose the pediatric patient, given the controversial nature of treating GD. Then, maintenance of care and follow—up would not require a specialist. Working with a family’s primary care provider, who they see regularly, could increase the comfort level of families and patients. Creating a strong infrastructure for telehealth, would also improve education and decrease costs and travel time for the patient.

The goal for educational institutions is to train competent medical professionals to treat patients. Increasing the number of providers who care for pediatric transgender patients protects this population from discrimination through legislation, as there is strength in numbers. Training for providers can be given in medical schools, physician’s assistant or nurse practitioner programs, residencies, and/or through CME opportunities. By revising the curriculum in health professional schools, incoming providers will have foundational knowledge on the transgender population. This knowledge would only grow during their ongoing training, and they would be more comfortable discussing this topic with families. Having CME opportunities available that focus on pediatric transgender care is necessary to address knowledge gaps among providers who are already in practice.

Policy makers must create policies that are representative of the society they are working for, which includes the trans population. In the 2020 legislative session alone, there were 20 bills proposed in state legislatures across the U.S. that would directly prohibit healthcare access for transgender youth [16]. This discriminatory legislation was described by a provider as “misguided and without

any background on the topic.” Education about the transgender population and properly treating gender dysphoria is vital to prevent discriminatory bills from being created and passed in the legislature. As a policy maker, it should be ones’ duty to speak out against discriminatory legislation and instead propose legislations that promotes an inclusive environment and protects the health and safety of trans youth [2]. These recommendations send a message to the trans community that, as human beings and citizens of the U.S., they should have the same rights as their cisgender counterparts.

Conclusions

Providers in Midwestern states who regularly work with pediatric transgender patients experience similar limitations regardless of location of practice and have similar streams of thought when it comes to improving care for this patient population. By educating the general and medical community about the transgender population, a more inclusive environment can be created. An inclusive environment would improve the quality of life for trans youth, as they would face less harassment and discrimination for their gender identity and have better access to proper healthcare [2, 6, 7]. The recommendations identified in the study focused on ways in which healthcare facilities, educational institutions, and policy makers can create an inclusive environment for trans youth and improve the quality of life of this community.

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