COMMUNITY-BASED PEDIATRIC PROVIDERS ON MEETING THE UNIQUE NEEDS OF LGBTQ+ IDENTIFYING YOUTH: A FOCUS GROUP

By

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Abstract

LGBTQ+ youth are an increasingly at-risk population due to health disparities such as increased risk of adversity, anxiety, depression, suicidal ideation, homelessness, violence, substance use, obesity, disordered eating, and sexually transmitted infections. Yet there is a gap in graduate pediatric provider education to address the unique needs of this population. To learn more about this gap, we conducted a focus group of currently practicing pediatric providers. Analysis of transcripts was then conducted using a content and thematic analysis and prior literature review. Through this, we identified an overarching theme of LGBTQ+ patient wellbeing supported by three domains: 1) Increasing At-Risk Population 2) Inclusive Institutions 3) Empowering Pediatric Providers. The three domains were supported by 10 facilitators and 11 barriers, with these barriers being even greater in rural communities. This, in conjunction with previous literature, enabled us to propose directions for future educational interventions. Further research in additional clinical settings is needed to confirm conclusions present.

Introduction

LGBTQ+ populations are growing (Diana & Esposito, 2022), and although medical schools have started to implement education regarding treatment of adult members of this population, there is still much to be done regarding pediatric populations. LGBTQ+ youth consist of nearly 15% of all adolescents which includes individuals who describe themselves as lesbian, gay, bisexual, transgender and queer (Kann et al., 2017), yet over half of providers do not recall any formal training on

LGBTQ+ youth as indicated from survey data at University of California San Francisco (Azhir et al., 2019).

LGBTQ+ youth experience increased risk of adversity and trauma (Baams, 2018), anxiety, depression, suicidal ideation (Mustanski & Espelage, 2020), homelessness (Rhoades et al, 2018, Gambon & Gewirtz O'Brien, 2020), substance use (Kann et al., 2015), obesity, disordered eating (Calzo et al., 2017, Schvey, 2020), sexually transmitted infections and HIV (Hunt et l., 2018, Kann et al., 2015), bullying, harassment, and violence (Earnshaw et al., 2017). These disparities are consistent with LGBTQ+ adults which suggests that they may carry on from childhood. This suggests prevention in childhood could alleviate a lifetime of risks, poor health outcomes, and lifetime complication. These risks are increased even more when focusing further on transgender/gender diverse (TG/GD) individuals (Chong et al, 2021, Rafferty et al., 2018, Rider et al., 2018, Delozier et al., 2020) where earlier social, hormonal and/or surgical affirming care during adolescence for TG/GD youth improves psychosocial outcomes but historically has been sparsely provided (Olson et al., 2016). There is room for significant improvement to better care for this at-risk population.

Many barriers exist for LGBTQ+ individuals that can impede their ability to receive adequate care. For instance, discrimination, or the unjust or prejudicial treatment of certain groups, in medical settings can contribute to a lifelong hesitancy to seek out care or disclose their sexual identity with providers (Rossman et al., 2017). This compounds disparities. Other reasons for self-nondisclosure include internalized stigma, and the belief that being LGBTQ+ and health are not related (Rossman et al., 2017). This can cause missed opportunities with exploring individual sexual risks,

providing appropriate screening, and offering anticipatory guidance, information, and support (Zelin et al., 2019). When individuals did disclose, they experienced a wide range of reactions from providers including discrimination and disbelief to respect and affirmation (Rossman et al., 2017).

Roughly 70% of LGBTQ+ adolescents aged 14-19 have experienced at least one experience of enacted stigma (Gower et al., 2019). Stigmatization, referring to the internal state of shame or fear of being associated with a condition or identity, can lead to enacted stigma; victimization such as bullying, harassment, microaggressions or violence; or discrimination (Parker et al., 2018). Not only stigma and discrimination in healthcare settings, but discrimination and stigma present in other settings such as school, home, and community environments can contribute to barriers in accessing healthcare. This may be due to stigmatization associated with political or religious beliefs, and misinformation spread by the media including that sexuality is a choice (Hodges, 2021), children are too young to know and make decisions about their sexuality and gender identity (Robinson & Davies, 2016), gender neutral facilities are a threat to safety and order (Blumell et al., 2018), and definitions surrounding proper ways to love and what it means to be married (Duarte, 2017). There is also increasing legislation in many states being made to limit what care can be provided especially for TG/GD youth (Park et al., 2021, Janssen & Voss, 2021, Barbee et al., 2021, Turban et al., 2021).

In rural communities, concerns for stigma and discrimination are even greater (Shaver et al., 2018, Henriquez & Ahmad, 2021). Limited access to care and fewer support resources makes seeking care and treatment challenging (Coughlin et. al,

2019). These factors alongside the uniqueness of living in a smaller community can combine to create fear associated with anonymity and confidentiality when seeking care. A higher level of density of acquaintanceship, or proportion of members of a community known by the inhabitants of that community (Freudenberg, 1986), in rural areas reflects this. Rural communities are also more often faith-based than urban locations which can further increase fear of discrimination, as well as there are decreased resources and support services available due to geographic isolation (Henriquez & Ahmad, 2021). Lastly, there has been shown to be an even greater variation in rural areas in knowledge across LGBTQ+ content areas (Shaver et al., 2018).

In addition, there are barriers to receiving care grounded in lack of provider knowledge and comfort providing care. A survey of residents in Yale pediatric and combined medicine and pediatric residency programs comparing historical results from 1998 to 2012, showed an improvement in asking about sexual history and orientation with patients under age 14 currently, yet 45% of residents still feel they don't know enough about these patients' needs to have effective discussions (Zelin et al., 2019). At Columbia, most residents lacked knowledge of where to refer patients for mental health care, transgender care, support groups, emergency shelters, and family resources and few providers felt comfortable asking about gender and sexuality when conducting a patient history (Roth et al., 2021). In addition, pediatricians claimed that they had limited training on medication management for transgender patients such that less than 60% of respondents felt comfortable providing care as of 2017 (Vance et al., 2017). Many of these providers indicated they are highly interested in receiving more education (Shires

et al., 2017, Roth et al., 2021). The mixed graduate educational experiences and lack of standards defining LGBTQ+ evidenced-based care begs to question, is this a systemic failing in our healthcare system, and how can it be improved?

Sample curriculums have showed progress on this topic, although research is rather limited. At University of California San Francisco (UCSF), a week-long resident-led curriculum increased terminology knowledge and provider perceived preparedness (Azhir et al., 2019). In addition, six-online models in conjunction with an observational experience at a UCSF pediatric gender clinic increased knowledge of medical and psychosocial issues facing transgender youth (Vance et al., 2017, Vance et al., 2020). At Columbia, a yearlong curriculum increased provider comfort level and knowledge, self-reported clinical practice, and faculty preparedness in teaching this material for asking about sexual orientation, gender identity and sexual practices as well as psychosocial screening and preventative/medical screening guidelines and managing transgender patients (Roth et al., 2021). A quality improvement study at an outpatient primary care clinic in North Carolina with optional trainings, modernized intake documents, and welcoming signage visual cues increased provider preparedness and empowerment (McKinnish et al., 2022).

Pediatricians have a vital role in health outcomes for these individuals because often they are the first to provide care. Thus, there is an urgent need to improve education and overall, forward an inclusive healthcare system through these providers unique opportunity to connect patients to services and affirm identities (Azhir et al., 2019, Diana & Esposito, 2022, Marcell et al., 2017). Various recommendations to increase inclusivity include mandatory trainings of all office staff to not presume

heterosexuality of patients, provide the context that being LGBTQ+ is normal to support and affirm LGBTQ+ identities, being able to answer questions and correct misinformation surrounding LGBTQ+ topics, advocacy to promote policy changes in the community, symbolism associated with displaying pride flags, and knowledge of organizations that serve LGBTQ+ populations (Azhir et al., 2019*,* Geist et al., 2021, Earnshaw et al., 2017, Chong et al., 2021*).* For TG/GD informed care, recommendations include emphasizing early recognition of TG/GD youth and the associated mental health disparities, fostering inclusive and welcoming clinical environments, limiting provider assumptions of patient sexuality and gender identity, incorporating gender-affirming reproductive health care, and expanding clinical research regarding this population (Geist et al., 2021).

The combination of facilitators and barriers to evidence-based care suggest there is an extreme need in improving healthcare for LGBTQ+ youth, especially those residing in rural areas. Literature identifies a knowledge gap among most providers and suggests a lack of comfort in providing care such that providers do not feel equipped to meet the needs of their patients within this population of interest. There is a major gap in research and education surrounding appropriate care of LGBTQ+ youth.

Methods

This study was conducted via a focus group methodology and was approved by IRB at the PI's institution. Inclusion criteria for providers included being board certified in pediatrics under their respective licensing authority and to have been practicing for at least a year.

Recruitment was conducted with purposive sampling via a google form through organizations that employ community-based pediatricians (publicly available organization email addresses were used to request dissemination of the recruitment flyer, email, and google form to the provider population). Upon confirming the potential participants met inclusion criteria, a consent form was emailed to the potential participants for review. Then, participants were scheduled for a 60-minute Zoom focus group based on collective availability.

Participants were instructed the interviews were recorded on Zoom and were asked to provide their verbal consent to participate in the focus group. Participants were given the option to withdraw at any time and were not compensated in any way.

Upon review of the interview, the video recording was immediately deleted, and the audio recording was deleted after 20% of the transcripts were validated. Using a qualitative descriptive approach, we conducted analysis of transcripts. This included going through the transcripts and making notes where research questions aligned with or separately from the literature. Then, collective themes were identified. This data was utilized to propose future directions for educational interventions.

The focus group consisted of semi-structured questions:

- Do family circumstances of LGBTQ+ youth / individual provider beliefs impact how care is provided to LGBTQ+ youth?
- What are the perceived roles as a community-based provider in a patient's sexual and gender identify?
- What graduate training experiences did providers receive related to LGBTQ+ youth and how comfortable are providers in providing care?

- What do providers perceive as barriers to care and services for the LGBTQ+ youth population they serve?
- What do providers feel would be most beneficial for other community-based pediatric provider's learning needs in supporting the LGBTQ+ youth?

Results

A total of two pediatric nurse practitioners with doctorate of nursing practice degrees and twelve years of total collective experience at the same community-based health center were interviewed. One of which has exclusively provided LGBTQ+ care being the sole provider in their county to possess the skills to manage medications for transgender patients, and the other having more general exposure to these populations in primary care settings.

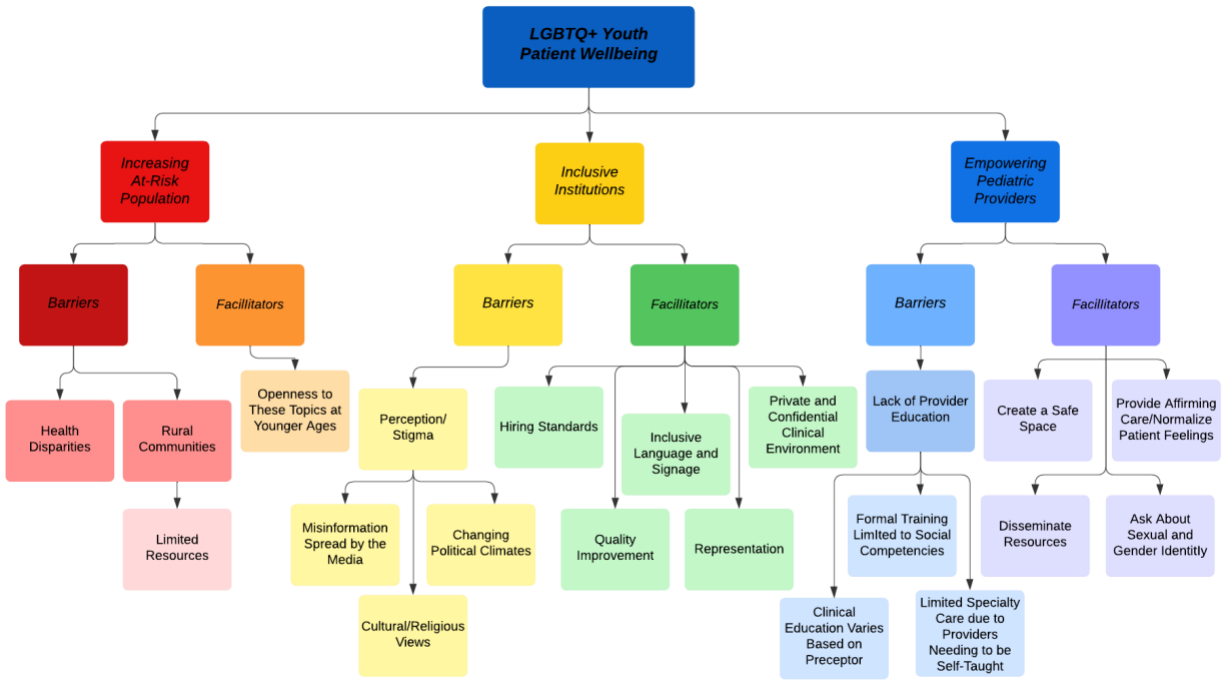

Figure 1: Flowchart identifying key factors and themes in LGBTQ+ Youth Patient Wellbeing

An overarching theme of LGBTQ+ Youth Patient Wellbeing was identified, supported by three domains (1) Increasing At-Risk Population (2) Inclusive Institutions (3) Empowering Pediatric Providers. These three domains were supported with 10 facilitators and 11 barriers.

Increasing At-Risk Populations:

Facilitators of this theme were identified as that new generations are more open to these topics at younger ages. This increases the amount of people who feel comfortable in their identity.

Barriers include the significant amount of health disparities this population faces as identified previously. In rural communities specifically, geographical isolation and expansive rural landmass were identified as barriers that limit specialized care available. There are less resources and support associated with sheer less population density such that it is much harder to form a support group or get funding for fewer people. The expansive rural landmass makes it especially important to point out the major responsibility for one of the participants—being the sole provider providing gender affirming care to a county larger than the states of Connecticut and New Jersey. An internal referral process was proposed to aid this though.

Inclusive Institutions:

Facilitators of this theme include standards upon hiring such that the credentialing scope of practice is such that transphobic and homophobic attitudes are not tolerated, and providers must be prepared to work with all types of people. Also, their community-based health center participates in their local pride parade, has signage and inclusive language to show support, cultivates a private and confidential

clinical environment, and heads quality improvement initiatives such as task forces to ensure best practices are continually improved upon with meeting the needs of this population. The policies in place by the health center of the participants are an excellent example of leadership for expectation management and inclusivity practices. This maintains a safe environment for patients in clinic, which is especially important in rural communities due to the fishbowl effect, but also the healthcare team, and should be implemented in other healthcare settings. These findings were also identified in the literature.

In addition, representation was identified as a facilitator for inclusive institutions. A new finding regarding patient disclosure of sexual and gender identity was that some patients are more likely to disclose on their own prior to being asked about their sexual and gender identity if their provider presents as queer. This reflects that LGBTQ+ patients may feel more comfortable around queer presenting providers.

Barriers of this theme include perception, such that in certain areas culturally there is more of a stigma around these topics and thus patients feel less comfortable discussing them. This, alongside perception due to changing political climates, can make policy changes take a long time to get approved in the U.S.

Empowering Pediatric Providers:

Facilitators of this theme include providers fostering a safe space as a safe adult patients can get advice from. This is especially important as they are often the one continuous provider pediatric patients have. Pediatric patients may not feel comfortable disclosing their identity with their parents and often patients may disclose their identity

to their providers before they have told anyone else, thus providers can help disclose essential safety information and resources as well as normalize patient feelings.

In terms of transgender medicine and disclosure to providers, helping patients get to a point where they can tell their parents is an important step to move forward with the affirming care process. Often patients have been thinking about coming out for several years before they bring these conversations up in the first place. When parents aren't supportive, providers can help patients move forward with other aspects of the gender affirming care process such as psychiatric consultations in preparation for a potential transition once they turn eighteen years-old, alongside continuing to foster a supportive environment. Ultimately though, it was stated that earlier affirming care improves outcomes.

Another role of pediatric providers is to follow standards of care surrounding asking patients verbally about their sexual and gender identity at age twelve. These topics may come up sooner if the patient has other mental health concerns or trauma history. Providers will often ask the parent or guardian to leave the room for these types of conversations, but the parent or guardian will not always do this. There was discussion about the difference between asking via questionnaire, which some teens may be more comfortable answering, or asking verbally, which fosters human connection among patients and may feel more confidential than something written. This finding has not been previously explored amongst this population before and would be interesting to investigate further.

Barriers of this theme include lack of training surrounding these topics. In the nursing school experiences of the participants specifically, the social aspect and cultural

competency of LGBTQ+ patient care was discussed but not the medical aspect such as coinciding disparities or treatment. In the clinical setting, education can be very individualized, such that depending on the preceptor students may not get any exposure to this population and these topics. This reflects the literature and the lack of comfortability surrounding caring for these populations by providers and motivates a call to nursing and medical education. There was no education on medication management for transgender patients, thus providers must be entirely self-taught, seeking out those resources and mentors on their own. Most providers, unless they self-identify, are not actively seeking out this information. This is something that may be improving with more modern education programs though.

On the research side of things, medication management needs to be studied more. This can be a bit scary as a provider, not knowing how to handle certain situations, but virtual communities have formed to support these efforts and uplift providers.

In the context of one of the participants providing gender affirming care, it was stated that they get a lot of questions from providers with limited education about this population and their care, that the reasoning behind some providers lack of education is not being against it, but rather having “fear of the unknown”. Another participant disclosed that they do not feel that they are the most ideal person to provide this care.

Discussion

We conducted a focus group with currently practicing pediatric providers to expand information on meeting the unique needs of LGBTQ+ pediatric patients in the hopes of providing direction towards improving patient wellbeing. Ultimately, there are

knowledge gaps among providers related to treatment needs of LGBTQ+ Youth, especially those residing in rural areas.

We identified a series of themes through the focus group including increasing prevalence of these topics at younger ages; lack of training or varying training across preceptors; empowerment in the role they can provide in primary care; many barriers due to stigma and perception, isolation, and expansive rural landmass; the difference in verbal or questionnaire-based disclosure; their community-based health center prioritizing inclusive expectations of providers; and representation. Commonalities represented in the literature and focus group were increasing LGBTQ+ populations, limitations in graduate training, inclusive expectations of facilities and providers, and barriers to care. Specific to rural communities, limitations are even greater due to expansive landmass and lack of resources. New findings included the difference in verbal or questionnaire-based disclosure; providers needing to have a better sense of the gender affirming care process and pharmacology; and representation increasing LGBTQ+ patient openness.

There are limitations to this research though including recruitment challenges resulting in a small sample (n=2). In addition, both providers clinical experience is solely in the community-based setting within one organization further limiting comparison. Lastly, we didn’t speak to providers currently in education so there is a chance that some of the results discussed are outdated in the context of current graduate educational programs, although applicable to providers who have been out of school for a significant amount of time.

Future directions include the opportunity to conduct additional focus groups among pediatric providers in more diverse settings to gain additional perspectives. Also, these findings in conjunction with the previous curriculums presented in the introduction could be applied to create an informed educational intervention, emphasizing especially providers gaining a better sense of the process for gender affirming care and some basic pharmacology.

Conclusion

The findings of this project support the need for further research aimed at how providers can improve meeting the unique needs of LGBTQ+ youth. Without appropriate care, there are significant negative impacts to development and quality of life for this increasing population. This project illuminates knowledge gaps such that standardization of pre-licensure and continuing medical education surrounding these topics should be discussed further. Significant barriers to care must be addressed to improve LGBTQ+ pediatric patient wellbeing at both the provider and institutional level.

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