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PRELIMINARY RESULTS

A Community Survey of Referral Sources to Identify Primary Care and Gender-Affirming Care Providers

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Introduction: Barriers exist in access to primary care as well as specialty healthcare such as gender-affirming care. Understanding the referral sources used to identify new providers for these types of care can help healthcare systems facilitate access.

Methods: Using data from a community-based survey, demographics and information relevant to finding new healthcare providers were assessed.

Results: Data from 165 participants suggest that seeking a new primary care provider was perceived as challenging. The most common referral sources for primary care providers were family/friends, a doctor, or a medical center website. The most common referral sources for gender—affirming care providers were a doctor, family/friends, or social media. There were significant differences in the types of referral sources most likely to be utilized for primary versus gender-affirming care.

Conclusions: Personal connections, including trusted doctors, can be important sources of provider referrals. Additional resources may be needed to facilitate their ability to make quality connections. Community resources and social media can be important sources when existing social networks may not have knowledge about the needs of particular communities, especially those who may be at risk of discrimination. More inclusive and secure referral sources may be needed to ensure gender-affirming care referrals are made.

INTRODUCTION

Primary care is an entry point to the healthcare system for most individuals. Primary care providers are responsible for integrated, regular health care that is focused on both promoting wellness and managing disease.[1,2] Many individuals also engage in specialty care, including gender-affirming care, which encompasses a range of services designed to support or affirm one's gender identity and can include counseling, medication, or surgery.[3] NIH defines gender as a multidimensional social and cultural construct that includes gender roles, expressions, behaviors, activities, power dynamics, and/or attributes that a given society associates with being a woman, man, girl, or boy, as well as relationships with each other, whereas sex is defined as a biological descriptor. Gender-affirming care is associated with improved mental health outcomes for gender-diverse individuals.[4,5]

Although both primary care and gender-affirming care have important benefits, barriers exist in access, including health insurance coverage, provider shortages, geographic and transportation barriers, and availability

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of appointments.[5] Structural barriers can be compounded by potential, perceived, or actual discrimination against certain groups, including gender-diverse individuals, resulting in significant disparities in availability and access to high-quality care.[6] Taken together, these barriers can make searching for a new provider for primary care or gender-affirming care a daunting prospect. Understanding how people identify care providers can have important implications for healthcare systems to facilitate access, for both primary care as well as more specialized care such as gender-affirming care.

The objective of this study was to identify the key referral sources used to identify providers for primary or gender-affirming care. These 2 unique contexts can provide insight into the similarities and differences in the approach to identify a provider for more basic care as well as specialty care, which may carry some stigma. Both types of care are usually expected to be long-term relationships initiated by the patient, compared with some specialty care in which the relationship to the provider may be initiated through an inpatient transfer or only expected to be sustained through an acute illness. As such, there may be a heightened need in both types of care to ensure that the provider is an appropriate fit.

METHODS

Recruitment

Participants were adults recruited from community settings in 1 metro area in the U.S. from October to December, 2022. Surveys were distributed through family medicine clinics, online community forums, and local LGBTQ+ organization events and listservs. As part of a quality improvement project focused on improving access to gender-affirming care, the university IRB determined that this study was exempt from review. Participants received an information sheet before completing the survey outlining the study goals and the voluntary nature of the survey, but no documentation of consent was deemed to be required. All survey responses were anonymous. Respondents were given the option of $10 compensation upon completion.

Measures

The survey captured demographic information, as well as information about participants' experience and perception regarding seeking a provider for primary care or gender-affirming care, adapted from the Looking for Health Information module of the National Cancer Institute's Health Information National Trends Survey. Specifically, participants were asked about the difficulty in searching for a new provider, their confidence in finding a new provider, and what referral sources they would use to find a new provider. Descriptive analysis was conducted on quantitative data.

RESULTS

Experience Finding a Provider

Demographic and descriptive information is shown in Table 1. Among the 165 respondents, 63 reported having searched for a new primary care provider in the past 12 months. Open-ended responses indicated the most common reason was relocation/location, followed by dissatisfaction with a previous provider and aging out of pediatrics or losing student status.

When asked about the perceived ease or difficulty of finding a new primary care provider in their last search, only 15% reported it was very or somewhat easy, whereas 37% reported it was at least somewhat difficult and 10% reported they were unable to find a provider. Participants were roughly divided in their confidence in their ability to find a new primary care provider if needed (48% very/somewhat confident vs 52% a little/not at all confident).

Of the 165 respondents, 23 identified as non-cisgender (14%); 18 of those (78%) had sought medical care for gender dysphoria or other gender identity concern. Participants indicated in open-ended responses that they were most often referred to their gender-affirming care provider by a previous provider, searched on their own, and used word of mouth.

Referral Sources for Finding Primary Care or Gender-Affirming Care Provider

All participants were asked about the sources they would use to identify a new primary care provider and a provider if they were to seek gender-affirming care for a friend or family member. Table 2 shows participant responses. Open-ended prompts to provide additional details about referral sources for both primary care and gender-affirming care largely focused on friends and family, particularly those with healthcare experience. Affinity-based sources were identified as important resources for finding primary care; these included a focus on inclusion based on ethnic background, gender, body size, or disability. Similarly, LGBTQ+ community groups were named frequently as referral sources for finding gender-affirming care.

A paired sample t-test was conducted to determine the difference in the likelihood of using each referral source. Participants were significantly more likely to use referrals from a doctor ($t = -3.32$; df=159; $p=0.001$), social media ($t = -6.97$; df=157; $p<0.01$), and community health agency ($t = -5.99$; df=157; $p<0.01$) for

Table 1. Demographic Characteristics of Participants

Characteristics	Mean (SD) or *n* (%)
Age, years, mean (SD)	32 (12.7)
Gender identity, *n* (%)	
Not cisgender	23 (14)
Cisgender	132 (80)
Prefer not to answer	4 (2)
Missing/no response	6 (4)
Sexual orientation, *n* (%)	
Straight or heterosexual	112 (68)
Gay, lesbian, or homosexual	7 (7)
Bisexual	22 (13)
Pansexual	3 (2)
Asexual	1 (0)
Prefer to self-describe	5 (3)
Prefer not to answer	4 (2)
Missing /no response	6 (4)
In a relationship, *n* (%)	
No	52 (32)
Yes	103 (62)
Prefer not to answer	3 (2)
Missing/no response	7 (4)
Race, *n* (%)	
American Indian/Alaska Native	2 (1.2%)
Black/African American	4 (2.4%)
White/Caucasian	119 (72.1%)
Asian	32 (19.4%)
Native Hawaiian or Pacific Islander	1 (0.6%)
Other/prefer to self-describe	4 (2.4%)
Prefer not to answer	3 (1.8%)
Highest level of schooling, *n* (%)	
Some college or vocational school	11 (6.7%)
College graduate	86 (52.1%)
Graduate or professional degree	60 (36.4%)
Prefer not to answer	2 (1.2%)
Missing	6 (3.6%)
Hours worked per week for pay, *n* (%)	
35 or more	40 (24.2%)
Less than 35	19 (11.5%)
Not working for pay	95 (57.6%)
Prefer not to answer	5 (3.0%)
Missing/no response	6 (3.6%)
Financial situation, *n* (%)	
Not very good	46 (27.9%)
Comfortable	81 (49.1)
More than adequate	20 (12.1)
Prefer not to answer	11 (6.7)
Missing/no response	7 (4.2)
Primary insurance, *n* (%)	
Employer	34 (20.6)
Spouse's employer	8 (4.8)
Purchased myself	7 (4.2%)
Medicare	10 (6.1)
Medicaid	50 (30.3)
Other government program	1 (0.6)
Somewhere else	42 (25.5)
Not insured	1 (0.6)
Don't know	1 (0.6)
Prefer not to answer	5 (3.0)
Missing	6 (3.6)
General health, *n* (%)	
Poor	1 (0.6%)
Fair	11 (6.7)
Good	55 (33.3)
Very good	60 (36.4)
Excellent	31 (18.8)
Missing	7 (4.2)
Ever searched for a new primary care provider, *n* (%)	
Yes	63 (38)
No	102 (62)
Perceived difficulty in finding a new provider, *n* (%)	
Very easy	4 (2)
Somewhat easy	21 (13)
Somewhat difficult	38 (23)
Very difficult	23 (14)
Did not find a new provider	16 (10)
Missing	63 (38)
How confident in finding a new primary care provider if needed? *n* (%)	
Very confident	20 (12)
Somewhat confident	59 (36)
A little confident	45 (27)
Not at all confident	41 (25)

finding a provider for gender-affirming care vs primary care, but they were significantly more likely to use referrals from an insurance website (t=3.11; df=158; p=0.002) for primary care vs gender-affirming care.

DISCUSSION

This study confirms previous research that personal contacts are generally valued in finding a provider compared with online sources[7] in both primary and gender-affirming care. Friends and family are often trusted to know their preferences and values, and in particular, individuals may rely on those with better health literacy, such as those with healthcare experience, to help make decisions such as which provider to see.[8]

Table 2. Reliance on Provider Referral Sources

	Primary care, *n* (%)				Gender-affirming care, *n* (%)			
	A lot	**A little**	**Not at all**	**Missing**	**A lot**	**A little**	**Not at all**	**Missing**
A doctor	71 (43)	66 (40)	26 (16)	2 (1)	93 (56)	51 (31)	16 (10)	5 (3)
Family/friends	90 (55)	61 (37)	22 (7)	3 (2)	90 (55)	60 (36)	9 (6)	6 (4)
Social media	26 (16)	53 (32)	82 (50)	4 (2)	56 (34)	62 (38)	41 (25)	6 (4)
Internet review	30 (18)	74 (45)	57 (35)	4 (2)	39 (24)	71 (43)	50 (30)	5 (3)
Medical center website	52 (32)	85 (52)	24 (14)	4 (2)	47 (28)	81 (49)	31 (19)	6 (4)
Insurance website	39 (24)	46 (28)	76 (46)	4 (2)	17 (10)	57 (35)	86 (52)	5 (3)
Community health agency	24 (14)	60 (36)	76 (46)	5 (3)	40 (24)	79 (48)	41 (25)	5 (3)
Government health agency	12 (7)	49 (30)	100 (61)	4 (2)	14 (9)	50 (30)	96 (58)	5 (3)
Other	5 (3)	21 (13)	86 (52)	53 (32)	2 (1)	20 (12)	81 (49)	62 (38)

Similarly, existing providers can be important sources of referrals. Many participants indicated that they often seek new providers not because they are dissatisfied with their current provider, but often because of relocation or changing needs (e.g., aging out of pediatric care). A major challenge to relying on existing providers for referral is that providers have few resources to facilitate these transitions, even when anticipated.[9] Instead, providers may rely on their own networks of colleagues, which may be limited geographically and may include those with full patient panels. At a minimum, accurate and up-to-date medical center or insurance websites may assist with identifying available providers.

These findings also suggest that, beyond personal relationships, trusted affinity groups, including LGBTQ+ community groups, may be an important resource for those who may have concerns about inclusion or potential discrimination. The willingness to use social media or other online sources to find a provider for gender-affirming care in this sample may reflect lack of familiarity with this type of specialized care in participants' personal social networks. Furthermore, although the survey was conducted in a relatively progressive area, individuals may be more cautious about approaching a search for gender-affirming care given increasingly more overt discrimination and anti-transgender legislation. Referral sources that are seen as both accepting and allowing anonymity may be important for those whose friends and family are unable or unwilling to navigate seeking gender-affirming care. This desire for anonymity may explain the low preference for insurance websites to find a provider for gender-affirming care compared with primary care.

Limitations

One strength of these data was capturing relatively high diversity in SES and a relatively high proportion of LGBTQ respondents. Despite this, our racial/ethnic diversity was low. Although this sample generally mirrors the broader community population, our sampling methods and the use of an online survey may overrepresent those with higher community engagement and comfort using the internet, which may limit generalizability. In addition, our data focused on hypothetical searches for providers; actual searches may rely on different referral sources.

CONCLUSIONS

Finding a primary care provider or gender-affirming care provider can be challenging. Personal contacts, including family, friends, or healthcare providers, are valuable resources for identifying new providers. Although this study focuses only on primary care and gender-affirming care providers, these findings may generalize to other types of clinicians, particularly those who engage in long-term relationships with patients and may deal with sensitive or stigmatized issues, such as those who engage in mental health care. Healthcare systems can help those without personal connections find new providers by providing accurate data on provider availability in a way that is seen as secure, as well as ensuring that providers are seen as trustworthy around potentially sensitive issues, such as gender-affirming care.

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REFERENCES

1. Shi L. The impact of primary care: a focused review. *Scientifica*. 2012;2012:432892. https://doi.org/10.6064/2012/432892.
2. Friedberg MW, Hussey PS, Schneider EC. Primary care: a critical review of the evidence on quality and costs of health care. *Health Aff (Millwood)*. 2010;29(5):766–772. https://doi.org/10.1377/hlthaff.2010.0025.
3. Boyle P. *What Is Gender-Affirming Care?* 2022.
4. Almazan AN, Keuroghlian AS. Association between gender-affirming surgeries and mental health outcomes. *JAMA Surg*. 2021;156(7):611–618. https://doi.org/10.1001/jamasurg.2021.0952.
5. Office of Disease Prevention and Health Promotion. Access to Primary Care. 2023.
6. Edmiston EK, Donald CA, Sattler AR, Peebles JK, Ehrenfeld JM, Eckstrand KL. Opportunities and gaps in primary care preventative health services for transgender patients: a systemic review. *Transgend Health*. 2016;1(1):216–230. https://doi.org/10.1089/trgh.2016.0019.
7. Tu HT, Lauer JR. *Word of Mouth and Physician Referrals Still Drive Health Care Provider Choice*. Washington, DC: Center for Studying Health System Change, 2008.
8. Edwards M, Wood F, Davies M, Edwards A. 'Distributed health literacy': longitudinal qualitative analysis of the roles of health literacy mediators and social networks of people living with a long-term health condition. *Health Expect*. 2015;18(5):1180–1193. https://doi.org/10.1111/hex.12093.
9. Sharma N, O'Hare K, O'Connor KG, Nehal U, Okumura MJ. Care coordination and comprehensive electronic health records are associated with increased transition planning activities. *Acad Pediatr*. 2018;18(1):111–118. https://doi.org/10.1016/j.acap.2017.04.005.