
Health Service Research

Primary care access and foregone care: a survey of transgender adolescents and young adults

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Abstract

Objective. To examine the issues of primary care access and foregone health care among transgender adolescents and young adults.

Methods. This cross-sectional analysis of data from the Canadian Trans Youth Health Survey was conducted online during 2013–2014. Participants included 923 youth aged 14–25 (323 adolescents aged 14–18 and 600 young adults aged 19–25). Main outcome measures were self-reported general and mental health status, comfort discussing transgender identity and health care needs with general practitioners, and types of and reasons for self-identified foregone health care.

Results. Most youth reported poor/fair general and mental health status. Comfort with a family doctor was positively correlated with both general health ($r(528) = 21, P < 0.001$) and mental health ($r(450) = 26, P < 0.001$) status, as was having a doctor who was aware of one's transgender status. 47.2% ($n = 219$) of young adults reported foregoing needed health care. Among adolescents, levels of comfort with family doctor were negatively correlated with foregone mental health care in the previous 12 months ($F_{3,166} = 3.829, P = 0.011$), but not correlated with foregone physical health care ($F_{3,165} = 0.506, P = 0.679$). Reasons for missing needed care spanned the dimensions of health care access, ranging from cost barriers to previous negative experiences with health care providers, and concerns that a doctor would be uneducated about transgender people.

Conclusion. General practitioners can play a key role in improving the health of transgender youth by demonstrating understanding of the health care needs of transgender youth and competence in gender-affirming care, and by ensuring that their practices are accessible to all transgender youth in need of care.

Keywords: Adolescent, adolescent health services, health services accessibility, health services for transgender persons, primary health care, transgender persons.

Introduction

Transgender adolescents and young adults are at increased risk for many negative health outcomes, including depression, anxiety and suicide (1,2). Research has documented that transgender adults and cisgender (non-transgender) adolescents may experience barriers to health care, and that foregone care is associated with poorer physical and mental health outcomes (3–5). Barriers to medical care experienced by transgender adults range from negative past experiences

with doctors to outright denial of care by clinicians (4,6,7). Existing studies with general adolescent populations indicate that young people may forego health care for stigmatized needs (e.g. mental health) (8) or if they are members of stigmatized populations (e.g. gay, lesbian, bisexual) (9).

North American youth are disclosing transgender identities in greater numbers and at earlier ages, leading to growing recognition of the need for gender-affirming care in childhood and adolescence (10).

Transgender youth may experience barriers to accessing necessary primary, endocrine and mental health care. However, issues of primary care access and foregone care among transgender young people have remained unexamined, even as general practitioners are increasingly called upon to provide non-specialist transgender care for adolescents and adults, often without sufficient training (11–13).

Objective

The objective of this study was to examine issues of primary care access and foregone health care among transgender adolescents and young adults, using data from the Canadian Trans Youth Health Survey (14).

Method

The Canadian Trans Youth Health Survey was conducted online in English and French from 1 October 2013 to 31 May 2014. Institutional ethics approval was obtained from the University of British Columbia, University of Winnipeg and Dalhousie University. Canadian youth aged 14–25 who self-identified as transgender or genderqueer were recruited through a national network of health professionals and investigators across Canada, transgender youth advisory council members, community organizations, social media and online advertising. The lower age limit of 14 corresponds with an age at which youth are allowed to consent to health care in many Canadian provinces and territories; age 25 reflects the upper age limit for youth-focused transgender health services. Due to the unknown population size and anonymous nature of the survey, response rate could not be calculated.

Survey design

The survey included questions about health and health care experiences drawn from existing population health surveys. Adolescents (aged 14–18) responded to questions primarily drawn from the British Columbia Adolescent Health Survey (BCAHS) (15), and young adults (aged 19–25) were given questions drawn from the Canadian Community Health Survey (CCHS) (16). All youth reported their general health using an item originally from the 36-Item Short Form Health Survey (poor, fair, good, very good, excellent) (17) and similar questions from the BCAHS and CCHS addressed general mental health status (poor, fair, good, excellent) of adolescents and young adults, respectively. All participants were asked to rate their level of comfort discussing their transgender status and transgender-specific health care needs with their family doctor (very uncomfortable, uncomfortable, comfortable, very comfortable) using questions from the Trans PULSE study (6). Questions regarding reasons for foregone health care were based on items from the BCAHS. Participants were invited to provide free-text responses at several points throughout the survey, including when they selected ‘other’ from a list of options and at the end of a survey section. The following open-ended questions elicited the majority of responses related to health care access: (i) If you have never taken hormones, which best describes your situation? [other] (ii) Thinking of the most recent time, why didn’t you get care? [other]; (iii) Anything else you want to tell us about your health that we didn’t ask about?; (iv) Is there anything else you’d like to tell us?

Participants

A total of 923 youth responded to the survey (mean age: 20.0, SD 3.03), including 323 adolescents and 600 young adults. Of the 923 total participants, 531 (61%) completed the entire survey. All Canadian provinces were represented in the sample and

the distribution of participants across the country was representative of the general population. Almost three-quarters (73.9%) of participants identified their ethnicity as white, 10.2% Indigenous (which included First Nations, Inuit and Métis), 6.0% East Asian or Southeast Asian, 1.8% West Asian or Arab, 1.7% Black, 1.3% Latino, 1.3% South Asian and 3.8% other or multiracial. Of respondents, 90.7% lived in urban and suburban areas and 9.3% lived in rural settings. When participants were given a choice among three gender identity response options, 16.6% identified as trans-feminine, 42.4% as transmasculine and 41.0% as non-binary. One hundred and two additional comments related to health care access were provided in free-text boxes by 98 participants.

Analyses

Statistical analyses were conducted using SPSS 22.0. Differences in prevalence were assessed using chi-square tests and relationships between ordinal variables were assessed using Pearson’s correlation coefficients. There were two types of missing data: from participants who chose to not answer a specific question and those who terminated the survey before reaching the survey’s end ($n = 392$ premature terminations). Missing data were handled on a question by question basis; participant responses to the questions they answered were included in the analyses even if they had skipped other questions or did not persist to the end of the survey. Free-text responses related to health care access and foregone care were analysed using qualitative content analysis, with Penchansky and Thomas’ five dimensions of health care access (18) serving as a conceptual framework.

Results

Family doctors

The majority of respondents had a regular family doctor (70.3%); however, almost half used walk-in clinics as their main source of health care (44.3%). Approximately half of youth with a family doctor reported that their doctor knew about their transgender identity or experience (52.6%), while 8.5% were not sure. Participants were asked to rate their level of comfort discussing their transgender status and transgender-specific health care needs (scale 0–3, very uncomfortable, uncomfortable, comfortable, very comfortable) with a new doctor [$M(SD) = 0.91(0.838)$] and with their family doctor [$M(SD) = 1.29(1.028)$], if they had one.

Health status

Participants rated their general health on a 5-point scale (0 minimum–4 maximum) ($M = 1.77$; $SD = 0.958$) and their mental health on a 4-point scale (0 minimum–3 maximum) ($M = 0.96$; $SD = 0.795$). Comfort discussing transgender status and related health care needs with one’s family doctor was positively correlated with both general health ($r_{528} = 0.21$, $P < 0.001$) and mental health ($r_{450} = 0.26$, $P < 0.001$). Participants who responded that their transgender identity or experience was known by their doctor reported better general health than those who indicated their doctor was unaware, or were unsure if their doctor knew ($F_{2,525} = 8.405$, $P < 0.001$). Youth who reported their doctors knew they were transgender also had higher overall mental health scores than those whose doctors did not know ($F_{2,444} = 5.234$, $P < 0.01$).

Foregone care

More adolescent respondents reported foregoing needed mental health care in the last 12 months (68.4%, $n = 162$) than foregoing needed physical health care (33.5%, $n = 79$). Among adolescents,

levels of comfort with family doctor were negatively correlated with foregone mental health care in the previous 12 months ($F_{3,166} = 3.829$, $P < 0.05$), but not correlated with foregone physical health care. A broad range of barriers to care were selected by adolescents as reasons for foregoing both physical and mental health care (Table 1). Among young adults, 47.2% ($n = 219$) reported foregoing needed health care at least once in the previous 12 months. The type of care most often missed was treatment of an emotional or mental health problem (Table 2).

Dimensions of health care accessibility

The responses reported in Table 1 indicated reasons for forgone care that potentially fell within each of the five dimensions of health care accessibility: availability, affordability, appropriateness, approachability and acceptability (18). Participants' free-text responses expanded on these reasons for foregone care, clearly mapping onto all five dimensions. For example, care being unavailable in the respondent's area, or only with unacceptably long waiting periods, illustrated failures of availability leading to foregone care. Availability assessments are somewhat subjective, as there was no standardized metric provided in the survey regarding how far was too far or how long was too long; rather these statements reflected the participants' perception that care was unavailable to them. The CCHS, which similarly allows respondents to self-define how long a wait is too long, or what makes an appointment too difficult to get to, found that 'waiting too long' was the most common reason reported by Canadians aged 15 and older for having difficulty accessing health care (19); therefore, it is not surprising that transgender youth would report similar challenges.

Related to availability barriers, foregone care due to costs or lack of time indicated issues of affordability. Canadian youth are able to access medical services (e.g. primary care and endocrinology appointments) through a single-payer health care system. However, costs for mental health services (e.g. psychologist), travel to appointments and prescription medications are not universally covered. Youth may have these costs paid through extended (private) health insurance or through government programs for those with lower income or disability. While policy is in place to cover medical services deemed essential, this does not ensure that there are providers trained to offer needed gender-affirming health care in all geographic areas. In our study, barriers related to care availability and affordability were described by several participants. Rural and remote youth in particular described transportation barriers to accessing care that was only available in urban areas. Costs related to medical care contributed

to some youth foregoing care or employing substitutes for care (e.g. obtaining unprescribed hormones). One 17-year-old transmasculine respondent described responding to such barriers with illicit medication sharing among youth as an ad hoc harm-reduction strategy:

I gave what was left in my vial (~7 ml) to a FTM acquaintance who was getting it [testosterone] off the streets. There's no way he'd stop (he has a rough time with being misgendered at school) and this way I know it's clean and pure. I think the philosophy is called risk management or something, kinda similar to safe injection sites: if you can't get them to stop, at least make it safe for them.

Youth also described many past negative care encounters, indicating diverse, widespread experiences with inappropriate and inadequate care. A 19-year-old transfeminine youth described frequent interactions with walk-in clinic doctors who were unfamiliar with appropriate transgender care:

On the subject of walk-in doctors. . . . I feel uncomfortable because almost consistently, the older doctors I see looking to get a refill on my [hormone therapy] don't understand what being trans is, and will treat me with skepticism and concern, sometimes refusing to give pills at all because they were never trained in trans issues.

Uncomfortable and frustrating encounters with doctors were common in this population, and participants described a variety of informal methods of sharing information regarding how to obtain appropriate care, with peer-to-peer information exchange filling gaps left by formal systems. A 24-year-old non-binary respondent explained, "Many resources about accessing health as a Trans* person I find through peer support or online. Almost never through public health sectors or government facilities".

Past experiences of unacceptable or inappropriate care sometimes led to ongoing barriers related to approachability. Clinicians who lacked knowledge regarding transgender issues were perceived as unapproachable, and fears regarding care being non-confidential or inadequate implied a lack of acceptability. A 17-year-old transmasculine youth volunteered the following explanation of their foregone care due to past experiences with their doctor:

I'm very uncomfortable around my doc right now because she didn't know anything about trans people and I've been on [testosterone] long enough to pass as male.

A 20-year-old non-binary youth similarly described their experiences with lack of approachability and accessibility, explaining that long

Table 1. Results from descriptive statistics measuring reasons for their most recent foregone care of adolescents who responded to a 2013–2014 survey on transgender health

Reason for not getting care	Physical health ($n = 79$)	Mental health ($n = 162$)
Thought or hoped the problem would go away, no. (%)	55 (69.6)	99 (61.1)
Afraid of what the doctor would say or do, no. (%)	47 (59.5)	86 (53.1)
Didn't want parents to know, no. (%)	38 (48.1)	113 (69.8)
Too busy to go, no. (%)	28 (35.4)	45 (27.8)
Didn't know where to go, no. (%)	27 (34.2)	71 (43.8)
Had negative experiences before, no. (%)	26 (32.9)	69 (42.6)
Didn't have transportation, no. (%)	19 (24.1)	45 (27.8)
Parent or guardian would not take me, no. (%)	19 (24.1)	33 (20.4)
Afraid someone I know might see me, no. (%)	17 (21.5)	48 (29.6)
Didn't think I could afford it, no. (%)	13 (16.5)	54 (33.3)
Couldn't go when it was open, no. (%)	3 (3.8)	18 (11.1)
The service is not available in my community, no. (%)	4 (5.1)	11 (6.8)

Table 2. Results from descriptive statistics measuring type of care most recently foregone of young adults who responded to a 2013–2014 survey on transgender health

Types of care foregone	<i>n</i> = 161
Emotional or mental health, no. (%)	59 (36.6)
Physical health, no. (%)	41 (25.5)
Regular check-up, no. (%)	20 (12.4)
Injury, no. (%)	9 (5.6)
Other, no. (%)	18 (11.2)
Don't know, no. (%)	14 (8.7)

wait times and lack of a sense of allyship from health care providers could become life-threatening:

In my own experience the system seems more like it's designed to gate keep people than it is to help them. By the time I get cleared to have the surgery I need, it may be too late. I'm afraid that I'll take my life before I can get the surgery to help me, because it's such an arduous and unnecessarily difficult path. I just want to live.

Conclusion

Poor self-rated health has been identified as a strong predictor of mortality, especially among young people (24). Our findings indicate that Canadian transgender youth are reporting health status levels that are lower than general Canadian youth populations, with a mean of 1.77 using a 5-point scale (0–4). In contrast, 87% of adolescents aged 12–19 in British Columbia reported good or excellent health, while 13% reported their health status as poor or fair (15), findings that are consistent with a national survey in which 95.8% of Canadian youth rated their health as good, very good or excellent, the remainder (4.2%) reporting poor or fair health (25). On a 2013 survey of British Columbia youth aged 12–19, 6% of males and 10% of females reported foregoing needed medical care within the past year (15), while Canadian transgender youth in this study reported higher rates of foregone health care (e.g. 33.5% of adolescents foregoing physical health care).

In general, we found that transgender adolescents' and young adults' health status is related to comfort with their doctors. Lack of comfort with and confidence in the transgender competency of physicians (13) may lead some transgender youth to forego needed care, and particularly to leave mental health needs unmet. Despite the Canadian Medical Association passing resolutions in 2014 and 2015 in support of 'accessible, comprehensive and high-quality care for transgender patients' (21), 'integration of sex/gender diversity education into medical school curricula and programs' (22) and 'development of clinical tools' (23) to help physicians and medical students better understand LGBT health needs, Canadian medical schools provide a median of 4 hours in pre-clinical education and 0 hours of clinical education on the entirety of LGBT topics (20). It is therefore not surprising that many clinicians may be unskilled, unknowledgeable or uncomfortable providing health care for transgender youth.

Strengths and limitations

This is the first national population survey of transgender youth known to document foregone health care and barriers to accessing care. Mixed methods study design allowed for triangulation of findings. The size of the transgender youth population in Canada is undocumented; therefore, the representativeness of our sample is

unknown. The proportion of transfeminine participants was smaller than might be expected, possibly reflecting the impact on restrictive masculine gender norms on the ability of transfeminine youth to come out and to access gender affirming services. Online survey administration may have contributed to non-response bias (e.g. safety concerns due to lack of private internet access; limited internet access to due socioeconomic status or geographic location), and recruitment through transgender health care providers may have skewed the sample toward youth with greater health care access. The strategy to reduce this bias included advertising through clinical and community settings, as well as social media in order to reach rural youth and those not connected with care providers.

Recommendations

According to the current standards of care from the World Professional Association of Transgender Health (26), provision of gender-affirming care (e.g. prescribing and monitoring endocrine therapy) is within the scope of general practitioners. Meeting the health care needs of trans youth will require both awareness on the part of general practitioners and acquisition of the competencies necessary to provide accessible gender-affirming care for this population. Improvements in clinical training and clinical practice tools could ameliorate some of the issues transgender youth described as diminishing the availability, appropriateness, approachability and acceptability of health care they had attempted to access. Technology such as telehealth may improve availability and affordability for youth living outside urban centres, while policy solutions are necessary to address affordability gaps for mental health and pharmaceutical care. Opportunities for continuing medical education are expanding through professional associations (e.g. World Professional Association for Transgender Health, Canadian Professional Association for Transgender Health), conferences (e.g. Gender Odyssey, Philadelphia Trans Health Conference) and health care organisations (e.g. The Fenway Institute, UCSF Center of Excellence for Transgender Health, Rainbow Health Ontario, Trans Care BC).

General practitioners can play a key role in improving the health of transgender youth by demonstrating understanding of the health care needs of transgender youth and competence in gender-affirming care, and by ensuring that their practices are accessible to all transgender youth in need of care. Given the discomfort youth report around disclosing their transgender identities and discussing their health care needs, trained gender-affirming practitioners may address these barriers through steps such as adopting gender-inclusive intake forms and discussing gender in a manner that is inclusive of transgender and non-binary identities. Future research should include surveying youth in other countries and obtaining larger sample sizes to allow for more in-depth analysis related to urban versus rural locations, regional variations and cultural groups experiencing intersecting health-related barriers. Interventions to improve general practitioner competencies and health care accessibility should be evaluated in terms of their impact on health status, comfort with general practitioners, foregone care and the dimensions of health care accessibility.

Declarations

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Ethical approval: Institutional ethics approval was obtained from the University of British Columbia (certificate #H12-03129), University of Winnipeg (certificate #GT856) and Dalhousie University (certificate #2012–2804).

Conflict of interest: none.

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