

# Forgone Health Care: A Secondary Analysis of Survey Data on the Experiences of a Sample of Transgender and Nonbinary Nova Scotians

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## Abstract

**Introduction:** International research has identified that transgender and nonbinary populations experience high rates of discrimination, stigma, and negative health care experiences (Clark et al., 2018; Costa et al., 2018; Ercan Sahin et al., 2020). Collectively, these experiences can lead to forgone health care, defined as patients not accessing necessary health care due to many barriers, which can negatively impact health outcomes (House of Commons Canada, 2019). **Objective:** This study focuses on examining challenges in accessing gender-affirming health care among a sample of transgender and nonbinary Nova Scotians, and explores how these experiences may contribute to forgone health care. **Methods:** This research utilized secondary data analysis of a subset of data from an existing province-wide online survey of transgender and nonbinary Nova Scotians. The methodology of this study utilizes thematic analysis of closed-ended and open-ended survey response categories. The socio-ecological model was used as the conceptual framework to describe the various levels of influence contributing to transgender and nonbinary people forgoing health care. **Results:** Three main themes emerged from the data. Fear of discrimination leading to decreased quality of care, poor availability of transgender- and nonbinary-specific health services, and perceived or actual low levels of cultural competency among health care providers. **Conclusion/Discussion:** These factors contributed to forgone health care within this population, to which we respond with a number of recommendations to improve patient-provider interactions. Specifically, we recommend additional resources and training for health care providers and trainees to improve their cultural competency in providing gender-affirming care.

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## Introduction

Although Canada has a long-standing history as a signatory for the World Health Organization's declarations on health care

access as a human right, as well as a reputation on the world stage for being a leader in health equity, challenges remain in meeting the needs of LGBTQIA2 populations. There is a long history

of this community self-advocating and fighting for their rights, with same-sex marriage legalized only in 2005 and the recent banning of conversion therapy occurring nationally in 2022 (Aiello, 2022; Eichler, 2021). This history of advocacy is recognized in a 2019 report on LGBTQIA2 health from the Canadian House of Commons Standing Committee on Health, which identified challenges facing LGBTQIA2 people and culminated in the development of recommendations for provinces and territories to act on (House of Commons Canada, 2019). A key recommendation was the need for uniform coverage across the country for gender-affirming health care (House of Commons Canada, 2019). According to the World Health Organization, gender-affirming health care is defined as “social, psychological, behavioural or medical ... interventions designed to support and affirm an individual’s gender identity” (World Health Organization, Regional Office for Europe, n.d., para 9). Although the federal government has acknowledged the need for appropriate, consistent, and gender-affirming health care for LGBTQIA2 Canadians, the reality is a fragmented health care system with variable health care access for LGBTQIA2 people across the country.

Access to gender-affirming health care and care in a gender-inclusive space, which facilitates health care usage, is necessary for transgender and nonbinary populations to maintain optimal health and well-being (Clark et al., 2018; Colpitts & Gahagan, 2016; Edkins et al., 2016; Gahagan & Subirana-Malaret, 2018). Transgender and nonbinary populations are defined as those whose “sex assigned at birth does not completely align with their current gender identity” (Price-Feeney et al., 2020, p. 264).

However, there are concerns regarding how sex and gender are conceptualized within health research and how this may inaccurately represent health inequities and access (Gahagan et al., 2015). For example, in research, transgender and nonbinary populations may be grouped together with the larger LGBTQIA2 community, but this larger community may have differences in challenges to accessing health

care. LGBTQIA2 is an acronym for lesbian, gay, bisexual, transgender, queer and/or questioning, intersex, asexual, and Two Spirit. There is ongoing debate among academics on the most appropriate acronym to use, but this study will consistently use LGBTQIA2, while recognizing there may be considerable differences within subsets of this population.

In Canada, existing data indicate that transgender and nonbinary individuals have worse health outcomes in general when compared to the general population and other subsets of the LGBTQIA2 community (Abramovich et al., 2020; Giblon & Bauer, 2017; Veale et al., 2017). Such disparities may be associated with unique barriers to health care, including fear of—or actual experiences of—discrimination and stigmatization, the feeling that health care workers would not be educated to address their needs, and cost barriers to gender-affirming treatments (Abramovich et al., 2020; Clark et al., 2018; Colpitts & Gahagan, 2016; Edkins et al., 2016; Gahagan & Subirana-Malaret, 2018; Harbin et al., 2012; Kenagy, 2005; Lee et al., 2021; Socías et al., 2014; Whitehead et al., 2016). These barriers may lead to what is referred to as forgone health care, which is generally characterized as patients not accessing health care despite a need to do so (Clark et al., 2018; House of Commons Canada, 2019).

Evidence suggests that health care providers may not have the knowledge or skills needed to specifically address the unique health care needs of these populations in an affirming manner (Harbin et al., 2012; Lee et al., 2021; Gahagan & Subirana-Malaret, 2018). Transgender and nonbinary individuals have expressed concerns they will not receive accurate and appropriate medical advice from their primary health care providers, which can lead to their forgoing health care (Colpitts & Gahagan, 2016; Socías et al., 2014). Furthermore, research on transgender individuals has demonstrated that comfort with their family physicians is positively correlated with better general and mental health outcomes, while levels of discomfort have been associated with forgoing health care, which can lead to

poorer health outcomes (Clark et al., 2018). Taken together, these two points mean that level of comfort and confidence in health care providers impacts the likelihood of transgender and nonbinary people accessing health care.

Research examining forgone health care within transgender and nonbinary populations in the Canadian context is needed to recognize the specific barriers contributing to this health inequity, as well as to provide interventions. This is particularly pressing, given Canada's publicly funded health care system and longstanding commitment to health equity (Colpitts & Gahagan, 2016; Gahagan & Subirana-Malaret, 2018; Harbin et al., 2012).

This research offers a secondary data analysis of an existing data set, which is the first of its kind within the Nova Scotian context aimed at advancing our understanding of how transgender and nonbinary populations access health care (Colpitts & Gahagan, 2016; Gahagan & Colpitts, 2017; Gahagan & Subirana-Malaret, 2018). Currently, individuals residing in Nova Scotia seeking specific types of gender-affirming surgery must travel to Quebec (Nova Scotia Health Library Services, n.d.), creating barriers that may lead to forgone health care and the potential loss of follow-up back in Nova Scotia. Furthermore, local health care practitioners may not be culturally competent with regard to transgender and nonbinary patients (Hadland et al., 2016; Klein & Nakhai, 2016; Margolies & Brown, 2019). Cultural competence is defined as "cultural knowledge, welcoming attitudes towards diverse populations, and skills in communicating with people from different groups" (Margolies & Brown, 2019, p. 38). If cultural competence is poor regarding transgender and nonbinary individuals, an extra barrier to care accessibility is created.

In addition to concerns that health care providers may lack cultural competence in relation to transgender and nonbinary health care, current medical students often lack LGBTQIA2-specific training in their curricula, which may further contribute to an overall lack of affirming health care providers (Arthur et al., 2021; Click et al., 2020; Greene et al., 2018). For

example, health care providers who practise with an assumption that every patient is cisgender (identifies with their assigned gender at birth) can harm patients, and there is evidence to suggest medical students must receive further training to best address this population's health needs in a safe, gender-affirming, and culturally competent manner (Arthur et al., 2021; Click et al., 2020; Greene et al., 2018; Lee et al., 2021).

## Methods

### Guiding Framework

The socio-ecological model (SEM), developed by Urie Bronfenbrenner, provides the conceptual framework to contextualize the survey responses (Kilanowski, 2017). Examining the contributions and interactions between individual-, community-, and policy-level factors allows us to gain an understanding of forgone health care among transgender and nonbinary populations in Nova Scotia. The SEM has been used in research to describe the influence of stigma and discrimination on health outcomes for transgender and nonbinary populations (Johns et al., 2018). Further, the SEM provides a useful conceptual framework in analyzing questions related to levels of influence, ranging from macro-level consideration (such as primary health care access) through to micro-level issues (such as comfort with primary care providers and perceived competency of primary care providers on trans-specific needs; Do & Nguyen, 2020; Johns et al., 2018; King et al., 2020; Lacombe-Duncan et al., 2021).

### Participants

The inclusion criteria for this research study is based on the original study design: (a) individuals who self-identify as transgender or nonbinary, (b) live in Nova Scotia, (c) are eighteen years or older, and (d) have the ability to complete survey questions in English. Participants were voluntarily recruited through prideHealth's social media to complete the survey. prideHealth is an organization that offers support for LGBTQIA2 communities within the Halifax Regional Municipality of Nova

Scotia and aims to improve access to primary health services (Nova Scotia Health Authority, n.d.). After being presented with the study information/consent form, participants selected “I consent” on the first survey page on the online platform *Opinio* before beginning the survey, indicating they had read and agreed to participate. Data collected through *Opinio* is stored on servers managed by Dalhousie University.

### Study Design

The survey gathered data about key health issues facing transgender and nonbinary Nova Scotians, including self-rated health measures, social support, demographic questions, whether they had a primary health care provider, which health region they lived in, what they regarded as their key health priorities, and what was missing from their health care needs. Questions related to forgone health care among transgender and nonbinary populations were selected for the secondary data analysis and inform the results presented in this paper.

The online survey questions included both closed-ended and open-ended response categories. There were 238 partially completed surveys and 109 fully completed surveys included in our data set, all of which were included in analysis to obtain a larger sample size more representative of the population. Thematic analysis was used to organize open-ended questions with supplemental descriptive statistics from demographic data, in an effort to examine the experiences of transgender and nonbinary people contributing to forgone health care (Braun & Clarke, 2012; Johns et al., 2018). The process of thematic analysis included sensing themes, recognizing themes consistently, developing codes, and interpreting themes in the context of socio-ecological model (Boyatzis, 1998). Analysis was completed by both authors. Ethics approval through the Dalhousie University research ethics board was obtained (REB # 2021-5590) prior to utilization of existing data.

## Results

### Health Care Usage

Access to health care, including regular health care checkups, is noted in the literature as an important contributing factor to health outcomes across the life course. In relation to this issue, when asked “When was the last time you went in for a routine checkup?” the majority of participants (55%) reported having had a routine checkup within the past 12 months. Participants reported that the most common reasons for the checkup were a blood pressure check (65%), a mental health screening (40%), and STI screening (31%).

When asked “How often have you sought primary health care services for your own personal health concerns in the past 12 months?” many participants (42%) reported seeking primary health care services between two and five times in the past 12 months. Other studies have shown a higher uptake of primary health care services in transgender individuals compared to their cisgender counterparts, but this is thought to be due to individuals actively medically transitioning and the frequent appointments of this process (Abramovich et al., 2020).

In terms of using health-related programs or services in their community in the past 12 months, the most frequently utilized service indicated was walk-in clinics (63%), followed by emergency departments (44%) and sexual health centres (36%).

Access to health care can be stymied by lack of proximity to prevention programs, and it may be noted that most health care resources in Nova Scotia are located in or close to Halifax (Veugelers et al., 2003). When asked “In which of the nine former district health authorities do you generally access health services at present?” the majority (68%) stated they access health services within Capital Health/IWK, which is located in the Halifax Regional Municipality. Respondents were also asked whether they access health care services in a different former district health authority than the one they currently live in, and why. Those who reported



accessing care in other areas of Nova Scotia described a lack of transgender- or nonbinary-specific health services in their local communities, and the need to “access transition-related services in Halifax.” Participants also described a cycle of being misgendered after reminding local health care providers, and one participant felt their health concerns were “not being taken seriously.”

### **Access to Primary Care Provider and Satisfaction Level**

Although there are approximately 8% of Nova Scotians currently without a primary health care provider (Grant, 2021), we found that the majority of participants (80%) reported that they currently have a primary health care provider or doctor. For those who reported “no” to this question, the majority of those participants (71%) identified a lack of primary health care providers or doctors accepting new patients in their community as a reason for not having a primary health care provider or doctor. In addition, many participants (43%) also identified a lack of LGBTQIA2-friendly or affirming primary health care providers or doctors in their community as a reason for not having a primary health care provider. The lack of LGBTQIA2-friendly primary health care providers could help explain our findings of a large proportion of participants accessing walk-in clinics to receive health care. In terms of the level of overall satisfaction with their primary health care provider or family doctor, approximately one third (32%) of respondents reported being “satisfied.”

### **Disclosing Identities**

Disclosure of one’s gender identity and/or gender expression can be impacted by stigmatization, and we found that, in terms of comfort in discussing issues of gender identity/gender expression with their primary health care provider or family doctor, the responses varied. A five-point Likert scale was used, with the following response categories: very uncomfortable, somewhat uncomfortable, uncertain, somewhat comfortable, and comfortable. The greatest frequency (33%) was “somewhat uncomfortable” in discussing gender

identity/gender expression with their primary health care provider or family doctor.

Without disclosure of one’s transgender identity, individuals may have difficulty gauging the cultural competency of their provider. When asked “Are you ‘out’ to your primary health care provider or family doctor?” the majority of participants (72%) responded yes. In addition, among those participants (20%) who are not “out” to their primary health care provider, it was indicated they did “not feel as though it would be safe and could possibly jeopardize the quality of care [they] receive,” and that their “provider ignores [their] transness.” Furthermore, a participant noted gendered language is used “in the appointment process and I don’t feel safe outing myself as non-binary yet.”

Participants were asked “How trans friendly is your primary health care provider or family doctor?” A five-point Likert scale was used with response categories of the following: very trans friendly, somewhat trans friendly, uncertain, somewhat trans unfriendly, and not at all trans friendly. The highest proportion of participants were “uncertain” of how trans friendly their primary health care provider or family doctor was, at 38%.

### **Health Care Provider Familiarity with Transgender and Nonbinary Health**

When asked “How would you describe your primary health care provider or family doctor’s knowledge of health issues specific to gender identity/expression?” 34% of participants were uncertain about their provider’s knowledge of these health issues.

Trust within the physician-patient relationship is paramount in patient-centred care. With respect to the extent to which participants trust their primary health care provider or family doctor to provide the best health and wellness care possible for them, only 31% of participants reported trusting their primary health care provider or doctor completely.

When asked “In general, how would you describe the inclusiveness of health care service

environments in Nova Scotia for LGBTQ populations?” 32% of participants responded that they were uncertain of the inclusiveness of health care service environments in Nova Scotia.

In terms of having had a negative health care experience(s) in Nova Scotia in the last five years related to their orientation/behaviours or gender identity/expression, the majority of participants (70%) indicated a negative health experience(s).

In describing what made the experience(s) negative, participants identified various reasons, with the most frequent being the following: health care providers making assumptions about participants’ gender identity/gender expression (65%), medical intake forms using heteronormative or cisnormative language (65%), and the health care providers not being knowledgeable about health issues specific to participants’ gender identity/gender expression (60%). Other reasons cited by participants included “refused to acknowledge my identity in anyway [sic],” “switch family doctor to avoid discrimination/ignorance,” “being deadnamed regularly causing me much dysphoria,” and “chosen name not used consistently by providers.”

Conversely, when asked “Have you had a positive health care experience(s) in Nova Scotia in the last five years related to your orientation/behaviours or gender identity/expression?” the majority of participants (75%) had had a positive health care experience.

In terms of what made this experience positive, the majority of participants (90%) indicated that an LGBTQIA2-friendly health care provider (90%), an inclusive environment (70%), and comfort discussing sexual orientation/behaviours with the health service provider (67%) were key contributors to a positive experience.

When asked to rate key factors that are important to improving LGBTQIA2 health care experiences in Nova Scotia, the following were highly rated:

- making health service environments more inclusive and welcoming by posting signs and posters that reflect my gender identity,
- removing heteronormative and cisnormative language from medical intake forms,
- having patient advocates to assist transgender populations in navigating health care systems,
- education and/or training for health service providers on transgender- and nonbinary-specific health concerns,
- training health service providers how to be more transgender-friendly in their service provision, and
- advocacy and education for trans populations regarding their rights related to health care.

Specifically, participants noted it is “very important” to have education and/or training for health service providers on transgender- and nonbinary-specific health concerns (90%), training for health service providers on how to be more trans friendly in their service provision (86%), and advocacy and education for trans populations regarding their rights related to health care (76%).

**Theme 1: Fear of Discrimination and Decreased Quality of Care**

The first theme identified is fear of discrimination and decreased quality of care, originating from the finding that a notable portion of participants (40%) indicated their negative health care experiences were due to discrimination based on their LGBTQIA2 identity. In the open-ended responses, a participant noted that they had to “switch family doctors to avoid discrimination/ignorance” and that there was a culture of “transphobia in [rural] County.” Considering these experiences, it is unsurprising that 20% of participants were not “out” to their primary health care providers, with participants indicating they feel it could “possibly jeopardize the quality of care,” and

they “don’t feel safe outing myself as non-binary yet,” so to receive “proper treatment ... have to lie about my gender presentation.” At the individual level, this fear of discrimination may prevent transgender and nonbinary individuals from sharing their identity with their health care provider or accessing health care services.

### **Theme 2: Poor Availability of Transgender/Nonbinary-Specific Health Services**

The second theme identified is poor availability of transgender/nonbinary-specific health services. Specifically, the reasons for accessing health care services in a different former district health authority include accessing “transition related services in Halifax, due to unavailability of these services locally” and “no trans health services exist in [rural] County.” Participants noted travel from their local communities to Halifax for gender-affirming care, citing the Halifax Sexual Health Centre as their “only option” and that Halifax offers “more knowledgeable [providers] for trans people you wouldn’t find in the [rural location].” The survey data suggests that varying degrees of access within Nova Scotia to transgender- and nonbinary-specific health services is creating barriers to health care.

### **Theme 3: Perceived or Actual Poor Cultural Competency of Health Care Providers**

The third theme identified is perceived or actual poor cultural competency of health care providers. Participants’ responses varied in their perceptions of their health care provider’s knowledge of health issues specific to their gender identity/gender expression, with 34% being uncertain of their provider’s knowledge level. Only 31% of participants reported trusting their primary health care provider completely to provide the best health and wellness care. The SEM can help situate this at the interpersonal level, where participants have varied confidence in their provider’s ability to address their specific health needs. Most participants (90%) reported it was “very important” that providers have education and/or training on the specific health concerns of transgender and nonbinary populations. This suggests there may be a

discrepancy in the perceived competency of providers regarding transgender and nonbinary health needs, and highlights how strongly participants feel it is necessary for providers to have such knowledge. This points to larger systemic issues at the institutional level with medical education, with evidence from other studies suggesting that medical students do not feel their training is preparing them to adequately address the health needs of their transgender and nonbinary patients (Arthur et al., 2021; Click et al., 2020). A consequence of these issues is transgender and nonbinary populations forgoing necessary health care, which in turn may lead to poorer health outcomes overall.

### **Discussion**

These results provide insight into the health care experiences of transgender and nonbinary populations in Nova Scotia. Three major themes emerged: fear of discrimination and decreased quality of care, poor availability of transgender- and nonbinary-specific health services, and perceived or actual poor cultural competency of health care providers.

Participants repeatedly expressed fear of discrimination and decreased quality of care, which may prevent individuals from accessing health care. This aligns with previous research that found uptake of cervical cancer screening by transgender men was influenced by their health care provider’s acceptance of their gender identity (Semlyen & Kunasegaran, 2016). If transgender and nonbinary individuals fear discrimination, they may forgo needed health care and consequently have worse health outcomes.

Poor availability of transgender- and nonbinary-specific health services was an emerging theme among participants. This lack of access to specific services means transgender and nonbinary individuals in Nova Scotia may go without appropriate supports for social and medical transitioning.

Perceived or actual poor cultural competency of health care providers was a prevalent theme in analysis. If providers are not

culturally competent in regard to transgender and nonbinary populations, individuals may feel they will not receive adequate care and instead choose to forgo health care. A seemingly obvious solution would be to increase cultural competency training for health care providers. However, the evidence has shown mixed results in increasing the quality of care and comfort level of providers to service provision after cultural competency training (Raffoul & Lin, 2015). This suggests individual-level interventions, such as cultural competency training for individual health care providers, will be ineffective at targeting systemic change. Research must be completed on how to effectively improve cultural competency on a systems-wide level, in order to best address the needs of transgender and nonbinary participants.

A limitation of this study is the exclusion of participants under the age of eighteen. Transgender and nonbinary adolescents may experience unique health care challenges specific to their age group that lead to forgone health care that were not examined in this study. This is an underexamined area that warrants further research.

### **Conclusion**

This Nova Scotia-based study is the first to explore transgender and nonbinary health experiences in relation to forgone health care and to offer concrete recommendations on addressing the noted gaps as identified from the participants' responses.

The findings from this study can be useful in advancing our understanding of how to address key shortcomings in meeting the unique health concerns facing transgender and nonbinary populations in Nova Scotia. The key themes identified from the survey data have provided guidance for the following recommendations to improve transgender and nonbinary Nova Scotians' experience accessing health care, with an eye to reducing forgone health care and improving health outcomes:

1. Complete further research to uncover the most effective methods of increasing

provider cultural competency relating to transgender and nonbinary patients.

2. Include perspectives of transgender and nonbinary people under the age of 18 regarding health care access concerns.
3. Expand categories of demographic data to include transgender and nonbinary populations during provincial health care data collection to gain a better understanding of health indicators for these populations.
4. Further research and action should explore policy-level changes, to allocate greater provincial health care funding for transgender- and nonbinary-specific health services and health navigation programs, such as prideHealth, to improve access across all communities in Nova Scotia.

As noted in this research, and despite Canada's long-standing commitment to health equity, more needs to be done to better meet the unique health care issues and health disparities facing transgender and nonbinary populations. Further, as Canada begins to mobilize on the key recommendations from the House of Commons Canada report, this may provide an opportunity for Nova Scotia to leverage resources and support in addressing these disparities. However, in order to mobilize for change at the various levels of influence, as noted in the SEM, more attention needs to be paid to the needed structural changes, including how we train the next generation of health care providers to be more gender-affirming and how we mobilize the equitable provision of health care in Nova Scotia. Until we more fully address these various levels of influence on health care access, we will continue to see worse health outcomes among transgender and nonbinary Nova Scotians.



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