ONTARIO HIV TREATMENT NETWORK

Barriers to accessing health care among transgender individuals

Questions

- What barriers prevent transgender individuals from accessing health care and sexual health care on a holistic level?
- What recommendations have been made to overcome these barriers?

Key Take-Home Messages

- Transgender individuals require health care that addresses their unique health concerns, including transition-related medical procedures and mental health (1).
- Poor health outcomes are disproportionately experienced by transgender individuals, and certain socio-economic factors can increase the likelihood of poor health outcomes (2-5).
- Due to combined layers of stigma associated with transgender identity, transgender individuals face unique challenges in accessing quality health care. Barriers to care can also intersect, and act on multiple levels (1, 6-9).
- Best practices to address barriers to care for transgender individuals include policy change (1, 7), additional education for health care providers (1, 5, 10-15), involvement of transgender individuals in research and program development (6, 8, 9, 11, 12, 16, 17), implementation of best practices (1, 5, 7, 8, 10, 12-15, 18, 19), and changes to health survey forms (1).

The Issue and Why It's Important

While there are other culturally-specific terms used to describe gender non-conforming people, this rapid response will use the term *transgender* to refer to people whose gender identity differs from the sex assigned at birth (20).

Transgender individuals have many of the same health needs as the general population; however, some transgender individuals also require specific forms of care. For example, transition-related or gender-affirming medical care – designed to align physical characteristics with gender identity (1) – may be sought. Care may

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also include hormone therapy, genital reconstruction, breast or chest surgery, hysterectomy, or facial reconstruction (1). Transgender individuals may also have unique health needs regarding reproductive care, gynecologic and urologic care, and mental health services (21).

Specific programs and services are also necessary to address the existing health disparities between transgender individuals and the general population. Transgender individuals are at greater risk for HIV and for poorer physical and mental health outcomes (2-5). For example, the US *National Transgender Discrimination Survey Report on Health and Health Care* (NTDS) reported that transgender individuals in the United States experience over four times the national average of HIV infection, and are over 25 times more likely to have attempted suicide (4). Transgender individuals disproportionately experience homelessness and poverty, compared to the general population as well. According to the NTDS, 19% of transgender individuals reported that they had been homeless at some point in their lives (4). In Canada, the Trans PULSE survey reported 34% of respondents were living in poverty, compared to 13.5% of all Canadians (22). These disparities further contribute to poorer health outcomes (2, 3, 5). For example, in the US, transgender individuals experience twice the rate of unemployment (13) and nearly seven times the rate of homelessness (23) compared to the general population.

Unfortunately, many transgender individuals under-utilize or avoid health care services altogether (2, 3, 5). A study conducted in Ontario found that, in 2013, 29% of transgender individuals who needed emergency services were unable to access them (24). Understanding what prevents transgender individuals from accessing health care, including environmental, social, and legal barriers, is crucial for improving the overall health and wellbeing of this population.

What We Found

A holistic approach to health considers mental, physical, emotional, social and political factors as shaping the experience and conditions of health (3). To understand the factors that influence access to care among transgender individuals on a holistic level, it is important to consider intersectionality. Intersectionality refers to the interconnected nature of different social identities, and how they overlap to create interdependent and reciprocal systems of inequity and discrimination (1, 6-8). In the transgender context, stigma based on gender identity may be compounded by stigma based on race, age, sexual orientation, and socioeconomic status (4). For example, according to the NTDS, higher rates of discrimination in health care settings are experienced by Native American transgender individuals (36%) than white transgender individuals (17%); Native Americans also experience rates of HIV infection more than nine times that of the general US population (4). Sex work, illicit drug use, homelessness, and incarceration also disproportionately affect

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transgender individuals, putting them at greater risk of poor health outcomes and further stigmatization (1).

Accessing health care is particularly complex for transgender individuals, who often have multiple marginalized identities (1, 6-9). Barriers to care have been reported by a number of different populations, including transgender men (10, 18), transgender women (14, 16), HIV-positive transgender women (6, 8, 12), African American HIV-positive transgender women (15), transgender youth (17, 19), transgender seniors (7), immigrant Latino transgender individuals (9), previously incarcerated transgender individuals (1), transgender individuals who use illicit drugs (1), and transgender individuals involved in sex work (1). In short, although the cited studies address different groups, many of the same barriers appear regardless of the group in question. These broader barriers are discussed below. These barriers, while listed separately, are interconnected and mutually constitutive of one another.

Individual-level barriers

Individual-level barriers may affect an individual's ability to access health care, as well as their motivation to do so (8, 12, 17). Many transgender participants in the studies we found described feelings of mistrust in relation to health care providers, services, and institutions (1, 5, 8, 10-13, 15, 18, 19). In some cases, the distrust stems from previous negative experiences with health care providers or from transphobia encountered within health care environments (1, 5, 8, 15, 18, 24). Transgender individuals who feel mistrust are more likely to disengage from previously used health care services, or to lack motivation to use health care services in the future (10, 24). For example, one Ontario study showed that 21% of transgender participants reported avoiding emergency services when needed for this reason (24).

Some transgender individuals lack knowledge of where to find trans-competent care (10, 17, 19), and lack of health literacy may act as a barrier (10, 17, 19). For example, one US study interviewing transgender men (as well as lesbian, bisexual, and queer women) reported that misconceptions about pap test guidelines, such as believing that one must be in a sexual relationship with a man to require a pap test, influences the likelihood of seeking cervical cancer screening (10).

Research has found that, in jurisdictions without universal health care, transgender individuals have postponed medical care due to cost. While unaffordable health care is a problem for many (13, 14, 16), it is a particularly acute issue for transgender individuals, who experience high unemployment rates (1, 12, 13, 16) - twice the national average in the US (13) - and less access to employer-based health coverage (1, 13). In addition, some transition-related treatments, such as hormone therapy, may not be covered by insurance policies (16).

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The resulting instability from unemployment and insecure housing often causes many transgender individuals to prioritize safety, food, and shelter over medical concerns (12). The time and energy needed to access care or adhere to medications and therapies becomes unmanageable, with individuals putting off health care needs (12), or simply forgetting to tend to them (8).

Instability can be especially acute early in transition, among those who choose to transition (8). Some transgender individuals may feel forced to choose between transition-related health care and other health care concerns; and transitioning will often take precedence (8, 12, 14, 16). One qualitative study conducted in San Francisco reported that fear of HIV medications interfering with hormone therapy leads some transgender individuals to decline antiretroviral therapy in favour of continuing to take hormones (8).

Mental health is also an individual-level factor that may prevent access to care (11, 12, 16). The NTDS reported that lifetime suicide attempt rate for transgender individuals was 41%, compared with 1.6% for the general population (4). In Ontario, the Trans PULSE project reported 43% of transgender individuals have attempted suicide, and more than half experience symptoms consistent with clinical depression (22). One US study reported that transgender women who experienced depression related to traumatic experiences such as abuse or rape were less likely to adhere to medication (16). According to the NTDS, up to 26% of transgender individuals in the US use or have used drugs or alcohol to cope with trauma, abuse, or transphobia (4), and studies have shown that substance use may interfere with transgender individuals' ability to seek medical care or adhere to medications (1, 8).

Gender dissonance may also act as a barrier to accessing sex-specific procedures. For example, a US study reported that gynecological exams or procedures may remind transgender men that have not received gender-affirming surgery of the mismatch between their gender identity and sex assigned at birth (10). The intense emotional distress felt in these situations can deter them from seeking these services (10).

Lack of social support and isolation may further contribute to poor mental health or substance abuse, and is often experienced early in transition (8, 10). Family rejection, loss of community, and lack of peer support were also reported by some US studies as influencing access to and engagement with care (8, 10).

Interpersonal-level barriers

Study participants identified several access barriers within patient-provider relationships (1, 5-15, 17-19).

Provider competency in transgender health issues may act as

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a significant barrier. Many transgender study participants reported that they felt providers lacked the knowledge or skills required to accurately assess, treat, test, and care for transgender patients (5, 6, 8, 10-15, 19). Many transgender individuals spoke of having to educate their provider on transgender issues (1, 5, 11, 24), including 54% of transgender respondents in one Ontario study (24). In one US study, lack of transgender-specific knowledge did not vary with type of provider, indicating that this barrier was persistent across health care environments (14).

Studies also indicated that a shortage of providers and specialists who focus on, or are comfortable with, providing care for transgender individuals was a barrier. This was particularly true when transgender individuals were seeking hormone therapy and gender-affirming surgery (1, 8, 14). There was also a shortage of providers specialized in areas such as HIV risk (8, 13), substance abuse (8, 11, 13), and mental health (7, 8, 11, 13, 16, 17) for transgender individuals.

Many of the studies we found reported that transgender participants perceived a lack of sensitivity to transgender identity among health care professionals. Transgender individuals indicated that health care providers expressed negative attitudes or transphobic behaviours, including discrimination (7-9, 11, 14, 15, 17, 19, 24), harassment (1, 5-7, 11-13, 18, 19), physical or verbal assault (13), or direct refusal to provide services (1, 11, 24). In one study conducted in Nova Scotia, transgender individuals described receiving questions or procedures unrelated to their health care visit (5). For example, one transgender man reported that his physician asked how a man would have sex with him, and then received a breast and pelvic exam, neither of which was relevant to the care he was receiving (5). In another US study, one transgender woman reported that her provider assumed that she was a sex-worker and referred her to substance abuse programs, when she was neither using illicit drugs nor involved in sex work (15). Overt experiences of discrimination such as these can cause transgender individuals to discontinue care with that provider, postpone seeking care, or stop seeking any health care (5, 8, 10, 12, 15).

Studies also reported that transgender individuals experience subtler forms of discrimination, such as being called by the wrong pronoun, name, or gender during provider encounters (1, 5-7, 11-13, 18, 19). Being "outed" by health care providers was a barrier reported in some cases, as transgender individuals felt that they had to explicitly declare their transgender identities in health care environments (5, 18). One Canadian study reported that subtle acts of discrimination may be more common than overt discrimination, but both forms of discrimination may have detrimental effects on transgender individuals accessing care or feeling excluded from care (5). For example, being "outed" or misidentified by providers may potentially target transgender patients for discrimination or harassment from other staff/patients (13). In fact, harassment from other patients within health care environments was another interpersonal barrier to care reported by some studies (7, 13, 19).

Organizational-level barriers

Several studies reported barriers related to the physical location of health services (5, 14, 15, 19). Two studies described transgender-specific facilities as being in areas that were hard to reach, unsafe, or that lacked privacy (5, 15). Transgender individuals from one study conducted in Nova Scotia felt that rural settings were much less tolerant of transgender identities than urban settings, and that they feared transphobia more often at rural health care locations (5).

The immediate physical health care environment can also create barriers to care. The studies found indicated that public restrooms and change rooms restricted by gender, or the absence of gender-neutral restrooms, make the environment feel unsafe for transgender individuals (1, 5, 11, 13). In some studies, a lack of privacy in waiting rooms, emergency departments, and other health care environments was also described as posing a challenge for those who did not feel comfortable discussing transgender health issues in front of other patients, for fear of harassment (1, 5, 17). Trans-friendly posters or pamphlets were also described as being absent from health care settings, and information on transitioning or transgender-related health risks as not readily

available in some of the studies found (5, 6, 11, 15). This poses a barrier not only to quality care, but to transgender individuals learning about their unique health issues (5). It was also described as an indication that the environment was not safe or welcoming for transgender people to disclose their gender identity, which may lead many to avoid or discontinue care with these environments (1, 5, 8, 10, 11, 15, 17, 18).

Medical paperwork that is not inclusive of transgender identities can also pose barriers to accessing health care (5, 6, 13). For example, one Canadian study reported that transgender individuals feel uncomfortable when filling out gender-binary medical forms, and that this affects their experience and utilization of health care (5). Health care IT solutions, including electronic health records (EHRs), billing and coding systems, and laboratory information systems will often rely on binary male/female identification of patients (13). Since preferred names and pronouns, as well as gender identity, often differ from the information provided on legal or health insurance documents, the likelihood of being misidentified is increased when this information is not recorded (13). Transition history and sexual anatomy is also rarely recorded in many EHRs or billing and coding systems, which hinders the collection of accurate medical information from transgender individuals and impacts quality of care. For example, a male-to-female transgender person may outwardly present as a woman but retain the anatomy to require prostate examinations; a female-to-male transgender person may present as a man but retain the anatomy to require screening for breast, ovarian, cervical, or uterine cancers. Medical professionals, therefore, may be unaware that a transgender patient requires certain procedures. Even if they do, procedures that are "mismatched" with recorded gender can greatly affect insurance coverage (13).

A lack of programs and services tailored to the needs of transgender people was a barrier sited by many of the studies we found (1, 5, 6, 8, 11, 13, 15, 16). Transgender individuals reported that services either did not exist (11), were only located in metropolitan areas (8, 15) or were inadequate, lacking options for appropriate treatments (5, 11). This was true with general health care, as well as specific health areas such as mental health services (11, 16), substance use treatment (8, 11), and HIV treatment (6, 15). Some transgender individuals perceived services to be transphobic, or cis/hetero-normative (6, 11) as well, services segregated by gender (8) or sexual orientation (15) can alienate transgender individuals and result in unmet needs. For example, a US study interviewing transgender women living with HIV reported that transgender women are less likely to engage with services that are not sensitive to their gender identity, and may reject being "lumped together" with either services for men who have sex with men or for cisgender heterosexual women, if they do not identify with those groups (8). Another study interviewing African American transgender women living with HIV found that a lack of transgender staff and providers in health care environments can affect the health care experience and motivation to seek care (15).

Societal/Institutional-level barriers

"Institutional erasure" is defined as a lack of policies that accommodate transgender identities, including "the lack of knowledge that such policies are even necessary" (3). Invisibility and lack of policies that meet the needs of transgender individuals has been found in both the United States and Canada (6). Lack of transgender-specific information in educational, health care, and other institutions reinforces inaccessibility, as providers and policy makers may not be aware that these issues exist (5).

Several transgender study participants noted that the absence of trans-specific training in many medical, nursing, and paramedical school curricula, led them to feel that transgender health is ignored by academic institutions (1, 5, 8, 13). One Canadian study reported that transgender individuals feel that exclusion of transgender identity within the social environments of academic institutions potentially fuels the interpersonal discrimination they experience regularly with health care providers (5).

In Canada, gender affirming surgeries are covered as insured services under many public health care plans (25, 26). However, the surgeries (and some non-surgical procedures) are not covered in all

provinces and territories, and among those where coverage is available, some specific surgeries may not be included (26). Furthermore, in order to access these services, patients must meet the criteria for "gender dysphoria" as defined by the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5). This includes the strong and persistent discomfort with current sex that causes clinically significant distress in social or occupational functioning (1, 26, 27). Some researchers argue that, while a mental health diagnosis can accelerate access to care and support insurance coverage, framing transgender identity as a mental disorder perpetuates the stigmatization of gender non-conformity that creates barriers to medical care in the first place (1, 13).

Transgender individuals must also meet eligibility and readiness criteria for surgical procedures, which can be a complicated, stressful, and emotional process (1, 13, 25). Routine care of retained sex organs can also be affected by insurance coverage, as many procedures may be considered not "medically necessary" due to incompatibility with patients' genders, and subsequently not covered by public health care plans (13).

Best practices

The studies we found made the following recommendations to overcome barriers to accessing health care for transgender individuals:

- Include coverage of transition-related care in government-funded health centres, without requiring a DSM-5 diagnosis (1). Implement guidelines at the provincial level to protect transgender individuals from discrimination, including the denial of health care coverage as being not "medically necessary" (1, 7). Separate organ systems and related procedures from gender on electronic health records, and billing and coding systems, to facilitate this process (13, 18).

- Incorporate trans-competent care into undergraduate and postgraduate curricula in medical and nursing schools, as well as residency training and licensing examinations. Include education for primary care providers as well as specialists in fields including endocrinology, urology, obstetrics and gynecology, and plastic surgery (1, 5, 10-15). Involve members of the transgender community in the design, development, and delivery of these curricula (1, 11, 13) and award federal grants for programs teaching postgraduate-level care of transgender patients (1).

- Implement guidelines for creating safe environments for transgender people, such as the *Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People* provided by the World Professional Association for Transgender Health (21), in Canada. Include protocols and training for culturally competent behaviour, prominently displaying non-discrimination policies in common areas, creating of gender-neutral restrooms, and changing intake forms and health records to include preferred names, gender identities, pronouns, transition history, and current anatomy (1, 5, 7, 8, 10, 12-15, 18, 19).

- Conduct research in partnership with diverse groups of transgender individuals to design, implement, and evaluate transgender-specific health care programs and services (6, 8, 11, 12, 16). For example, provide transgender-specific mental health services for coping with depression, trauma, abuse, violence, discrimination, and harassment (8, 11, 16, 19). Engage transgender patients, families and transgender communities in assessing and adapting existing services (6, 9). Ensure that existing programs and services that address the needs of transgender individuals have community outreach and communications activities that signify safe environments for transgender individuals seeking care (9, 11, 19), and that educate the community about transgender health issues (6).

- Demonstrate a commitment to the equitable treatment of transgender individuals in hiring and recruitment processes at health care organizations. This could help facilitate

a better understanding of transgender health concerns and reduce stigma (1, 8).

- Institutionalize best practices for transgender clients that discourage stigmatization at community social service organizations, including employment services. Offer social support and assistance with health care system navigation, and offer referrals to transition-related and trans-competent health care facilities (12, 15, 19).

- Include questions about gender identity on national surveys and health-related data sets to gather information on health outcomes among transgender people and build a foundation of knowledge about the health needs of this population (1). More research exploring transition-related health care (18), unique groups of transgender individuals (11), and the impact of intersecting marginalized identities on access to health care (6, 7, 15) is needed.

Factors That May Impact Local Applicability

Almost all primary studies included were from urban US centres, excluding four studies (2, 5, 6, 24). Regional differences between transgender communities in both the American and Canadian context must be considered when interpreting this review, but given that the HIV epidemic in the US as well as barriers to accessing health care among transgender individuals are roughly comparable to that in Canada, these findings and best practices may have potential to be adapted to the Canadian context.

What We Did

We searched Medline using a combination of (text terms (transgender or [trans* adj men[or [trans* adj women] or transsexual) or MeSH terms Transgender Persons or Transsexualism) and (text terms [healthcare or health care or health service*] or MeSH term Delivery of Health Care). Reference lists of identified reviews were also searched. All searches were conducted on July 27, 2017 and results were limited to English articles published from 2007 to present in high-income countries. The search yielded 1,022 references from which 27 studies were included. Sample sizes of primary studies ranged from 6 to 408.

Rapid Response: Evidence into Action

The OHTN Rapid Response Service offers quick access to research evidence to help inform decision making, service delivery and advocacy. In response to a question from the field, the Rapid Response Team reviews the scientific and grey literature, consults with experts, and prepares a brief fact sheet summarizing the current evidence and its implications for policy and practice.

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