IMPROVING THE HEALTH CARE OF LESBIAN, GAY, BISEXUAL AND TRANSGENDER PEOPLE:
Understanding and Eliminating Health Disparities

THE FENWAY INSTITUTE
IMPROVING THE HEALTH CARE OF LESBIAN, GAY, BISEXUAL AND TRANSGENDER (LGBT) PEOPLE: Understanding and Eliminating Health Disparities

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INTRODUCTION

The LGBT community is diverse. While L, G, B, and T are usually tied together as an acronym that suggests homogeneity, each letter represents a wide range of people of different races, ethnicities, ages, socioeconomic status and identities. What binds them together as social and gender minorities are common experiences of stigma and discrimination, the struggle of living at the intersection of many cultural backgrounds and trying to be a part of each, and, specifically with respect to health care, a long history of discrimination and lack of awareness of health needs by health professionals. As a result, LGBT people face a common set of challenges in accessing culturally-competent health services and achieving the highest possible level of health. Here, we review LGBT concepts, terminology, and demographics; discuss health disparities affecting LGBT groups; and outline steps clinicians and health care organizations can take to provide access to patient-centered care for their LGBT patients.

LGBT DEFINITIONS, CONCEPTS, AND TERMINOLOGY

Sexual orientation, to which the first three letters of the LGBT acronym refer, can be thought of as consisting of three components: behavior, identity, and desire. These components are not necessarily congruent in any given individual. For instance, some individuals engage in same-sex sexual behavior but do not identify as lesbian, gay, or bisexual; others experience same-sex attraction but are not sexually active with members of the same sex. In one recent study of men in New York City, 73% of those who reported sexual activity with men identified as heterosexual; these men were more likely than their gay-identified counterparts to be foreign-born, married, members of racial or ethnic minorities, and of lower socioeconomic status (Pathela 2006). More than three-quarters of self-identified lesbians also report prior sexual experiences with men (Diamant 1999).

Given the incomplete overlap between behavior, identity, and desire, the terms “men who have sex with men” (MSM) and “women who have sex with women” (WSW) are often used in research and public health initiatives to collectively describe those who engage in same-sex
sexual behavior, regardless of their identity. However, patients rarely use the terms MSM or WSW to describe themselves. Other than “lesbian,” “gay,” or “bisexual,” some patients may prefer terms such as “same-gender loving” to describe a non-heterosexual sexual orientation (Potter 2008).

The T in the LGBT acronym stands for transgender, which has been used as an umbrella term to describe individuals who do not conform to the traditional notion of gender in which one’s gender expression or desired expression is consistent with one’s birth sex. Transgender individuals may alter their physical appearance, often though not always through hormonal therapy and/or surgery, in order to affirm their gender identity. In the medical setting, the term “male to female” (MTF) transgender has been used to describe a person born with male genitalia but who identifies as a female; the term “female to male” (FTM) has been used for the reverse. Gender nonconformity, however, may take other forms. Some reject the binary nature of gender as being either male or female; these individuals may see themselves as reflecting some of each or neither gender and refer to themselves as genderqueer, bi gender or androgynous. Some people will occasionally adopt the gender expression of another gender and dress to reflect this. These individuals are referred to as “cross-dressers.” While a great deal has been learned about gender development and expression, there is still much research to be done and understanding to be gained if we are to be able to provide knowledgeable care to individuals with non-conforming gender identities.

**LGBT DEMOGRAPHICS**

It is difficult to define the size and distribution of the LGBT population. This is due to several factors, including: the heterogeneity of LGBT groups; the incomplete overlap between identity, behavior, and desire; the lack of research about LGBT people; and the reluctance of some individuals to answer survey questions about stigmatized identities and behaviors. However, combining results from multiple population-based surveys, researchers have estimated that approximately 3.5% of United States adults identify as lesbian, gay, or bisexual and that 0.3% of adults are transgender. This amounts to approximately 9 million individuals in the United States today (Gates 2011). Greater numbers of individuals report same-sex behavior and attraction; in one national survey of 18 to 44-year-olds, 8.8% reported a history of same-sex sexual behavior, and 11.0% reported same-sex attraction (Chandra 2011). In addition, the 2010 United States Census identified more than 600,000 households throughout the country headed by same-sex couples (Abigail 2011); there is at least one such household in 99% of all United States counties (Gates 2004). It is thus likely that most clinicians have encountered LGBT individuals in their practices, whether they are aware of such patients’ sexual orientation and gender identities or not.
WHY IS LGBT HEALTH IMPORTANT?

Clinicians must be informed about LGBT health for two reasons. First, there is a long history of anti-LGBT bias in healthcare which continues to shape health-seeking behavior and access to care for LGBT individuals, despite increasing social acceptance. Until 1973, homosexuality was listed as a disorder in the Diagnostic and Statistical Manual of Mental Disorders (DSM), and transgender identity still is (Potter 2008). In keeping with a pathologic understanding of homosexuality and transgender identity, many LGBT individuals were subjected to treatments such as electroshock therapy or castration in the past (Context 2011). Such treatments have now fallen from favor in the medical community and been formally disavowed by many medical and professional societies, but some clinicians continue to harbor anti-LGBT attitudes. As recently as the 1990s, nearly one-fifth of physicians in a California survey endorsed homophobic viewpoints, and 18% reported feeling uncomfortable treating gay or lesbian patients (Smith 2007). Attitudes have improved, but in a national survey in 2002, 6% of United States physicians still reported discomfort caring for LGBT patients (Kaiser 2002). Because of prior experiences of bias or the expectation of poor treatment, many LGBT patients report reluctance to reveal their sexual orientation or gender identity to their providers, despite the importance of such information for their health care (Eliason 2001).

LGBT HEALTH DISPARITIES

Second, although there are no LGBT-specific diseases, clinicians must also be informed about LGBT health because of numerous health disparities which affect members of this population. Both a recent Institute of Medicine Report and the Department of Health and Human Services Healthy People 2020 initiative have highlighted these disparities and called for steps to address them (IOM 2011, Lesbian 2012). These disparities stem from structural and legal factors, social discrimination, and a lack of culturally-competent health care.

Members of the LGBT community are more likely than their heterosexual counterparts to experience difficulty accessing health care. Individuals in same-sex relationships are significantly less likely than others to have health insurance, are more likely to report unmet health needs, and, for women, are less likely to have had a recent mammogram or Papanicolaou test (Buchmueller 2010). These differences result, at least in part, from decreased access to employer-sponsored health insurance benefits for same-sex partners and spouses (Mayer 2008).

Sexually transmitted infections, including human immunodeficiency virus (HIV), are major concerns in some LGBT groups, particularly MSM and male-to-female transgender persons. MSM account for nearly half of all people living with HIV in the United States, despite making up approximately 2% of the general population (CDC 2010). In addition, they accounted for almost two-thirds of new cases of HIV in 2009, the last year for which such data are available. In urban areas, the HIV prevalence among MSM exceeds the general population prevalence in many sub-Saharan African countries where HIV is widely perceived as a public health emergency (WHO 2008). Young, black MSM, in particular, represent the only demographic
group in which the incidence of HIV is increasing, with an increase of 50% from 2006 to 2009 (Prejean 2011). Overall, black and other non-white MSM are more disproportionately affected by HIV than white MSM; among black, urban MSM, the HIV prevalence is estimated at 28%, versus 18% for Hispanic and 16% for white MSM (CDC 2010). The racial disparities in HIV do not appear to be due to differences in unsafe sexual behavior but rather other factors, such as decreased access to antiretroviral therapy in non-white communities (Oster 2011). Data on HIV rates in transgender persons are sparse, but a recent systematic review estimated an HIV prevalence of approximately 28% in male-to-female transgender persons in the United States (Herbst 2008). Aside from HIV, MSM account for 63% of reported syphilis infections and more than one-third of gonorrhea infections (CDC 2007, Mark 2004). Antibiotic-resistant gonorrhea is also more prevalent in MSM than other groups (Bauer 2005). Finally, rates of human papilloma virus-associated anal cancers among MSM are seventeen times those of heterosexual men, with even higher rates among individuals concurrently infected with HIV (CDC 2012).

Several other diseases and conditions are differentially distributed between LGBT and non-LGBT groups. Compared to heterosexual women, lesbians are more likely to be overweight or obese (Boehmer 2007). In addition, eating disorders and body image disorders may be more common among gay and bisexual than heterosexual men (Ruble 2008), and high school students of both sexes who have same-sex sexual partners more commonly engage in unhealthy eating behaviors than those with only opposite-sex sexual partners (Robin 2002). There is little data on cancer rates among LGBT individuals, but some evidence suggests higher rates of breast and cervical cancer among lesbian and bisexual versus heterosexual women (Valanis 2000). If true, whether such differences stem from lower rates of screening, greater nulliparity or other factors is unknown.

LGBT and non-LGBT groups also differ with regard to the prevalence of substance abuse and mental disorders. Members of the LGBT population are approximately twice as likely to smoke as the general population (Lee 2009); indeed, they have some of the highest smoking rates of any sub-population (Tobacco 2008). In addition to tobacco abuse, alcohol and other drug abuse may be more common among LGBT than heterosexual men and women, although studies on this subject have been conflicting and some have been prone to methodological problems (Song 2008). In some LGBT sub-populations, such as gay men and male-to-female transgender persons, drug use is associated with unsafe sex and the transmission of infections, including HIV (Mayer 2008). Several studies have also suggested higher rates of depression, anxiety, and suicidal ideation among gay, lesbian, and bisexual individuals (Ruble 2008). Although attributed to the pathology of homosexuality or non-standard gender identity in the past, the higher rate of substance abuse and mental disorders in LGBT patients is now theorized to result from “minority stress,” in which real or expected prejudicial experiences result in internalized homophobia, depression, and anxiety (Meyer 2003). For many LGBT individuals, the minority stress they experience on the basis of sexual orientation and gender identity intersects with inequalities associated with race, ethnicity, and social class (IOM 2011).
Finally, recent, highly-publicized cases of suicide among teenagers bullied for being gay, lesbian, bisexual or transgender have shed light on the violence and victimization experienced by LGBT groups. Indeed, gay, lesbian, and bisexual high school students are more likely than their heterosexual counterparts to be injured in a fight, threatened or injured with a weapon while at school, experience dating violence, be forced to have sexual intercourse, and avoid school because of safety concerns (Kann 2011). LGBT adults are also victims of violence; after race and ethnicity, sexual orientation may be one of the most common motivations for hate crimes (Massachusetts 2009). Such events often produce an environment of stress and intimidation even for those not directly impacted. While rates of intimate partner violence appear to be similar between same-sex and opposite-sex couples, partner abuse in LGBT relationships has been under-recognized and under-addressed by the medical community (Ard 2011). Intimate partner violence likely affects transgender individuals more commonly than those who are heterosexual, gay, lesbian, or bisexual (Massachusetts 2009).

**MARRIAGE, REPRODUCTION, AGING**

Aside from health disparities, several other legal, political, and social issues impact the health and well-being of LGBT individuals. Marriage is a priority for many members of the LGBT community, but same-sex marriages are licensed in only six states; another two states recognize same-sex marriages performed in another jurisdiction, and another twelve states provide at least some state-level spousal benefits to same-sex couples. Thirty-nine states have laws banning same-sex marriage (NCSL 2012). Other than permitting same-sex couples to receive the same material and legal benefits available to others, the right to marry has also been associated with greater feelings of social inclusion among LGBT individuals, whether married or not (Badgett 2011).

In addition to marriage, many LGBT individuals raise children or have a desire to do so. In the 2002 National Survey of Family Growth, 52% of gay men and 41% of lesbian women expressed a desire to have children (Gates 2007). Approximately 19% of gay and bisexual men and 49% of lesbian and bisexual women report having had a child (Family 2011). The pathways to child-rearing for lesbian and gay couples vary. In many cases, children being raised by same-sex couples are the products of previous, opposite-sex relationships (Family 2011). Otherwise, adoption provides a pathway to child-rearing, although a few states explicitly ban same-sex couples or gay or lesbian single individuals from becoming adoptive parents. Even in the absence of explicit laws or policies, individual adoption agencies vary in their willingness to place children in the homes of LGBT persons. International adoption is rarely an option due to other countries’ bans on LGBT adoption (Adoption 2012). Donor insemination and surrogacy are other options for building families, although these may be prohibitively expensive for many.

Beyond marriage and child-rearing, LGBT individuals face unique challenges as they age. The current cohort of LGBT seniors grew up in periods of less social acceptance of LGBT lifestyles and thus may harbor greater fears of stigma and discrimination than their younger counterparts. Such fears may become particularly acute when LGBT elders are no longer able to live independently and must move into communal housing arrangements or avail
themselves of social services, prompting some to newly conceal their sexual orientation after years of living openly (Johnson 2005). Less likely to have children, LGBT elders may have fewer options for family support in the face of illness and disability. Older adulthood may also be more economically precarious for LGBT individuals, as they do not have access to spousal, survival, or death benefits through Social Security and thus may be impoverished by the death of a spouse or partner (Joint Commission 2011). These challenges notwithstanding, many LGBT persons demonstrate resilience as they age. Indeed, a majority of respondents in one recent survey of aging LGBT individuals felt that their LGBT status had prepared them for aging by fostering inner strength (MetLife 2010).
CREATING A WELCOMING ENVIRONMENT

How can clinicians begin to address the health needs of their LGBT patients? The first step is to create an environment inclusive of all LGBT people. LGBT patients report that they often search for subtle cues in the environment to determine acceptance (Eliason 2001). Simple changes in forms, signage, and office practices can go far in making LGBT individuals feel more welcome. For instance, intake forms can be revised to be inclusive of a range of sexual orientations and gender identities. The Institute of Medicine recommends inclusion of structured data fields to obtain information on sexual orientation and gender identity as part of electronic health records (EHRs). Figure 1 illustrates a flow diagram of possible ways to obtain such information. Patients can be invited to input such information electronically, prior to their visit, or at the time of registration; patients may feel safer discussing their health risks and behaviors once such information has been disclosed in this way, and it streamlines the process of entering the data into the electronic medical record. Allowing patients to enter their own information into a database also relieves providers from having to collect all the information about both sexual orientation and gender identity during a busy clinical encounter. Whether obtained via face-to-face history-taking, paper forms, or secure electronic mechanisms, information on sexual orientation and gender identity permits clinicians to identify, and thus better meet the health needs of, their LGBT patients. Regardless of how it is obtained, this information can be entered into an EHR, recognizing that it is critical to assure appropriate use of the information and confidentiality. Figure 2 illustrates a registration form used at Fenway Health in Boston indicating how information regarding sexual orientation is included with other demographic data in the context of registration material. Figure 3 shows how information that is helpful in the care of transgender individuals can be obtained in a structured format; these questions were developed by the Center of Excellence for Transgender Health at the University of California at San Francisco.

Health care settings can also develop and prominently display non-discrimination policies that include sexual orientation and gender identity. All staff, including receptionists, medical assistants, nurses, and physicians, can be trained to deal respectfully with LGBT patients, including using patients’ preferred names and pronouns. Educational brochures on LGBT health topics can be made available where other patient information materials are displayed. The Joint Commission has recommended these and other approaches in a recently published field guide; it can serve as a self-assessment tool for clinicians or healthcare organizations seeking to become more inclusive (Joint Commission 2011). In addition, since 2011, all healthcare organizations participating in Medicare or Medicaid are required to allow patients to decide themselves who may visit them or make medical decisions on their behalf, regardless of sexual orientation or gender identity.

Figure 3. Recommended Data To Be Obtained Regarding Gender Identity: Adapted from: Primary Care Protocol for Transgender Patient Care, April 2011. Center of Excellence for Transgender Health. University of California, San Francisco, Department of Family and Community Medicine

1. What is your current gender identity? (Check an/or circle ALL that apply)
   - Male
   - Female
   - Transgender Male/Trans Man/FTM
   - Transgender Female/Trans Woman/MTF
   - Genderqueer
   - Additional category (please specify): ____________________________
   - Decline to answer

2. What sex were you assigned at birth? (Check one)
   - Male
   - Female
   - Decline to answer

3. What pronouns do you prefer (e.g., he/him, she/her)? ____________________
Beyond environmental cues and LGBT-inclusive policies, clinicians can also make strides in improving the health of their LGBT patients by fostering a welcoming environment within the examination room and by educating themselves about LGBT health topics. Taking an open, non-judgmental sexual and social history is key to building trust with LGBT patients. Rather than making assumptions about sexual orientation or gender identity based on appearance or sexual behavior, clinicians should ask open-ended questions, mirroring the terms and pronouns patients use to describe themselves. For example rather than asking a patient: “Are you married?” or “Do you have a boy/girlfriend?”, consider asking “Do you have a partner?” or “Are you in a relationship?”, and “What do you call your partner?” Such questions allow clinicians to initiate a discussion about relationships and sexual behavior without assuming heterosexuality.

In the process of obtaining information on sexual orientation and gender identity, it may become clear that clinicians are some of the first individuals to whom patients have disclosed non-heterosexual identity, behavior, or desire. Reassuring responses from health care providers may thus be important for patients in the nascent stages of “coming out,” or adopting a public identity as a lesbian, gay, bisexual, or transgender individual. However, coming out is an individual process unique to each person’s family and social circumstances, and aside from providing support, clinicians should be wary about encouraging or discouraging the pace or form of this process.

Not all clinicians can become experts in LGBT health, but they should learn to address some of the specific health concerns of this population (Makadon 2006). Training about LGBT health is sparse in medical schools; a recent report demonstrated that a median of only five hours during all of clinical training was devoted to LGBT issues at United States and Canadian medical schools (Obedin-Maliver 2011). In the absence of formal instruction in this area, clinicians can turn to multiple national guidelines and recommendations. For instance, the Centers for Disease Control and Prevention (CDC) provide

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**Figure 4. Recommended Annual† Sexual Health Screening for MSM (CDC)**

<table>
<thead>
<tr>
<th>HIV serology</th>
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<tbody>
<tr>
<td>Syphilis serology</td>
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<tr>
<td>Urine NAAT* for <em>N. gonorrhoeae</em> and <em>C. trachomatis</em> for those who had insertive intercourse in the past year</td>
</tr>
<tr>
<td>Rectal NAAT for <em>N. gonorrhoeae</em> and <em>C. trachomatis</em> for those who had receptive anal intercourse in the past year</td>
</tr>
<tr>
<td>Pharyngeal NAAT for <em>N. gonorrhoeae</em> for those with a history of receptive oral intercourse in the past year**</td>
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* Nucleic acid amplification test
** Pharyngeal testing is not recommended for *C. trachomatis.*
† The screening interval is shortened to 3-6 months for those with multiple or anonymous sexual partners or those who use drugs in association with sex.
recommendations on the screening for and prevention of sexually-transmitted infections in MSM (Workowski 2010). These include yearly screening for HIV, syphilis, gonorrhea, and Chlamydia; the recommended screening interval is shortened to three to six months for those at particularly high risk, such as individuals with multiple or anonymous sexual partners or those who use illicit drugs in conjunction with sex (Figure 4). Hepatitis A and B vaccination is also recommended for all MSM. Given the high rates of HPV-associated anal cancers in MSM, some authorities recommend anal cytology screening for such patients, followed by high-resolution anoscopy when abnormalities are found; however, the utility of screening has not yet been demonstrated, and no formal guidelines recommend this approach. Most would screen HIV-infected MSM as well as those with peri-anal HPV lesions (Palefsky 2012). The CDC recommendations differ from those of the United States Preventive Services Task Force (USPSTF), which support HIV and syphilis but not Chlamydia and gonorrhea screening for MSM. The Affordable Care Act has adopted the USPSTF’s recommendations as the basis for reimbursement; it is unclear if this will jeopardize payment for CDC-recommended services (Fessler 2012). Lesbians and bisexual women should be screened with Papanicolaou smears and mammography as indicated for all women. There are otherwise no formal guidelines regarding screening for sexually-transmitted infections in lesbians or bisexual women. Providers should screen these individuals based on their risk factors, as determined through a careful sexual history.

Given the high incidence of HIV in some LGBT populations, HIV prevention constitutes a critical aspect of the care of many LGBT patients. In addition to safer sex counseling and the identification and treatment of sexually-transmitted infections, non-occupational post-exposure prophylaxis (nPEP) is recommended by the CDC for those with a high-risk HIV exposure. nPEP consists of the administration of antiretrovirals following a sexual exposure to HIV. Therapy must begin within 72 hours of exposure and is typically continued for four weeks (Smith 2005). Providers uncomfortable prescribing nPEP themselves should identify a local resource to which patients can be referred in a timely manner; emergency departments are often able to provide this service. For patients at particularly high risk of HIV acquisition, a recent study supports the use of pre-exposure prophylaxis (PrEP) for HIV, consisting of daily antiretrovirals taken in advance of sexual exposure along with provision of condoms and safer sex counseling (Grant 2010). Providers can access preliminary guidelines on the use of PrEP at www.cdc.gov/hiv/prep.

Resources are also available to assist providers in learning about the care of transgender patients. Online primary care protocols for transgender patients are available from the Center of Excellence for Transgender Health at http://transhealth.ucsf.edu. In addition, the Endocrine Society has developed clinical practice guidelines on the prescription and monitoring of hormonal therapy for transgender individuals, available at www.endo-society.org/guidelines. An area of particular confusion for many primary care providers is cancer risk and prevention in
transgender patients. In general, transgender persons who have not undergone gender-affirmative surgeries or used hormonal therapy should be screened for prostate, breast, or cervical cancer according to established guidelines for their birth sex. However, for those patients who have undergone surgery or hormonal treatments, screening recommendations must be modified; for instance, mammography is suggested for male-to-female transgender persons over age 50 who have taken feminizing hormones for more than five years, due to a theoretically increased risk for breast cancer, and Papanicolaou smears are not indicated in the assessment of surgically-constructed neovaginas (UCSF 2012). Female-to-male transgender individuals should still have mammography even if they have had breast tissue removed in light of the possibility of developing cancer in residual tissue.

CONCLUSION

The success of health-care organizations of all types—from academic medical centers, community hospitals, and community health centers to the many community-based services with which they work to ensure continuity of care—depends on providing high-value care to patients that optimizes quality and clinical effectiveness while keeping costs in check. Central to doing so will be the practice of population health using the model of the patient-centered medical home (PCMH). In the case of LGBT people, successful PCMHs must end LGBT invisibility in health care by identifying the sexual orientation and gender identity of their patients and then use this knowledge to address the issues of greatest complexity for the care of LGBT patients in a manner that is cost-effective and informed by the best evidence available. These issues include, but are by no means limited to, behavioral health, HIV prevention, and transgender care. In many ways, however, providing culturally-competent care to LGBT patients does not differ from providing patient-centered care to any other group. As with all patient populations, effectively serving LGBT patients requires clinicians to understand the cultural context of their patients’ lives, modify practice policies and environments to be inclusive, take detailed and non-judgmental histories, educate themselves about the health issues of importance to their patients, and reflect upon personal attitudes that might prevent them from providing the kind of affirmative care that LGBT people need. By taking these steps, clinicians will ensure that their LGBT patients, and indeed all their patients, attain the highest possible level of health.
## REFERENCES


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