Cancer Care Considerations for Sexual and Gender Minority Patients

ore than 5 percent of the U.S. population identifies as lesbian, gay, bisexual, transgender, queer, or intersex (LGBTQI).¹⁻³ Inclusively termed "sexual and gender minorities," LGBTQI people have unique health and healthcare needs that are not being met by most healthcare providers.⁴ Emerging research has demonstrated poorer health promotion behaviors, healthcare avoidance, and health disparities among sexual and gender minorities due to chronic social stigma, past or anticipated discrimination, or outright denial of care.⁵ Lack of healthcare provider cultural and clinical competence—including knowledge of and attitudes toward sexual and gender minorities, culturally affirming behaviors, and clinical management strategies—has a direct impact on sexual and gender minority patient experiences with healthcare, healthcare-seeking behaviors, and health outcomes.

In 2013 the World Health Organization described healthcare for sexual and gender minorities as inadequate: "Few healthcare providers or practitioners can provide adequate information, let alone comprehensive, safe, and appropriate services."⁶ Specific to cancer care, the American Society of Clinical Oncology issued a position statement that called for five strategies to improve the health of sexual and gender minorities patients diagnosed with cancer, including improved patient and provider education, policy solutions, and inclusive research.⁷ Lack of knowledge among healthcare professionals regarding the degree of stigma, bias, and unique challenges faced by sexual and gender minorities impacts all aspects of cancer care.

Healthcare providers want to know how to care for sexual and gender minority patients. In a recent national survey of oncologists at National Cancer Institute-designated cancer centers, 70.4 percent of respondents were interested in more education about the needs of sexual and gender minority patients.⁸ Nevertheless, healthcare practitioners have few opportunities to learn about sexual and gender minority health.⁹

Fortunately, some online training has recently become available to healthcare practitioners.¹⁰⁻¹² Further, though the U.S. Preventive Services Task Force (USPSTF) is silent on recommendations specific to sexual and gender minorities, consensus-based guidelines exist for transgender cancer screening.¹³ Various modalities of training at different points in pre-clinical, clinical, and postgraduate education are optimal for learner self-reflection and application of new knowledge through skill-building.¹⁴

This article aims to partially fill this learning gap by summarizing clinical considerations across the cancer continuum of care and providing resources for providers interested in learning more about how to better serve sexual and gender minority patients.

Healthcare providers can do much to make sexual and gender minority people feel safe in the clinical environment. Visible signs of inclusion, such as brochures and posters that reflect sexual and gender minorities, as well as availability of relevant patient education information demonstrate that the environment is welcoming.

Impact of Social Context on Health

Lack of knowledge among healthcare professionals regarding the degree of stigma, bias, and unique challenges faced by sexual and gender minorities impacts all aspects of cancer care. Sexual and gender minorities have statistically higher rates of tobacco, alcohol, and substance abuse compared to heterosexual and cisgender (nontransgender) peers, increasing risks for cancer and chronic disease.⁵ Sexual practice risk factors increase prevalence of sexually transmitted infections and HIV.¹⁵ Sexual and gender minorities also experience access to care barriers, including discrimination, outright denial of care, and subsequent healthcare avoidance—which result in lower rates of cancer screening and higher rates of anticipatory anxiety.⁵

Maladaptive coping strategies may develop, in part, from chronic stress due to lack of visibility in healthcare data and legal discrimination. Overall, 21 states currently have religious exemption laws that allow individuals, organizations, and businesses to refuse services to sexual and gender minorities.¹⁶ In addition, sexual and gender minorities remain largely invisible in national and state-level health data.¹⁷ The proposed 2020 Census plans to capture same-sex households, but single sexual minorities and all transgender, genderqueer, and intersex people will remain uncounted.¹⁷

Invisibility of intersex people in mainstream society (approximately 1.7 percent of the population)³ is even greater.¹⁸ Research to optimize healthcare of intersex people is severely lacking, and education on what is known about intersex medical management is sparse in current medical school curricula.⁹ Though only a portion of intersex people have ambiguous genitalia, it is vital to note that the longstanding practice of surgical intervention for ambiguous genitalia is not medically indicated and leads to unnecessary and painful lifelong repercussions—including high potential for additional surgeries and infections. In 2017 three former U.S. surgeons general called for a moratorium on intersex infant genital surgeries.¹⁹

Patient-Centered Communication

Often healthcare providers have not been taught basic terminology to communicate with sexual and gender minorities. Table 1, right, provides a list of basic terms that healthcare providers should know. Patient-centered communication for transgender people requires use of their correct name and pronouns. To provide affirming communication, opportunities for disclosure of gender identity are paramount.

Healthcare providers may not realize the extent to which sexual and gender minority people are harmed by heteropresumptive or cis-presumptive care settings. Sexual and gender minorities may delay or refuse healthcare until needs are urgent out of fear of anticipated or past discrimination or mistreatment in healthcare settings.⁵ For example, in the 2011 National Transgender Discrimination Survey, almost 20 percent of transgender respondents reported having been refused medical care.²⁰

Healthcare providers can do much to make sexual and gender minority people feel safe in the clinical environment. Visible signs of inclusion, such as brochures and posters that reflect sexual and gender minorities, as well as availability of relevant patient education information demonstrate that the environment is welcoming. Allowing patients opportunities to disclose sexual orientation and gender identity on intake forms and through open and non-assumptive dialogue is also crucial (see Figure 1, page 30). Most sexual and gender minority patients who are "out" to their providers must awkwardly correct hetero-sexist and cis-genderist assumptions from their healthcare providers.¹⁵ Providers should listen carefully to the words that patients use. Affirming language includes referring to patients using their chosen names and pronouns, referring to body parts the way a patient refers to them, using gender-neutral language when gender is not clear, and minimizing hetero-presumptive and cispresumptive language and policies. Affirming care requires attention from not only the practicing physician but the entire healthcare and administrative team, so all staff must receive training.

In terms of responsive clinical care, competent care means shifting from the mindset of male versus female cancers—and "women's health" centers—to assessment of cancer risk based on patient anatomy. Competent care also requires ongoing provider self-reflection on how personal beliefs and assumptions might affect patient access to and experiences of care.

Finally, lifelong learning is paramount. Sexual and gender minority patients—particularly those who are transgender or intersex—are often frustrated by having to teach their care providers over and over again about their healthcare needs. These patients need their provider(s) to already be knowledgeable about their healthcare needs. Proactively seeking information and edu-

Table 1. Basic Terminology

Bisexual: Person who has a sexual attraction to people regardless of sex or gender.

Bottom surgery: Gender-affirming surgical intervention on genitalia (could include a variety of procedures ranging from orchiectomy to vaginoplasty for transfeminine people or phalloplasty for transmasculine people; more commonly performed for transfeminine than transmasculine people in the United States due to complexity and cost of procedure as well as maturation of surgical technique).

Cisgender: Person whose gender identity aligns with their sex assigned at birth.*

Difference of sex development: Term that replaced "disorders of sex development."*

Disorders of sex development: Outdated term for many congenital conditions in which development of chromosomal, gonadal, and/or anatomical sex is atypical.

Gay: A person who primarily identifies romantic and sexual feelings toward same-gender persons.

Gender: Socially constructed term to describe characteristics perceived as "male" or "female."

Gender identity: Distinct from sex, the gender that a person feels through their lived experience.

Gender-affirming: Positive and affirming behaviors toward a person's gender and gender identity.

Gender dysphoria: Significant distress due to discordance between sex and gender identity.

Genderqueer: Challenging gender norms, including transgender and nonbinary/agender people.

Heterosexism: Beliefs and/or systems that assume that opposite-sex sexuality is the norm.

Homophobia: A range of negative reactions to same-gender attraction or behavior.

Intersectionality: The multiple ways in which an individual identifies in terms of sex, sexual orientation, race, ethnicity, socioeconomic experience, geography, and other personal descriptors

Intersex: Preferred term for people whose sex falls between male-typical and female-typical forms.

Lesbian: A nonheterosexual person who identifies primary romantic and sexual feelings toward women.

Queer: Umbrella term referencing nonmainstream sexual orientation and/or gender identity.

Sex: Sex karyotype and phenotype at birth.

Sexual orientation: Complex construct comprised of sexual identity, attraction, and behavior.

T: Short for testosterone.

Transgender: Individuals whose gender identities do not align with their sex assigned at birth.

Top surgery: Gender-affirming surgical intervention on breasts (reduction or removal for transmasculine people, enhancement for transfeminine people).

Transitioning: Process of adopting and/or affirming a gender identity different from sex assigned at birth; may but does not always include hormonal and/or surgical interventions.

Transphobia: Range of negative reactions toward gender-nonconforming people.

Two-spirit: Term used by some Native American communities for people who have both feminine and masculine qualities.

*Term is not universally embraced.

Figure 1. I Want You to Know ... Intake Form

My legal name is:		Please call me:	
My pronouns are:	(ex. she/her, they/them, he/him)		
l identify as a person who is:	race/ethnicity	sexual orientation	& gender identity
I am most comfortable using	this language or language	5:	
I believe in:		religion/faith	
These are the people I want i	nvolved in my care (check	all that apply):	
Spouse/Partner	Child	Friend	Anyone else?
Parent	Sibling	Relative	
I would like them to be able t	to (check all that apply):		
Come to appointments		information, materials, a	and resources
Come into the exam roo		treatments	
Stay in the waiting room		ake financial decisions	
Help make decisions	Anythin	ig else?	
Ack questions			
Ask questions) 6 🕧	S	6 🕂 🛇
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Over the past three (3) month Transportation Childcare Housing Money Food		School Personal safety Insurance	15
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Over the past three (3) month Transportation Childcare Housing Money Food Job or work	hs, I have been worried abo	Dut: School Personal safety Insurance Spiritual concern	15

Table 2. Recommendations to Improve Communication with Sexual and Gender Minority Patients

- 1. Provide visual displays of inclusion in the clinical environment.
- 2. Provide a safe space for patients to disclose sexual orientation and gender identity.
- 3. Remember that you do not have to share the beliefs of your patients in order to ethically care for them.
- 4. Consider how your assumptions and reactions toward patients might affect their healthcare experience.
- 5. Use the words the patient uses—including chosen names, pronouns, and names for body parts.
- Consider hormones, anatomy, and body composition rather than gender when making clinical recommendations.
- 7. Ensure that questions are clinically relevant and for the well-being of the patient.
- 8. Support the patient's chosen caregivers.
- 9. Apologize when you make a mistake.
- 10. Do your homework. Educate yourself on the health and healthcare needs of sexual and gender minorities.

(continued from page 28)

cation on sexual and gender minorities' healthcare needs, asking clinically relevant questions, and apologizing when a mistake is made show that providers take their responsibilities as clinical caregivers seriously. Table 2, above, lists ten recommendations to improve communication with sexual and gender minority patients.

Cancer Prevention

Healthcare providers should screen for alcohol, tobacco, and other substance use among sexual and gender minority patients. Sexual and gender minorities are more likely to use and abuse substances compared to the general population.⁵ Because gay bars were the only safe spaces for sexual and gender minorities for decades, a bar culture developed. In addition, tobacco companies heavily targeted sexual and gender minority communities in the 1990s, leading to higher rates of tobacco use among sexual and gender minorities.²¹ There are few substance abuse and tobacco cessation programs tailored for sexual and gender minorities.²² However, responsive interventions can build on evidence-based practices from the Substance Abuse and Mental Health Services Administration.²³ Tailored programs should address the social context factors that are underlying drivers of substance abuse and take place in non-judgmental environments with affirming, patient-centered communication.^{22,24} Social context factors include higher rates of family rejection, lack of social support, stigma, discrimination, and abuse.^{22,24}

Though the human papillomavirus (HPV) vaccine is important for everyone starting at age 11 through 45, the risk for sustained HPV infection is more likely in people living with HIV—and men who have sex with men as well as transgender women have higher rates of HIV infection.²⁵ In addition, men who have sex with men, as well as anyone engaging in anal sex, have a heightened risk for HPV-associated anal cancer.²⁶ In short, all eligible people should be vaccinated, but risks may be higher among sexual and gender minorities in the long term.

Cancer Screening

Providers should recommend colorectal and lung cancer screenings to all sexual and gender minority patients as they would for any other patient—based on age and risk factors. The USPSTF recommends colonoscopy every 10 years; computed tomography colonography every 5 years; flexible sigmoidoscopy every 10 years with annual fecal immunochemical test (FIT), annual FIT, or fecal occult blood test screening; or FIT-DNA every 1-3 years for colorectal cancer for all average-risk people aged 55-75 years old.²⁶ The USPSTF recommends annual low-dose computed tomography screening for people aged 55-80 years old with a 30 pack-year history of smoking and who currently smoke or have quit within the past 15 years.²⁷

Queer people who are not transgender or intersex should generally receive cancer screenings based on USPSTF guidelines for other cancers as well. One exception to this rule is anal cancer screening. Though there are no USPSTF guidelines for anal cancer screening, men who have sex with men and people living with HIV have an increased risk for anal cancer.^{25,28} The European Society of Medical Oncology recommends that high-risk populations, defined as men who have sex with men and anyone who has anal intercourse, receive anal Pap testing and high-resolution anoscopy.25 The American Cancer Society indicates no general recommendation for anal cancer screening but notes that men who have sex with men, women with cervical or vulvar cancer, and people living with HIV are at increased risk and that digital rectal examination can help to identify cancer early.28 Transgender women of color bear a disproportionate burden of HIV and should be included as part of this high-risk population.²⁵

It is important not to confuse sexual orientation and gender identity. Lesbian, gay, and bisexual people have a minority sexual orientation but do not necessarily have body parts or exogenous hormones that could alter cancer screening and clinical management recommendations. Cancer screening for transgender and intersex people can be confusing, because hormone balance, anatomy, and body composition may vary widely. No rigorous studies have been conducted to inform clinical practice for transgender or intersex individuals. However, the University of California San Francisco has consensus-based guidelines for the care of transgender people. The university recommends, "As a rule, if an individual has a particular body part or organ and otherwise meets criteria for screening based on risk factors or symptoms, screening should proceed regardless of hormone use."²⁹ Specifically, breast, prostate, cervical, and endometrial/ovarian cancer screenings for transgender and intersex people merit discussion.

Assessing hormone risks and hormone receptor status is important when creating treatment plans for transgender patients. The prospect of abandoning hormonal treatment in order to treat cancer can be extremely distressing to anyone on the transgender spectrum receiving hormonal treatment.

All transgender people are potentially at risk for breast cancer. A recent large population-based study in The Netherlands demonstrated that though hormone treatment for transmasculine individuals had a protective effect, breast cancer risk for transfeminine individuals using estrogen increased in a short period of time on hormones: 83 percent of breast cancer cases in these transgender women were estrogen positive.³⁰ Consensus-based guidelines from the University of California San Francisco indicate that breast cancer screening should be performed every other year for transfeminine people with 5 or more years of estrogen therapy who have achieved the age of at least 50.³¹ Screening for transmasculine people should be individualized based on degree of breast tissue if breast reduction or bilateral mastectomy has been performed.³²

Cervical cancer screening should be recommended by clinicians for anyone with a cervix. The USPSTF recommends Pap testing every 3 years for cisgender women in their 20s, which can continue on the same schedule through age 65 or Pap and HPV DNA co-testing or HPV testing alone every 5 years for cisgender women aged 30-65 years.³³ Transmasculine individuals may be less likely to receive cervical cancer screening than cisgender people even within a strongly affirming environment due to gender dysphoria.³⁴ Results of cervical cytology for transmasculine people can also appear unsatisfactory due to changes in histology resulting from testosterone.35,36 Interventions to improve cervical cancer screening among transmasculine people are critically needed. Genderaffirming procedures should include clear communication regarding each step of the screening process, use of a smaller speculum, patient insertion of speculum if desired, use of water-based lubrication, and anti-anxiety medication when necessary.³⁶

National guidelines recommend that cisgender women be informed about risks and symptoms of endometrial and ovarian cancer at the onset of menopause—and instructed to promptly report post-menopausal bleeding to their healthcare provider.³⁷ Routine screening for asymptomatic women is not recommended. No screening modality has yet been found to be effective.³⁸ Consensus guidelines recommend that transmasculine individuals who retain internal reproductive structures and who no longer have menses follow the same recommendations.³⁸

For men aged 55-69 years, the USPSTF recommends that prostate cancer screening be an individual decision after discussing risks and benefits with their healthcare provider.³⁸ Healthcare providers need to remember to have these discussions with transgender women who retain a prostate and are therefore at risk for prostate cancer. Providers also need to know how to interpret prostate-specific antigen levels in this population, because levels are usually lower for transgender women on estrogen than for cisgender men: consensus guidelines recommend that a prostatespecific antigen of 1 ng/mL should be considered the upper limit of normal.³⁹ Table 3, right, outlines cancer screening considerations for transgender and intersex people.

Cancer Treatment

As mentioned above, hormones affect risk for cancer among transgender individuals. For example, estrogen increases risk of breast cancer for transfeminine people compared to cisgender males but not to the degree of cisgender females.³⁰ Assessing hormone risks and hormone receptor status is important when creating treatment plans for transgender patients. The prospect of abandoning hormonal treatment in order to treat cancer can be extremely distressing to anyone on the transgender spectrum receiving hormonal treatment. Some patients may choose to abandon cancer treatment, finding discontinuation of hormonal therapy unacceptable.⁴⁰ Professional psychosocial support should be provided to patients, with a focus on shared decision making after considering both the risks and benefits of discontinuing versus continuing hormonal therapy while undergoing cancer treatment.

Non-screenable cancers that show some risk among transgender people include meningioma and prolactinoma in transgender women.⁴¹ However, only four cases of meningioma have been reported in the literature among transgender women and only eight cases of prolactinoma have been reported among transgender women.⁴¹ Clinicians should note that given the elevated risk for HIV among men who have sex with men and transgender women, risk for Kaposis sarcoma and non-Hodgkin lymphoma should be considered based on symptoms.²⁴

For intersex people, cancer risk factors depend on specific chromosomal status, specifically Y-chromosomal material and gonadal position.⁴² For intersex people with no Y-chromosomal material (those with congenital adrenal hyperplasia), cancer risk is not greater than that for non-intersex people.⁴³ Testicular cancer is greater in postpubertal people with androgen insensitivity syndrome who have undescended testes.⁴² Risk of germ cell tumors in patients with androgen insensitivity syndrome with undescended

Cancer Screening	Transfeminine	Transmasculine	Intersex
Breast	Screen per USPSTF guidelines for women if estrogen exposure is ≥5 years and age is 50+.	If top surgery has been performed, individualize screening based on amount of breast tissue and risk profile. If top surgery has not been performed, screen using USPSTF guidelines for women.	Individualize screening based on amount of breast tissue and risk profile.
Cervical	Not indicated	Screen per USPSTF guidelines for women if cervix is retained. Gender dysphoria is strong and gender-affirming precautions should be taken. Histological changes for people on testosterone may result in false positive screening.	Screen per USPSTF guidelines for women if cervix is present.
Endometrial and ovarian	Not indicated	If bottom surgery, not indicated. If no bottom surgery, inform of risks and symptoms; encourage patient to report unexpected bleeding.	Inform patients with a uterus of risks and symptoms. Encourage patient to report unexpected bleeding.
Prostate	Individualize based on risk factors, (e.g., ≥50 years old, African Ameri- can) and benefits. Prostate-specific antigen 1 ng/mL is upper limit of normal if patient is on estrogen therapy.	Not indicated	Research is insufficient to provide recommendation. Individualize based on risk and benefits if patient has a prostate.

Table 3. Cancer Screening Considerations for Transgender and Intersex People

testes can be as high as 50 percent.⁴² Gonadoblastoma is almost entirely limited to intersex people with undescended testes.⁴² Treatment for these conditions includes informed consent for radical gonadectomy. Comprehensive genetic screening of Ychromosomal material with genetic counseling is important for these patients.

Hormonal and chromosomal considerations are not limited to transgender and intersex people at risk for or diagnosed with cancer. A recent review of sex-based differences in cancer outcomes found that 53 percent of clinically actionable genes (60/114) had sex-based signatures.⁴³ Differential efficacy of cancer therapeutics based on sex chromosomes and hormone status may have enormous implications not only for transgender individuals on crosssex hormones and those anatomically discordant with their natal chromosomal signature but for cisgender men and women as well.⁴³

Despite the elevated risk for some cancers among sexual and gender minorities, current National Comprehensive Cancer Network (NCCN) guidelines do not include clinical management considerations for sexual and gender minority patients specifically. Additionally, a recent survey of NCCN panel members found that most panelists had no plans to address these considerations in future guidelines.⁴⁴ Given the dearth of information in the clinical literature to inform cancer care management, this may appear reasonable. However, a growing body of sexual and gender minorities research demonstrates that behavioral risks, anatomical

Table 4. Clinical Guidelines, Advocacy, and Legal Resources

Association of American Medical Centers Sexual and Gender Minority Health Resources: aamc.org/initiatives/diversity/lgbthealthresources

Center for Excellence for Transgender Health: transhealth.ucsf.edu

Endocrine Treatment of Gender-Dysphoric/Gender-Incongruent Persons: An Endocrine Society. Clinical Practice Guideline 2017: academic.oup.com/jcem/article/102/11/3869/4157558

Gay and Lesbian Medical Association: glma.org

GW Cancer Center. "Addressing the Need for LGBTQI-Affirming Care: A Focus on Sexual and Gender Minority Prostate Cancer Survivors": cancercenter.gwu.edu/news/prostate-cancer-awareness-month-resources

InterACT, Advocates for Intersex Youth: interactadvocates.org

National Center for Transgender Equality: transequality.org

Lambda Legal: lambdalegal.org

LGBT Cancer Network: cancer-network.org

National LGBT Health Education Center: lgbthealtheducation.org

Sage, Advocacy & Services for LGBT Elders: sageusa.org

World Professional Association for Transgender Health: wpath.org

features, hormone balance, and chromosomal risk factors of sexual and gender minorities affect cancer risk and treatment efficacy. Furthermore, sexual and gender minorities have unique psychosocial support needs. Therefore, collection of sexual orientation and gender identity data across all areas of health research is critical to inform future care for patients diagnosed with cancer and other conditions.

Cancer Survivorship

Cancer survivorship can be uniquely challenging for sexual and gender minorities given heteronormative assumptions. For example, a clinical assumption that every person who has breast surgery will want breast reconstruction can be disaffirming to genderqueer individuals and sexual minority women. A qualitative study of genderqueer patients with cancer who had bilateral mastectomy or a hysterectomy showed that for some patients surgery constituted both cancer treatment and gender-affirming care.⁴⁵ Another study showed that some lesbians resented pressure to conform to social expectations for breast reconstruction.⁴⁶ For these patients, assumptions that all patients want cisgender female breast reconstruction or that a hysterectomy is unwelcome contradicts the tenets of patient-centered care.

Compared to straight counterparts, queer prostate cancer survivors have reported worse urinary, bowel, and hormonal symptoms; worse mental health; and greater fear of recurrence.⁴⁷ Erectile dysfunction and other late effects of treatment result in differential experiences for men who have sex with men compared to their straight male peers, regardless of whether the patient is anal penetrative or receptive.47 Current pharmaceutical options to treat erectile dysfunction for prostate cancer survivors are inadequate for men who have sex with men.47,48 The GW Cancer Center offers a guide to help healthcare professionals support queer prostate cancer survivors. "Addressing the Need for LGBTQI-Affirming Care: A Focus on Sexual and Gender Minority Prostate Cancer Survivors" includes a checklist for monitoring care preferences, relationship concerns, sexual dysfunction, urinary dysfunction, bowel dysfunction, and other long-term and late effects.48 See Table 4, above, for a link to this online guide, as well as other resources for continued learning.

Conclusion

Sexual and gender minorities need and deserve patient-centered care. Lack of provider competence in caring for sexual and gender minorities is due, in part, to lack of education and lack of evidencebased clinical care guidelines. Graduate school education on sexual and gender minority health and healthcare needs and ongoing practitioner continuing education are needed. Collection of sexual orientation and gender identity data is vital in cancer care and research in order to improve evidence-based guidelines in the future. Though we await evidence to inform better clinical and supportive care for sexual and gender minorities, this article provides some resources and strategies to provide affirming care for sexual and gender minority patients based on what is known now.

Mandi Pratt-Chapman, MA, PhD, is associate center director, Patient-Centered Initiatives and Health Equity, The George Washington University Cancer Center, Washington, D.C. She is part of the executive leadership team for the GW Cancer Center. Her personal mission is to make evidence-based healthcare and disease prevention strategies available to more people as quickly as possible. Her research focuses on patient navigation, cancer survivorship, evidence-based cancer control, and health equity for lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI) communities. Jennifer Potter, MD, is professor of medicine at Harvard Medical School; director of the Women's Health Center at Beth Israel Deaconess Medical Center; and director of LGBT Population Health and co-chair of The Fenway Institute, Boston, Mass. She has designed and implemented numerous training programs for health professionals focused on LGBTO health and cancer survivorship, co-edited two seminal textbooks on LGBTQ health, and co-authored an Association of American Medical Colleges blueprint to assist medical educators in integrating LGBTQI health content across the undergraduate medical curriculum. Currently, Dr. Potter serves as an advisory dean and director of medical student wellbeing at Harvard Medical School and is faculty co-director of two Harvard Medical School curricular themes focused on sexual and gender minority health equity and trauma-informed care.

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