Title

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Journal

The Hastings Center Report, 44(s4)

ISSN

0093-3252

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Publication Date

2014-09-01

DOI

10.1002/hast.371

Peer reviewed

Hastings Cent Rep. 2014 Sep;44 Suppl 4:S48-52. doi: 10.1002/hast.371.

Eliminating LGBTIQQ Health Disparities: The Associated Roles of Electronic Health Records and Institutional Culture.

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Abstract

For all humans, sexual orientation and gender identity are essential elements of identity, informing how we plan and live our lives. The historic invisibility of sexual minorities in medicine has meant that these important aspects of their identities as patients have been ignored, with the result that these patients have been denied respect, culturally competent services, and proper treatment. Likely due to historic rejection and mistreatment, there is evidence of reluctance on the part of LGBT patients to disclose their sexual orientation (SO) or gender identity (GI) to their health care providers. There is some perception of risk in sharing SO and GI for many patients who have had bad prior experiences. Despite these risks, we argue that we can improve the quality of care provided this population only by encouraging them to self-identify and then using that information to improve quality of care. One strategy both to prompt patient self-identification and to store and use SO and GI data to improve care centers on the use of electronic health records. However, gathering SO and GI data in the EHR requires a workforce that knows both how to obtain and how to use that information. To develop these competencies, educational programs for health professionals must prepare students and educators to elicit and to use sexual orientation and gender identity information to improve care while simultaneously ensuring the safety of patients, trainees, and staff and faculty members as SO and GI become openly discussed and integral parts of ongoing medical discussion and care. As determination of SO and GI demographics becomes more common in health research, we will more fully understand the health risks for all the LGBTIQQ populations.

Introduction

In 2011, the Institute of Medicine (IOM) released a groundbreaking report describing serious health disparities for lesbian, gay, bisexual, and transgender (LGBT) populations that had received little prior attention.[1] This report created an ethical obligation for medicine to improve LGBT health by recognizing LGBT people and their unique prevention and treatment needs. In identifying LGBT patients, health care delivery systems assume the ethical challenge of protecting them from harm through inappropriate use of their identity, while medical schools face the challenge of both educating all trainees on how to elicit and use LGBT identity to improve care while also ensuring the safety of LGBT trainees.

The IOM report spoke little of health disparities experienced by members of other sexual minority populations, whose health disparities are less well documented. These groups include those who are intersex[2] (**I)** (born with ambiguous genitalia, or experiencing sexual developmental differences at puberty); those who identify as queer (**Q)** (vocally embracing non-heterosexual orientation or non-binary gender identity); and those who are questioning (**Q)** (unsure of or testing sexual orientation or gender identity). These groups are sometimes joined with LGBT populations in an LGBTIQQ designation. This paper addresses ethical issues associated with identification of all these populations in medicine, but to simplify this paper we will use the LGBT descriptor as referring to all.

For all humans, sexual orientation and gender identity (SO/GI) are essential elements of identity, informing how we plan and live our lives. The historic invisibility of sexual minorities in medicine has muted these important aspects of LGBT patient identities, doing wrong by denying respect, proper treatments, and needed services. Rejecting invisibility around SO/GI comes with risks, however. Historically, recognition of minority SO/GI status has led to mistreatment[3] and despite federal achievements, there continue to be numerous states with little or no protection (i.e. employment, housing, hate crimes) for LGBT individuals.[4] If health care is to realize the benefits of enhanced LGBT visibility for reducing disparities, we must also accept the ethical charge to change health care so that LGBT patients are respected and not harmed by sharing their SO/GI information. Simultaneously, health care professionals must learn to comfortably and competently solicit and use this information.

Visibility, Invisibility, and LGBT Health Disparities

Health inequities for LGBT individuals can be perpetuated by both "visibility" and "invisibility". Visibility, either through self-identification or by being perceived as LGBT, can expose individuals to mistreatment due to homophobia[5] or unconscious bias.[6] Historically, visibility to peers has resulted in bullying which increases rates of depression and suicidal ideation among LGBT youth and adults above those of heterosexual peers.[7] Invisibility, or not being recognized, also carries the risk of limited access to personalized, quality services. Invisibility also occurs when patients delay or avoid care because of prior negative experiences with providers.[8] The Lambda Legal Survey report entitled, "When Healthcare is Not Caring", documents harsh physical and emotional treatment of LGBT patients at the hands of their medical providers.[9] Nearly 5,000 LGBT people completed the survey and over half reported instances of discrimination in their care. Such treatment often triggers avoidance of regular appointments with providers, thus increasing the rate of treatment in emergency rooms.[10] Emergency room care is much more expensive than primary care visit, but more critically, often marks late diagnoses of preventable conditions as the odds of cure decline. Other sources of mistreatment can also impact health.

The painful experiences of bullying and stigmatization, sometimes by family and/or playmates, often lead to adopt maladaptive coping behaviors in adolescence (smoking, substance use, unhealthy eating, unsafe sexual practices, etc.) which offer short-term relief while leading to long-term damage to the individual's health.[11] The IOM documents multiple health disparities that appear to stem from long-term maladaptive coping. For example, lesbian and bisexual women and gay men report greater smoking rates[12] and more alcohol consumption[13] than heterosexuals; thus LGBT rates of lung and liver diseases are likely higher as well. Family rejection can exacerbate maladaptive coping in addition to preventing or limiting youth access to health care. It is estimated that 40% of homeless youth are LGBT.[14] Transgender youth and adults with little emotional or financial support are more likely to engage in sex work or "survival sex", often without condoms, in exchange for food or housing, leading to higher rates of HIV and sexually-transmitted infections.[15] Thus, there is a critical need to recognize LGBT patients in order to provide appropriate care, especially for youth at risk for rejection by their parents as they come out.[16] These scenarios illustrate providers' ethical responsibility to know patients' SO/GI in order to provide needed care.

Visibility, Acceptance and Opportunity to Improve LGBT Health Outcomes

Since the American Psychiatric Association removed homosexuality as a mental disorder from the Diagnostic manual (DSM-III) in 1973, there have been substantial increases in cultural acceptance of LGBT people, although discrimination continues. [17] That acceptance fosters hope that needed changes in health care are possible. Although these changes will likely occur unevenly, as has cultural acceptance, embedding prompts for documentation of SO/GI in the EHR can accelerate needed changes in care. However, use of the EHR to improve care also carries increased ethical responsibilities for protecting LGBT people from misuse of that information and mistreatment because of their increased visibility.

Collection of sensitive data in the LGBT community is not new given over 25 years of effort to protect HIV testing or HIV/AIDS status information. At the same time, twenty-nine states currently fail to protect people from employment discrimination based on sexual orientation while 34 states fail to protect against discrimination because of gender identity[18] making it critical that 1) patient autonomy be respected (patients have the right not to reveal SO/GI data; and 2) data gathered to enhance health care ought never be used to harm the employment or reputation of patients. With the steady flow of people across state lines for residence and work, the lack of a unified and clear federal policy of protection from discrimination permits glaring differences in protection geographically. Robust security for electronic information is imperative to assure protection of patients who choose to disclose their SO/GI.

Thus, in choosing to gather sensitive information about an individual's SO/GI, health care institutions assume increased responsibility for assuring that this information is kept secure and is not misused. Further, patient autonomy demands that individuals have the right to refuse to include this information in their chart or EHR. Health centers already recognize the need for protecting personal health information. As electronic record usage has increased, safeguards for electronic patient data have increased around HIV status, infectious diseases (e.g. tuberculosis, syphilis), mental health, cancer diagnoses, substance abuse and other potentially stigmatizing conditions.[19] Institutional safeguards include monitoring for external hacking efforts and internal misuse, for instance with policies that forbid employees not involved in the care of a patient to

access that patient's medical record. Sanctions against employees who violate this rule are powerful, including potential termination.

In one recent paper, other safeguards for patients are identified.[20] These safeguards include development of an LGBT-Welcoming Provider List to allow patients to arrange care with supportive clinicians, and training of patient relations staff in supporting LGBT patients who have negative care experiences. With any new EHR venture, ongoing evaluation will be needed to determine whether these measures are sufficient protection. Clearly, inclusion of SO/GI data in medical care needs to occur within a context of increased staff sensitivity training and heightened security of records.

We believe the potential benefits of using the EHR to gather and document SO/GI demographics are substantial but procedures and safeguards to reduce potential risks are also needed. Perhaps the greatest benefit gathering SO/GI data can achieve is helping health care providers become champions of healthier practices for LGBT patients and their families. Family acceptance as teens come out can help maintain good health,[21] while family rejection can harm health.[22] Young adults who report strong family acceptance of their SO/GI also report higher self-esteem, better general health, lower rates of depression and substance abuse, and fewer lifetime suicide attempts.[23] Thus, youth with accepting families appear less likely to develop maladaptive coping and less prone to develop lifelong health disparities. With these findings, health professionals can support LGBT health by encouraging family acceptance of youth as they come out. Since families often seek health care as units, providers can educate parents who seek counsel on acceptance of their child's SO/GI. Physicians can invite youth to share their SO/GI if they observe maladaptive coping behaviors beginning, and can refer both youth and families to helpful resources while facilitating conversations about physical and mental health benefits of acceptance. As providers treat LGBT adults, knowledge of the patient's SO/GI can trigger exploration of social history including sexual practices, social stressors, and family structure and a broader assessment of the patient's strengths and needs and yield tailored health plans. Clinician acceptance of youth SO/GI demographics is likely to increase appropriate use of primary care services. These improvements in care become possible by incorporating SO/GI into the EHR as standard demographic data, but many in the current health workforce are not yet competent in such care.

Developing a Competent Workforce to Reduce LGBT Health Disparities

The electronic health record is one tool that can reduce health disparities in LGBT populations, but such efforts can only be effective if used by an LGBT competent workforce. For providers to deliver better care, undergraduate, graduate and post-graduate health curricula need to integrate LGBT health information. Likewise, trainees, staff and faculty need to experience systemic safety if they are to learn and provide care as effectively as possible. The unevenness of attitudes toward LGBT people across geographic areas and provider beliefs requires that talking about SO/GI must be incorporated in all levels of health education including continuing professional education. Even simple skills in asking and documenting SO/GI have not yet been included in standard medical training.[24] A crucial next step is to develop and integrate competency based health curricula to prepare health professionals for care of LGBT patients.[25]

Simulated patient scenarios can allow practice of comfortable discussions of SO/GI in pre-clinical training while all lectures need to be scrutinized as potential homes for nuggets of information on LGBT health. As medical schools teach cultural humility and cultural awareness, LGBT issues must be systematically included. These lessons should make health care professionals mindful of LGBT health disparities and clinician's roles in reducing them.

Successful enhancement of openness about SO/GI calls for additional focus on the hidden curriculum (the set of unintended, generally negative assumptions learned in health care systems). Traditional anti-LGBT prejudices have been sustained in the hidden curriculum through homophobic taunting in operating rooms, emergency departments and other high intensity sites. A systemic effort to reduce joking that marginalizes LGBT or other patients and trainees is critical to making health institutions safer. Institutional culture must work to embrace and celebrate diversity, fostering a positive environment for all.

Curricular development requires a focus on developing a sensitive and competent health workforce capable of a team-based approach to quality care for LGBT patients. Cultural congruence in this workforce is an important consideration to addressing LGBT patient issues and disparities, yet there continue to be significant hurdles to stewarding policies into practice at academic health centers and building an LGBT-competent health workforce. In developing the health workforce, graduate trainees and faculty are sub-sets of particular importance since each is critical to developing the next generation of clinicians. Their integration of LGBT respectful health education is essential to ultimately reducing LGBT health disparities.

The Role of Graduate Safe Zone Programs

An increasing number of students are graduating from high schools and universities that provide supportive climates and programming, such as Safe Zones. In Safe Zone workshops, individuals and offices commit to creating supportive spaces and services for sexual minorities. Safe Zone Programs first appeared in the late 1960s on college campuses and since then have spread to many high schools and universities. Students with Safe Zone Programs at their institutions graduate with an expectation of tolerance and pride for the LGBT community. Although rigorous evaluation of Safe Zone Programs has not been documented, these programs lead many students to expect an accepting environment in professional training. Pre-health advisors, graduate program admissions' committees and advisors are now challenged to discuss how various graduate programs and institutions may or may not provide a supportive climate for personal and professional development of LGBT students and students interested in LGBT health. Only in a safe environment can an LGBT trainee function optimally, and enhance their colleagues' competence in care for LGBT patients.

Faculty members also deserve personal and professional development. Faculty members hold multiple roles in academic health centers: providing clinical care, teaching, conducting research, and providing service. Faculty members are also role models and mentors in students' personal and professional development. A major challenge is the lack of "out" faculty to advise LGBT students. Unlike the current generation of students, many senior faculty in positions of power did not experience a supportive learning environment. These faculty members may lack the confidence and fundamental skills to help students excel as out providers or scholars on LGBT health research or curriculum development. For some faculty, who may perceive their own success as tied to remaining in the "closet", their recommendations to students may focus on them being less "out" or not "out" in graduate school in comparison to their undergraduate or familial environment. Homophobia documented in "When Healthcare is Not Caring"[26] needs to be confronted by out LGBT faculty and straight allies if there is to be a workforce capable of reducing or eliminating LGBT health disparities.

To change medicine for LGBT patients, health-related graduate programs need to maintain belief systems of tolerance and pride for the LGBT community. To date there are few health related graduate programs with a Safe Zone program. One example is the Safe Zone

Program at the Albert Einstein College of Medicine, Bronx, New York. Implemented in December 2011, its mission is to establish and maintain an environment to support the personal and professional development of LGBT students and to prepare all students to address LGBT-related health disparities and health care issues. Through on-going evaluation measures that capture the perspective of students, staff, and faculty, Einstein's Safe Zone Program has developed activities to promote a more supportive climate. Listed in table 1 are the objectives and activities undertaken by the Safe Zone Program that may serve as a model for our institutions.

Conclusion

There is now broad consensus at the policy level that reducing health care disparities is a moral imperative in our health care system. In this paper, we argue that health care providers and institutions need to commit to reducing health disparities among LGBT patients, in part by using the EHR systematically as a tool. Use of the EHR to gather and share SO/GI demographics carries obligations to protect patient information. Medical schools must also address provider education and institutional atmosphere to foster comfort and competence in soliciting and using SO/GI information. Welcoming environments in which LGBT patients and health care workers feel safe and accepted must be developed and enhanced. These efforts taken together can help create a health care delivery system that treats LGBT patients and health care professionals with respect, reduces health disparities, and promotes a more just and beneficial health care system.

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1.

Table 1. Safe Zone Program at the Albert Einstein College of Medicine, Objectives and Activities, 2011-2013

Objectives	Activities
Help develop and attract qualified LGBT students and students interested in LGBT-related health care disparities and health care to Einstein's academic programs; Through mentorship, ensure the personal and professional development of LGBT students and students interested in LGBT-related health disparities and health care; Create an institutional climate that supports all LGBT students, staff, faculty, and patients; Raise an awareness of LGBT history and current challenges in promoting LGBT health equity; Facilitate the development of future LGBT leaders by promoting student involvement in institutional, local, national, and international leadership roles.	Visibility • Webpage (including inclusion on Admissions webpage) • Pins, Stickers, Magnets • Yearly calendar of events • Brochure for incoming students • Newsletter Student/Faculty Development • Safe zone ally and mentor workshops • Allies guide Building Community and Networks • Social events • Inclusion in institutional mentoring program • Steering committee includes representatives from each of the teaching affiliates and institutional leadership Education and Scholarship • Inclusion on medical education committee • Students and faculty working to develop educational material for clinical rotations • Students and faculty partnering on new LGBT-related research initiatives • Involvement in the National LGBT Health Workforce Conference