

A Crisis of Erasure: Transgender and Gender-Nonconforming Populations Navigating Breast Cancer Health Information

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Abstract

In this paper, we use the topic of breast cancer as an example of health crisis erasure in both informational and institutional contexts, particularly within the transgender and gender-nonconforming population. Breast cancer health information conforms and defaults to conventional cultural associations with femininity, as is the case with pregnancy and other “single-sex” conditions (Surkan, 2015). Many health information and research practices normalize sexualities, pathologize non-normative gender (Drescher et al., 2012; Fish, 2008; Müller, 2018), and fail to recognize gender-nonconforming categories (Frohard-Dourlent et al., 2017). Because breast cancer health information is sexually normalized, an information boundary exists for the LGBTQ+ community, particularly among transgender and gender-nonconforming adults who are at greater risk of discrimination in healthcare settings (Casey et al., 2019). Transgender and gender-nonconforming people experience unique marginalization and risk with respect to breast cancer. We call upon and propose library and information research, education, and practice opportunities inclusive of the health information needs of transgender and gender-nonconforming populations.

Keywords: breast cancer; health crisis erasure; gender-nonconforming population; public libraries; public librarians; transgender

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Introduction

During a crisis, public librarians are on the front line, adapting as best practices evolve to respond to and serve urgent community needs. Public libraries engage in training and preparedness efforts to provide critical community resources while responding to a growing range of community and population resources and services inclusive of community health, opioid use, homelessness, natural disasters, and more.

Global health crises like the COVID-19 pandemic or the HIV/AIDS epidemic bring to the forefront a pronounced worldwide need for unencumbered access to quality health information. In Canada, health librarians collaborate with public library colleagues to meet the health information needs of Lesbian, Gay, Bisexual, Trans and Queer (LGBTQ) people (Ganshorn & Giustini, 2017). In the U.S., the Centers for Disease Control and Prevention (CDC) encourages those seeking health

information to take advantage of their local public libraries: “Libraries of all types, including public and medical libraries, are important partners in community-based health literacy efforts” (CDC, 2021). Case in point, the Public Library Association (PLA) (which is a unit of the American Library Association (ALA), along with the National Network of Libraries of Medicine), provides guidance to improve community health literacy, resources, and guides for public libraries (Allen, 2020). Libraries are expected—and often mandated—to provide information services and programming for diverse communities. ALA provides a dedicated resource page on supporting transgender patrons and staff. However, neither the PLA nor the ALA’s health and diversity resources indicate specific information about the intersections between community health literacies and LGBTQ+ communities.

In some regions of the world, LGBTQ+ expression or existence is criminalized (Patel et al., 2020). Thus, there may be little support for libraries that address the health information needs of all patrons (Wexelbaum, 2017). At times, the lack of formalized, transparent funding and support may force librarians to create non-traditional environments and provide underground services to protect their most vulnerable patrons as they navigate personal and professional resource limitations. We posit that such a scenario is an example of a “crisis erasure,” meaning that the LGBTQ+ community is experiencing a health information crisis which is allowed to be ignored, deprioritized, and addressed inequitably due to a history of stigma, criminalization, and the stunted development of health librarianship (Morris & Roberto, 2016). We build from prior research and frontline work, acknowledging that no work done to increase the visibility of concern for LGBTQ+ health can exist without also considering how healthcare has produced multiple points of marginality across various systems of oppression (Wagner & Kitzie, 2021). From here, we investigate how health crisis erasure is enacted in informational contexts and institutions and how library and information professionals might respond.

Background

We learn from a synthesis of current LIS, clinical, and patient engagement literature to connect with transgender erasure in healthcare systems literature that contextualizes a health crisis erasure lens to begin to enter additional knowledge of transgender and gender-nonconforming populations erasure enacted by informational and institutional contexts (LeBreton, 2013; Bauer et al., 2009).

LIS researchers demonstrate how libraries serve as centers in their community engagement, education and are critical in their role to provide access to health information (Whiteman et al., 2018). Within any library service community, there are diverse groups to consider (Cooke, 2016). Further, governmental agencies such as the Centers for Disease Control (CDC) in the U.S. encourage those seeking health information to take advantage of their local public libraries: “libraries of all types, including public and medical libraries, are important partners in community-based health literacy efforts” (2021). We find a paucity of LIS literature contributing knowledge of health information resources and services with transgender and gender-nonconforming people navigating health information needs.

Recognizing the health information needs of transgender and gender-nonconforming people in information seeking contexts involves not only the study of material realities, but also the uncomfortable realization of the privileged positions of LIS researchers and professionals in their coexistence within information institutions (Halberstam & Halberstam, 2005). So, LIS is responding to highlighted health information needs of transgender and gender-nonconforming

people navigating health information needs. Our research contributes to continue to document this much-needed scholarly attention.

Method

Study Design

The authors conducted a literature search and thematic analysis of health information behaviors of transgender and gender nonconforming persons with respect to breast cancer to consider the question: Are there any intersections between the health information behaviors of transgender and gender-nonconforming persons and breast cancer? We use the specific topic of breast cancer as an example of health crisis erasure in both informational and institutional contexts, particularly within the transgender and gender-nonconforming population. Breast cancer health information conforms and defaults to conventional cultural associations with femininity, as is the case with pregnancy and other “single-sex” conditions (Surkan, 2015). Many health information and research practices normalize sexualities, pathologize non-normative gender (Drescher et al., 2012; Fish, 2008; Müller, 2018), and fail to recognize gender-nonconforming categories (Frohard-Dourlent et al., 2017). Because breast cancer health information is sexually normalized, an information boundary exists for the LGBTQ+ community, particularly among transgender and gender nonconforming adults who are at greater risk of discrimination in healthcare settings (Casey et al., 2019). Transgender and gender-nonconforming people experience unique marginalization and risk with respect to breast cancer.

To guide our literature search we grounded our research in the following research question: How are transgender and gender-nonconforming populations represented within clinical, patient engagement, and library literature sources on breast cancer?

To conceptualize the literature we planned to assess, we determined that our framework revolved around three concepts: Trans, LGBTQ+, and Breast Cancer. We used related terms for the concepts as follows:

Trans: transgender or transsexual or transexual or gender variant or gender nonconforming;

LGBTQ+: LGBTQ or lesbian or gay or homosexual or bisexual or transgender or homosexual or queer or sexual minority; and,

Breast Cancer: breast cancer or breast neoplasm or breast carcinoma or breast tumor or breast malignancy.

We searched the related terms in *Library Literature & Information Science Full Text* (H.W. Wilson), *LISTA* (Library, Information Science & Technology Abstracts), *PubMed*, and *Web of Science*. In addition to databases, we reviewed 21 publications authored by library and information science (LIS) practitioners and relevant health information professional organizations. We reviewed articles individually to determine relevance based on our research question. The authors also used *Web of Science* to investigate citation chains of the most relevant articles to identify additional articles.

Three authors met to review the literature to identify themes and document a codebook using open coding that helped to identify categories and topics. Ultimately, we were able to group our

open codes into axial codes and then higher-level codes. During a weekly research team meeting, we unanimously coded an article. As we read the article, we associated passages of text with items in the codebook. Then, we compared our individual coding, discrepancies were discussed, and conflicts were resolved by consensus. In developing this consensus, we were not interested to know whether coders A and B used the same open codes, but rather whether coders A and B linked the same quotations to the same axial codes after open coding. The research team worked in this inductive, iterative fashion throughout the study. After the team meeting, a revised codebook was drafted until team members agreed that no new themes were emerging and no difficulties were encountered with existing themes. In this way, the coding team reached saturation of axial themes (Creswell & Creswell, 2018) and a working codebook. Previously, coded articles were then recoded with the final codebook to ensure consistency of coding practices over time.

Thematic Analysis

Our data were composed of 21 scholarly documents we retrieved from our purposeful literature search strategy. Our literature search strategy is explained and detailed in the search strategy method above. We conducted a thematic analysis of each literature document using the NVivo software to perform an open coding to discern emerging themes to map to the document's text (Hsieh & Shannon, 2005). We comparatively analyzed to build on general themes fitting all the individual documents. Our findings from this thematic analysis are detailed below.

Themes

Libraries are centers for community engagement and education, and they provide access to health information (Whiteman et al., 2018). Within any library service community, there are diverse groups to consider (Cooke, 2016). The community health information needs of transgender and gender-nonconforming people are specific and should be supported. Our research revealed three overarching themes emerging from the literature that serve as barriers to breast cancer health information among transgender and gender-nonconforming people: (1) access, (2) erasure, and (3) quality.

Access

Transgender and gender-nonconforming patients and their caregivers may have difficulty accessing information, healthcare, and support services that primarily serve them. Drake and Bielefield (2017) report from their research that

[c]ertain types of information needs were more likely to be unmet. Study participants were always or very often unable to find the information they needed... about 26% for trans issues and about 28% for medical health information about trans issues. (p. 164)

Breast cancer diagnoses are highly emotional (Mazzocco et al., 2019) and heavily influenced by family health history (Koehly et al., 2009). Transgender and gender-nonconforming people living with breast cancer may be less likely to rely on support from biological families due to bigotry and non-acceptance (Parker et al., 2018), and their support networks may include people beyond their nuclear relatives. Brown and McElroy (2018) confirm in their research that "survey participants reported stress around potential provider reactions to SOGI [sexual orientation or

gender identity] disclosure and concerns about provider recognition of their relationships” (p. 1194).

Transgender and gender-nonconforming patients may have additional obstacles accessing health information in clinical settings for a number of reasons, such as limited appointment time with healthcare providers, lack of specific knowledge about breast cancer, and forgetting pertinent details about one’s own health. Also, it can be challenging to reach healthcare providers outside of appointments for more information due to busy schedules or long waiting times for callbacks (Borman & McKenzie 2005). Breast cancer information is complex, and patients need support accessing information outside of the clinical setting to fully understand their medical situation and make well-informed decisions (Kwon & Kim, 2009).

Erasure

There is a unique problem of erasure of transgender and gender-nonconforming people, that sets this population apart from other marked categories of identity, such as race or ethnicity, which are often visually inscribed on the body in ways that sexual and gender identities may not be. Erasure reduces the accessibility of transgender and gender-nonconforming health information and lowers the quality of health information available. Although a significant issue for the LGBTQ+ community at large, visibility is especially critical for transgender and gender-nonconforming patients seeking healthcare and navigating health information systems, underscoring the importance of validation and appropriate data collection for critical treatment or risk reduction (Brown & McElroy, 2018; Horncastle, 2018; Müller, 2018; Quinn et al., 2015; Whitehead et al., 2016). For example, after a breast cancer diagnosis, Horncastle (2018), a queer patient themselves, described an information gap between themselves and their surgeon that was mired in “standard, mainstream care for female mastectomy patients in Australian public hospitals,” which, according to Horncastle, “accommodate[d] normalised gender with gusto” (p. 386).

Horncastle’s experience of erasure as a non-normatively gendered breast cancer patient meant that they were unable to articulate their desire for a surgical option not imagined by their carers. Horncastle (2018) reflected, “[p]erhaps I want too much,, “but if breast cancer bodies are shaped in the hands of breast-oncology surgeons ... when they cannot even speak the words: gender, masculinity, cis, trans, what does this mean for humanising their care practices?” (p. 387) There is a direct relationship between visibility, language, and ultimately surgical outcomes:

Teaching the breast cancer surgeon about queer or non-normative options is contingent upon the capacity to act in a different register, and heurism rests too, on being a carer for the carer and enriching someone else’s conceptual and professional landscape. In order to do this one must not feel invisible. (Horncastle, 2018, p. 388)

Brown and McElroy (2018) also addresses visibility via SOGI categories:

Historically, SGM [sexual and gender minority] identities of cancer patients have mostly been invisible to healthcare providers, and patients often struggled with the question of disclosure or with being disappointed by healthcare provider reactions to disclosure. (p. 415)

Quality

Patients who are gender-neutral or gender-nonconforming endure higher rates of discrimination (White Hughto et al., 2017) and verbal attacks (Ard & Makadon, 2011; Grant et al., 2011; Lambda Legal, 2010). Providers of health information must be aware of the dimensions of gender and the consequences of patient disclosure. Transgender and gender-nonconforming patients must carefully decide how and when to disclose their gender identity to their medical providers or information agents (i.e., reference librarians). Drake and Bielefield (2017) point out that for transgender and gender-nonconforming patients, “when asked about their use of library reference services, most said they had not used them for fear of discrimination” (p. 164).

The decision to disclose is a profound burden because failing to disclose may result in adverse health outcomes due to avoiding treatment or withholding information (secrecy). Disclosure concerns may reduce the quality of health care received because health status, risk, and diagnosis may be inaccurately assessed (Müller, 2018). Treatment options may be limited or misaligned. The quality of health care depends on adequate recognition of the perspectives from both providers and patients as valid to foster understanding and identify cross-cultural differences (Hudak et al., 2018). This approach enables providers and patients to work together to pursue culturally sensitive medical options and achieve desired health outcomes (Ahmed & Bates, 2010). Frohard-Dourlent et al. (2017) assert that:

We can also use language that explicitly communicates that the research is inclusive of trans and non-binary participants, and circulate recruitment ads among trans organizations, even when the research is not focused on trans or non-binary experiences. For the CTYHS [Canadian Trans Youth Health Survey], including both “trans” and “genderqueer” on the recruitment materials resulted in a robust sample of non-binary youth respondents. (p. 5)

Researchers have found that higher quality provider-patient relationships are associated with higher patient satisfaction levels (Campbell et al., 2007). Culturally competent practices inform clinical and research settings across diverse axes of intersecting identities for LGBTQ+ people/patients (Margolies & Brown, 2019; McGinniss et al., 2018, including race/ethnicity, socio-economic status, and age, with particular emphasis on youth and elders (Ahwireng-Obeng & Loggerenberg, 2011; Matthen et al., 2018; Evans et al., 2017; Tamargo et al., 2017; Wahlert & Fiester, 2014). Sarkin (2019) asserts that:

In reshaping health system design to be more patient-centered, we should be gravitating toward intersectional understandings of patient identity as defined by the patients themselves. Kumas-Tan et al. (2007) prompt that the meaning of culture in medical encounters needs to expand to include gender, age, sexual orientation, income, ability, and faith, in addition to race and ethnicity. (p. 9)

However, a long history of LGBTQ+ bias in the healthcare system continues to make these populations avoid or delay treatment (Margolies & Brown, 2019). Cultural competency of medical providers when serving transgender and gender-nonconforming people is low, with 33%-50% of transgender and gender-nonconforming individuals reporting having to educate their medical providers about transgender health (Grant et al., 2011; James et al., 2016). A study conducted by Sabin et al. (2015), found that health care providers held strong implicit preferences for heterosexual people and providers often lacked education about transgender health issues.

Morris and Roberto (2016) found that “[h]ealth care professionals can benefit from training to understand their LGBTQ patients’, and colleagues’ distinct concerns and to provide a more culturally competent and welcoming environment; we believe the same is true for medical librarians” (p. 214). And in particular, while considering quality of interaction, Sarkin (2019) found that:

Exploring the nature of what constitutes “womanhood” through gender policing and medicalization, is relevant to LGBTQ+ breast cancer communities, and deconstruction of these frameworks may reveal potential interventions for improving ways that physicians and care providers address illness and bodily modifications as well as other concerns. (p. 6)

Internationally, there are voices from the Global South, which need to be heard to address the needs of the LGBTQ+ community without the gaze of the Global North. Bao (2005) posits that:

Queer people in the Global South are often seen as powerless victims that passively await salvation by their liberated brothers and sisters from the Global North. In priding itself on gender and sexual diversity and in seeing itself as the epitome of human civilization, the Global North has deployed the dichotomy of a sexually liberalized North versus a sexually illiberal South, and this further consolidates the unequal power relations between the North and the South. (p. 310)

When cultural competence is lacking, it reinforces information boundaries and marginalization. LGBTQ+ patients will share information among their peers and community members but are not adequately served by the larger world’s health services and information providers. Pohjanen and Kortelainen’s (2016) study revealed that “sharing information played a big part in the information behaviour of the transgender informants. Information was shared among the peer group, which represents wider personal networks (Williamson, 1998) and can be considered as the most important source of information in this study” (p. 183). For LIS professionals, Hawkins et al. (2017) advise that

[t]he creation of a library subject guide or dedicated resource list on LGBTQ health is another strategy that would indicate a willingness on the part of librarians to engage with LGBTQ health professionals and their questions, and demonstrate that the library has appropriate expertise and knowledge. (p. 214)

Discussion

We next applied our findings to our guiding research question to describe how clinical, patient engagement, and library literature sources on breast cancer represent transgender and gender-nonconforming populations. Our method here returned more knowledge, sources, and services on broader LGBTQ+ health information both generally and topically focused on breast cancer as compared with specifics that are inclusive of transgender and gender-nonconforming people. Our current lack of information resources and services that directly represent transgender and gender-nonconforming people, while growing, continue to serve to actively erase transgender and gender-nonconforming representation in institutional and information contexts.

We further articulated the primary themes emerging from our literature survey of transgender and gender-nonconforming peoples’ documentation of access and experiences in health

information and institutional contexts as: (1) access, (2) erasure, and (3) quality. Each theme reveals areas of opportunity to further acknowledge transgender and gender-nonconforming health information erasure as a crisis requiring dedicated attention, from library and information health professionals and researchers. Access issues reveal specific health information gaps, including a lack of knowledge resources dedicated to access for folks engaged with seeking health information on breast cancer that represents transgender and gender-nonconforming health information. While potentially difficult to professionally navigate the acknowledgement of lacking evidence-based health resources, this gap presents the opportunity to explore how to navigate the gaps purposefully. This knowledge gap is a significant issue that also impacts the intersecting themes of erasure and quality. Our research highlights this health information knowledge gap that results in a lack of resources available to LIS professionals as well as health care professionals. To address this knowledge gap we synthesize our findings to identify actionable strategies to acknowledge a transgender and gender-nonconforming health information crisis and how LIS communities might continue to respond to this crisis of transgender and gender-nonconforming health information erasure.

Understandably, LIS resources and attention are allocated to respond to the crises experienced and expressed by communities; however, our investigation led us to question how crises, especially health crises, are acknowledged by health LIS communities and how health LIS communities do and might respond.

This literature survey reveals the stark lack of transgender and gender-nonconforming health information resources available. This challenge of inequitable health information access further leads us to argue that this knowledge gap intensely impedes overall information access for transgender and gender-nonconforming people. Furthermore, inequities outlined herein further contribute to the erasure of this health information on a global scale.

Our investigation did not find literacy to be the primary challenge here, but rather, found access, erasure, and quality to be the primary challenges faced by transgender and gender-nonconforming people navigating and experiencing health information contexts and institutions.

Additionally, one significant challenge in addressing transgender and gender-nonconforming people's health is often centered on sexuality. Yet, gender identity is different than sexuality. All too often, community health information tailored for transgender and gender-nonconforming people is sexualized in a manner that erases other health-based needs. We observed library collections where items listed as priorities had little to do with the community's general health needs. For example, breast cancer may be a significant information need. Still, the collection may solely focus on mental health and sexually transmitted diseases. There must be a strategy to reach communities with appropriate health information that is helpful to them when they have concerns about breast cancer. Inclusion is a good start, but more can be done to realize actual support for the lived experiences and everyday health information needs for transgender and gender-nonconforming people. We have identified the following recommendations to improve meeting transgender and gender-nonconforming people's health information needs. We now focus this discussion on actionable recommendations informed by our research.

Inclusive LIS Education

We recommend the need for additional instruction during LIS professional preparation to recommend additional research effort to dedicate to understand how transgender and gender-

nonconforming people might be further included in LIS educational health topics. Our observation of the conflation of sexuality with gender identity particularly concerned us. This led us to recommend addressing not only the inclusion of transgender and gender-nonconforming representation in LIS education but also a greater representation of sexuality and gender identity information.

Robust Transgender and Gender-Nonconforming Resources and Services

We recommend the need to understand better not only LGBTQ+ content as broadly conceived as resources that librarians work to make accessible to communities but also the specific resources for transgender and gender-nonconforming people. It is not the library's responsibility to author the content, but they should partner with academic health libraries to curate content. LIS education must include tools and information on supporting references and classification to develop these distributed networks and safe spaces for transgender and gender-nonconforming folks.

Advocacy

Reviving our literature-based survey findings, we identify health allied and LIS community work to actively dedicate advocacy and institutional resources service transgender and gender-nonconforming people in their communities. We note the considerable work required to achieve growth in quality resources to meet transgender and gender-nonconforming health information needs. In April 2021, current United States Assistant Secretary for Health, Dr. Rachel Levine, stated that discrimination and oppression were challenging equity in transgender health (Sullivan & Shapiro, 2021). Levine's position shares the importance of legislation to decriminalize transgender and gender-nonconforming behaviors and afford equal protections. This stance in advocacy might help globally to address transgender and gender-nonconforming health inequity, inclusive of health information.

Conclusion

In this study we found the LIS community has an opportunity to address the paucity of dedicated informational resources available to transgender and gender-nonconforming people. We highlighted issues and our current recommendations in three areas: 1.) LIS Education; 2.) Transgender and Gender-Nonconforming Resources and Services; and 3.) Advocacy. We noted a recurring issue of the conflation of sexual orientation-based health, and gender and gender identity-based health after reviewing the existing information literature. We offer these recommendations for librarians and allied professionals who are faced with this health information erasure and note the need for improved equity in health information access issues, of transgender and gender-nonconforming people. We acknowledge the lack of reliable health information available in this review and the implications of access and erasure. With those limitations in mind, this paper provides recommendations to fill this knowledge gap by identifying actional future work in LIS education, resources and services, and advocacy.

Appendix

Table 1. Categorization of Articles included in the Sample

Article Number	Article	Discipline
Article 1	Bao, H. (2020). The queer Global South: Transnational video activism between China and Africa. <i>Global Media & China</i> , 5(3), 294-318. https://doi.org/10.1177%2F2059436420949985	Patient Engagement
Article 2	Brown, G. R. (2015). Breast cancer in transgender veterans: A ten-case series. <i>LGBT Health</i> , 2(1), 77-80. https://doi.org/10.1089/lgbt.2014.0123	Clinical
Article 3	Brown, M. T., & McElroy, J. A. (2018). Sexual and gender minority breast cancer patients choosing bilateral mastectomy without reconstruction: "I now have a body that fits me." <i>Women Health</i> , 58(4), 403-418. https://doi.org/10.1080/03630242.2017.1310169	Clinical
Article 4	Bryson, M. K., Ristock, J., Boschman, L., Taylor, E. T., Hart, ryson, M. K., Ristock, J., Boschman, L., Taylor, E. T., Hart, T., Gahagan, J., & Rail, G. (2019). The Cancer's Margins project: Access to knowledge and its mobilization by LGBTQ/T cancer patients. <i>Media and Communication</i> , 7(1), 102-113. https://doi.org/10.17645/mac.v7i1.1718	Patient Engagement
Article 5	Dhand, A., & Dhaliwal, G. (2010). Examining Patient Conceptions: A Case of metastatic breast cancer in an African American male to female transgender patient. <i>Journal of General Internal Medicine</i> , 25(2), 158-161. https://doi.org/10.1007/s11606-009-1159-6	Clinical
Article 6	Drake, A. A., & Bielefield, A. (2017). Equitable access: Information seeking behavior, information needs, and necessary library accommodations for transgender patrons. <i>Library & Information Science Research</i> , 39(3), 160-168. https://doi.org/10.1016/j.lisr.2017.06.002	Library
Article 7	Fikar, C. R., & Keith, L. (2004). Information needs of gay, lesbian, bisexual, and transgendered health care professionals: Results of an Internet survey. <i>Journal of the Medical Library Association</i> , 92(1), 56-65. https://www.ncbi.nlm.nih.gov/pubmed/14762463	Library
Article 8	Frohard-Dourlent, H., Dobson, S., Clark, B. A., Doull, M., & Saewyc, E. M. (2017). "I would have preferred more options":	Patient Engagement

	Accounting for non-binary youth in health research. <i>Nursing Inquiry</i> , 24(1), e12150. https://doi.org/10.1111/nin.12150	
Article 9	Hawkins, B. W., Morris, M., Nguyen, T., Siegel, J., & Vardell, E. (2017). Advancing the conversation: Next steps for lesbian, gay, bisexual, trans, and queer (LGBTQ) health sciences librarianship. <i>Journal of the Medical Library Association: JMLA</i> , 105(4), 316-327. https://doi.org/10.5195/jmla.2017.206	Library
Article 10	Horncastle, J. (2018). Practicing care: Queer vulnerability in the hospital. <i>Social Identities</i> , 24(3), 383-394. https://doi.org/10.1080/13504630.2017.1387038	Clinical
Article 11	Liu, P. L., & Yeo, T. E. D. (2019). Breast health, risk factors, and cancer screening among lesbian, bisexual, and queer/questioning women in China. <i>Health Care for Women International</i> , 1-15. https://doi.org/10.1080/07399332.2019.1571062	Clinical
Article 12	Morris, M., & Roberto, K. R. (2016). Information-seeking behaviour and information needs of LGBTQ health professionals: A follow-up study. <i>Health Information and Libraries Journal</i> , 33(3), 204-221. https://doi.org/10.1111/hir.12139	Library
Article 13	Movius, L. (2018). An exploratory case study of transgender and gender nonconforming inclusion at a metropolitan library in the Southeastern US. <i>The International Journal of Information, Diversity, & Inclusion (IJIDI)</i> , 2(4), 38-51. https://doi.org/10.33137/ijidi.v2i4.32202	Library
Article 14	Parikh, U., Mausner, E., Chhor, C. M., Gao, Y., Karrington, I., & Heller, S. L. (2020). Breast imaging in transgender patients: what the radiologist should know. <i>Radiographics</i> , 40(1), 13-27. https://doi.org/10.1148/rg.2020190044	Clinical
Article 15	Petrey, J. (2019). Development and implementation of an LGBT initiative at a health sciences library: The first eighteen months. <i>Journal of the Medical Library Association</i> , 107(4), 555-559. https://doi.org/10.5195/jmla.2019.422	Library
Article 16	Pohjanen, A. M., & Kortelainen, T. A. M. (2016). Transgender information behaviour. <i>Journal of Documentation</i> , 72(1), 172-190. https://doi.org/10.1108/JD-04-2015-0043	Library
Article 17	Rossmann, K., Salamanca, P., & Macapagal, K. (2017). A qualitative study examining young adults' experiences of	Patient Engagement

	disclosure and nondisclosure of LGBTQ identity to health care providers. <i>Journal of Homosexuality</i> , 64(10), 1390-1410. https://doi.org/10.1080/00918369.2017.1321379	
Article 18	Sarkin, C. A. (2019). Queering healthcare: Why integrating cultural humility into medical education matters for LGBTQ+ patients. <i>Journal of Critical Thought and Praxis</i> , 8(2), 1-14. https://doi.org/10.31274/jctp.8207	Patient Engagement
Article 19	Sattari, M. (2015). Breast cancer in male-to-female transgender patients: A case for caution. <i>Clinical Breast Cancer</i> , 15(1), e67-69. https://doi.org/10.1016/j.clbc.2014.08.004	Clinical
Article 20	Seelman, K. L., Colón-Díaz, M. J., LeCroix, R. H., Xavier-Brier, M., & Kattari, L. (2017). Transgender noninclusive healthcare and delaying care because of fear: connections to general health and mental health among transgender adults. <i>Transgender health</i> , 2(1), 17-28. https://doi.org/10.1089/trgh.2016.0024	Patient Engagement
Article 21	Vera, A. N., Wagner, T. L., & Kitzie, V. L. (2020). "When it's time to come together, we come together": Reconceptualizing theories of self-efficacy for health information practices within LGBTQIA+ communities. In <i>Roles and responsibilities of libraries in increasing consumer health literacy and reducing health disparities</i> . Emerald Publishing Limited.	Patient Engagement

References

- Ahmed, R., & Bates, B. R. (2010). Assessing the relationship between patients' ethnocentric views and patients' perceptions of physicians' cultural competence in health care interactions. *Intercultural Communication Studies*, 19(2), 111-127.
- Ahwireng-Obeng, F., & van Loggerenberg, C. (2011). Africa's middle class women bring entrepreneurial opportunities in breast care medical tourism to South Africa. *The International Journal of Health Planning and Management*, 26(1), 39-55.
<https://doi.org/10.1002/hpm.1034>
- Allen, S. (2020, June 1). Public Library Association, National Network of Libraries of Medicine continue partnership with new digital literacy, citizen science tools. *ALA Member News*. [Press release]. <https://www.ala.org/news/member-news/2020/06/public-library-association-national-network-libraries-medicine-continue>



- Ard, K. L., & Makadon, H. J. (2011). Addressing intimate partner violence in lesbian, gay, bisexual, and transgender patients. *Journal of General Internal Medicine*, 26(8), 930-933. <https://doi.org/10.1007/s11606-011-1697-6>
- Bao, H. (2020). The queer Global South: Transnational video activism between China and Africa. *Global Media & China*, 5(3), 294-318. <https://doi.org/10.1177/2059436420949985>
- Bauer, G. R., Hammond, R., Travers, R., Kaay, M., Hohenadel, K. M., & Boyce, M. (2009). "I don't think this is theoretical; this is our lives": How erasure impacts health care for transgender people. *Journal of the Association of Nurses in AIDS Care*, 20(5), 348-361. <https://doi.org/10.1016/j.jana.2009.07.004>
- Borman, C. B., & McKenzie, P. J. (2005). Trying to help without getting in their faces: Public library staff descriptions of providing consumer health information. *Reference & User Services Quarterly*, 45(2), 133-146.
- Brown, G. R. (2015). Breast cancer in transgender veterans: A ten-case series. *LGBT Health*, 2(1), 77-80. <https://doi.org/10.1089/lgbt.2014.0123>
- Brown, M. T., & McElroy, J. A. (2018). Unmet support needs of sexual and gender minority breast cancer survivors. *Supportive Care in Cancer*, 26(4), 1189-1196. <https://doi.org/10.1007/s00520-017-3941-z>
- Bryson, M. K., Ristock, J., Boschman, L., Taylor, E. T., Hart, T., Gahagan, J., & Rail, G. (2019). The Cancer's Margins project: Access to knowledge and its mobilization by LGBTQ/T cancer patients. *Media and Communication*, 7(1), 102-113. <https://doi.org/10.17645/mac.v7i1.1718>
- Campbell, S., Reeves, D., Kontopantelis, E., Middleton, E., Sibbald, B., & Roland, M. (2007). Quality of primary care in England with the introduction of pay for performance. *New England Journal of Medicine* 357(2), 181-190. <http://dx.doi.org/10.1056/NEJMs065990>
- Casey, L. S., Reisner, S. L., Findling, M. G., Blendon, R. J., Benson, J. M., Sayde, J. M., & Miller, C. (2019). Discrimination in the United States: Experiences of lesbian, gay, bisexual, transgender, and queer Americans. *Health Services Research*, 54(S2), 1454-1466. <https://doi.org/10.1111/1475-6773.13229>
- Cooke, N. A. (2016). *Information services to diverse populations: Developing culturally competent library professionals*. ABC-CLIO, LLC. <http://ebookcentral.proquest.com/lib/fsu/detail.action?docID=4742121>
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5th ed.). SAGE Publications.
- Dhand, A., & Dhaliwal, G. (2010). Examining Patient Conceptions: A Case of metastatic breast cancer in an African American male to female transgender patient. *Journal of General Internal Medicine*, 25(2), 158-161. <https://doi.org/10.1007/s11606-009-1159-6>

- Drake, A. A., & Bielefield, A. (2017). Equitable access: Information seeking behavior, information needs, and necessary library accommodations for transgender patrons. *Library & Information Science Research*, 39(3), 160-168. <https://doi.org/10.1016/j.lisr.2017.06.002>
- Drescher, J., Cohen-Kettenis, P., & Winter, S. (2012). Minding the body: Situating gender identity diagnoses in the ICD-11. *International Review of Psychiatry (Abingdon, England)*, 24(6), 568-577. <https://doi.org/10.3109/09540261.2012.741575>
- Evans, Y. N., Gridley, S. J., Crouch, J., Wang, A., Moreno, M. A., Ahrens, K., & Breland, D. J. (2017). Understanding online resource use by transgender youth and caregivers: A qualitative study. *Transgender Health*, 2(1), 129-139. <https://doi.org/10.1089/trgh.2017.0011>
- Fikar, C. R., & Keith, L. (2004). Information needs of gay, lesbian, bisexual, and transgendered health care professionals: Results of an Internet survey. *Journal of the Medical Library Association*, 92(1), 56-65. <https://www.ncbi.nlm.nih.gov/pubmed/14762463>
- Fish, J. (2008). Navigating Queer Street: Researching the intersections of lesbian, gay, bisexual and trans (LGBT) identities in health research. *Sociological Research Online*, 13(1), 104-115. <https://doi.org/10.5153/sro.1652/>
- Frohard-Dourlent, H., Dobson, S., Clark, B. A., Doull, M., & Saewyc, E. M. (2017). "I would have preferred more options": Accounting for non-binary youth in health research. *Nursing Inquiry*, 24(1), e12150. <https://doi.org/10.1111/nin.12150>
- Ganshorn, H., & Giustini, D. (2017). New directions in health sciences libraries in Canada: Research and evidence based practice are key. *Health Information & Libraries Journal*, 34(3), 252-257. <https://doi.org/10.1111/hir.12190>
- Grant, J. M., Mottet, L. A., Tanis, J., Harrison, J., Herman, J. L., & Keisling, M. (2011). *Injustice at every turn: A report of the National Transgender Discrimination Survey*. National Center for Transgender Equality and National Gay and Lesbian Task Force. https://transequality.org/sites/default/files/docs/resources/NTDS_Report.pdf
- Halberstam, J. J., & Halberstam, J. (2005). *In a queer time and place: Transgender bodies, subcultural lives* (Vol. 3). NYU Press.
- Hawkins, B. W., Morris, M., Nguyen, T., Siegel, J., & Vardell, E. (2017). Advancing the conversation: Next steps for lesbian, gay, bisexual, trans, and queer (LGBTQ) health sciences librarianship. *Journal of the Medical Library Association: JMLA*, 105(4), 316-327. <https://doi.org/10.5195/jmla.2017.206>
- Horncastle, J. (2018). Practicing care: Queer vulnerability in the hospital. *Social Identities*, 24(3), 383-394. <https://doi.org/10.1080/13504630.2017.1387038>
- Hudak, N. C., Carmack, H. J., & Smith, E. D. (2018). Student perceptions of providers' cultural competence, attitudes towards providers, and patient satisfaction at a university health center: International and US student differences. *Journal of International Students*, 8(2), 960-976. <https://doi.org/10.32674/jis.v8i2.122>

- Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288. <https://doi.org/10.1177%2F1049732305276687>
- James, S., Herman, J., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. A. (2016). *The report of the 2015 U.S. Transgender Survey*. <http://hdl.handle.net/20.500.11990/1299>
- Koehly, L. M., Peters, J. A., Kenen, R., Hoskins, L. M., Ersig, A. L., Kuhn, N. R., Loud, J. T., & Greene, M. H. (2009). Characteristics of health information gatherers, disseminators, and blockers within families at risk of hereditary cancer: Implications for family health communication interventions. *American Journal of Public Health*, 99(12), 2203-2209. <https://doi.org/10.2105/AJPH.2008.154096>
- Kwon, N., & Kim, K. (2009). Who goes to a library for cancer information in the e-health era? A secondary data analysis of the Health Information National Trends Survey (HINTS). *Library & Information Science Research*, 31(3), 192-200. <https://doi.org/10.1016/j.lisr.2009.01.006>
- Lambda Legal. (2010). *When health care isn't caring: Lambda Legal's survey of discrimination against LGBT people and people with HIV*. <https://www.lambdalegal.org/publications/when-health-care-isnt-caring>
- LeBreton, M. (2013). The erasure of sex and gender minorities in the healthcare system. *Bioéthique Online*, 2, 1-5. <http://bioethiqueonline.ca/2/17>
- Liu, P. L., & Yeo, T. E. D. (2019). Breast health, risk factors, and cancer screening among lesbian, bisexual, and queer/questioning women in China. *Health Care for Women International*, 1-15. <https://doi.org/10.1080/07399332.2019.1571062>
- Margolies, L., & Brown, C. G. (2019). Increasing cultural competence with LGBTQ patients. *Nursing2020*, 49(6), 34-40. <https://doi.org/10.1097/01.NURSE.0000558088.77604.24>
- Matthen, P., Lyons, T., Taylor, M., Jennex, J., Anderson, S., Jollimore, J., & Shannon, K. (2018). "I Walked into the Industry for Survival and Came Out of a Closet": How gender and sexual identities shape sex work experiences among men, two spirit, and trans people in Vancouver. *Men and Masculinities*, 21(4), 479-500. <https://doi.org/10.1177/1097184X16664951>
- Mazzocco, K., Masiero, M., Carriero, M. C., & Pravettoni, G. (2019). The role of emotions in cancer patients' decision-making. *Ecancermedicalscience*, 13. <https://pubmed.ncbi.nlm.nih.gov/31123497/>
- McGinniss, M. A., Tahmassi, A. G., & Ramos, E. (2018). Towards cultural competence in the genomic age: A review of current health care provider educational trainings and interventions. *Current Genetic Medicine Reports*, 6(4), 187-198. <https://doi.org/10.1007/s40142-018-0150-0>
- Morris, M., & Roberto, K. R. (2016). Information-seeking behaviour and information needs of LGBTQ health professionals: A follow-up study. *Health Information and Libraries Journal*, 33(3), 204-221. <https://doi.org/10.1111/hir.12139>

- Movius, L. (2018). An exploratory case study of transgender and gender nonconforming inclusion at a metropolitan library in the Southeastern US. *The International Journal of Information, Diversity, & Inclusion (IJIDI)*, 2(4), 38-51. <https://doi.org/10.33137/ijidi.v2i4.32202>
- Müller, A. (2018). Beyond 'invisibility': Queer intelligibility and symbolic annihilation in healthcare. *Culture, Health & Sexuality*, 20(1), 14-27. <https://doi.org/10.1080/13691058.2017.1322715>
- Parker, C. M., Hirsch, J. S., Philbin, M. M., & Parker, R. G. (2018). The urgent need for research and interventions to address family-based stigma and discrimination against lesbian, gay, bisexual, transgender, and queer youth. *Journal of Adolescent Health*, 63(4), 383-393. <https://doi.org/10.1016/j.jadohealth.2018.05.018>
- Patel, S., Cuneo, C. N., Power, J. R., & Beyrer, C. (2020). Topics in global LGBTQ health. In J. R. Lehman, K. Diaz, H. Ng, E. M. Petty, M. Thatikunta, & K. Eckstrand (Eds.), *The equal curriculum: The student and educator guide to LGBTQ health* (pp. 261-288). Springer International Publishing. https://doi.org/10.1007/978-3-030-24025-7_14
- Petrey, J. (2019). Development and implementation of an LGBT initiative at a health sciences library: The first eighteen months. *Journal of the Medical Library Association*, 107(4), 555-559. <https://doi.org/10.5195/jmla.2019.422>
- Pohjanen, A. M., & Kortelainen, T. A. M. (2016). Transgender information behaviour. *Journal of Documentation*, 72(1), 172-190. <https://doi.org/10.1108/JD-04-2015-0043>
- Quinn, G. P., Sanchez, J. A., Sutton, S. K., Vadaparampil, S. T., Nguyen, G. T., Green, B. L., Kanetsky, P.A., & Schabath, M. B. (2015). Cancer and lesbian, gay, bisexual, transgender/transsexual, and queer/questioning (LGBTQ) populations. *CA: A Cancer Journal for Clinicians*, 65(5), 384-400. <https://doi.org/10.3322/caac.21288>
- Rossmann, K., Salamanca, P., & Macapagal, K. (2017). A qualitative study examining young adults' experiences of disclosure and nondisclosure of LGBTQ identity to health care providers. *Journal of Homosexuality*, 64(10), 1390-1410. <https://doi.org/10.1080/00918369.2017.1321379>
- Sabin, J. A., Riskind, R. G., & Nosek, B. A. (2015). Health care providers' implicit and explicit attitudes toward lesbian women and gay men. *American Journal of Public Health*, 105(9), 1831-1841. <https://doi.org/10.2105/AJPH.2015.302631>
- Sarkin, C. A. (2019). Queering healthcare: Why integrating cultural humility into medical education matters for LGBTQ+ patients. *Journal of Critical Thought and Praxis*, 8(2), 1-14. <https://doi.org/10.31274/jctp.8207>
- Sattari, M. (2015). Breast cancer in male-to-female transgender patients: A case for caution. *Clinical Breast Cancer*, 15(1), e67-69. <https://doi.org/10.1016/j.clbc.2014.08.004>
- Seelman, K. L., Colón-Díaz, M. J., LeCroix, R. H., Xavier-Brier, M., & Kattari, L. (2017). Transgender noninclusive healthcare and delaying care because of fear: connections to

- general health and mental health among transgender adults. *Transgender health*, 2(1), 17-28. <https://doi.org/10.1089/trgh.2016.0024>
- Surkan, K. (2015). The fat man is giving birth. In N. Burton (Ed.), *Natal signs: Cultural representations of pregnancy, birth and parenting*. Demeter Press. <https://doi.org/10.2307/j.ctt1rrd8tc>
- Tamargo, J., Rosano, G., Walther, T., Duarte, J., Niessner, A., Kaski, J. C., Ceconi, C., Drexel, H., Kjeldsen, K., Savarese, G., Torp-Pedersen, C., Atar, D., Lewis, B.S., & Agewall, S. (2017). Gender differences in the effects of cardiovascular drugs. *European Heart Journal-Cardiovascular Pharmacotherapy*, 3(3), 163-182. <https://doi.org/10.1093/ehjcvp/pvw042>
- Vera, A. N., Wagner, T. L., & Kitzie, V. L. (2020). "When it's time to come together, we come together": Reconceptualizing theories of self-efficacy for health information practices within LGBTQIA+ communities. *Advances in Librarianship*, 47, 263-282. <https://doi.org/10.1108/S0065-28302020000047013>
- Wagner, T. L., & Kitzie, V. L. (2021). 'Access necessitates being seen': Queer visibility and intersectional embodiment within the health information practices of queer community leaders. *Journal of Information Science [OnlineFirst]*. <https://doi.org/10.1177%2F016555152111040658>
- Wahlert, L., & Fiester, A. (2014). Repaving the road of good intentions: LGBT health care and the queer bioethical lens. *Hastings Center Report*, 44(s4), S56-65. <https://doi.org/10.1002/hast.373>
- Wexelbaum, R. S. (2017). Global promotion of LGBTQ resources and services through social media. In *Library Faculty Publications 59*. https://repository.stcloudstate.edu/lrs_facpubs/59/
- White Hughto, J. M., Rose, A. J., Pachankis, J. E., & Reisner, S. L. (2017). Barriers to gender transition-related healthcare: Identifying underserved transgender adults in Massachusetts. *Transgender Health*, 2(1), 107-118. <https://doi.org/10.1089/trgh.2017.0014>
- Whitehead, J., Shaver, J., & Stephenson, R. (2016). Outness, stigma, and primary health care utilization among rural LGBT populations. *PLoS one*, 11(1), e0146139. <https://doi.org/10.1371/journal.pone.0146139>
- Whiteman, E. D., Dupuis, R., Morgan, A. U., D'Alonzo, B., Epstein, C., Klusaritz, H., & Cannuscio, C. C. (2018). Public libraries as partners for health. *Preventing Chronic Disease*, 15. <https://doi.org/10.5888/pcd15.170392>

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