Evidence Based Library and Information Practice

Transgender and Gender-Nonconforming Populations Experience Unique Challenges in Health Information Environment Developed for Heteronormative Audience

Tenny, C. S., Surkan, K. J., Gerido, L. H., & Betts-Green, D. (2021). A crisis of erasure: Transgender and gender-nonconforming populations navigating breast cancer health information. The International Journal of Information, Diversity, & Inclusion, 5(4), 132–149. https://doi.org/10.33137/ijidi.v5i4.37406

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Résumé de l'article

Objective – To understand the lived experiences of transgender and gender-nonconforming populations in seeking health information about breast cancer.

Design – Thematic literature review.

Setting – Four English-language databases featuring clinical, patient engagement, and library and information sciences (LIS) research.

Subjects – Twenty-one published articles.

Methods – The researchers chose three concepts (trans, LGBTQ+, and breast cancer), identified related terms for each, and used these terms to conduct literature searches in four databases: PubMed, Web of Science, Library Literature & Information Science Full Text, and Library, Information, Science & Technology Abstracts. Search results were reviewed for relevance to the research objective. The researchers applied grounded theory to analyze the 21 selected articles through open, axial, and selective (thematic) coding. The qualitative research software NVivo was used to perform thematic analysis of each article, and a shared codebook was developed to ensure saturation of axial themes and consistency of coding amongst researchers.

Main Results – Three overarching themes emerged from selective coding that exemplify experiences of transgender and gender-nonconforming persons seeking health information about breast cancer: access, erasure, and quality. Compared to their cisgender peers, these historically marginalized populations and their caregivers experience more difficulty accessing the already limited breast cancer information, healthcare, and support services suited to their needs. In particular, transgender and gender-nonconforming patients are often burdened with choosing between receiving health information and care designed for heteronormative persons and risking self-disclosure and possible discrimination by culturally incompetent health professionals.
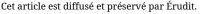
Conclusion – The researchers noted the alarmingly limited resources available for gender-nonconforming patients seeking information and support for health matters other than mental health or sexually transmitted diseases. The researchers also called for increased efforts by LIS curriculums and professionals to study and understand the needs of transgender and gender-nonconforming patrons, and to improve the quality and quantity of information resources specifically dedicated to these unique populations.

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A Review of:

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Abstract

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Commentary

As humanity recovers from the worldwide COVID-19 pandemic, this study provides timely advocacy for the creation of, and access to, quality health information for historically underserved populations. The article contributes to existing LIS research by bringing attention to the lack of inclusive information sources for transgender and gender-nonconforming audiences about health topics not explicitly related to their sexual identities.

An examination of this study using the Evidence Based Librarianship (EBL) Critical Appraisal Checklist (Glynn, 2006) yielded an overall validity below the accepted threshold of 75%. The majority of the validity issues were associated with the population and data collection sections of the EBL checklist. Several EBL appraisal elements for those sections were not applicable to narrative literature reviews, and sectional validity ratings were therefore skewed by a limited number of lower-rated elements. However, the study design and results did achieve sectional validities above the threshold. The researchers provided sound rationale for choosing grounded theory to investigate their research question and included citations of all the articles they analyzed. Norming practices employed during each coding stage were also intentional and appropriate for the chosen methodology.

Nevertheless, database search protocols and article selection parameters for the study were frustratingly opaque, and such lack of replicable details raise significant concerns regarding validity of the findings. A simple keyword search in any of the four databases used in this study would return hundreds of articles indexed with the same search terms identified by the authors, yet only 21 were selected for the thematic analysis. It is unclear how the researchers constructed each literature search, how they determined whether a resulting article is "most relevant" (Tenny et al., 2021, p. 134) to the research question, and how many articles were found then eliminated in the review process. Timing of the searches and publication date range were also not addressed. Moreover, each of the four chosen databases offers some unique search functions, such as the major concept limiters in PubMed, and it is unclear whether these functions were considered or used. Consequently, those interested in replicating the study or applying similar methodology to a different issue or population would find it difficult, if not impossible, to reliably do so.

Because of these validity concerns, readers are advised to consider the representativeness of findings with reservation. Nonetheless, this article highlights a pertinent health information resource gap experienced by historically marginalized populations. Not only do the study findings provide practical implications for LIS professionals interested in improving equitable, inclusive access to health information for all patrons, but they may also inspire future researchers to investigate similar resource gaps in inclusive health information availability and access experienced by other underserved populations.

References

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