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Disparities in cervical cancer screening among rural LGBTQ+ individuals

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KEY FINDINGS

- **Cervical cancer screening is underutilized among rural LGBTQ+ individuals compared to their urban and heterosexual cisgender peers.**
- **Many LGBTQ+ individuals report stigmatizing and/or non-affirming experiences in the healthcare setting.**
- **Clinicians may not receive sufficient training in affirming and nondiscriminatory care to adequately address the needs and experiences of their LGBTQ+ patients in this circumstance.**

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INTRODUCTION

Cervical cancer is one of the most preventable cancers in the world, with vaccines that can prevent nearly 100% of cancers associated with HPV types [16, 18, 31, 33, 45, 52], and 58.1 However, only 60% of those aged 13-17 have received the first vaccine dose, and only 37% have received all three doses.[2] Further, an excess of cervical cancer incidence and mortality can also be prevented and effectively treated through the routine utilization of screening exams (to include Pap and HPV DNA tests).[3,4] However, despite being a USPSTF-recommended prevention service and covered without patient cost by insurance companies due to the Patient Protection and Affordable Care Act, less than 73% of eligible women are up-to-date with screening guidelines.[5, 6, 7] Unfortunately, there exist disparities in both vaccination and screening by such criteria as race/ethnicity and geography (rural vs urban).[8, 9, 10, 11] These disparities may be exacerbated among specific populations, for a variety of reasons and ways to address this cancer risk disparity should be explored. Further, while routine vaccination is recommended only until age 26 (older for some individuals based on personal circumstances), screening is recommended from age 21 through 65.[12, 5] For this review we will focus attention on cervical cancer screening utilization.

Screening among rural LGBTQ+ individuals

As mentioned, there are known disparities in cervical cancer screening associated with geography, with only 77.7% of rural women up to date with screening versus 84.4% of urban.[11] There are also significant disparities in screening associated with sexual orientation and gender identity, with the proportion reporting never receiving screening at 18.5 and 9.8% for gay/lesbian and bisexual women, respectively (versus 6.5% for heterosexual women) and 24.6% of transgender men (versus 7.1% for cisgender women).[13] In this review, we are interested in the intersection of rurality

and LGBTQ+ status. Though data are few for this specific circumstance, data from our team indicate that rural lesbian women are significantly less likely than urban heterosexual women to be current with USPSTF Pap test guidelines.[14] Still, studies of this sort are exceedingly few, and further exploration is needed.

Stigmatizing healthcare experiences

LGBTQ+ individuals frequently experience healthcare-related stigma, and while rates of insurance are similar to non-LGBTQ+, they are less likely engage with healthcare on a routine basis or disclose their sexual orientation/gender identity-both of which are directly related to health outcomes.[15, 16, 17, 18, 19, 20] Rural LGBTQ+ face compounding barriers to healthcare access and utilization such as finances, lack of competent providers, and past/anticipated discrimination.[21, 22] Recent literature reviews found consistent concerns regarding service access and use, cultural competency, care quality, and poor experiences.[23, 24] Transgender individuals specifically may also experience emotional distress associated with sexual health care, and healthcare avoidance due to lack of provider competency.[25, 26, 27] There is a paucity of work exploring healthcare disparities LGBTQ+ may experience in rural areas, where stigmatizing experiences may be further exacerbated by more frequent conservative values and policies. While often mirroring urban LGBTQ+ experiences, there was increased impact of distance and lesser care availability associated with rural residence. Rural transgender individuals are up to three times more likely than their cisgender LGB+ peers to travel >1 hour to their primary care provider, and recent work indicates a consistent lack of affirming provider availability.[28, 29]

Clinician training regarding LGBTQ+ health

Overall, there is little data available regarding formal medical training (e.g. for medical doctors) in aspects of care specific to LGBTQ+ patients. While the American Association of Medical Colleges published a roadmap curriculum to address LGBTQ+ health and training, there were no policies or other incentives to drive adoption.[30] Generally speaking, medical education in LGBTQ+ healthcare is often limited, absent, and uniquely variable across institutions. A study of North American medical schools showed a median of 5 hours (total) time spent on LGBTQ+ healthcare, 33% of schools failed to cover any LGBTQ+ content during clinical years, and 7% lacked any LGBTQ+ training during pre-clinical years.[31] Subsequent work revealed that many physicians do not feel comfortable providing quality care to LGBTQ+ patients and hold biases against these populations.[32] This is not to say that medical schools to not offer any LGBTQ+ training, and a recent survey (2020-2021) of medical students across three schools found that while a large majority felt comfortable caring for LGBTQ+ patients, knowledge of specific health aspects was low.[33] According to a report from the National Transgender Discrimination Survey, 50% of survey respondents said they had to educate providers about transgender care.[34] The overall effect is a limitation regarding the number of physicians with competence in LGBTQ+ healthcare.

WHY SHOULD WE NOW CONSIDER CERVICAL CANCER SCREENING AMONG RURAL LGBTQ+?

Cancer risk and disparities among rural LGBTQ+ populations is a relatively new area of study and is occurring in part due to the increased recognition of LGBTQ+ social determinants of health and life experiences resulting in a health and risk profile distinct from cisgender heterosexual individuals. For example, data from our research program (ruralHarmony) among LGBTQ+ individuals in central and southern Illinois has found that:

- Many (34-58%) LGBTQ+ do not reveal their sexual orientation and/or gender identity to their medical provider, and even more have avoided medical care due to their LGBTQ_ status (38-79%).[35]
- Gay/lesbian and bisexual individuals are more likely to report depressive symptoms than heterosexual individuals (adjusted odds ratios of 3.1 and 2.8, respectively), and transgender more likely than cisgender individuals.[36]
- Current self-rated overall health among rural LGBTQ+ is associated with medical bill payment ability and respectful treatment by healthcare administrators and clinicians.[37]

Specific to cervical cancer experiences, a series of interviews were conducted among rural LGBTQ+ in 2022.[38] We found that:

- Approximately 50% were up-to-date with cervical cancer screening and all who were up-to-date reported having a trusted and respectful provider.
- Screening barriers included: prior poor experiences in clinical setting, gender dysphoria, financial cost of care, and trauma associated with past sexual assault.
- Participant recommendations for improving screening adherence included: creating an expressly LGBTQ+ affirming clinic environment with clear markers of inclusivity; correct use of pronouns and use of appropriate language and terminology; providers asking appropriate questions without making assumptions or judgments, and practice of trauma-informed care.

There is growing tension and controversy regarding instruction in LGBTQ+ issues in some contexts that may make examination of LGBTQ+ healthcare disparities more problematic. Thus, there is an increasing need to identify evidence-based needs and practices such that health equity can continue to be forwarded. The recent SCOTUS decision to overturn Roe has potential ripple effects in this climate. Landmark decisions such as Obergfell v Hodge, which permitted same-sex marriage, and Lawrence v Texas, which effectively overturned anti-sodomy laws, were both based on the decision of Roe and face legal challenges that may result in loss of healthcare access through marriage or lead to criminal penalties for LGBTQ+ individuals.[39] In 2023 alone, over 520 anti-LGBTQ+ bills, 220 specifically targeting transgender and non-binary individuals, were introduced in U.S. statehouses. To date, at least 70 have been enacted that range from bans on gender-affirming care for youth, the criminalization of drag, 'Don't Say Gay' curriculum laws and outing of queer youth to their caregivers.[40, 41] With these changes, LGBTQ+ individuals and families of queer youth have resorted to going back in the closet, moving to pro-LGBTQ+ states, and/or driving great distances to receive affirming care.[42] The political environment of anti-LGBTQ+ will likely drive further healthcare disparities for these individuals, necessitating equitable solutions to prevent or reduce the long-term consequences.

WHAT CAN BE/IS BEING DONE?

While there exist significant LGBTQ+-specific disparities in cervical cancer screening, there are also multiple means whereby they may be addressed. These include pressure from regulatory and quality agencies; mission-driven initiatives to improve healthcare quality and equity; and engagement with existing community-based and social services in new ways to act as peer champions and conveners to better engage those not currently adequately represented.

Addressing Rural LGBTQ+ Screening Disparities

There needs to be purposeful outreach and engagement of LGBTQ+ patients, especially in rural areas, regarding cervical cancer risk and prevention. This can be accomplished through a variety of methods.

A. All healthcare providers should make screening ascertainment a priority for all their patients, but especially for LGBTQ+ who may attend visits less frequently or be otherwise reticent. As sexual orientation and gender identity data are inconsistently captured or provided, the collection of this data in a positive and affirming manner may also be a separate initiative.

B. Community-based organizations, advocacy groups, and other social networks with large LGBTQ+ participation should be engaged in disseminating messages and information regarding cancer screening importance and how it may be obtained. This may include collaborating with other allied organizations, state agencies, and university cancer programs.

C. As research examining cancer risk and prevention among rural LGBTQ+ populations is in its relative infancy, additional research should be directed toward LGBTQ+-specific cancer risk factors and barriers to accessing and utilizing screening services.

Addressing Rural LGBTQ+ Healthcare Experiences

Addressing past poor experiences is admittedly challenging. There are several strategies that might be pursued. For example, the Commonwealth Fund has published a document of guidelines, challenges, and examples regarding

how healthcare entities might systematically adopt a position that seeks and promotes health equity across the healthcare and patient experience.[43] Strategies include examining institutional practices, training and support for all staff, and engagement with patients regarding experiences and expectations. By adopting such a framework and purposeful practice model, and including collaboration with organizations that represent affected groups, healthcare organizations may be able to offer and provide a more affirming and satisfactory experience. In addition, providers can also improve their patient care environment and intake processes to be more LGBTQ+ friendly, thereby creating a safe space for patients. Some of these could include differentiation between sex assigned at birth, sex and current gender identity, prominently displaying non-discrimination policies, and training on using a patient's provided pronouns, amongst others. [44]

Complementary to this may be the implementation of peer-based encouragement and navigation services. Individuals with past poor experiences may benefit from hearing how things might be different from 'someone like them'. Such peer champions are generally ill-defined but are yet in a position to provide an evidence-based intervention of "one-on-one education [that] delivers information to individuals about indications for, benefits of, and ways to overcome barriers to cancer screening with the goal of informing, encouraging, and motivating them to seek recommended screening."[45] Their ability to improve trustworthiness and reduce stigma, and serve as vital trust builders with the more extensive healthcare system, has been demonstrated for other topics (e.g., HIV risk reduction).[46, 47] When transgender peers are involved with social marketing and education efforts, champion acceptability is demonstrated.[48]

Addressing Clinician Training Regarding LGBTQ+ Patients

Medical students with greater LGBTQ+ clinical experience provide higher quality care to LGBTQ+ patients than students with less experience.[49] As described before, guidelines for comprehensive curriculum have been promulgated, but there needs to be incentives to drive adoption.[30] Adjusting formal clinician training to increase students' ability to be effective LGBTQ+ care providers is both possible and a longer-term strategy. An example from the University of Washington illustrates a model of student engagement whereby first and second-year medical students across the region are accepted into a 4-year LGBTQ Health Pathway which provides training on LGBTQ+ health issues through a set of pre-clinical and clinical training components, including 36 hours longitudinal community service/advocacy and clinical clerkship focused on LGBTQ+ health.[50] Further, there are opportunities for educational accrediting boards (e.g., LCME; Liaison Committee on Medical Education) to adjust their standards to reflect this purpose. LCME standards in the past have resulted in increased representation by women and racial and ethnic minorities among medical students.[51]

In a more immediate sense, there is an opportunity to educate and inform clinicians of all ranks through the continuing medical education (CME) mechanism. These are specified by each state (number of hours, allowable content), and opportunities to craft CME experiences that address LGBTQ+ care are therefore possible means to reach current providers. For example, many options for CME experiences are available from the National LGBTQIA+ Health Education Center.[52] However, again there is a lack of incentive models which might encourage clinicians to choose these versus other educational opportunities. One potential mechanism to drive this specific education may be through quality improvement initiatives (e.g., HEDIS; Healthcare Effectiveness Data and Information Set) promulgated by insurance carriers and other regulatory bodies. While these are most frequently focused on clinical measures, they may be expanded to include aspects that are specific to LGBTQ+ care and engagement, such as the collection of patient sexual orientation and gender identity data, and patient satisfaction surveys incorporating aspects of LGBTQ+ -specific care.

Addressing Underrepresentation of Queer Identities in Clinical Care

Just as peer workforces can improve health outcomes due to shared experiences or identity, investment and expansion of a queer clinical workforce may further reduce these disparities, build equitable solutions, and improve patient satisfaction.[53, 54, 55] Current learning environments are rife with heterosexist ideals and discriminatory behaviors,

leading to almost 30% of LGBTQ+ medical students concealing their identity and many reporting discrimination from faculty. Prior to medical school admissions, almost 40% of pre-medical undergraduates had been advised to not disclose their sexual orientation or gender identity.[56] LGBTQ+ - identified providers are sought by others in the queer community as perceptions of stigma are lower and comfort in discussing medical concerns increases.[57] By increasing the proportion of queer providers, the visibility of the community is raised for both patients and colleagues of these providers, potentially leading to increased cultural competency and better access to healthcare.

CONCLUSION

In sum, rural LGBTQ+ individuals experience disparities in cervical cancer screening. While cervical cancer is nearly entirely preventable through vaccination, rates of uptake are low (and not unique to LGBTQ+ individuals). Screening is an effective means to identify and treat cervical cancer in the precancerous and early stages, but adherence to recommended guidelines is also suboptimal. Here we can observe clear disparities between specific populations, such as rural vs urban and LGBTQ+ vs cisgender heterosexual. These disparities may be exacerbated at the intersection of rural and LGBTQ+, but data are few and further research regarding the disparity extent and rural LGBTQ+ -specific context is urgently needed.

Still, there are strategies that may be pursued that might address and alleviate the to-date known screening disparities among rural LGBTQ+. There are multiple means whereby local clinical organizations may adjust their practices to better identify and serve their LGBTQ+ patients (many of whom may currently be unknown to be members of this group). There are also strategic investments that healthcare may make to be more inclusive and affirming, to purposefully provide staff training, and to work with patients and representative organizations to increase patient engagement. Further, formal and continuing medical education may be a key element to increasing clinician capability and competency. Still, all such efforts may be more widespread to regulatory agencies and training and quality standards are revised to promote and document aspects of inclusivity and affirmation among healthcare organizations.

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