Building Families Through Healthcare: Experiences of Lesbians Using Reproductive Services

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Abstract

The use of assisted human reproduction (AHR) represents a meaningful and important life event for lesbians wishing to create biologically related families. Despite increasing numbers of lesbians utilizing AHR services, barriers to access persist. This qualitative study investigated the experiences of lesbians and their interactions with reproductive services in Ontario, Canada, where limited public funding is available for all AHR patients and where the lesbian, gay, bisexual, transgender, and queer (LGBTQ) community makes up to 30% of clientele. Eleven semi-structured interviews were conducted, and findings revealed a wide range of experiences. Lesbian patients expressed a desire for more support from their care providers in navigating a complex and costly medical journey through a system largely designed for the needs of heterosexual patients. Additionally, private fertility clinics, as the environment for accessing publicly funded services, were felt to contribute pressure to pay out-of-pocket for add-on medical procedures. To improve the quality of care, participants recommended providing more high-level information on the medical journey and taking an individual approach with lesbian patients, in particular, assuming a patient has sufficient fertility until proven otherwise.

Keywords

healthcare experiences, lesbians, assisted human reproduction, health system navigation, qualitative research

Introduction

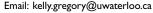
Lesbian, gay, bisexual, transgender, and queer (LGBTQ) individuals may be principally dependent upon assisted human reproduction (AHR) services to create biologically related children. Many jurisdictions, like the Canadian province of Ontario, have adopted legislation to support same-sex families through the provision of public healthcare services. In 2015, Ontario's legislation saw increases to AHR funding, covering costs for one round of in vitro fertilization (IVF) per patient per lifetime (1). Such services are delivered in privately funded healthcare facilities, where LGBTQ individuals can make up to 30% of clientele (2). Compared to average heterosexual patients who access AHR for fertility problems, most lesbian patients navigate the health system in search of reproductive materials, services, or expert consultation (2). As a result, a mismatch can appear between patient needs and health system services, contributing to redundant or irrelevant provision of care (2). The AHR medical journey for lesbian patients is often complex and multi-staged, requiring many transitions and decision

points. Lesbian patients must decide which fertility clinic to use, which partner will carry the child, whether the sperm donor will be known or anonymous, how many insemination attempts will be made, which insemination procedure will be used, and whether add-on services, such as acupuncture or herbal remedies, will be purchased to supplement fertility (3,4).

Despite increasing rates of service utilization in Canada, little up-to-date research exists on the unique needs or experiences of this population (5–7). International research describes heterogenous accounts of lesbians' experiences utilizing reproductive services. Lesbians from the Nordic region shared both supportive encounters and indifference from

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healthcare providers in relation to their sexual orientation (8), in addition to routine experiences of marginalization and homophobia (9,10). For example, in Sweden, heteronormative biases were shown to contribute to less treatment for lesbian patients, or a lack of adaptation for their specific needs (11). Additionally, lesbians in Australia reported experiencing exclusion, inappropriate questioning, refusal of services, and assumptions of heterosexuality (12,13), while patients in Brazil described being treated with technologies for infertility despite the presence of fertility (14).

North American research discusses the erasure of LGBTQ patients, through the implementation of non-inclusive and outdated protocols (15,16) as well as heterosexism in the fertility system environment (17). LGBTQ invisibility was also noted in the review of web-based information pertaining to LGBTQ family building in the United States (18,19). Patient literature or language used by health service providers that presumes heterosexuality risks alienating lesbian patients who are already more reluctant to access health services, leading to lowered preventative health screening and vaccine uptake (20). As such, this population has an elevated risk for negative reproductive health outcomes related to HIV, HPV, and other STIs, and faces a range of potential barriers to accessing AHR services (21,22). Lastly, lesbian mothers in North America whose partners carry the child, sometimes referred to as social or nonbiological mothers, face their own unique challenges. For example, a lack of biological and legal relationship to the infant and limited social recognition may contribute to feelings of exclusion from health services (4).

Canadian literature suggests that lesbians predominantly have positive experiences with allied health professionals when seeking reproductive services, yet show low satisfaction with their experiences in fertility clinics, or with physicians (5). Since the release of these findings in 2006, there had been little follow-up to investigate if, or how these findings have been integrated into medical training, or health systems. As such, this research set out to ask: (1) How do lesbians perceive their interactions with health care providers and administrators? (2) Do lesbians perceive their fertility needs as being met by health care services? and (3) Are there any recommendations that lesbian patients have to offer in relation to their experiences?

Methods

After receiving ethics clearance from a university human research ethics board, recruitment took place through a snow-balled convenience sample initiated by the sharing of a recruitment poster over social media. The study recruited women who identified as lesbian and had undergone consultations, or attempted to utilize reproductive services in Ontario, Canada, since legislative funding changes on December 21, 2015. Eleven participants (n = 11) aged 25–45 were recruited, some of whom experienced miscarriages

and unsuccessful conceptions. All but one participant had one to two children conceived through AHR.

With written or verbal informed consent obtained and archived, semi-structured interviews were conducted in person (n=2), or over the phone (n=5) and were recorded and transcribed verbatim with the substitution of pseudonyms for confidentiality. Three of these interviews were conducted one-on-one, three were conducted in pairs with partners, and one was conducted with a pair of close friends who had previously utilized services together.

The choice to use qualitative methods reflects the inquiry into experiences, perspectives, and points of view. Interview questions were open-ended and explored participants' experiences with the care they received and the areas where they felt improvements could be made. Anonymized interview transcripts were uploaded to NVivo 12 Pro software for analysis.

At the initial phase of analysis, grounded theory (22) was used to attribute codes in a line-by-line approach and inductively identify themes in the data. Situational analysis (23) was then employed to begin making sense of the themes, by asking: "Who and what are in this situation?", "Who and what matter in this situation?" and "What elements 'make a difference' in this situation?". Lastly, findings were contextualized within a relational and institutional lens to identify key issues and provide a deeper understanding of the experiences (24).

Results

A Lack of Support for Lesbian Patients Navigating a Complex Healthcare Journey

Primary care providers were generally found to be supportive of providing their patients with initial referrals, but consistently lacked an understanding of the process that lesbians must undertake when accessing reproductive services. Sarah, a new mother who worked for her municipal health center, struggled alongside her nurse practitioner to navigate the AHR process for lesbians:

"I worked in healthcare at the time and I didn't know of any resources either.... Like literally my job was to know- was to maintain a database of health services in (the region) and I had no idea of anything."

As with Sarah's experience, not a single participant across the study sample reported that their family doctor knew anything at all about the process of AHR as it pertains to the specific needs of lesbian patients.

Participants also reported feeling unclear about costs associated with AHR, including payment for services that exist beyond public funding structures, particularly those conditional upon test results, or offered as add-on services for boosting fertility. In some cases, mounting unexpected fees forced patients to halt their process entirely.

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The AHR medical journey was confusing for most participants, as described by one set of partners sharing "we didn't know what we were in for", who found themselves in a situation they could no longer financially, or emotionally sustain.

Some women discussed lack of biological knowledge as a barrier to understanding the overall process, while others attributed it to lack of communication on the part of the fertility clinic. Some participants expressed their desire to have the information provided up front, including all possible routes they might follow, while others said this would be overwhelming and unnecessary if it did not apply to their personal situation. Regardless of their preferences, the majority of participants referred to the process as "overwhelming" and difficult to navigate.

In response to this challenge, personal agency, or the ability to make free choices and advocate for oneself, was routinely mentioned as a requirement for successfully utilizing reproductive healthcare services. Participants felt this attribute played a significant role in successfully identifying and reaching reproductive goals, and suggested that agency was attributable to their shared knowledge gained through the LGBTO community.

A community-organized example offered in Ontario's largest urban center includes the intensive course "Dykes Planning Tykes" that takes lesbians through all aspects of the assisted reproduction process. This program was identified as a valuable resource and system of sharing, enabling relationship building and bringing a sense of belonging to the members who engaged with it.

Mandatory Provisional Steps Perceived as Irrelevant or Redundant Were Frustrating to Lesbian Patients

Participants described feelings of "jumping through hoops" or needing to pass tests to unlock access to the services they were seeking. For example, mandatory processes such as multi-staged fertility tests, were often irrelevant to a patient's goals and frustrating when participants perceived themselves as fertile, but were required to access a sperm sample for insemination. Another example is the one-time mandatory psychologist-led counseling session, billed directly to the patient, which all patients receiving reproductive care must undergo before they can access any services or materials. While a few participants found these sessions helpful, most participants referred to them as tedious, expensive, judgmental, and even insulting:

"...and then, the counselling, the idea is that they'll work through the issues of how will you tell the children... but, ... that's really kind of a moot point for lesbians ...my son is always going to know that neither of us is his biological father."

In response to hearing about negative experiences from other community members, some participants felt they needed to give the "right" answers to the questions posed by their counselor, for fear of 'failing the test' and being denied access to services. Such concerns were particularly the case for questions about family history or social support from family members:

"...a lot of the questions were 'Is your family supportive?' and 'Who is going to be supporting you?' and I think that's important but sometimes, like... in same-sex relationships ... families *aren't* supportive and I felt like if we were going to disclose that... it was going to jeopardize our clinic saying, 'yes, we'll take you on as a patient' or not."

As Marina described, important questions that may feel neutral for the heterosexual patient population may elicit unintended consequences with lesbian patients.

Participants also described frustration regarding their desire to use a known sperm donor; a preference that brings meaning and community to the process of creating an LGBTQ-supportive family. The lengthy and expensive process required donors to provide semen to the only sperm bank facility available at the time, located in the province's largest urban center. Once arrived, the sample must be processed and quarantined for 6-8 months, for safeguarding mother and baby against infections with long incubation periods; a process which incurs both upfront and monthly fees. By contrast, a heterosexual couple would typically have a sample collected and processed directly within any clinic, as safety regulations in Ontario, at the time of writing, do not apply to sperm obtained from a spouse, common law partner, or sexual partner (25). Alice, for whom it was important to use sperm from someone she had a friendship with, experienced these system-level obstacles as heteronormative and unjust:

"...the way that the reproductive like, funding works... it leaves people like us out who want to use a known donor. So, ...we could walk into the clinic and, like, pretend our donor was my husband, and we would get fully funded services... which just like, felt... unfair..."

When faced with geographical inconsistencies and system-level restrictions, it was logical for Alice to abandon the health system entirely and just hope that home-insemination would suffice. Some participants understood home insemination with a known donor to be outright illegal. Others used this constraint to decide which fertility clinic to use, based on its geographical proximity to the only sperm bank available.

Fertility Clinics as an Interface of Public and Private Healthcare Models

Many references were made to the high volume of patients flowing through the clinic environment. Most participants shared stories of feeling rushed, of how busy their clinicians Journal of Patient Experience

were, and how little time could be spent with them as patients. While high patient flow is a consistent challenge observed in the publicly funded care setting, participants largely attributed this challenge to the privately funded nature of fertility clinics.

Several participants reported feeling pressured by service providers to purchase add-on services, such as acupuncture, or herbal remedies, to increase insemination success. Lara shared that her lack of medical expertise made her feel vulnerable to this pressure:

"... they were, like, pushing all these tests on us that cost extra, and we didn't know- so we said yes to everything, and it turned out... I was like extremely fertile so, it was not an issue, but they kinda fear-mongered some of that stuff..."

Pressure to make purchases was also discussed by Pam, who was attempting to buy sperm from a carefully selected donor:

"...the donor we wanted was on backorder, so the clinic was just pushing us to order someone else, *anyone* else. Which was also just a weird suggestion by them. Like, 'well, there's lots of good people, why don't you just pick one of those?""

Pam described her experience of pressure to make a quick decision on a very meaningful aspect of her conception process as a frustrating result of having to use a private system to access a public service.

Discussion

Overall, participants shared a wide range of experiences, including stories of support and alienation; findings not commonly represented by the preexisting problems-based literature (5–7). Such variation may point to a lack of standardization and regulation for service provision across the region. This variability may be particularly relevant in the privately funded context of service delivery, which encourages organizations to protect their business practices from competitors.

The mélange of public and private service provision appears to muddy the navigation process for patients. At the onset, patients spend a significant amount of money for baseline services, but if the process is not initially successful, patients may be more likely to purchase additional services alleged to increase fertility (26,27). As the journey progresses, sometimes lasting several years, the increased spending begins to act as its own source of pressure, leading to the purchase of further add-on services in hopes of a successful outcome.

In the current context, all patients who wish to create their families with the support of government-funded services must wade through the jungles of private fertility clinics, face overwhelming patient experiences, and well-funded sales tactics. However, lesbian patients must also do so while navigating a system that is not designed for them, yet is their only option for accessing insemination services through the healthcare system. These are the systemic structures that LGBTQ people must navigate to reach the deeply meaningful and personal goals of building biologically related families. Beginning this process while "not knowing what you're in for" with the risk of snowballing costs in a clinical setting motivated to make sales, pushes the boundaries of ethical service delivery in a country with publicly funded healthcare. The experience is made more unfortunate by the fact that so many lesbians possess no fertility challenges and are more likely to earn less than their heterosexual counterparts (28).

Relying on individual-level support does little to ensure lesbians possess an understanding of the complex medical journey of conception through fertility services, particularly outside major urban centers. Furthermore, a lack of formal support and integration suggests to the LGBTQ community that their needs are unimportant, further distancing and marginalizing these individuals.

When considered against previous Canadian research by Ross, Steele, and Epstein (3,5), our findings suggest there are some resolved issues and some challenges that continue. Some findings that echo those of our colleagues' include the difficulties of using a known sperm donor, the presumption of infertility, and calls for standardization of care that increases support outside of larger urban centers. Specifically within urban centers, community-level support programs continue to contribute toward positive clinical experiences. In contrast, many participants reported feeling safe and welcomed in clinical environments, and there were no accounts of patient home visits or police checks, which were previously identified as routine and problematic practices (2,5).

Limitations

Limitations to this research include its sample that is predominantly made up of Caucasian, moderate-to-high-income earning, non-rural lesbians. As such, the results may not be applicable to a more diverse range of lesbians, but rather, represent a sample of women who were financially and geographically capable of utilizing fertility health services. Despite this positionality, our participants still expressed challenges related to cost and location, so it is likely that these concerns would be present and even perhaps amplified among lower-income and/or rural-dwelling lesbians. It is our hope that further studies will continue to elucidate the wide variety of viewpoints on AHR that are experienced within the larger LGBTQ community.

By employing situational analysis, we were able to consider the ecological context of the situation. However, this assessment was limited to the view of the patient's perspective exclusively. Further analysis would be strengthened by

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the perspectives of other stakeholders such as physicians, allied care providers, and policy makers, representing opportunities for future research.

Conclusion

In light of their experiences, participants recommended support for social networking avenues that might help to connect patients willing to share their experiences with others, as a service that may be especially helpful to those who reside beyond major urban centers.

There were also calls for more transparency and clarity around the process of purchasing sperm and total potential costs. Both a general overview and an explicit step-by-step guide were common requests, which could take the form of a brochure, an online video, or even a website.

Funding a transition of the "Dykes Planning Tykes" program into an online format that could be widely accessed represents another recommendation. Through this delivery, important sections of the program could be completed by LGBTQ patients as a substitute for the mandatory counseling session that was often perceived as irrelevant.

Additionally, some participants recommended taking a different approach with lesbian patients altogether, where sufficient fertility of the patient is assumed until proven otherwise; a recommendation that has also been discussed previously in the literature (3,29). Predominantly, the reasons that participants sought reproductive resources were not founded in biological pathology. However, to access government-funded services to support their conception, lesbians currently have no other choice than to navigate a delivery system that views its patients through a problems-based lens.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Approval

Ethical approval to report this research was obtained from (blinded for peer review) Institutional Review Board (approval number/id blinded for peer review).

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Statement of Human and Animal Rights

All procedures in this study were conducted in accordance with the (blinded for peer review) Institutional Review Board (approval number/id blinded for peer review) approved protocols.

Statement of Informed Consent

Written and verbal informed consent was obtained from the patient(s) for their anonymized information to be published in this article.

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