Sexual and Gender Minority Peoples' Recommendations for Assisted Human Reproduction Services

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Abstract

Objective: To determine what recommendations lesbian, gay, bisexual, trans, and queer (LGBTQ) people have for provision of assisted human reproduction (AHR) services to their communities.

Methods: Using a semi-structured guide, we interviewed a purposeful sample of 66 LGBTQ-identified individuals from across the province of Ontario who had used or had considered using AHR services since 2007.

Results: Participants were predominately cisgender (non-trans), white, same-sex partnered, urban women with relatively high levels of education and income. Participants made recommendations for changes to the following aspects of AHR service provision: (1) access to LGBTQ-relevant information, (2) adoption of patient-centred practices by AHR service providers, (3) training and education of service providers regarding LGBTQ issues and needs, (4) increased visibility of LGBTQ people in clinic environments, and (5) attention to service gaps of particular concern to LGBTQ people.

Conclusion: Many of the recommendations made by study participants show how patient-centred models may address inequities in service delivery for LGBTQ people and for other patients who may have particular AHR service needs. Our results suggest that service providers need education to enact these patient-centred practices and to deliver equitable care to LGBTQ patients.

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Résumé

Objectif : Chercher à connaître les recommandations que formuleraient les personnes lesbiennes, gaies, bisexuelles, transgenres et allosexuelles (LGBTQ) en ce qui concerne l'offre de services de procréation assistée (PA) à leurs communautés.

Méthodes : En utilisant un guide semi-structuré, nous avons interviewé un échantillon choisi à dessein de 66 personnes s'identifiant comme étant LGBTQ et provenant de partout dans la province de l'Ontario qui avaient utilisé ou qui avaient envisagé d'utiliser des services de PA depuis 2007.

Résultats : Les participantes étaient principalement des femmes cisgenres (non transgenres), blanches, ayant une partenaire du même sexe et vivant en milieu urbain qui comptaient des niveaux relativement élevés de scolarité et de revenu. Les participantes ont formulé des recommandations visant l'apport de modifications aux aspects suivants de l'offre de services de PA : (1) accès à des renseignements pertinents pour les personnes LGBTQ, (2) adoption de pratiques axées sur la patiente par les fournisseurs de services de PA, (3) formation et éducation des fournisseurs de services à l'égard des enjeux et des besoins des personnes LGBTQ, (4) accroissement de la visibilité des personnes LGBTQ en milieu clinique et (5) octroi d'une attention aux lacunes en matière de services qui préoccupent particulièrement les personnes LGBTQ.

Conclusion : Bon nombre des recommandations formulées par les participantes à l'étude illustrent la façon dont l'adoption de modèles axés sur la patiente pourrait combler les inégalités en ce qui concerne l'offre de services aux personnes LGBTQ et à d'autres patientes pouvant avoir des besoins particuliers en matière de PA. Nos résultats semblent indiquer que des ressources éducatives devraient être mises à la disposition des fournisseurs de services pour leur permettre de mettre en œuvre de telles pratiques axées sur les patientes et d'offrir des soins équitables aux patientes LGBTQ.

INTRODUCTION

Although lesbian, gay, bisexual, transgender, transsexual, queer, and other sexual and gender minority (LGBTQ) people have always parented children, over the last decade, increasing numbers of LGBTQ people are seeking to have genetically related children through assisted human reproduction (AHR)[1] (Appendix). This increase may be attributable to changes in the social visibility of LGBTQ people and resulting changes in medical policy and practice. For example, in 2009, the Ethics Committee of the American Society for Reproductive Medicine released a statement concluding that "ethical arguments supporting denial of access to fertility services on the basis of marital status or sexual orientation cannot be justified."[2] Recently, the World Professional Association for Transgender Health recommended that all trans people be counselled regarding fertility options before initiating medical transition.[3] LGBTQ individuals will therefore likely continue to make up an increasing proportion of AHR service users. Indeed, some fertility clinics in Toronto estimate that as many as 30% of their service users identify as LGBTQ.[4]

AHR is one area of medicine in which LGBTQ people often have distinctly different health needs from their heterosexual, cisgender (non-trans) counterparts. For example, most LGBTQ people who access AHR services have no known fertility problem when they contact a fertility clinic, but only seek to access reproductive assistance (which often includes access to reproductive materials and/or labour). In addition, many trans people access AHR services without an immediate desire to procreate, but rather to store gametes before a process of medical transition to allow future family building. Because of these differences, the study of LGBTQ patient experiences with AHR services may offer insights into potential challenges in the delivery of equitable health care to LGBTQ people in other areas of medicine. Further, the AHR service experiences of LGBTQ people can also provide insights into the experiences of other service users who have particular AHR service needs (e.g., single prospective parents and cancer patients who wish to preserve reproductive material).

Despite their unique health care needs, very little research has addressed LGBTQ individuals' experiences with AHR services. We were able to identify only seven published studies examining the experiences and/or satisfaction of LGBTQ people with AHR services, all of which were limited to samples of lesbian and bisexual women. These studies suggest that lesbian and bisexual women face a range of potential barriers to accessing AHR services, including a lack of lesbian-positive services or expectations that providers will be homophobic, and having to prove their parenting abilities, for example, through requirements to complete police background checks and home studies before they can access services.[5–12] We could identify no published studies that specifically investigated the AHR service experiences of gay and bisexual men or trans or queer-identified people. These data are necessary to determine whether existing AHR services are meeting the needs of the growing number of potential LGBTQ service users.

To address this gap, we interviewed 66 LGBTQ individuals from across Ontario to answer the following research question: "What recommendations do LGBTQ people have for provision of AHR services to their communities?" We consider our findings in light of their implications for AHR service delivery both to LGBTQ people and to other (non-LGBTQ) patient groups.

METHODS

Interview participants were recruited between July 2010 and March 2011 through online networks, flyers posted at relevant service organizations, and in person at Pride celebrations across Ontario. Interested individuals contacted the study office and were screened by telephone to determine eligibility. Participants were eligible if they identified as LGBTQ, were aged 18 years or older, had used or had considered using AHR services since 2007, and used health services in Ontario. Purposeful sampling was used to select a group of interviewees who were reflective of the broader screened group.[13,14]

Interviews took place between December 2010 and August 2011. Before the interview, each participant completed a sociodemographic questionnaire. After written informed consent was obtained, interviewers followed a semi-structured guide in conducting interviews that lasted 60 to 90 minutes. For this study, data were drawn primarily from participants' responses to our final interview question: "Based on your experiences, if you had five minutes with someone who could really make change in the AHR system, what would you recommend to them?." Thematic content analysis of verbatim interview transcripts was undertaken to identify common themes in the data generated from this question.[15,16] Two of the authors independently analyzed the transcripts, and results were compared for consistency. The identified recommendations were then organized into categories. This project received ethics approval from the Research Ethics Board at the Centre for Addiction and Mental Health and the Human Participants Review Committee at York University.

RESULTS

In total, 118 individuals or families expressed interest to participate in the study. Of these, we were able to contact 108 to complete eligibility screening, 100 of whom (93%) were eligible. The primary reason for ineligibility was use of AHR services before 2007. Since participants often chose to be interviewed as families, a total of 66 individuals participated in 40 interviews. As mentioned, purposeful sampling was used to identify 40 individuals/families from across Ontario who reflected the diversity of experiences with AHR services identified among the individuals screened. Interview participants were also selected on the basis of their sociodemographic characteristics (i.e., sexual orientation, gender identity, racial/ethnic identity, and geographic location) in an effort to represent the diversity of the LGBTQ population in Ontario. Detailed sociodemographic characteristics of study participants are provided in the Table.

In our analysis, we have classified participants' recommendations into categories relevant to AHR service provision (elsewhere, we describe strategies relevant to AHR policy and legislation[17]). Specifically, we describe participants' recommendations regarding the following aspects of AHR service provision:

1. access to information about AHR services,
2. AHR service provider practices,
3. training and education of AHR service providers,
4. clinic staffing and environment, and
5. service gaps.

Unless otherwise indicated, the recommendations were not specific to any one sexual orientation or gender identity group, as data for each theme were drawn from interviews with three or more of the sexual orientation and gender identity groups (lesbian, gay, bisexual, trans, or queer); the recommendations reflect the LGBTQ communities collectively. Illustrative quotations are provided in the online eAppendix.

Access to Information

Participants noted that most AHR information available through clinics and other sources (e.g., Internet, libraries) lacks content specific to LGBTQ needs and experiences, and lacks representation of LGBTQ people in the accompanying visuals.

Participants also sought information from clinics and/or service providers about whether they served LGBTQ people, and felt that this could be indicated on clinic/provider websites and mission statements.

Participants suggested that clinics could also share this information through active outreach to LGBTQ potential service users (e.g., at open houses). Participants also recommended that in smaller communities where there is no easy access to fertility specialists family physicians should be able to provide basic family planning information relevant to LGBTQ people.

Service Provider Practices

Many participants recommended that AHR service providers adjust their practices to better meet their clients' needs. Most of the practices recommended by our participants did not address LGBTQ-specific concerns; rather, they reflected a perception that the overall quality of care delivered in this sector is inadequate for all those who are not infertile heterosexual couples. The preferred approach was described by a cisgender, queer participant who was in the process of trying to conceive a second child through anonymous donor insemination, together with her partner who is a trans man: "Our private decisions were very much respected about the family planning . . . We got to do our own family planning and their job was to help support us do it. And to support us through it in the way that could make us as comfortable as possible."

Non-LGBTQ-specific practices recommended by our participants included:

1. considering the service user's wishes and expertise in their own body in developing a plan of care;
2. providing sufficient time and information for service users to give informed consent for procedures;
3. providing care in a more personal, humanizing, or respectful manner; and
4. actively working for the involvement of the non-pregnant partner and/or co-parent(s).

Although these are non-LGBTQ-specific practices, some have a particular impact on LGBTQ people. For example, considering the service user's wishes regarding choice of treatment may be particularly relevant since LGBTQ people will usually enter the clinic with no prior evidence of infertility. Also, an intended parent who is not biologically related to and/or conceiving the child often feels invisible and so may particularly value being actively included as a parent-to-be in the AHR process. Finally, providing care in a humanizing way may be particularly important to LGBTQ people whose experiences of discrimination in health care often leave them feeling marginalized or pathologized by the medical system.

Participants made the following four LGBTQ-specific recommendations:

Selected demographic characteristics of participants

Variable	N = 66 n (%)	Notes
Gender identification		
Female (cisgender)	48 (72.7)	
Male (cisgender)	9 (13.6)	
Trans man/FTM spectrum	7 (10.6)	
Trans woman/MTF spectrum	2 (3.0)	
Sexual orientation		
Lesbian	21 (31.8)	• 1 also identified as queer
Queer	18 (27.3)	
Gay	11 (16.7)	• 2 also identified as queer
Bisexual	11 (16.7)	• 1 also identified as queer/pansexual
Two-spirit	1 (1.5)	• also identified as bisexual
Straight	2 (3.0)	• both identified as trans
Other	2 (3.0)	• included: homoandrophilic, fluid/no label
Cultural/racial background		• 1 missing
White	48 (72.7)	• Participants could select more than one, so frequencies do not total 100%
Mixed	8 (12.1)	
Black/African/Caribbean	6 (9.1)	
Aboriginal	3 (4.5)	
South Asian	2 (3.0)	
Other	3 (4.5)	
Relationship status		• 2 missing
Legally married	37 (56.1)	• Participants could select more than one, so frequencies do not total 100%
Common-law	20 (30.3)	
Partnered	2 (3.0)	
Multiple partners	1 (1.5)	
Single	6 (9.1)	
Divorced	1 (1.5)	
Region in Ontario		• Sub-regions of Ontario according to the Ontario Ministry of Community and Social Services (2011)
Toronto region	34 (51.5)	
Southwest	10 (15.1)	
Eastern	9 (13.6)	
North Eastern	4 (6.1)	
Hamilton/Niagara	3 (4.5)	
Central East	2 (3.0)	
Central West	2 (3.0)	
Northwest	2 (3.0)	
Highest level of education		• 3 missing
High school	1 (1.5)	
College	7 (10.6)	
University	24 (36.4)	
Postgraduate	31 (47.0)	

continued

Continued

Variable	N = 66 n (%)	Notes
Household Income, $		• 3 missing
< 20 000	1 (1.5)	
21 000 to 35 000	2 (3.0)	
36 00 to 50 000	4 (6.1)	
51 000 to 65 000	6 (9.1)	
66 000 to 80 000	15 (22.7)	
81 000 to 100 000	8 (12.1)	
>100 000	27 (40.9)	
Age, years		
26 to 30	7 (10.6)	
31 to 35	22 (33.3)	
36 to 40	21 (31.8)	
41 to 45	15 (22.7)	
45 to 50	1 (1.5)	

FTM: female to male; MTF: male to female

1. that clinic staff use inclusive language (i.e., language that does not presume heterosexuality, cisgender identities, or particular family configurations);
2. that service providers be honest about what they do not know about LGBTQ people or family creation and ask questions respectfully;
3. that providers ask direct, respectful questions to ascertain the relationships between all involved parties; and
4. that forms and documentation be revised to reflect the diversity of sexual orientations, gender identities, and family structures of individuals accessing fertility clinics.

Education and Training

Several participants explicitly recommended training and education for providers of AHR services, while others pointed to the necessity of such training through their descriptions of provider practices that did not meet their needs.

Participants recommended that providers receive training in LGBTQ identities and terminologies, the various family configurations and AHR services LGBTQ people may consider, and non-discriminatory practices for provision of health care to LGBTQ people in general, and to trans people in particular (e.g., use of appropriate pronouns). One participant, a trans woman whose cisgender woman partner conceived their child using her sperm, with the assistance of AHR services, noted that the fertility doctor

> was really not educated about what it was to deal with trans clients. So for example, when we were going over our medical history, she kind of dismissed—and this is a literal quote—'your transgender *stuff*' [which] was basically my medical history.

Participants emphasized that all clinic staff, including physicians, clinical managers, reception staff, and laboratory technicians should have access to appropriate training.

A lesbian participant who conceived a child with her lesbian partner using known donor insemination with assistance from AHR services reported a positive experience:

> The nurses are well trained with people. His secretaries are well trained. Everybody is happy to see you, and they refer to your wife as your wife. They know a lot about lesbians reproducing, so when you go in there they know more than you do, which is great, because we feel like as lesbians we're always usually the ones educating people.

One participant made a recommendation concerning the modality for this training, suggesting that providers experienced in working effectively with LGBTQ people could provide mentorship to less experienced providers.

Clinic Environment

Participants also made recommendations related to LGBTQ-invisibility in the clinic space: participants reported that everything from clinic websites to the pictures and posters decorating the space to the pornography supplied

in the sperm donation rooms reflected the presumption of a heterosexual and cisgender service user population.

Participants made two primary recommendations to address this invisibility:

1. recruit, support, and retain "out" LGBTQ-identified people to work in clinics; and
2. create a visible LGBTQ presence in clinics through photos, posters, and other materials.

Trans participants also commented on the need for the physical space to be reorganized to have gender-neutral washrooms (rather than women's washrooms only) located near the ultrasound rooms for trans men pursuing pregnancy and gender neutral or women's washrooms near the andrology laboratory for trans women wishing to freeze sperm.

Service Gaps

Finally, some participants made recommendations about specific services they would like AHR clinics to offer. A number of participants requested that clinics provide services (e.g., STI and semen testing) for known sperm donors. Participants commented that it would be helpful if the donor could have all the tests done through the clinic with a physician who "knows what's going on," and pointed out that this is done for the male partners of heterosexual women who are using the clinic.

Participants also emphasized the need for support and information for the partner and/or co-parents(s) who would not be pregnant. Emotional support was seen as particularly relevant for LGBTQ people, given a social context that can often mean a relative lack of support from families of origin throughout the conception process. Participants noted that couples counselling—not just fertility counselling—would be helpful. However, participants noted that this counselling support should be provided by staff who had adequate training and information about LGBTQ people and experiences. In some cases, participants had opted not to access peer support groups available through their AHR service providers, since they felt that support from a group of heterosexually identified individuals struggling with infertility (and presumably, led by a heterosexually identified counsellor) would not be effective in addressing their LGBTQ-specific needs and concerns.

DISCUSSION

As LGBTQ people increasingly rely on AHR services to assist with formation of their families, providers will need to develop their capacity for working with this population. AHR services may have to be adjusted to meet the needs of LGBTQ people, who may not have fertility problems.

Some of the recommendations made by participants in this study have been made in other studies,[8] but our data suggest they are not yet being consistently implemented. This raises questions about potential barriers to implementation. Lack of education about LGBTQ health may be one such barrier. LGBTQ-specific information is seldom included in medical school curricula,[18,19] and physicians (and other health care providers) therefore often lack the basic information necessary to provide competent care to LGBTQ people. Improved access to training opportunities, in the standard curriculum and as part of continuing education, will be essential to ensuring that AHR service providers can meet the needs of the increasing numbers of LGBTQ people seeking their support.

Common to many of the recommendations in this study is a requirement that providers broaden their understanding of AHR service users to ensure more equitable access for those who do not fit the current model. The finding that a number of our participants' recommendations are not LGBTQ-specific further suggests the potentially broad impact of addressing them to provide "patient-centred care."[20] It is notable that one of the few studies to investigate patient-centred care in fertility medicine identified elements consistent with the recommendations made in this study (e.g., with respect to access to information, competency of clinic staff).[21]

Our sample consists of predominantly cisgender, white, same-sex partnered, urban women with relatively high levels of education and income, though this reflects the predominant users of AHR services from within LGBTQ communities. This study captured only the perspective of service users; research exploring the service provider's perspective would assist in identifying additional institutional or policy barriers to the implementation of these recommendations.

To our knowledge, this study, despite its limitations, represents the largest investigation to date of LGBTQ people and AHR services. The resulting recommendations suggest practical steps towards ensuring accessibility of quality AHR services to all prospective parents.

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APPENDIX. GLOSSARY OF LGBTQ TERMS*

Term	Definition
Sexual orientation	A term for the emotional, physical, romantic, sexual and spiritual attraction, desire or affection for another person. Examples: gay, straight, bisexual, lesbian.
Sexual identity	One's identification to self (and others) of one's sexual orientation. Sexual identity is not always the same as sexual orientation and/or sexual behaviour (what people do sexually).
Gay	A man whose primarily sexual orientation is to other men. This term is sometimes used by lesbians (i.e., gay woman).
Lesbian	A woman whose primary sexual orientation is to other women.
Bisexual	A person whose sexual orientation is directed towards individuals of more than one sex/gender, though not necessarily at the same time.
Queer	A term that has traditionally been used as a derogatory and offensive word for sexual and gender minority people; however, many, particularly younger people in urban areas, have reclaimed this word and use it proudly to describe their identity. For many, 'queer' is a way of identifying their non-heterosexual orientation yet avoiding the sometimes strict boundaries that surround lesbian, gay, bisexual and trans identities. Sometimes 'queer' is used as an umbrella term for minority sexual orientations and gender identities or as a synonym for LGBT.
Heteronormativity	The assumption, in individuals or in institutions, that everyone is heterosexual, and that heterosexuality is superior to homosexuality and bisexuality.
Sex	A biological construct that encapsulates the anatomical, physiological, genetic, and hormonal variation that exist in species.
Gender	A multidimensional construct that refers to the different roles, responsibilities, limitations, and experiences provided by individuals based on their presenting sex/gender. Gender builds on biological sex to give meaning to sex differences, categorizing people with labels such as man, woman, and trans. These categories are socially constructed and gender is performative (see Gender Expression).
Gender identity	A person's own identification of being masculine, feminine, male, female, or trans. Gender identity is unrelated to sexual orientation; not all trans people identify as lesbian, gay, bisexual, or queer.
Gender expression	The public expression of gender identity; actions, dress, hairstyles, etc., performed to demonstrate one's gender identity.
Cisgender	A person whose gender identity matches the gender they were assigned at birth; someone who is not trans.
Trans	An umbrella term referring to people who do not embrace traditional binary gender norms of masculine and feminine and/or whose gender identity or expression does not fit with the one they were assigned at birth; can refer to transgender, transitioned and transsexual people, as well as some two-spirit people.
Transgender	An umbrella term describing anyone who falls outside of traditional gender categories or norms. Literally means "across gender," and conveys the idea of transcending the boundaries of the gender binary system. Not necessarily a desire to be of the "opposite" sex.
Transsexual	Someone who feels their gender identity does not match the sex that they were assigned at birth. Many transsexual people choose to go through sex reassignment, including hormone treatment and surgeries, so that their sex and gender identity match.
Transition	The process of changing from the sex one was assigned at birth to one's self-perceived gender. May involve dressing in the manner of the self-perceived gender, changing one's name and identification, and undergoing hormone therapy and/or sex reassignment surgeries to change one's secondary sex characteristics to reflect the self-perceived gender.
FTM	Trans man; a female to male transsexual; someone who was assigned as female at birth and identifies as male.
MTF	Trans woman; a male to female transsexual; someone who was assigned as male at birth and identifies as female.
Two-spirit	An English language term used to reflect specific cultural words used by First Nations people who have both a masculine and a feminine spirit or to describe their sexual, gender and/or spiritual identity.

*Compiled by L.A. Tarasoff in May 2012.

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