Addressing Fertility Preservation for Lesbian, Gay and Bisexual Adolescents and Young Adults with Cancer

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Adolescents and young adults (AYAs) with cancer are informed of their risk of sub-fertility and options for fertility preservation (FP) with the intention that, if possible, they are able to consider having biologically-related children after treatment. Previous research indicates that assumptions of heterosexuality are a prevalent experience in healthcare among lesbian, gay, bisexual and transgender (LGBT) populations.1,2 Accordingly, the widespread heterosexual bias among providers may frame conversations on reproduction among AYAs with cancer, implying that fertility is only possible within a heteronormative cisgender (a person who identifies with their assigned sex at birth) opposite-sex relationship.3 The purpose of this paper is to address the subpopulation of lesbian, gay and bisexual (LGB) AYAs with cancer. The authors have intentionally chosen to focus on cisgender LGBs. Access to healthcare can be more stigmatizing and discriminatory for transgender populations than for cisgender sexual minorities;4 including transgender AYAs may indirectly promote comparisons to a cisgender norm. Thus, the unique experiences of the transgender community should be recognized independently. This paper will address issues of disclosure among LGB AYAs in healthcare and consider how providers can deliver informative FP options that are inclusive and respectful of LGB AYAs with cancer. The authors will draw on implications for healthcare practice and policy, and recommend strategies to enhance the applicability of educational materials and promote open and comprehensive practice.

Disclosure of Sexual Orientation for LGB AYAs in Healthcare

Estimates suggest that there are approximately 420,000 to 1,000,000 LGBT cancer survivors in the United States.5 Research conducted among sexual minority cancer survivors illustrates a recurring pattern of negative clinical experiences, indicative of healthcare providers’ discriminatory attitudes and assumptions of heterosexuality.6-8 Stigmatizing encounters or fears of expected bias and mistreatment have resulted in a certain unwillingness to disclose sexual orientation in healthcare settings.9-12 Non-disclosure for LGB adults may, consequently, have significant health and mental health risks.6 A study conducted in the United States, for instance, demonstrated that non-disclosure among LGBs with cancer increased distress and negatively affected health outcomes and subsequent referrals to suitable care settings.13 The experiences of LGB adults are not meant to profess intentional bias of healthcare providers, or disregard affiliations and organizations that have established policies to address LGB care. For example, the American Medical Association14 and the American Academy of Nursing15 have circulated position statements that advocate a commitment to develop strategies to foster best practices and culturally competent care across LGB populations. Moreover, in 2014 the Association of American Medical Colleges16 released guidelines to form comprehensive standards that promote skill development to care for LGBT patients.

Notwithstanding these important changes, LGB AYAs have reported similar obstacles in healthcare to their adult counterparts.17-20 Recent statistics estimate that 6.4% of young adults (aged 18-29 years old) in the United States identify as LGBT.21 Although empirically-based
research on LGB AYAs with cancer is significantly limited, there is evidence to suggest that LGB AYAs have encountered negative and discriminatory general healthcare practices. Identifying a practitioner as unaccepting can act as a barrier to care; it may foster a reluctance to arrange routine examinations or follow-up appointments, which may ultimately result in delayed screening practices, preventative care and poorer health outcomes. Acts of bias reported among LGB AYAs include: not being asked directly about their sexual orientation, a lack of LGB positive signs, inclusive brochures and educational materials, and a providers’ lack of knowledge and training on LGB-specific healthcare concerns and needs.

Although sexual orientation may not always need to be at the forefront of practice (e.g. a cold is just a cold), disregarding a patient’s sexual orientation may unintentionally facilitate non-disclosure. If a provider does not ask about sexual orientation, LGB AYAs are often less inclined to disclose and, consequently, will likely perceive subsequent healthcare interactions as biased. Conversely, when providers reflect upon sexual diversity and LGB specific issues and concerns in their practice, LGB AYAs are often more forthcoming, leading to positive health and mental health outcomes, and promoting health-seeking behaviours. Practices that acknowledge LGB AYAs can increase access to care and foster equitable and informative service provision.

**Family-Centered Care and Disclosure for LGB AYAs**

The coming out process for LGB AYAs is an essential component of identity formation and integration; it is an ongoing process that occurs in various stages over the course of a lifetime. The decision for LGB AYAs of whether or not to disclose their sexual orientation presents an added ethical dimension that is not as common with LGB adults. For some LGB AYAs, non-disclosure to healthcare providers may be due to familial involvement. In a 1998 study conducted among 102 LGB youth, 75% of LGB youth surveyed reported that they chose not to disclose to a healthcare provider because they did not want to discuss their sexual orientation in front of a parent; 57% were afraid that a provider would tell their parent; and 26% did not disclosure because a parent was in the examination room. Although this study was conducted over a decade ago, issues of confidentiality, privacy and concerns over parental disclosure remain important considerations for LGB AYAs in healthcare settings.

Adolescents and some young adults with cancer are often accompanied to the hospital by their parents, and healthcare providers must try to balance patient engagement with parental involvement. Parents may have a strong preference to be spoken with first or to actively participate in discussions about their child’s cancer care. Although parents’ concerns should be addressed, initiating a joint family dialogue for all AYAs may not only be disconcerting, but may also lead to deleterious consequences. Non-disclosure may be a deliberate action to uphold family values and to mitigate potential conflict. Families can have a range of reactions to an AYA’s sexual minority disclosure, and many LGB AYAs anticipate negative results. Experiences of shock, disappointment, anger, as well as verbal and physical abuse have been recurrent.

Family rejection and discrimination may impact the health and mental health of LGB AYAs, potentially leading to depression, substance use, and suicide. Receiving a cancer diagnosis is a time of increased stress and anxiety and, as such, disclosure may cause further harm when parents are often relied upon as systems of care and support. This may be particularly salient with respect to fertility preservation (FP), a topic deeply rooted in sex and sexuality, and one that may foster discomfort, unease and embarrassment among all AYAs in a family context.

**Fertility Preservation (FP) for LGB AYAs with Cancer**

The increasing social and political inclusivity of LGBs have encouraged a growing
number of AYAs to incorporate biological parenthood into their planned life course trajectory. A 2007 study conducted among 15-19 year old LGB youth (n=528) reported that 36% of females and 20% of males were extremely likely to raise children, while 67% of males and 55% of females indicated some degree of likelihood in raising children. Out of these respondents, 58% of males and 54% of females expected to raise their own biological children. There is a paucity of more recent research on child-rearing expectations and intentions of LGB AYA. However, it may be assumed that as emerging developments of assisted reproductive technologies and LGBT rights escalates, interest among LGB AYA to have children will continue to grow.

Previous scholarly work has demonstrated that intentions of fertility and aspirations of parenthood are likely different for LGBs than for heterosexuals, potentially influenced by legal regulations (e.g., prohibitions surrounding same-sex marriage, adoption or surrogacy), as well as negative social attitudes and discriminatory practices that have created obstacles to parenthood, and have impeded access to fertility services for LGB individuals and same-sex couples. The implicit and explicit messages of heterosexual bias are grounded in stigmatizing narratives that perpetuate the belief that LGB individuals are morally unfit to parent, and claim that children who have LGB parents will experience emotional and psychological harm; these unsubstantiated concerns continue to be reflected in institutional and individual levels of discrimination potentially influencing the way in which LGB AYAs contemplate their FP options and their intentions for parenthood.

The impact of social stigma on LGB parenting may be beyond the scope of practice for healthcare providers. However, how these negative experiences may shape LGB AYAs’ considerations of FP is important to bear in mind. A priori assumptions of sexual orientation influence the capacity to respond to a patient’s unique needs, interests and experiences. LGB AYAs with cancer may not encounter the same psychosocial reactions and responses associated with possible infertility as their heterosexual counterparts. Therefore, their intentions, experiences and expectations of FP may be entirely distinct from heterosexual singles and partners. FP guidelines may require further elucidation or re-negotiation to accurately reflect patient diversity. A comprehensive and responsive dialogue with all AYAs, irrespective of sexual orientation or partnership-status, is critical to provide accurate information.

**Healthcare Practices to Address FP for LGB AYAs**

Addressing FP among LGB AYA may be difficult as a patient may not always be willing to disclose their sexual orientation. Integrating FP options that are attuned to sexual diversity as a routine standard of practice, across all AYA populations, can demonstrate consistent knowledge, training and care among providers regarding LGB issues. A standard of care may also respect an LGB AYA’s decision of whether or not to disclose adequately referencing LGB issues without necessarily coercing the patient to divulge this information due to potential fears of bias or the need for more relevant resources. To engage in a standard of practice, becoming mindful of sexual communication skills is important to promote open and inclusive dialogue, incorporate appropriate language and terminology, and gain familiarity with LGB issues and referral sources. Sensitivity training on sexual diversity may help to identify personal biases, homophobic attitudes, and heteronormative assumptions that may impact practice. This can be an important self-reflexive exercise, and one that may enhance patient inclusivity.

Moreover, training, workshops and educational programming are recommended to provide applicable skills to navigate discussions on FP if and when they arise. To help enhance LGB competencies, strategies can include addressing: (1) how to use gender neutral language when referring to a potential partner or inquiring about a relationship status (e.g., ‘partner’ or
distinct FP needs and experiences of LGB AYAs with cancer and inform practice for these imperative offers LGB Network advocates for the provision of culturally competent and their families regarding LGBT support and care. Dedicated to LGBT health and complete psychosocial histories bisexual, transgender Academy of Pediatrics (AAP) to develop shifts to identify questions, and build support workers who have experience in case management, psychoeducational activities, forming a multidisciplinary team to promote comfort, safety, and familiarity. Developing in sensitivity training, skill development, and the implementation of gender-neutral language in assessment and intake forms are critical to promote inclusive FP options for LGB AYAs. Nevertheless, an increase in training and knowledge may not necessarily repair the lack of time that is often a determining factor in the provision of FP. Time to assess family dynamics, build a sense of trustworthiness, and find ways to enhance confidentiality and privacy among AYAs is needed. A multidisciplinary team may be an accompanied strategy that can help with the referral process and foster patient support.

Inter-professional collaboration and engagement with AYAs and their families can promote opportunities for consultation, therapeutic support, and relevant educational materials. Forming a multidisciplinary team (specifically with the help of nurse practitioners and social workers who have experience in case management, psychoeducational activities, therapeutic support, and referral networking) can lead to increased time and opportunities for patients to ask questions, and build comfort, safety, and familiarity.

**Policies to Address FP for LGB AYAs**

Educational resources accessible to both patients and healthcare providers may require a shift to identify sexual diversity. Policy changes may help support this reform, providing tools to develop inclusive and non-discriminatory FP information. For example, the American Academy of Pediatrics (AAP) issued a report entitled “Office-based care for lesbian, gay, bisexual, transgender, and questioning youth (LGBTQ),” recommending comprehensive care and complete psychosocial histories for sexually diverse youth. A subdivision of the AAP is dedicated to LGBT health and wellness, providing informative resources for providers, patients and their families regarding LGBT support and care. Additionally, the National LGBT Cancer Network advocates for the provision of culturally competent and equitable cancer care among LGBT populations. The agency has training programs, as well as a best practice manual that offers strategies on how to address and identify culturally competent practice.

Policies included in both the AAP and the National LGBT Cancer Network are imperative first steps to foster inclusive and equitable healthcare access for LGBs with cancer. These statements can be used to further implement accessible and relevant information available for LGB AYAs about family planning opportunities. Incorporating guidelines can help monitor and inform practice to deliver age appropriate and sexually diverse material that addresses the distinct FP needs and experiences of LGB AYAs with cancer.
Practice and policy directives can also advise members of multidisciplinary cryopreservation teams to address patient diversity and inclusivity. Fertility specialists and cryopreservation staff may unintentionally approach (or may be perceived as approaching) patients with bias; collaborating with oncology teams shows equivalent investment in skills-based training and in-service workshops to promote inclusive and supportive care for LGB AYAs with cancer.

**Conclusion**

The ultimate aim of this paper is to inform an ethically competent and nonjudgmental approach to conversations surrounding FP without *a priori* assumptions of sexual orientation (whether heterosexual, LGB, questioning, or unlabeled). Finding a healthcare team that is empathic, knowledgeable and supportive—irrespective of sexual orientation or partnership status—is vital to effectively address FP decisions among AYAs with cancer and to present a hospital environment that is accepting, welcoming, and inclusive of sexual diversity. Thus, FP should be provided to all AYAs with cancer without being guided by presumptions of sexual orientation, partnership status, or the sex of an AYA’s future partner; a standard of practice that routinely addresses the needs, experiences and expectations of all AYAs, while continually addressing and remaining cognizant of potential LGB issues, is critical to inform care.

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