

Expanding the Clinical Definition of Infertility to Include Socially Infertile Individuals and Couples



Weei Lo and Lisa Campo-Engelstein

Introduction

The Centers for Disease Control currently defines infertility as “not being able to get pregnant (conceive) after one year (or longer) of unprotected sex” (CDC 2017). “Unprotected sex” here refers exclusively to vaginal-penile intercourse. This definition is widely used in the medical literature and is used as the clinical definition of infertility by professional medical organizations like the American Society of Reproductive Medicine (ASRM); ASRM defines infertility as “the inability to achieve pregnancy after one year of unprotected intercourse” (ASRM 2012). Yet, this clinical definition of infertility excludes people not in heterosexual, cisgender couples. This means that heterosexual single cisgender individuals and lesbian, gay, bisexual, transgender, and queer (LGBTQ) individuals and couples are technically not able to be diagnosed and treated as infertile due to their relationship status. Infertility due to relationship status is known as relational infertility or social infertility (Murphy 1999) and can be contrasted with physiological infertility, which is infertility due to a medical condition (e.g., low sperm count, blocked fallopian tube). Individuals can have both social infertility and physiological infertility. For example, a lesbian woman can be socially infertile because she is in a same sex relationship but also physiologically infertile due to endometriosis.

In this paper, we argue to expand the definition of clinical infertility because the current definition is discriminatory, creating unequal access to ART and preventing insurance coverage of assisted reproductive technology (ART) for people not in

W. Lo

Albany Medical College, New York, USA

e-mail: low@amc.edu

L. Campo-Engelstein (✉)

Alden March Bioethics Institute, Department of Obstetrics and Gynecology,

Albany Medical College, Albany, NY, USA

e-mail: campoel@amc.edu

heterosexual, cisgender couples. Others have argued that relational infertility should be recognized as its own diagnosis (Rank 2010). We instead argue for an expansion of the current clinical definition of infertility to treat socially infertile people equally, rather than creating separate categories of infertility that may perpetuate stigma and barriers to healthcare. Specifically, we focus our discussion on how the clinical definition of infertility is interpreted and applied by infertility specialists and insurance companies in the United States. We will limit our discussion to single cisgender women and cisgender lesbian couples. Single men, gay male couples, and transgender individuals without internal female reproductive organs require the assistance of a gestational surrogate, which is not currently covered by infertility mandate of any state and is thus beyond the scope of this essay.¹ Furthermore, a lesbian couple consisting of a transgender woman and a cisgender woman may be able to use sperm from the transgender woman, which may not require medical intervention.

Discriminatory Definition of Infertility

One major problem with the current clinical definition of infertility is that it automatically excludes anyone not engaging in vaginal-penile intercourse from being diagnosed as infertile. While heterosexual intercourse is the most common way people become pregnant and the failure to achieve a pregnancy through heterosexual intercourse can be an indicator of infertility, there are various medical technologies that can also demonstrate infertility in the absence of heterosexual intercourse. For example, healthcare professionals can test patients' hormonal levels and the quality and quantity of gametes in order to make a diagnosis of infertility. Yet, the definition of infertility requires patients to partake in a *specific* type of sexual activity—i.e., vaginal-penile intercourse—in order to make a diagnosis. The requirement to engage in heterosexual intercourse for the sole purpose of proving a medical diagnosis is discriminatory toward single, heterosexual women and lesbian women and couples. People's participation in a specific action that violates their personal beliefs and/or identity should not be mandatory for any medical diagnosis or treatment when alternative diagnostic tools and treatments exist. The heteronormative bias of this definition of infertility assumes that reproduction only occurs via vaginal-penile intercourse, thereby excluding single women and lesbians from consideration.

Although LGBTQ or single cisgender people are not forced to engage in vaginal-penile intercourse to establish infertility, the criterion of vaginal-penile intercourse has the de facto effect of excluding this population. For many individuals who have a strong desire for gestating genetically related children, especially those who live

¹Although we will not discuss the ethical issues surrounding surrogacy, it is important to note that heterosexual couples who meet the current clinical definition of infertility may also benefit from surrogacy coverage. For instance, a woman who underwent a hysterectomy due to endometrial carcinoma may wish to start a family after she is cancer free. Even if she has the foresight, opportunity, and means to preserve her eggs, she cannot carry a pregnancy due to her surgery and will need to seek the assistance of a surrogate.

in states with limited ART access for people not in heterosexual relationships, the only way to conceive may be to engage in vaginal-penile intercourse. The strong desire for gestational and genetic parenthood may lead people to make choices they would not otherwise make if they had more options, including entering mixed-orientation relationship, when two partners have different sexual orientations (Clemons 2016; Tatlow 2015). In countries that criminalize homosexuality, refuse to recognize same-sex marriage, and have sparse ART access, a heterosexual relationship (i.e., vaginal-penile intercourse) remains the only plausible and legal method for their citizens to conceive a child. China is one such an example, where 80% of, or 16 million, gay men marry women to conceive children and/or fulfill cultural expectations. Although there is less data on lesbian women entering marriage with men for the same reason, it is a known practice in the LGBTQ community in China (Davison 2011; Tatlow 2015). Without plausible options to access ART, partly perpetuated by the discriminatory definition of infertility, people across the globe may engage in unwanted vaginal-penile intercourse to become genetic parents.

Some critics may argue that engaging in heterosexual intercourse is not an unfair demand because being single or lesbian is a “lifestyle” choice and women could just as easily choose to participate in vaginal-penile intercourse. This criticism is often based in religious or philosophical objections to homosexuality and “nontraditional” gender norms, rather than grounded in empirical data. The American Psychological Association asserts that most people have little or no sense of choice about their sexual orientation (APA 2008). Likewise, single heterosexual woman may not be able to find a suitable male partner, which has contributed to the burgeoning egg freezing market as a way to anticipate and prevent age-related infertility (Hodes-Wertz et al. 2013). Even if we were to grant these critics, their objection that being single or lesbian is a choice, this in no way justifies requiring people to engage in unwanted sexual activity to establish a medical diagnosis when other options exist. The objection that women can “choose” to engage in heterosexual intercourse is simply a way of affirming the heteronormative belief that reproduction should be limited to heterosexual couples and should exclude single women and lesbian couples.

We recommend changing the clinical definition of infertility to “a condition of an individual with intent of parenthood but unable to produce conception due to social or physiological limitations within a period of twelve months.” This expanded definition of infertility will push the medical community to recognize social infertility as a clinical diagnosis that is treatable with many of the same options already available for physiological infertility. Broadening the term will also inform and encourage the policy makers and insurance companies to cover social infertility under existing infertility insurance mandates.

Since the current clinical definition of infertility depends on heterosexual intercourse, it assumes that the only cause of infertility is physiological. Individuals with physiological infertility have reduced fertility due to factors indicated by physiological causes. Examples of physiological infertility could include a woman with chronic pelvic inflammatory disease secondary to a gonorrhea infection or a man with a low sperm count. This population is currently the only group recognized by

the clinical definition of infertility. For 30% of heterosexual couples who are involuntarily childless, no medical cause can be identified after the standard infertility evaluation (The Practice Committee of the American Society for Reproductive Medicine 2013). These couples are diagnosed with “unexplained infertility,” with the presumption that there is a physiological etiology, but it cannot be identified. Because they meet the criteria of the clinical definition of infertility, heterosexual couples with unexplained infertility are presented with the same treatment options as other physiologically infertile heterosexual couples.

It is sometimes mistakenly assumed that physiological infertility affects only heterosexual couples, and social infertility is limited to LGBTQ couples. Yet, physiological infertility and social infertility are not mutually exclusive. While single women and lesbian couples are socially infertile due to their relationship status, they may also suffer from physiological infertility. Heterosexual couples can also experience both physiological infertility and social infertility. For example, take the case of a heterosexual couple in which the man has poor sperm motility (physiological infertility) and the woman has a strong preference against vaginal intercourse due to a history of sexual trauma (social infertility). Both their physiological and social infertility contribute to their difficulty conceiving as a couple. Heterosexual individuals can be physiologically fertile but socially infertile as in the case of a single heterosexual woman.

It was not until 2013 that the ASRM formally recognized the medical needs of socially infertile people and discouraged fertility specialists from restricting ART access to this population (The Ethics Committee of the American Society for Reproductive Medicine 2013). Although it was an important step for the ASRM to strongly recommend nondiscriminatory access to ART, regardless of a patient’s sexual orientation or relationship status (The Ethics Committee of the American Society for Reproductive Medicine 2013), the organization stopped short of redefining clinical infertility. While this policy statement may influence the actions of healthcare providers, it does not necessarily affect the insurance industry. In fact, despite the reproductive medicine community’s recent acknowledgment and acceptance of social infertility—including the World Health Organization’s announcement in 2016 that it would expand its definition of infertility to include single individuals and LGBTQ individuals (Bodkin 2016)—health insurance companies in the United States still base infertility coverage on the narrow clinical definition, generally denying ART coverage to individuals with social infertility.

The Impact of Infertility

One common criticism of ART coverage is that infertility, and especially social infertility, is not a “real” disease because it does not cause physical harm. It is important to recognize that some diseases that cause physiological infertility may also manifest physical symptoms and are therefore indicated for medical interventions. For instance, in some cases, endometriosis can cause dyspareunia, or pelvic pain, and can also potentially cause infertility. A woman who is experiencing pelvic

pain should clearly receive treatment for such pain. However, if this same woman has no physical symptoms, there would be no reason to undergo treatment unless she intends to conceive a child. Indeed, most physiologically infertile women will never know they are infertile until they attempt to become pregnant. Can a woman in a heterosexual relationship with no desire to have a biological child with her male partner suffer from infertility? The diagnosis of infertility and the decision to seek treatment rely heavily on social and situational factors and the individual's desire to become a parent. A diagnosis of physiological or social infertility may not have much impact on those with no desire to have children. However, the same diagnosis would keenly impact another woman whose identity and life goals include becoming a genetic mother. Both the intent to achieve pregnancy and the inability to conceive are necessary for a clinician to diagnose someone with infertility.

Some dismiss the desire to have biological children as unimportant or at least not within the medical purview. Yet, this criticism fails to recognize the psychological harms associated with infertility. According to a Pew Research Center report in 2011, 27% of childless men and 36% of childless women between ages 15 and 44 reported "it would bother them a great deal" if they never have children (Livingston and Parker 2011). In another 2010 survey, Pew found 60% of surveyed childless women under the age of 50 and 63% of childless men under age of 60 reported they want to have children one day, regardless of their marital status. Up to 83% of unmarried individuals who would like to get married in the future indicated that they wanted children one day. But even among single people who have no plans for marriage, 31% of them still reported a wish to have children someday (Pew Research Center 2010).

Infertility creates a low-control stress situation, in which individuals lack the ability to influence the outcome (Terry and Hynes 1998), and is a significant psychosocial stressor comparable to death of a family member or somatic disease such as cancer or HIV (Baram et al. 1988; Domar et al. 1993). In previous studies on involuntary childlessness, individuals who meet the clinical definition of infertility have shown increased risk of depression, anxiety, guilt, grief, sexual problems, reduced relationship satisfaction, and marital distress (Kraft et al. 1980; Möller and Fällström 1991; Lukes and Vacc 1999; Peterson et al. 2003; Sundby et al. 2007; Luk and Loke 2015). Infertility also contributes to social isolation, reduced self-esteem, loss of identity, and poor body image (Luk and Loke 2015; Whiteford and Gonzalez 1995; Wirtberg et al. 2007). Chronic adverse effects on interpersonal and social relationships secondary to distress precipitated by infertility have been reported even 20 years after failed pregnancy attempts (Whiteford and Gonzalez 1995). Despite significant emotional distress, many infertile women do not seek professional counseling or participate in support groups (Sundby et al. 2007), which may be because of the shame and stigma associated with infertility. Not surprisingly, involuntarily childless individuals reported reduced quality of life in comparison with individuals who have children (Chachamovich et al. 2010).

Much of medicine today focuses on treating conditions that may not be life-threatening but that significantly impact people's quality of life, such as seasonal allergies, back pain, anxiety, poor vision, and sexual dysfunction; and infertility is no different. The psychosocial harms of infertility are not limited to heterosexual,

cisgender couples. All individuals, regardless of their relationship status, who want biological parenthood but are unable to achieve it may suffer from infertility. Socially infertile women have the same intent to become biological parents as their physiologically infertile counterparts and can suffer the same psychological harms associated with infertility. For these reasons, we believe social and physiological infertility should be recognized as the same illness with different etiologies.

Although heterosexual, cisgender couples are culturally elevated as ideal parents, or at least the norm, many single individuals and LGBTQ couples also desire parenthood. Furthermore, contrary to dominant cultural narratives, single individuals and LGBTQ couples can be good parents, and their children are generally just as well adjusted as children raised in heterosexual, two-parent households.

As of 2008, 25% of American children lived in single-family homes (Pew Research Center 2010). The increase in single-parent households in the United States reflects changes in family structure. Many single families have extended social support such as aunts, uncles, grandparents, and godparents that help the single parent to raise the children. Although single-parent households historically have faced significant stigma, 86% of participants surveyed in 2010 consider a single person with a child to be a family (Pew Research Center 2010), which shows that the cultural definition of family has expanded to include single-parent households. The majority of single-parent families are single mothers. Traditionally, these single-mother families have been associated with divorce, separation, or unplanned pregnancy. However, there is a growing trend of single motherhood termed “solo mothers.” These are women without a partner who chose to enter parenthood and conceive children through donor insemination (Weissenber et al. 2007). A sharp increase of this “non-standard request” at the fertility clinic has been observed in recent years as more single women decided to pursue single motherhood before their fertility declines (Golombok et al. 2016). Many of the 31% of surveyed heterosexual single persons who wanted children one day but did not want to marry would likely use ART if they were ultimately unable to find a willing and appropriate opposite-gender partner. Their desire to have biological children is no different than individuals in heterosexual relationships who are using ART due to physiological infertility.

Although children raised in a single-family home may face some disadvantages such as less parental time and lack of two-adult income, children raised in stable single family do not suffer from significantly worse cognitive development, health outcome, or school performance compared to children raised in two-family homes. In fact, family stability appears to be a more important factor in children outcome. Children raised in stable single-parent homes, after taking consideration of confounding factors, show no significant differences in cognitive development or behavior issues compared to children raised in stable two-parent homes (Waldfogel et al. 2010). Similarly, the maternal education level appears to have a stronger correlation to a child’s school performance than the family structure (Amato et al. 2015). Children raised in a loving, supportive, and stable single-parent home with extensive social support network are therefore not at a significant disadvantage compared to children raised in other family structures.

Just like many heterosexual single individuals, many LGBTQ individuals desire biological parenthood. According to the Pew survey, 28% of childless LGBT adults under age 60 would like to have children one day, while 34% remained undecided (Pew Research Center 2013). Although the stigma in our society against single parenting appears to be in decline, the prejudice against same-sex couple parenting remains high. According to the 2010 Pew Research Center survey, only 63% of respondents considered a same-sex couple with children to be a family, compared to the 86% of respondents considered single parent with children to be a family (Pew Research Center 2010). This indicates a persistent bias against LGBTQ couples. The legalization of same-sex marriage in the United States has encouraged LGBTQ couples to engage in heteronormative activities, such as starting two-parent families and raising children (Hopkins et al. 2013). Interestingly, the public is more likely to classify a same-sex couple as “a family” when they are raising children together. Only 45% surveyed respondents considered same-sex couples without children a family, in comparison with 63% for same-sex couples with children. The presence of children in a same-sex household appears to have a legitimizing effect on the relationship and allows them to be further assimilated into society. This is yet another reason why same-sex couples may wish to have biological children.

Societal arguments against LGBTQ parents and families are often disguised as concern for the children but are constructed to justify discrimination against LGBTQ parents in an effort to maintain a heterosexist status quo (Clarke 2001). In a study reviewing 21 empirical studies on the outcome of children born to planned lesbian families compared to children born to planned heterosexual families, there have been no significant differences in the cognitive functioning, emotional development, or peer relationships. Children from the planned lesbian household, however, showed less aggressive behaviors. Mothers from these planned lesbian families also shared parenting responsibilities more equally, with a higher quality of parent-child interaction and parenting awareness skills (Bos et al. 2005).

Even if one is supportive of single women and LGBTQ couples having children, it is frequently suggested in public discourse that people suffering from infertility (physiological or social) should choose to adopt rather than undergo ART (Davenport 2016). However, the process of adoption is also costly and time-consuming. Depending on the type of adoption and adoption agency, it may cost up to \$50,000 (Child Welfare Information Gateway 2016). Although there are loans, grants, and tax credits available to lessen the cost of adoption, the financial burden of adoption is comparable to the cost of undergoing at least two ART cycles. Since infertility is a long-term stressor associated with personal identity and the social expectation of one’s ability to conceive a biological child, adoption may not necessarily resolve the psychological and emotional burden of infertility. Moreover, some couples highly value both partners sharing biological kinship with each of their children, thus making adoption a less appealing option to start a family. Lesbian couples can both share biological parenthood with their children, which is typically defined as experiencing gestation and/or being genetically related to the child, via *in vitro* fertilization (IVF) by fertilizing one partner’s oocyte with donor sperm and transferring the embryo to the other partner for gestation (Marina et al. 2010).

Additionally, single women and lesbian couples may face additional barriers in trying to adopt since some adoption agencies will not place children with single parents and LGBTQ couples. A single individual may face significant difficulty adopting children due to the social stigma attached to single parenthood, especially against single women (Pakizegi 2007). LGBTQ couples may encounter homophobia and heterosexism biases present on the individual, interpersonal, and organizational levels of an adoption agency that prevent children placement (Ryan et al. 2004).

Insurance Coverage for Social Infertility

Demonstrating medical necessity is the main hurdle many single women and lesbian couples face when seeking reproductive assistance, especially in states without an infertility insurance mandate. Because social infertility is currently not a recognized medical condition nor is it part of the broader diagnosis of infertility, it is deemed medically unnecessary by the insurance companies. Broadening the current clinical definition of infertility to include social as well as physiological infertility recognizes that single people and LGBTQ couples will likely need the assistance of a fertility expert since they will not be able to conceive through sexual intercourse.

While this change in the clinical definition of infertility may seem too radical for some, it is worth noting that infertility is a relatively new medical condition. A heterosexual couple's inability to conceive a child was historically considered to be a private issue, not a public or medical problem. It was not until the 1950s, in conjunction with the development of fertility medications, that infertility became a recognized medical condition (Greil 1991). The labeling of physiological infertility as a medical condition meant that heterosexual couples were justified in seeking and receiving medical assistance in having biological children. Social infertility is slowly becoming recognized, especially as prominent lesbian celebrities, such as Wanda Sykes and Melissa Etheridge, publicly discuss using ART to have children (Long 2015). Similar to physiological infertility, social infertility has entered the public consciousness as a social issue that can be solved with the same medical technologies that many heterosexual couples have had access to for years.

Once social infertility becomes part of the clinical definition of infertility as a medical diagnosis, socially infertile individuals can become eligible for insurance coverage (though perhaps only in states where infertility is covered by insurance), and their reproductive goals would be legitimized by the medical community (Murphy 1999). Without insurance coverage, only the privileged and wealthy can afford ART (Greil et al. 2011; Bell 2016). A single round of IVF is estimated to range between \$12,400 and \$27,000 for women without insurance coverage (Nachtigall et al. 2012). The per successful outcome (i.e., a live birth baby), however, may cost over \$61,000 (Katz et al. 2011).

According to the FertilityIQ employment report, less than 27% surveyed Americans who underwent fertility treatment received insurance coverage for the

service (FertilityIQ 2017). In the states that mandate the group insurers to offer variable degree of infertility benefit to employers, religiously affiliated and small employers are generally exempted as well (Devine et al. 2014). Even in the states with a comprehensive fertility insurance mandate, ART is covered by insurance solely for heterosexual couples based on the current clinical definition of infertility. This narrow definition allows insurance companies to deny ART coverage to paying members who do not engage in coupled heterosexual intercourse while providing coverage to members who do. Without adequate insurance coverage, the unaffordability of ART procedures becomes a barrier to single women and lesbian couples seeking to start a family via reproductive assistance.

In the United States, only 15 states currently require health insurers to offer coverage for infertility diagnosis and treatment (RESOLVE 2017).² Of these 15 states, Massachusetts offers the most inclusive health insurance coverage due to the 2010 amendment that changed the definition of infertility to “a condition of an individual who is unable to conceive or produce conception during a period of year if the female is under the age of 35, or during a period of six months if the female is over the age of 35.” The Massachusetts definition of infertility does not rely on the “married individual” qualifier found in the Rhode Island mandate or the “unprotected intercourse” requirement of the New Jersey mandate (National Conference of State Legislatures 2017). The Massachusetts mandate also covers both the primary beneficiary and her or his spouse. There are also fewer limitations on the types of procedures or number of treatment cycles a woman can undergo under the Massachusetts mandate (Basco et al. 2010). The Massachusetts review system allows new medical technologies to be incorporated into coverage as they mature. Most importantly, Massachusetts has broadened the coverage for single women and lesbian couples who have attempted low-tech conception methods (Health Policy Commission Office of Patient Protection 2013).³

Besides Massachusetts, Illinois is another state to provide a potential pathway for lesbian couples and single women to resolve childlessness via ART. The Illinois mandate covers women after “efforts to conceive as a result of one year of medically based and supervised methods of conception, including artificial insemination, have failed and are not likely to lead to a successful pregnancy” (Illinois Department of Insurance 2014). In April 2017, New York State became the third state to mandate infertility coverage for lesbian couples and single women by insurance companies (New York State Financial Services 2017). However, the current clinical definition of infertility still perpetuates the stigma and bias against single women and lesbian couples, potentially delaying their access to ART. As of 2017, only Massachusetts, Illinois, and New York mandate broad insurance coverage of all women regardless

²The 15 states that currently require health insurers to offer coverage for infertility diagnosis and treatment are Arkansas, California, Connecticut, Hawaii, Illinois, Louisiana, Maryland, Massachusetts, Montana, New Jersey, New York, Ohio, Rhode Island, Texas, and West Virginia.

³Although the Massachusetts infertility mandate has the most extensive ART coverage in the United States, it still does not include surrogacy. Single men and gay couples therefore will not receive coverage for all of the technologies and services they need to build a biological family.

of their relationship status. A more inclusive approach to infertility insurance coverage in other states would benefit socially infertile individuals throughout the country, especially for non-hetero, non-coupled, and nontraditional families.⁴

One potential concern with expanding the clinical definition of infertility is that it may cause insurance premiums to increase in states with infertility insurance coverage. If social infertility became a recognized and treatable medical condition, it would be hard to justify the continued exclusion of single individuals and LGBTQ couples, especially since these previously excluded populations have already been paying the same premiums to support the cost of infertility treatment for heterosexual couples. It is also worth noting that while ART is quite expensive for individuals, it makes up a very small percentage (only 0.06% in 2009) of the total healthcare expenditure in the United States (Chambers et al. 2009). Another potential concern with a broader definition of infertility is that the utilization of ART will also likely increase. Yet, many other factors have recently contributed to an increased utilization of ART, such as the normalization of such technologies, increased insurance coverage for ART (due to state mandates and insurance company policy changes), and “delayed” childbearing among women. Continuing to deny ART to single women and LGBTQ couples while simultaneously expanding its use among other groups does not seem to be a tenable position. Expanding the definition of infertility may entail financial implications. However, we should not allow speculative economic considerations to prevent us from upholding reproductive justice and providing access to ART for single and lesbian women.

Conclusion

In this chapter, we have claimed that social and physiological infertility may be viewed as the same illness with different etiologies. The recognition of physiological infertility as a medical condition has allowed some heterosexual couples to receive insurance coverage for certain types of ART. Only Illinois, Massachusetts, and New York provide some insurance coverage for the socially infertile women. The remaining 12 states that currently also require some insurance coverage for infertility unfortunately exclude single individuals and the LGBTQ community. The current definition of infertility is written under a heteronormative assumption of what constitutes a family and prevents socially infertile people from accessing treatments that may meet their medical needs.

⁴Male infertility care is often overlooked in discussions of infertility. Although almost half of the infertility cases among heterosexual couples are caused by male factors, only six states (California, Connecticut, Massachusetts, New Jersey, New York, and Ohio) mandate coverage for male infertility care. Two other states (Montana and West Virginia) mandate undefined infertility services only for health maintenance organization plans. Among these states, Massachusetts once again provides the most comprehensive coverage for male infertility treatment, including sperm procurement, processing, banking, as well as reversal of elective sterilization (Dupree 2016). However, the Massachusetts coverage plan is designed only for males in heterosexual relationships.

We have proposed an expanded clinical definition of infertility that recognizes the contribution of both social and physiological factors to infertility. We asserted that a more inclusive definition of infertility will provide single individuals and LGBTQ couples in states with infertility insurance mandates improved access to ART. Future work is needed to examine and compare the psychosocial and emotional effects of involuntary childlessness among single individuals, LGBTQ couples, and heterosexual couples. The impact of infertility may have different or worse effects on the socially infertile as they face many different hurdles to achieving biological parenthood.

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