

POLICY FORUM

Infertility, Inequality, and How Lack of Insurance Coverage Compromises Reproductive Autonomy

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Abstract

Disparities in access to infertility care and insurance coverage of infertility treatment represent marked injustices in US health care. The World Health Organization defines infertility as a disease. Infertility has multiple associated billing codes in use, as determined by the *International Statistical Classification of Diseases and Related Health Problems*. However, the often-prohibitive costs associated with infertility treatment, coupled with the lack of universal insurance coverage mandates, contribute to health care inequity, particularly along racial and socioeconomic lines.

The Problem of Infertility

Infertility has been unequivocally defined as a disease state by the World Health Organization (WHO).¹ The WHO recognizes that infertility confers a disability, and it is now fifth on the international list of serious disabilities in women.¹ Moreover, it is a disease with billable codes that physicians can use when charging patients and their insurance companies, as determined by the *International Statistical Classification of Diseases and Related Health Problems*.² Despite the expense associated with infertility treatment, the lack of [mandated insurance coverage](#) for this disease implies that infertility is a condition undeserving of financial assistance and minimizes its importance to patients.

Infertility, a broad disease state that encompasses the inability to achieve a viable pregnancy within 1 year of attempting to conceive,³ is a condition affecting millions of patients in the United States. A recent survey found that, in the United States, 12% of women aged 15 to 44, or 7.3 million women, have used infertility services.⁴ The same survey reported that 12.1% of women have impaired fecundity (the ability to conceive biologic offspring), and 6.7% of married women are infertile.^{4,5} Among men in that age group, the rate of infertility is 9.4%, with 15.8% of married men aged 25 to 44 classified as infertile or subfertile.⁶

There are myriad causes of infertility. In women, these causes include tubal abnormalities, ovulatory dysfunction, premature ovarian insufficiency, and uterine

factors such as fibroids or congenital uterine anomalies.⁷ In men, they include factors such as decreased sperm count or motility and abnormal morphology.⁸ And, in both sexes, idiopathic infertility and impaired fertility are the result of treatment of malignancies.^{7,8}

Infertility affects people in a wide variety of ways and can have significant detrimental effects on quality of life. For example, approximately 40% of infertile women suffer from anxiety and depression, about twice the rate seen in fertile women.⁹ One study of 488 American women found that infertile women had rates of anxiety or depression equivalent to those of patients diagnosed with cancer, hypertension, myocardial infarction, or HIV.¹⁰

The Universal Declaration of Human Rights of 1948, proclaimed by the United Nations General Assembly, states that all people have a right to found a family.¹¹ The 2015 American Society of Reproductive Medicine (ASRM) Ethics Committee states that “reproduction is a fundamental interest and human right.”¹² However, reproductive autonomy is being threatened by the exorbitant costs associated with infertility treatment. In 2015, as part of the Access to Care Summit, the ASRM reported that the average cost of one IVF cycle was \$12 400.¹³ There are additional fees for genetic or chromosomal testing of embryos, ranging from \$2000 to \$5000, and yearly fees for egg and embryo storage are around \$1000.¹⁴ Many patients may require multiple treatment cycles in order to achieve a pregnancy.¹⁵

In this essay, we aim to illustrate how the lack of broad insurance coverage for infertility further propagates health care disparities for marginalized populations in the United States.

The State of Insurance Coverage

Private insurance. Currently, there are 16 states that have infertility coverage mandates for private insurers, with requirements developed on a state-by-state basis (Arkansas, California, Connecticut, Delaware, Hawaii, Illinois, Louisiana, Maryland, Massachusetts, Montana, New Jersey, New York, Ohio, Rhode Island, Texas, and West Virginia).¹⁶ Only 6 states have what is considered comprehensive coverage that includes all or most of the costs associated with IVF (Connecticut, Illinois, Maryland, Massachusetts, New Jersey, and Rhode Island).¹⁶

Data from 1998 shows that, overall, the use of infertility services increased nearly 3-fold in states where there is an insurance mandate.^{17,18} In the most recent data available from 2015, there were 2832 assisted reproductive technology (ART) procedures performed per 1 million women of reproductive age.¹⁹ Of the 13 states and federal districts with rates of ART utilization that exceeded the national rate (California, Connecticut, Delaware, the District of Columbia, Hawaii, Illinois, Maryland, Massachusetts, New

Hampshire, New Jersey, New York, Rhode Island, and Virginia), 9 had insurance mandates as of 2015 (California, Connecticut, Hawaii, Illinois, Maryland, Massachusetts, New Jersey, New York, and Rhode Island), although California and New York exclude IVF.¹⁹ Today, 10 of the 13 states on this list (including Delaware) have insurance mandates.²⁰ Data from the United States stand in contrast to many European countries where ART is much more affordable and corresponding rates of ART utilization are much higher. In Denmark and Belgium, for example, there are more than 12 500 ART cycles per 1 million women ages 15 to 45.²¹

Government insurance. There is no coverage for infertility treatment for patients with public or federal insurance. Federal civil service employees working for the US government, for example, have no insurance coverage for infertility treatment.²² As of March 2018, there were 34.7 million adults enrolled in Medicaid, none of whom have insurance coverage for infertility.²³ For those on public assistance requiring government aid, mandating coverage for infertility treatment is a controversial topic, one that falls outside the scope of this brief essay. However, financial limitations alone should not be paramount in determining which citizens are appropriate parents. For most people, paying for ART out of pocket is impossible, leaving many without a financially feasible way to manage their disease or achieve their reproductive goals.

Disparities in Access to Care

Minority patients face substantial [barriers in seeking treatment for infertility](#). There is evidence that African American, Chinese, and Hispanic patients are much less likely to seek care than white patients and that African American and Hispanic women, despite having higher rates of infertility, are underrepresented in the infertility clinic population.^{17,18,24-26} After failing to conceive spontaneously, it takes an average of 4.3 years for African American women to present to infertility care centers compared to 3.3 years for their white counterparts.¹⁸ When cost barriers are reduced and access is equalized, as demonstrated in a study of patients with at least partial insurance coverage provided through the Department of Defense, there is a 4-fold increase in utilization of assisted reproduction services among African Americans relative to the US ART population.²⁴

Once patients present for care and begin treatment, however, poorer outcomes have been observed in minority patients compared to white patients. A large single-site study demonstrated that, compared to white patients, African Americans had significantly higher spontaneous abortion rates (28.9% vs 14.6%) and lower clinical pregnancy rates (24.4% vs 36.2%) and live birth rates (16.9% vs 30.7%) following IVF.²⁵ A recent systematic review of 24 studies, including 5 US registry-based studies, confirmed these findings.²⁶ Moreover, the review concluded that lower clinical pregnancy rates and live birth rates are also observed in Hispanic and Asian women compared to their white counterparts.²⁶

It has been hypothesized that increased rates of obesity, tubal factor infertility, and uterine factor infertility secondary to fibroids might explain the poorer outcomes following infertility treatment in these populations.^{24,26} However, sociocultural and financial barriers encountered by many minority patients are very likely contributing to the disparities in ART outcomes manifested, and they may partially explain why minority patients are underrepresented in infertility clinics and present later for care.^{18,26} The ASRM has stated that “the access, treatment, and outcome disparities that are associated with ART are a form of stratified reproduction that warrants correction.”¹²

Disparities in Treatment

Tubal factor infertility. Tubal factor infertility typically affects 25% to 35% of IVF patients and provides a good example of how insurance status can dictate care.²⁷ Tubal dilation or damage can be incurred from a variety of insults such as ectopic pregnancy or gonorrhea or chlamydia infections. The presence of a hydrosalpinx, or dilation of the fallopian tube, directly impacts the success of ART, with pregnancy rates essentially doubling for patients who have undergone either laparoscopic salpingectomy (removal of the affected tube) or proximal tubal occlusion (34% vs 17%) prior to starting IVF. Thus, it is now a formal recommendation of the ASRM to surgically treat hydrosalpinges, if present, prior to starting ART.²⁷

In a survey including over 400 infertility specialists, physicians practicing in states without an insurance mandate were more likely not to perform salpingectomy or proximal tubal occlusion before providing ART due to lack of infertility insurance coverage.²⁸ This finding suggests that patients without insurance coverage with tubal factor infertility secondary to hydrosalpinges are likely to receive substandard care and are likely to have worse outcomes if they do pursue self-pay IVF without the appropriate surgery. Because chlamydia infection, a common cause of tubal factor infertility, is 6 times more common in black women and 2 times more common in Hispanic women than in white women, the practice of bypassing surgical treatment prior to ART represents a disparity in treatment that falls along both economic and racial lines.²⁹

Oncofertility. Fertility preservation for patients with a new diagnosis of malignancy provides another example in which socioeconomic barriers prevent appropriate care. Women who face losing their fertility secondary to surgery, chemotherapy, or radiation may be strongly motivated to pursue oocyte or embryo cryopreservation. The cost of ovarian stimulation, oocyte retrieval, and cryopreservation ranges from \$10 000 to \$13 000, and the cost of ovarian stimulation, oocyte retrieval, fertilization of eggs, and embryo cryopreservation ranges from \$13 000 to \$16 000, both with substantial associated yearly storage fees beyond the first year.¹⁴ However, most states do not mandate insurance coverage for fertility preservation, and only 4 states mandate coverage for iatrogenic infertility related to treatment for malignancy.¹⁶ Although patients with breast cancer commonly report significant concerns about fertility, it has

been shown that wealthier patients are more likely to pursue fertility preservation.^{30,31} The financial burden associated with cryopreservation of oocytes or embryos is prohibitive for many patients and thus poses a direct threat to their reproductive autonomy.

Conclusion

Infertility is a disease with a substantial psychosocial burden, and the lack of affordable options may have significant detrimental effects on the quality of life of millions of Americans. Because of the current lack of universal insurance coverage mandates for ART, infertility is implicitly designated as a disease undeserving of financial support, leaving many patients unable to fulfill their reproductive goals. Improving access to care via broader insurance mandates and coverage plans would help rectify these disparities. The fundamental right to reproduce is currently under threat, and these disparities will only intensify if the financial barriers to infertility care are not directly and promptly addressed.

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