

# Disparities in access to effective treatment for infertility in the United States: an Ethics Committee opinion

Ethics Committee of the American Society for Reproductive Medicine

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In the United States, economic, racial, ethnic, geographic, and other disparities exist in access to fertility treatment and in treatment outcomes. This opinion examines the factors that contribute to these disparities and proposes actions to address them. (Fertil Steril® 2015; ■: ■-■. ©2015 by American Society for Reproductive Medicine.)

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## KEY POINTS

- Creation of a family is a basic human right.
- In the United States, economic, racial, ethnic, geographic, and other disparities exist in access to fertility treatments and in treatment outcomes.
- Economic factors are the chief contributors to disparities in access to effective treatment, but social and cultural factors play a role, as well.
- Further research is needed and encouraged to understand documented disparities in treatment success and to improve treatment methods to reduce those disparities.
- It is the responsibility of all assisted reproductive technology (ART) stakeholders, including physicians, policy makers, and insurance providers, to address and lessen existing barriers to infertility care. Efforts should include increasing insurance coverage, reducing the economic and noneconomic burdens of treatment, improving public and physi-

cian awareness of the existence and causes of treatment disparities, and reaching underserved populations and geographic areas.

Involuntary childlessness due to infertility can profoundly impact people's lives, causing medical, social, economic, and psychological harm. According to the National Survey of Family Growth (NSFG), approximately 6.7 million women in the United States, or more than 11% of those of reproductive age, experience difficulty having children due to impaired fecundity (1). Some 9.4% of men are subfertile or nonsurgically sterile (1). Globally and nationally, access to safe and effective methods for addressing infertility is, for many, an essential but often elusive path to family formation. When a treatment gap or inequality affects members of certain disadvantaged subgroups of the population, it is considered a health disparity (2). This opinion discusses disparities in access to and use of effective reproductive medical treatments in the

United States, the causes of these disparities, the ethical implications, and some possible responses. Disparities in access to effective treatment in reproductive medicine are tied to many factors, including socioeconomic status, geography, race, ethnicity, religion, sexual orientation, gender identity, marital status, and conscious or unconscious discrimination (3).

The importance of reproduction in modern American life has been recognized by our legal system for many decades. At the height of World War II, the US Supreme Court declared procreation "one of the basic civil rights of man...fundamental to the very existence and survival of the race" (4). Decades later, the Court reiterated the importance of reproduction, calling it "a major life activity" deserving of protection under the federal law prohibiting discrimination against persons with disabilities (5). The right of reproductive liberty in the United States is commonly understood as a right to be free from governmental interference with an individual's reproductive decision making; at the same time, reproductive liberty is not understood to obligate the government or private persons to provide services that fulfill an individual's reproductive desires (6).

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International legal norms also recognize the importance of reproduction in a person's life. In 2011 the World Health Organization (WHO) declared, "Infertility generates disability (an impairment of function), and thus access to health care falls under the Convention on the Rights of Persons with Disability" (7). The Inter-American Court of Human Rights recently recognized the obligation not to obstruct the fundamental right to reproduction in its decision to overturn Costa Rica's ban on in vitro fertilization (IVF) (8). In overturning the 12-year ban, which had been premised on the "personhood" rights of embryos, the Court found that citizens' rights to enjoy reproductive autonomy and privacy, to access reproductive health services, and to create a family outweighed the interests of non-implanted embryos.

### UNMET NEED IN TREATING INFERTILITY

Many individuals in the United States with impaired fertility go untreated or undertreated. In 2009 an international panel of experts estimated that only 24% of the assisted reproductive technology (ART) needs in the US population were being met (9, 10). ART accounts for approximately 1.5% of births in the United States, compared with an average of 3% of births in Europe, and higher percentages in many countries that publicly fund IVF, such as Denmark (5.9%), Belgium (4.0%), and Sweden (3.5%) (11–13). Although detailed statistics are not available on the number of infertile men and women in the United States treated by means other than ART (e.g., surgery, medication, or intrauterine insemination), the NSFG reports that during the period 2006–2010, just 38% percent of nulliparous American women with current fertility problems had ever used infertility services, and most commonly those were medical advice and testing (14). Fertility preservation prior to gonadotoxic therapy is another category of general ART access where only a subset of patients receives appropriate referral and treatment (15). From these figures, it seems apparent that many US women and men with impaired fecundity, or the threat thereof, go untreated or undertreated.

For the individuals and couples concerned, inability to reproduce is a health and life crisis; it may be detrimental to the individual's, couple's, or family's overall health, social status, and family stability. Infertility may cause persons to be stigmatized within or ostracized from a community; it may contribute to violence and to psychological disorders, including suicide and depression (16, 17).

Improving access and utilization is vital, but these measures alone will not address all aspects of the disparity problem; growing research suggests that current therapies may not be adequate for successful treatment of all patients. Some common biological causes of infertility (e.g., fibroids, polycystic ovary syndrome, azoospermia, sexually transmitted diseases, age of menopause) that may vary by race, ethnicity, or sex are inadequately researched along these demographic lines (18, 19). Studies have shown that some groups, including minority women, tend to seek medical advice after a longer duration of infertility, potentially contributing to lower pregnancy success rates (20–22). Physician referral patterns in some instances vary by patient

ethnicity, sexual preference, and socioeconomic status when it comes to fertility preservation, and these patterns may apply to referral for other fertility treatments as well (23).

### ECONOMIC BARRIERS TO TREATMENT

The majority of patients who undergo IVF in the United States pay out of pocket for their medical treatment because either they lack health insurance or their insurance policies exclude fertility care, cover infertility diagnosis only, or exclude IVF. A recent report places the median price of a cycle of IVF in the United States, including medications, at \$19,200 (24). A single cycle may represent 50% of an average person's annual disposable income (10), whereas a full course of treatment may cost significantly more (25). Men with male-factor infertility face the same financial pressures when trying to build a family. In a recent survey at an urban academic medical center, almost half of the men reported that the cost of treatment caused financial strain and precluded certain therapeutic options (26). Non-IVF fertility treatments, too, may be cost-prohibitive for patients at or below median income levels. The US Centers for Disease Control and Prevention (CDC) has recognized that "Infertility treatment can also be expensive, and ... [e]conomic, regional, and racial/ethnic disparities in access to and use of infertility services are clearly present" (27). Studies confirm that, compared with their presence in the US population, persons of middle to lower socioeconomic status and persons of African American or Hispanic ethnicity are underrepresented in the population of infertility patients (14).

Six states (Connecticut, Illinois, Maryland, Massachusetts, New Jersey, and Rhode Island) provide comprehensive or near-comprehensive coverage for infertility treatment to at least some residents through state law mandates. These mandates require that private insurers cover diagnosis and treatment of infertility, including IVF. Although mandated coverage can result in better overall access, several state mandates carry significant restrictions (e.g., Maryland imposes a 2-year waiting period, exempts religious employers, covers only married couples, and requires that the husband's sperm be used). Mandated coverage is further curtailed by federal law. Under the Employee Retirement Income Security Act (ERISA), state law mandates, including the infertility mandates, cannot regulate or apply to plans that are self-insured, as are the plans of many large employers (28).

State-mandated insurance coverage has been shown to increase approximately 3-fold the utilization of infertility services. This increased utilization brings the per-capita rate of IVF closer to that in other countries that subsidize IVF, suggesting that the presence of insurance permits the medical community to address fertility needs that go unmet in other states (29). Broader insurance coverage is also linked to better public health outcomes. A series of studies has shown that in states with mandated insurance coverage, the rate of IVF high-order multiple births (three or more infants) and, in one study, twin births, is significantly lower than in non-mandated states. Observing that fewer embryos are transferred per cycle in the mandated states, researchers believe that insurance coverage reduces the financial pressure to transfer more than one or two embryos in any one cycle

(29–32). Indeed, studies suggest that patients choose elective single-embryo transfer more frequently when cost pressure is reduced through insurance coverage or other reduced-price financing (33). With a lower rate of multiple births comes improved maternal and newborn health, both desirable public health goals. For patients, the benefits of insurance coverage for infertility are clear: they are able to obtain appropriate, needed medical treatment without incurring sometimes significant financial hardship. For physicians, the benefits include being able to provide care based on medically indicated factors rather than on what the patient can afford; facilitating elective single-embryo transfer and similar limits; and sparing physicians from having to turn away patients because of inability to pay, thus serving a social justice goal.

As important as they are, insurance mandates are imperfect in achieving equal access to and use of infertility treatments. Most critically, they are able to reach only a portion of the population in the mandated state. As noted above, mandates apply only to persons who have private insurance, and only to those policies that must comply with the state insurance law. This means that infertility coverage may not be available to people who are uninsured, who obtain health coverage through Medicaid or other government programs, or who obtain health insurance from employers that are either [1] self-insured, [2] too small to be subject to the mandate (e.g., mandates in Illinois, Maryland, and New Jersey apply only to employers over a certain size), or [3] based outside of the mandated state. Studies have shown that even in states with comprehensive infertility mandates, infertility care is utilized disproportionately by non-Hispanic white women of high socioeconomic and educational status (34, 35). No state mandates include coverage for fertility preservation procedures prior to gonadotoxic therapy or for subsequent storage fees. These limitations will be overcome only when fertility treatment is included in all health insurance coverage, whether private or public (e.g., federal employees, retired and active-duty military benefits, veterans benefits, Medicaid), as are diseases affecting other major bodily systems.

The Affordable Care Act (ACA) of 2010 presented an opportunity to expand coverage for infertility to a much broader swath of the population; unfortunately, there is little indication it will achieve that result. The ACA may improve disparities in infertility prevention, as men and women who previously were uninsured have access to sexually transmitted disease screening, treatment, and counseling. In addition, it should prevent infertility from being treated as a pre-existing condition that disqualifies individuals from obtaining future insurance coverage. On the other hand, the ACA does not expand access to infertility treatment except in the states that had infertility mandates before December 2011. Infertility care is not explicitly included in the list of “Essential Health Benefits” that all individual and small group policies are required to offer. It is unclear how the federal government may modify the benefits permitted under the ACA as the law evolves. As written, the ACA disincentivizes states from adding additional mandates, so expansion is not anticipated in the immediate future. There is also concern that existing mandated infertility benefits may be in jeopardy.

## OTHER DISPARITIES IN ACCESS TO INFERTILITY TREATMENT

Economic barriers are not the only impediments to accessing infertility care. Chief among the noneconomic barriers are cultural and societal factors. Researchers who have studied African American, Hispanic, Muslim, and Asian populations in the United States have noted that communication differences, cultural stigmas (including male and female aversion to being labeled “infertile”), cultural emphasis on privacy, and unfamiliarity or prior bad experiences with the US medical system can dissuade members of certain racial, ethnic, or religious groups from seeking care for infertility (36–41). Language differences may also discourage non-English-speaking patients from seeking care. Physicians may consciously or unconsciously make assumptions or possess biases about who deserves to be a parent and who wants or deserves treatment (41).

Another obstacle is the burden of pursuing infertility treatment, particularly cycle-based treatments like IVF. In addition to being able to afford treatment, the patient must be able to take substantial time off from work for office visits and be able to travel to medical facilities that may be geographically distant (42, 43). Many treatments require repeated visits and the ability to follow complex medical instructions (44).

Geographically, the distribution of obstetrician-gynecologists and IVF centers varies widely among states and locales, and there is growing public health awareness that they are inaccessible to many communities (45–47). As of 2015, 16 US states had five or fewer reproductive endocrinologists in practices accredited by the Society for Assisted Reproductive Technology (SART) (47). The highest concentrations of IVF centers and male reproductive specialists are found in states with mandated IVF insurance and high median income (48, 49). Thus, geographic unavailability may impede many from seeking or obtaining treatment.

Patients may be denied access to effective care if the institution at which they seek treatment does not inform them of treatment options such as IVF that are not offered because they conflict with the religious precepts of the institution. Fair access is also impaired by providers who decline to treat unpartnered individuals and same-sex couples. Survey research indicates that at least some practices refuse to accept single women, single men, and same-sex couples as patients. Although laws in some states do prohibit provider discrimination on the basis of marital status or sexual orientation, such laws do not exist at the federal level or in every state, leaving gaps in protection against discrimination based on patient demographics (50).

## DISPARITIES IN OUTCOMES OF INFERTILITY TREATMENT

As recently summarized, the research on IVF outcomes and race/ethnicity, including three SART database studies, suggests that when African American, Asian, and Hispanic women attain access to ART, they experience lower success

rates compared with non-Hispanic white women (36). The findings include evidence of lower implantation and clinical pregnancy rates, as well as increased miscarriage rates among certain minority women. These differences in treatment success are concerning; they are poorly understood and insufficiently studied, with explanations ranging from biological factors to modifiable behavioral factors. Their rectification is critical to achieving reproductive health equity among women and men of different racial and ethnic backgrounds. More research is urgently needed to identify the causes and the remedies for these disparate outcomes.

## ETHICAL BENEFITS OF IMPROVING ACCESS AND OUTCOMES

Reproduction is a fundamental interest and human right, and the access, treatment, and outcome disparities that are associated with ART are a form of stratified reproduction that warrants correction. Moreover, supporting increased access to ART appropriately recognizes infertility as a disease, in keeping with pronouncements by the WHO and worldwide trends (7). The status of fertility treatment as available mainly to non-Hispanic whites and the “economic elite” perpetuates the dismissal of fertility treatment as a “lifestyle choice” or as a luxury comparable to elective cosmetic surgery.

Improved access to ART also serves social justice ends. An Ontario, Canada, governmental panel on reproductive health has articulated these interests this way:

We believe all Ontarians should have opportunities to build a family free from discrimination based on socio-economic status, geography, reproductive health needs, marital status or sexual orientation....

The way Ontario’s assisted reproduction system is currently operating is not acceptable. The cost of services means that treatments are out of reach for many people. Social and legal barriers limit access and, in some cases, force people to use less than ideal alternatives.... We imagine an Ontario where people are given information on fertility and assisted reproduction, those who need assisted reproduction are not limited by what they can afford to pay, and where the services they receive are safe and effective (51).

These interests apply equally in the United States and argue for universal coverage for infertility on par with coverage for other diseases. In December 2014, the Canadian Fertility and Andrology Society issued a position statement supporting public funding of IVF in Canada (52). The ASRM, in its 2014–2019 Strategic Plan, lists as a priority “assuring that infertility is treated by medical establishments and governmental agencies with the same level of attention and concern as are all other diseases” and calls for “a specific new focus on accessible care for all as a stretch goal” (53).

Legal scholars have argued that the lack of insurance coverage for infertility in the United States operates to

discriminate against significant groups of people and prevents them from obtaining medical assistance to reproduce (54, 55). In contrast, others have argued that expanded insurance coverage is not appropriate. This argument includes several subparts, including a disavowal that infertility is a disease or its treatment a medical necessity; that adoption is a suitable substitute for treatment to have a child (56); that insurance coverage is too expensive or is an unjustified use of limited health-care dollars; or that physicians do not relish the difficulties of dealing with insurance companies.

The ASRM has joined the worldwide trend of recognizing infertility as a disease, and so arguments to the contrary or against the medical necessity of treatment are unpersuasive (57). Infertility represents the dysfunction of a major bodily system and burdens the quality of life in significant ways (58, 59). The continued exclusion of infertility treatment from most private health-care insurance policies and governmental programs of health care in the United States, long after fertility treatment has ceased to be experimental, operates to discriminate against those who need medical help to procreate. As for adoption, it is an excellent family-building choice for many people, but it is paternalistic to mandate that it should be the sole (and again, expensive and self-pay) family-building option for all those who cannot conceive without medical assistance, and that its existence obviates the need for fair access to medical treatment.

Cost should not be a barrier, as the price of insurance coverage for fertility treatment is modest. In a 2006 survey of more than 600 employers that offered an infertility benefit, 91% reported that it did not add significant cost (60). Large employers have reported in other studies that a limited infertility benefit accounted for <0.5%–0.85% of their health-care expenditures (61, 62). Although these low percentages may seem preordained because both of the infertility benefits at issue had lifetime monetary caps, Massachusetts, which has the most comprehensive infertility insurance mandate in the country and no monetary cap, also reports modest costs for coverage. According to a 2013 report submitted to the Commonwealth as part of legislatively required reporting, infertility treatment accounted for somewhere between the outer bounds of 0.23% and 0.95% of premium costs (63). Viewed in a broader context, infertility treatment is significantly less expensive than many insured medical procedures. For example, a cycle of IVF costs one third as much as hip replacement surgery (64).

As for physician concerns, securing fair reimbursement rates from insurers is necessary, to be sure. Although there has been little empirical review of how accepting insurance may alter the practice of ART from the physician’s perspective, one study found the median number of IVF cycles performed annually per physician was significantly higher in states with mandated insurance vs. those without (98.2 vs. 78.2 cycles, respectively) (48). The concentration of physicians offering IVF per 100,000 reproductive-age women was also significantly higher in mandated vs. non-mandated states, which suggests it is economically feasible to practice ART when most patients are covered by insurance (48).

## STRATEGIES FOR INCREASING ACCESS TO ART

There are no easy prescriptions to remove the above-described obstacles; actions by individuals are necessary but not sufficient to address systemic problems in access to reproductive health care. Physicians and other health-care providers are encouraged to be aware of obvious and subtle obstacles to access and to be mindful of measures that can be taken to improve utilization of fertility and fertility-preserving treatment, to reduce the impact of disparities, and to improve pregnancy outcomes for all.

Multilingual staff and physicians as well as interpreters may help overcome some barriers. Cultural competence training has been implemented in most medical schools and residencies with some, albeit limited, benefit (65). Physicians are encouraged to locate practices in underserved geographic locations. Medical practices may also consider adopting policies to guide physicians' efforts to increase access. In a related vein, if physicians avoid certain treatments because of their own or their institutions' religious beliefs, patients nonetheless should be informed of those treatments and where they may be obtained.

Public education about prevention, signs, and treatments of infertility, particularly if aimed at underserved populations and geographic areas, may alert patients to the possibility of treatment. Primary care physicians in all settings should be sensitized to their patients' fertility needs regardless of race, ethnicity, socioeconomic status, marital status, gender identity, or sexual orientation. Providers may assist researchers in monitoring trends in access by more consistently reporting patients' race/ethnicity where requested on the Society for Assisted Reproductive Technology Clinic Outcomes Reporting System (SART-CORS) forms; currently, race and ethnicity are recorded only approximately 65% of the time (66).

Clinicians should engage in efforts to develop simplified and lower-cost methods of treatment so that the cost burdens of infertility care can be reduced. Consonant with ASRM's contribution to the Choosing Wisely® campaign of the ABIM Foundation, physicians should work with patients to minimize or eliminate diagnostic procedures and treatments for which the clinical or cost-effectiveness is uncertain (67). The details of setting up and financing a low-cost IVF program have been discussed in other literature (68–70). Economic analyses indicate that lower prices will increase utilization both of IVF and of single-embryo transfers (71).

Employer and insurer exclusion of coverage for infertility from the majority of private health-care policies and public health-care programs in this country remains a significant barrier to access to ART treatment in the United States. This Committee supports expansion of this coverage as a matter of just access to health-care resources and urges reconsideration of any existing provider policies or practices of not accepting insurance. ART providers are further encouraged to establish or continue programs for lower-resource patients, either offering pro bono, shared-risk, or reduced-price care or contributing to or partnering with nonprofit organizations that help patients afford fertility treatment. Members are encouraged to participate in efforts to preserve existing mandated coverage that may be in jeopardy as the ACA

evolves. The Ethics Committee urges all ART stakeholders to actively support legislation aimed at reducing the economic burden on patients paying for infertility treatment.

## SUMMARY

In the United States and globally, health-care disparities are pervasive; infertility prevention and treatment are not exceptions. The high price of treatment, inaccessibility of medical care, infertility that could have been prevented but was not (e.g., untreated infections leading to tubal damage), and differences in success rates pose immense burdens for infertile individuals. Several international organizations including the WHO and the United Nations have made reproductive well-being a global health-care priority; in the United States, the CDC has issued a National Action Plan on the public health implications of infertility (27). The ASRM Ethics Committee encourages all reproductive medicine stakeholders to pursue opportunities for establishing affordable, safe, effective infertility services and treatments for underserved populations and for those in the United States who lack insurance coverage for needed treatment.

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**1 Disparities in access to effective treatment for infertility in the United States: an Ethics Committee opinion**

Ethics Committee of the American Society  
for Reproductive Medicine  
*Birmingham, Alabama*

This opinion examines the factors that contribute to disparities in access to fertility care in the United States and proposes actions to address them.