

Perspective

Selective justice: state mandates for assisted reproductive technology and reproductive justice

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Received October 9, 2013; Accepted November 10, 2013; Epub December 7, 2013; Published December 15, 2013

Abstract: Fifteen states have adopted legislative mandates with an eye towards covering the costs associated with assisted reproductive technology (ART). This review summarizes the current state of ART coverage in the states in question and explores how the limits of mandated coverage constrain the access of certain infertile subjects to ART. Specifically, note is made of barriers compromising the access of same-sex couples and unmarried women. We propose herein that the theoretical framework of reproductive justice can be used to advocate for more inclusive coverage of ART thereby resulting in better fertility outcomes. It remains to be seen how the implementation of the Affordable Care Act will change the landscape of insurance coverage for ART and the limitations thereof.

Keywords: Infertility, assisted reproductive technology, reproductive justice, mandate, insurance

Introduction

Infertility, defined as the inability to conceive after one year of unprotected sexual intercourse, affects about 7.3 million women and their partners in the United States, or 12% of the reproductive-aged population [1-3]. This number is expected to rise as more women delay childbearing [4]. Those affected may well harbor feelings of anger, powerlessness, and isolation, the impact of which on overall health and wellbeing is frequently underestimated [2]. Causes of infertility are female factors, male factors, a combination of the two, or other unknown factors [5, 6]. Importantly, however, most of the relevant etiologic factors are eminently treatable [4].

Assisted reproductive technology (ART) constitutes a leading form of infertility therapy that involves the transvaginal recovery of oocytes from a woman's ovaries, the *in vitro* fertilization of the same, and the transfer of the resultant embryos to the woman's uterine cavity [5]. ART includes *in vitro* fertilization (comprising 99% of all ART treatments), zygote intrafallopian transfer (ZIFT), and gamete intrafallopian transfer (GIFT). In the United State alone, approximately 1 in every 100 babies born is now conceived

through ART [1, 4]. The above notwithstanding, the costs of infertility treatments can be daunting. It is therefore crucial to understand the factors that limit access to ART and the consequences thereof especially for members of traditionally marginalized groups [7].

The leading factor limiting access to ART is the lack of insurance coverage. Indeed, only fifteen states have adopted legislative mandates that, to varying extents, require resident insurers to cover ART. This paper will discuss how the structure of state mandates and their attendant exclusionary language discourage or outright preclude certain social groups, such as single women and same-sex couples, from pursuing ART by rendering them ineligible for insurance coverage. It follows that these state mandates would have to be modified in the spirit of inclusiveness if they are to support standards of equitable treatment, prevent discriminatory practice, and improve fertility health outcomes.

At some level, the question as to what should be included in a state mandate to cover ART is a question about the philosophy of mandated health insurance: "to whom and what we owe them" [8]. By considering the problem of limited insurance coverage for ART in the framework of

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Table 1. Elements of Insurance Coverage for Infertility/ART by state [6, 7, 9]

	Mandate to cover or offer?	Infertility treatments included in public assistance programs?	Years of sexual relations without contraception (#)	Years of infertility (#)	Must use own gametes	Spousal language	Medical or unexplained cause of infertility**	Medical necessity
Arkansas	cover				x	X		
California	offer		x					
Connecticut	cover			x				x
Hawaii	cover		x		x	X	x	
Illinois	cover							
Louisiana	no*							
Maryland	cover		x		x	X	x	
Massachusetts	cover			x				x
Montana	cover	no						
New Jersey	cover	no						
New York	cover							
Ohio	cover	no						x
Rhode Island	cover	no		x		X		x
Texas	offer				x	X	x	
West Virginia	cover							

*explicitly excludes IVF coverage. **"Medical or unexplained cause of infertility" is the legal language used by a state that requires infertility to be linked to a specific medical condition, or that remains "unexplained" after testing for infertility of biological cause.

reproductive justice, we can consider not only whether an individual has a legal right to reproduce, but also how we as a society should ethically accommodate those reproductive rights.

The statutory patchwork of insurance coverage and regulation of ART

Understanding who qualifies for insurance coverage for ART is a painstaking process. Fifteen states have adopted a legislated mandate to offer coverage or to cover infertility treatments to varying degrees [9]. **Table 1** lists these states and their mandate restrictions on the types of treatments covered and on eligibility. It should also be noted that because of the Employee Retirement Income Security Act, self-insured employer benefit plans are exempt from the mandates in question.

The example of Massachusetts illustrates the complexity of coverage. Massachusetts requires insurers who provide pregnancy-related benefits to also provide infertility benefits to patients considered "infertile" (Massachusetts uses the definition of women who have an inability to conceive after one year of unprotected sexual intercourse if under age 35, and after 6 months if over age 35) [10]. These individuals may reside in, or, have their primary place of work in Massachusetts. ART, including IVF and

ZIFT, is covered under the mandate, and there is a specific clause that insurers cannot impose limitations or restrictions on fertility drugs differently than for other drugs. However, experimental procedures, cryopreservation, or surrogacy are not covered.

In Massachusetts, individuals must prove that infertility treatment is a "medical necessity", which is problematic for individuals who may meet the definition of infertility but are not medically "dysfunctional"—such as unmarried women [11]. Private insurers may deny infertility treatments based on their own social or medical criteria, such as if there is no male partner present or if one or both partners smoke. In the latter case, insurance may require additional tests, such as urine tests to prove nicotine-free status [12].

Furthermore, the Massachusetts mandate exempts dioceses, raising thorny issues of individuals' legal rights when employers have religious objections to certain medical treatments (Seven states permit some kind of exemption for religious institutions and organizations with religious affiliations) [6]. Special medical circumstances of infertility, such as for cancer patients who have undergone life-saving treatment at the expense of their fertility, have already raised ethical and legal questions

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about criteria for infertility coverage. For example, cancer patients who have reproductive organs removed as part of treatment are not fully covered for infertility in Massachusetts, despite not bearing the same “causal responsibility” for their infertility as do women who choose to delay childbearing for any number of reasons [13].

Multiplying the difficulties of understanding mandated coverage for one state by fourteen gives some idea as to the legal acrobatics required to understand ART coverage in the United States. Even the definition of infertility varies by state. New York uses the American Society for Reproductive Medicine definition, Illinois deems patients who have tried to conceive for one year or who cannot sustain a successful pregnancy infertile, and in Rhode Island patients must be married and have tried to conceive for two years. In Montana, “infertility” is not even defined by the law, although all HMOs are required to infertility services as part of basic health services [6].

These differing definitions of infertility reflect the variable extent of coverage that each state provides to patients who meet the criteria of infertility. The New York mandate limits eligibility to women aged 21-44, and requires insurers to cover diagnostic tests and infertility procedures, but not IVF, GIFT, ZIFT, or reversal of voluntary sterilization [4]. The states of New York, California, and Louisiana explicitly do not require coverage of IVF, which is the most-used form of ART. In Connecticut, up to four cycles of ovulation induction will be covered, while in Massachusetts, there is no lifetime cap [7].

The international ART market is beyond the scope of this discussion, but in light of the patchwork of forms of health insurance and benefits in the United States, it is instructive to consider that in other developed nations with comprehensive national health insurance, a greater proportion of infertile women seek ART (67-95%) than women in the US (approximately 50%) [3, 11]. Other nations have developed national or multi-state regulatory bodies for ART (such as Britain’s Human Fertilisation & Embryology Authority or Australia’s Reproductive Technology Accreditation Committee) that may be models for growing interstate cooperation in the United States to determine insurance eligibility and benefits.

However, internationally there are still issues of restrictive or actually discriminatory language, and a question of feasibility of accessing ART at all in countries ranging from Australia and Canada to Denmark and Norway. In other countries, waitlists can be very long, and those who can afford to pay out of pocket can get faster treatment at a private clinic [14]. Examples of restrictions abound: South Australian couples must have no outstanding criminal charges and “no disease or disability” that could interfere with their capacity to parent a child; France prohibits treatment of single or lesbian women; Norway treats only heterosexual couples and prohibits egg donation or surrogacy [3]. There is no international consensus on how to cover ART [3].

In the United States, the lack of a national policy on ART insurance coverage means that individual clinics and providers are responsible for determining who is allowed to receive and pay for ART. It follows that individual clinics may inadvertently become screeners of “parental fitness”. One survey showed that almost 50% of US fertility clinics indeed see themselves as fulfilling that role, which has led to a legacy of suits against clinics for refusing to treat patients based on certain conditions and characteristics, some of which were medical, and some of which were social and not relevant to the patient’s desire for fertility [10]. Although clinics’ selection of ART patients is justified in most cases, like potentially abusive or drug-addicted parents, it is problematic that a surprising number of clinics would reject same-sex couples for no other reason than them being same-sex [14-17]. Given that a considerable number of clinics and providers admit to underlying assumptions about an individual’s ability to parent based on demographic characteristics, it is perhaps unsurprising that public support for inclusivity, as demonstrated through the state mandates, is patchy [18].

How might the new insurance exchanges impact existing eligibility for ART coverage? The answer is unclear, since states have approached the creation of healthcare exchanges and deciding on benchmark plans differently. Because infertility treatment is not considered an essential health benefit under healthcare reform legislation, ART coverage would only increase in states with insurance mandates if infertility services, including ART, became part

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of the state's benchmark plan. In these states, ART could be considered an essential health benefit—with no dollar limit on spending—if the benchmark plan selected would have covered ART as part of the state mandate prior to October 1st, 2013.

So far, it seems that there has been reluctance on the part of insurers and states to include infertility treatment as essential health benefits in benchmark plans. For example, in a 2012 Milliman report on selecting a benchmark plan for New York, it was noted that the state employee Empire Plan had the most generous coverage for infertility services. If this plan were chosen as a benchmark, there would be no dollar limit on infertility services, which could force commercial plans to also expand their coverage of infertility services [19]. The benchmark plan chosen in the end was the Oxford EPO, the state's largest small group plan—a plan that covers ART to varying extents based on individual members' benefits and eligibility criteria [20]. Cost of infertility services was certainly not the sole factor at play in this decision, but it appears that the fear of incurring substantial cost related to ART may mean that while health insurance options for consumers expand, actual coverage for ART may not change very much at all.

The system of individual state mandates, especially in light of the new healthcare exchanges, is complex and in its current state, must be applied to individuals on a case-by-case basis because of a lack of oversight. National organizations such as the Centers for Disease Control and the American Society for Reproductive Medicine collect data on ART utilization and outcomes, but do not enforce guidelines of practice. Because of the patchwork of state mandates, individuals may be subject to clinic-specific or state-specific discriminatory practices that exclude them from ART coverage [18]. The peculiarities of state mandates have created legal holes that individuals seeking fertility treatments may fall into.

Specific social exclusions in state mandates

State mandates for ART insurance coverage include or exclude certain patients based on either “external” or “internal” factors. External factors are those that apply to every patient, and include the type of procedure, structural

abnormalities that prohibit carrying a pregnancy, or lifetime spending cap. For example, Arkansas has an individual lifetime maximum cap of \$15,000, regardless of who is seeking treatment, and Rhode Island has a lifetime cap of \$100,000 [9]. However, most state mandates also judge individual characteristics, or “internal factors”—marriage status, sexual orientation, or medical disability—that may prevent the patient from qualifying for insurance coverage [7].

Just as public insurance cannot deny coverage to individuals based on non-medical factors such as race, age, or occupation, eligibility for ART coverage should not be based on non-medical factors. State mandates that use internal factors such as marriage status and sexual orientation as criteria for insurance coverage exclude whole social groups. This has led some scholars to argue that all state legislation on ART suffers from implicit or explicit bias against certain social groups, namely, unmarried women and same-sex or transgender couples [6].

For example, five states have mandates that only cover married couples: Arkansas, Hawaii, Maryland, Rhode Island, and Texas. Of the five states that require a married couple, only Maryland, and more recently, Rhode Island and Hawaii, legally recognize same-sex marriage. Therefore, unmarried individuals, and same-sex couples in states that do not legally permit same-sex marriage, are categorically prevented from having coverage for ART in these states. Of note, in four of those states, the “wife's” eggs must be fertilized with the “husband's” sperm, which also rules out the use of donated eggs or sperm [6].

The particular case of requiring marriage—a status that depends on uncontrollable factors such as finances, family, and personal preference—does not acknowledge the current reality of demographic shifts in childbearing or the desire for ART. The 2010 US Census shows that 51.5% of American women have never married by the ages of 40-44, and that 23.2% of unmarried women have at least one child [21]. Over one-third of all IUI consumers in the US are unmarried women [7]. Given the upward trend in maternal age, it is reasonable to assume that more women, with or without partners, will be interested in ART.

Four states require it to be shown that ART is a “medical necessity”. But for those who are situationally infertile—such as unmarried individuals—or who have an “unknown” combination of factors leading to infertility diagnosis, medical treatment of infertility with ART would be difficult. For example, New Jersey requires that infertility be caused by a disease or condition that results in “abnormal” function of the reproductive system [22]. This would not include gays, lesbians, and unmarried heterosexual women with “normal” reproductive structures. Using “normal” as a standard for coverage opens up patients to discriminatory practices. Thus, although wording in these mandates may appear medically appropriate, it has consequences that disproportionately affect traditionally marginalized social groups.

State mandates must accommodate changing social and legal trends, such as recent court rulings that have opened the path for same-sex marriage. There are about 650,000 same-sex couples in the US, and as of 2000, it was estimated that 33% of lesbian and 22% of gay male couples were raising children [23]. Same-sex couples could benefit greatly from having ART as a reproductive option. However, in states where mandates explicitly cover only heterosexual marriages, those in same-sex relationships are excluded from coverage. Laws that intentionally or unintentionally exclude same-sex couples from pursuing ART imply that these individuals are not equals with heterosexual couples. Public support for marriage equality, as well as government requirements for equal treatment, may put pressure on states to include traditionally socially marginalized groups. Maurice Rickard also makes a convincing argument that infertility is a legitimate medical problem even for “socially infertile” couples [24].

Individual legal cases have created a framework that has broadened the legal rights of infertile individuals. *Griswold v. Connecticut* ruled that “procreative rights are grounded in the individual, not the married couple” (The Uniform Parentage Act has now updated as of 2002 to include unmarried and married parents equally) [7]. *Eisenstadt v. Baird* also supported the reproductive rights of unmarried individuals by acknowledging that certain medical conditions, such as HIV-positive status, could indirectly cause situational infertility [25].

In *Bragdon v. Abbott*, the Supreme Court ruled that under the American Disability Act, reproduction was a major life activity and infertility was a disability to be protected under federal law. However, while this would support insurance coverage for those with unknown medical causes of infertility, it would not apply to gay or unmarried persons with healthy reproductive function [26].

But as *Saks v. Franklin Covey Co.* shows, defining infertility as a condition to be covered doesn’t obligate private insurers to offer coverage as long as the same benefits are offered to all policyholders [27]. Along this line, in *Krauel v. IMMC*, the Court found that the Pregnancy Discrimination Act doesn’t apply to infertility because pregnancy and childbirth “occur after conception [and] are strikingly different from infertility, which prevents conception” [6]. Using this argument, infertility must be due to a condition unique to women in order to qualify under the Pregnancy Discrimination Act [4]. This kind of reasoning could lead to individuals seeking treatment for infertility being denied coverage under the pretense of equal treatment of policyholders.

Because insurance coverage is one of the limiting factors for patients seeking ART, state-by-state exclusions of whole groups of people are, in the words of Sandra Dill, “arguably immoral and...contrary to the principle of individual autonomy”, as well as reproductive justice [3]. Radhika Rao goes one step further and says laws limiting ART coverage to married and/or heterosexual couples have “no real basis for the distinction other than societal disapproval or prejudice” [28]. Despite social and legal strides for fertility equality, state mandates for ART coverage continue to discourage some patients from seeking ART because of socially significant factors.

Reproductive justice as a framework for ART coverage

The current system of state-by-state mandated insurance coverage for ART is complicated and excludes certain groups based on social characteristics. The Ethics Committee of the American Society for Reproductive Medicine has taken the stance that “there is an ethical obligation, and in some states a legal duty, to treat all persons equally, regardless of their

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marital status or sexual orientation” [29]. The committee acknowledges changes in family structures, increased births to unmarried women, and social and political shifts in attitudes towards gays and lesbians and argues that there is no sound medical or ethical justification for denying certain social groups access to fertility treatment. Denying access to infertility treatment becomes a form of legitimizing oppression of these social groups through medical means [18].

In order to remedy the situation, there must be a national policy on ART eligibility that protects individuals from being excluded based on social characteristics. What are steps then that we can reasonably take towards equitable treatment, to start building a consensus on what, and who, should be included in fairer ART coverage? Fairness can be equated with the ethical principle of “justice”, or distribution of goods based on what one is entitled to. We must consider justice in a sense beyond individual benefits—as societal efforts that promote fair opportunity. If people are equals, then they should qualify for equal treatment. A person cannot be expected to “pay their fair share” to receive benefits if they have not been given a share to begin with.

Reproductive justice theory provides a guide as to how we should conduct a discussion about broadening ART coverage. Reproductive justice seeks to support equal access to ART for all individuals and couples, advocate for policies that affirm family formation for people with disabilities and LGBTQI individuals, prevent eugenic outcomes, and require high industry standards for health and safety of ART [15, 30, 31]. Reproductive justice promotes reproductive rights—the ability to become a parent, parent with dignity, determine whether or when to have children, to have healthy pregnancy, to have healthy and safe families and relationships—within the overall mission of improving legal equality, identifying environmental causes of reproductive dysfunction, and requiring high standards of reproductive care [32]. According to SisterSong, one of the founding organizations of reproductive justice, “It represents a shift for women advocating for control of their bodies, from a narrower focus on legal access and individual choice (the focus of mainstream organizations) to a broader analysis of racial, economic, cultural, and structural constraints on our power” [33].

Reproductive justice suggests that we can improve the medical legitimacy and social productivity of state mandates for ART coverage by using more inclusive language. Infertility, regardless of the cause, has the same end result. ART can certainly treat infertility of both biological and situational causes, so “the focus should be on the inability to reproduce, regardless of whether it is caused by a medical disease or otherwise” [7, 29]. Instead of socially exclusionary language, eligibility for insurance coverage could be based on more quantitative limits based on external factors like lifetime spending. Attempts such as the Family Building Act would have accomplished this by placing lifetime caps and only covering certain procedures after less-expensive options had been explored [7].

Furthermore, socially inclusive ART coverage could lead to more standardized practices adhering to professional guidelines or federal law. In providing greater coverage, states could also disincentivize risky procedures like multiple embryo transfer that might lead to poorer health outcomes and more costly care [11]. Increasing coverage might give more momentum to research on ways to address environmental and social causes of fertility, such as pelvic inflammatory disease, which is caused by *Chlamydia*. ART is underutilized among racial minorities, a disparity that persists after adjusting for socioeconomic status [34, 35]. In addition, greater insurance coverage might renew the focus on looking at factors in utilization patterns [36, 37].

However, insurance expansion for ART has its critics. Some cite adverse health outcomes for mother and child as a reason for limiting ART coverage. This is understandable, given the high rate of multiple births and complications from ART births. In 2003, multiple births accounted for 34% of all live births conceived through the use of ARTs, but only 3% of the general population [4]. However, this is not a reason to restrict ART coverage to heterosexual married couples. In fact, Jain et al found that the number of embryos transferred per IVF cycle was lower in states with complete coverage of IVF than in states with partial or no coverage, and that states with mandated coverage had lower rates of multiple births [38]. More generous insurance coverage actually lowers adverse risks for mother and children.

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Some have argued that expanding ART coverage would raise premiums and put undue financial burden on the average policyholder. Studies have shown that ART would add anywhere from \$0.26 to older estimates of \$175 per year [4, 7]. While the cost may not be insignificant, as technology improves and industry regulation increases, costs will likely run towards the lower estimates. In addition, expanding coverage would actually increase the number of low-cost procedures, lowering costs overall, because patients and physicians would not feel pressured to choose high-risk multi-transfer procedures in the hopes of succeeding in as few tries as possible.

Exploring ways to improve state mandates by seeing infertility as a medical condition that affects people of all groups has positive long-term effects. By expanding ART coverage, the reproductive medicine community, patients, and lawmakers would be given an opportunity to define what kinds of fertility treatments deserve to be paid for, and what kinds do not [11]. Debating under what circumstances our society would want to subsidize an individual's ability to procreate would lend the same rigor by which treatments such as types of hip replacement devices or vascular interventions are judged. Public conversations about defining qualities that may legitimately affect "parental fitness"—such as substance abuse or a history of violent behavior—may improve understanding not only for patients seeking fertility treatment, but also fertile individuals and their families. All this would ultimately strengthen the legitimacy of a patient's ability to seek fertility treatment and the ethical principles upon which the practice of reproductive medicine is founded.

Conclusions

By asking questions about ART coverage, we are really examining how philosophy and ethics intersect with infertility medicine: What are legitimate limits on the right to be a parent? How far can the state intervene in regulating the family? How can we achieve recognition and protection for new and evolving family structures [6]? There are no easy, universal answers, but reproductive justice outlines important issues that we should consider when making public policy. Justice in the healthcare system and vigorous study of broader medical

and social issues that contribute to infertility are imperative. By being sensitive to socially exclusionary language, and striving to create a rational, organized healthcare system, we can address grievances and inefficiencies encountered in treating individuals with ART.

This paper has shown that state-by-state coverage results in a patchwork of coverage that leaves out certain eligible individuals, and would benefit from national guidelines. The Family Building Act of 2009, an attempt to require insurance coverage of infertility on a national level, may have failed, but perhaps there will be a reincarnation in the future. Given that the Affordable Care Act—which as of now does not cover infertility treatment—will begin to take full effect in 2014, it is worth considering how to regulate insurance coverage of ART on a federal level. Infertility treatment is not currently listed as an "essential health benefit"; physicians and patient advocates should see this as a golden opportunity to insist on more inclusive, standardized ART coverage [35]. Furthermore, advocates should focus on persuading private insurers to follow suit, since private insurers are not always subject to the state mandates. It remains to be seen how the new insurance exchanges will affect this process.

Reproductive justice is also predicated on education about the issues. If the public is to be convinced that ART coverage needs to be more socially inclusive, there need to be reliable sources of information and accurate representation of ART in popular media [3, 39]. Lawmakers should be made aware of the need for counseling and other supportive services during cycle treatments, since ART can be a life-changing "emotional rollercoaster" for patients [40, 41].

Medical guidelines that specify age range and medical conditions invariably exclude some from ART coverage. But in order to be just, we must seek a coverage system that is socially inclusive by changing the language of individual state mandates to accommodate people of all social backgrounds. Until we have serious, coordinated national discourse on who should be allowed to reproduce and in what forms—a discourse that involves laypeople, medical professionals, and community/religious leaders—ART coverage will remain a problematic recapitulation of existing social biases.

Disclosure of conflict of interest

None.

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