In vitro fertilisation with preimplantation genetic testing: the need for expanded insurance coverage

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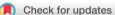
ABSTRACT

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To cite: Kilbride MK. J Med Ethics Epub ahead of print: [please include Day Month Year]. doi:10.1136/ medethics-2019-105879 Technological advances in genetic testing have enabled prospective parents to learn about their risk of passing a genetic condition to their future children. One option for those who want to ensure that their biological children do not inherit a genetic condition is to create embryos through in vitro fertilisation (IVF) and use a technique called preimplantation genetic testing (PGT) to screen embryos for genetic abnormalities before implantation. Unfortunately, due to its high cost, IVF-with-PGT is out of reach for the vast majority of Americans. This article addresses an issue that has been underexplored in the medical ethics literature: the lack of insurance coverage for IVF-with-PGT.Within the US system, a key concept in insurance is that of medically necessary care, which broadly consists of diagnostic services and treatment services. In this article, I argue that IVF-with-PGT could be classified as either a diagnostic service or as a treatment service. To make this case, I show that IVFwith-PGT is similar to other types of services that are often covered by US insurance providers. In light of these similarities, I argue that the current system is inconsistent with respect to what is—and is not—covered by insurance. To promote consistency and fairness in coverage, like cases should be treated alike—starting with greater coverage for IVF-with-PGT.

INTRODUCTION

Technological advances in genetic testing have enabled prospective parents to learn about their risk of passing a genetic condition to their future children. Those who want to ensure that their biological children do not inherit a genetic condition currently have two options. The first is to conceive naturally, undergo prenatal diagnosis (PND) to test for genetic abnormalities and, if the fetus is found to have a genetic issue, terminate the pregnancy. Unfortunately, this forces the mother to choose between ending a wanted pregnancy and having a child with a genetic condition. The other option is to create embryos through in vitro fertilisation (IVF) and use a technique called preimplantation genetic testing (PGT) to identify genetic conditions in embryos before implantation.¹

Many prospective parents with a known genetic risk find IVF-with-PGT to be more acceptable than PND with pregnancy termination. Unfortunately, IVF-with-PGT is often cost prohibitive. In the United States (US), for example, a standard IVF cycle costs about \$12000. This price does not include fertility medications or PGT, which typically add another \$3000-\$5000 and \$3000-\$6000, respectively, to the overall cost of the procedure. Moreover, multiple IVF cycles are often needed to achieve a successful pregnancy.² Despite these high out-of-pocket costs, insurance coverage for IVFwith-PGT is very limited in the US.^{3 4}

Inadequate insurance coverage for IVF-with-PGT in the US stands in sharp contrast to the increasing availability and affordability of genetic testing. Today, almost every major US insurer covers genetic counselling and testing.⁵ The rise of direct-toconsumer genetic testing has also increased accessibility—even if one lacks adequate insurance coverage, many genetic tests can now be purchased online, typically for a few hundred dollars.⁶

Genetic information can help people make informed decisions about their healthcare and reproductive plans. But to realise these benefits, individuals need access to follow-up care. Scholars have, so far, addressed the state of insurance coverage for individuals who are themselves diagnosed with a genetic condition.^{7 8} This article addresses an issue that has been underexplored in the medical ethics literature: inadequate insurance coverage for IVF-with-PGT.

In arguing for expanded coverage for IVFwith-PGT, I situate my discussion within the existing US insurance framework. Under the US Centers for Medicare & Medicaid Services (CMS) guidelines, a key concept in insurance is that of medically necessary care-that is, the set of '[h]ealth care services or supplies needed to diagnose or treat an illness, injury, condition, disease or its symptoms and that meet accepted standards of medicine'.⁹ Medically necessary care is therefore comprised of two broad categories: (1) those supplies and services that are needed to make a diagnosis and (2) those supplies and services that are needed to treat an illness, injury, disease, or other condition or its symptoms. While terms like 'illness' and 'disease' are used in everyday parlance, there is an ongoing debate among bioethicists and other scholars about their meaning and significance. I do not take up this discussion in the current article. Rather, in arguing for expanded coverage for IVF-with-PGT, I assume a broadly naturalistic account, according to which a health condition, be it an illness, injury, disease or genetic risk, is a state of an organism that 'interferes with the performance of some natural functionie, some species-typical contribution to survival and reproduction characteristic of the organism's age...^{10 11}

Given CMS's understanding of 'medically necessary' care, I argue that IVF-with-PGT should count as such. Specifically, I maintain that IVF-with-PGT could be classified under either of the two broad categories—diagnostic services or treatment services that together comprise medically necessary care. To make this case, I show that IVF-with-PGT is similar to other types of services that are often covered by



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US insurance providers. In light of these similarities, I argue that the current system is inconsistent with respect to what is—and is not—covered by insurance. To promote consistency and fairness in coverage, like cases should be treated alike—starting with greater coverage for IVF-with-PGT.

This article proceeds as follows. Part I defines the scope of my discussion. Part II then argues that IVF-with-PGT should qualify as medically necessary care and that the lack of insurance coverage isinconsistent with prevailing norms. In the first section of Part II, I argue that IVF-with-PGT can be categorised as a diagnostic service because IVF-with-PGT serves the same diagnostic purpose as PND, a service that is routinely covered by insurance. Although IVF-with-PGT is costlier than PND with pregnancy termination, I show that, when certain conditions are met, there is precedent for covering a more expensive intervention even when a less expensive option is available. IVF-with-PGT, I maintain, meets these conditions. In the second section of Part II, I argue that IVF-with-PGT can also be categorised as a treatment service. Typically, medical treatment involves the care and management of a health condition or its associated symptoms, which may include restoring or compensating for a lost or impaired function. I contend that, like other treatment services that are often covered, IVF-with-PGT also compensates for the loss of an important function-namely the ability to have children who do not inherit a genetic condition. As such, consistency in coverage determinations calls for expanded coverage of IVF-with-PGT.

SCOPE

As Linda Bergthold writes, the term 'medically necessary' has been 'rarely defined, largely unexamined, generally misunderstood, and idiosyncratically applied in medical insurance practice'.¹² Although it would be a worthwhile endeavour to explore the philosophical and ethical dimensions of this term, that is not my objective here. Instead, my argument concerns how the US CMS have defined 'medically necessary'. To than end, my primary goal in this article is to identify inconsistencies in insurance coverage by showing that IVF-with-PGT is similar in important respects to other services that are considered medically necessary and, as such, are often covered by insurance.

Before proceeding, I want to address another concept that was mentioned in the Introduction— the idea of a 'serious genetic condition'. Among both professional organisations and scholars, there is a trend towards embracing ambiguity about what constitutes a serious genetic condition. While certain considerations may be relevant to coverage determinations—a condition's age of onset, its degree of penetrance, and its impact on quality of life and life expectancy, as well as the availability, effectiveness and invasiveness of risk management options—I neverthelessagree withTimothy Krahn's general conclusion that 'the whole enterprise of trying to draw lines of what is to count as a "serious" condition is itself problematic and in certain ways morally misleading'.¹³

Krahn's philosophical view is supported by empirical work; according to an international survey, genetics professionals do not want professional organisations, laws or ethics committees to define 'serious' in order to classify genetic conditions. Most importantly, the study found that 'there is not sufficient consensus among experienced genetics professionals to define serious genetic conditions for purposes of law or policy'.¹⁴ Recognising the concerns raised by drawing boundaries, I will endorse the open-ended view, advanced by the Society for Assisted Reproductive Technology and the American Society for Reproductive Medicine, that PGT 'is indicated for couples at risk of transmitting a specific genetic disease or abnormality to their offspring'.¹⁵

Finally, it is also worth addressing one potential criticism of expanded coverage for IVF-with-PGT. The criticism is that focusing on improving access to services that enable prospective parents to have genetic children overlooks and undervalues non-biological approaches to building a family, particularly adoption.¹⁶⁻¹⁸ Along these lines, Francoise Baylis argues that having genetically related children is not a need, but rather a want.¹⁹

If we accept the colloquial understanding of wants versus needs and consider it in the context of healthcare and insurance, then the category of wants includes the majority of medical services that are not necessary to sustain life, from orthopaedic procedures to improve joint function to breast reconstruction after mastectomy to create a more natural appearance. When it comes to insurance coverage, medically necessary care includes a range of wants in addition to strict needs. Attempting to develop a set of necessary and sufficient conditions for determining which wants should be covered is beyond the scope of this paper. Instead, I aim to show that, even if one considers IVF-with-PGT to be want, it is a want that is similar to other wants that are often covered by insurance.

IVF-WITH-PGT AS NECESSARY MEDICAL CARE

According to the US CMS, medically necessary care consists of those '[h]ealth care services or supplies needed to diagnose or treat an illness, injury, condition, disease or its symptoms and that meet accepted standards of medicine'.⁹ Against this backdrop, I argue that IVF-with-PGT for serious genetic conditions could be classified as either a diagnostic service or as a treatment service. Throughout this section, I show that IVF-with-PGT is similar in kind to other services—diagnostic and treatment—that are routinely covered by US insurance providers. As such, considerations of fairness and consistency call for greater coverage for IVF-with-PGT.

IVF-with-PGT as a diagnostic service

Almost every public and private insurer in the US covers PND through either amniocentesis or chorionic villus sampling,though some plans may limit these services to women who meet certain criteria.^{20 21} The primary purpose of PND is to detect genetic abnormalities in the developing fetus. To the extent that PGT is also used to detect chromosomal abnormalities and genetic conditions, it functions in the same diagnostic capacity as PND, just at the earliest stage of embryonic development. Why, then, are insurers typically unwilling to cover PGT, and the IVF process that is necessary to perform it? Cost is likely a determinative factor. Since PND can detect the same genetic disorders as PGT, and PND with pregnancy termination is far cheaper than IVF-with-PGT, insurers have little financial incentive to cover the latter.

The higher cost of IVF-with-PGT does not, however, justify denying coverage for it. Although both PND and PGT can detect the same genetic conditions, it is important to recognise that PND is not intended for prospective parents who already know about their genetic risks before conceiving. Instead, its purpose is to diagnose unanticipated, relatively rare abnormalities in a pregnancy. Specifically, one of the main uses of PND is to diagnose aneuploidy, a category of chromosome mutations that includes Down syndrome. Despite being among the most common fetal abnormalities, a Down syndrome diagnosis is still a low-probability event for any particular pregnancy, including women with known risk factors. Consider, for instance, that a 40-year-old woman—who is at higher risk because of her age—only has about a 1% chance of having a child with Down syndrome.²²

By comparison, if both a woman and her reproductive partner are carriers for the same recessive condition, any child they conceive together will have a 25% chance of inheriting the condition for which the parents are carriers. The risk is even higher for dominant conditions-if either member of a reproductive couple has a dominant condition, any child conceived by the parent with the dominant condition will have a 50% chance of inheriting its parent's condition. For many women, the prospect of getting pregnant, undergoing PND several months into the pregnancy, waiting for the test results, learning that the fetus has inherited a genetic condition, and then having to decide whether to terminate a wanted pregnancy is physically burdensome, and emotionally and psychologically agonising.^{23 24} Moreover, some prospective parents may have to repeat this process several times and, even with multiple attempts, may not ultimately succeed in having a child without a genetic condition.²⁵

A number of studies that have explored attitudes towards IVFwith-PGT report that most patients prefer PGT to PND.²⁴ ^{26–29} Notably, one study found that, among 210 genetically at-risk couples who were of reproductive age and wanted to conceive, 74% preferred testing with PGT to testing with PND.²⁴ Overall, the evidence suggests that patients' preference for PGT is largely driven by the desire to avoid the possibility of pregnancy termination.²³ ²⁶ ^{28–30}

Although IVF-with-PGT is far costlier than PND with pregnancy termination, insurers will sometimes cover a more expensive procedure even when a less expensive option is available. Consider surgical breast reconstruction after mastectomy to treat breast cancer. According to a 2018 study of North American women who underwent mastectomy, 60% opted to pursue breast reconstruction. ³¹ For women who choose this route, reconstruction typically has a significant positive impact on their lives, with improvements in body image, sexuality, quality of life and satisfaction with their appearance.^{31 32} Recognising the potential benefits of reconstruction, US federal law mandates that group and individual health plans that cover mastectomies also cover reconstruction.³³

The case of breast reconstruction represents an instance where insurers are required to cover a more expensive procedure when a far less expensive option—custom-made breast prosthetics is available. Moreover, insurance providers are being required to cover a procedure that, from the standpoint of improving long-term survival, does not affect a woman's prognosis after cancer treatment. This suggests that there are other compelling reasons for covering certain procedures besides cost reductions or improved patient survival, including considerations related to promoting patient well-being, along multiple dimensions, and respecting patient preferences for different treatments.

Similar reasons would also justify covering IVF-with-PGT. As is true for breast construction, IVF-with-PGT does not improve patient survival. But, much like breast reconstruction can improve the well-being of patients who have had a mastectomy, IVF-with-PGT can improve the well-being of patients with known genetic risks. While patient-reported benefits of IVF-with-PGT have been studied far less than those associated with breast reconstruction, multiple studies affirm that patients perceive an important benefit of IVF-with-PGT that bears on their well-being—the opportunity to avoid the burdens of terminating a desired pregnancy.^{23 26 28-30}

When it comes to healthcare choices, patients often have different preferences that are based on their own values and desires. Inasmuch as insurance plans are designed for groups and must control costs, they cannot reasonably be expected to accommodate the full set of preferences that individuals may have. They can, however, be expected to accommodate some range of preferences. This is particularly true when a significant proportion of individuals facing a healthcare decision express a preference for an option. In the case of postmastectomy decisions about breast reconstruction, the majority of women choose breast reconstruction over other options, including remaining breastless or wearing a prosthetic.³¹ Their reasons for pursuing reconstruction are also largely similar, centering on a desire to avoid wearing a prosthetic, regain femininity, achieve a natural appearance and feel whole again.³² Likewise, among reproductive couples who are at risk of passing a genetic condition to their children, the vast majority prefer IVF-with-PGT to PND with pregnancy termination. And they largely prefer it for the same reason-to avoid pregnancy termination.²³ ²⁶ ²⁸⁻³⁰ Yet, despite the similarities between IVF-with-PGT and breast reconstruction, the latter is almost always covered by insurance while the former rarely is. Expanding coverage for IVF-with-PGT would be a step towards remedying this inconsistency.

IVF-with-PGT as a treatment service

As discussed at the beginning of Part II, the umbrella of medically necessary care encompasses two broad categories—diagnostic services and treatment services. Considered as a treatment service, IVF-with-PGT is similar in kind to other treatment services that are typically covered by insurance. Consistency in coverage determinations therefore calls for expanded coverage for IVF-with-PGT.

The array of healthcare services or supplies that are used to 'treat an illness, injury, condition, disease or its symptoms' serves a range of health-related goals, from curing an underlying health issue (eg, antibiotics for a bacterial infection) to relieving pain or discomfort (eg, anti-nausea medications during chemotherapy) to compensating for a lost or impaired biological function (eg, insulin for type 1 diabetes).⁹ Despite these different aims, most treatment services are, broadly speaking, directed at the same goal—managing, in one way or another, a biological dysfunction or disorder.

In discussing notions of function and dysfunction, it is important to distinguish between descriptive claims and normative claims about the moral valence (positive, negative, neutral) of a particular state of an organism. Naturalistic theories of function and dysfunction, such as the one advanced by Christopher Boorse, offer a way to define 'dysfunction' without attaching moral significance to an organism's state.¹⁰ Specifically, Boorse appeals to notions of 'species-typical functioning' to characterise disease. Under his conception, disease is a state of an organism that 'interferes with the performance of some natural function-ie, some species-typical contribution to survival and reproduction'.¹⁰ Thus, whether an organism has a disease is a value-neutral, biological matter; if an organism's current state is interfering with, which is to say that it is preventing or limiting, the organism's ability to perform an important natural function, then the organism has a disease. Although Boorse focuses on disease, his theory has also been explored in other contexts, including that of disability.³⁴

Many genetic risks interfere with survival to the extent that they cause life-threatening diseases at younger ages. Take Lynch syndrome (also known as hereditary non-polyposis colorectal cancer), an autosomal dominant genetic condition that significantly increases an individual's lifetime risk of developing colorectal and other cancers, with disease often manifesting in the 40s and 50s.³⁵ Besides interfering with survival, genetic risks can also interfere with species-typical reproduction, which, for adults of reproductive age, involves the ability to have children who do not have a genetic condition that puts them at a dramatically increased risk of developing a potentially life-threatening health condition (eg, cancer) relative to the general population.

IVF-with-PGT functions as a treatment by virtue of compensating for a lost or impaired biological function-the ability of prospective parents with a known genetic risk to have children who do not have a genetic condition. In many respects, IVFwith-PGT is similar to other treatment services that are often covered by insurance. Consider infertility treatment, a service that is adjacent to IVF-with-PGT. As Josephine Johnston and Michael Gusmano point out in their paper arguing for greater coverage for infertility treatment, particularly IVF, 'most infertility patients are unable to reproduce without medical assistance due to disease or deformity.¹⁷ By circumventing the underlying cause of a couple's infertility, which, among other things, could be caused by Fallopian tube damage or blockage or poor sperm delivery, infertility treatment compensates for a lost or impaired biological function in the prospective parents-the ability to successfully reproduce by normal sexual means. In the same vein, IVF-with-PGT is a treatment that compensates for an impaired ability to have children who are free of a genetic condition; by selecting and implanting genetically normal embryos, IVF-with-PGT circumvents an individual or couple's risk of passing on a genetic condition to their future children. In the case of a recessive risk, although the members of a reproductive couple are unlikely to be affected by the condition themselves, they have a latent genetic risk that could be triggered by having a child together.

While significant gaps in coverage for infertility treatment remain, patients have benefited from a movement towards greater coverage; currently, 17 US states have laws requiring insurance coverage for infertility treatment, though the extent of coverage varies considerably by state.³⁶ IVF-with-PGT has not seen the same growth in coverage. Increasing coverage for IVFwith-PGT would be an important step towards bringing coverage for IVF-with-PGT in line with coverage for similar services.

CONCLUSION

In this article, I have argued that considerations of fairness and consistency call for greater insurance coverage for IVF-with-PGT. Specifically, because IVF-with-PGT is similar in kind to other services—diagnostic as well as treatment—that are routinely covered by US insurance providers, there is a powerful argument for expanding insurance coverage to include IVF-with-PGT.

Bringing IVF-with-PGT within reach of more people would undoubtedly benefit those patients who are at risk of passing a genetic condition to their future children, but who do not want to pursue PND with the possibility of pregnancy termination. Although increased access is called for, its possibility raises a number of questions for future exploration. How, for example, should expanded coverage for IVF-with-PGT be implemented? Should there be a federal mandate like the one for breast reconstruction? Or should we follow the approach taken for infertility treatment, which is to allow state governments to decide whether to pass laws requiring coverage for IVF-with-PGT?

Another key issue concerns the potential impact of expanded coverage for IVF-with-PGT on insurance costs, including premiums. There are competing considerations. On the one hand, including IVF-with-PGT could, in the short term, increase costs for insurers that cover this service. But on the other hand, including IVF-with-PGT icould, over the long term, rdecrease costs for the healthcare system as a whole by reducing the number of children who are born with genetic conditions that require expensive medical care. Ultimately, though, these are empirical questions for future research. In this article, my goal has been more foundational—namely to show that expanded coverage for IVF-with-PGT is consistent with existing coverage decisions.

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Original research