

ESHRE Task Force on Ethics and Law 14: Equity of access to assisted reproductive technology

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Justice and access are among the most urgent questions for medically assisted reproduction. This paper analyses this question not only for people suffering from infertility, but also for people who need assistance to prevent the birth of a child with a specific genetic disorder. Based on the impact of not being able to have a child on the quality of life of a person, the position is defended that infertility treatment should be at least partially reimbursed. Simultaneously, the medical professionals have an obligation towards their patients and the health care system to bring down the costs as far as reasonably possible.

Keywords: access; cost reduction; equity; infertility; justice

Equity in health care means equal access to basic health care without excessive burdens. Health care in general is important because it secures and protects access of people to the normal range of opportunities and because it allows people to flourish. Given the importance of health for the general well-being of a person, every person, regardless of his or her income or financial means, should have access to a decent minimum of health care.

Part I. Determination of decent health care and the place of reproductive needs

The first question is whether assistance to reproduction should be included in basic health care and thus can be eligible for reimbursement. In analysing this question, the wish to reproduce is seen as encompassing not only people suffering from infertility, but also people needing infertility techniques in order to prevent the birth of a child with a specific genetic disorder. People with a high risk of having an affected child may need IVF combined with preimplantation genetic diagnosis (PGD) to realize their wish for a child. In the present paper, we consider assisted reproductive technology (ART) in a broad sense, including ovulation induction, insemination etc.

Infertility

In most developed countries, the status of infertility has been discussed since the very start of infertility treatment. It may be considered as a disease, a handicap or as a purely subjective personal wish. The more the desire for a child is considered as a personal choice, the lower it is placed on the priority list for

funding. The differences in position seem to revolve around the question whether infertility treatment is ‘medically necessary’ or not. However, this approach of the problem is not very fruitful because there is considerable confusion about the meaning of the label ‘medical’ and because infertility treatment includes a broad range of ‘causes’ (age related fertility decline, lack of male partner, blocked Fallopian tubes etc.) and applications that cannot all be covered by the same framework. The pivotal point in the discussion rather seems to be whether the desire for a child should be considered as a fundamental need or as a personal wish. People who want to restrict medical treatment to purely medically caused dysfunction (presupposing they are able to define these) would not support the provision of treatment outside this definition. Those who consider the desire to procreate as a wish will evaluate infertility treatment as elective treatment that should be left to the private sector. The opposite view, adopted by ESHRE, argues that infertility may be a serious handicap that prevents people from realizing an important life goal. This life goal is the possibility to parent a genetically related child or a child created within the current relationship. Procreation is of paramount importance for a large number of people because infertility or subfertility blocks the realization of this part of a person’s or couple’s life plan. Infertility treatment allows people to express their autonomy by realizing their reproductive choices and substantially increases their well-being.

A high risk of a genetically affected child

For people with a high risk of having a child with a disability, and not willing to consider pregnancy termination following a

prenatal diagnosis (PND), it may be difficult to justify procreation unless they are able to decrease the risk. Their appeal to ART is primarily based on the wish to have a child unaffected by a particular disease. They thus prevent harm both to themselves and to their offspring. Moreover, IVF combined with PGD also respects the principle of justice as it gives people at high risk for an affected child an equal opportunity to have an unaffected (genetically related) child. The arguments in favour of funding PGD equally apply to infertile and fertile couples at high genetic risk, as members of both groups may feel that they have no real reproductive alternative.

Part II. Equity of access

General remarks

In most countries, there exist disparities in the use of ART. However, these disparities do not necessarily demonstrate inequity. If, for instance, a particular group does not want to use ART for cultural or religious reasons, this inequality does not show inequity. Disparities in use demonstrate inequity when the factors that cause the inequality should not influence access to treatment. The best known factor in health care is the ability to pay. If procreation is considered a part of basic health care, this factor is clearly unacceptable. The decision to have or not to have children should not depend on income. Equity in access to infertility treatment not only means that people are not excluded for discriminatory reasons but also that they should have access without excessive burdens, meaning that the impact on the annual household income should be limited. The same point obviously extends to the fees for private insurance in countries where infertility treatment requires additional insurance.

Funding of infertility treatment, however, is not sufficient to eliminate inequity completely. Non-financial barriers may be as important. Even in countries with mandatory insurance coverage or full reimbursement by the public system, groups with low income and low education make significantly less use of health care provisions. Research on health care inequalities in general confirms that education and awareness also play a large role. Therefore, in order to create real equity, reimbursement of treatment should be accompanied by campaigns to raise public awareness of fertility affecting factors and the availability of treatment options and by improved education in general.

Cost reduction

The health authorities may enforce regulation to reduce costs as a condition for funding. Practitioners have a duty towards their patients and towards the health care system to bring down the costs as far as reasonably possible. There is evidence that certain types of treatment are cheaper than others, mainly because of milder stimulation protocols and thus lower drug costs. This obligation is especially strong when public funding of infertility treatment is requested. The cost reduction would benefit other patients as more infertile couples could be helped with the same amount of money. In addition, practitioners should endeavour to minimize the risk of multiple pregnancies which is a major source of avoidable

complications and expenses. Measures to reduce costs should be guided by research that demonstrates the safety and efficiency of these measures.

Criteria to restrict funding for infertility treatment

The inclusion of infertility treatment in the basic health care tier at least partially depends on the general level of welfare in the society. In relatively affluent societies, like most European countries, it is difficult to justify that no public funding at all would be provided. Still, given the righteous claims of other types of health care and other fundamental needs in society, funding cannot be expected to be unlimited. We consider a number of criteria that can be used for a just limitation of funding of medically assisted reproduction.

Minimal effectiveness

Effectiveness is an important criterion in the evaluation of infertility treatment. In a society with limited resources, there should be a minimal effectiveness before treatment can be reimbursed. There are two intuitions in this debate: on the one hand, funding is extremely difficult to justify if the chance of success is close to zero. Some people argue, however, that everyone should have had at least one chance (however small) to a child and that therefore every couple should have the chance to avail themselves of treatment. On the other hand, it would be unacceptable to give access only to patients with a high chance of getting pregnant. Nevertheless, some people argue that the available resources should be distributed as efficiently as possible, implying that those persons with the highest chance of success should have priority. The intermediate solution for health care systems would be to fix a threshold below which a patient would not be eligible for funding and simultaneously to reject prioritization according to chance of success above that threshold. As can be expected, there is dissent among experts regarding the precise threshold point to be used for access to IVF. This threshold point is usually introduced in the form of an age limit for the woman because statistical evidence demonstrates a clear link between female age and success rate. However, equity demands that all factors affecting the success rate are taken into account (e.g. ovarian reserve). Moreover, when it will be possible to make reliable predictions about success on the basis of biological parameters, age may no longer be the determining factor. As part of the same effort to increase effectiveness and reduce costs, patients also have a certain responsibility to avoid factors that negatively affect their fertility. It is, however, difficult to operationalize this idea because one should simultaneously avoid arbitrariness and discrimination. The specific implications of this responsibility for treatment are beyond the scope of this statement.

Limited number of treatments

Almost all countries that fund medically assisted reproduction have fixed a maximum number of cycles or interventions that will be reimbursed. The main consideration is the control of the health care budget. Unrestricted financial support for infertility treatment will deprive other domains that cover different

societal needs (like education) of their means. A fixed maximum number of interventions will result in an unequal chance of success for patients since the chance of success of a patient is determined by individual characteristics. It is impossible at the moment to determine the individual success rate because of the multitude of interacting variables. The balance of health care rationing and equality is found in an equal number of reimbursed interventions. Regarding this option, two rules can be determined: (i) the more cycles/treatments are reimbursed for everyone, the weaker the claim for funding of additional cycles/treatments, and (ii) the lower the cost of a cycle, the more cycles can be provided within the fixed budget.

Secondary infertility and number of children

It has been argued that limited resources should be attributed to those who need them most. The concept of 'need' can, however, be defined in different ways. It can be defended that people who suffer from secondary infertility within the existing relationship (with the exception of people who want frozen embryo transfer) should get lower priority since they have realized and experienced part of their family formation and reproduction. When only one patient can be treated, priority should be given to a childless couple above a couple who already have a child in their present relationship. People who already have a child (either by ART or by natural conception) should not usurp the resources that could give other people a chance of having a child. According to some, it can also be argued that couples in which one partner has a genetically related child from a former relationship should have lower priority. However, in view of both the complexity of family relationships and the fact that the presence of a child from a previous relationship may increase the pressure to have an additional child together, these couples should be considered on equal grounds. Policy makers may, depending on the amount of money available for infertility treatment, adapt the number of children a couple is allowed to have before they are excluded from reimbursement. Such measure is not

based on a normative conception of the family but on considerations of distributive justice.

Criterion to restrict funding for genetic diagnosis

In principle, reimbursement of IVF combined with PGD can only be offered when there is a high risk of a serious handicap or disability. The question of where to draw the line is notably difficult to answer. Certainly, to collectively fund PGD of low-penetrant susceptibility genes would be unjustified in view of more serious health risks and needs. The application of PGD for HLA typing constitutes a special case that indirectly has a medical indication as it may save the life of a seriously diseased child. As this strategy may be the only therapeutic option available, funding is appropriate.

Conclusions

- (i) Medical interventions, both to have a child and to avoid a genetically affected child, should be funded at least partially in relatively affluent societies.
- (ii) Funding of medically assisted reproduction should be considered in a structured way including efficiency, safety and equity to avoid unjustified discrimination.
- (iii) It is not unjust to collectively fund a fixed number of cycles/treatments for everyone even when this means that those who need more treatment have to pay for it themselves.
- (iv) Practitioners have a moral obligation towards their patients and the health care system to reduce the cost of treatment as far as reasonably possible. This reduction enables the fertility centres to offer more cycles/treatment for the same amount of money. In order to do this safely and effectively, more research needs to be performed to discover and develop cheaper and more effective infertility treatment.

Submitted on January 11, 2008; resubmitted on January 11, 2008; accepted on January 25, 2008