

## Ethical issues of infertility treatment in developing countries

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The provision of infertility treatment in developing countries is controversial. Reports over the last decades have inculcated in people from Western countries the belief that overpopulation is the major problem of developing countries. This paper will analyse the different arguments advanced for and against providing infertility treatment to resource-poor countries. There are two arguments in favour: reproductive autonomy and the huge burden of infertility in these countries. Pronatalism, which reigns in almost all developing countries, is to a great extent responsible for the devastating effects of infertility. The five arguments against the application of infertility treatment are overpopulation, prioritization of limited resources, prevention rather than cure, justice and equal access and risk of abuse. The importance of a person's reproductive autonomy demands that efforts should be made to enable people to determine how many children to have. This is equally true in developing countries. However, given the enormous difficulties of resource-poor countries to provide even the most basic goods, the contribution by society should be directed mostly at prevention and should depend on a strong cost reduction for assisted reproductive technology.

**Key words:** Justice, low-cost IVF, overpopulation, prevention, QALY.

### Introduction

Whenever one mentions the provision of infertility treatment in developing countries, the reaction of the people is almost unanimously negative. Reports over the last decades have inculcated in people from Western countries the belief that overpopulation is the major problem of developing countries. This conviction was and still is the main barrier to even consider infertility treatment in resource-poor countries. This conviction leads to a bias in Western people's way of looking at the provision of contraception and fertility control in resource-poor countries. For them, these technologies are ways to reduce population growth, not means to address the needs of people to control when and how many children to have. Worries of people in rich countries about immigration and fears of being overrun by the South probably also play a role (Grimes, 1998). Nevertheless, things are very slowly changing. A pivotal point for the new evolution was the Conference on Population and Development in 1994 in

Cairo on reproductive health. The conference adopted a definition of reproductive health that integrates both fertility control and infertility treatment in general family planning. 'Reproductive health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so' (United Nations, 1994). Family planning implies both avoiding unwanted children and having wanted children. Framing infertility treatment in the general context of reproductive health and family planning is crucial for the ethical evaluation.

Two preliminary warnings should be issued. First, we should be aware of the large heterogeneity of 'developing' countries in terms of wealth, population growth, health care resources etc. This point may have a huge impact on the debate as people may

think of very different countries when they discuss infertility treatment in developing countries. If people think of Soudan, Sierra Leone or Rwanda, countries which have been the battlefield of civil wars for decades, lacking a central government and minimal medical infrastructure or organization, it is not surprising that they are baffled by the suggestion of introducing in vitro fertilization (IVF) there. In order to prevent such misunderstandings, we stipulate that infertility treatment can only be considered when two conditions are fulfilled, namely minimal political stability and a minimal basic structure of health care provisions. Secondly, the discussion frequently focuses on high technological interventions like IVF. However, other interventions of a lower technical nature can be offered to treat infertility. The general consensus at the Arusha meeting was that there are three levels of technical difficulty: IUI, IVF and ICSI. The technical level as well as the timing of the introduction of a technique will have to be country-specific, depending on the wealth and the general development (Van Balen and Gerrits, 2001).

### **Pronatalism, patriarchy and suffering**

Reproduction and fertility have a different meaning in Western and non-Western countries (Van Balen and Inhorn, 2002). In developed countries, reproduction is a self-chosen goal and a largely personal choice made by an individual or couple. Although there are attempts by others to influence a couple's family planning, these attempts have no moral basis. In non-Western societies, having children is also a social obligation, a performance that is due to the family (-in-law) and the community. Social pressure and stigmatization are logical consequences of this position. Norm violations are generally met with repudiation or sanctions. The different meaning of infertility and parenthood is mirrored in the motives people have for wanting to become parents. Children secure one's marriage, confer social status, guarantees rights of property and inheritance, assist with labour, offer social security in old age and provide continuity by maintaining the family name (Dyer, 2007).

The significance of involuntary infertility is socially constructed and gender roles play a major role in constituting the social meaning of infertility. This is true in the developed as well as the developing world (Becker and Nachtigall, 1994). Infertility is at least in part a cultural problem, generated by pronatalist and patriarchal ideologies. A pronatalist society holds the belief that a person's social and moral worth is linked to reproduction (Ulrich and Weatherall, 2000). The more one believes in the cultural construction of infertility, the more one will believe that infertility should be tackled not by treat-

ing the infertile but by targeting the ideologies that cause the problem (Sandelowsky and de Lacey, 2002). Still, also in largely egalitarian societies, people want children as part of their life plan and they suffer when they cannot realize this wish. However, because parenthood has deeper social roots in developing countries, the social and psychological consequences of involuntary childlessness are often more severe. Not surprisingly, the problem of infertility in developing countries is frequently introduced by pointing at the large impact on the lives of men and especially women (Ombelet and Campo, 2007). 'Common scenarios include unstable marriages, divorce, polygamy and ostracism of the women' (Vayena et al., 2002). Especially for women, social status and female identity depend on their ability to produce children. 'They [the women] are usually blamed for infertility and can be ostracized and assaulted by their families, even driven to suicide or killed. By supporting the development of low-cost IVF, governments can help make such treatments more widely available' (Editorial, 2006). As the previous quote shows, low-cost IVF is proposed as a solution to the social problems of the infertile.

According to the main ethical theory, i.e. utilitarianism, one should do whatever maximizes happiness or well-being. A utilitarian could defend that it is best to cure infertility in countries with the direst consequences. More well-being would be created or more unhappiness avoided by providing assisted reproductive technology (ART) to a couple in Africa than to a couple in Europe. However, it is not clear to what extent these negative consequences of infertility in developing countries justify the provision of infertility treatment. Two reactions are possible. The first reaction is to focus on changing the existing moral and social order so that infertile people will no longer be ostracized and discriminated. We should adopt measures to diminish the pronatalist ideology and its undesirable consequences. This can be done in several ways. An important step is education as a means for women to obtain a job which gives them an alternative route to increase their self-esteem and to ensure economic independence and security. The second reaction is to provide infertility treatment as a medical solution for a social problem. Many current health problems, like obesity, are solved by medical interventions. From a utilitarian position, the choice between these reactions can only be made on empirical evidence. If more well-being can be gained by avoiding the social and psychological consequences than by providing ART, the former should be done.

If a pronatalist society justifies provision of infertility treatment, does a sexist society justify social sexing? Women who are unable to give birth

to a son are also discriminated. Like infertility, it is a reason for a man to divorce his wife (Chan et al., 2002). Mothers who have only daughters in India and China undergo ostracism, are at risk for suicide, and often face beatings, divorce or fatal 'accidents' (Holmes, 1995). The main argument against this analogy is that wanting a child is acceptable while wanting a child of a certain sex is unacceptable. However, this presupposes that there are standards to judge the acceptability of wishes, rules and practices independent of the culture. The acceptance of pronatalism, however, seems to be based on the conviction that Western people should not judge other societies which attribute a different value to parenthood. Those who argue in favour of infertility treatment in pronatalist societies on the basis of cultural autonomy, should also defend social sexing in sexist, patriarchal and misogynist societies. Cultural relativism cannot be adopted whenever one agrees with a deviant practice and rejected when one disagrees. My position is that discrimination on the basis of health or disability (to have children) is unacceptable and pronatalism leads to such discrimination. Moreover, the highly negative consequences for infertile people and the fact that some people will remain infertile even with high-tech infertility treatment are good reasons to attenuate the pronatalist attitude.

### **Overpopulation**

One of the demographic paradoxes is that countries with the highest overall fertility are also those in which the prevalence of secondary infertility is highest (Nachtigall, 2006). It is highly unlikely that high-tech interventions will have an impact on the population in developing countries since only a small minority of the population can afford them. However, it does not really matter whether only a small additional number of children will be created by ART. It could be argued that any child that is added to the already excessive population growth, is one too many. However, this argument would count against every new child, regardless of how it came into being. In its extreme form, the argument would lead to the conclusion that an overpopulated country should promote measures causing infertility. However, the reasoning of some authors that this implies that we would not have a reason to save people's lives in developing countries makes little sense (Daar and Merali, 2002). There is an enormous difference between letting existing people die and not bringing potential people into existence. In the latter case, no one is harmed.

The overpopulation argument attributes a high value to societal benefits at the expense of the

individual. The personal good is sacrificed for the sake of a collective or aggregate good. These individual rights have a very high status in their negative form. That explains why we so strongly reject coercive (eugenic) measures like forced sterilization. In fact, people who use the overpopulation argument to deny infertile persons access to ART use the same reasoning as people from the eugenics movement use to deny some people the right to reproduce for the sake of society. Nevertheless, there may be circumstances in which coercive measures to defend the public good are justified. This is the case when it can be shown with reasonable certainty that a major catastrophe can only be avoided by infringing people's rights. This justification is not applicable to the overpopulation problem because population growth can be restricted much more effectively by other means that do not infringe people's rights such as educating women, providing contraception and safe abortions etc.

The second argument against the reference to overpopulation is related to distributive justice: the total burden of the overpopulation should not be carried by the infertile alone. Why should they alone remain childless? One could for instance encourage fertile people to have fewer children. China has given the example of an egalitarian approach to the overpopulation problem with its one-child-per-family policy. Regardless of the objections one may have against this system, it is certainly a more balanced and just measure than the proposal that infertile couples should remain childless because their neighbours have too many children (and even more than they want themselves). The child wish expresses a personal need that cannot be satisfied by the neighbours having a child (Shah, 1994). Referring to the children of others to explain the refusal to assist the infertile in having children demonstrates a serious misconception of what it means to want a child.

### **Prioritization and limited resources**

Most developing countries are struggling to provide a basic minimum of care. They are confronted with immense problems of poverty and deprivation of the most basic goods like clean drinking water and food, which also affect the general health of the population. A mean life expectancy around 50 years is no exception in developing countries. The question then becomes whether governments should not spend their money trying to resolve these problems rather than embarking on expensive high-technology programmes for non-life threatening conditions like infertility. When considering this question, we have to look at the broader picture of the allocation of the total national budget. Most developing countries

spend, 5% of their gross national product on health care and the largest part thereof is private money (World Health Organisation, 2007). If we accept this starting point, the provision of high technology infertility care obviously implies that already underfunded and essential programmes like maternal and child care will receive even less money. However, there is no reason why we should accept the existing health care budget as fixed. On the contrary, there are very good reasons to urge the governments to increase the public health care budget. The whole resource allocation policy should be questioned and evaluated. For instance, what percentage is spend in those countries on military equipment or prestige projects? South Africa is organizing the world championship football in 2010 which will cost around 2 billion euro. Should the country not rather spend this money on helping AIDS victims or treating infertility? Generally speaking, the inability to pay for health care and other basic needs is due more to mismanagement of funds than to the lack of resources. Allocating additional funding to health care would considerably improve the global situation. Still, regardless of the amount that is directed at health care, we will still have to discuss to which treatments the money will be given (Pennings and Ombelet, 2007).

The ambiguous status of infertility puts it in a disadvantaged position when different needs are ranked. Infertility is not life threatening and is not even considered as a disease by many people. This means that it loses against almost any other lifesaving health-related service. This is confirmed by the currently most frequently used method for ranking diseases, i.e. Quality Adjusted Life Year and its mirror concept Disability Adjusted Life Years (DALY). The DALY is a measurement technique to assess the overall burden of a disease. It includes both the time lost due to premature death (mortality) and the time lived with a disability (morbidity). One does not need much imagination to see that combining both quality of life and length of life in one single number is difficult. This index runs into serious conceptual and methodological problems (Arnesen and Nord, 1999). Nevertheless, the DALYs are put forward by the World Health Organisation and the World Bank as the basis for public health policy and resource allocation. The DALYs are used to determine the priorities for the allocation of health care resources. Given this practical use, it is extremely important to review and refine the process to make sure that infertility, and reproductive health in general, is ranked at the position it deserves. In the International Classification of Diseases (ICD), which is the basis for the calculation of the DALYs, infer-

tility is included only as a disability outcome of sexually transmitted diseases (STD) and postpartum and post-abortal sepsis and not as a non-fatal disease in its own right (AbouZhar, 2000). The calculation method, moreover, raises a number of difficult questions when applied to infertility. For instance, the DALYs are calculated by multiplying the expected duration of the disability by a disability weight that measured the severity of the disease compared with death. This would imply that, in cases of primary infertility, a man or woman would be infertile from the age of 18 till approximately 45. It would be odd to talk of infertility before and after the natural reproductive life span. Moreover, infertility is only a disability when there is a child wish. Women becoming infertile due to abortions or pelvic inflammatory disease at an age at which they have no further child wish, will not consider themselves disabled (Vos, 2001). Nevertheless, the (primary) infertile persons will continue to suffer the consequences of their disability after the reproductive period because of a lack of support during old age. These conceptual problems are caused by the focus on 'infertility' as a disability while the effects are connected to childlessness. A second problem is that socioeconomic, cultural and environmental factors are excluded in determining the burden of disease. Infertility has important social (exclusion, ostracism etc.) and economic consequences (poverty in old age, divorce etc.) that are not incorporated in the DALY. Third, the disease of one person may affect the well-being of others. Infertility is a disability of a couple in Western countries, but influences the well-being of the larger family of both partners in developing countries. Fourth, the DALYs have been criticized because the burden of disease is largely determined by experts and epidemiologists while people's own perceptions are left out of the calculation. When community members are questioned about the value of certain health states, some diseases which are fairly trivial from a clinical point of view, move up in the ranking despite their low prevalence. One study showed that socially stigmatized conditions like erectile dysfunction and infertility are considered more serious than non-stigmatized conditions (Kapiriri and Norheim, 2002). Studies in Nigeria, Mozambique and South Africa revealed that life without children is perceived as unhappy and not worth living (Dyer, 2007). The clinical criteria used in the calculation of DALYs strongly underestimate the impact of certain conditions, like infertility and skin diseases, on a person's life. This is a plea to extend the criteria used to calculate the DALY of a disability in order to obtain a more complete picture of the global effect on a person's quality of life.

## Prevention

The 'prevention' argument is a specified version of the 'prioritization' argument. It expresses the conviction that the available resources should be directed first towards programmes to prevent infertility. Okonofua (1996) gives three reasons for this position: (i) prevention programmes are less expensive, benefit a greater number of people and are more effective in eliminating the social consequences of infertility; (ii) prevention programmes will improve the health status of women in other ways and (iii) such programmes could provide impetus for the utilization of other prevention services, such as family planning. In general, there is little doubt that prevention is better than cure. Cure and therapy usually is more painful and burdensome. Moreover, for diseases such as AIDS, there is no cure. However, some moral points can be raised against the automatic priority given to prevention. In allocating medical treatment, one of the important criteria is medical need. People who are ill normally have priority on healthy people. When resources are allocated almost exclusively to prevention, one ignores the people who already attracted the disease (Verweij, 2007).

It helps to distinguish a 'moderate' and a 'radical' form of the 'prevention' argument. The radical form defends the position that all available resources should be directed completely at prevention. The untenability of the radical 'prevention' argument can be shown by looking at the response to AIDS. Most countries spend a lot of money and health care resources providing anti-retroviral therapy to HIV positive persons. If the prevention/cure distinction would be an all or nothing question, they should spend all their money on prevention and let the infected persons die. The moderate form of the prevention argument states that priority should be given to prevention but, depending on a number of criteria, one should also direct part of the resources to cure. The criteria to determine the distribution are, among others, the degree of scarcity of the resources, the cost-effectiveness of both prevention and cure and the difference in cost between the two. I find the argument about the double benefit of preventive measures particularly strong for numerous reasons. First, the prevention of AIDS, infections etc. is realized by securing other rights of (mostly) women. Access to safe abortions not only prevents tubal infections, but also respects women's right to control their fertility. Secondly, although the preventive measures are directed at healthy people, they are the ones most at risk of infertility due to lack of contraceptive devices and untreated STDs (Luna, 2002). Finally, cure without prevention would be a waste of

effort: the number of infertile couples would continue to grow and no developing country will have the means to treat all these people by means of ART. 'The development of expensive IVF units, whether public or private, in countries where there are no programmes for the prevention and early management of STDs, amounts to a national crime' (Toubia, 1994). In conclusion, the government should give priority to prevention when allocating resources for public health. However, this does not mean that no money should go to infertility treatment at all, especially not when treatment can be made less expensive. One should not ignore the plight of the people who are infertile now.

## Justice

Equity in health care means equal access to basic health care without excessive burdens. Health care in general is important because it secures the normal range of opportunities and allows people to flourish. The question of justice in health care is not limited to developing countries. The difference between developed and developing countries is a matter of gradation. Poor people in rich countries without insurance coverage for infertility treatment have no access to high-tech treatment either. In the United States, for instance, access to IVF is limited primarily to middle-or upper-class persons. Access to treatment can be determined by looking at the cost of infertility treatment in comparison to the mean income. In developing countries, the cost borne by the infertile patients themselves for IVF is more than half of the average annual income of the citizens (Collins, 2002). In resource-poor countries, infertility treatment is almost exclusively provided in private hospitals to the upper-class.

The principle of justice contains two dimensions: equality and access. Justice can be promoted by either increasing equality (no one has access or everyone has access) or by increasing access (the more people can obtain the treatment the better). The people who focus on equality tend to conclude that when access cannot be guaranteed for everyone, no one should have access. This results in what Engelhardt has called an 'ethics of envy': if I cannot have it, no one should. This difference in emphasis is important in the discussion. Regardless of the techniques that will be used and the cost reductions that can be realized, not every infertile person in developing countries will have access to infertility treatment. People who focus on equality believe that no action should be taken unless everyone (including the poorest) can obtain treatment. I think on the contrary that cost reduction for infertility treatment is morally defensible even if the treatment is only

available to the more affluent groups in society because it increases the number of people who can afford treatment. Moreover, a small decrease in cost may result in a much higher increase in utilization (Collins, 2002). Nevertheless, the ideal situation combines equality and universal access. This can be obtained in several ways, either by reimbursement of treatment through public funding, affordable private health insurance or direct cost reduction. Given the problems encountered in resource-poor countries, the latter is the most realistic route. All parties can contribute to this goal. Pharmaceutical companies can provide cheaper drugs as they do for AIDS. Researchers and professional organizations can invest in cheaper, more effective and simpler procedures to facilitate introduction in less sophisticated health care systems and physicians can work for minimal fees.

There are two considerations to keep in mind when private clinics start to offer high-technology infertility treatment. One argument is that it does not affect others when people have to pay for ART out-of-pocket. However, this is only correct when direct costs are taken into account. One should take into account the indirect costs in terms of health care resources and capacity. The private clinics will attract scarce qualified people like embryologists and gynaecologists with higher wages. The 'health conveyor belt' shifts qualified personnel from public to private clinics. The end result is an exodus from the public health sector (Schrecker and Labonte, 2004). Moreover, one should also beware of 'cream skimming': doctors in public hospitals refer public hospital patients to their private practices for follow-up and more sophisticated treatment if, of course, the patients are willing and able to pay (Sundby, 2002; Inhorn, 2007). This leaves the public hospitals with only poor patients.

Finally, one should think proactively about a number of problems that will arise when low-cost IVF will be introduced without public funding. Low-cost does not mean that everyone will be able to afford it or will have access. This raises the question of which criteria (if any) should be used to rank the patients. One possibility would be to exclude, at least as long as there is great scarcity, secondary infertility. It can be argued that the scarce resources should first go to men and women who have no child of their own. A second issue is more related to cost-effectiveness. The treatment of some categories of patients will be more expensive than that of others. In the present discussion, severe male factor infertility is not included because ICSI cannot be performed for the same price as 'standard' IVF. The same applies to HIV positive persons who need infertility treatment. The inclusion of these patients

automatically implies that fewer patients can be treated with the same amount of money.

### **Abuse and exploitation of patients**

The patient-physician relationship is characterized by a power imbalance. This is due both to the vulnerability of the sick person and to the inequality in terms of knowledge and skills. This inequality holds a possibility of abuse by the more powerful party that can only be avoided by the virtuousness of the physician (his or her integrity) combined with regulation. Several authors have expressed their concern about the high rates of medical malpractice in the management of infertility in the developing world (Macklin, 1995; van Zandvoort et al., 2001; Aboulghar et al., 2007). 'Unregulated private practices offer considerable potential for making large profits from infertile women, and this can attract doctors who are more interested in wealth than 'good practice' (Aboulghar et al., 2007). This danger obviously is linked to any profit-driven practice, in developed as well as developing countries. The chance of abuse may be higher when patients are uneducated, desperate and willing to invest all their savings. The risk may be exacerbated by the lack of knowledge, experience and competence on the part of the practitioners (Macklin, 1995). However, the solution is not to prevent or block the introduction of high-technology infertility treatment but to regulate the practice by licensing providers, close monitoring of the activities and verifying results.

### **Conclusion**

Most arguments against the provision of infertility treatment in developing countries cannot be sustained. On the contrary, a combination of measures such as increased investment in health care and considerable reduction of the cost of ART would justify at least some public funding. However, given the difficulties of resource-poor countries, the lion's share of the effort should be directed at the prevention of infertility.

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