

Considerations regarding government funding of assisted reproductive techniques in low-resource settings

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Key words: infertility, assisted reproduction, developing countries, cost, access to treatment.

Introduction

Recent years have seen a global expansion of assisted reproductive techniques (ART). Although the availability of ART is still variable, 78% of the world's population live in countries in which IVF and ICSI services are offered (Collins, 2002). This observation makes it tempting to conclude that the majority of people in need of treatment have access to ART. In reality, many barriers exist including cost of treatment, culture, religion, distance to travel, and education. While each comes with its own difficulties, the issue of funding is particularly challenging.

How to fund and regulate access to ART is probably debated in all countries providing ART. This debate is especially complex in developing countries where the need for treatment is high (due to the high prevalence of infertility and the many negative psychological and social consequences of infertility), resources are sparse and competing health needs are prominent. At the same time people have limited ability to pay for health services, and out-of-pocket expenditure may result in a downward spiral of asset depletion and poverty (Russell, 1996). Moreover, political willingness to improve infertility management in developing countries is often lacking. This is usually attributed to overriding concerns relating to population growth, although other motives, such as the belief that the world's poor should not be offered assistance to reproduce, have also been suggested (van Balen and Gerrits, 2001; Inhorn, 2009).

The legitimacy of the claim for public funding is linked to the debate whether infertility is a disease,

a disability or a personal desire. The more infertility is contextualised as the latter, the less convincing the argument for public funding becomes (ESHRE Taskforce on Ethics and Law, 2008). Unfortunately the status of infertility is unresolved in many countries, especially in the developing world. As a result the discussion on public funding for ART gets frequently entangled in the debate on the status of infertility, and the outcome is not very fruitful.

According to the European Society of Human Reproduction and Embryology (ESHRE), infertility is a serious handicap. This view is based on the understanding that for many people procreation is a fundamental need and important life goal. Infertility treatment in turn allows people to realize their reproductive choices and substantially increases their well being (ESHRE Taskforce on Ethics and Law, 2008). This statement applies equally to all people, irrespective of their country of origin or their level of income. But the unfulfilled desire for children is likely to have more profound implications in developing countries when compared to the Western industrialised world.

Psychosocial consequences of infertility

The first attempt to classify the psychosocial consequences of infertility comes from Daar and Merali (2002), who proposed that infertility results in a continuum of harm across six levels of increasing severity (Table 1). The authors furthermore stated that in developed countries the consequences of infertility rarely exceeded level 2, whereas in African and Asian countries they were rarely as mild as level 3.

This is an important observation, based on a considerable body of literature. Briefly this literature comprises many publications from Asia and Africa which attest to verbal and physical abuse (level 3 and 4) secondary to infertility (Widge, 2005; Ali and Bustamante-Gavino, 2007; Ameh *et al.*, 2007). Social alienation and loss of social status (level 3 and 4) is frequently observed (Dyer *et al.*, 2002; Hollos, 2003). The underlying reasons are complex but at least partly attributable to the fact that men and particularly women obtain their status in the family and community through the number of their children (especially sons) and, in the absence of material wealth or education, have no other avenues to social recognition. Loss of social status in turn results in further abuse and in deprivation (level 5) (Hollos, 2003). Deprivation may also be directly incurred by the absence of children, as children usually form an important part of the household and community work force, and provide old age security.

Table 1. — Continuum of the consequences of infertility (Daar and Merali, 2002).

Level 1	Guilt, self-blame, fear
Level 2	Marital stress, economic stress, helplessness, depression
Level 3	Mild marital and social violence and abuse, serious economic hardship, social alienation
Level 4	Moderate to severe marital and social violence and abuse, severe economic deprivation, social isolation and abuse culminating in loss of social status
Level 5	Death, violence-induced suicide, starvation/disease
Level 6	Lost dignities in death

Mortality from infertility (level 5) is rarely documented, although suicides as a result of infertility have been reported (Shukla *et al.*, 1990). It has also been observed in African countries that infertility induces high-risk sexual behaviour involving formal and informal polygamy in the attempt to overcome the dreaded condition of childlessness (Gerrits, 1997; Ikechebelu *et al.*, 2002). The observation that HIV prevalence rates are higher in infertile women when compared to pregnant controls is therefore not surprising (Favot *et al.*, 1997).

Lastly, infertility may impact on funeral rites, which are highly regarded in most societies but especially in some developing countries. Examples for the lost dignity in death (level 6) include among others the burial of infertile bodies outside community land (in the belief that these bodies may reduce the fertility of the soil), and burial with a marker to inform gods or ancestors of the unproductive status

of the dead (Leonard, 2002; Hollos, 2003; Mariano, 2004).

Recently, van Balen and Bos (2009) conducted a systematic literature review of the social and cultural consequences of infertility in poor-resource areas. Following interpretative phenomenological analysis, the authors proposed four categories of socio-cultural consequences, comprising community effects, economic and in-law effects, legal and family aspects, and religious and spiritual effects. Each category captures four levels of intensity. Social isolation, for example, reflects the most severe community effect while loss of social status represents the mildest form in this category. The review documented again the many serious consequences of infertility in developing countries. Collectively these data question the concept that infertility is a ‘mere desire’ rather than a ‘legitimate’ disease or disability in need of funding.

Measuring the burden of infertility

It can be argued that in low-resource settings, health services should preferentially be allocated to people who have the biggest need and to interventions that provide the greatest benefit. In the context of infertility treatment, this implies the need for: 1) a comparison with other diseases that also compete for public money, and 2) a comparison with alternative interventions such as prevention.

When allocating limited resources to competing health needs, money is usually directed to the management of medical conditions (i.e., diseases and disabilities) which put people’s lives at risk or which severely compromise their quality of life. Premature death is the worst possible outcome within a quality of life calculation. Unfortunately, infertility does not score well in this line of argumentation. Firstly, it brings us back to the unresolved debate on the status of infertility. Secondly, it requires a quantitative measure of the impact of infertility on health and quality of life. This evidence is largely lacking. Studies indicate that infertility might result in death, but there is no data from which to estimate mortality rates or years of life lost. Moreover, any such mortality would be attributed to the direct cause of death (i.e., HIV/AIDS, starvation or suicide) rather than to underlying infertility. Similarly, there are numerous studies documenting infertility-related suffering, but there is a scarcity of data evaluating quality of life. Researchers seeking to close this information gap encounter another difficulty, and that is finding a suitable instrument. Standard generic instruments (i.e., instruments which are not disease specific and which allow comparison between different conditions) are sensitive to infertility only

through measures of anxiety and depression. But anxiety and depression are inadequate surrogate markers for some of the distressing experiences outlined above. It is possible that the more recent instruments used to assess quality of life in disabled individuals, which include measures of social participation (e.g., the WHO Disability Assessment Schedule II or the Craig Hospital Inventory of Environmental Factors), are more sensitive to the reality of infertility, but this remains to be established.

Approaching infertility from the angle of Burden of Disease (BoD) is similarly problematic. At present, the social and economic consequences of childlessness are not incorporated in the BoD calculation which is likely to affect the ranking of infertility. Yet these consequences are the main reason why in some African countries life without children is perceived as unhappy, unfulfilled and not worth living (Dyer, 2007). It could also be argued that the burden of a particular disease is best determined by those suffering from it (Pennings, 2008). Some socially stigmatizing conditions, like erectile dysfunction and skin diseases, would score much higher when ranked by people affected rather than by experts who only consider 'objective' consequences. Even local populations may rank the various descriptor conditions differently when compared to the global BoD ranks. In a study conducted in Zimbabwe, urban non-professional residents ranked infertility much higher than its 'official' position on the global BoD scale (Jelsma *et al.*, 2000). This was attributed to the fact that according to Shona culture infertility threatened collective survival and prevented individuals from participating effectively in the community. The authors expressed concern that the global BoD values represented the opinion of an international elite of health workers which was underpinned by Western emphasis on self-determination and individualism. Alternative measures of the BoD have been explored, such as the 'willingness to pay' approach, in which potential recipients indicate how much value they attach to a successful outcome or solution, but these measures also suffer from conceptual problems (Devlin and Parkin, 2003).

Infertility treatment competes not only with other diseases for public money but also with infertility prevention. Generally speaking, prevention should have priority (Ombelet, 2008; ESHRE Taskforce on Ethics and Law, 2009). The main reasons in favour of prevention are that prevention is less expensive and benefits a greater number of people and that the measures used to prevent infertility simultaneously improve the health status of women. Access to maternity care and safe abortions, for example, contribute to the prevention of infertility and secure other rights of women such as reproductive health

and family planning. However, this is not an all or nothing debate. There are very good reasons to reserve at least some money for treatment, especially when this is low cost treatment (Pennings, 2008). The main argument here is that sick people normally have priority on healthy people based on medical need. The plight of people who already attracted a disease or became infertile should not be ignored or dismissed. In the rest of this paper, we will look at some problems arising when this is accepted.

ART in low-resource settings

Public funding of ART requires special considerations relating to treatment safety and success. This applies to both affluent and non-affluent societies although the specific aspects differ according to circumstances and resources. In relatively affluent societies the mandate to minimise risk focuses predominantly on the number of embryos transferred, while minimal effectiveness is mostly influenced by patient-related prognostic factors, such as age (ESHRE Taskforce on Ethics and Law, 2008). In the developing world safe ART treatment also requires the availability of appropriate maternal and neonatal services and, in many countries, access to treatment for HIV/AIDS (ESHRE Taskforce on Ethics and Law, 2009). ART success in turn is heavily influenced by the quality of the clinical and laboratory services, which are often less standardised and controlled than in developed countries. Although success rates in low resource institutions may therefore be lower when compared to affluent ART units, they should not drop below a certain threshold in order to maintain a balance between cost and benefit. Thresholds are likely to differ in different settings, but once determined they require regular audit. In developed countries, this audit is established clinical practice, in addition to which there are national and regional ART registers which are of proven benefit (International Committee for Monitoring Assisted Reproductive Technologies, 2009). In many low resource settings, the success of infertility interventions is not systematically evaluated, and as a result resources may be squandered on interventions which are of little benefit (Inhorn and Buss, 1993; van Zandvoort *et al.*, 2001). In addition, the lack of ART services may contribute to this wastage as less effective interventions continue to be pursued if superior alternatives are not available (Orhue and Aziken, 2008). This is an interesting point in the whole debate since opponents frequently focus on the money that may be spent on admittedly expensive treatment, while ignoring the large sums that are already spent by people or governments on unproven or ineffective procedures to cure infertility.

Ideally, evaluation of treatment benefit should not be limited to pregnancy but also comprise the overall impact on quality of life. Moreover, it is important to carefully consider unintended disadvantages of providing (relatively) high-tech treatments in settings which are not familiar with modern Western medicine. It can be anticipated for instance that many people who receive ART treatment will not become pregnant for a variety of reasons, and it is fairly difficult to predict how patients and their environment will react to treatment failure. While some authors have suggested that treatment failure may facilitate adaptation to childlessness and improve well-being, others have documented a negative association between previous ART treatment failure and quality of life among women attending ART clinics in Italy and Brazil (van Balen and Trimbos-Kemper, 1994; Ragni *et al.*, 2005; Chachamovich *et al.*, 2007). It is also not known how the social environment will react to children born after ART, especially in communities where witchcraft and other beliefs in supernatural powers are prominent. Further research is required to explore these consequences of ART and to assess similarities and differences across regions.

Prioritizing infertile patients for treatment

Publicly funded ART also requires us to revisit the debate on resource allocation, albeit now within the context of the infertile population. Again it must be decided who to treat when insufficient funding is available to treat everyone. Different criteria have been proposed: need, chance of success, treatment cost and parental income.

One approach is to prioritise those in greatest need and to give preference to couples who are childless (ESHRE Taskforce on Ethics and Law, 2008; 2009). On the one hand, this recommendation may be viewed as too stringent or even euro-centric in cultures which value large families and male offsprings. On the other hand, it seems reasonable to argue that when treatment can be offered either to a childless woman or to a woman who already has a child, the childless woman should have priority. This reasoning is also partly based on the fact that pregnancy and childbirth itself affect a woman's status in her community (Gerrits, 1997; Dyer *et al.*, 2002).

A second criterion for selection is chance of success. In circumstances of relative wealth, every person should have equal access to medical treatment. In times of great scarcity, however, the rules may have to be adapted in order to increase the total benefit and to improve efficiency. In such circumstances, 'wartime triage' may be applied, whereby the people who have the lowest chance of becoming pregnant are excluded (Rhodes *et al.*, 1992). An

alternative is a threshold system which tries to find a compromise between the principle of justice (the equality of opportunity) and the principle of utility (the maximisation of outcome in terms of pregnancies) (Pennings, 2001). The trade-off includes two steps: firstly, the minimal threshold of success is determined. Secondly, no interpersonal comparisons of success are made above that threshold. The biggest problem, obviously, is to determine how small the chance of success should be to deny access to treatment.

Patient eligibility may also be influenced by the differential costs of treatment. The treatment of some categories of candidate patients, such as severe male infertility and HIV positive people, will cost considerably more than the treatment of others. One ICSI cycle for severe male factor infertility may equal the cost of several IVF cycles. It has therefore been suggested to restrict treatment at least in the initial phase of ART implementation to female infertility and moderate male infertility (ESHRE Taskforce on Ethics and Law, 2008). Again, unintended side effects should be taken into account. The exclusion of HIV patients for instance may aggravate stigmatization as well as induce high-risk sexual behaviour in the attempt to overcome infertility. The (temporary) exclusion of severe male factor infertility may decrease the willingness of men to support and pay for ART (both at individual and government level), which in turn may prevent women from accessing treatment.

Last but not least, patient eligibility should also be based on the socio-economic background of the couple themselves. On the one hand, care must be taken not to allocate scarce resources to couples who can afford privately funded ART. On the other hand, some couples requesting fertility assistance may live in such poverty that the basic welfare of a child is threatened. In these circumstances, in which there is a high risk of serious harm to the child ensuing from the treatment, society (as represented by the fertility specialist) has the right to refuse treatment (Pennings, 2003). This is a particularly difficult question because it may demand a revision of the Western standard of responsible parenthood and acceptable risk taking. Western parents and physicians tend to strive for zero risk, partially because all kinds of interventions (e.g., prenatal diagnosis) are available to eradicate or reduce the risk for the child. However, people who lack these resources and who are constantly exposed to relatively high risks in their daily lives may put the threshold of acceptable risk higher. At no time, however, should this concern for the welfare of the child be misused to enforce the view that poor people do not deserve to have children (Inhorn, 2009).

Summary

Infertility is a common reproductive health problem in developing countries. It is associated with negative psychological and social consequences which exceed, both in frequency and intensity, those reported from the Western industrialised world. The resultant demand and need for ART is currently largely unmet as access to available facilities is usually limited to affluent people. In order to motivate governments to allocate scarce public funds to ART, new data are required documenting the impact of infertility on people's quality of life and allowing comparison with other health conditions. Implementation of ART services must be accompanied by quality control measures and go hand in hand with the delivery of appropriate maternal and neonatal health services. Access to publicly funded ART should be regulated according to fair and transparent criteria.

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