Quality of infertility care in poor-resource areas and the introduction of new reproductive technologies

Frank van Balen¹,³ and Trudie Gerrits²

¹Department of Education, Faculty of Social and Behavioural Sciences, University of Amsterdam, PO Box 94208 1090 GE Amsterdam, The Netherlands, and ²Section Medical Anthropology, Faculty of Social and Behavioural Sciences, University of Amsterdam

³To whom correspondence should be addressed. E-mail: vanbalen@educ.uva.nl

The quality of infertility care is dependent upon adequate material resources and the appropriate use of it. In addition, a mutual understanding between physicians and patients is necessary. These imperatives are more salient in the era of the new reproductive technologies. However, in poor-resource areas these imperatives are insufficiently met. Moreover, in developing countries the negative consequences of childlessness are much stronger than in Western societies. Until recently, the problem of infertility in Third World countries has received little public attention. A plea is made for a stronger policy interest in Third World infertility care. In this it is important to focus on prevention, appropriate diagnosis and treatment at primary and secondary health-care level and to take the existing cultural beliefs into account.

Key words: assisted reproductive technologies/developing countries/infertility care

Introduction

The aim of much of the research in reproductive technology is to develop and improve diagnostic and therapeutic technologies and procedures to help men and women who have problems having children. However, developing new technologies in a research setting is one thing; using them in an effective and responsible way in a clinical context is another. Introducing new technologies for diagnosis and treatment is expensive and demands a specialized and well-organized medical and paramedical staff for optimal utilization of current knowledge (Hamberger and Janson, 1997). Not only are requirements of a biological, medical and technical nature regarding reproductive technology necessary in order to improve the fate of infertile or childless couples, but also a supply of material goods and resources has to be guaranteed, the materials have to be of good quality, and services have to be accessible and affordable. Moreover patients and physicians need to interact within an ambience of co-operative understanding. Ideally, physicians should be able and willing to explain and discuss such things as the specific characteristics of the investigations and treatments, the different treatment options, the expected success rates, and the potential risks. In addition, they should deliver their services with respect to the cultural and religious context of the patient groups. Patients, from their side, have to comply carefully with the prescriptions for medications, to attend to appointments, properly time the production of semen, and to follow all the other intricate rules that come with the new reproductive technologies (NRTs). In short, there must be a health-care, socio-cultural and economic context in which NRTs can be successfully applied.

In most Western countries such a context is available, although even in the Western world not all parts of the population have equal access to NRTs. NRTs are costly and, while in some countries NRTs are paid for by state health care systems or included in the national or private medical insurance policies, this is not always the case, and nowhere is the use of NRTs unconditional. Moreover, subsidized NRTs are not always of the same quality as the services on the private market. Patients have to know their way around in the medical world to find the right treatment (Sandelowski et al., 1989; Templeton et al., 1990; van Balen and Trimbos-Kemper, 1992; van Balen et al., 1997). When we focus on developing countries, these deficiencies are many magnitudes larger. In developing countries, NRTs are either unavailable or are very scarcely available; and the large majority of the population is not able to afford the use of NRTs, and as such has no access at all.

It is generally recognized that, in poor resource areas, the quality of general and specialized health care services is worse than in developed countries. Many common medical products, e.g. drugs, are difficult to obtain, there is a shortage of refrigerators, a lack of trained medical and paramedical personnel, modern equipment, adequate housing, etc. These circumstances complicate the provision of good quality medical
services in general and the provision of infertility services does not form an exception. Moreover, the very particular nature of the infertility problem and of infertility care makes them different from other medical problems and services in developing countries. Here we describe the specific problems of infertility and infertility care in developing countries, and pay particular attention to the interplay between aspects of health policy and health-care, socio-cultural and biomedical aspects.

Consequences of infertility: personal suffering and social stigmatization

In Western countries, childlessness has a profound influence on the personal well-being of the women and men concerned (Abbey et al., 1991; Stanton et al., 1991; van Balen and Trimbos-Kemper, 1993; Greil, 1997). Recent studies show that in developing countries (where children are highly valued for personal as well economic and socio-cultural reasons) childlessness often creates enormous problems for the women and men involved, within the couple, the extended family, and the community at large. In particular, childless women suffer a lot, because women are generally blamed for the infertility, and motherhood is often the only way for women to enhance their status within the family and community. In many areas, the social stigma of childlessness is very outspoken, and may lead to isolation and neglect. In many different regions, e.g. Egypt (Inhorn, 1991), Nigeria (Okonofua, 2000), Mozambique (Gerrits, 1997), the Gambia (Sundby, 1997), Zanzibar (Kielman, 1988), Laos (Liamputtong-Rice, 2000), and Bangladesh (Nahar et al., 2000), infertile women are excluded from societal events and ceremonies and/or despised and perceived as evil beings. Childless women complain about domestic violence, and disrespectful treatment by husbands and families-in-law; others are abandoned by their husbands or end up as a second wife in a polygamous marriage. However, considerable variation is found among regions. For instance, among the matrilineal Macua in the north of Mozambique, men are quite often blamed for infertility, which can lead to divorce initiated by the women or their relatives. In studies in India and Thailand, it appeared that husbands were supportive of their infertile wives (Bharadwaj, 2000; Boonmongkon, 2000). In a multi-site research study among couples visiting infertility clinics in India, Bharadwaj (2000) found that (contrary to the popular belief) men are no less affected by the stigma of infertility than women, and the fear of being considered impotent was found central to the anxiety that some men experience. Couples perceived both the infertility and the clinical management of it as stigmatizing conditions. Therefore, several respondents accepted donor oocytes or spermatozoa only as long as secrecy was maintained, because in this way others would consider their offspring as biologically natural, while adoption would make their infertility visible for the public, and was therefore seen as a more problematic and stigmatizing option. Differences between countries and regions regarding social isolation and rejection of childless women are (among others) influenced by the specific kinship systems, family and conjugal ties, by moral and legal rules and religious customs. Generally speaking, it seems that the relatively low status of women compared with men is associated with a strong negative response to infertile women.

Barrenness amongst plenty: infertility, a neglected problem

Politically, there has been a huge interest in reducing the number of births in developing countries. In reproductive health matters, strong emphasis has been on family planning programmes, in order to bring about a decrease in fertility. However, these programmes have not originated from ‘planning for the family’, following the family’s own perceptions, but rather from a political ‘top-down’ perspective (Hamberger and Janson, 1997). In the past, infertility care, i.e. attempting to improve the fate of childless parents by means of medical intervention, has received little attention. As a field worker of a family-planning project in India told the authors: ‘When I visited the villages, gave our message and delivered medications, there were always some childless women standing in the back, sometimes asking ‘When do you have something for us?’’. It has been established that in some developing areas, especially in various countries of sub-Saharan Africa, the prevalence of infertility is exceptionally high, affecting ~20–30% of women (Larsen, 2000).

However, since the 1994 United Nations International Conference on Population and Development in Cairo, important changes have occurred in the international field of reproductive health. ‘Prevention and appropriate treatment of infertility, where feasible’ were mentioned as issues for future action. Although this can be considered as a first step in the right direction, no guidelines were given on how to translate this statement in concrete strategies and programmes in low-resource countries. Since then the topic has received some attention from researchers and policy makers. Anthropological studies have been undertaken in several developing countries, which underline the importance of the problem from the perspective of the people involved, and at the same time demonstrate how little formal health services have to offer to the majority of the infertile people in developing countries. In some developing countries, government agencies and clinics have started to formulate policy and guidelines for the treatment of infertility, including regulations for the institutionalizing and use of modern reproductive technology (Okonofua, 1999; Rowe, 1999). Similar steps are probably being taken in other developing countries. Next to the issue of political willingness to give attention to the infertility problem, considerations of priorities in health resource allocation, costs, feasibility, quality control, sustainability and equity in access to health care, undoubtedly (and evidently) play a role (Okonofua, 1999). It is important to mention here that emphasizing the need to formulate a policy on ‘how to deal with infertility’, does not necessarily imply that NRTs should be introduced and financed by the public health system. What it should do is: (i) to stimulate health policy makers to document and evaluate the state of affairs in their country, with regard to infertility and its prevention, treatment, counselling and non-medical solutions and options; and, (ii) to improve the scope and
quality of this care, given the significance of infertility in the country in quantitative terms (how many people are affected), and in qualitative terms (how severely does it affect the women and men involved) (Van Zandvoort, 2000).

The search for conception: searching for fertility in biomedical and traditional health care

In studies on help-seeking behaviour in the case of infertility problems, it was found that help is sought from various sources, varying from home treatment, the formal medical system (public and private; general practitioners and specialists), herbal and spiritual healers, traditional reproductive health specialists, diviners, and priests (Inhorn, 1994; van Balen et al., 1997, 2000; Gerrits et al., 1999; Inhorn and van Balen, 2000). Sometimes the various health and other professionals were visited simultaneously, sometimes one after another. In several studies it was found that medical help was sought from traditional healers rather than from the modern health sector. Regarding traditional healers, e.g. herbalists and spiritual healers, it is sometimes said that they have some advantages over Western style medical and paramedical personnel (Mogobe, 2000). They use traditional, long-established medicines, know the people of the area, are often famous and trusted persons, speak the local language, and live according to the same culture. In contrast, the Western-style educated physicians often come from a distance, speak a different language or dialect, have different manners, and are often hampered by the lack of sufficient means, e.g. medicines and medical tools. Moreover, the local population may have serious problems in understanding their remedies and following their guidelines. This has also been found in studies of infertility treatment among migrant ethnic groups that have established themselves in Western societies, e.g. the Turks in Berlin (Scholz et al., 1999) and the Ghanese in Amsterdam (Yebei, 1999). Also, in some migrant groups there is a limited knowledge about the biological foundation of fecundity (Yüksel et al., 1995).

Traditional healers dealing with infertility problems are likely to have different ideas about the cause of infertility than biomedical thinking: ‘Supernatural forces’ are often considered to be the origin of the infertility problem. This was found for such different ethnic groups as among the rural Macua of Mozambique (Gerrits, 1997), the towns-people of Alexandria in Egypt (Inhorn, 1991), the islanders of Pemba, Tanzania (Kielman, 1998), the Dhaka slum dwellers (Nahar et al., 2000), and the Hmong mountain people from Laos (Liamputtong Rice, 2000). Liamputtong Rice (2000), for instance, describes menstruating girls taking a bath in the river; this is supposed to disturb the River God and hence may lead to infertility. The perceived cause may influence the fertility-seeking behaviour; the inverse can be true as well. Inhorn (1991) observed that the infertile town-women of Alexandria could mention the biomedical causes of infertility as falling neatly into the various categories of infertility promulgated by biomedical. The women were, in general, well informed about possible causes of infertility, due to extensive exposure to the biomedical discourse through their contacts with medical and paramedical staff, other clinic patients and the media. However, they were rather uninformed about their own particular case because of the reluctance of physicians to give information.

Fertility-seeking behaviour of the infertile is partly related with the perceived cause of the infertility problem. Other factors which influence this are the availability and accessibility of various health care practitioners and services and, more importantly, their own or others’ previous experiences with these services. Fertility-seeking behaviour often starts in a rather early phase, sometimes as early as 6 months after not conceiving (Inhorn, 1991; Gerrits, 1997; Bhatti et al., 1999; V.Mulgaonkor, personal communication). The search for conception is often depicted as a never-ending story. Infertile women, and sometimes men, are constantly looking for new options to try, often suggested and stimulated by people around them. People can be remarkably pragmatic in testing and evaluating health-care alternatives. Western and traditional medicine are, from the perspective of the patient, often seen not as competitive, but rather as complementary.

Iatrogeny and the boom of IVF clinics for the rich

Western biomedicine has the appeal of being new and effective. However, new methods have to be properly applied and used in appropriate circumstances. Evidence-based medicine has shown that some standard Western treatments are not all that good. Even in well-equipped Western clinics, using up-to-date knowledge, assisted reproduction can have serious complications, due to ovulation induction, laparoscopy, oocyte retrieval and laboratory practices (Schenker and Ezra, 1994). In poor-resource countries, lower quality laboratories and a lack of qualified paramedical personnel can enhance these negative effects. Added to this, physicians in developing countries use sometimes outdated knowledge, which may lead to iatrogenic effects. For instance, Inhorn and Buss (1993) describe the use of dilatation and curettage, thermocauterization of the cervix, as a standard treatment for infertility in Egypt. Reports from the Gambia (Sundby, 1997) and from Zimbabwe (Sundby and Jacobus, 2000) show that dilatation and curettage is still practised in many poor-resource areas as a standard cure for infertility. On the other hand, some traditional therapies, e.g. the insertion of certain herbs into the vagina, may also have iatrogenic consequences. Mogobe (2000) argues that practising Western biomedicine for infertility in poor-resource areas may be as iatrogenous as traditional medicine.

NRTIs have a received a lot of media attention in both developed and developing countries. IVF and intracytoplasmic sperm injection (ICSI) have rapidly become popular among the infertile members of the elites in developing countries, and their use is now spreading to the upper layers of the middle classes. In sub-equatorial Africa, IVF clinics are extremely sparse, and of poor quality. Well-to do infertile couples travel to the IVF clinics of the Republic of South Africa. Inhorn (2000) describes how formerly only the very rich infertile couples from Egypt travelled to IVF clinics in the Gulf states. However, at present 35 IVF clinics operate in Egypt which demand a fee that is still more than twice the annual income.
of the average Egyptian. It is obvious that having several IVF treatments can ruin one’s middle class status.

Some useful steps for improvement and prevention

In discussions about infertility care in developing countries, it is often proposed to focus on prevention. Of course, prevention is extremely important. Reproductive tract infections, particularly sexually transmitted diseases (STDs), are the leading preventable cause of infertility. In a World Health Organization (WHO) multinational study it was found that 60% of infertile women in sub-Saharan Africa had diagnoses that could be attributed to infection (WHO, 1987). The public must be made aware of the risk of STDs, including human immunodeficiency virus (HIV), regarding infertility. Prevention, however, does not help the ones that are already confronted with infertility. In addition, it is often proposed to concentrate on low-technology treatment; however, low-technology treatment for male infertility is not really successful (Gerris, 1998; Kamischke and Nieschlag, 1999), and artificial insemination using donor spermatozoa (AID) is not acceptable in various areas for religious reasons. Moreover, because of the risks of autoimmune deficiency syndrome (AIDS), AID is no longer safe using fresh semen and, by deep-freezing, the treatment becomes more ‘high tech’. Ovulation induction is a fairly successful treatment, but it is not an easy treatment, especially in areas were medicines are difficult to obtain, and proper monitoring is impossible. Sundby and Jacobs (2000) describe some simple measures at the community level in poor resource areas, that may reduce infertility (Sundby and Jacobs, 2000). Nurses and primary practitioners can advise on the timing of intercourse, the need to involve the (often reluctant) husband in semen testing and other services, and the need to test and treat STDs.

Given the magnitude of the problem (in terms of numbers and in terms of the impact on peoples’ quality of life) it is important that developing countries start to elaborate a policy on infertility care, ideally as part of an integrated reproductive health care programme. A policy should be based on a concise analysis and evaluation of the functioning of the actual health care structure, and its availability and effectiveness regarding infertility. The part to be played by primary, secondary and tertiary levels of health services should be carefully described, in order to reach an adequate and cost-effective referral system. Defining the role to be played by each category of health professional, and the training and updating of staff are of utmost importance (Rowe, 1999). In this respect it is also vital to stimulate local physicians to work in public hospitals by giving them incentives, in the hope of reducing the ‘brain drain’ of qualified gynaecologists either to private practice or abroad. Co-operation with (international) professional organizations is essential, as this will facilitate access to the latest scientific findings and gives the opportunity to learn from the experiences of others.

IVF and ICSI are presently out of reach of the bulk of the populace in many parts of the world. Sometimes even relatively well-to-do people end up in the slums by spending all their money on IVF (Mulgaonkor, 1999). To what extent ‘high tech’ diagnosis and treatment procedures with proven efficacy and safety can be part of a national infertility policy, and who will pay for these, remains an issue. Care should be taken that infertile people are given realistic information on the success rates of various treatment options and possible adverse effects, in order not to raise false expectations and to prevent wastage of resources. In addition, information should be given to infertile women about unnecessary and potentially harmful treatments, e.g. dilatation and curettage, cervical electrocauterization, and vaginal douching. It should also be explained that beliefs about the benefit of oral contraceptives and of random administration of antibiotics for the treatment of infertility are unfounded.

We are aware that only the general socio-economic development of the poor resource areas may bring efficient infertility treatment within reach of all. Meanwhile, it is important to raise the awareness of policy makers and health staff to give due attention to the issue of infertility, and the needs of infertile patients. In addition, the public awareness should be raised, not only to improve their own preventive behaviour, but also to diminish the stigmatization and social exclusion of infertile women and men, which may contribute tremendously to their quality of life.

Acknowledgements

Recently the International Conference on ‘Social Science Research on Childlessness in a Global Perspective’, was held in Amsterdam, The Netherlands from 8 to 11 November 1999. Participants attending this conference came from Asia, Africa, Australia, USA, and Europe. The authors, who were the organizers of this conference, were stimulated by the interesting papers presented at this conference to write this overview article and wish to express their gratitude to the participants. A copy of the Conference Proceedings can be requested from F.van Balen.

References


