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Biomedical infertility care in poor resource countries
Barriers, Access and Ethics

Social Science Study Group of the
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and the **WHO**



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Biomedical infertility care in low resource countries: Barriers and Access

Introduction

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***Key words*: ART, infertility, reproductive technologies, IVF, developing countries, access, reproductive rights.**

Introduction

Infertility and involuntary childlessness can have a devastating impact on the life and well-being of the women and men involved. In the last two decades the manifold consequences of infertility, most significant within developing countries, at personal, conjugal, family and community levels, and financially, have been well documented (Inhorn and Van Balen, 2002; Schuster and Hörbst, 2006; Van Balen and Bos, 2009; Van Balen and Gerrits, 2001). These studies have also shown that the way people experience, explain and deal with infertility is strongly related with their socio-cultural and economic life circumstances as well with the availability and non-availability of health care options.

Since the early nineties of the previous century various declarations and policy documents of international organizations and meetings, including the International Conference on Population and Development (ICPD) in Cairo, 1994, the World Health Assembly 2004 and the World Summit 2005, have underlined the importance of the prevention and appropriate treatment of fertility problems by recognizing the right to found a family, in high and low resource settings alike (Ombelet, 2009). However, in practice sexual and reproductive health care programs often neglect infertility and it is generally not viewed as a public health issue. This lack of attention for infertility care, including assisted reproductive technologies (ARTs), from the public health sector in developing countries is generally explained by referring to concerns about overpopulation, the heavy burden of life-threatening conditions (such as maternal mortality and HIV/AIDS) and the scarcity of health resources. Despite this lack of public policy attention for infertility care, a rapid globalization of ARTs has taken place in the past few decades. Worldwide the number of (primarily) private fertility clinics is steadily increasing, including within developing countries.

Limited information is available pertaining to the ways biomedical infertility care is supplied and used in different developing countries and within low resource contexts, though the number of studies in this area has increased over the last decade (Gerrits and Shaw, 2010; Hörbst, 2010; Inhorn, 2003; Inhorn and Tremayne, 2012; Sundby, 2002; Widge and Cleland 2009). These and other studies have provided insight into financial, political, socio-cultural, ethical and religious issues regarding access to infertility care, specifically with regard to ARTs. The aim of this Monograph is to bring together insights from various local realities in order to increase our understanding of factors and circumstances that are constraining, complicating and/or facilitating the provision and use of infertility services in different contexts. In addition, this Monograph addresses some of the challenges that the high prevalence of HIV/AIDS in many low resource areas can present within the delivery of infertility services.

This Monograph is the outcome of a two day Expert Workshop on 'Socio-cultural and ethical aspects of biomedical infertility care in poor resource

countries', when the contributors presented earlier versions of their articles. The Expert Workshop, which was held in Genk, Belgium, in November 2012, was organized by the Social Science Study Group of the ESHRE Special Task Force on 'Developing countries and infertility' ([1]), in cooperation with the Walking Egg Foundation, the World Health Organization and the Amsterdam Institute of Social Science Research (AISSR) of the University of Amsterdam. Besides making an inventory of the current state of the provision of infertility care in various low resource contexts, the Expert Workshop also aimed to reflect on further studies needed to examine and address barriers to access to infertility care, and to support, assess and track the introduction of accessible and affordable infertility care in developing countries.

The articles included in this Monograph give insight into the current day situation regarding the provision and use of ARTs in 11 countries on four continents. The 11 countries include three Low Income Countries (LIC) ([2]): Mali, Rwanda and Bangladesh; three Lower-Middle Income Countries (LMIC): Egypt, Sudan and Vietnam; and five Upper-Middle Income Countries (UMIC): Botswana, Brazil, Iran, South Africa ([3]) and Turkey. In the LMIC and UMIC vast disparities in income per capita exist, which appears to have significant implications for their access to ART services.

The articles show the manifold barriers that the provision and use of these technologies confront. Yet, they also provide us with insights into how some of these barriers have been, albeit partially, addressed. It should be noted that some of the articles present new insights, not previously published elsewhere; others are a digest of fuller papers about country situations that have already been published elsewhere but updated for the Expert Meeting and this Monograph. This introduction highlights major themes addressed in the contributions of this Monograph.

Policy

The articles re-confirm the notion that infertility care and the use of ARTs receive minimal attention from national policy makers and the public health system in developing countries. In the LIC, Bangladesh, Mali and Rwanda, infertility is almost completely neglected in public health care and policy; and in Sudan and Botswana, a lower and upper middle income country respectively, there is also limited attention paid to infertility care in the public health system, while ARTs are not offered. Regarding Brazil, authors Makuch and Bahamondes comment that infertility is receiving limited policy attention; yet, a few public (university) clinics do provide access to ARTs. In the other lower and upper middle income countries represented in this monograph the national health policy is addressing infertility and infertility clinics offering ARTs are available in the public health sector, and in some of these countries with some success within in the private sector.

Nahar, in her article about Bangladesh, attempts to unravel how, at the policy level, the neglect of infertility continues to exist despite the harsh consequences of infertility in the country (Nahar and Richters, 2011). She concludes that reproductive health policies in Bangladesh continue to be shaped by the discourse of population control (which started in the 1970s), and are mainly demographically and epidemiologically driven.

In contrast, in the Islamic Republic of Iran, which in the 80s and 90s of the former century had successfully undertaken a campaign to reduce population growth, policy makers – strategically – also paid attention to the treatment of infertility. In this way, according to Tremayne, in her article about ARTs in Iran, the policy makers hoped to prevent public resistance to the campaign, as Iranian culture and Islam highly value fertility and childbearing. As a result, currently several Iranian governmental clinics provide ARTs for free or at low cost, thus also making these technologies available for poor people. A similar story applies to Egypt, a developing country that, according to Inhorn and Gürtin, is generally regarded as overpopulated, but which has managed to reduce its population rates while at the same time addressing the infertility problem, including the provision of state subsidies for infertility care.

Inhorn and Gürtin show how the governments of both Egypt and Turkey – two pronatalist countries in which Islam is the predominant religion and parenting is highly valued – have paid attention to infertility services and made efforts to broaden access to infertility care, including ARTs, for the economically disadvantaged. Besides the countries being pronatalist, the authors also refer to particular circumstances that might have led to this increased

[1] See: www.eshre.eu/ESHRE/English/Specialty-Groups/Task-forces/Task-force-Developing-Countries-and-Infertility and www.thewalkingegg.com

[2] The division among income groups is according to 2010 gross national income (GNI) per capita, calculated using the World Bank Atlas method. The groups are: low income, $1,005 or less; lower-middle income, $1,006–3,975; upper-middle income, $3,976–12,275; and high income, $12,276 or more (Worldbank, 2010).

[3] It should be noted that the contribution of the South African based authors is a systematic review of the economic impact of infertility on women in developing countries, including some examples from South Africa.

political interest in addressing infertility. Egypt, for example, has an extended corps of highly trained IVF doctors and two FIGO directors, one of them having underlined the importance of care for families when fertility is threatened; and in Turkey, a strong and active patient support organization has successfully lobbied and advocated for the rights and interests of infertile couples.

The Social Republic of Vietnam, after a long period focusing on a one or two child family planning policy that successfully decreased the country's fertility to replacement level, has also recently recognized infertility as a problem at the policy level. This shift in policy reflects, according to Pashigian, a major cultural concern in Vietnam that highly values motherhood. Currently there are several functioning assisted reproduction centres, many even in the public health sector, a contrast to many other places worldwide.

Legislation

In most countries where ARTs have been introduced their use has preceded their regulation and legislation. Worldwide ART legislation and regulations diverge enormously, both in terms of *what* they regulate and *how* they are regulated, including, for example, the types of treatments offered and to whom (Jones and Cohen, 2004). Often, these regulations are shaped in the context of local cultural values and the predominant religion in the country. In this Monograph, several contributions report on the Islamic position on assisted reproduction, which varies between countries. This variation is mainly related to the particular form of Islam – Sunni or Shi'a – that is predominant in the country in question. The most striking difference between the Sunni and the Shi'a position regarding ARTs – as explained by Inhorn and Gürtin – is that Sunni Islam does not accept any form of third party gamete donation while Shi'a Islam does so under certain conditions. Tremayne refers to the manifold ethical and moral complications the Shi'a position leads to in actual clinical practice, where the rules are locally interpreted, as the religious edicts "cannot predict every eventuality arising within the practice of ARTs" (Tremayne, this Monograph).

With regard to Vietnam Pashigian observes that the government has put in place a comprehensive law to govern the provision and use of biomedical infertility treatments. According to the author, the law created opportunities, such as a relatively high cut off ages for infertility services, but also limitations. These limitations "include a ban on surrogacy; limited services for single women; restricted the use of donor ova to married couples; restricted the use of Vietnamese donor gametes to ethnic Vietnamese only; and sperm banks were largely restricted to the state sector" (Pashigian, this Monograph). While the law clarified a number of issues regarding the use of ARTs, the author argues that it also contributed to the stratification of those having access to these technologies, based on criteria such as marital status, ethnicity and reproductive needs.

In some of the other countries reported here the provision of ARTs is fully unregulated. This is for example the case in Sudan, where IVF is only offered in private clinics. Khalifa and Ahmed state that the country does not have an accreditation body to regulate issues such as the quality and safety of care, laboratory procedures, training requirements and pregnancy rates. The lack of ART regulation implies that the full responsibility for these aspects of care rests on the shoulders of the professionals running the private clinics, a situation that Hörbst also observed at the private clinics in Mali. This non-regulation, Hörbst claims, does not only provide them with the professional and moral liberty to do things in their own way, but also constitutes a level of instability for their investments.

While national legislation in some countries forbid the provision and use of some ARTs in certain situations and for certain persons, inhabitants of these countries travel abroad to seek the infertility services that they cannot find at home. For those who can afford it, crossing the border – cross border reproductive care – may be the only way to get access to certain forms of treatments, in the hope to accomplish their desire for a child, as mentioned in a number of contributions in this Monograph (Gürtin and Inhorn, 2011). In addition, wealthy infertile people from Sudan and Mali for example also seek treatment abroad out of distrust in the treatments offered in their own country.

Costs

The high costs of ARTs are a recurrent theme in all contributions in this Monograph. While costs in private facilities are higher than within public sector facilities, the latter are also unaffordable for the majority of the countries' population, leading to dramatic inequity in care. The costs of a single IVF treatment varies greatly across the various countries. Moreover, as in all countries infertility services are available only in the capital city or in a few big cities, expenses for travel and accommodation increase the total burden associated with infertility treatments. Thus, as with many areas of health care, geographical distance to clinics is an additional barrier to fertility treatment, increasing access inequity.

In some of the countries represented in this Monograph (Brazil, Egypt, Iran, Turkey and Vietnam) the state, health insurance, and/or public clinics cover part of the costs of IVF and other ARTs. In Turkey, for example, health insurances cover two cycles of treatment; in Egypt, governmental clinics providing ARTs receive some state funding to compensate for the expenses incurred by the infertile who are identified as being poor. However, only limited funds are available to financially support the infertile, which restricts the number of treatments that can be covered, as was explicitly stated in the cases of Brazil and Vietnam. This leads to the introduction of a selection criteria, prioritizing certain requests for reproductive assistance above others.

While limited funds are a recurring theme in almost all contributions in this Monograph, they also show that providers and users become creative in finding funds for treatments. For example, in Brazil it is reported that part of the expenses associated with ART treatments could be covered by health insurance, by using declaration codes that were recognized by the system for other gynaecological treatments (such as hormonal measurements and ultrasound scans). In Mali doctors give discounts for multiple treatments and they offer some monitoring for free; in addition they attempt multiple embryos transfers in the hope of increasing pregnancy rates.

Infertile women and men are also creative in finding means to cover the costs for infertility care. In Mali, Hörbst found that women can qualify for bank credits when they are employed. Female saving circles and financial support from relatives working abroad are other mechanisms to secure funds to overcome financial obstacles to treatments.

Notwithstanding the initiatives of governments, health insurance clinics, providers and users to find financial means to pay for infertility treatments, covering all expenses remains extremely difficult. Consequently, as noted by Dyer and Patel in their review of the economic impact of infertility on women in developing countries, infertility in low resource settings may lead to "impoverishing health expenditure, which threatens survival, or creates or deepens poverty" (Dyer and Patel, this Monograph). In addition to costs related to actual treatments the authors suggest that other economic consequences of the state of infertility (resulting in childlessness) should be recognized as well.

Private providers

The private sector has taken up the provision of ARTs in several countries. Based on research in Mali and other Francophone African countries (Togo and Senegal), Hörbst points to the many obstacles professionals intending to run a private fertility clinic confront. While there is sometimes a tendency to portray clinicians working in private clinics as persons who are making huge profits on the back of (poor and desperate) infertile women and men, Hörbst shows us the other side of the coin. Setting up a private fertility clinic demands a huge investment, in financial terms, in order to establish a clinic location and to buy medical instruments, materials and medicines, but also in self-development, in order to acquire and maintain updated knowledge and skills required to provide the services of a fertility clinic. At the same time, though, there is no guarantee that the clinic will be successful, in the sense of achieving pregnancies, attracting sufficient clients and being profitable. Various types of partnership models have been developed to enable the functioning of these private practices. These partnership models include for example a north-south partnership or an embryologist outsourcing lab services catering for more than one infertility clinic. Khalifa and Ahmed refer to similar challenges for private clinics in Sudan, where highly trained foreign staff have to be recruited for competitive salaries in addition to cost and travel reimbursements.

Culture and religion

The cultural and/or religious importance of bearing children, both for women *and* for men, is reconfirmed in the contributions of this Monograph. In many places women without children might be badly treated by their husbands or in-laws and feel the threat of divorce and polygamy; childless women as well as men fear that they will not have someone to care for them in old age or to bury and remember them when they pass away; at family and community level they are often stigmatized, disrespected and undervalued. The cultural and religious value placed on childbearing may thus, in this way, aggravate the – personal and emotional – suffering of involuntary childless women and men, when they are unable to achieve the cultural ideal of parenthood.

As we see from the contributions in this Monograph, it is (partly) because of the cultural importance – imperative – of childbearing that several national governments have taken the initiative to pay attention to infertility and infertility care. The contributions also show how this cultural importance of childbearing and the negative implications of infertility affect the way infertile women and men use infertility services. Several authors point to the secrecy surrounding their help seeking behaviour: visits to the fertility clinic, the diagnosis, the use of a particular form of treatment (such as the use of donor material) and/or the birth of a child resulting from ARTs may all be hidden from the partner, family and/or

community at large. Moreover, study findings from Mali show that men are often unwilling to go to a clinic as they have already fathered a child in another relationship or because they fear being diagnosed as the one who is causing the problem; or they would rather opt for social solutions (taking a second wife or fostering a child) than taking the uncertain route of expensive treatments. In Sudan, IVF is only offered in combination with ICSI (Intra Cyto-plasmatic Sperm Injection), a treatment offered for serious male factor infertility. This might indicate that in the case of female factor infertility no treatment will be sought, a tendency that has also been observed by Hörbst in Mali. The secrecy that may surround the use of infertility treatments and the unwillingness of men to be involved in these treatments may lead to undesirable ethical dilemmas in clinical and counselling practices.

Infertility care in the context of the HIV/AIDS epidemic

Finally, Dhont and Bochow address the double burden – and double stigmatization – of infertility and HIV/AIDS in respectively Rwanda and Botswana, both countries having a high HIV/AIDS prevalence. Mechanisms explaining the association between HIV and infertility are manifold – yet, under researched – and related with physical factors as well as with social, sexual and reproductive behaviour. Dhont states that when examining the interplay between HIV and infertility two different situations can be distinguished. First, HIV infected couples who want children and are subsequently faced with the situation of the inability to conceive; and secondly, couples suffering from infertility, faced with the diagnosis of HIV infection in one or both partners during infertility examinations. With regard to the first group of couples the questions arise: how does HIV infection impact their desire for childbearing and how does the infertility care seeking behaviour of HIV infected couples differ from non-HIV infected couples. For the second group the primary question is how the diagnosis of HIV affects their desire for a child. Dhont indicates that hardly any research has been done addressing these questions. Based on her study in Rwanda she draws our attention to a number of key ethical, psychological and medical issues that have to be considered when planning infertility services in sub-Saharan Africa, which by necessity includes the management of HIV infected couples.

National policies regarding the way child wish desires of HIV positive people should be responded to vary across countries. In Botswana, for example, the formal policy is that these women should be counselled to adopt a child. However, as Bochow shows, this policy is not always put in practice: medical doctors vary in their response to requests of HIV+ women to conceive. Both contributions show that the patients, professionals and policy makers who are confronted with the double burden of infertility and HIV/AIDS still have a long way to go to find adequate responses to the many questions and dilemmas raised.

Conclusion

The articles in this Monograph point to the many obstacles infertility care and ARTs in low resource settings are facing. At the same time we learn of mechanisms which have been found to (partially) overcome obstacles to access and care. The examples of Egypt, Turkey, Iran and Vietnam show how governments have started to pay attention to infertility care, while paying attention to family planning aiming to decrease fertility rate and (successfully) bringing down population growth. These examples prove what Frank (1983), a population researcher, alluded to many years ago: women and men will be more inclined to use contraceptives, if they know that their concerns and fears about infertility are also taken seriously. These examples have also shown the importance of leading figures and organizations in lobbying and advocating for infertility care.

Financial obstacles remain an important hurdle for all stakeholder: governments, (private) providers and clients. As several of the authors have indicated, innovative ways have to be found to make infertility services – from prevention to treatment – more available, accessible and affordable. The contributions in this Monograph stimulate us to think creatively about innovative approaches, including: 1) the development of new types of partnerships (public-private, transnational, outsourcing components of treatments); 2) exploring existing insurance mechanisms as well as alternative ways of health financing; and 3) the development of low cost and simplified ART procedures, including a one-day diagnostic procedure, on which the ESHRE Task Force is focussing.

Policy makers, legal structures and clinical practitioners regulating and providing infertility care and ARTs see themselves confronted with several questions and dilemmas – legally, ethically and psychologically – which often are a result from cultural and religious contexts. These questions and dilemmas need careful consideration, to avoid increasing gender and other inequalities among those in need of infertility treatment, particularly in areas where the HIV/AIDS epidemic augments these challenges.

Finally, paying intention to biomedical infertility care – as part of a reproductive rights approach – will

not resolve the situation of many currently infertile women and men. Even if ARTs would become widely available, this would not bring an end to the problems infertile and childless people see themselves faced with, given the existing cultural and religious value placed on childbearing. Biomedical infertility care does not tackle the problem of their maltreatment and stigmatization (it might even increase it), which is a theme that was highly debated in the 2011 Genk Expert Meeting. Next to interventions increasing access to biomedical infertility care, interventions to decrease stigmatization and suffering from infertility and childlessness are needed. Raising public awareness about biomedical causes of infertility is necessary, underlining, for example, the fact that male factor infertility is as common as female factor infertility. Further, ways should be found to address the vulnerable position of infertile women at the conjugal, familial and community level. As discussed in the Expert Meeting the 'coming out' of successful childless women (and men) in the mass media could be one means to achieve this. In this realm insights from studies showing, for example, that the fate of Indian elderly childless women is not always dramatic (Riessman, 2002) and that higher educated women in Ghana felt less stigmatized compared to lower educated women (Donker and Sandall, 2007), are promising. Life courses of infertile women in a globalizing world – where experiences, viewpoints and medical practices are contantly changing – do not remain static, but also change over time. Participants at the Expert Meeting identified this as one of several important themes for future studies. In addition to, for example, studies addressing barriers to accessing infertility care, and studies to prepare, assess and follow up the supply and use of accessible and affordable infertility care in different low resource contexts. Participants at the Expert Meeting showed to be committed to take these topics along in their own research agenda. Time has come to properly address infertility, a reproductive health concern that too long has been neglected.

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Global access to infertility care in developing countries: a case of human rights, equity and social justice

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Abstract

According to WHO data more than 180 million couples in developing countries suffer from primary or secondary infertility. The social stigma of childlessness still leads to isolation and abandonment in many developing countries. Differences between the developed and developing world are emerging because of the different availability in infertility care and different socio-cultural value surrounding procreation and childlessness.
Although reproductive health education and prevention of infertility are number one priorities, the need for accessible diagnostic procedures and new reproductive technologies (ART) is very high. The success and sustainability of ART in resource-poor settings will depend to a large extend on our ability to optimise these techniques in terms of availability, affordability and effectiveness.
Accessible infertility treatment can only be successfully introduced in developing countries if socio-cultural and economic prerequisites are fulfilled and governments can be persuaded to support their introduction. We have to liaise with the relevant authorities to discuss the strengthening of infertility services, at the core of which lies the integration of infertility, contraceptive and maternal health services within public health care structures.
After a fascinating period of more than 30 years of IVF, only a small part of the world population benefits from these new technologies. Time has come to give equitable access to effective and safe infertility care in resource-poor countries as well.

Key words: **Developing countries, equity, government, human rights, infertility treatment, involuntary childlessness, low cost ART, social justice.**

Introduction

As the power of medical technology advances, more and more difficult questions are raised about what sorts of rights to such technologies people might have, especially in resource-poor countries. People surely have a right to basic medical care, therefore global access to infertility care should be seen as a fundamental human right, with respect to socio-cultural, ethical and political differences worldwide.

Although IVF and related procedures get all the public attention, infertility care cannot be reduced to assisted reproductive techniques alone. Other options are equally important such as a listening ear and psychological support for infertile couples, the availability of basic diagnostic procedures, easy methods of ovarian stimulation and timed coitus, intrauterine insemination, reproductive surgery etc.

The level of infertility care we are aiming for will differ from country to country. Many variables can be important such as the economical and political situation of the country, the level of education and reproductive health care, actual facilities concerning medical care including the quality of the hospitals,

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the available equipment, facilities to perform surgery in case of complications, the level of mother care and many others.

It is our aim to describe the facts and our views and vision on the issue of childlessness and infertility in developing countries.

The Facts

The large majority of childless couples are residents of developing countries. According to the WHO it is a silent population of more than 180 million couples facing the consequences of infertility day by day (Rutstein and Iqbal, 2004). Infertility care is probably the most neglected and underestimated health care issue in developing countries. Although the negative consequences of childlessness are much more pronounced in developing countries when compared to Western societies, interest of the international community and local health care providers is still lacking (Ombelet et al., 2008).

In less-developed countries the 12-month **infertility prevalence rate** ranges from 6.9 to 9.3% (Boivin et al., 2007). Substantial geographical differences are noted and these differences can be explained by different environmental, cultural and socioeconomic influences. In Sub-Saharan Africa infertility is caused by infections in over 85% of women compared to 33% worldwide (Cates et al., 1985; WHO, 1987). Approximately 70% of pelvic infections are caused by STDs while the other 30% are attributable to pregnancy-related sepsis (Ericksen and Brunette, 1996). Similarly, many cases of male factor infertility are caused by previous infections of the male genitourinary tract (Kuku and Osegbe, 1989). Both conditions are preferably treated by assisted reproductive technologies but most infertile couples in developing countries can't afford ART because the techniques are too expensive and mostly limited to private centres (Nachtigall, 2006; Murage et al., 2011).

The **consequences of involuntary childlessness** are much more dramatic in developing countries and can create more wide ranging societal problems compared to Western societies, particularly for women. Negative psychosocial consequences are often severe and childless women are frequently stigmatised, isolated, ostracized, disinherited and neglected by the entire family and even the local community. This may result in physical and psychological violence and polygamy (Daar and Merali, 2002; Dyer 2004, 2005; Umezulike and Efetie, 2004; Ombelet et al., 2008). Women are usually blamed for infertility and can be ostracized and assaulted by their families, even driven to suicide or killed (Anonymous, 2006). Because many families in developing countries completely depend on children for economic survival, childlessness has to be regarded as a social and public health issue and not only as an individual medical problem (Gerrits and Shaw, 2010; Papreen 2000; van Balen and Gerrits 2001, 2009).

Reduced fecundity in HIV-infected individuals has been described and marital instability and polygamy secondary to infertility may in turn increase the spread of HIV-1 infection. HIV is 3 times more prevalent in infertile couples when compared to fertile controls in the same population (Nabaitu et al., 1994; Dhont et al., 2011a, 2011b). **HIV and infertility** share the same determinant of high risk sexual behaviour. Both conditions are more common in resource-poor countries, may lead to stigmatisation and isolation and are strongly influenced by socio-cultural and economic conditions. Treatment options are expensive and in both cases the final result is a diminished population. On the other hand, HIV treatment is becoming more effective and available at lower prices which are not the case for infertility treatment. Awareness, attention, documentation and research of the HIV problem are much more pronounced compared to the infertility problem which remains mainly hidden. Public solutions are being applied for HIV, for infertility the solution is mainly found in the private sector. It is striking, almost fascinating, that budgets for HIV research are huge and the information on HIV is easily available while the contrary is true for infertility.

Do we care? Despite the well documented observations of the social and economic consequences a surprisingly low interest is shown on the issue of infertility and childlessness on a national and international level. The two key arguments against treatment of infertility in developing countries are overpopulation and limited resources.

The argument of **overpopulation** suggests that in countries where overpopulation poses a demographic problem, infertility management should not be supported by the government.

It is well known that the world population is expected to increase from 6.7 billion inhabitants in 2005 to 9.2 billion in 2050 (United Nations, 2007). By 2050, the population of the developing world would be adding 35 million annually, 22 million of whom would be absorbed by the least developed countries. Therefore, national and international health strategies have always focussed on reducing total fertility rates (number of children per woman) while infertility care has received little or no attention (Hamberger and Janson, 1997).

But even if infertility treatment could be made more accessible in developing countries it would probably account for less than 1% of all deliveries.

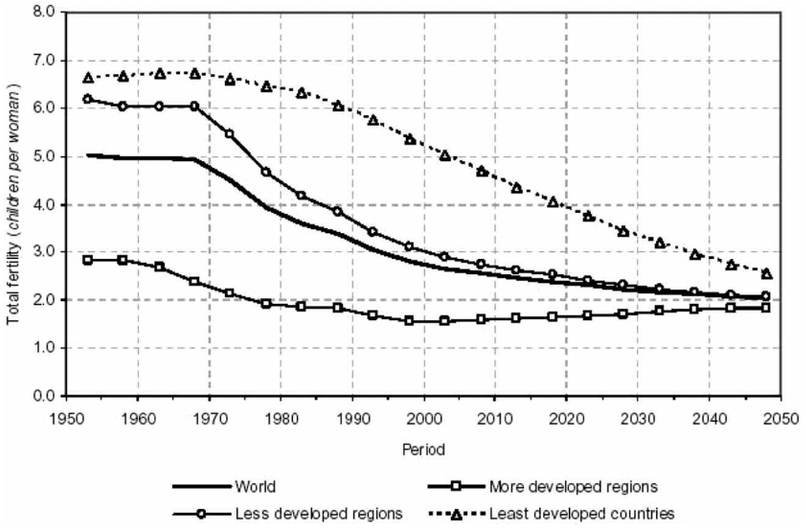

Fig. 1. — Total fertility trajectories for the world and the major development groups, 1950-2050 (*World Population Prospects: The 2006 Revision, page 6)*

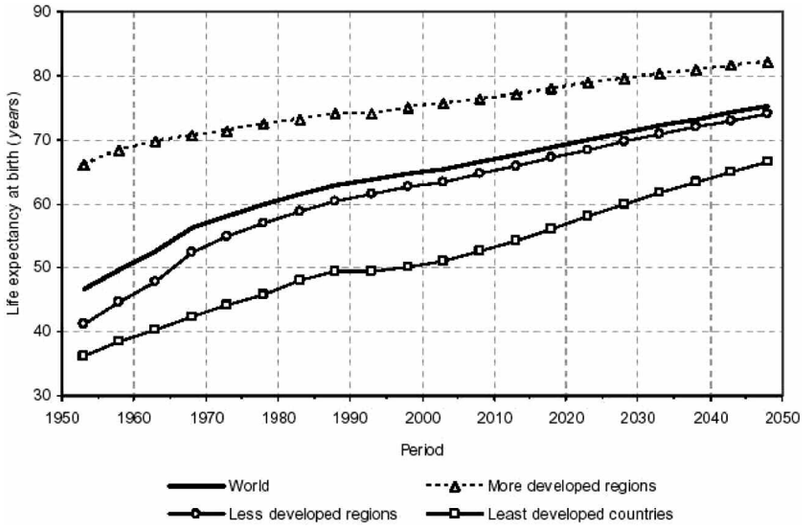

Fig. 2. — Life expectancy at birth for the world and the major development groups, 1950-2050. (*World Population Prospects: The 2006 Revision, page 12)*

Increasing efforts on family planning and health education can readily overcome this small contribution to the fertility rate. Denying infertile couples access to infertility care is not a fair population restriction policy. United Nations data not only show that the majority of developing countries already succeeded to drop their global fertility rate below 2.5, the data also show that the expected population growth in developing countries is mainly due to an improved life expectancy and not to high fertility rates (United Nations, 2007, Fig. 1, Fig. 2).

To illustrate the complexity of the problem: it is well known that the fertility rate of a specific country is positively related to infant mortality, which is understandable because aged couples will depend economically from their children in many developing countries (Palloni and Rafalimanana, 1997).

According to the **'limited resources'** argument it is hard to justify expensive fertility treatment in settings with few resources and more important challenges to deal with. Can expensive techniques be justified in countries where poverty is still an important issue and where health care systems still struggle with the huge problem of infectious diseases such as malaria, tuberculosis and HIV? In most developing countries the reduction of maternal mortality and the promotion of contraception are considered to be the reproductive health priorities (Aboulghar, 2005). Improved "reproductive health education programmes" have proven to be an excellent preventive



Fig. 3. — Some of the most important foundations, NGOs and international societies linked to reproductive health. In none of these organisations "infertility care in developing countries" is mentioned as an issue they support.

tool against overpopulation, sexually transmitted diseases (STDs) and pregnancy-related infections. But even with better education and preventative care programmes, involuntary childlessness will remain an important problem for millions of couples.

Reproductive autonomy is the main argument in favor of the provision of infertility treatment in developed countries. People have the right to decide when, how many and how to have children. Why would citizens of developing countries not have the right to have at least one child, especially if we succeed to simplify the methods of infertility care and make them affordable for a much larger part of the population?

To get **funding for infertility care** is nowadays almost impossible. We recently carried out an internet-search for possible donors. A questionnaire dealing with the scope of their actions and the interest in infertility care in developing care was sent to the most important foundations, NGOs and international societies linked to reproductive health (Fig. 3). They all showed interest in the issue of childlessness in developing countries, but in none of these organisations infertility care has been funded before and no future projects were planned. Considering local governments: it is not only the resource constraint which prevents the providing of infertility services in many developing countries. With the dominant discourse focusing on controlling overpopulation it is no wonder that infertile women are marginalised and consequently excluded from health sector interventions. Infertile women are victims of the systematic process of 'cultural' exclusion, but in some countries they are also 'institutionally' excluded (Papreen Nahar, Bangladesh, personal communication).

International statements: promises and promises: "Men and woman of full age, without any limitation due to race, nationality or religion, have the right to marry and to raise a family". This statement was adopted 60 years ago at the 1948 UN Universal Declaration of Human Rights and can't be misunderstood: it implies the right to access to fertility treatments when couples are unable to have children. At the United Nations International Conference on Population and Development in Cairo in 1994 the following statement was made "Reproductive health therefore implies that people have the capability to reproduce and the freedom to decide if, when and how often to do so … and to have the information and the means to do so …". In 2004 the World Health Assembly proposed five core statements, including "the provision of high-quality services for family-planning, including infertility services" (World Health Assembly, 2004). The International Federation of Obstetricians and Gynaecologists (FIGO) stated that "women and men have the right to the highest available standard of health care for all aspects of their sexual and reproductive health" (FIGO, 2003).

Political statements and commitments need to result in appropriate actions but progress towards the attainment of these goals on the subject of infertility in developing countries remains however slow. The reasons are multiple and include, among others, the problem of 'brain drain', lack of collaboration, budgetary constraints and lack of political commit-

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Table I. — Global access to infertility care in developing countries: facts, views and vision.

(DC = Developing Countries, STDs = Sexually Transmitted Diseases, OHSS = Ovarian Hyperstimulation Syndrome, NGOs = Non-Governmental Organisations)

Global access to infertility care in developing countries

FACTS

- Prevalence of infertility: similar to Western countries
- Negative consequences of childlessness are much stronger in DC
- Prevention and alternative methods are not always successful
- ↑ secondary infertility due to STDs and unsafe abortions / deliveries
- HIV and infertility: very comparable on many determinants and final results
- HIV and infertility: very different in how the issue has been treated by the international community
- Global access to infertility care – **arguments contra**
  - Overpopulation
  - Limited resources
  - Problem of funding: "the battle for money' between initiatives on reproductive health care
- Global access to infertility care – **arguments pro**
  - ↑ Demand from developing countries
  - ART techniques can be simplified
  - Social justice and equity

VIEWS

- A need for ↑ reproductive health care education
- A need for ↑ prevention programmes
- Raising awareness: support of media and patients networks needed
- Implementation of more and accessible infertility centres
  → Urgent need for simplified, safe and effective methods (diagnostic procedures and ART)
- Prevention of complications is crucial: OHSS, multiple pregnancies
- Facilities to handle complications have to be available, including facilities for surgery

VISION

- Simplified methods of infertility care will be available in the near future
- The demand from developing countries to introduce ART will increase
- The implementation of accessible infertility centres should be part of an integrated reproductive care programme including family planning and contraception, mother care, and reproductive health.
- Foundations, NGOs and international societies have to be convinced about the value of this project

ment (Fathalla et al., 2006). On the other hand, the most important non-profit international organisations including Family Health International, WHO, International Planned Parenthood Federation (IPPF) and The Population Council still focus on safe motherhood, the reduction of unsafe abortions, prevention of STDs and HIV/AIDS. The implementation of infertility treatment in developing countries is not a priority for these organizations.

Views

The level of **reproductive health care education** is very low in most developing countries although it is the most cost-effective strategy in the prevention of unwanted pregnancies and sexually transmitted diseases (Lutz and Goujon, 2001). A better education is clearly associated with lower fertility rates and an increasing access to education for women is probably the best strategy for an optimal population control (Fig. 4). Incorporation of reproductive health education in general health education should be supported by the governments. Data from social researchers have shown that an important barrier to use contraception is the fear for consequent infertility. Family-planning and infertility are clearly linked and should be handled in the same centres. Public education on prevention of infertility includes not only prevention of STDs and pregnancy-related infections, but also life style factors, iatrogenic infertility, environmental pollution and contamination. Education programmes are essential and should be updated.

Prevention of infertility remains the most cost-effective treatment strategy particularly in countries with a high prevalence of pregnancy-related infections and STDs. Advantages are numerous: prevention programmes are more cost-effective and benefit a greater number of people, they are more effective in eliminating the social consequences of infertility

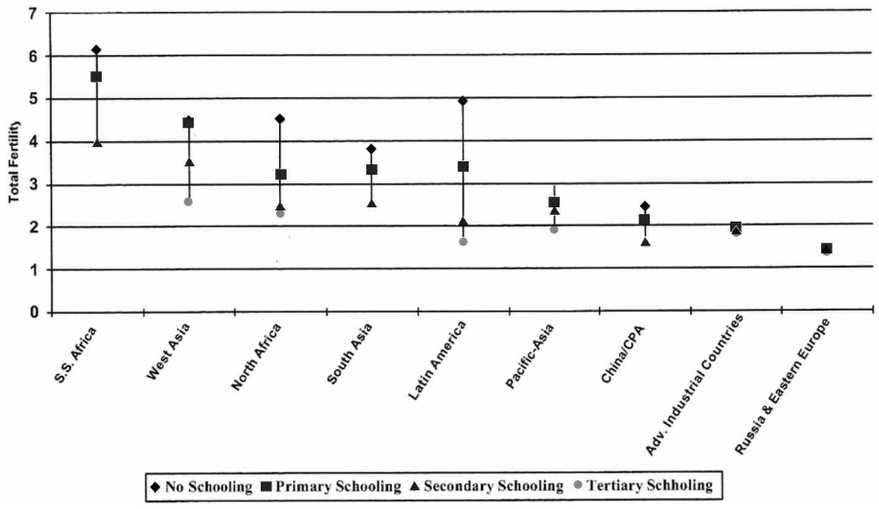

Fig. 4. — Differentials in total fertility by women's education, circa 2000, for selected regions. (replacement level = 2.1). **Source**: Adapted from Lutz W, Goujon A. The world's changing human capital stock: multi-state population projections by educational attainment. Population and Development Review 2001;27:323-9.

and will improve the health status of women in other ways. Last but not least, prevention programmes can easily be integrated within existing mother-care and family-planning services.

On the other hand, when resources are exclusively allocated to prevention programmes due to limited resources, millions of childless couples are ignored because prevention will fail in a substantial number of couples. Although it is our belief that the governments should give priority to education and prevention programmes, this does not mean that no money should go to infertility treatment at all, especially if we could make infertility care less expensive and affordable.

From an **ethical and socio-cultural** point of view we have to ask ourselves whether we can justify withholding infertility treatment, including ART, in those cases where prevention has failed. Believing that the arguments of overpopulation and limited resources are strong enough for not helping infertile couples in developing countries doesn't take into account the human rights in general and the reproductive rights in particular (Vayena 2002). Efforts should be made to reduce the excessive social reactions to infertility inspired by pronatalism. Therefore infertility treatment should be part of an integrated reproductive care programme including family planning and contraception, mother care, and reproductive health. Education, empowerment of women and economic prosperity are the most effective solutions to most problems related to both population growth and infertility. Simultaneously, investments in low-cost interventions are justified (Pennings et al., 2009). Reproductive autonomy, justice and equity support our efforts to make ART available and accessible worldwide subject to political stability and a basic level of medical infrastructure.

Raising awareness is another very important issue and should be done with great care. Most important is to focus on changing the existing moral and socio-cultural beliefs in so far that childless couples are no longer isolated and discriminated. We will need the media, patient organisations and interested politicians to reach this goal. Obstacles will be numerous and will depend on local socio-cultural, political and religious influences. Providing infertility care in developing countries can only be successful if we are able to diminish the socio-cultural, psychological and economic consequences of unwanted childlessness.

Patient support networks already claimed the right to equitable access to infertility treatment all over the world (Dill, 2007). Patients' voices will be crucial when the issue of infertility has to be discussed with policy makers and health care providers.

If we want to **implement accessible fertility services** in developing countries, the first objective is to simplify the diagnostic procedures (Malpani and Malpani, 2002). This can easily be organised in one-day clinics. The suggested work-up is very simple, reliable and comparatively inexpensive. Moreover, all of these procedures can be performed by a small team of health care providers within a short period of time in an inexpensive setting (Ombelet and Campo, 2007).

Implementing **low cost ART** is only possible if we succeed to simplify the methods of treatment in such a way that they still are effective and safe, but affordable. The number of scientific papers on simplification of ART is growing every year.

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For the recruitment of oocytes in an IVF programme we should avoid the use of high doses of expensive ovarian stimulation medication such as gonadotrophins, GnRH agonists and GnRH antagonists, if possible. The use of clomiphene citrate, a very cheap oral drug, has been proven in many studies to be an optimal alternative with acceptable results, minimal side effects and a very low complication rate (Ingerslev et al., 2001; Verberg et al., 2009; Aleyamma et al., 2011).

Lowering the costs associated with laboratory procedures, namely fertilization and culture of eggs and embryos, represents another challenge. One possible approach is the use of a 'humidicrib', a plastic box which is commonly used for keeping newborns snug, instead of an expensive laminar flow hood (Hovatta and Cooke, 2006; Pilcher, 2006). For a tenth of the price this box can be modified to be used as a portable, near sterile environment for the handling of gametes and embryos. Expensive cylinders of carbon dioxides required to incubate the embryos may be abandoned in favour of exhaling across the culture medium before sealing it in a plastic bag. This bag, containing the Petri dish with the embryos, can be dropped into a warm bath without the need for expensive incubators. This technique has been successfully used for more than ten years in veterinary IVF (Vajta et al., 1997, 2004).

Other strategies using very simple incubation systems are presently tested and the preliminary results are very promising (van Blerkom, personal communication).

Intravaginal fertilization and culturing is another inexpensive method for low cost IVF (Frydman and Ranoux, 2008). A tube filled with culture medium containing the oocytes and washed spermatozoa is hermetically closed and placed in the vagina. It is held by a diaphragm for incubation for 44 to 50 hours. Over 800 cycles cycles have been published worldwide with a very reasonable clinical pregnancy rate of almost 20% (Frydman and Ranoux, 2008).

Presently we don't know if IVF, even minimal stimulation IVF, is feasible in less than ideal conditions when compared to centres with high standards of laboratory equipment and using standard stimulation protocols. Therefore, studies on simplified, low-cost diagnostic procedures and ART techniques are urgently required in a low-cost setting. We have to avoid that accessible ART doesn't mean poorer quality, otherwise we will create an unacceptable double standard in therapy.

Risks of implementing ART in developing countries include the inability to deal with complications following infertility treatment. Ovarian hyperstimulation syndrome, multiple pregnancies, premature babies, ectopic pregnancies are not uncommon in an ART programme. These complications should be avoided at all price and the facilities and knowledge of the staff should be adequate to handle these problems. Reproductive tourism by attracting international clients from Western countries because treatment can be offered at lower prices is a real danger and is already reported in India (Vayena, 2009).

We also have to realize that even if universal access to infertility care will be available, **barriers** will always remain considerable. Not only in many Islamic countries (Serour, 2006) but also in Latin America the use of ART is severely restricted because of religious doctrines (Inhorn, 2003). In India a conflict with the normative value of Hindu because of the involvement of a third party which compromises the process of conception has been described (Bharadwaj, 2003). Patients in many non-Western countries upholding traditional belief systems are mostly unfamiliar with the technology of 'modern medicine" and therefore might be not willing to accept ART as such (Qiu 2003). Consequently, traditional healers will play an important role and have to be educated about the new developments in infertility practice. Because they speak the language of the local people and appeal to local cultural belief, their support and cooperation will be crucial.

Vision

Infertility care has to be an essential part of a more comprehensive reproductive health care program including infertility and HIV prevention, family-planning and safe mother-care, a go-together of prevention and treatment programs (Sharma et al., 2009).

December 2007 the Special Task Force "developing countries and infertility" of ESHRE (European Society of Human Reproduction and Embryology) organised an expert meeting on in Arusha, Tanzania: the **Arusha-project** was born! Global access to infertility care is the key message but can only be implemented and sustained if they are supported by local policy makers as well as the international community. Accessible infertility care should only be provided in developing countries if there is a political will to support actions for gender equality and women's empowerment through education.

The implementation of new reproductive technologies will require well-organised education and training programmes. Regular audits and systems of accreditation and registration should be implemented in order to maintain appropriate standards of care in all centres involved.

The need for funding is crucial and is likely to require input and collaboration from various role players. Funding is needed for the fixed costs of new

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Table II. — Important challenges for the Arusha Project (C Janisch, 2011, personal communication)

- A coherent strategy is required
- A business plan with clear cost structures must be formulated.
- Personnel are required for advice, training, and implementation.
- Protocols and management policies must be defined
- A Lead Organization should be identified to support the planning and design phase.
- Locations for pilot-projects need to be decided
- Cooperation between different societies is needed
- Organization of scientific studies in the different pilot-countries
- Define service packages in order to convince people to donate knowing exactly what they are paying for
- A voucher scheme can be used to improve the quality of services through the development of an accreditation process and enhanced competition among service providers
- The integration of family planning, safe motherhood care and infertility services will be crucial

fertility centres (building, equipment, ...), the running services (consumables, medication, medical interventions, staff salaries), for training the medical, paramedical and administrative staff and for education the public which implies contacts with schools, politicians, traditional healers and the media (Sallam, 2008).

I hope that the **medical and pharmaceutical industry** will also make relevant contributions such as providing cheap medication, manufacturing of basic ultrasound and laboratory equipment at low price etc. **Foundations** have to be convinced about the value of this project, taking into account the growing demand from the developing countries itself and the case of equity and social justice. Many **International Organizations** have already expressed their will to participate in this initiative such as the WHO, ESHRE, IFFS, ICMART (International Society for Monitoring Assisted Reproductive Technology) and ISMAAR (International Society for Mild Approaches to Assisted Reproduction). All these organization can contribute actively in the realisation of this project. Table II summarizes the urgent needs for the Arusha Project.

Conclusion

The great majority of infertile and childless couples are residents of developing countries. Bilateral tubal occlusion due to sexually transmitted diseases (STDs) and pregnancy-related infections is the most common cause of infertility in developing countries. Consequently most cases of infertility are only treatable by using assisted reproductive technologies (ART) which are either unavailable or very costly and only within reach of the happy few who can afford it.

Prevention remains the number one priority, not only the prevention of STDs but also the prevention of infertility due to unsafe abortions and deliveries.

We urgently need a better public education on reproductive health and raising awareness of health care providers and politicians on the importance of childlessness. Most striking is the total lack of interest of the international society including foundations and non-governmental organizations working in the field of reproductive health.

Time has come to change policies and to realize that access to infertility care is one of the largest emerging fields in global medicine. The immense problem of childlessness in developing countries requires greater attention at national and international levels for reasons of social justice and equity. Keystones in the successful implementation of infertility care in low-resource settings include simplification of ART procedures in order to establish accessible good quality infertility services at low cost.

To conclude, I believe that global access to infertility care in developing countries can only be achieved when good quality but affordable infertility care is linked to more effective family planning and safe motherhood programmes. Only a global project with respect to socio-cultural, ethical, economical and political differences can be successful and convince those who believe that the issue of overpopulation is still an absolute argument to deny the "forbidden desire' of many childless women in developing countries.

"In a world that needs vigorous control of population growth, concerns about infertility may seem odd, but the adoption of a small family norm makes the issue of involuntary infertility more pressing. If couples are urged to postpone or widely space pregnancies, it is imperative that they should be helped to achieve pregnancy when they so decide, in the more limited time they will have available."

Mother or nothing – the agony of infertility - M. Fathalla, WHO Bulletin, 2010

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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

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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 treating 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 considerable 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, infertility 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) of 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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Infertility and Assisted Reproduction in the Muslim Middle East: Social, Religious, and Resource Considerations

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Abstract

This paper discusses the social, religious, and resource considerations around infertility and the provision of assisted reproductive technologies in the Muslim Middle East. Demonstrating the social need for IVF by millions of involuntarily childless Muslim men and women, as well as the religious permissibility of the technique according to Islam, we provide the positive examples of Turkey and Egypt regarding how resource concerns may be tackled and access to ARTs broadened. We end the paper by making a call for ARTs and infertility treatments to be incorporated into comprehensive reproductive care regimes, and for reproductive rights to encompass the facilitation as well as the control of fertility.

Key words: **Assisted reproduction, IVF, Islam, Muslim Middle East, Turkey, Egypt.**

Introduction

For involuntarily childless couples around the globe, "reproductive health" means achieving a much-desired pregnancy, thereby overcoming the stigmatization and heartbreak of childlessness. At the dawn of the 21st century, the globalization of assisted reproductive technologies (ARTs) has meant that achieving this dream with the help of medical intervention is increasingly a global reality for men and women in many parts of the world. Indeed, perhaps nowhere is this globalization process more apparent than in the more than 20 nations of the Muslim Middle East, where pronatalist social norms and strong child-desire have contributed to a flourishing in vitro fertilization (IVF) industry. For example, Egypt hosts over 50 IVF clinics, Turkey over 100, and the tiny country of Lebanon has one of the highest per capita concentrations in the world. However, even here, ART provision remains variable and heterogeneous, mediated through numerous "arenas of constraint" (Inhorn, 2003a, 2003b). Despite the deliberate efforts of some nations to increase access to ARTs, social, religious, and resource considerations create variability and inequality across the Middle Eastern region.

This article outlines some of the key social, religious, and resource considerations regarding infertility and ARTs in the Muslim Middle East. Social considerations demonstrate the gendered and human suffering of involuntarily childless men and women, showing that IVF and related technologies are desperately needed by many infertile couples in the Muslim Middle East, particularly because neither childlessness nor alternative routes to parenting (including adoption) are acceptable. Religious considerations illustrate the paramount importance of practicing reproductive medicine according to Islamic law in this part of the world, where third-party reproductive assistance is largely banned. However, while there has been a strong and enduring consensus among the Sunni Muslim authorities regarding the nature of these parameters, Shia Muslim clerics have provided a variety of opinions, leading

Iran and Lebanon to become the only two countries within the Muslim Middle East to practice third-party reproductive assistance. Resource considerations, with specific examples from Egypt and Turkey, demonstrate that while ARTs must of course compete with other pressing priorities, if approached with creativity and sensitivity, their provision can become part of broader reproductive health and reproductive rights frameworks. We end the paper by making a call for ARTs and infertility treatments to be incorporated into comprehensive reproductive care regimes, and for reproductive rights to encompass the facilitation as well as the control of fertility.

Social Considerations

Strong pronatalist norms across much of the Muslim Middle East, as well as in many developing countries, mean that children are highly desired and parenthood is culturally mandatory. As a result, infertility may be an especially pernicious form of "reproductive disruption" (Inhorn, 2007). Infertile couples face not only emotional difficulties due to their inability to conceive, but also severe difficulties in achieving their social security, social power, and social perpetuity desires (Inhorn, 1996). Infertility leads to profound social suffering, particularly on the part of women (Inhorn and van Balen, 2003). Women's lack of pregnancy is both physically and socially visible, especially in high-fertility societies where women are typically blamed for reproductive failures, even in cases of male infertility. Involuntarily childless women may face various forms of community ridicule and social ostracism: they may be taunted about their barrenness and lack of femininity; they may be turned away from life-cycle rituals involving other women and their children; and they may be accused of casting the evil eye on other women's children through their uncontrollable envy (Inhorn, 1994, 1996).

Although the gender burden of infertility is particularly pronounced for women, men, too, suffer from their infertility and attempt to overcome it (Inhorn, 2012). Male infertility remains deeply hidden in most societies around the world, because it is among the most stigmatizing of all male health conditions (Inhorn, 2004, 2012). Such stigmatization is clearly related to issues of sexuality. Male infertility is popularly, although usually mistakenly, conflated with impotency, as both disrupt a man's ability to impregnate a woman and to prove one's virility, paternity, and manhood. Although little is known about the experience of male infertility worldwide, recent research from the Middle East shows that contrary to popular expectation, male infertility is more common than female infertility and, like female infertility, may have profound effects on personhood, marriage, and family relations, particularly since Middle Eastern Muslim men are expected to father offspring (Inhorn, 2012). Furthermore, men in these societies may be subjected to ineffective, even iatrogenic medications and genital surgeries in an attempt to overcome their infertility (Inhorn, 2004, 2012). However, the promise of fatherhood is a strong incentive for involuntary childless men to pursue ARTs.

Recent research, by more than a dozen social science scholars working across the Middle Eastern region (Inhorn and Tremayne, 2012), shows that infertile Muslim couples – including *both* men and women – are increasingly willing to pursue assisted reproductive technologies in pursuit of parenthood, often within the context of long-term loving marriages. In part because of the cultural and religious valorization of marriage and parenting, Islamic authorities have condoned assisted reproduction as a "marriage savior" and the solution to the human suffering brought about by childlessness. The Islamic permissibility of ARTs is counterbalanced by the Islamic prohibition on adoption: namely, child adoption is prohibited in the Islamic scriptures and thus is not legally available in the vast majority of Muslim societies. Because adoption is not a viable path to "social" parenthood for most Muslim couples (Inhorn, 2006a), men and women in the Middle East often vigorously pursue "biological" parenthood, which requires them, in many cases, to pursue ARTs to the best of their abilities. Indeed, as shown in recent anthropological work by numerous Middle East scholars (Inhorn, 2012; Inhorn and Tremayne, 2012), Middle Eastern men and women from a variety of social classes and backgrounds are attempting to access ARTs in their 21st-century quests for conception.

Religious considerations

Unlike in many other parts of the world, in the Muslim Middle East, ARTs are practiced according to religious guidelines. Not only are Islamic religious authorities keen to establish the parameters within which assisted reproduction is and is not acceptable, but many infertile couples are also extremely concerned about making their "test-tube babies" in the correct and religiously endorsed fashion.

Sunni Islam is the dominant form of Islam throughout the world, with its followers accounting for nearly 90 per cent of the world's Muslims. The Sunni Islamic position on assisted reproduction was outlined in a seminal *fatwa* (an authoritative religious proclamation issued by an esteemed religious scholar) by the Grand Sheikh of Egypt's famed Al Azhar University on 23 March 1980. This initial *fatwa* – issued only two years after the birth of

Louise Brown – has proved to be truly enduring. Its main tenets have been upheld by subsequent *fatwas* and have achieved widespread acceptance throughout the Sunni Muslim world (Inhorn, 2006b, 2012). The main points of the Sunni Islamic position on ARTs are as follows (Serour, 2002, 2008; Inhorn, 2012):

(1) Artificial insemination with the husband's semen is allowed, and the resulting child is the legal offspring of the couple.

(2) In vitro fertilization of an egg from the wife with the sperm of her husband, followed by the transfer of the fertilized embryo(s) back to the uterus of the wife is allowed, provided that the procedure is indicated for a medical reason and is carried out by an expert IVF physician.

(3) An excess number of fertilized embryos can be frozen through cryopreservation. The frozen embryos are the property of the couple alone and may be transferred to the same wife in a future frozen cycle, but only during the duration of the marriage contract.

(4) Sperm or gonads may be cryopreserved before exposure to radiotherapy or chemotherapy and used later in life by the same individual who has survived cancer treatment.

(5) Pregnancy in post-menopausal women is allowed using a woman's own cryopreserved embryos, oocytes, or, in the future, ovaries.

(6) Multifetal pregnancy reduction (a.k.a. selective reduction) is allowed if the prospect of carrying twins or a high-order multiple pregnancy (HOMP, i.e., triplets or more) to viability is very small. It is also allowed if the health or life of the mother is in jeopardy. As a form of selective abortion, the intention is to preserve the life of the remaining fetuses and minimize complications for the woman.

(7) PGD is allowed and even encouraged, where feasible, as a diagnostic option to avoid clinical pregnancy terminations among couples at high risk of genetic disorders in their offspring. PGD may also be used in cases of "family balancing," when couples have children of only one sex.

(8) Embryo research, for the advancement of scientific knowledge and the benefit of humanity, is allowed for fourteen days post-fertilization on surplus embryos that are donated for research with the informed consent of the couple. These research embryos should not be returned to the woman's uterus.

(9) In the future, gene therapy may be approved, not to promote genetic advantage or privilege in offspring, but rather to remediate genetically or otherwise physically inherited genetic diseases and pathological conditions.

(10) In the future, uterine transplantation will be allowable as a remedy for women who are lacking a competent uterus. The transplanted uterus may be obtained from a postmenopausal donor or a woman of childbearing age who has completed her family. Uterine transplantation has been performed in the Middle East (i.e., Saudi Arabia and Turkey), but to date, a viable pregnancy in a transplanted uterus has yet to occur.

All of the Sunni majority countries in the Muslim Middle East practice ARTs according to these parameters, even secular Turkey (Gürtin, 2012). However, there has been a divergence of opinion among Shia Muslim clergy. Namely, although many Shia authorities support the majority Sunni view, some prominent Shia clerics have disagreed on the matter of third-party assisted reproduction. In 1999, the Supreme Leader of the Islamic Republic of Iran, Ayatollah Ali Hussein al-Khamene'i, the successor to Iran's Ayatollah Khomeini, issued a fatwa effectively permitting donor technologies to be used. As a result, all forms of ART – including sperm donation, egg donation, embryo donation, and gestational surrogacy – are now practiced in Shia-dominant Iran (Inhorn and Tremayne, 2012). In addition, Shia-dominant Lebanon has followed suit (Clarke, 2009; Inhorn, 2012), making it the only other Muslim-majority country, to provide third-party reproductive assistance to married infertile couples (Inhorn and Tremayne, 2012).

Given this situation, both Iran and Lebanon have become recipients of "reproductive tourists" from neighboring Sunni-majority countries, who quietly slip across international borders in pursuit of donor technologies (Inhorn, 2011). For those Muslim couples who do pursue third-party assisted reproduction, egg donation is deemed much more acceptable than sperm donation, and both are widely regarded as "last resorts" when all else fails (Inhorn et al., 2010). Such third-party reproductive assistance is usually conducted under conditions of extreme secrecy, for this practice is widely refused by the great majority of Sunni Muslim men and women, as well as some Shia Muslims. Across the Sunni Muslim world, stretching from Morocco to Malaysia, third-party reproductive assistance is effectively banned, making this prohibition widely relevant for infertile Muslim couples from many countries.

Resource considerations

Having said this, it is very important to point out that most other forms of assisted reproduction *are* allowed within both Sunni and Shia Islam. As a result, a burgeoning ART industry is unfolding across the Muslim Middle East. However, here, as throughout the world, the availability of infertility services is a

complex product of public and private health policies and economic, political, and social forces that determine the allocation of personnel, equipment, and facilities (Nachtigall, 2006). As a result of rapid globalization, ART services are gradually reaching larger populations even in the resource-poor nations of the region (e.g., Egypt, Morocco, Yemen). Despite this, however, if there is a reproductive "right" to ART – under a rights-based approach to family planning – then this right has yet to be achieved by millions of infertile couples throughout the Middle East (Inhorn, 2009). The average cost of an ART cycle in the Middle East ranges from the low of about $US 1,000 (e.g. Iran and Egypt) to the high of about $US 6,000 (e.g. the UAE), with many countries in between (e.g., $2,000-$5,000 in Lebanon). These represent prohibitively high costs for large sectors of the population, whose access to ARTs can only be mediated through government, NGO, or philanthropic provisions. Although ARTs often face strong competition for scarce healthcare resources, Turkey and Egypt provide two important examples where efforts have been made to broaden access to infertility services for the economically disadvantaged, as we have discovered in our ethnographic research in these different contexts.

Turkey: Turkey's first IVF baby was born in 1989 but it was not until the new millennium that the ARTs experienced a rapid expansion throughout the country. Funding for two cycles of IVF treatment, redeemable through state and social insurance institutions as of 2005, accelerated both the demand and encouraged the growth of the industry. The number of IVF centers increased by 50 percent between 2005 and 2007, from 66 to 91, and the number of annual treatment cycles doubled. The total IVF expenditure in 2007 was reported to be in excess of 300 million dollars, which according to national newspapers (e.g. Hürriyet, 31.01.2008) ranked Turkey as "The World's 7th Biggest IVF Market" (behind Israel, France, Spain, England, US, and Germany). Currently, there are over 110 clinics throughout Turkey, and while many are concentrated in urban areas, clinics are increasingly opening across the nation, signaling both an increase in access and a decrease in social taboos towards infertility and its treatment (Gürtin, 2012). Moreover, Turkey has a very active patient support organization for infertility, which has been influential in the development of the fertility sector. ÇIDER - the name an acronym of the Turkish words "I Want a Child Solidarity Association" – is an organization whose character cannot be readily inferred from is counterparts in the US or in the UK. Its activities are a mix of patient advocacy, awareness-raising, and community building (putting involuntarily childless people in contact with another), alongside medical marketing and the harnessing of consumer power. It was founded in 2000 by Sibel Tuzcu – as simply a website with some information on infertility and fertility treatments – but has since, through extremely hard working and committed leadership, become an important player within the Turkish IVF industry, with over 40,000 members. As well as holding information provision and public awareness meetings all over the country, ÇIDER also canvasses the opinions of its members, lobbies regulators, and liaises with clinics to secure preferential fees for its membership. Combining a consumer activism model with civil society engagement, ÇIDER has given voice to many infertile Turkish men and women, and has effectively advocated for their interests and rights at the clinical, regulatory, and social levels. However, despite these positive factors, it must also be noted that Turkey recently regulated "reproductive tourism", by taking a step to prohibit its citizens from seeking ARTs with third-party reproductive assistance, even in other jurisdictions (Gürtin, 2010, 2011).

Egypt: Egypt was one of the first three Middle Eastern countries (along with Saudi Arabia and Jordan) to introduce ARTs in 1986. Since then, Egypt has developed a thriving IVF sector, with more than 50 IVF clinics serving an infertile population estimated at 15% of all married couples (among a total population of nearly 80 million) (Inhorn, 2003b, 2012; Serour, 2008). Five of these clinics are located in government hospitals and receive some state funding to offset expenses for the infertile poor. The busiest clinic is located in Al-Azhar University, Egypt's oldest and most famous institute of religious learning, under the auspices of the Al-Azhar International Islamic Center for Population Studies and Research. The clinic was started by Prof. Gamal I. Serour, director of Al-Azhar's Islamic Center and former president of FIGO (2006-2009). Designed to serve the needs of Egypt's infertile poor, the clinic provides generously subsidized IVF cycles to hundreds of lower-income couples each year. This example from Egypt is instructive. Egypt is a resource-poor, developing country, which has generally been regarded as seriously overpopulated. Nonetheless, Egypt has managed to bring down its population growth rates while, at the same time, experimenting with state subsidization of infertility care, including the provision of ARTs (Serour, 2008). Why has Egypt moved in this direction? A combination of cultural and political factors may provide the answer. Culturally, Egypt is a pronatalist Muslim country, where both marriage

and parenting are religiously extolled virtues (Inhorn, 1994, 1996, 2003a; Serour, 2008). Politically, the country hosted the famous "Cairo conference" (ICPD 1994), where "prevention and appropriate treatment of infertility, where feasible" was mentioned as an issue for future action (van Balen and Gerrits, 2001). Furthermore, Egypt has produced a remarkable cadre of highly trained IVF physicians, as well as two FIGO presidents. One of these former presidents, Mahmoud Fathalla, has argued, through the prism of reproductive rights, that "family planning must also mean planning for families" (Fathalla, 2002).

Conclusion

Unfortunately, effective infertility treatments and ARTs are generally inaccessible in the resource-poor and mostly rural nations of the developing world, leading to a grim scenario of untreated and intractable infertility across large portions of the globe. The nonexistence of IVF and other ARTs in these countries is often rationalized in terms of population control, scarcity of health care resources and infrastructure, and the heavy burden of other life-threatening diseases. While these concerns raise major questions about prioritizing infertility as a global reproductive health problem, the silence surrounding infertility in the resource-poor world may also reflect a tacit eugenic view that the infertile poor are unworthy of treatment; thus, overcoming their infertility problems, including through provision of ARTs, contradicts Western interests in global population control.

A meeting convened by the World Health Organization in 2001 recommended that infertility be considered a global health problem and called for more innovative approaches in its treatment (Vayena et al., 2002a). There is no doubt that, especially in developing countries, ARTs will always face tough competition for precious resources. However, it is time to shift attitudes from the polarized approach of being "for" or "against" ARTs to a more constructive approach of exploring new possibilities and innovative ways of making ARTs available in a manner that suits the needs and the particular situations of low-resource settings in the developing world (Vayena et al., 2009). Infertility services span a broad spectrum from prevention to treatment. While prevention of infertility may be considered by governments and public healthcare providers as a societal and resource priority (Vayena et al., 2002b), it nonetheless ignores the plight of men and women who find themselves involuntarily childless and whose lives may be seriously impacted - on an emotional, relational and economic level – as a consequence. Infertility treatment should be part of an integrated reproductive care program including family planning and motherhood care (Pennings et al., 2009), and the prevention and treatment of infertility need to be seen as being on a continuum of care, rather than contrasting or opposite approaches.

Indeed, almost 20 years post-Cairo, it is time to rethink the meaning of reproductive "rights" through a framework that includes prevention and treatment of infertility through the provision of ARTs. In addition to the right to *control* fertility, reproductive rights must encompass the right to *facilitate* fertility when it is threatened. For millions of couples in developing countries, including those in the Muslim Middle East, facilitation of fertility may require them to resort to ARTs. In short, achieving full reproductive rights around the globe means achieving access to IVF and related technologies. Although the barriers to ART provision in the developing world, and in the Muslim Middle East, are continually cited in the policy literature, it is time to move beyond repeated justifications for inaction. Turkey and Egypt provide positive examples of real progress in ART service provision. Several other Middle Eastern countries, including Iran and the United Arab Emirates, to name only two, have followed suit with at least limited provision of state subsidized ARTs. As we enter the second decade of the new millennium, it is time for other developing countries to follow suit, thereby helping their infertile citizens to achieve their reproductive rights through becoming loving parents.

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Invisible women in Bangladesh: Stakeholders' views on infertility services

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Introduction

Infertility remains a neglected issue in Bangladesh's reproductive health policy; instead, the emphasis has always been on the problem of overpopulation. As a result the dominant state ideology in Bangladesh is related to controlling fertility, and the implementation of Family Planning programmes has become a success story for the country (Ahmed and Chowdhury, 1999; Country Report, 2006). Although no epidemiological study has been conducted in the national level to know the prevalence rate of infertility in Bangladesh, a global review of infertility from the World Fertility Survey and others estimated infertility rates in South Asian countries stated 4% in Bangladesh. Another estimate of overall primary and secondary infertility in South Asia, on the basis of women at the end of their reproductive lives in the age group 45-49 years, suggests an infertility rate of approximately 15% in Bangladesh (Vaessen, 1984; Farely, 1988, cited in Kumar, 2007), which is the highest among all South Asian countries.

There is evidence that potential causal factors of infertility are also widely present in Bangladesh. Studies showed that in the South Asian region reproductive health problems such as sexually transmitted diseases (STD), urinary tract infections (UTI), reproductive tract infections (RTI), unhygienic delivery, postpartum infection and unsafe obstetric and abortion procedures are linked to sepsis and pelvic infections, which can cause infertility (Unisa, 2010; Ali et al., 2007; Prasad 2005; WHSEA, 2002a; Jejeebhoy, 1998). A report by WHSEA (2002b) suggested that the prevalence of STDs in Bangladesh is still unknown, but following their analysis of small scale studies conducted between 1989 and 1997, Bangladesh has a high prevalence of STDs. Other investigation reported that the estimated number of people with STDs in the country is around 2.3 million (SDNP-2002). A recent study of truck drivers in Bangladesh found a high prevalence of the herpes simplex virus (HSV-2), at 25.8% (Gibney et al., 2002). WHSEA's (2002b) report also suggested that in Bangladesh the prevalence of RTIs amongst women is 56% in rural and 60% in urban settings.

It is noted in addition, that because of the underreporting of secondary infertility in health facility based studies, the information that is available on causes of infertility is likely to consistently underestimate the role of infections, which are the most frequent cause of secondary infertility, 55% as reported by WHSEA (2002a). Compounding the problem is the increasing number of abortions and unhygienic birth practices in Bangladesh, which can also result in a higher likelihood of pelvic infections. It has been observed that only 5% of births in Bangladesh are attended by a health professional (WHSEA, 2002b) and abortion practice have increased in recent times in the country (Rahman, 2000). A cross-sectional study revealed that 66% of the women surveyed reported that they had experienced at least one complication during their last pregnancy and/or childbirth (Ahmed et al., 1998).

Furthermore, the other indirect causal factors of infertility are also worth mentioning here, such as poverty, tuberculosis, malnutrition, anaemia, and low-birth-weight. For example it is already acknowledged that poverty increases the risk of infertility in many ways, for example, the scarcity of water and the lack of access to nutrition and health care make women more vulnerable to RTI, which may cause secondary infertility among them (Unnithan-Kumar, 2001). This is the case in Bangladesh, where 36% of people live below the poverty level. Also a number of studies done in India found that tuberculosis is another indirect causal factor of female infertility

(Haque, 2002; Kumar, 2008). Haque (2002) reported globally Bangladesh ranks as the fourth highest country in terms of the prevalence of TB, and contains 3.6% of the TB cases diagnosed worldwide. There is also evidence of the effect of maternal nutritional status, e.g. weight and mid-arm circumference, and anaemia on the incidence of sterility (Jejeebhoy, 1998; Singh, 2007). According to a Human Development report, 59% of young girls suffer from chronic malnutrition in Bangladesh (WHSEA, 2002b). This is further confirmed through the Government of Bangladesh Country Report (2000), which stated that approximately 70% of pregnant mothers in Bangladesh suffer from malnutrition and high rates of anaemia (Country Report, 2000). Another factor contributing to infertility is low-birth-weight, with 50% of all infants in Bangladesh being born underweight (Fuchs, 1992).

In addition to these practical issues, infertility has a deep cultural dimension. Whilst Bangladesh is an anti-natalist state, the society is pro-natalist. For various economic, cultural and religious reasons children are necessary and extremely valued in this society. Consequently, being childless has a wide range of consequences for both rural and urban Bangladeshi women, in terms of social stigma, familial violence, and psychological or economic disadvantages, with the essence of all these consequences being 'suffering'. Studies show that in a patriarchal society like Bangladesh where motherhood is synonym of womanhood, childlessness destroys the identity of womanhood, which results in marginalisation (Nahar and Richters, 2011; Nahar, 2010b, 2010c, 2012).

However, despite the fact that there are significant potential risk factors for infertility in Bangladesh, and that infertility results is a serious disruptions to people's/women's wellbeing, there are hardly any services available for infertility in Bangladesh (UNFPA, 1996). In a comparatively recent discussion of maternal health in Bangladesh, Graham (2001), by using the source of 'Bangladesh Demography and Health Survey' data, provided a list of reproductive health care services in Bangladesh. There too was no mention of infertility service in the list.

A more recent qualitative exploration, the experiences of infertile women in terms of their health seeking in Bangladesh, found that there are hardly any public or NGO services for infertile people/women. Along with a wide range of informal private services, there are only a few biomedical services available in the private sector, and these are expensive (Nahar, 2010a). With this as a backdrop, in this paper I will explore the stakeholders' views on the lack of infertility services in Bangladesh.

Methods

This paper is based on a larger ethnographic study carried out in Bangladesh in 2003-2004, which explored cultural constructions and the consequences, resilience of infertility amongst rural and urban childless women (Nahar, 2007). The current paper is mainly based on key-informant interviews. Key-informant interviews are qualitative in-depth interviews with the individuals who are likely to provide needed information, ideas, and insights on a particular subject.

The 24 key-informants included stakeholders from government and non-government organisations, such as GO and NGO programme implementers (#6), policy makers (#4), donors (#3) and public health researchers (#2). The result of the interviews provided broader socio-political understanding of the reasons behind the unavailability of infertility services in Bangladesh. In addition, to understand the reasons behind the availability of infertility services in the private sector, private biomedical infertility practitioners (#3) and verities of informal providers (#6) were also interviewed. The key-informant interviews took place in the stakeholders' office or health centres. Each interview lasted at least for an hour. An open ended 'guideline' was used for interviewing; the topic list was altered for different groups.

Results

In this section, I will present the stakeholders' views of the reasons for including or not including infertility in the policy or services of their respective sectors. These views will be navigated by means of a vertical grouping of key stakeholders involved in reproductive health issues. I start my journey at the very bottom level of the ladder of stakeholders, and reach the top by the end of my journey.

Reasons behind not providing infertility services in the public sector

Implementers' views

All the interviewed government and NGO representatives acknowledged the need for infertility services. Since they worked at the grass roots level, they frequently came across the consequences of childlessness and had noticed the harassment of childless people in terms of health seeking. However regarding the reasons for not including infertility in the agenda, both government and NGO representatives mentioned that they could not include infertility

in their programmes because infertility was not a priority issue for the Bangladesh government's health agenda, and nor were donors interested in it. NGO representatives added that infertility services require specialist training for the doctors, pathology lab workers and the organisations did not have these human resources.

However, it is important to note that programme implementers are placed at a level below the policy makers, so they are not in a position to influence national decisions on health interventions, including infertility services. I therefore then turned to the Bangladeshi health policy makers in order to investigate the perspectives of people who do have the power to influence.

Policy makers' views

It was found that policy makers including the directors of different relevant Wings of Health Ministry of Bangladesh Government and the NGO Reproductive Health Programme directors did not have any plans to include infertility in their agenda in the near future. The major constraint mentioned by the government representatives was a limit in resources and having other priority issues. The representatives strongly believed that there were many other priority issues within reproductive health that needed to be focused on, for example fertility control and maternal health. As one of the government representative said, "There is no money to provide any other additional services within this budget. Due to fund limitations, we are even struggling with our existing family planning programme, the most crucial problem of the country".

The NGO policy makers mentioned other reasons for not including infertility, such as an absence of technical facilities within their resources, not having a person/department to refer to in the district level government hospital for infertility treatment. Moreover NGOs follow the principle of 'prevention' which is another reason for excluding infertility but including STDs and maternal health. Finally, the main reason NGOs are prevented from including infertility services in Bangladesh according to the NGO policy makers is the lack of willingness of both the donors and the government. A representative of an NGO stated:

> *"Our Government does not or cannot do any research in order to fix priorities. Whatever donors want, that becomes our area of interest. This is how donors give emphasis to some issues and other issues remain ignored. Sometimes donors do not consider the local reality, they just make a general proposal for every country. I believe infertility is ignored for this reason as well".*

With this in mind, I explored the views of donor agencies.

Views of donor agencies

The representatives of prominent donors of reproductive health in Bangladesh were interviewed ([1]). They did not consider that infertility could be included in the reproductive health programmes in Bangladesh in the near future. None of the donor representatives believed that infertility was a priority issue for the country. The donor representative from donor (A) stated that they have other priority issues to address at the moment. She said, "Infertility is out of our mandate at this moment". She suggested donor (B), the major fund-giving organisation in Bangladesh, could play a bigger role in tackling infertility.

I subsequently talked to donor (B)'s reproductive health programme head. According to her, one of the major reasons for not providing funds for infertility care in Bangladesh is that Bangladesh has neither the technical expertise in the field of infertility, nor the infrastructure that would be required for setting up infertility clinics. It would require huge investments to address this issue. Moreover, she remarked that to set up a programme one has to justify the problem by showing the incidence and prevalence rates, especially in a resource-poor country like Bangladesh. Unfortunately, no information on the infertility rate is available in Bangladesh. She added that because of the resource constraints, donor (B) funds for reproductive health issues are applied on a priority basis. According to her, infertility is not a problem for the majority of the population, and so it is not a priority issue for the country. However donor (B) representative suggested donor (C) might have a plan on this, as family planning is their main area of activity.

At this point I went to interview donor (C)'s country representative. This person informed me that donor (C) never make any decisions about fixing priorities for any country. It was the Bangladesh Needs Assessment Team who had prioritised maternal mortality reduction for the country in the last headquarter meeting, which she saw as logical considering that Bangladesh has a maternal mortality rate of 322 per 100,000 live births. As a result most of donor (C)'s funds go to the programmes that address this issue and family planning programmes. The representative said, "We do not fund infertility services. We think that high maternal mortality and morbidity is still a

[1] Donors' fictive names are used as A, B and C.

problem for Bangladesh and that needs to be addressed first. Moreover, overpopulation is a constant threat, and infertility is not a threatening issue for the country". She further added that donor (C) would need to know the prevalence rate of infertility before they began to address it. Therefore a survey report with statistics would be needed, which currently does not exist.

Researchers opinions

At this stage I continued my journey by interviewing the researchers from the leading international health research institute in Bangladesh, one of them is a demographer who works mainly on family planning, the other one is a social scientist who works on health equity issues. Both of them highlighted how government and donors prioritize fertility control as their health agenda pushing aside issues like infertility. In addition, they also mentioned some methodological complications of epidemiological or demographic research on infertility. For example, the definition of infertility in demography itself may exclude some infertile women from the survey; thus under report prevalence rate. One researcher thought that the traditional approach of public health, which focuses on mortality reduction and fertility control, and conceptualizes women's health as maternal health, is the reason for organisations ignoring infertility. Figure 1 shows the top down approach of decision-making of infertility services in the public sector in Bangladesh.

Motives behind providing infertility services in private sector:

In a context where both the public health services provided by the government and NGOs in the formal sector remain silent about infertility and offer hardly any services to the sufferer, it is the private health providers of the formal and informal sectors that have filled the gap. In order to gain a better understanding of the infertility service sector dynamics I explored the motives of private sector providers for providing services for childlessness. Figure 2 shows the availability of infertility services in the private sector in Bangladesh.

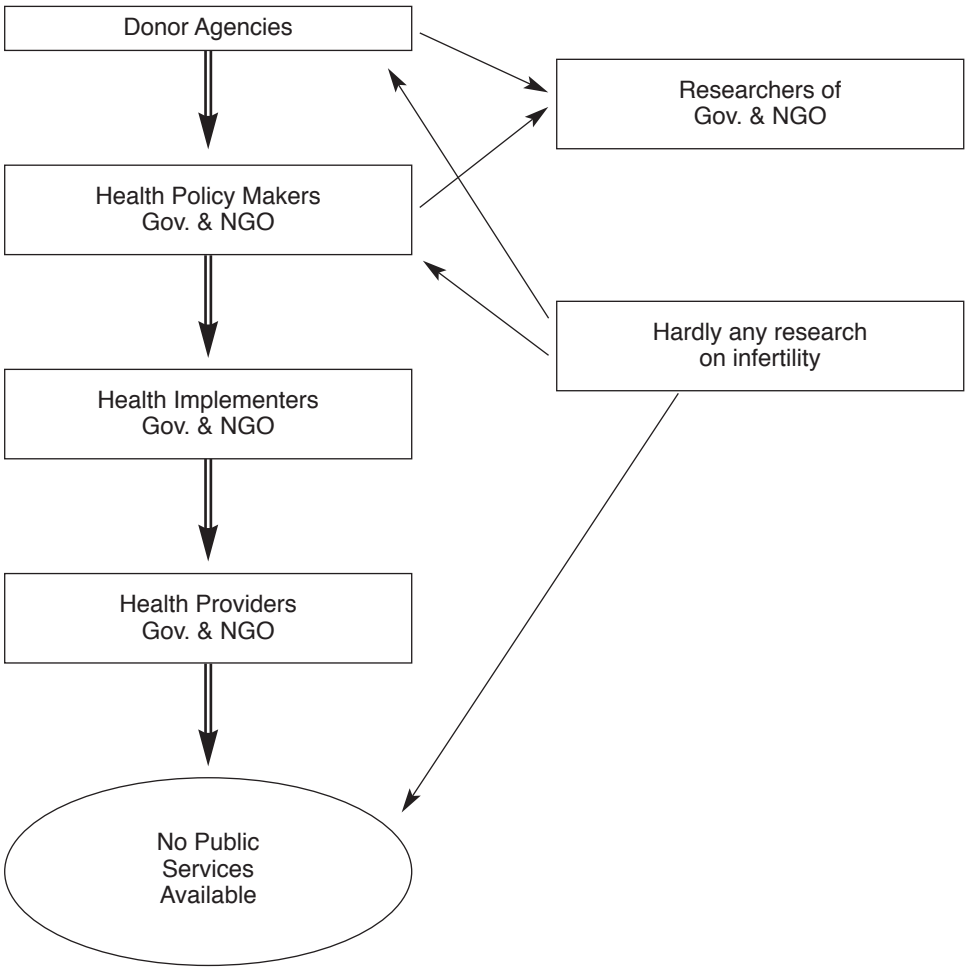

Fig. 1. — Top down approach of decision-making of infertility services in the public sector in Bangladesh

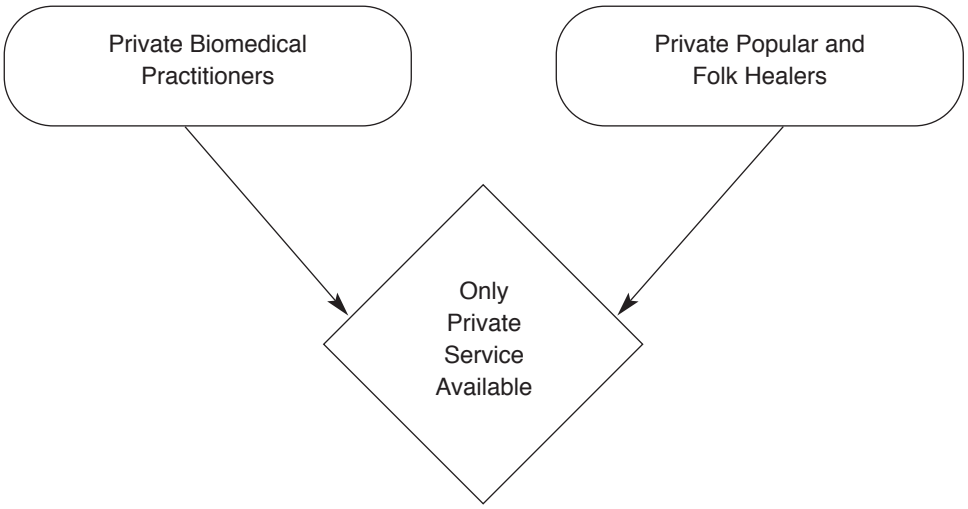

Fig. 2. — Availability of infertility services in the private sector in Bangladesh

Private practitioners in the formal sector

Although they are few in number, private biomedical doctors are the major infertility service providers in the formal sector. I interviewed specialist physicians who were providing infertility treatments in the private formal sector, and they mentioned different reasons for becoming involved in infertility treatment. They admitted that their involvement was mainly for business purposes, but also partly for humanitarian reasons. One specialist, who was one of the pioneers of assisted reproductive technologies (ARTs) in Bangladesh, explained his reasons as follows:

> *"As a gynaecologist I frequently used to encounter infertile cases, but I could not do anything for them. At best I could diagnose which one of the couple had the problem. But I couldn't do anything; I also couldn't refer them, as there was no facility anywhere to treat infertility. I really felt pity for these couples. Finally I decided that I should do something for them. I then trained myself in Europe and started treating infertile people with various assisted reproductive technologies. I am happy that as almost none of the government facilities are able to provide any service to infertile couples, I am able to provide at least something".*

The second specialist took up infertility because it was a promising career option. The third specialist also mentioned her professional career as a reason for taking up infertility treatment. She said that as the arena of infertility was relatively empty, it was a potential field of business.

The informal sector

I mentioned earlier that for the rural population, infertility treatment in the formal (private) sector is neither affordable nor accessible (Nahar, 2010a). The treatment that is available in the rural informal sector is mainly in the form of herbs, amulets, holy water (enchanted with Quranic or other religious verses), certain drugs and various spiritual rituals.

All the rural traditional providers stated that they did not intend to become specialists in infertility treatment, but obtained their knowledge of this treatment along with other treatments when they were trained by their *Gurus*. They therefore treat infertility alongside other diseases. They also mentioned that folk providers are sometimes more interested in infertility treatment because the financial rewards for a positive treatment outcome are much better than for any other illness. All of them however mentioned that they provided infertility treatment to make God happy by helping helpless people. Ultimately, the thanks goes to God for a positive outcome. One old Hindu provider said that he never claims any financial reward when providing infertility treatments because he believes that it is God (*Eshwar*) who creates babies and God deserves the thanks. But if women give him presents after having a baby he does not refuse them. Figure 3 shows the reasons for providing infertility services in the private sectors in Bangladesh.

Discussion

It is clear from the reactions of policy makers, researchers, and donors that infertility is not currently on anyone's agenda in Bangladesh. It is obvious that the government and NGO policy makers' and donors' main concern is to emphasise family planning and maternal & child health care. This is because, according to them, overpopulation, as well as high

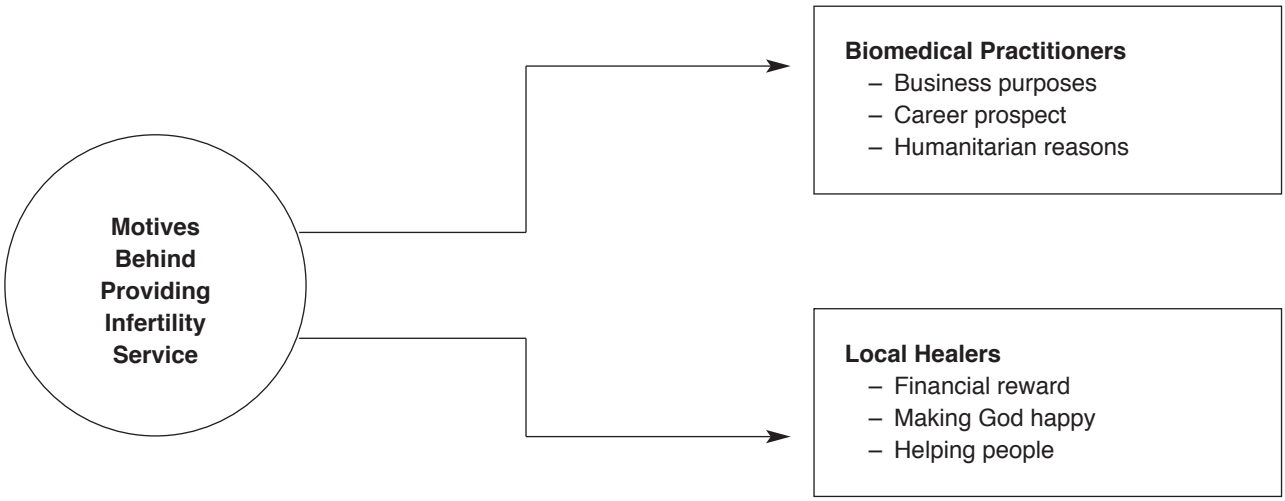

Fig. 3. — Reasons for providing infertility services in the private sectors in Bangladesh

maternal and infant mortality and morbidity, is considered the main public health problem of the country. As infertility is not a highly prevalent condition in the country (disregarding that no data are available) and there are constraints in terms of the availability of resources and technical experts, infertility has not ever been considered as an issue for public health intervention. The motive for infertility care among biomedical private providers is mainly profit making, and as a result it is only affordable to the urban, wealthy population; the rest must seek treatment from informal healers. A study done among slum dweller married adolescent women in Dhaka, Bangladesh stated that due to the lack of infertility service in the public sector, the understandings and health seeking practice surrounding infertility among the deprived population is guided by various superstitious beliefs (Rashid, 2007).

However, there are also counterarguments in favour of providing infertility services in a developing country like Bangladesh. A number of authors have shown how health policies are created in developing countries by means of a top down approach, and how this is influenced by the ideologies of powerful, developed countries. Rowland (1996) and Akhter (1992) have shown how the fear of a population boom generated in the 1970s by a few Western scholars still influences the current population policies in Bangladesh. The agenda of fertility control has thus overshadowed other issues of reproductive health in Bangladesh, resulting in the current lack of infertility services.

On the other hand, prioritising public health issues based only on epidemiological indices is also problematic; as epidemiological indices do not capture psychological and socio-cultural responses; for this, qualitative studies are required. A number of authors have argued that as childless women in developing countries bear a major burden (due to their childlessness) in comparison with those in developed countries, investment in modern infertility treatment options in developing countries can easily be justified (Sen, 1994; Edouard and Olatunbosun, 1997; Daar and Merali, 2002; Akande, 2008; Ombelet, 2009; Nahar and Richters, 2011).

Moreover, the high prevalence of all the potential causal factors present in Bangladesh has been mentioned in the introduction. This high number of potential causal factors for infertility in Bangladesh also justifies the provision of infertility services in the country.

Finally, infertility services are also justified from an equity perspective. Evans et al. (2001) mentioned poverty, marginalisation, urban/rural differences, differences in social status, education, gender, social context and social policy as key factors to understanding inequity. Braveman (2003) emphasised the issue of fairness and justice in his discussion of inequity. Referring to these arguments, it is unfair to make ARTs available only to the wealthier sector of the population whilst the suffering of childlessness is just as intense in the poorer population; in some cases the intensity of consequences are even more among the deprived groups (Nahar and Richters, 2011). It is the poor who are more vulnerable to potential risk factors of infertility. In such a context infertility service in Bangladesh is definitely an example of unfairness.

Conclusion

Through the analysis of stakeholders' interviews on infertility policies and services via a vertical process, we can clearly see that everyone is busy placing the

blame on someone else for not taking care of the issue of infertility, whilst infertile/childless women/people are deprived of biomedical infertility treatment. It is almost as if they don't exist; or are invisible. The government and policy makers in Bangladesh do not want to admit that this is a problem; they are keen to promote a reduction in the child birth rate and to improve maternal and child health care, while remaining silent about infertility.

Recommendation

I argue that the obstacle of providing infertility service in Bangladesh is not at the provider or public health programme implementers level as the health service provision is guided by the decisions of the policy makers, which again are steered by the views of the donor agencies. It is therefore important to change the conceptualization of prioritising public health problems by the donors and government policy makers, which principally is guided only by epidemiological data. Strong advocacy is needed to promote the point that epidemiological data do not capture the impact of this burden on the wellbeing of infertile people. It is also important to highlight the significant prevalence of infertility risk factors in Bangladesh. More research is needed on infertility both from epidemiological and social science perspectives in Bangladesh. By increasing the body of knowledge on infertility through greater numbers of research and through rigorous advocacy for alleviating the sufferings of infertile persons, it is possible to change the views of government policy makers and donors, which will ultimately make evident the need for better care for infertility.

However, taking the reality of resource constraints into account, it is still possible to provide infertility service at a low level using the existing set-up. For example pathological tests for diagnosis of infertility and assessment of causal factors, primary treatment for gynaecological problems, media campaigns (particularly against stigma) and counselling for infertility can be provided within the present infrastructure. In addition, low cost infertility treatment could also be introduced for infertile couples.

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The economic impact of infertility on women in developing countries – a systematic review

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Abstract

Background: **It is the responsibility of health systems to provide quality health care and to protect consumers against impoverishing health costs. In the case of infertility in developing countries, quality care is often lacking and treatment costs are usually covered by patients. Additional financial hardship may be caused by various social consequences. The economic implications of infertility and its treatment have not been systematically explored.**
Methods: **A systematic MEDLINE search was conducted to identify English language publications providing original data from developing countries on out-of-pocket payment (OoPP) for infertility treatment and on other economic consequences of involuntary childlessness.**
Findings: **Twenty one publications were included in this review. Information on OoPP was scant but suggests that infertility treatment is associated with a significant risk of catastrophic expenditure, even for basic or ineffective interventions. Other economic disadvantages, which may be profound, are caused by loss of access to child labour and support, divorce, as well as customary laws or negative attitudes which discriminate against infertile individuals. Women in particular are affected.**
Conclusion: **Pertinent data on OoPP and other economic disadvantages of infertility in developing countries are limited. According to the evidence available, infertility may cause impoverishing health costs as well as economic instability or deprivation secondary to social consequences. Health systems in developing countries do not appear to meet their responsibilities vis-à-vis infertile patients.**

Key words: **Catastrophic health cost, childlessness, developing countries, economics, infertility, out-of-pocket payment.**

Introduction

Health systems have the responsibility to provide health services and to meet consumer satisfaction. Increasingly, their responsibility to protect households against excessive or catastrophic health costs is also recognised. Key mechanisms of financial risk protection against illness include risk pooling and prepayment. Four main insurance mechanisms exist, comprising state-funded Ministry of Health systems or national health services; social health insurances which generally are not for profit and reliant on payroll deductions; community-based health insurances which are also non-profit, involve voluntary membership and are controlled by the community; and private health insurances based on payment of premiums (Gottret and Schieber, 2006). In the partial or complete absence of financial risk protection, health care costs are covered through out-of-pocket payments [OoPP] by consumers.

In many low-resource settings infertility is common and frequently associated with negative psychosocial consequences including marital instability, divorce, social isolation and stigmatisation (van Balen and Gerrits, 2001; Dyer, 2007; van Balen and Bos, 2009; Gerrits and Shaw, 2010). Against this back-drop, infertile women often engage in relentless health-seeking behaviour accessing both biomedical and traditional health services (van Zandvoort et al., 2001). In many developing countries infertility management in the public health sector is, however, of relatively poor quality or entirely

lacking. Use of existing services may be free or require payment of user fees, either over or under the counter. Alternatively women may access private health care, where available, encountering a range of treatment options which may be of inconsistent quality and benefit (Macklin, 1995). Insurance for private infertility care rarely exists, and costs are usually covered through OoPP. Interventions in the traditional health sector rely on various ceremonies and remedies, again relying on patient payment or payments made in kind. The usual lack of cost regulations regarding infertility interventions puts patients at the additional risk of exploitation.

It follows that infertility in low-resource settings may be associated with a significant risk of impoverishing health expenditure, in other words OoPP which threatens survival, or creates or deepens poverty (Habbema, 2008). To our knowledge the frequency and impact of this risk has to date not been reported. To address this information gap we conducted a systematic literature review on OoPP for infertility care and other economic consequences of infertility in developing countries. Two previous systematic reviews on infertility in low-resource settings included some information on economic consequences, but neither of them focussed on this theme and one review only included publications from sub-Saharan Africa (van Balen and Bos, 2009; Gerrits and Shaw, 2010). We therefore anticipated that the results of this review would make a relevant contribution to the existing literature and provide new insights into what extent health systems meet or fail in their responsibilities towards infertile patients.

Methods

The primary objective of this review was a systematic evaluation of reported OoPP for infertility care in developing countries including both the biomedical and traditional health sector. Other economic implications of infertility were included as a secondary objective.

A MEDLINE search was conducted on English paper publications using the key words 'infertility' and 'involuntary childlessness' in combination with 'developing countries', 'low resource-settings', 'Africa', 'Asia', 'Latin America' and 'out-of-pocket payment', 'health-cost', 'catastrophic cost', 'impoverishing cost', 'economic consequences', 'social consequences'. All manuscript titles generated by the MEDLINE search were read. Abstracts and manuscripts were reviewed if within the field of interest. In addition, the bibliographies of retrieved manuscripts were searched for further references. Only publications presenting original research data, conducted in developing countries and accessible through South African University Libraries were considered for inclusion. Developing countries were defined as low-income and lower middle income countries according to the World Bank classification of countries by Gross National Income per capita (The World Bank Group, 2012).

We used the terms 'impoverishing expenditure' and 'catastrophic expenditure' in keeping with previous research. Accordingly, these terms describe *qualitatively* health costs that threaten the survival of individuals or their households because of financial collapse, or cause or deepen poverty. In *quantitative* terms catastrophic expenditure has been defined as a direct health cost that exceeds 40% of a household's annual expenditure excluding payments for food, although some authors have worked with a lower threshold of 20% (Xu et al., 2003, 2007; Habbema, 2008). Annual household expenditure, after subtracting the cost of food, has been considered a more reliable indicator of purchasing power than annual household income (Xu et al., 2003).

Results

A total of 485 manuscript titles were read. Following abstract and manuscript review, 21 papers were identified for inclusion in this review. Table I provides an overview of the publications, research methods and key findings from African countries, and related information from Asia is presented in Table II.

Out-of-pocket payment for infertility care

Few studies provided quantitative information on the OoPP for infertility treatment. In a study from Northern India, 53% of couples attending an 'infertility camp' at a primary care facility had spent in excess of 1000 Indian Rupees (IR) on prior treatment (Singh et al., 1996). The majority had first accessed the traditional health sector, and 46% of couples had accessed four or more sources for help. The authors contrasted this OoPP to the national average annual income per capita of IR 3835 and concluded that it was a 'considerable expenditure'. Similar results have been reported from Rwanda where women had spent a mean total of 73 USD (range 27-270 USD) on infertility treatment, and male partners had spent 91 USD (range 22-200; difference not statistically significant) (Dhont et al., 2010). This cost was double their monthly income for 50% of women, and for 25% it was six times their monthly earnings. Most patients had accessed treatment from the public and/or private health sector. Interventions involved clomiphene citrate or a combination of antibiotics, hormones, non-steroidal anti-inflammatories and

Table 1. — Cost of treatment and other economic consequences of infertility: Studies from Africa.

Study	Area	Methods	Sample	Cost of Treatment	Other Economic Consequences
Barden-O'Fallon J. 2005	Malawi	Qualitative: Interviews	15 women, 11 men	–	lack of domestic support and of financial security in old age.
Dhont N et al. 2010	Rwanda	Quantitative: Hospital based survey	312 infertile women, 254 male partners	For 75% of women fertility costs were ≥ twice their monthly income. Treatment included clomiphene, hormones, steroids, antibiotics	–
Dhont N et al. 2011	Rwanda	Quantitative & Qualitative: FGD[1]	Quantitative: 312 fertile and 312 infertile couples. Qualitative: 7 FGD[1]	–	Lack of financial support from husband; loss of security and land-claim rights; men less motivated to work.
Feldman-Savelsberg P. 1994	Cameroon	Qualitative: Interviews	Number not specified	–	Lack of financial support;greater risk of divorce; may need to repay bride wealth; may be rejected by family; no children to expand workforce
Gerrits T. 1997	Mozambique	Qualitative: Interviews	34 infertile women	–	lack of domestic support/child labour.
Hollos M. 2003	Nigeria	Qualitative: Life Stories	6 women	Infertile women have to self-fund or husbands are only willing to pay for traditional healers.	Infertile woman had to pay the bride wealth for additional wives; Children help to establish land claims and expand the labour force.
Hollos M et al. 2009	Nigeria	Quantitative & Qualitative: interviews with Ijo and Yakurr people	Enumeration: 812 and 966 areas identified. In depth interviews: 25 fertile and 25 infertile women	Treatment expensive and ineffective. Women self-fund.	Infertile women divorced or ridiculed; no right to residence or inheritance from husband's estate; must return to their own family and risk being marginalized.
Study	**Area**	**Methods**	**Sample**	**Direct Out of Pocket Economic Cost**	**Indirect Economic Cost**
Mogope DK. 2005	Botswana	Qualitative	40 infertile women	–	Lack of social, economic security; lack of support/financial security in old age.
Okonofua FE. 1997	Nigeria	Qualitative: FGD[1]	25 women	Infertile women at risk of financial and sexual exploitation by traditional healers.	No financial security; excluded from inheritance.
Pearce TO. 1999	Nigeria	Qualitative	Number not specified	–	Excluded from inheriting from deceased husband's estate.
Runganga AO et al. 2001	Zimbabwe	Qualitative: In depth interviews and FGD	42 informants	–	Loss of financial support; infertile couples used as social service to others
Seybold D. 2002	Senegal	Narrative	1 infertile woman	Self-funded fertility treatment with cost supplementation from husband. Traditional healer accessed after apparent failure of treatment. Attempt at sexual exploitation by traditional healer.	–
Sundby J. 1997	Gambia	Quantitative & Qualitative	Quantitative: 243 infertile women. Qualitative: 4 infertile women	Traditional healers are accessed first, at high cost. Perception that private hospitals are better than state facilities but these are very expensive and women cannot afford them.	–

[1] FGD: Focus Group Discussion.

Table 2. — Cost of treatment and other economic consequences of infertility: Studies from Asia.

Study	Area	Methods	Sample	Cost of Treatment	Other Economic Consequences
Nahar P, Richters A. 2011	Bangladesh	Life histories	20 rural, illiterate women, 11 urban middle class women.	Cost of 'high tech' infertility treatment 2000-6000€, may cause poverty. Rural women visit indigenous healers who are less costly. Women reduce expenditure on other and basic needs. Lengthy treatment unaffordable.	Financial insecurity. Threat of divorce. Divorced women economic burden to parents; parents may have to raise 2nd bride price. Infertile women cannot work. Husband may lose motivation to work.
Nahar P et al. 2000	Bangladesh	Qualitative	120 non-infertile men & women; 20 infertile women; other key informants	–	Women suffer marital insecurity, abuse. Financial insecurity. Infertile men and women are not offered jobs. Women may resort to prostitution.
Sami N, Ali TZ. 2006	Pakistan	Descriptive case series	400 infertile women	–	Threat of divorce and subsequent financial insecurity
Singh A et al. 1996	Northern India	Quantitative	129 infertile couple	53% of couples spent > 1000IR[1] on previous treatment; 46% had accessed 4 or more sources for help;	–
Unisa S. 1999	India	Quantitative & Qualitative: household survey and Interviews	332 infertile women and 101 men; 60 case studies	Poor public services, private care preferred although more costly;	–
Widge A. 2005	India	Qualitative: Interviews	4 couples, 18 women	ART cost 600-1000USD; cost 'exorbitant'	–
Wiersema N et al. 2009	Vietnam	Quantitative & Qualitative: questionnaire survey and interviews	118 infertile couples. 28 men and women were interviewed	Cost of ART 3000 USD; self-funded; many cannot afford treatment; take loans or sell assets	–
Winkvist A, Akhtar HZ. 2000	Pakistan	Qualitative: Interviews	42 women (18 urban, 24 rural), 8 mother-in laws, 6 local healthcare providers	–	Women suffer abuse, lack of financial support; threatened with divorce; forced to do additional work.

[1] IR: Indian Rupees.

steroids for women and testosterone and clomiphene citrate for men.

Three studies provided information on the range of cost. A qualitative study which evaluated the experiences of middle and upper-middle class urban Indian women with assisted reproductive techniques (ART), reported the cost of ARTs at 600-1000USD (Widge, 2005). Informants uniformly described this cost as 'exorbitant'. No further information on available income or the impact on households was provided. The author concluded that ART was financially stressful and highly commercialized, and that couples were at risk of being exploited. Patients undergoing infertility treatment in Vietnam had to self-fund the cost of treatment. The cost for ART was 3000USD, which was unaffordable to most despite some interviewees stating they were willing to sell their homes (Wiersema et al., 2006). A study from Bangladesh, collecting raw data by means of life histories, reported a cost of 2000-6000€ for 'high-tech' infertility treatment which, according to informants, could cause poverty (Nahar and Richters, 2011). Despite the cost, almost all urban women had undergone such treatment. Rural women usually went to a traditional healer, and although the cost was less it was still noted to be 'hard earned money'. Both urban and rural women cut down on expenditure for basic needs and social events without further details given. Lengthy treatment was unaffordable to both groups.

Some further insight is provided by qualitative studies which refer to the cost of treatment in the context of descriptions of health-seeking behaviour or the overall experience of infertility. According to life histories of infertile women living in Nigeria, some men refused to pay for infertility treatment, possibly because they already had children from other women/wives (Hollos, 2003). These women had to use their own earnings or forfeit care. Other men paid for their wives, but unless conception occurred the marriage usually failed. Infertile women in the Gambia spent 'considerable amounts' on traditional health care (Sundby, 1997). Treatment in the

biomedical sector was perceived to be of limited quality, with most doctors providing poor care and good doctors being unaffordable. Focus group discussions from Nigeria and the life history of a woman living in Senegal revealed that traditional healers may exploit infertile women financially or sexually, but according to one Nigerian informant this 'was the price to pay' in order to conceive (Okonofua et al.,1997; Seybold, 2002).

Other economic consequences

Thirteen manuscripts were identified which described other economic consequences. Although some manuscripts provided rich detail, the overall amount of information was scant. Five types of consequences emerged from the data, namely (1) loss of income through lack of work done by children; (2) economic disadvantages caused by customary law or cultural traditions; (3) economic disadvantages caused by negative attitudes of individuals; (4) loss of financial security following divorce/abandonment; and (5) loss of old age security.

According to studies from Africa and Asia, children assist with domestic and subsistence related activities, and the labour contribution of children of all ages has been described as being considerable (Feldman-Savelsberg, 1994; Gerrits, 1997; Hollos, 2003; Barden O'Fallon, 2005; Hollos et al., 2009). Furthermore, ethnographic research from Cameroon described how children allowed women to create an essential network of exchange and support that infertile women were unable to establish (Feldman-Savelsberg, 1994). Research from Bangladesh emphasised the importance of sons, who are supplementary earners. In this setting poverty was further aggravated by the fact that women were not permitted to seek work outside their homes, either because this would shame their husbands, who were responsible for providing for their households, or because of feared infidelity (Nahar and Richters, 2011).

Some cultural traditions or customary laws create economic difficulties for infertile couples or women. In Nigeria and Cameroon land claims are negotiated through the number of children (Feldman-Savelsberg, 1994; Hollos, 2003). Studies from sub-Saharan Africa have documented that a childless widow may face poverty as she had little or no right to inherit from her deceased husband (Sundby, 1997; Okonofua et al., 1997; Pearce, 1999). In addition, widowed women were reported to lose their right to reside in their deceased husband's compound unless they had born a son (Hollos 2003; Hollos et al., 2009). The traditional payment of bride wealth may create economic hardship. In sub-Saharan Africa the bride wealth is paid by the husband to the family of his bride. In case of infertility this price may have to be repaid. This burdens the relatives of the infertile woman, who in turn may face ostracism from both families (Feldman-Savelsberg, 1994). Hollos (2003) described the strategy of one woman who raised the bride wealth to pay for two additional wives for her husband. Although this gained her the respect of the co-wives and their ten children, she still ended up leaving her husband and living with her brother, who barely tolerated her. Qualitative research conducted in Bangladesh reported the concerns of a female relative of a divorced, infertile woman who said: "If we have to raise the money again for her 2nd marriage we will become beggars" (Nahar and Richters, 2011).

Negative attitudes towards infertile people, including stigmatisation and abuse, frequently exist and these attitudes can have economic implications. In Cameroon, an infertile woman may receive fewer gifts from her husband (Feldman-Savelsberg, 1994). Outright deprivation results when husbands withhold financial support including basic necessities such as food, clothes or fuel, as reported from both African and Asian countries (Nahar et al, 2000; Winkvist and Akhtar, 2000; Dhont et al., 2011; Nahar and Richters, 2011). "Many days I just starve. He says, unless you show me your pregnancy I will not give you food and remarry soon" said a rural woman living in Bangladesh (Nahar and Richters, 2011). In the same study, another woman described how she would sit alone in her dark hut at night, forgotten by everyone, as her husband did not provide fuel for a lamp. Another qualitative study from Bangladesh reported that infertile men and women living in urban slums would not be offered jobs, and that women may have to resort to prostitution in order to survive (Nahar et al., 2000). Two studies from Rwanda and Zimbabwe outlined that infertile couples were frequently used as social servants within the family, being burdened with the care of the financially needy, sick or disabled without being consulted (Dhont et al., 2011; Runganga et al., 2001). Other people's children may also be placed in their care, which could be a burden or a blessing (Okonofua et al., 1997; Dhont et al., 2011). Lastly, infertility may create negative work attitudes among men, who may lose their drive to prosper, resulting in reduced household income and means (Dhont et al., 2011; Nahar and Richters, 2011).

Divorce or abandonment, which is not uncommon in the case of infertility, often carries economic consequences. Women may lose access to land, which is usually owned by men, as well as other belongings and their homes (Feldman-Savelsberg, 1994; Runganga et al., 2001; Hollos, 2003; Sami and

Ali, 2006; Hollos and Larsen, 2009; Dhont et al., 2011; Nahar and Richters, 2011). One woman living in Zimbabwe explained that she had to leave three homes because of her inability to conceive (Runganga et al., 2001). Women who are divorced may have to return to their own families where they may face further economic hardship and have little prospect of remarriage (Hollos 2003; Hollos et al., 2009; Nahar and Richters, 2011).

Lastly, infertile women, and at times men, voiced fear of economic difficulties in old age as they would lack the support of children (Feldman-Savelsberg, 1994; Koster-Oyekan, 1999; Hollos, 2003; Barden O'Fallon, 2005; Mogobe, 2005). Since most studies included participants of reproductive age, lack of old age support was mostly a fear of future economic hardship rather than current life experience. Fostered children or children of relatives were generally deemed unreliable in providing old age security (Sundby, 1997; Hollos, 2003; Barden-O'Fallon, 2005; Wiersema et al., 2006).

Discussion

There is a dearth of information on OoPP for infertility treatment in developing countries. As outlined above, quantitative evidence of catastrophic health costs requires not only information on the direct cost of care but also on annual household expenditure. In this review only four studies provided some quantitative information on the cost of care, and of these two referred to a range of cost only. No study provided information on participants' annual household income or expenditure. There is therefore insufficient evidence to quantitatively determine the occurrence of infertility related catastrophic OoPP. At the same time the evidence is suggestive of the fact that infertile individuals are likely to face catastrophic expenditure. The qualitative data on payment for infertility treatment further support this assumption.

The cost of infertility treatment in general and ART specifically is often cited as a major barrier, especially, but not only, in developing countries (Nachtigall, 2006; Inhorn, 2009; ESHRE Taskforce on Ethics & Law, 2009). In this context it is often assumed that those who cannot afford the cost, forfeit treatment. Our findings support this concept to some extent, as some of the qualitative studies documented that women could not access treatment because of cost, could not afford to pay for 'good' doctors or could not undergo 'lengthy' treatment. At the same time the data challenge the conclusion that cost prevents access to care. Instead, the studies have documented that some patients seek and pay for treatment despite the fact that they cannot afford it, thereby incurring crippling financial burdens.

Health economists have previously emphasized that willingness to pay does not imply ability to pay (Russel, 1996). Indeed it is the very act of willingness to pay for treatment that is unaffordable, which puts households at risk of catastrophic or impoverishing health costs. Studies that have evaluated catastrophic OoPP for health care in developing countries have, as yet, not included infertility. A detailed review of this literature is beyond the scope of this manuscript, but a few observations are pertinent to this discussion. According to health economists and researchers, treatment is likely to be purchased despite serious financial restrictions if the disease is considered to be severe (Russel, 1996). According to evidence from Vietnam and Burkina Faso, catastrophic expenditure was not necessarily caused by acute, dramatic illness but rather by relatively small but recurrent costs for chronic ill-health (Su et al., 2006; Thuan et al., 2006). Critical to the financial coping of individuals or households is a network of support from which financial and other assistance can be drawn. Women, especially if widowed, divorced or childless have been recognised as particularly vulnerable in this context (Russel, 1996). Health system variables associated with catastrophic OoPP have included poor coverage, poor quality of services, and user fees (Chuma et al., 2007). Poor quality public services result in higher utilization of private care, which in turn is another risk factor for catastrophic expenditure and long term debt (Van Damme et al., 2004; Su et al., 2006). In addition, poor people paid higher fees for the same private health services when compared to better-resourced patients, and paid higher interest rates to money lenders, according to evidence from Cambodia (van Damme et al., 2004).

All of the above risk factors apply to the problem of infertility in developing countries. In conjunction with the data presented in this review this indicates that involuntary childlessness is a significant risk factor for catastrophic or impoverishing health expenditure. Data are urgently needed, and to this extent we have recently conducted a survey of 150 couples undergoing ART in the public health sector of South Africa, where treatment was subsidised but required co-payment by patients. Outcome measures included direct and indirect cost burden on households, financial coping strategies and frequency of catastrophic expenditure. While final results are being analysed, interim findings indicated that one in three households incurred catastrophic cost. Financial coping strategies included the borrowing of money, selling of assets, and reduction of household expenditure including basic necessities and education (Dyer et al., unpublished data).

As noted, the cost of infertility treatment and ART is not only problematic for developing countries but

also for high-income countries. According to reviews on the health economics of ART, the cost for ART treatment was 25% of the average annual household expenditure in Canada and 50% of an individual's annual disposable income in the USA, from which authors concluded that 'if unsubsidized, direct cost [for ART] represents a significant burden to patients' (Collins, 2002; Connolly et al., 2010). This suggests both similarities and differences between developed and developing countries. In both regions couples may face crippling costs which may reach catastrophic proportions. In developed countries, however, this cost appears to be mainly associated with ART, while this review indicates that catastrophic payment may be incurred for basic interventions such as hormones and antibiotics, which may frequently be ineffective. Moreover it is likely that the implications of catastrophic expenditure on households differ between developed and developing countries, with, for example, more patients in low-income countries living close or below the poverty line and having little or no resource to governmental social security.

The review of other economic consequences related to infertility revealed both a richness and dearth of information. The richness is generated predominantly by some qualitative studies which describe vividly the suffering, the financial disadvantages and the economic deprivation that people, especially women, experience because of their inability to conceive. According to this evidence, involuntary childlessness has far reaching economic consequences, starting with lack of access to child labour and old age security, and aggravated by cultural traditions or customary laws which disadvantage infertile women and to a lesser degree men. Arguably the worst economic hardship is however caused by individual attitudes reflecting severe ostracism and stigmatisation. At the same time there is a striking absence of information. Firstly, no study focussed entirely on the economic implications of infertility, and in only a few studies these were specifically reported as one of various outcome measures. In most instances the economic consequences were reported briefly and as part of other social experiences. In addition, there are no data at all from many countries and entire regions. No studies within our scope of enquiry, could, for example, be identified from South America. In view of the magnitude of the problem, based on the number of infertile women in developing countries and the impact of infertility on peoples' lives, this lack of information is difficult to explain. Perhaps this information gap still reflects an on-going belief that overpopulation and not infertility requires attention in developing countries.

Invariably this review has limitations. Firstly, the information presented is based on relatively few studies. The available data were very heterogeneous making it difficult to extract findings. Moreover, the exact source of information was not always clearly stated. More data are required from more countries for a better understanding of the economic consequences of infertility and its treatment. While we may speculate that experiences may be similar in other low-resource settings, the findings apply to the context in which they were collected and cannot be extrapolated to all developing countries. At the same time the absence of evidence of negative economic consequences of infertility must not be interpreted as the evidence of the absence of such implications. A further limitation is the extent of our literature search. It is likely that valuable information exists in papers not accessible in South Africa and especially in non-English and non-medical literature. Lastly, the authors are not health economists but clinicians with a clinical and research interest in infertility-related psychosocial consequences and quality of life in low-resource settings.

Conclusion

Available evidence, although scant, documents that infertility is associated with a range of economic disadvantages resulting at times in outright deprivation. It also indicates that patients who access care are at risk of catastrophic expenditure even for basic, traditional or ineffective medical interventions. Catastrophic payment for health has been referred to as the 'medical poverty trap' (Whitehead et al., 2001). It would appear that for many women in developing countries infertility is a 'medical and social poverty trap'. While some of the social aspects of this economic hardship are outside the remit of health systems, the overall lack of quality infertility care and the absence of financial risk protection against infertility-related OoPP cannot be overlooked. Indeed, it may be seen as a severe infringement of women's right to reproductive health.

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"You need someone in a grand boubou" – barriers and means to access ARTs in West Africa

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Abstract

Many francophone West African countries rank as low resource states, and are dependent on donor nations and remittances from migrants working abroad. Their health system is in a less favourable state and basic health care is not accessible for all its citizens, and in particular, private clinics offer highly specialized services such as assisted reproductive technologies (ARTs) for infertility care. Drawing from my research on ARTs particularly in Mali but also including Senegal and Togo, I will specifically outline the contextual barriers for African actors, both patients and professionals, to gain access to ARTs in the public or private health sector and mechanisms they have developed to cope with them.

Key-words: **Assisted reproductive technologies, ART, barriers, infertility private health sector, West Africa.**

Assisted reproductive technologies (ARTs) are cost-intensive treatments to cope with infertility. In global health and developmental arenas, medical and social science literature, the question to support the application of ARTs, in order to make them more available in developing countries, triggers ethical discussions in which mainly overpopulation and scarce public health resources are brought forward (Pennings et al., 2009; Ombelet, 2008; Schuster and Hörbst, 2006; Daar and Merali, 2002). Yet ARTs have already travelled successfully to many sub-Saharan African contexts, including West African states, for instance Togo, Senegal and Mali. These onsets of ARTs in West Africa are, with the exception of Nigeria (Giwa-Osagie, 2002), mainly organised by providers in the private health care sector.

While money is for many sub-Saharan clinicians and couples the most drastic barrier, there are others to consider too. In this article I will outline the obstacles West African gynaecologists and involuntary childless couples struggle with on their journey to access ARTs and embed these strategies within African health contexts. I argue that for any activities to improve infertility care and the availability of ARTs in sub-Saharan Africa, the private health sector and private providers are crucial cooperation partners.

My description and analysis is based on data resulting from social anthropological fieldwork (altogether 15 months) on infertility and ARTs conducted between 2004 and 2011 mainly in Mali (Bamako), but also in Senegal (Dakar) and Togo (Lome). In Mali I particularly accompanied the process to establish and provide ARTs in one private clinic through non-participant observation (in consultation and all stages of treatments). During these years, data were gathered via participant observation in two public clinics as well as in other private gynaecological clinics. Informal and formal narrative, semi-structured interviews with directors, doctors and health staff were conducted in all these sites. I also focused on life histories and patients' (18 women and men and seven couples) experiences with ARTs (retrospective, prospective and concomitant) through following up visits and interviews sometimes covering seven years, recruited in and beyond the clinics. Four focus group interviews with (21) non-afflicted men and women from various social milieus were carried out, while interviews with

and visits to non-biomedical practitioners (hunters, marabouts, individual and organised phytotherapists and Imams) were also conducted. I also carried out interviews with Islamic religious leaders from different subgroups in Mali as well as interviews with state health institutions and the National Ethics Council. While in Dakar (Senegal) I conducted (informal) interviews with two gynaecologists from two different private clinics and with one laboratory director, in Lomé (Togo) I carried out a one week stay of fieldwork in a private fertility clinic where I also interviewed five of the clinic's patients. In terms of education, occupation, property and affluence the majority of the interviewees can roughly be grouped as members of the middle or lower upper class. In 2009 I attended the founding conference of the GIERAF (Francophone African Fertility Society) in Lomé, where I talked with and listened to the presentations of many gynaecologists engaged with ARTs in various francophone African countries (Horbst, 2009). During all these years I also spoke with anyone available (waiters, acquaintances, taxi drivers, market sellers, neighbours etc.) about the issue of infertility, its social handling and their attitude toward ARTs.

Mali: a health care system in crisis

For roughly a decade (until very recently) the Islamic oriented Mali was considered one of the solid and promising democracies on the African continent, which triggered an increasing flow of developmental aid from developed countries, while Libya and Arab countries supported the government as well. International philanthropic agencies and non-governmental organisations finance numerous projects and offer solid working places for many educated Malians. Bamako, the capital of Mali, became one of the "booming" cities in West Africa. In this process, the gap between poor and rich opened up tremendously and became literally more and more visible in the streets of Bamako. As in many other West African countries, a growing middle class with access to higher education and financial means is emerging, and the urban population is becoming increasingly fragmented in terms of economic and social power.

Concerning social order, various frames of orientation (following respectively Malian 'traditional' values, Western style, Muslim and Christian behaviour and morale) offer a messy variety of world views and rules of social practices in terms of family, gender relations, business activities, religion and health care. In day-to-day practice, most people draw on bits and pieces from these different frames of orientation and, according to specific social situations and social fields of activity, can enact what appear to be contradicting values in social interactions by applying an intersecting mix of styles.

Embedded in these complex processes, the Malian state still remains in a rather weak economic position. With a gross domestic product estimated to be about USD 10.29 billion USD in 2011, Mali is recognized as a low-income nation. The gross national income per capita figures between USD 691 and USD 1100 according to different sources (WHO, 2009; Deutsches Auswärtiges Amt, 2012). The Malian state and its investments in the health arena (as in other areas) depend heavily on funding by international development cooperation and by philanthropic donor agencies. In 2009 the total expenditure of the Malian GDP on health was 5.6% (WHO, 2009), while in 2005 external resources already financed 25.6% of the national health sector (WHO, 2007). These aspects suggest a rather high political influence of international donors concerning questions of which investments, plans and strategies are followed in the public health sector.

However, the public health care sectors of many West African countries – including Mali – are in a state of structural crisis due to several factors which include bad management and failed structural adjustment programs implemented by IWF and the World Bank in the 1980s, which triggered a general monetisation and liberalisation of public health care institutions, where patients have to pay for treatment (Jaffré and Olivier de Sardan, 2003; van Dijk and Dekker, 2010). As in other West African cities, the public health sector is characterised to a high degree by various forms of corruption. Patients are often asked to pay under-the-desk fees besides the officially fixed amounts for receiving care. Medical staff in public institutions is paid quite badly and often not regularly. Working morality, motivation and commitment of health personal to provide quality of care is often constrained (Jaffré, 2012; Jaffré and Olivier de Sardan, 2003). While this situation is pervaded by financial shortages it is also combined with local working management and organisation arranged upon hierarchical values of social organisations that additionally build barriers to smooth team cooperation. These aspects inherent within those health systems create a certain "local moral economy", due to health staff's own precarious living situation, where "personal survival" has to be secured in a difficult socio-economic context (Jaffré, 2012). Many patients utilizing public hospitals suffer from arrogant behaviour by health staff who often ignore patients altogether and suffer from highly unreliable treatment arrangements with often poor outcomes. This unhealthy configuration seems to result in what a young Bamakonian taxi-driver nicely brings to the point:

> People don't trust doctors [*in public institutions*]… because you are not dealt with the way you would like to be. If you don't have acquaintances in the hospital, they don't even look at you. Or you have to bring someone along in a *grand boubou*.

As a "grand boubou" is the wearing of Malian traditional clothing for important social events and demonstrates high socio-economic status, this metaphor underlines that some one is needed who, at least, enjoys a high reputation, who has the necessary relations to important health staff in the hierarchy and has money in order to receive (good) care (Jaffré, 2012). "With the private clinics", the taxi driver continued

> …this is different, that is the reason why nowadays all over the city private clinics and small private doctors' offices are mushrooming. They treat you nicely, they are friendly with you, they help you, and they examine and medicate you. They know you will pay… Even if you actually cannot afford them, you go there.

This explanation mirrors a tendency, characteristic of many West African hospitals (Jaffré and Olivier de Sardan, 2003) and specific consequences of it: health care in public hospitals suffers from a bad image within the population, while a trend emerges for those who are economically stable to show preference for accessing health care from the private sector. As underlined by the taxi driver, also less affluent Malians try to gather resources in order to receive treatment in private institutions. This dynamic is fuelled by the fact that in recent years graduates from Malian medical, pharmaceutical and/or nursing schools cannot always enter the public sector, as the Malian state does not have enough resources to employ them. In order to make their living, they try to position themselves within the private market.

Simultaneously, a brain drain from public services to better paid positions in the private commercial and non-commercial sector is taking place. As in other sub-Saharan countries, in Mali tasks expected of the public health system are partially taken over by the private sector including NGOs, private-public-partnerships, religious institutions and private clinics, and medical and nurses offices. This non-public environment for health care seems to further strain the situation in public hospitals and to contribute to their increasing malfunction.

This complex scenario complicates access to provisions for ARTs in public hospitals in Mali. Coupled with the national low-resource budget allocations for the public health sector, and the above mentioned often dysfunctional social and organisational working management, all together these factors seem to play a further adverse role for implementing ARTs within the public health domain. As in many developing countries (Inhorn, 2002), infertility and ARTs are not a priority to the Malian state nor to the international developmental aid arena; as argued elsewhere, no money flows or funding strategies from the global donor community include health issues associated with fertility problems. (Hörbst and Wolf, 2007).

Obstacles for providing ARTs

Upon analysis of interviews with private health care providers from francophone West Africa, investment barriers in the private sector are found to be quite similar to those in the public one: prominent economical obstacles are evident, as lab equipment and tools are expensive. To embark on such an adventure is, in case of failure, associated with a risk of no profitability and of high (private) encumbrance, including the potential for social and professional ostracisation. Adding to those challenges is the fact that knowledge and skills concerning ARTs have to be acquired from outside the country. Thus, gynaecologists face a lack of knowledge, skills and experience concerning the different steps (hormonal stimulation and monitoring, harvesting of ova, fertilization in lab, transfer etc.) required for assisted reproductive interventions. In addition, they are confronted with a scarcity of trained professionals in order to assemble a team, which includes lab assistants, embryologists and nurses. To successfully manage these challenges, beyond access to theoretical literature and guidelines available online, gynaecologists are in need of international contacts to ART specialists and embryologists, through which they may acquire and improve skills through training from internships. If they want to provide ART treatments, they also must deal with the fixed equipment needs: they have to find out what and where to purchase basic "hard ware" they need for providing ARTs (such as microscopes, micro-injector, incubator, intake pumps, harvesting needles, lab fluids etc.). Linked to this are further challenges: for instance, lab fluids have to be imported; they are taxed, and thus can often become more expensive than in European countries. Short expiration dates on expendable items add further problems, and cost-effectiveness (for clinics and patients) will depend on how many couples' cycles can be covered by one bottle of fluid before it expires.

Additionally, in the local health system context, as noted by different Malian providers, a sharing of leading responsibilities and an efficient cooperation among private health care providers are not common practice. Such forms of cooperation, gynaecologists repeatedly explained to me, are often mistrusted by actors due to a very hierarchical and tutorial

distribution of dependency and responsibility in terms of work, money and blame, and as such sharing of investments are not easily feasible (comp. Giwa-Osagie, 2002). Thus motivation for teamwork cooperation has to be developed and organised, and has, as the Malian ART provider told me, to be constantly nurtured, for instance through regularly increasing salaries and/or by some sort of share holding.

At the same time, in many West African countries, there is no stable policy existing concerning laws and regulations on ART practices. In Mali, the National Ethics Council has debated ARTs and handed a (rather restrict) proposal excluding the use of donor gametes over to the Ministry of Health. However, until 2011 no laws or regulations were enacted. This legal uncertainty of whether and which variants of ARTs will finally be accepted, creates an ambivalent situation for the clinicians interested in ARTs: on the one hand, this legal lacuna allows physicians a professional liberty for practising all variants of ARTs according to what they consider is (biomedical or sociocultural) necessary for success in fertility treatment; on the other hand, this lack of legal clarity disrupts their private investments as future regulations might prohibit some treatments or variants (for which they already have invested).

In the Malian public health sector, according to my data, current budgets and working configurations hardly allow for acquiring the cost intensive technical equipment (as it is problematic to buy second-hand devices in the public sphere) and render it difficult to acquire personal with the specific skills needed for providing comprehensive ARTs or to train them to develop those skills. Further on, without a working nation-wide health insurance system, granting access to ART through the public sector for non-affluent people would cause the Malian state to also face the challenge of organising a funding scheme. Given this context, it comes as no surprise that a professor who had dreamed since 2005 of providing ARTs in the Bamakonian University Hospital, and had contacted NGOs and professional acquaintances in France, has yet to realise his dream.

Private providers' ways to cope with challenges

While struggling and navigating step-by-step with these challenges and their specific situational shape, on their journey to provide ARTs locally in different West African cities, several 'models' were pragmatically developed by gynaecologists and biologists, which can be roughly clustered into three different types.

In the Togolese case, a North-South start-up partnership eased the way to put ARTs to work. The gynaecologist and director of a private clinic explained to me that he entered in a partnership with a French ART specialist. In the beginning, himself and an embryologist received extra training in France, while local training in Lomé was organised for laboratory assistants and nurses. While the Togolese team conducted the hormonal stimulation, harvesting of ova and fertilization, the French specialist and a team regularly travelled to the clinic, in order to carry out embryo transfers until the Togolese gynaecologist was able to successfully perform this key step in the IVF procedure (Hörbst, 2012b). The French team's travel and accommodation expenses were fully covered by the Togolese clinic. Similar proceedings for putting ARTs to work were developed in Cameroon, Cote d´Ivoire and Burkina Faso ([1]).

In Dakar, the capital city of Senegal, in 2007 a different model was developed: a local director of a laboratory for biomedical analysis started a split-off or "outsourced" lab service for the fertilisation of gametes. He provides the full lab equipment and skills for IVF and ICSI and offers the fertilisation process (including cryopreservation) to various gynaecologists from different private clinics. The gynaecologists carry out the hormonal stimulation and harvesting of ova in their clinics, while the gametes are then brought to the lab where the fertilisation of ova and sperm is processed. The embryo transfer procedure is done by the gynaecologist within special rooms of the laboratory. This model reduces cost for the gynaecologists, who do not need to buy laboratory equipment and maintain a skilled laboratory team, etc. With specific funding arrangements, this model could also allow for the provision of ART treatment in public clinics ([2]).

In the Malian case, a rather "South-bottom-up" procedure emerged in different phases. In the beginning, the clinic director employed a biologist who trained and managed two members of the lab team himself. To keep investments low he (mainly) bought second hand equipment to start insemination and IVF, but not ICSI. At the same time he enlarged and enacted his already existing transnational professional networks in order to arrange for training internships for him and the biologist in several clinics abroad. While in 2007 they had success with

[1] The last statement is drawn from personal communications and oral presentations at the GIERAF conference in Lomé, February 2009. In Uganda a similar model was developed, see Platteau et al. 2008.

[2] The statements here are a brief summary from an interview with the director held in 2007 when visiting the laboratory and are also drawn from the director's presentation at the GIERAF conference in Lomé, February 2009.

inseminations, their efforts with IVF still proceed to fail. They attempted to overcome this situation by trying to receive additional (technical and financial) support from a Dutch NGO, but it was unfortunately in vain. The Malian gynaecologist then extended the application of insemination for cases that, according to European standards, would have recommended IVF and/or ICSI. With recommendations by French specialists, he simultaneously started to treat younger women with less complicated case histories and to also offer donor oocyte cycles from a sister or cousin for IVF in older women. He became a founding member of the francophone African fertility association at its first conference in 2009, which resulted in obtaining helpful information for improving his activities and triggered a dynamic optimism. On this basis, the biologist and gynaecologist decided to risk new private investments. Entering in a business partnership, they asked for a high bank loan, with which they purchased new lab equipment, which included the micromanipulators required for ICSI. Further on, anonymous gamete donors were found and utilized in donor cycles, and in 2010 the first babies after IVF and ICSI were born in Mali. An increase in patients and cycles carried out was noticeable in 2011 and cryopreservation is in the planning ([3]).

Patients coping with obstacles

While many Malians have heard at least rumours about so-called "test-tube" babies, most of them have only superficial information on the different care options that can be summarized under ARTs. In my research, the majority of involuntary couples had spent thousands of euros on repeated conventional biomedical treatments with various specialists (public and private), before they had begun an ART cycle. My data suggest that this practice is triggered to a certain degree by gynaecologists' recommendations and by a certain denial to refer women to colleagues; it also intersects with patients having a rather individual-related trust in specific doctors' skills than in the biomedical techniques applied, along with a desperate "hope against hope" for success before moving on to another provider.

This behaviour also relates to a lack of resources, as for the majority of Malians a treatment with ART is hardly or not at all financially feasible. Even in cases of couples from the more affluent middle or higher economic strata, as in my research sample, there are situational shortages particularly based on the priority of other family members' demands such as school fees, marriages, other health treatments and investments necessary for business affairs etc. The more powerful and economically successful a Malian family is, the more obligations they have towards relatives and clients. Moreover, with a majority of Malians belonging to Islam, social solutions such as marrying a second wife or fostering other children to realize a child wish are acceptable; and, many extended families have reservations against spending huge amounts on ARTs. However, for many involuntary childless couples, particularly for women, ART treatments are more attractive: if successful, they allow women to become pregnant, and visible pregnancy can suffice as a means to overcome the social stigmatization and exclusion of infertility (Hörbst, 2012b).

In general, these financial barriers are easier to deal with, if the women earn money themselves. Employments can also be used for organising bank credits. Income from informal female saving circles can be very helpful, as much as substantial contributions made by elder sisters or brothers living and earning abroad (Hörbst, 2012b). This is of particular importance in cases where husbands already have children with another wife and/or if female factor infertility is diagnosed. If the husband has no children and/or male factor infertility is diagnosed, husbands seem to be more inclined to pool the money for ARTs. But these tendencies are highly dependent on frames of orientation and education, on individual understanding of marriage and partner relationships, as well as the duration and persistence of the problem, while also a distinction between generations is notable from my data.

Furthermore, some men in my study were suspicious about a diagnosis that would refer to them as being infertile, causing them to go for additional opinions. Some men did not accept an infertility diagnosis at all, as in the Malian public narrative women are usually accused of being the cause of infertility in a marriage (Hörbst, 2012a). Additional issues, surfaced: while some men feared the mistaken identity of ova or sperm in the lab, several couples expressed reservations against African clinics offering ARTs in general, but in contrast showed a high trust in the 'technical/scientific superiority' of European clinics (particularly following failures with local ART treatments).

[3] After having reshaped the fertility centre, according to the Malian clinic, they have lifted the prices of an IVF cycle from approximated 150 euro. In 2010, the cost for insemination was nearly 400 euro, with a discount for three attempts it is about 900 euro. A single IVF attempt costs around 1300 euro, with a package solution buying two attempts in advance it will be roughly 2300 euro. ICSI costs 1900 euro, with a package solution it will be around 3100 euro. Depending on the specific situation, around 1000 to 1700 euro have to be added to each attempt for hormonal stimulation, monitoring and ultrasounds.

In the process to put ARTs to work in Mali, clinics (along with other West African ones) responded to patients' financial and local socio-cultural barriers to undergo ARTs. On the one side, the gynaecologist provides some monitoring treatment (ultrasound) for free, or gives discounts in cases where couples have unsuccessfully attempted ART cycles several times. The clinic also can offer a "package solution" with reasonable discounts if three inseminations or two IVF/ICSI cycles are purchased at the beginning ([4]). On the other side, multiple (up to four) embryo transfers are provided, as the gynaecologist explained to me, in order to heighten chances for success and to save money.

While money is for many Malians the most significant obstacle, there are socio-religious obstacles that can be, for some, easier to tackle. Some men in my research distrusted the treatments completely, as the gynaecologist's work appears to be untraceable or unverifiable. One main question was: "Do they do anything at all?" To calm those fears, the Malian clinic started to show the couples the main steps done in the lab. They made sperm visible via a computer screen before and after treatment, they showed them the embryos before the transfer and explained, based upon visualization techniques, on embryo quality and the decisions made about which embryos to transfer.

As Islamic views in Mali prohibit the use of donor gametes, rejection of donor gamete cycles is often expressed. However, some infertile women and men (including religiously committed ones) in my study accepted donor cycles, by handling the religious question rather pragmatically. Their argument was, "I do not harm anyone, so Allah will forgive me", and therefore they consider this act a private decision that they have to resolve with Allah only. In some cases, where women fear their husbands might be reluctant to use donor ova, the women explained to me that they simply conceal this aspect from their husbands and, as long as the husband does not ask, as the gynaecologist told me, the clinic does not tell him either. In the case of donor sperm, the same procedure is applied concerning the wife. Moreover, the clinic allows men to collect sperm at home – an instance that also enables men to clandestinely bring, for instance, a brother's sperm for ART procedures (Hörbst, 2012b).

Conclusion

The interest and demand for ARTs is increasingly matched by the development of private institutions catering to this need in increasingly more West African countries. The sub-Saharan specialists and teams engaging in ARTs have developed several models to put ARTs to work. Due to these efforts, ARTs have become locally accessible and, in consequence, also more easily affordable for the more affluent francophone African upper and middle class couples suffering from involuntary childlessness. The teams providing ARTs have appropriated some of the current prevailing international standards (such as single embryo transfer, low dose protocols, transparency between partners) to specific local socio-cultural configurations: they are aware of different relations between the married partners and thus provide consultations with one partner only and allow for the concealing of information between partners. Many cycles are multiple embryo transfers, and, as gynaecologists and/or patients from Mali, Togo, Senegal and Cote D'Ivoire expressed, they are rather positively evaluated as a mean to heighten chances and save the patient's money. However, private clinics have already implemented structures and have successfully organised teams for efficient cooperation in providing successfully ART treatments to their patients although they have appropriated some standards to local social and economic configurations. Looking at the huge and multiple factor problems of public health institutions, these private actors seem important partners to engage with in order to implement new or to improve treatments for infertility with ARTs. As these private clinicians and embryologists have developed strong networks and experience, and have risked investments often of their private money, they should not be overlooked but actively involved in future activities to provide more affordable ARTs which would be more feasible and thus accessible for a larger number of involuntary childless couples in francophone West Africa.

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[4] If the first cycle of treatment is successful, the couple can come, for instance, one year later for another attempt, or they can transfer the right to a further attempt to another couple. In Togo similar package solutions are offered.

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Reviewing infertility care in Sudan; socio-cultural, policy and ethical barriers

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Abstract

This is a facility based survey that reviews infertility care in Sudan. Both authors interviewed lead physicians of functioning ART clinics. There are seven functioning privately owned fertility centres in Sudan, all situated in Khartoum state. The first centre was established in 2000. Public hospitals provide consultation and baseline investigations only. All centres have ICSI setups and do not offer standard IVF. The success rate claimed by centres is between 25-30%. HBV screening is routine in all centres while HIV screening is routine in only two centres. However, one centre declines further treatment for HIV positive couples. Centres are not affiliated with any local or regional body for reporting or quality assurance. Currently, there are common significant barriers to infertility care mentioned by all centres – high cost and inaccessibility. The cost of one cycle of IVF/ICSI treatment with drugs starts at 2,500 USD in all centre. Couples with male factor infertility have a better chance obtaining funding for ARTs compared to couples with female factor infertility. Cost reducing recommendations include: government subsidies for fertility drugs and lab media, centres sharing embryologists and cryogenic banking.

Key words: **Barriers, infertility, private ART, accessible public care.**

Introduction

Infertility care is neglected in health care systems and health care research in most developing countries. Many argue that infertility issues in developing countries should not be a priority due to over population and an already overstretched health care budget (Vayena et al., 2009). As a result, infertility care response in developing countries is primarily focused on prevention and early treatment of sexually transmitted diseases (STD) and pelvic inflammatory disease (PID). Recent surveys in sub-Saharan Africa show a prevalence of 3% for primary infertility and up to 23% of secondary infertility (Republic of Central Africa) (Larsen, 2000). There are noticeable inconsistencies in infertility definitions used in population based surveys within and between countries. In demographic studies in African countries, primary infertility is usually measured by the proportion of childlessness among women who entered their first marriage at least seven years before the date of survey (Larsen, 2000). Secondary infertility is measured by being 'subsequently infertile' from previously parous women.

Sudan is a developing country with the third largest territory in Africa. It has a population of 36,787,000 giving rise to a population density of 18.33 people/ km^2 and a population growth rate of 2.48% (World Bank, 2011), therefore it is not an over populated nation. The needs of Sudanese infertile couples are not addressed by resource allocation, health policies, community level education or advocacy campaigns. As with other male dominated pronatalistic societies, the effects of infertility have far reaching social effects especially on the spouse diagnosed with infertility. Bearing babies is encouraged in Sudanese society and it is of upmost importance in maintaining family stability. It is equally important for men as well as for women. Infertile couples carry the burden of lower social status, pity

and gossip. Local research in Sudan has shown that the society does not acknowledge men's contribution to infertility. Male fertility is greatly tied to male virility and sexual ability. Women should be the ones to seek help & treatment, while bearing the social stigma. Women are left helpless and are forced to accept abandonment or share a husband with a new wife (El Safi, 2007). Although these beliefs are not as severe in urban Sudan, they are still routed in society and accepted by some. Such socio-cultural effects, coupled with a lack of access to infertility services, exacerbates suffering, causes desperation, and worsens health disparities (Larsen, 2000).

Infertility is currently becoming more of a burden in Sudanese society mainly because both men and women are marrying at an older age and during difficult financial and socio-economic circumstances. Now women are having shorter reproductive periods and men want to ensure that they, as a couple, can procreate as they are unlikely to remarry. Traditional healers play a bigger role in infertility care especially in areas outside Khartoum (El Safi, 2007). Usually they are the first to be consulted before any health personnel. Primary health facilities, especially outside of Khartoum, cannot provide the minimum infertility investigations; hence women are usually frustrated and usually turn back to traditional healers. Economic factors stand in the way of seeking help in upper level health facility. Women still complain of resistance for their husbands to seek help although male infertility is increasing locally as well as globally. Hence the limited role of male involvement in seeking medical help for infertility is a barrier for many women (El Safi, 2007).

It is widely hypothesized that infertility in some regions in Africa is linked to female circumcision (FGM/C), especially to more severe forms of FGM, due to the higher risk of subsequent untreated pelvic infections. Research indicates that infertility among uncircumcised women is not significantly different from infertility among "Sunna" circumcised women (most minimal form of FGM). Two local studies found significant association between primary infertility and the most severe form of FGM. "Pharonicly" circumcised women showed a higher prevalence of primary and secondary infertility than uncircumcised women. This was explained by the higher risk of girlhood pelvic inflammatory infections increasing the risk of tubal factor infertility (Almroth et al., 2005; Ahmed et al., 2009)

Role of traditional healers in infertility care

Anthropological studies conducted in Sudanese societies regarding reproductive and sexual beliefs reflect the poor knowledge people have about infertility and sterility. Very fatalistic attitudes are expressed towards these issues. In many parts of Sudan, especially the Northern & Nubian region, traditional healers are a first point for consultation. These healers provide women with magical-religious potions and recipes, or subject women to bizarre rituals and ceremonies (Nadel, 1978). At that point women are disparate due to the immense social stigma they are facing. The problem with healers is that women face considerable delay in seeking proper biomedical care.

National infertility statistics in Sudan

There is a clear lack of infertility statistics in Sudan. Studies in parallel African countries showed the main cause of infertility among females is tubal factor due to chronic infections (post partum infection, PIDs and STDs) (Osman, 2011). In Sudan, one study provided prevalence data in 10 states in Sudan (11.5%), primary infertility being more prevalent than secondary infertility (79.5% and 20.5% respectively) (Ahmed et al., 2009). Female factor infertility constituted 37% of the total determinates of infertility while male factor constituted 20%. Anovulation was the most common female factor (69.5%) mostly due to hyper-prolactinemia (47.5%) (Ahmed et al., 2009). Another study also showed that primary infertility is the dominant type of infertility with female factor being the most common mainly due to failure of ovulation (60.3%) (Elussein et al., 2008). Another study showed male factor infertility constitutes a third of infertility cases seen in fertility laboratories. Among those, gonorrhoea had a high frequency, second to varicocoele (Ahmed et al., 2009). These local statistics suggest that medical treatments for infertility as well as STD prevention strategies are key modalities that could tackle infertility in Sudan. Although these statistics cannot constitute national determinants of infertility, they do draw attention to assisted reproductive technology (ART) as a lower priority issue among decision makers.

Infertility and Reproductive Health Policy

Sudan Reproductive Health policy is formulated towards enabling Sudan to reach its commitments in fulfilling its Millennium Development Goals (MDGs), specifically MDG5 (Sudan National RH Policy, 2010). MDG5 does not place infertility care as a priority nor does it have it as one of its indicators. Sudan's RH policy vision is to control fertility via family planning as a mean for reducing maternal morbidity and mortality through birth spacing and

enabling women to survive pregnancy and childbirth. Sudan's RH policy should abide with the World Health Assembly's first global strategy on RH that states; "infertility care services are to be provided within family planning services; they should basically include appropriate medical evaluation of the infertile couple and should offer possible treatment options that do not necessarily require ART for some couples" (World Health Organization, 2005). Infertility care is sated in the policy as a component of family planning services. It is stated that it should be provided through primary health care (PHC) in the public health sector (Sudan National RH Policy, 2010). Resource allocation for infertility care is currently not a priority and will not be in the near future. Provisions of infertility care are not catered for in the values and principles of the RH policy. The policy is stipulated under six guiding values and principles; quality, rights based, equity & empowerment, PHC based, multidisciplinary approach and participation with communities. Sudan's RH policy has failed to recognize infertility care from a rights based perspective: every human being has a right to bear children. Quality infertility care is neither provided at the primary health care level nor is there equitable access to the available private services across different socio-economic levels. Furthermore, Sudan's RH policy does not have a clear implementation strategy as to date.

Methodology of review

The authors surveyed existing ART services in Sudan from Sept 2011 up to November 2011. Data were obtained via personal interviews with the leading physicians/owners of functioning ART centres. They were OB/GYN physicians (senior consultants) specializing in infertility care. The authors used a semi structured questionnaire containing questions on the establishment of the clinics, ART services and procedures offered at the time of interview, cost of procedures, staffing, running costs, age restrictions for ART treatment, information on the types of infertility presenting to the clinics, the types of routine testing offered, success rates, guidelines and protocols followed regarding the different procedures offered and quality control measures. Physicians were interviewed about ethical issues encountered during their practice. The interview gave them the chance to state obstacles faced in running the centres and to put forward recommendations as well. Both authors conducted interviews and each interview lasted three hours. Interviews took place at the clinics' premises. Data were manually analysed to be presented in a descriptive manner.

Public level infertility care in Sudan

Public infertility care in Sudan is purely consultative and diagnostic; at the primary health care level couples may find consultative care but will not find diagnostic care. If couples are referred to secondary or tertiary level care, or if they present there as their first point of entry, they could receive, in addition, some diagnostic tests (e.g. hormonal profile, semen analysis, HSG and diagnostic laparoscopy, +/- simple ovulation induction). No further management is available in the public health sector. In Sudan ARTs are only available in private level care. This arrangement leaves couples with infertility complaints consulting regular OB/GYN ANC clinics in the public sector. Consequently, couples will have no privacy or proper counselling, females will usually attend alone and there will constantly be concerns regarding the quality of the diagnostic tests performed.

In Khartoum state, with a population of five million people, only three public hospitals out of 12 offer diagnostic laparoscopy. In the remaining 14 states of Sudan, with a total population of 26.3 million, only four public hospitals out of 86 offer diagnostic laparoscopy for infertility. There is clearly inequity in the distribution of care even at the diagnostic level between different states in Sudan. The National Health Insurance covers doctors' fees, and fees for diagnostic tests at both the private and public level care. In some cases it is extended to cover fees for ovulation induction drugs for only one cycle of intra cytoplasm sperm injection (ICSI) or in vitro fertilisation (IVF). No further management of infertility is covered by any type of local health insurance. Any further expenses are paid out of pocket. Most of the private fertility centres do not accept results of tests performed in public hospitals and request repetition of tests; the National Health Insurance of course will not cover this.

ART services in Sudan

ART services are all privately owned and very recent in Sudan. The first centre opened in 2000. All ART centres are situated in Khartoum state. No ART services are offered outside of Khartoum state. Up until November 2011 there were seven functioning ART centres, one none functioning and one centre due to open in 2012.

Centres claim no age restrictions for ART treatment. Physicians across all centres agreed that primary infertility is the most commonly presenting type mainly due to female factor, but there is consensus that cases of secondary infertility and male factor infertility are alarmingly increasing. Whether this is a true increase in incidence or a shift in health

Table I. — List of hospitals with laparoscopy setup.

Khartoum State hospitals
1. Soba Teaching Hospital
2. Khartoum Teaching Hospital
3. Omdurman Maternity Hospital
Hospitals outside Khartoum State (14 States)
1. Mek Nimir University Hospital
2. Medani Teaching Hospital
3. Elfashir Teaching Hospital
4. Port Sudan Hospital

seeking behaviour is yet to be studied. This observation on male factor infertility made by treating physicians emphasizes results from local study (Ahmed et al., 2009). This could be an indicator of growing male infertility in Sudan. Centres reported success rates ranging from 25-30% with an average of 15-20 ICSI cycles per month. Two centres commented on an increase in multiparous women seeking ART for the purpose of gender selection. Sex selection by preimplantation genetic diagnosis (PGD) is not offered in the centres; however, one centre provides sex selection using density gradient separation of the X and Y chromosomes, claiming success. The average staffing across centres are two fertility physicians, one embryologist, less than one andrologist, two nurses and three lab technicians. None of the centres offered counselling by professional counsellors. All interviewed physicians stated that patients prefer counselling from their treating physicians hence not recruiting counsellors was seen as cost effective.

Range and cost of ART services

All centres provide basic diagnostic tests. All provide intra uterine insemination (IUI) and ICSI. IVF is not offered across all centres as the setup for ICSI is available in all the functioning centres. Sperm and embryo banking is offered in five centres while two centres stated it was not cost effective to offer it. PGD is offered in one centre not for the mere purpose of sex selection since this is implicitly forbidden in Islam (Serour, 1997). All centres claim not more than two embryos are transferred in an ART procedure. Selective foetal reduction is routinely offered if more than two embryos develop. Sperm donation, ovum donation, embryo donation and surrogacy are not offered in any centre. Hepatitis B testing is obligatory in all centres for couples undergoing any form of ART treatment. HIV testing is obligatory in two centres.

The cost of one cycle of ICSI, including drugs, is more than 8000SDG (approximately 2500 USD at time of reviews). This amount is constantly fluctuating as the USD exchange rate against the Sudanese currency increases. The high cost is due to lack of government subsidy on; drugs, running costs and equipment. These costs are considered astronomical for an average Sudanese patient with a minimum wage of 150 USD per month. Another major contributor to the high cost of IVF for patients is the higher risk of multiple pregnancies. An IVF baby admitted to a Sudanese neonatal intensive care unit will cost the couple 875 USD per week. Neighbouring countries like Egypt and Jordan offer cheaper ART but calculating the cost of travel and accommodation, the total cost would exceed local ART cost.

Common misconception about infertility/ART in Sudan

Infertility physicians still have difficulty addressing common misconceptions among their patients. The most common misconception among men, as well as women, is that men who have no sexual problems or have fathered children before cannot have infertility problems later in life. Women will resist bringing their husbands if they fathered children before. Another misconception among Sudanese couples is their preference for IUI over IVF/ICSI due to deep-rooted misplaced fear of religious origin. A local study on couples with ART pregnancies revealed that couples with an IVF/ICSI child hide the fact from their surrounding community due to fear of stigma towards that child (Gaily et al., 2010).

Ethical issues

A number of ethical issues arose when ART was first offered in Sudan. Fertility physicians initially faced resistance from the community due to limited knowledge of the religious boundaries of these services. Communities feared that IVF/ICSI would be forbidden in Islam. They also feared mixing of ova, sperm or embryos in laboratories. Since there were no clear guidelines or legislation in Sudan regulating ART services, in the early 2000 physicians started a number of television and radio advocacy campaigns to increase community acceptance. Gradually the public opinion changed. ART now is widely accepted in society as long as there is no third party involvement in any ART procedure (Serour and Omran, 1992). Furthermore, there were ethical and religious concerns when foetal reduction was addressed. A fatwa was issued stating selective foetal reduction is allowed if the health of the mother or embryo is jeopardized (Serour et al., 1995). Gender selection by PGD is not performed in the centres. PGD is offered to women of older age to detect chromosomal abnormalities. Sperm, egg, embryo donation and

surrogacy are perceived, in all centres, as forbidden in Islam hence they are not offered even if couples are not Muslim (Gaily et al., 2010). One centre has specific guidelines refusing ART to HIV positive couple. This is a form of violation of human rights (Khan et al., 2003).

An ethical issue emphasised by the interviewed physicians arises when couples try to secure funding for ART: they have a lower chance of sustaining the funding if the infertile party is found to be the woman than if it is due to male factor infertility. A man diagnosed with male factor infertility has a better chance of securing sustained funding. A male with an infertile wife will have a better chance of funding a second marriage than to treat his wife.

Practicing physicians noted that a large proportion of Sudanese couples, especially of higher socioeconomic level, consult centres outside Sudan. Sudanese generally have low trust in the quality of the Sudanese health care system. Also, the instance of unsuccessful cases seems to have a negative effect on centres' reputations. Centres do not do their part to publicize success rates so as to gain the confidence of future patients.

Main obstacles to infertility care in Sudan

Inequity in access to ART services is one of the main obstacles recognized, as all centres are located in Khartoum state. In addition, no referral mechanisms or partnerships with public fertility care have been established to date. The average Sudanese couple cannot afford ART without support. Sustaining support or funding greatly depends on personal efforts and connections, which will delay receiving treatment. In addition, there is no accreditation body, local or regional, which regulates quality & safety of care, monitors laboratories or surveys outcomes of IVF/ICSI treatments. There are no clear training requirements or credentials for physicians to establish private ART centres.

Centres complain of high running costs compared to the low number of patients. There is no government subsidy or support. To maintain quality and due to lack of qualified local trained staff, especially embryologists and fertility nurses, centres have to recruit foreign trained staff by offering competitive salaries and packages. This is extremely difficult to maintain without increasing patients' costs. Centres are demanding government subsidy on fertility drugs and/or exceptions from taxation so as to decrease ART cost. There is need for surveillance system for infertility prevalence, treatment and outcomes. Data collection and reporting on ART access, efficacy, safety and quality is needed for all stakeholders: for patients to make decisions on treatment options, and for professionals to allow them to make clinical policy adjustments, regulations and resource allocation (Vayena et al., 2009). Cost analysis has not been done on Sudanese couples undergoing any type of ART. A recent analysis of preliminary data calculating the potential cost-effectiveness of low-cost IVF has indicated that for sub-Saharan Africa one cycle of IVF would need to cost $50–$75 to be included in regular public health packages (Habbema, 2008).

Recommendations

One of the most urgent recommendations is establishing partner satellite fertility centres outside Khartoum state. These centres could be public or private with a setup that enables them to do initial workup, ovulation induction, COH and IUI with referral of ICSI cases to Khartoum for egg retrieval and embryo transfer. This could be an optimum example of public-private partnership that would ultimately improve the quality of public services and reduce cost of private services. Fertility clinics should also aim to address the psychological and emotional needs of their patients as well as their medical needs. Infertility consultation differs from other symptom – or disease – oriented consultation (Blyth, 2012). Individuals dealing with fertility problems have consistently been found to exhibit psychological distress (Hakim et al., 2012). Counsellors are not dealing with subjectively defined suffering determined by various personal and psychological features (Blyth, 2012). Diagnostic procedures and medical treatment in infertility have an important impact on the intimate life of the patients. Therefore the couple's relationship, dynamic sexuality and ability to cope with the psychological and emotional effects caused by this process must be considered in addition to the course of treatment options. Follow-up research is needed to monitor maternal and foetal outcomes and to monitor long term effects of ART on mother & child. The recommendation that will have the most effect on influencing major policy changes is establishing a continuous data collection and reporting system for all functioning centres. This can be used to influence major changes in resource allocation at the government level as well as build community confidence in infertility care available in Sudan. With the modest evidence of infertility currently available in Sudan, it greatly suggests the need to move beyond prevention and expand quality infertility treatment services to all public level health care and to ensure all levels of the community have access. To maintain quality of existing and future ART services, there is need to establish accreditation bodies and to set up clear training requirements/credentials for physicians establishing private ART centres.

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The Growth of Biomedical Infertility Services in Vietnam: Access and Opportunities

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Abstract

This article focuses on the rise of biomedical infertility services in Vietnam since the late 1990s. While the number of ART service sites has grown over the past fifteen years, the patient demand outpaces the supply, and the economic and supply barriers are insurmountable for many potential patients. The article focuses on legal, economic and supply factors that affect the experience of seeking medical care for infertility, as well as explores the sociocultural context that shapes values related to the pursuit of treatment.

Key words: **ART, assisted reproductive technologies, barriers, infertility, IVF, surrogacy, Vietnam.**

Introduction and Background

From an anthropological perspective the challenge of infertility and the use of assisted reproductive technologies (ARTs) for its treatment must be viewed as complex – intertwining sociocultural values, and structural and institutional variables that shape the experience of infertility, its prevention, and treatment. The globalization of ARTs has enabled new reproductive possibilities, more recently in low-resource countries, although not equity in access (Ombelet, 2011). In most settings the use of ARTs has preceded its regulation. Regulations have arisen in contexts of local cultural values and institutional processes. It is in these settings in which everyday practices are enacted, reflecting "local moral worlds" of cultural values and politics that shape and situate the experience of infertility (Kleinman, 1995). How do the regulations of the state influence the practices of infertile patients and practitioners? Moreover, how do such regulations work in concert with regulations in regional countries to shape the local moral worlds of those seeking treatment for infertility?

Vietnam is a relative newcomer to biomedical infertility treatments, such as in vitro fertilization (IVF), and has benefitted from the global circulation of ARTs. After extensive planning beginning in 1990, overseas training of doctors, and collaboration with French infertility specialists, one state-run hospital Từ Dũ Hospital in Ho Chi Minh City, Vietnam created a highly successful IVF and microsurgery centre. Vietnam's first IVF births occurred in 1998. Từ Dũ Hospital made rapid strides in providing infertility services. The infertility clinic in this one hospital has more than 20,000 visits and more than 10,000 infertile couples per year, including 3000 IUI cycles, and 2000 IVF and related procedures (Wiersema et al., 2006). Anecdotally, doctors who planned the microsurgery centre reported a high level of tubal-factor infertility, although reliable national statistics are difficult to come by. Since 1998, more than ten assisted reproduction centres have been put into place in Vietnam, primarily in major urban areas (Ho Chi Minh City and Hanoi), and primarily in the state sector. Initially, unlike numerous other countries in which ARTs have flourished in the private medical sector, the proliferation of IVF was largely limited to public sector, including Từ Dũ Hospital, which quickly became the leader in biomedical assisted reproduction in Vietnam. Privatization of medicine has been gradual in Vietnam, initiated only in the late 1980s. The provision of ARTs in Vietnam reflects this trajectory and IVF has been slow to proliferate widely in the private sector in Vietnam, in part due to a guarded process of privatization of the medical services industry.

The IVF technology was received initially with some scepticism by women I spoke with, not all of

whom were infertile, and who questioned the quality of children that might be produced through the procedure. Ultimately, the technology was embraced by those seeking fertility treatments. The application of IVF itself, and the techniques associated with it developed quickly. Legal regulations of the use of the technologies followed after a delay of several years. After numerous IVF births and the first cases of surrogacy, in 2003 the law on Childbirth by Scientific Methods was promulgated which stipulated the use and limitations of ARTs in Vietnam, including the banning of surrogacy and restricting ARTs in unmarried women (Official Gazette, 2003).

Infertility has long been a cultural concern in Vietnam, where it is generally held that all women should become mothers (in addition to filling other roles in society), and infertility is seen as a serious social problem for women. Yet, only recently has infertility become a recognized problem on a policy level. For decades, infertility in Vietnam was eclipsed by emphasis on family planning, aiming to increase the use of contraceptives and to reduce the total fertility rate. Funding supported family planning efforts, but did not exist to grow the quality and availability of infertility treatments. After a focus on a one- or two- child family planning policy beginning in 1988, which reduced the fertility rate to replacement level, Vietnam shifted its policy emphasis to focus on population quality and setting reproductive health goals (Socialist Republic of Vietnam, 2006a). The national reproductive health strategy included objectives to reduce the incidence of infertility, and to promulgate laws on in vitro fertilization and surrogacy, an important recognition of the problem of infertility (Socialist Republic of Vietnam, 2006b). In its current Population and Reproductive Health Strategy (2011-2020) one of the objectives is to improve accessibility to infertility services and lower by half secondary infertility rates (Socialist Republic of Vietnam, 2011). The gradual inclusion of infertility in these strategies reflects the recognition of the need for effective infertility treatment, the stabilization of the total fertility rate, and socioeconomic change that has occurred as Vietnam has moved from a low- to middle-income country. These strategy decisions have coincided with the increase in infertility services and pre-existing desire for such services among the affected population. However, a number of intersecting factors currently exist that shape the experience of infertility and complicate the search for its treatment in Vietnam, and which constitute the focus of the current article.

Methodology

This article is based on ethnographic research conducted for nearly sixteen months in Hanoi, Vietnam and surrounding areas in 1995, 1997 and 2004, as well as interviews in 2007 with medical professionals in France involved in Vietnam's first IVF births, and reviews of legal documents and media sources. The ethnographic research focused on the sociocultural and treatment experiences associated with infertility among 40 women who presented themselves as infertile and a comparison group of ten women who had at least one child and had not experienced infertility. Women ranged in age from twenty-one to fifty-five. Most interviews were tape-recorded, transcribed and translated. The primary sample of infertile women was drawn from one urban maternity hospital in Hanoi from women presenting as infertile. Follow-up interviews took place in women's homes or locations of their choosing. I also interviewed healthcare providers of infertility services, including medical doctors and traditional medicine practitioners. Follow-up research in 2004 with key informants from the same group examined changes in assisted reproduction treatments in Vietnam, perspectives on IVF, and the development of legislation regulating the use of ARTs. Ethical clearance for the research was provided by UCLA and Bryn Mawr College. I am unaware of any conflicts of interest.

Sociocultural Pressures and Infertility

Infertility is a serious social concern in Vietnam, especially for women who are often seen as the key to perpetuating the husband's patriline through the birth of a son. Culturally, the achievement of motherhood is important for women in Vietnam to attain full adult status. The birth of a child is believed to create a special form of sentiment (*tình cảm*) between a wife and husband. *Tình cảm* also grows between a pregnant woman and her foetus in utero and lays the groundwork for a close relationship with her child after birth. In addition to the growth of sentiment in utero, some people believe that the mother and foetus share nutrients and blood during gestation and these shared substances link them through the intimacy of the womb (Pashigian, 2009a). Infertility in a couple is often blamed on the woman and infertile women in Vietnam can be subjected to ostracism in their husband's extended family and community. Infertility in men is an understudied subject in Vietnam. Some men deny that they might be the cause of infertility in their marriage and avoid evaluation. Infertility threatens their masculinity and virility. Some women will assume the blame for infertility in their marriage even when the source is their husband. Women with primary infertility have a higher rate of divorce than their fertile counterparts. In a DHS study of women self-identifying as infertile, sixteen per cent of women with primary infertility were divorced or separated (Rutstein and Shah 2004).

In addition to the threat of divorce, numerous infertile married women fear their husband will take a second wife, with or without their knowledge (Pashigian, 2009a). Some of these women were asked by their husband to seek out a second wife for him. For centuries, polygamy served as a way to expand lineages and to address infertility, but has been illegal in Vietnam since 1959 (Pashigian, 2009a). The pressure to take a second wife can also come from the husband's parents and other relatives. Many of the social pressures to bear children have to do with beliefs about maintaining connections between the living and the deceased. Parents believe that when they are deceased, a son, typically the eldest son, must attend to them and previous generations of the patriline in both death and commemorative ceremonies to provide for the needs of the deceased in the spirit world. Thus, the greatest pressure to bear a child, particularly a boy who will continue to propitiate the ancestors, falls on the eldest son and his wife. Adoption is undesirable as the child is not from one's own "blood line" and people believe that the possibility of a negative family history on the part of the adopted child could bring bad luck to the receiving family. Moreover, there is concern that the adopted child will abandon the adoptive parents to search for its birth mother. For a married couple, the social pressures associated with infertility can lead to divorce, polygamy, or physical violence, although there also are childless couples who withstand social pressures with less acrimony. For some, this social context makes for a secretive approach to treatment seeking, with couples keeping secret from their families their search for treatment; and some wives pursue treatment without the knowledge of their husbands for fear of marital instability.

Legal Matters

In 2003, five years after the first IVF births in Vietnam, the government of Vietnam put in place a comprehensive law to govern the provision and use of biomedical infertility therapies including IVF, artificial insemination and related practices (Official Gazette, 2003). The law did two things: It clarified who qualified for assisted reproduction services and who could provide services (primarily state entities). It stipulated age limits, marital status and citizenship requirements for those seeking IVF. While it created opportunities, such as a relatively high cut off age for services (45 years for gamete recipients) compared to many countries, it also created limitations that include a ban on surrogacy; limited services for single women; restricted the use of donor ova to married couples; restricted the use of Vietnamese donor gametes to ethnic Vietnamese only; and sperm banks were largely restricted to the state sector. While the law provided needed clarification about ART services, and protection of some groups, it also contributed to stratifying those who desired services by reproductive need, marital status, and ethnicity.

The law's ban on surrogacy has caused concern among medical practitioners whose patients might benefit from use of a surrogate, and among patients who seek surrogacy services. There has been a call for its revision (Tung, 2009). Currently, gestational surrogates are sought outside of Vietnam, or a woman willing to be impregnated by a man and give up the resulting child to him and his wife can be contracted illegally in the country. The law reflects cultural beliefs about gestation, that the woman gestating a pregnancy is culturally the mother even if she is not genetically related to the resulting child as in gestational surrogacy. However, like many other countries in the region that ban surrogacy, the restriction forces those desiring a child, and having no other assisted reproductive means to accomplish this than by means of surrogacy, to circumvent the law or seek services outside of the country.

Economic and Supply Barriers

Biomedical infertility treatment is expensive compared to the average household income. Treatment cost ranges from 1130-2265 euros per cycle, and services are only partly subsidized, so many costs are borne by the patient and family members (Tung, 2009). Monthly income on average for the country is 50 euros; 74 euros in urban areas; and 36 euros in rural areas (General Statistics Office of Vietnam, 2010b). For those who do not live in a metropolitan area with services, additional costs of treatment include travel to the hospital site, accommodation and food during the stay, which can be lengthy, and possibly transportation to and from the city and within the city during treatment. These costs alone can be prohibitive for those desiring services. The effects on access to treatment of the 2008 Vietnam Health Insurance Law, which mandates universal coverage by 2014, remain to be seen (Castel et al., 2011).

When demand for ARTs outpaces supply, there are multiple ways to stratify access and determine who should receive services. These can include: by need, chance of success, cost of treatment, and income of desiring parents (Dyer and Pennings, 2010). Since the first IVF births in Vietnam in 1998, there has been an unmet demand for services. Although there has been an increase in the number of clinical outlets for assisted reproductive technologies, there are still not enough accessible sites. Moreover, ART services are not available in rural areas where nearly 75 per cent of the population lives (General Statistics Office of Vietnam, 2010a). In the several years following the first IVF births and when only a few IVF centres existed in the country, the shortage of services led to instances of rationing with women

seeking services being turned away and asked to return at a later date (Pashigian, 2012a). For instance, one well-situated middle class teacher described her experiences seeking IVF treatment for the birth of her second child after an ectopic pregnancy. She was instructed by the hospital centre where she sought care to come back in several years if she had not yet had a child as there were women older than she who would be given priority (Pashigian, 2009b). She considered going to Ho Chi Minh City for treatment, concerned about her diminishing chances of having another birth as she aged. For this woman the most constraining factor in access to IVF treatment was a matter of availability based on stratification by perceived need, rather than cost. This sort of rationing reflected an orientation to a socialist, planned economy, long in place in Vietnam until the late 1980s in which the goal was to help as many people as possible by broadly distributing public resources, even if that meant – in this case - reducing the odds of birth success by privileging older bodies over younger ones. Thus, while wealth certainly makes it easier to pay for IVF treatments, access depends on a host of factors that include the qualifying criteria of the prospective patient including age and type of infertility condition.

Sperm donation also poses a dilemma. There are few sperm banks. The 2003 law regulating biomedical infertility therapies has restricted sperm banks to approved state sector facilities. Demand for sperm from the banks overwhelms supply. To contend with the shortage, the banks require patients who need donor sperm to bring a third party donor to the hospital to make a sperm deposit so the patient can make a separate withdrawal of an anonymous sperm sample (Tung, 2010). Some people prefer donor sperm that is anonymous. Cultural concerns about perceptions of incest and adultery shape the desire to seek sperm outside of the family. The desire for anonymous donor sperm stems from practical matters and cultural beliefs. Both individuals and medical practitioners have conveyed to me concerns that the mother of the child will pine for its father (the sperm donor), if she knows who it is, which will destroy her marriage to her husband. The 2003 law prohibits the sale of gametes, but penalties are minimal. Fresh sperm from the underground market has been reported in the mainstream media. Individuals sell sperm, as do brokers. Some donors reportedly are willing to have a health check and have sperm analysis if the customer pays for the medical check costs. Some are reportedly willing to impregnate a woman for a fee. Fees for donor sperm in the underground market have been reported to range from VND10million (364 euros) to VND6million (218 euros) depending on perceived quality of the donor in terms of education and other qualities such as height and attractiveness (Tuoi Tre, 2010). This supply issue poses a host of problems, first and foremost the public health implications of the potential risk of transmission of HIV and STIs, among other health consequences.

Treatment Trajectories

There are two major systems of medicine used for infertility treatment in Vietnam: biomedical assisted reproductive treatments, and those in traditional medicine (*thuốc Đông y*). While many women seek biomedical services of varying levels of sophistication, some women pursue traditional medicine first and delay biomedical evaluation and treatment. Such a treatment trajectory may be due to the availability and proximity of traditional medicine services in contrast to biomedical ARTs, as well as comfort and familiarity with traditional medicine treatments (Pashigian, 2012b). Traditional medicine is believed to balance the body and address idiosyncratic and changing bodily health needs to rectify infertility, in contrast to biomedical treatments in which treatment is selected from a narrow array of techniques and medicine applicable to all female patients with a particular infertility condition. Further investigation is needed into current treatment trajectories. Is this behaviour unduly delaying treatment and lengthening the course of infertility? How might both traditional medicine practitioners and biomedical practitioners be included in addressing infertility? The previous generation typically began their treatment with traditional medicine or alternated between traditional treatments and biomedical treatments. Given increasing numbers of IVF centres, but sustained supply barriers, will future patients follow a similar trajectory?

Regulation and Regional Movement

Vietnam's ART regulatory environment does not exist in a vacuum and patients who can afford to cross national borders in the region in search of medical care look to neighbouring countries such as Thailand to seek services they cannot access at home, such as surrogacy. Most countries in the region ban commercial surrogacy including Vietnam, Taiwan, Singapore, Japan, and Hong Kong. Some of these countries ban all forms of surrogacy. Thailand has been the exception, neither condoning nor condemning commercial surrogacy, although legislation on the matter of commercial surrogacy has been pending. These regulations also have created a market in which Vietnamese women go to Thailand on tourist visas to be ovum donors or surrogates. In 2011, such movement across borders produced an ethically complex international legal case surrounding the discovery by authorities in Thailand of Vietnamese commercial surrogates working in suburban Bangkok, reportedly carrying babies for

Taiwanese couples. The Vietnamese surrogates were taken into custody by Thai authorities and subsequently the surrogates and the developing foetuses and newborns (who were not necessarily genetically related to the surrogates) were together repatriated to Vietnam under the United Nations protocol to prevent and punish trafficking in persons. Cases such as this one speak to the need to address the movement of persons across borders for infertility services as well as improved access to local services in their home countries. But they also encourage discussions of access to assisted reproduction as a right (Inhorn, 2009, 2011) and how best to balance legal environments that serve the majority of people in a country with those in the minority who desire infertility services that may not be available within their national borders (Pennings, 2002).

Summary

Infertility continues to be a significant social and policy concern in Vietnam. Increased availability of biomedical infertility services has improved access to treatment for a select group of patients, however barriers to access persist that include financial and geographic barriers to accessing treatment, access to safe donor gametes, and for some access to services that are legally unavailable in country. Gender beliefs affect treatment-seeking behaviour in some couples such that men may be more reticent to seek services than their wives, and women may not receive efficient or effective care without the evaluation of their husband. Additional research on both sperm and ovum donation in Vietnam would benefit the field of study. The increasing privatization of ART services will expand access to biomedical infertility services. Ongoing changes to the structural and institutional factors cited here, along with the changing regulatory environment will continue to mediate the treatment experience in Vietnam presenting new opportunities for those seeking infertility services.

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Barriers to access to infertility care and assisted reproductive technology within the public health sector in Brazil

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Abstract

Background: **In Brazil, access to infertility care, including assisted reproductive technologies (ARTs), is restricted. This is the third report of a study on access to infertility care and ARTs within the public sector, focusing on the barriers to these services.**
Methods: **The study was anchored on quantitative and qualitative methods. For the quantitative study interviews were conducted with health authorities in each of the 26 states, the Federal District, the state capitals and 16 cities with ≥ 500,000 inhabitants and directors of infertility referral centres within the public sector. Qualitative case studies were conducted in five ART centres.**
Results: **Overall, 63.5% of the authorities reported that complex infertility treatments were unavailable. Barriers identified consisted of "lack of political decision to implement them", and "lack of financial resources". In addition, 75% reported to have "no plans to implement them over the next 12 months". At the facilities offering ART, the barriers to these procedures were the high costs, long waiting times, complex scheduling processes and lack of initiative to implement low cost ARTs.**
Conclusions: **Infertile couples' access to ART procedures is restricted due to the insufficient services and lack of political commitment to support existing and new services.**

Key words: **Barriers, inequity, infertility care, IVF, low-income populations, public health.**

Introduction

For women and men who decide to start a family, difficulties conceiving a child may become a source of strain and cause psychosocial problems. The impact of infertility on women and men's lives, and on their intrapersonal and interpersonal relationships has already been documented in the literature, reflecting the diversity of the problems faced by individuals confronted with the diagnosis of infertility and the physical and emotional strains of infertility treatments (Brkovich and Fisher, 1998; Daar and Merali, 2002).

Parenthood continuous to constitute an important life project for most women and men, and involuntary childlessness is a major life issue associated with strong psychological consequences. Furthermore, in some settings, infertile individuals, particularly women, are often stigmatized and isolated, and may experience diverse societal problems (Greil, 1997; Brkovich and Fisher, 1998; van Balen and Inhorn, 2002; Ombelet et al., 2008a; Inhorn, 2009; van Balen and Bos, 2009; Dhont et al., 2011).

In addition to the abovementioned challenges, in many developing countries infertile couples with limited resources are confronted with yet another challenge – that of gaining access to infertility services (Van Balen et al., 1996; Makuch et al., 2010, 2011). According to estimates from the World Health Organization (WHO) 180 million people around the world are affected by infertility problems (Rutstein and Iqbal, 2004). In developing countries, infertility is estimated to affect 9% of cohabiting couples and the demand for infertility treatment is estimated at

56% (World Health Organization, 1991; Boivin et al., 2007). Delay in gaining access to the diagnosis of infertility, to infertility services and to services that offer assisted reproductive technologies (ARTs) may negatively affect the possibility and the success of treatment for subfertile couples.

In Brazil, the federal constitution guarantees healthcare as a right for all citizens, and it is mandatory for the state to provide all health-related expenditures within the national health system, which is referred to as the *SUS* (*Sistema Único de Saúde* - Unified Health System) (Brasil, 1988, 2005). Despite the significant economic progress made by this country and its present position within the international scenario, inequalities persist between the higher and lower social classes in Brazil. Nevertheless, it has to be taken into account that significant progress has been made in improving and increasing the services covered by the SUS in its 20 years of existence (Viana and Machado, 2008).

Major efforts have been made to achieve reproductive health (RH) goals; however, these efforts have focused on reducing maternal mortality and morbidity, providing universal access to antenatal and obstetric care and family planning. However, there remains a wide gap between available reproductive healthcare, particularly obstetrical and gynaecological care, and access to specialized infertility services involving high-complexity procedures, including ARTs.

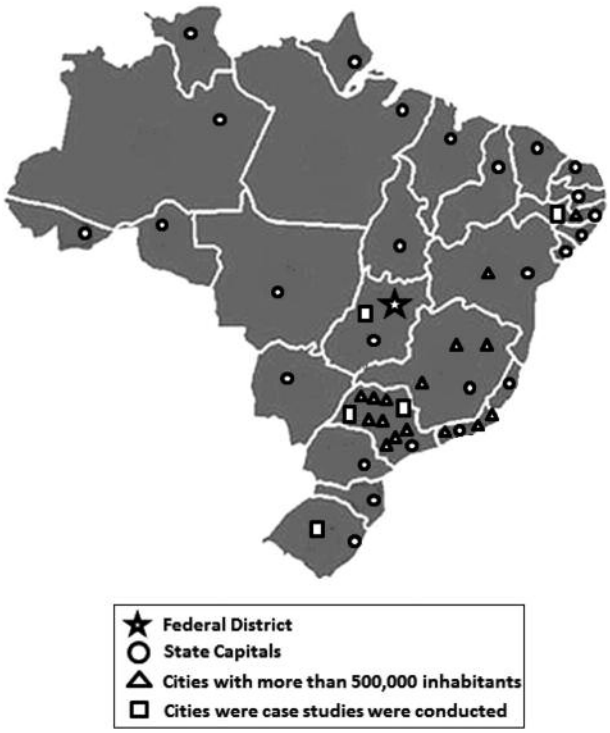

Fig. 1. — Brazilian map with indication of the place of interviews conducted.

The current situation in Brazil

A recent nationwide study, anchored on quantitative and qualitative methods, was conducted in Brazil (Makuch et al., 2010, 2011). This is the third report based on the results of this study. The main objective of this report was to identify barriers that hamper access to infertility care and to ART procedures within the public health services. The first stage of the study was based on a cross-sectional approach. Health authorities in all the 26 State Health Departments and the Department of Health of the Federal District, the 26 Municipal Health Departments in the capital cities of each state and another 16 cities with more than 500,000 inhabitants were contacted. Interviews were scheduled with the Director of the Women's Health Division or another designated person. In addition, 23 medical directors of referral centres for infertility services and 12 directors of university infertility services offering ART procedures, indicated by the state and municipal health authorities, were contacted for interviews. Based on the results of the first stage, qualitative case studies were conducted in five ART centres located in four of the five regions of the country (one region did not have any ART centres either partially or totally covered by the SUS). Health professionals and patients who had already undergone ART procedures or were waiting to initiate procedures in these centres were interviewed (Fig. 1).

It should be taken into account that of the total Brazilian population of 193 million, 140 million (72.5%) depend on the public sector healthcare system provided by the SUS (Santos et al., 2008; IBGE, 2011). Considering that there are almost 48 million women of reproductive age (15-49 years of age) in Brazil and around 5 million infertile couples (Santos et al., 2008; IBGE, 2012), it is reasonable to assume that almost 3.6 million infertile women depend on the public healthcare system for infertility care. The above figures show the magnitude of the problem, which is not habitually discussed by governmental authorities, and highlight the importance of improving women and men's access to services that offer diagnosis and treatment of infertility, including ART procedures.

Main barriers identified

A total of 64 out of 69 (92.7%) health authorities at the state and municipal level were interviewed. Additionally, interviews were conducted with 26 out of the 35 directors of the infertility referral centres identified by the health authorities, including those

Table I. — Barriers identified in the interviews with health authorities at the state and municipal levels.

	State	Municipal
Existence of infertility services		
Yes	8	16
No	17	23
Total	25	39
Reasons for not having infertility services		
Lack of political decision	13	10
Lack of resources	9	3
No healthcare facilities interested in implementing them	4	6
Issue not discussed by Health Department	4	6
There is no protocol	3	2
There is no demand	2	3
No plans to implement services in the next 12 months	17	35
Total	17	23

that had been identified as centres offering government-funded ART procedures.

Health authorities at both the state and municipal levels, 76% and 66.7% respectively, reported that no infertility services were available and that the public health administration had no future political commitment to provide these services. Also, 83% of the interviewed health authorities reported that no ART services were available within the SUS in their administrative region. The most common reason reported for the lack of these procedures within infertility services, both at the state and municipal levels, was lack of political decision to implement them, followed by lack of resources and lack of trained professionals. Furthermore, other important reasons given by the health authorities identified in the interviews for the inexistence of infertility services were "no services were interested in implementing ART" and "the issue had not been discussed by the Health Secretariat". Likewise, 75% of the authorities reported no plans to implement either infertility services or ART procedures in the 12 months following the interview. Both state and municipal authorities reported that infertile couples, including those who required ART procedures, were referred to centres specializing in women's healthcare or to university hospitals that are partners with the SUS in health service agreements (Table I).

The five infertility services visited during the study that offered ART procedures had been set up at the initiative of healthcare professionals interested in implementing services to offer high-complexity infertility treatments. To implement and maintain ART procedures as a component of the treatment offered to infertile couples, these professionals had articulated already existing resources within their institutions such as physical space, technical capacity, equipment, laboratory facilities and personnel dedicated to infertility care whose salaries were paid by their institution. Only one of the services, situated within a public hospital in the most developed region of the country, offered ART procedures completely free of charge to patients. The other four services that offered ARTs were located within public university teaching hospitals through agreements formed with the SUS healthcare system.

The healthcare professionals and the patients interviewed in this study reported that access to infertility services performing ART procedures was limited. Two patterns of access to these services were identified; one was through the SUS referral system, which involves an initial consultation at a primary healthcare unit in order to obtain a referral to a more complex infertility service, while the other route of access consisted of a consultation directly with the ART service. However, the number of couples with an ART referral, who finally have access to these procedures, is restricted due to the low number of procedures performed by these services.

According to the patients and the health professionals of the services visited, scheduling a consultation at an ART centre gave infertile couples access to the initial diagnostic routine. After completing this diagnostic phase couples were able to schedule ART procedures. Those couples that needed additional treatments prior to undergoing ART procedures had an additional delay, principally if the procedure was to be performed at a public service. Patients sometimes had to wait for several months to be able to undergo these additional treatments within the public healthcare network.

These services that offered ARTs determined how many procedures they would perform per month. For example, in the centre in which ARTs were provided

free of charge to patients, only 40 couples were scheduled per month. In general, the waiting time for ARTs varied from a few months to up to five years. The healthcare professionals recognized that there was a huge unmet demand; however, they were unable to calculate the magnitude of this demand since they only have contact with those patients who actually managed to gain access to their service.

Another barrier that hampered access to ART procedures was cost. With the exception of one service (subsidized by the government), at all the other centres patients were required to pay for the drugs used for ovarian hyperstimulation. The cost of these drugs is calculated at US$2,000 per cycle for IVF and/or ICSI procedures. Nevertheless, values as high as US$3,000 per cycle have been estimated in cases where additional costs such as anaesthesia, disposables and fees to cover general operating costs were required.

The professionals of the visited centres reported that some costs of ART procedures were performed under SUS coverage, in many cases using alternative diagnostic codes that were recognized by the system as other gynaecological conditions. This was done in the case of hormone measurement, ultrasound scans or ovum pick-ups, which could be performed using existing codes for other gynaecological complaints.

Despite the effort made by the four centres that were not subsidized by public health funds to reduce costs, the services were unable to offer ARTs free of charge to patients or at an accessible cost to the low-income segment of the population. Patients considered costs to be "very high" and one of the greatest impediments to accessing ART procedures. The professionals also reported knowing about low cost ART procedures and, furthermore, they recognized the need to implement simplified ART procedures in order to reduce costs for patients and for the service, and to improve access to more complex infertility treatment.

The interviewed professionals and patients suggested that the SUS should implement accessible infertility care in a greater number of public institutions or subsidize ART procedures in the institutions that are already offering these procedures in order to facilitate access. In addition, they stated that if more centres would be able to offer these kinds of treatments to infertile couples it would help to reduce the waiting time and waiting lists, and shorten time between screening and the initiation of the ART procedures.

Discussion

This is the third report originating from data of a nationwide study on access to infertility services and ART procedures conducted in Brazil (Makuch et al., 2010, 2011). To the best of our knowledge, this was the first study to be conducted in Brazil and is one of the largest to be conducted on these issues in a developing country. The survey focused on assessing the availability of infertility services within the public healthcare network, including the services that provide ART procedures, the access of patients to these services and the main barriers that hamper access such as the costs of the procedures, the waiting lists and the bureaucracy involved in gaining access to the service.

Brazil has a unique healthcare system in which the federal constitution guarantees that all health-related activities are covered by the state at no cost to patients. Brazil is a cosignatory of the United Nations International Conference of Population and Development (ICPD) and of the Oslo Declaration (United Nations, 1995; Oslo Ministerial Declaration, 2007). By signing these documents, as well as the other participating countries, Brazil recognizes that Reproductive Health (RH) is a human right and that RH care should include infertility care and treatment. Also by signing the Millennium Development Goals of the United Nations 2000, the country has included as one of its targets: "Achieve, by 2015, universal access to reproductive health" (United Nations, 2000).

In most developed and developing countries, parenthood continues to be an important issue in the life of the majority of the population, and in some developing countries infertile women are often stigmatized and are vulnerable to social and economical consequences (Daar and Merali, 2002; Dyer et al., 2002; Dyer, 2007). Access to the diagnosis and treatment of infertility, including ART procedures, contributes to assuring that the right of women and men to decide when they have children is guaranteed, and to enabling infertile couples to have at least one biologically related child (United Nations, 1995, 2000).

Most of the efforts made by Brazil to achieve its RH goals have been concentrated on increasing family planning services and access to contraceptive methods, and on reducing maternal morbidity and mortality (United Nations, 2008). Within this scenario, insufficient attention has been paid to infertility services and to improving the complexity of these services, including the implementation of ART procedures and guaranteeing access to these procedures as in many other settings (Ombelet et al., 2008b).

The present analysis identified and described different levels of barriers within the public sector that hamper the access of infertile couples to infertility care. The barriers described in this report were identified from interviews conducted with health

authorities, healthcare providers and patients at ART centres within the public network. According to the information given by the health authorities interviewed for this study, the most important barriers that hamper access to infertility care were the lack of services and the lack of political decision to implement ART services, as well as the lack of resources allocated to infertility care, and no plans for implementing either infertility or ART services within the 12 months following the interviews. At this level, another barrier hampering the implementation of infertility care identified was the fact that in accordance with the norms of the SUS, infertility care was the responsibility of the primary healthcare services which are principally dedicated to primary healthcare. These services do not have the capacity to implement complex infertility care procedures, including at a diagnostic and therapeutic level (lack of technical capacity and trained professionals).

Making infertility services available in low-resource settings often represents a challenge. The nonexistence of these services can be justified by the fact that there are other urgent and life-threatening health problems to be dealt with, including maternal morbidity and mortality, vaccination, malaria, dengue, yellow fever and the arsenal of drugs required for people living with HIV and AIDS (Okonofua, 1996; Hamberger and Janson, 1997; Nachtigall, 2006). An additional factor is that infertility care, particularly complex technologies such as ART procedures, demands expensive equipment and trained professionals within a scenario of budget constraints.

The cost charged to patients for ART procedures in four of the five centres visited in this study was incompatible with the income of the majority of the population that depends on the public healthcare system. It must be taken into account that the cost of an ART procedure in the public system varies between US$2,000-3,000 per cycle compared to around US$6,000 per cycle in the private sector (Makuch et al., 2010; 2011). However, only 5.3% of the total population in Brazil earns the amount paid per IVF cycle as a monthly income (range 3.8 - 8.1%). While the country has improved its economical position within the world context with a per capita gross domestic product of US$12,917 (Global Property Guide, 2012), it is still estimated that 21% of the population is below the poverty line (Index Mundi, 2012).

Strategies used by the professionals at these centres to minimize the cost barrier of patients consisted of the use of hidden codes through which procedures used for ARTs were charged to the healthcare system, since the same procedures are also used to investigate other gynaecological complaints and are covered by the SUS. In this way, the final costs to patients were reduced (Jones and Allen, 2009). However, despite the strategies used to reduce costs, these services were unable to offer ARTs at no cost or at an affordable cost to lower income patients.

Although the professionals who participated in the present study reported being aware of the need to implement ART procedures at lower costs, to the best of our knowledge, no institutions have implemented procedures using low cost drugs for stimulating follicular development, which also results in a low rate of complications (Ombelet et al., 2008a; Aleyamma et al., 2011; The Low Cost IVF Foundation, 2012), and low cost laboratory procedures (Ombelet and Campo, 2007; Frydman and Ranoux, 2008).

The implantation of the above mentioned approaches represents an excellent opportunity to provide ART procedures within the public sector and to evaluate these new approaches. Additionally, it is worthwhile to note that even though some professionals interviewed in this study mentioned low cost approaches as a possible solution to the cost barrier none of them reported any action towards reducing the cost of infertility diagnosis such as one-day work-up procedures, a strategy that has been previously reported as being effective (Malpani and Malpani, 1992; Ombelet, 2011).

Another barrier identified was the long waiting time for the initial consultation, as well as for the ART procedure, which led to additional emotional suffering and in many cases, particularly in the case of older women, to a reduced possibility of success (Daar and Merali, 2002; Dyer et al., 2002).

To overcome the aforementioned barriers that hamper access to infertility care, health authorities should take into account the needs of the low-income population for the provision of safe and effective ARTs at the lowest cost. This action is not a simple task and cannot depend solely on a voluntary process implemented and maintained by professionals in some services. It should be based on the implementation of appropriate care capable of reducing inequity, avoiding the waste of available funds and improving results (Jones and Allen, 2009). In addition, clear policies and commitments are necessary in order to offer more affordable ART options (Blackwell et al., 2001).

The access to infertility treatments including ARTs in low-resource settings is a challenge and a human right (Ombelet et al., 2011). The fact that developing countries need to allocate restricted resources to life-threatening diseases and other non-life-threatening ailments does not justify the fact that infertility care remains a neglected public health issue. Infertility is still considered a misfortune with negative psychosocial repercussions (Daar and

Merali, 2002; Dyer et al., 2002; Dyer, 2007) and in many settings it results in the stigmatization of individuals, principally women. Health authorities can no longer ignore that infertility is a legitimate medical problem.

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The dilemma of assisted reproduction in Iran

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Abstract

Assisted reproductive technologies (ARTs) have spread at a surprising speed in Iran, since their introduction three decades ago. Currently over 75 clinics offer fertility treatment, in all its forms, throughout the country. The practice of ARTs in Iran, which is an Islamic state, was made possible, initially, through the endorsement of leading religious authorities. While the use of these biotechnologies is now viewed more as a medical technology, social and cultural norms and practices remain an important factor in their acceptance. The third party donation of sperm and egg remains particularly problematic, especially in the cases of male infertility and sperm donation, and the practice has had unanticipated outcomes for kinship, gender and for the children born from such technologies. In this paper I examine the process by which ARTs have been legitimized and conclude that, so far, these modern technologies have not altered, profoundly, the attitudes of infertile couples, towards procreation, but they have become instrumental in the users' hands to perpetuate their understanding of what constitutes kinship and relatedness.

Key words: **Assisted reproductive technologies, barriers, *ijtihad*, infertility, third party gamete donation.**

Introduction

Assisted reproductive technologies (ARTs) reached Iran soon after their practice started in their countries of origin, and were received with open arms. Since their introduction, Iran has witnessed a rapid flourishing of infertility treatment centres in the major cities, and the country currently has over 75 such centres, which range from private to semi-sponsored to almost free public clinics. Between them these centres offer all forms of infertility treatment including third party donation of sperm, egg and embryo, and surrogacy. Some of the leading clinics also offer PGD sex selection and one works on stem cell research. As Marcia Inhorn (2005), the leading anthropologist on ARTs in the Muslim Middle East, mentions "Iran is definitely in the lead among the Muslim countries in the Middle East in the application of these [ARTs] technologies". In general, the use of ARTs in the Muslim Middle Eastern countries has been made possible by the approval of religious leaders. In Inhorn's (2006) words "in all of the Middle Eastern Muslim countries, Islamic *fatwas* have profoundly affected the practice of IVF in ways that are not commonly seen in the West". While the application of ARTs in the West is under the scrutiny of various medical, legal and ethical committees, in the Muslim countries of the Middle East the responsibility for such endorsement has remained largely with religious leaders regardless of whether the state is secular or theocratic. "Infertile couples in these countries are usually extremely concerned about making their test-tube babies in the Islamically correct way. To that end, they seek 'official' Islamic opinion on the practice of IVF in the form of a fatwa" (Inhorn, 2006). The religious leaders in these countries have therefore taken centre stage and play an active role in legitimising the use of ARTs. However, in doing so, the Sunni and Shia senior clerics have reached different conclusions and while the Sunni have banned all forms of third party donation, the Shia have allowed these by using some of the built-in mechanisms available to the Shia that have paved the way for the legitimisation of ARTs without breaking any divine rules (Inhorn and Tremayne, 2012).

In this article I shall briefly explain the process of legitimising ARTs, especially third party donation of sperm and egg, and argue that although no barriers exists for the use of third party donation, the path towards total success has not been a smooth one for

either the practitioners or the users of these technologies. I shall illustrate that the speed with which ARTs initially entered the market, combined with the high demand for them by infertile couples, forced the ruling religious leaders to engage in the debates on whether and how the practice of ARTs should be allowed, and after much deliberations some of the leading clerics issued their verdicts in forms of fatwas to allow their use. However, the legitimisation of ARTs was based on the interpretation of the Qur'an, and focused on the religious aspects of these practices, to ensure that they are carried out strictly within the Islamic rules. In legitimising ARTs the leading Muslim scholars focused on theorising the impact and ramifications of ARTs on reproduction, family and kinship, which are considered foundational, sacrosanct institutions and the guiding principle of human social organization. In doing so, the senior clerics, did not foresee the future outcome of the practices, and underestimated the agency of the medical practitioners and the infertile couples, in the way they interpreted and used the fatwas. In practice, the responses of the users of third party gametes, inadvertently, proved a direct challenge to cultural norms and kinship rules, the very institutions, which the religious leaders were anxious to protect, as I shall discuss briefly in this paper.

Methodology

The main sites of the research are Tehran and Yazd, in central Iran. Also, a considerable amount of data has been collected from in-depth research among Iranian women asylum seekers in the UK. These women had undergone third party gamete donation in Iran, and had to flee the country as a result of extreme violence inflicted on them by their husbands. The main method used throughout was that of participant observation and in-depth interviews at the clinics. I spent several months living with a family in Yazd, who I revisited several times, and developed a large network of contacts. I also worked in one of the main private hospitals in Yazd (Mojibian), which has a fertility treatment clinic, and met with infertile couples who allowed me into their homes and larger family networks. I carried out interviews with the doctors in both the Mojibian clinic and with Dr Aflatounian, the first medical practitioner to introduce IVF to Iran. In Tehran, I worked in three government sponsored clinics and two private ones, where I interviewed the infertile couples as well as the medical staff, psychologists, ethicists, statisticians and nurses. My work with Iranian women asylum seekers, between 2003 and 2010, provided a wealth of data, which even as an anthropologist doing fieldwork, one is not necessarily privy to. The purpose of this paper is to provide an overview of the practice of ARTs in Iran; it is not an examination of the Islamic context, which legitimized them.

Assisted Reproductive Technologies

The reasons for and the process of legitimising ARTs in the Muslim Middle East have been documented extensively elsewhere (Inhorn, 2005, 2006; Inhorn and Tremayne, 2012; Clarke, 2006a, 2006b, 2009; Serour, 1993; Tremayne, 2009, 2012, 2012b). A brief explanation is that the way the Muslim countries of the Middle East have approached the practice of ARTs differs between the Sunni and the Shia. The Sunni have argued that allowing the practice of third-party donation of gametes would lead to confusion in a family's lineage *(nasab*), which forms the foundation of the Muslim family, and would be equal to incest or adultery and, therefore, a threat to the stability of social relations (Inhorn, 2005; Clarke, 2009; Tremayne, 2009). The Sunni, therefore, have banned all forms of third party donation.

The Shia religious leaders in Iran, on the other hand, have been able to find solutions to legitimise third-party donation without breaking any of the Islamic rules. In doing so, they have focused on an in-depth examination of what constitutes lineage (*nasab*), and whether the practice of ARTs with all its ramifications would confuse the line of lineage. To do so, the senior Shia clerics resorted to independent reasoning *(ijtihad),* and concluded that certain forms of third-party donation could be allowed without breaching any divine rules (Inhorn and Tremayne, 2012). ARTs are therefore currently practiced in Iran with the full approval of the ruling religious leaders, although the use of donor sperm remains a more contentious issue, and its practice is limited. However, not all senior Shia clerics in Iran are in agreement with the interpretations that have led to legitimising third-party donation. Similar to the Sunni religious leaders, the opponents of such practices in Iran remain uncompromising in their interpretations of the Qur'an and forbid the use of third-party donation. And, similar to their Sunni counterparts, the Shia clerics also agree that no third party donation could take place outside the marital union. The legitimate solution to third party donation was therefore found in temporary marriage, a practice unique to the Shia, and through independent reasoning (*ijtihad*). It is this individualistic practice of *ijtihad* that has paved the way for the Shia to engage dynamically with most forms of biotechnologies and in the case of ARTs has resulted in the development of a wide diversity of opinions among Shia *marja's* (sources of emulation). These opinions can sometimes disagree and take opposing views on the inter-

pretation of the Qur'an, which has historically led to senior *marja's* forming their own groups of followers. However, this diversity has also led to considerable "flexibility" for the Shia in the regulation and practice of ARTs. (Inhorn and Tremayne, 2012).

Soon after third party donation was introduced to Iran, several Shia scholars engaged in exploring its legitimacy and provided their views on it. These differed fundamentally and ranged from rejecting it altogether, to others endorsing it in part and conditionally. One example of such deliberations is a pioneering conference organized by Dr Akhondi, the Director of one of the leading fertility clinics, the Avicenna Research Centre. The conference included experts from various disciplines and became a landmark for pushing the agenda forward and influencing the future decision-making processes. It was during similar gatherings that a solution was found for the third party donation of sperm and egg, using the Shia practice of temporary marriage.

Third party donation and temporary marriage

Temporary marriage, *sigheh* in Persian, is a form of marriage whereby a man and a woman agree to enter into marriage within a time limit, which can be from one hour to 99 years (Haeri, 1989). In the context of gamete donation, to receive gametes legitimately from a third party, if the wife is infertile, Islam permitting polygamy, the husband will marry the egg donor for one day, to receive her egg legitimately, without any bodily contact taking place between the two. Egg donors should be widows or divorcees and ideally already have children of their own. Once the egg has been donated, it is fertilized with the husband's sperm, outside the womb, and the embryo is planted inside the infertile wife's uterus. The Supreme Religious Leader of Iran, Ayatollah Khamenei's fatwa, issued in the late 1990s, went even further and did not make any mention of temporary marriage. It stated, "donation is allowed as long as no 'touch' or 'gaze' takes place". It also clarified the position of the biological and social parents vis-à-vis the donor child (born from third party donation) as follows: "both the egg donor and the infertile mother must abide by the religious codes regarding parenting. Thus, the child of the egg donor has the right to inherit from her, since the infertile woman who received the eggs is considered to be like an adoptive mother" (Khamenei,1999). In the case of the husband's infertility, the couple usually has two options. Either the wife divorces her infertile husband, as she cannot be married to two men at the same time, waits for three-and-a-half months (*edeh*), to ensure she is not pregnant, and enters into temporary marriage with the sperm donor, without any sexual contact taking place between them, and receives his sperm, which is fertilized with her egg outside the womb and is planted in her uterus. She then remarries her own husband. Or, the couple opts for receiving an embryo from a married couple, which will be planted inside the wife's uterus. Temporary marriage is no longer taking place in every case, and many clinics do not concern themselves with what they consider to be a formality, and the infertile couples problem, which should be solved between the couple and the donor outside the clinic.

Temporary marriage for women with infertile husbands has proved complicated and lengthy, and is rare despite some known examples. Couples in this position usually opt for embryo donation. In the case of sperm donation, according to Ayatollah Khamenei, the child takes the name of the social father rather than the sperm donor. However, as with egg donation, the child inherits from his biological father. These rulings however, are not always followed in practice, and gradually the clinics have moved to making gamete donation anonymous, or confidential, depending on whether the clinic is private or public. While the approval of egg donation has not raised any objection, the endorsement of sperm donation has been met with the strong objection of some senior clerics as well as a large majority of conservative groups in society.

The ethical, moral and legal problems that have emerged from third party donation were not initially anticipated. All three parties engaged in gamete donation – the medical practitioners, the donors and the recipients – are frequently faced with unanticipated situations, ranging from the right of the child, to claims of ownership by the donors, to financial disputes and emotional problems. Moreover, in the absence of clear religious instructions, all parties involved, resolve the problems as best they can.

Embryo Donation

With the introduction of embryo donation it became clear that *ijtihad* and *fatwas* alone could not justify its practice and a law was passed in August 2003, allowing embryo donation. Although this law also remains vague or insufficient in some areas, it is not nearly as problematic as the cases of sperm and egg donation, which have led to totally unexpected forms of donation to take place. To cite but a couple of examples, infertile women prefer to resort to the donation of their sisters' or other female relatives' egg, which will be fertilized with their husband's sperm and then transferred to their wombs. Following the Islamic rules of incest and adultery, such action, in theory, would be considered adultery, as it would be similar to the husband impregnating his

wife's sister. However, the fatwas, specifying, "as long as no touch or gaze takes place, donation is allowed" (Khamenei, 1999, among several other senior clerics), have led infertile couples to proceed with donation from their close relatives, without breaching any religious rules. Furthermore, based on the same fatwas, cases of brothers giving sperm to their sister's infertile husband, to be fertilized with their sister's egg, have come to the fore, which has taken doctors by surprise too, but since the request for such practices are legitimate, they do take place (personal interviews with doctors at clinics; Garmaroudi Naef, 2012). The biological and genetic implications of such practices notwithstanding, from the social and cultural point of view, in theory, the making of embryo between a brother and his sister, is a breach of the most elementary rules of kinship and equivalent to incest.

Surrogacy

Surrogacy has also been practiced in Iran since 2002 and initially remained limited in its application due to a shortage of surrogate mothers. In the early stages, only relatives were prepared to act as surrogate mothers, but, a decade on, in spite of many siblings, relatives and friends still acting as surrogate mothers, an increasing number of women are coming forward to act as commercial surrogate mothers (Garmaroudi Naef, 2012; Gestational surrogacy, 2011). So far, no separate law has been passed on surrogacy and permission from the courts, which use the same law as the one for embryo donation as their point of reference, is sufficient.

Stem cell research and PGD sex selection have also been allowed through fatwas, and are limited in their application (Saniei, 2012).

Facilities and barriers to ARTs

From the preceding it is clear that both the public and private sectors in Iran have made a considerable amount of provisions for infertility treatment. Many public hospitals include fertility centres, which are either free of costs or are low cost. To make the treatment more accessible to poorer couples, a bill has been passed by the parliament for the provision of medical insurance for infertility treatment, and infertility is no longer classified as cosmetic surgery, but is recognized as a form of disability. However, the public hospitals are limited in the range of the services they offer, and mainly treat female infertility. Even poorer infertile couples prefer to use private services, if they can cover the fees. In such cases the infertile couple's kin group often pull their resources together to provide the necessary funds for treatment. For example, parents or brothers sell their car or mortgage their house or other belongings, which they badly need themselves. There are also several charitable organisations, which are actively engaged in providing free treatment for infertile couples. But, in spite of substantial financial provisions, and other forms of support, the cost of ARTs remains a major constraint to infertile couples seeking treatment, even though this is low in comparison to many other countries, which attracts infertile couples from other Muslim countries.

Cultural norms and practices can also act, not only as barriers to the use of ARTs, but also lead to problems afterwards. Infertility remains a major stigma in spite of the efforts of various authorities to educate people about the biological facts of reproduction. Male infertility in particular is more problematic and studies show that infertile men go to great length to deny or hide their infertility. In one study an infertile man asked his wife to take the blame for the infertility and threatened to divorce her unless she agreed to do so (Abbasi-Shavazi, 2008). Other studies show that many infertile men have used donor sperm secretly, not even informing their wives, because they did not want to admit that they were infertile. The occasional discovery of the secret use of donor sperm has led to serious violence inflicted by men on their wives and the children (Tremayne, 2012). Violence towards women, in cases of male infertility, is so widespread that two leading clinics have launched their own research on violence in relation to infertility, and one of them has made a documentary on the subject (personal communication, 2011).

Conclusion

The flexibility of the Shia practices played an important part in allowing the adoption and accommodation of ARTs, in the early stages of their introduction. The fatwas endorsing their use were the result of senior clerics' lengthy engagement with other religious and secular experts, and through resorting to *ijtihad*. These were based on Islamic ethics, and proved above questioning by secular legal frameworks. While the fatwas initially played favourably into the hands of both the medical practitioners and the infertile couples, their inadequacy in dealing with emerging ethical and legal problems became apparent over time. The problems ranged from the conflicts arising as a result of gamete donation between siblings and close relatives, to disputes between the donors and recipients of gamete, to financial disagreements between the donors and recipients of gamete, among other issues. Furthermore, the impact of ARTs on the donor children went unaddressed, the assumption being that once a child

was born, all will be well and the family will become a happy one. The responses of the medical practitioners and the infertile couples to the unresolved and complex emerging situations were to focus each on their own priorities, which seemed to be opposite to each other. The medical practitioners, especially in the private clinics, tried to take control of the situation by increasingly keeping the donors of gametes anonymous to avoid future problems. Such action was in direct contrast to the initial fatwas, which emphasized that the child born from a donor gamete has to inherit from his biological parents. The infertile couples, on the other hand, showed that their priority laid in the continuity of their lineage and focused on the choice of the donors, which, whenever possible, included their close relatives, and thus ensured the 'purity' of their linage, by making their own reproductive decisions.

The data from the larger study (mentioned under the Methodology heading) also supports the finding that the use of ARTs has not altered the old norms attached to reproduction, and that the deeply rooted values on fertility/infertility, have been reinforced, rather than dislodged, through the possibilities offered by these state of the art reproductive technologies.

Finally, while Iran seems to be ahead of most countries in the world in its coverage and legalisation of ARTs – considerable services and facilities, both public and private, have been provided – the main obstacles to better and proper use of ARTs, in addition to financial constraints, remain social and cultural norms and values related to procreation.

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The double burden of HIV and infertility in Rwanda: what lessons can we learn for infertility care in sub-Saharan Africa?

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Abstract

Introduction: **When planning infertility services in sub-Saharan Africa (SSA) the management of HIV infected couples needs careful attention. Very little is known about the potential demand for infertility services among HIV infected couples, the interplay between HIV infection and infertility and the specific counselling needs of this group.**
Methods: **A review of the literature was combined with data from own field research, a case-controlled study in an infertility clinic in the Kigali University Teaching Hospital in Rwanda.**
Results and discussion: **Based on the limited available evidence it can be hypothesized that in SSA a substantial number of HIV infected couples suffer from decreased fertility but no firm conclusions can be drawn on the actual prevalence of infertility in HIV infected couples, or their potential demand for fertility services. The interaction between HIV and fertility desires is complex and varies considerably between individuals. The severe psychosocial problems HIV infected infertile couples face and the ethical dilemma between the right or desire to reproduce and the risk or fear of transmitting the virus adds considerably to the complexity of the infertility care of these patients.**
Conclusion: **The management of patients, carrying the double burden of HIV and infertility is challenging from an ethical, psychological and medical point of view and requires specific counselling skills.**

Key words: **Counselling, ethics, HIV, infertility, sub-Saharan Africa.**

Introduction

Infertility and HIV infection are affecting a large number of couples in sub-Saharan Africa (SSA) and several studies have shown that both conditions are linked in various ways. In 2009 it was estimated that HIV prevalence in SSA among adults (15-49) was 5.0 % with more than 22 million people living with HIV, 68% of the global total (UNAIDS, 2010). The prevalence of infertility is more difficult to estimate due to lack of proper prevalence studies and the use of different working definitions of infertility. The overall prevalence in SSA is about 9 % with certain countries reaching 30% with the rate of secondary infertility being responsible for the large variation (Boivin et al., 2007). The WHO estimated that in 2002 more than 186 million ever-married women of reproductive age (15 to 49) in developing countries (excluding China) were infertile because of primary or secondary infertility (Rutstein and Iqbal, 2004).

The relationship between HIV and fertility is bi-directional and highly complex (Zaba and Gregson, 1998).

Population based surveys in Uganda and analyses of data from antenatal clinics in a number of countries have suggested that fertility is lowered, between 25-40%, in women with HIV (Gray et al., 1998; Ross et al., 2004; Zaba and Gregson, 1998). From these studies it is difficult to ascertain the mechanisms through which HIV affects fertility, since infertility investigations were not part of the study procedures and many of the postulated mechanisms remain to be elucidated.

What are possible mechanisms explaining the association between HIV prevalence and infertility? Infertility in SSA is mainly caused by ascending genital tract infections, acquired through sexual transmission or after obstetrical and post abortion complications (Belsey, 1976). Since HIV is also sexually transmitted, co-infection with STIs could

partly explain the association. Moreover, research indicates that besides co-infection with STIs, there could be a direct effect of HIV on fertility through increased clinical and subclinical pregnancy wastage and anovulation in the female, and hypogonadism and impaired spermatogenesis in the male (Crittenden et al., 1992; Dondero et al., 1996; Gray et al., 1998; Lasheeb et al., 1997; Muller et al., 1998; Nicopoullos et al., 2004; Temmerman et al., 1992). There is also some limited evidence that HIV worsens the tubal damage caused by pelvic inflammatory disease (PID) (Kamenga et al., 1995; Moodley et al., 2002); whether HIV can directly cause tubal damage is not known.

The reverse - infertility increasing the risk of acquiring HIV infection - could also be true. In a cohort study of HIV infected and uninfected women in rural Uganda, subfertility existing before seroconversion to HIV accounted for almost 50% of the observed association between HIV and lowered incidence of pregnancy (Ross et al., 1999). From social research it is known that infertility causes marital breakdown and makes couples engage in extra marital affairs which exposes them to an increased risk of HIV infection (Barden-O'Fallon, 2005; Favot et al., 1997; Gerrits, 1997; Ikechebelu et al., 2002).

While the exact association between the prevalence of HIV and infertility is not known, the above clearly shows that efforts to plan infertility care in SSA will need to take on board the issue of HIV infection. To be able to do so the following questions need to be answered.

- What is the prevalence of HIV among infertile couples in SSA?
- What is the burden of infertility and the potential demand for infertility services among HIV positive couples in SSA?
- How does HIV infection interact with fertility desires in infertile couples in SSA?
- What are the challenges for the counselling of HIV infected infertile couples?

The current article, based on a literature review and our own research in Kigali, Rwanda, intends to address these questions.

Methods

Literature search

Medline was systematically searched for relevant peer-reviewed English language articles, combining two or more of the following search terms: infertility, fertility or childbearing or pregnancy intentions or desire, reproductive decision, counselling, HIV, Africa. We identified four papers reporting on HIV prevalence among infertile couples but no papers on the prevalence of infertility among HIV infected couples in SSA. On fertility intentions or childbearing intentions among HIV positive women and men over 100 papers were found but none among HIV positive infertile couples. There is no literature on the counselling of HIV infected infertile couples in SSA. A few papers from resource rich countries report on their experience with treating HIV infected couples, including counselling.

Case control study among infertile and fertile couples in Rwanda

Between November 2007 and May 2009, an infertility research clinic was opened at the Kigali Teaching Hospital in Rwanda (the largest public hospital in Rwanda). The primary objective of the study was to evaluate risk factors and determinants of infertility in Rwanda, including HIV and other reproductive tract infections. As secondary objectives the outcome of infertility investigations, the socio-cultural consequences of infertility and treatment-seeking behaviour in infertile couples were examined. Sexually-active women aged 21 to 45 years presenting with infertility problems at the infertility research clinic were invited to participate in the case-control study. Fertile controls that recently delivered were recruited from the community. In both groups 312 women were included. After inclusion, women invited their male partners to participate, of which 254 and 189 responded in the infertile and fertile groups respectively. In a face-to-face interview, participants were asked about socio-demographic characteristics and their sexual behaviour, and tested for HIV and STIs. Additionally, infertile couples underwent infertility investigations and, when feasible, infertility treatment and follow-up in the clinic. The methodology of this research has been described in detail elsewhere (Dhont et al., 2010, 2011a, 2011b).

Results and discussion

What is the prevalence of HIV among infertile couples in SSA?

The few studies that systematically measured HIV infection in African infertile couples all indicate that HIV prevalence is much higher in infertile couples than in the general population. In Tanzania, HIV infection was threefold higher among infertile women compared to fertile controls, 18.2% and 6.6% respectively (adjusted odds ratio (AOR) for age, residence and occupation 2.7; 95% CI = 1.4-5.3) (Favot et al., 1997). Similarly, in Nigeria, HIV infection among women undergoing laparoscopy

evaluation for infertility was fivefold higher compared to HIV prevalence among pregnant women and threefold higher in women with tubal factor infertility compared to the general population (Adesiyun et al., 2008; Ikechebelu et al., 2002).

In our case-control study in Rwanda the HIV prevalence was 16% among fertile women, 18% among primary infertile women (women who had never been pregnant before), and 43% among secondary infertile women (women who conceived at least once before). In fact, only secondary infertility but not primary infertility was associated with HIV infection for women (AOR = 4.03, 95%CI = 2.44-6.65; AOR = 1.63, 95%CI = 0.90-2.96, respectively) (Dhont et al., 2011a). Also remarkably, there were many more *newly* diagnosed HIV positive cases among men and women in infertile relationships compared to fertile relationships. Of the 312 women and 254 men in infertile relationships, 49 and 62 respectively had never been tested for HIV before and 79 new cases of HIV infection (48 women and 31 men) were diagnosed, representing more than half of all HIV infections in this group. In the fertile group only four women and 13 men had never received a HIV test and 16 new positive cases of HIV (11 women and five men) were detected in this group.

Although based on limited reports it can be hypothesized that in many regions of SSA, especially those with a high HIV prevalence, a considerable number of infertile couples will be HIV infected, making HIV testing compulsory for the infertile couples that visit the clinic for infertility examinations and treatment. In fact HIV counselling and testing of infertile couples may identify new HIV infections and considerably increase opportunities for HIV care and prevention.

What is the prevalence of infertility and the potential demand for infertility services among HIV positive couples in SSA?

Recently it has been recognized that the reproductive health needs of HIV infected couples deserve more recognition and attention (Delvaux and Nostlinger, 2007). Although calls are made by several authors to respect the fertility intentions of people living with HIV (PLWHIV), so far no attempt has been made to measure the burden of infertility among PLWHIV in SSA.

There are two studies from resource rich countries reporting on infertility factors among HIV infected couples. An audit of the Chelsea and Westminster HIV fertility clinic demonstrated a 40% prevalence of tubal factor infertility in HIV infected women, which is considerably more than the 14% prevalence found 20 years earlier in an unscreened UK population (Gilling-Smith et al., 2006). In Spain HIV positive women (not necessarily with history of infertility) were examined for tubal abnormalities in a preconception counselling clinic and a 28% prevalence of tubal blockage was found (Coll et al., 2007).

In a population based survey in Uganda, a history of subfertility – defined as the inability to achieve a pregnancy for two or more years – was significantly more often reported by HIV infected women compared to uninfected women (14.8% versus 7.8%, $p < 0.001$) (Gray et al., 1998). In our cohort of women in infertile relationships, HIV infected women were more likely to have tubal factors than non infected women (OR = 1.84; 95% CI = 1.00-3.37). To our knowledge other studies on this subject have not been performed in SSA. It seems reasonable to hypothesize that in SSA, with its background of high PID incidence, prevalence of tubal factors among HIV positive women will be high.

The only data on the demand for infertility services in HIV infected patients comes from a survey in the United Kingdom (UK). It was found that 16% of men and 4 % of women attending HIV specialist clinics had enquired about fertility treatment (Frodsham et al., 2006).

In conclusion, based on the limited available data it can be speculated that fertility is considerably decreased in HIV infected couples, but the actual prevalence of infertility and the demand for infertility services among these couples remains largely unknown.

How does HIV infection interact with fertility desires in infertile couples in SSA?

When examining the interplay between HIV and infertility two different situations can be distinguished. First, HIV infected couples (concordant or discordant and aware of their diagnosis) wanting children and subsequently faced with the situation of the inability to conceive; and secondly, couples suffering from infertility, faced with the diagnosis of HIV infection in one or both partners during infertility work-up.

Referring to the first group of couples the question arises: how does HIV infection impact on the fertility desires of these couples and how does infertility care seeking behaviour of HIV infected couples differ from non-HIV infected couples? The answer is very short: we know next to nothing about this. Studies on the impact of HIV on fertility desires among couples of reproductive age indicate that HIV can negatively influence the wish for childbearing, but for many couples especially those without any children and/or on highly active anti-retroviral therapy

(HAART) and/or in good health, the need to reproduce often overrules the fears of HIV transmission (Myer et al., 2007).

HIV programs in SSA are currently emphasizing the prevention of unwanted pregnancies among their clients and links with family planning services are currently being strengthened in several ways (Gillespie et al., 2009; Duerr et al., 2005). For those HIV infected couples who want to continue to bear children and are unable to do so, no services are yet in place. It is not known how many are expressing their desire and difficulties bearing child with the health care workers. It is possible that due to the ambivalent attitudes of health care workers towards their pregnancy desires , HIV infected women are more likely to underreport their desire for children (Nduna and Farlane, 2009). In Rwanda, formal policies do not forbid HIV infected couples to become pregnant but the integration of family planning with HIV services is currently a top priority. In our own experience many health care workers in Rwanda are reluctant to help HIV infected couples with infertility problems. In our study HIV positive women were less likely to have looked for infertility treatment in the past than HIV negative women, though the association was not statistically significant (33/51; 65% versus 194/162; 74%, respectively; $p = 0.16$).

The second situation raises the question on how infertile couples cope with the diagnosis of HIV and whether their desire for children is altered subsequently. Our literature search identified reports on this topic among a general population but not among infertile couples. In Ethiopia voluntary counselling and testing (VCT) clients were asked about their fertility intentions before and after receiving their HIV test results. Mainly discordant couples ceased desiring children (Bonnenfant et al., 2012). It remains to be seen whether this intention is a long-term one and whether this also applies to infertile or childless couples in whom the desire for children tends to be strong.

In our study we followed 98 HIV infected women in an infertile relationship throughout their infertility investigations and in some cases throughout their infertility treatment. Half of these women had received their HIV diagnosis in our clinic. Although we did not systematically investigate attitudes and behaviours of these couples with regards to their HIV status, reviewing the medical chart notes that were recorded by study staff during follow-up visits, we identified the following key findings:

- Disclosure of HIV diagnosis towards the partner is often very problematic; many couples have still not disclosed the diagnosis to their partner after one year of follow-up. This was the case for both women and men.
- In a few couples individual -and often intensive- counselling had a positive impact on the disclosure of one's HIV diagnosis to his/her partner and the general communication between partners.
- HIV discordant couples struggle with the wish to bear children and the fear of infecting the HIV negative partner when having sexual intercourse.
- Many HIV negative women cannot negotiate condom use with their HIV positive partner if he wants to bear children.
- The male partners of HIV positive women are less likely to participate in the infertility work-up than partners of HIV negative women (70/98, 71% versus 181/208, 87%).
- Many infertile couples in our cohort had marital and relational problems and these were exacerbated when HIV infection was found in one or both partners (especially when discordant).
- In some cases HIV infection makes one or both partners stop wanting children, but often there is disagreement between partners about this.
- Loss to follow-up is a problem among all infertile couples but even more so among HIV infected couples.

What are the counselling needs of HIV infected infertile couples?

The presence of an HIV infection in one or both partners adds to the often considerable medical, psychological and ethical complexity of infertility care (Tschudin et al., 2008).

First, from a medical point of view, HIV is a chronic disease associated with considerable morbidity and mortality, though potent antiretroviral therapy has drastically improved the prognosis of PLWHIV.

Second, the conflict between the desire and/or right to reproduce and the risk of transmitting the virus to the partner or the offspring is a major ethical dilemma both for the patient and the health care workers. This dilemma is at the core of the troubles HIV infected persons face with their intimate partners, often leading to domestic violence and disruption of their relationships. Furthermore they are often victim of stigmatisation and discrimination in their communities, adding considerably to the psychological burden of HIV (Bos et al., 2008; Ehiri et al., 2005).

Combined with the suffering caused by infertility these couples carry the double burden of conditions which have both tremendous negative impacts on psychological wellbeing and social relationships

(Dyer et al., 2002; Dyer et al., 2005; Gerrits, 1997; van Balen and Bos, 2009).

Based on insights gained in our study in Rwanda, we will focus in this section on two aspects of the counselling needs of HIV infected infertile patients: first, HIV diagnosis related issues such as disclosure to partners and need for treatment adherence and second, infertility treatment related issues.

If infertility clinics provide testing for HIV, as they arguably should do, many couples will learn for the first time their HIV positive diagnosis. The breaking of this news needs to be provided in a sensitive way. Issues which need to be emphasized and discussed at the first post-test counselling include: the fact that HIV is a chronic disease and will need lifelong treatment and follow-up; the prevention of the risk of HIV transmission to sexual partner(s) and child(ren); and the need of disclosing the diagnosis to one's partner.

Some patients will react in disbelief and will not accept this diagnosis immediately. It might need repeated testing and counselling to convince them to register in a HIV clinic for treatment. Disclosing the diagnosis to the partner and/or convincing the partner to take the test are often problematic, as was seen in our clinic. Many of these couples face already severe marital problems due to infertility and they fear that the diagnosis of HIV will scatter any hope to reconcile. That disclosure of one's HIV status to his/her intimate partner can be problematic has been described in numerous reports. A review of 15 studies from sub Saharan Africa and Asia found that disclosure rates among HIV positive women ranged from 17 to 80% (Medley et al., 2004). It has been recognized that health care workers need support as they negotiate the difficult balance between encouraging disclosure and keeping HIV status confidential. A number of reports indicate that trained counsellors can help with disclosure (Obermeyer et al., 2011).

In deciding which couples are eligible for infertility treatment there are always several aspects which need to be considered, including medical factors such as age, aetiology and available ARTs and ethical considerations about parenthood capacities. For couples where one or both partners are HIV infected, some additional elements have to be taken into account, making the decision even more complex. Questions to be addressed when considering infertility treatment for these couples and when counselling them include the following:

- Is the patient on HAART and adhering to treatment?
- Health status: stage of AIDS?
- Which partner is infected?
- Is the couple aware of each other's HIV status?
- How is the couple's relationship?

If the patient is treated with HAART there is less risk of transmitting the virus to the partner and from the mother to the child (from 30% without to less than 2% with HAART) and there is an increased life expectancy. In some sub-Saharan African countries HAART treatment is not readily available. In these cases it might be hard to justify infertility treatment for HIV infected couples and counselling should be directed towards double protection (against pregnancy and infection).

In a couple with a diagnosis of bilateral swollen and blocked tubes (hydrosalpinx) in the woman or absence of sperm (azoospermia) in the man, the chances of conceiving without any reproductive technologies are very slim. If these technologies are not available the couple should be counselled toward the point that the risk of infecting the partner is much higher than the chance to conceive and they should be strongly advised to use barrier methods in order to prevent HIV transmission.

Reproductive technologies (IVF, ICSI, IUI and sperm-washing) can help these couples to prevent transmission of the virus to the partner and/ or the child and their use can be life saving for the discordant couple, even in the absence of subfertility. If only the woman is infected, bed side insemination at home with sperm of the male partner (sperm of man is collected and drawn into a syringe and injected in his partner's vagina) could be an option. If only the man is infected, the woman could be inseminated with washed semen.

Conclusion

When planning infertility services in sub-Saharan Africa the issue of how to manage HIV infected couples needs careful consideration. At present very little is known about the prevalence of infertility and the demand for infertility services among these couples. Clinical studies investigating the prevalence of infertility and the different causes of infertility among HIV positive couples and their fertility seeking behaviour are needed to answer this question.

The provision of fertility treatment to HIV infected couples is challenging from an ethical, psychological and medical point of view and special counselling skills are needed to manage these couples appropriately. Further quantitative and qualitative research evaluating the interplay between fertility desires and HIV infection in these couples could provide useful insights in the counselling skills needed for the management of these couples in fertility clinics.

Against this backdrop, protocols for the management of infertile couples in resource poor countries, including the management of HIV infected infertile couples are urgently required and a prerequisite for the scale up of infertility treatment in SSA.

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Quest for conception in times of HIV/AIDS – (In)fertility care in Botswana

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Abstract

The article at hand attempts to assess medical care available for infertility patients in Botswana, a country with an exceptionally high HIV/AIDS infection rate. Therefore this contribution lays emphasis on understanding the relation between HIV and infertility and how Botswana's biomedical services are catered towards these special needs. The research shows that patients' acceptance of biomedical technologies not only depend on their financial situation but also on their age and education. It further emphasizes that suffering from childlessness is not only a social problem but is also a personal suffering as biological children represent the hope for personal and social continuity. Nevertheless, infertility care is not a priority in Botswana's health politics.

Key words: **Africa, Assisted Reproductive Technologies, ART, HIV/AIDS, health care, health politics, infertility.**

Infertility and HIV/AIDS: introduction

The correlations between infertility and HIV/AIDS are various and complex and they are rooted in medical factors as well as in social, sexual and reproductive behaviour. HIV/AIDS may facilitate the condition of infertility as people with an HIV/AIDS infection are prone to other secondary infections heightening their physical vulnerability to other venereal diseases. These in turn may cause infertility. In a developed stage, the immune deficiency weakens the body, which may also reduce a female's childbearing capacity. Research has pointed at infertility provoking risk behaviour, as women who wish to have children may engage in unprotected sexual intercourse in order to conceive and thus expose either themselves or their sexual partner to contracting the virus. In addition, seeking to conceive through sexual intercourse with multiple partners increases the risk of contract a number of other venereal diseases, thus impacting women's fertility (Lewis et al., 2004; Dhont, 2010). On the part of social science and public health research and (inter)national health politics, there has been a strange silence on the topic that might be attributed to an unspoken assumption among health professionals, NGOs and researchers alike that HIV positive people should not procreate in order to prevent the infection of their partners and their children (Wilcher et al., 2009). This, however, ignores the fact that fertility is of high cultural value in many societies and a matter of personal, gender and kinship identity (van Hollen, 2007).

My contribution is concerned with infertility and HIV/AIDS among educated professionals in Botswana. The country, situated in southern Africa, is one of the few middle income countries in Africa. Botswana's size is comparable to that of France but only hosts about two million inhabitants and has one of the highest HIV/AIDS infection rates, approximately 25 to 30 per cent, in the adult population. Of the women in the age group 30-34, 50 per cent have been estimated to be HIV positive (Ministry of Health, 2009). The percentage is probably smaller among the population at study as the average infection rate among women with tertiary education has been estimated to be 20 per cent. Nevertheless, these figures tell us that *a lot* of people are infected and the statistical probability of one's current sexual partner being HIV positive is, if not one out of two, than one out of five. The figures further suggest that the number of women who experience fertility problems due to other venereal infections as a consequence of

HIV/AIDS may also be considerable. In the course of my research I found that educated professionals practice safe sex even (or in particular) in their marriages, which effectively reduced the fertility of many women in my sample. Some women have remained childless due to safe sex practices (Bochow, in press).

There are no statistics about how many women experience either primary or secondary infertility in Botswana, but in the popular perception of Botswanans 'infertility' is a common problem and one that is feared by many. HIV/AIDS exposes women to the condition of infertility or secondary infertility in many ways so that in a context of high HIV/AIDS infection rates the likelihood to remain childless increases. Infertility, however, is a low priority in Botswana's health politics. Even though Botswana has a fairly well functioning public health care system, there is basically no infertility care available in the public health care system.

In the following, I will describe how gynaecologists and fertility patients seek solutions for infertility in Botswana, with a special focus on the problem of (in)fertility and HIV/AIDS. Thereby, I will first assess services for the fertility care that are available before I describe patient's expectations and specialists' recommendations.

About the research

I conducted my research on educated professionals with fertility problems during several visits to the field from 2009 to 2011 and recruited respondents at the Gaborone Private Hospital and at Bokamoso Private Hospital. As an independent researcher, I had limited access to patient consultations and no access to health records but rather interviewed patients and specialists separately. Most of the patients I met paid for their treatments themselves. As such, most of them represented upcoming groups in society; they differed, however, according to their status, their (ethnic) origin and their income. In my research on reproductive challenges among elite women in Botswana, I collected the reproductive histories of 70 women and about 15 men during three separate visits to the field in the years 2009, 2010 and 2011. For interviews, I met respondents mostly in public spaces, cafés or restaurants. The interviews, lasting between 45 minutes and two hours, represent specific forms of female subjectification as they resemble intimate chats that urban women are used to conducting. Twenty-five of these women sought medical assistance in order to conceive; only nine women had not given birth at all so far. I knew the HIV status of five of these women. All of them were guaranteed anonymity of data and signed a consent form.

Childlessness and educated professionals in Botswana

In the past fifteen years, the literature on childlessness in Africa and elsewhere has repeatedly pointed at women's suffering from being childless emphasizing women's experiences of being stigmatized, ostracized by their kin and communities, and threatened to be divorced and to be left with nobody to take care of them in old age (Gerrits, 1997; Feldman-Savelsberg, 1999; Sundby, 1997; Inhorn, 2004). On top of this, motherhood is considered to be of utmost importance for female personhood as has been recorded throughout the 20th century in Botswana (Schapera, 1966; Mogobe, 2005; Upton, 2001). Becoming a mother is seen as being the most important goal of every woman. Desires for children, however, have changed among educated professionals. While in farming communities 'having many children' was and is associated with wealth and prosperity, educated professionals plan and monitor their reproduction and reduce their fertility to two or three and sometimes even only one child. Nevertheless, remaining childless is experienced as severe personal and social suffering. Women who remain without children feel stigmatized and excluded from many important social activities that structure women's everyday life as well as their social interactions with their friends, kin and neighbours. They receive hostile 'comments' from people around them, be it in church, from their own family, and from their colleagues.

In the context of high HIV/AIDS infection rates, in which many people have experienced the loss of close kin, friends and lovers, children represent social continuity and are an important link in the otherwise disrupted kin relations. The imagination of 'genes' or 'DNA' passing from parents to children has replaced a procreative imaginary of male and female bodily fluids mixing and making the child (Schapera, 1966), speaking about the ongoing process of biologisation of parenthood in this region. By passing on their DNA, people believe they will pass on not only physical features but also their personality and soul. The same way they wish to have somebody who inherits their property, they wish that their achievements are cherished by coming generations. People's fear of remaining childless is not only directed towards their future and the question of who will care for them in old age. Rather they fear that when they die without a child, they will cease to exist. A child will continue their existence on earth after they died. Educated professionals suffering from childlessness are not so much concerned with their material well-being but rather with the social suffering as well as spiritual suffering that

threatens the cosmic order of social and individual continuation.

Technologies, infertility and HIV/AIDS

Studies on the appropriation of assisted reproductive technologies (ARTs) by patients have shown how specific the appropriation of these technologies can be in local populations (Hörbst and Hadolt, 2010), but also that they impact people's cultural and gender identities (Inhorn, 2004; Pearce, 1995). How people use and appropriate ARTs depends greatly on the availability of information and fertility services (Hörbst and Hadolt, 2010) as well as their affordability (Ginsburg and Rapp, 1995). While some researchers have recorded ethical and religious objections against ART procedures at various places, ARTs seem to be regarded as a solution to people's suffering from being childless in many places in the world and to be highly desired rather than rejected (Ombelet and van Balen, 2009).

In the context of HIV/AIDS, ARTs gain new importance as they offer not only a hope to conceive for those experiencing fertility problems but also the hope to conceive *safely* for those who are HIV positive *and* experience fertility problems without transmitting the virus to the partner. This is relevant also for a couple in which both partners have a seropositive status, as they can infect each other. So called cross-infections represent a considerable health threat as the virus tends to become more aggressive. The Fertility Clinic Vitalab in Johannesburg, for instance, advertises their fertility services also to HIV/AIDS positive patients with conception problems (Vitalab, 2010). They mainly address people with fertility problems in general, pointing out the various treatments and services available. However, browsing through their website one finds advertisements in which they address HIV positive people with unfulfilled desires for children. Here, they indicate their responsible attitude towards this specific group of patients by not only offering counselling to the couple but also by taking special precautions in dealing with HIV infected material. Their announcement already indicates some of the reservations that HIV positive people experience when faced with fertility problems, which I will come to speak of later on. It is important to note that not all HIV positive people with desires for children need to rely on ARTs.

Discordant couples and HIV positive couples with an unfulfilled child wish and no recorded fertility problem could also try conceiving without sophisticated technologies. According to what has become known as the 'Swiss Declaration', an article authored by a team of Swiss medical doctors, HIV positive people can conceive naturally without putting the partner at risk if they are on ARV treatment and the virus is undetectable (Vernazza et al., 2008). The paper is highly contested: critics point at the level of risk still involved in this practice; some believe it serves the interests of the pharmaceutical industry producing anti-retroviral medicaments (ARVs) ([1]) rather than the health of the patients, while it represents a hope to many to conceive 'naturally'.

Botswana has a comparatively well-functioning public health care system. There are, however, only minimal possibilities to diagnose and treat infertility in the public health system. Botswanans who wish to have a child and cannot conceive can seek help at private clinics where they need to pay the costs of consultations and treatments themselves. The costs are not covered by health insurances ([2]). Therefore, there is a market for private fertility care of which educated professionals are the main beneficiaries. Gaborone hosts two private hospitals that offer gynaecological services, the Gaborone Private Hospital (GPH) and the Bokamoso Private Hospital, with a staff of 14 private gynaecologists. The specialization of biomedicine is quite new in Botswana, which may partly be attributed to the fact that with its two million inhabitants the amount of patients requiring health services is still considerably small. The first gynaecologists started practicing in Botswana in the 1980s at the National Hospital Princess Marina.

Both private hospitals offer general gynaecological services including deliveries. Opened in 2010, the Bokamoso Private Hospital hosts specialists, among them trained gynaecologists/obstetricians and a theatre, as well as specially trained nurses and midwives (Women's Health Nurse). Many of the necessary tests, such as an HSG (hysterosalpingogram) ([3]) are administered there. Both hospitals offer fibroids operations, which were identified some years back as a common cause of conception problems in Botswana as elsewhere. Many gynaecologists who do not have special facilities or skills to diagnose the causes of infertility treat their patients with clomid, a hormonal treatment enhancing ovulation. One

[1] ARVs suppress the virus and therefore enhance the immune system, thus considerably prolong the lives of HIV patients. Botswana ensures each citizen in need of treatment has access to ARVs.

[2] Botswana is one of the few African countries with a health insurance system. Banks, the insurance industry and the public service sector insure people working in these sectors.

[3] A hysterosalpingogram (HSG) is an X-ray test that looks at the inside of the uterus and fallopian tubes and the area around them. The x-ray can show problems such as an injury of abnormal structure of the uterus or fallopian tubes, or a blockage that would prevent an egg from moving through a fallopian tube to the uterus.

practice – the Gynae and Care Clinic – specializes in fertility care; having trained at an infertility research centre in a European country, they analyze the hormonal menstrual cycles of their patients thoroughly and are able to fine-tune hormonal therapies.

IVF or ICSI are generally not available in Botswana in either the public or private sector, which reemphasizes the lack of services, and patients who desire to conceive through IVF have to seek treatment in South Africa. Private clinics and hospitals in Botswana cooperate with fertility clinics in South Africa where individual gynaecologists attend to patients differently. Most gynaecologists just point to the possibility, refer patients to the clinic in South Africa and give minimal information on the procedure. Others accompany the treatment very closely such as the Gynae and Care Clinic. They discuss with the patients the results of all tests they undergo, offer them appointments before or after working hours so that their patients who are indispensible at the work place are able to combine the treatments with their work and most importantly keep close communication during the IFV or ICSI treatment itself.

Seeking conception: infertility patients and gynaecologists

Experiences of patients

Patricia ([4]), at the time of the interview age 47, belongs to the few privileged in Botswana who can afford the costs of IVF that is not offered in Botswana. She has undergone IVF twice in the past three years. She married at the age of 30 and had no children by the time she started treatment. She remained childless in her short-lived marriage, and started fertility treatments only after her divorce. She underwent IVF for the first time in 2008 at the Cape Fertility Clinic in Cape Town, South Africa. It failed. The treatment cost her 60,000 BWP ([5]), excluding the cost of the flight and the guesthouse where she stayed.

Patricia belongs to the first generation of women I interviewed, of whom were in their prime fertile years in the 1990s. In these years, fertility medicine was less advanced and less known than in contemporary Botswana. At the beginning of the 1990s, fertility problems were treated by General Practitioners (up until today). Complicated cases were sent to South Africa to see specialists. Patricia sought treatment first in the mid-1990s and was diagnosed with 'fibroids'. The excrescent in the uterus was known to prohibit the settling of the foetus into the uterus. While medical research has advanced and does not attribute the main cause of infertility to fibroids anymore, in popular medical knowledge fibroids came to be known as the main cause of infertility.

Trying to recall the many specialists, Patricia had difficulties remembering all their names and she often confused them. Her narrative resembled that of many other women I interviewed (of all ages). She, like others, often felt that the specialists she saw were not competent in dealing with the issue of infertility. She received contradicting diagnoses from different doctors. On top of that, Patricia and others felt hidden or open discrimination by the treating doctors: their way of looking at them with disinterest, rejecting faces, short questions and statements that were breaking the 'news' that there was nothing that they could do for them after they heard their ages. One woman reported that she received comments such as: "You will never give birth. You are a useless woman." These experiences add to their personal and social suffering of not being able to conceive and their low self-esteem, as well as their feeling of helplessness.

Close follow up and frequent communication in the process of seeking conception is therefore highly appreciated. Patricia for instance recalled that her doctor called her everyday enquiring about the process of her treatment. "He has my number on his phone and I have his number on my phone." This quote suggests a strong personal relationship and identification between her and her doctor. Being available on the phone, according to which many relationships are evaluated in the city, makes Patricia's doctor an ally in her fight for a child, and, even though she is aware of the limitations of her chance to conceive this knowledge releases her psychological anxiety.

The second generation of women I interviewed faced slightly better conditions concerning fertility treatment. Even though biomedical knowledge about fertility treatments was (and is) still confined to a few specialists, gynaecologists are more aware of the various aspects of fertility treatment. The possibilities of undergoing IVF or ICSI are better known even though by far not affordable to all of my respondents. Depending on their educational background, women of this second generation are better informed about their own health and use other sources of information such as books and the internet to find out more about possible causes of infertility, and they even suggest possible solutions to their specialists. Women of that age group exhibited a strong

[4] All names are changed and other markers of people's identity are disguised.

[5] Approximately 6,000 euro.

trust in biomedical knowledge and technology, believing it would help them to conceive, as well they had a strong sense that it was their responsibility to seek out all possible options.

Other women showed less determination in dealing with their reproductive wishes. Some of the younger women had a history of repeated miscarriages and ectopic pregnancies, which damaged one of their tubes. They had gone through several gynaecologists before coming to Bokamoso and were insecure and timid. If the hospital could not diagnose a reason for their infertility, they were advised to go for IVF not to lose time. During the IVF treatment, many special tests are conducted that may show the causes for their infertility. Younger women often also do not have the resources to pay for IVF, including travelling costs. Some of them considered taking out a loan in order to be able to cover the costs for one ICSI cycle hoping that this would resolve their childlessness.

Patricia, at the age of 45, had the financial means. By then, she had a good position at the institution where she worked and a supportive husband. It seems however, that this help came too late for her. During her last IVF cycle, no eggs could be extracted. She was offered a donor egg but her husband did not want to have a child of 'foreign DNA', as Patricia expressed it. Her husband especially felt that he did not want her to carry the child of a stranger.

From the perspective of gynaecologists

"Infertilities? I don't like them," said one of the gynaecologists at GHP when I phoned him to introduce myself and my research to him. During our first meeting at the clinic, I asked him why. "These are frustrated people. It is difficult to deal with them," he explained to me. Some of his colleagues shared his experience. People would expect a quick cure when they came to the gynaecologists. They believed they would get a pill that would instantly cure their condition. But infertility treatment is a long process and needs patience, something that people do not understand. Rather, if they do not see an immediate result they move on to somewhere else. From the perspective of gynaecologists, some people's expectation of biomedicine resembles faith in miracle healing.

Gynaecologists indicated that they had HIV positive patients who wished to have children and were concerned about infection or cross-infection. Their recommendations vary on this point. The Gynae and Care Clinic recommends artificial insemination. In this procedure the sperm cells are removed from the semen and only the core remains. As the virus is outside the core of the cell it will not be infectious anymore. Another gynaecologist recommends lubricating and inserting the sperm with a syringe so that the mucous membrane would not break. The more common handling of such cases is to suggest to couples to not use a condom during the fertile days of the woman's cycle. While some clinics recommend to their patients to go on ARVs and control their virus load, others do not.

Two gynaecologists, however, expressed strong concerns about HIV positive women becoming pregnant. They feel these parents might not live long enough to raise their children, somewhat reflecting official politics. In Botswana's National HIV/AIDS Treatment Guidelines from 2008, it is recommended that HIV positive people should be counselled to adopt if they wanted to have a child, thus expressing the priority for not supporting HIV positive people's reproductive wishes.

Despite their reservations, the Gynae and Care Clinic offered one of their female HIV positive patients a possibility to conceive. The woman had stopped ovulating, her general health condition was not very good and she was already 47 years old. However, she was desperate to have a child. They found a donor egg for the woman and presented this option to her. The patient rejected the solution. I do not have any information referencing to this patient as the one I introduced at the beginning of the paper. But considering the similarities of both cases let us assume they are. In both cases, donor eggs were rejected as these offered a possibility to experience pregnancy and birth in addition to motherhood but did not appeal to the couple's conceptualizations of reproduction.

Conclusion

Social anthropologists and public health research have shown that 'childlessness' is a severe form of female suffering and should be acknowledged as a serious problem for public health (Feldman-Savelsberg, 2002). Access to adequate fertility care is however, in a landscape of stratified reproduction, not only restricted by economic possibilities as Ginsburg and Rapp (1995) have shown but also women's age and education impacts on their access to fertility care as shown in this paper.

This study further reveals that selected gynaecologists expressed reservations against HIV positive women becoming pregnant, somewhat reflecting official health policies, which do not recommend HIV positive people to become pregnant. Despite medical reservations, HIV positive people with a wish to carry out a pregnancy do receive medical assistance, whereas the care and information individual specialists invest into these patients varies greatly. The

realm of fertility care represents a health market that operates largely outside Botswana's public welfare system, and gynaecologists meet HIV positive patients' desires for children. These desires are greatly informed by the growing biologisation of parenthood, in which the 'gene' becomes an icon of social and personal continuity in the context of death and dying so that the context of HIV/AIDS adds urgency to these desires to see life going on. And this, I suggest, will not concern only relatively privileged parts of the population but many others who suffer from both HIV/AIDS and infertility.

The case study in Botswana clearly demonstrates that in the context of HIV/AIDS the needs for fertility care are heightened, not only because the problem of infertility is epidemically induced and therefore most likely to be higher in these settings but also because the personal-emotional needs for children appear to be more pressing for childless HIV positive people. Making ARTs available in a country like Botswana would be one of the many important steps to be taken. Gynaecologists in Botswana have often stressed the need for ARTs in Botswana; however, the complex problem of infertility in the context of HIV/AIDS needs to be addressed on many levels. It needs more political and public attention and should become a priority in health policies and health practices such as counselling services and general health services of HIV positive people.

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Future Perspectives

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Abstract

According to WHO data more than 180 million couples are confronted with the consequences of childlessness day by day. The consequences of involuntary childlessness are much more dramatic in developing countries, particularly for women. The most important reason for childlessness in developing countries is severe male infertility due to sexually transmitted diseases (STDs) and female infertility due to blocked tubes. Both problems can only be treated by "expensive" assisted reproductive technologies (ART) which are not available at all or only within reach of those who can afford it, mostly in a private setting.
Numerous barriers against infertility care provision in resource-poor countries are reported in this Monograph. It is clear that we need a global approach to reach the ultimate goal: the implementation of accessible infertility care services all over the world. Keystones for success include simplification of diagnostic procedures and ART methods, minimising the complication rate of interventions, providing training-courses for health care workers, paying attention to the psychosocial aspects of patients and the cultural settings. In this it is utmost important to incorporate infertility treatment into existing reproductive health care programmes. The Walking Egg Project aims to start with the implementation of low-cost "accessible" infertility services in developing countries, integrated within health care clinics dealing with good quality family planning, health education, maternity- and child care facilities.
The project needs the support of a strong network of social scientists doing research in the field of infertility, childlessness and assisted reproductive technologies in poor resource settings. This network can help the project in the preparation and follow-up of the pilot-centres including monitoring and assessment of the social, psychological, cultural, ethical and juridical aspects.

Key words: **Affordable, developing countries, ethics, infertility, IUI, IVF, low cost ART, politics, reproductive care, simplified methods, socio-cultural.**

Introduction

It is common knowledge that infertility is not prioritised as a public health problem in most developing countries. According to the evidence available, infertility care in resource poor countries still faces a large number of barriers against providing even basic care to childless couples. The most common barriers are the following: (1) lack of interest of governments, local health care providers and research institutions for infertility care as such (2) lack of financial support by NGOs, foundations and international societies in projects linked to infertility care, (3) inequity in access to ART (assisted reproductive technologies) services because of non-availability and/or high costs, (4) concerns about overpopulation, (5) the limited resources argument questioning that expensive techniques are justified in countries where poverty is an important issue and where health care systems still struggle with the huge problem of infectious diseases such as malaria, tuberculosis and HIV and (6) Millennium Development Goal 5 indicating that the reduction of maternal mortality has to be considered as the most important reproductive health priority, not mentioning the problem of neglected infertility care.

In most resource poor countries assisted reproductive technologies are either unavailable or very costly in so far that the large majority of the population cannot afford it. Mostly the treatment centres are located only in the capital or very large cities, which often require very long travels by the patients to reach these. The services mostly provide little or no guidance or psychological counselling making the treatment more stressful than needed. Also information about the treatment and the success-rates are frequently lacking or biased.

From a reproductive rights perspective and for reasons of social justice and equity it is our duty to provide equitable access to effective and safe infertility care in resource-poor countries as well. Time has come to change policies and to enable the delivery of comprehensive and accessible infertility care in developing countries, if possible in a project with a multidisciplinary and global approach. The contributions of socio-cultural research are helping in finding ways for braking down the barriers that exist against funding and prioritizing infertility treatment in poor resource areas. In the papers in this volume the existing barriers in various countries are scrutinized and suggestions for change indicated.

The Walking Egg Project

At the Arusha Expert meeting, a co-organization of the ESHRE Special task Force on "Developing countries and infertility" and The Walking Egg npo, held in Arusha (Tanzania) December 2007, it was decided that global access to infertility care in developing countries can only be achieved when good quality but affordable infertility care is linked to more effective family planning and safe motherhood programmes.

The Walking Egg Project aims to raise awareness surrounding childlessness in resource-poor countries and to make infertility care in all its aspects, including assisted reproductive technologies, available and accessible for a much larger part of the world population.

The most important aims and actions of The Walking Egg Project are the following

1. *Reproductive Health Care Education*

Public education on prevention of infertility including life style, prevention of STDs and postpartum and post-abortion infections has to be improved. Therefore the incorporation of reproductive health education in general health education is mandatory. This necessitates establishing relationships with schools, community leaders, traditional healers as well as the media, producing and distributing educational materials (brochures, posters and audio-visual material).

2. *To study the ethical and socio-cultural aspects surrounding this topic*

Because only a few studies describe the social effects of childlessness in resource poor countries, we want to initiate and expand an international network of social science scientists to perform more research on social, psychological, cultural, ethical, religious and juridical aspects of infertility in resource poor countries, including barriers to healthcare and access to treatment.
We aim to publish overviews of findings on socio-cultural aspects and psychological of childlessness and infertility care in resource poor countries and communicate the results with a wider audience including patients, medical professionals, the press, NGO's, political and governmental institutions.
It is also our goal to monitor, assess and follow-up the socio-cultural and psychological aspects of the pilot-projects for low cost infertility services and analyse ethical issues arising during the implementation of the project. Moreover it is also needed to measure the effects of treatment, in case of success as well as in case the couple stays childless after treatment.

3. *To study the economical aspects surrounding this topic*

We urgently need more studies on the prevalence of childlessness in developing countries. We also have to measure the reduction in the quality of life by infertility and childlessness and compare it to the reduction caused by other common diseases in developing countries. How cost-effective is infertility treatment in comparison with other measures aimed to improve health?

Country profiles, with existing data on resources, needs and resource gaps for infertility services and service integration into already existing structures have to be made. These studies are urgently needed to select the countries which have to be chosen to implement the first pilot-centres.

4. *Simplifying techniques of diagnosis and treatment of infertility: a simplified "one-stop clinic for the diagnosis of infertility"*

The feasibility of a model of centralized expertise with a one-stop diagnostic strategy in developing countries will be examined. The one-stop approach implements the responsibility of diagnosis and immediate management policy. The consequences of the results for the management of the couple have to be discussed with them on that same day. A protocol for the anamnesis and examination of the infertile couple has to be standardized and it has to be examined which simple diagnostic tests have to be performed.

5. *Simplifying techniques of diagnosis and treatment of infertility: To study the effectiveness of simplified IVF*

A strategy would be the use of a simple incubation system in tubes avoiding the necessity of expensive CO^2 based incubators and laminar-flow chambers. A prospective study comparing this very low cost simplified system with regular IVF is ongoing in Genk, Belgium. The first results of this new method are promising and reassuring.

6. *The implementation of accessible infertility services into (existing) reproductive health care programmes*

The ultimate aim is to establish accessible low-cost infertility services in developing countries with affordable, effective, safe and standardized diagnostic and therapeutic procedures, and protocols. The integration of infertility management into sexual and reproductive health care programmes and a reduction of costs are considered prerequisites for implementing "new reproductive technologies" in developing countries. Simplifying ART procedures and minimising the complication rates will be mandatory.

7. *The organisation of training-courses for fertility specialists and paramedical health care providers*

Training courses have to be organized on a regular basis with emphasis on the diagnosis and prevention of infertility in developing countries. Table I gives an overview of the training courses we have in mind. We will need the support of experts in the field, who are capable to tutor the training courses at the highest level in a very short time, taking into account the experience of the trainees and the quality of facilities that can be expected in the new pilot-centres.

8. *Data registration*

Following training, quality control, regular audit and systems of accreditation and registration should be implemented in order to maintain appropriate standards of care. It is our aim that within each pilot-centre the data will be registered already from the start, if possible "online".

Need for research collaboration and socio-psycho / counselling support

Depending on the countries where the first pilot projects of the Walking Egg project will be carried out, researchers with experience in that particular country (or region) could be involved in conducting studies. Various research questions/objectives and study designs can be considered, including the following:

(1) Studies to prepare the design of the different treatment and counseling procedures, ethical guidelines and informed consent forms for pilot-clinics delivering accessible and affordable infertility care.
(2) Qualitative interviews can be used to assess the way infertility services are actually delivered in these clinics during the pilot phase, including the experiences and viewpoints on feasibility and accessibility of the health care staff.

Table I. — Key categories of the training courses.

- Reproductive health care education basic course
  → Target group: **nurses, midwifes**
- A general and medical anamnesis of both partners and basic clinical examination
  → **clinician (medical)**
- Screening for infections and STDs
  → **clinician (medical, paramedical)**
- How to perform and evaluate a hysterosalpingography and/or hystero-salpingo-contrast-sonography
  → **clinician (medical, paramedical)**
- Standard Operational Procedures for the gynaecological and fertility ultrasound scan
  → **clinician (medical, paramedical)**
- Basic semenology training course according to WHO 2010 manual
  → **laboratory staff, (paramedical)**
- Sperm washing procedures
  → **laboratory staff, (paramedical)**
- Mini-hysteroscopy
  → **clinician (medical)**
- Documentation and registration
  → **administrative staff (clerical)**

(3) Semi-structured or qualitative interviews are the best tools to investigate the acceptance and effects of treatment procedures on subfertile couples – women and men – undergoing infertility treatment at different stages with special attention to the way they experience treatment practices, in particular aspects of quality of care. The counselling process has to be investigated with special attention to psychological strength, social support and cultural ideas.
(4) Assessing social repercussions of performing infertility treatment procedures at conjugal, family or community level with special attention to economic consequences and other implications in the cultural-religious domain. This can easily be done by means of ethnographic / qualitative research.
(5) Studies looking into issues of stigmatization and means to de-stigmatize infertility, the role of patient organizations, the media (soaps and TV-news, magazines and popular journals, examples of VIP's etc).
(6) Post-intervention studies are needed to investigate (a) changes in life, with or without child and (b) the socio-cultural response of the family and community.

Conclusion

The implementation of accessible infertility care services is not an unrealistic dream anymore. The success of the Walking Egg Project will largely depend on our ability to optimise these techniques in terms of availability, affordability and effectiveness. Many studies suggest and prove that the cost per ART cycle can and will decrease substantially although the exact price reduction have not been calculated yet.

To be successful the project has to be global with a very strong socio-cultural, psychological, ethical and economical component. It will need the support of a strong network of social scientists supporting the project by discussing the various socio-cultural, psychological and ethical aspects of biomedical infertility care in poor-resource areas. This network will be crucial in the introduction and follow-up of accessible infertility care services in resource poor countries.

The contributors to this volume and the initiators of the Walking Egg Project are, each in his or her own way, trying to achieve an improvement of the fate of the childless couples in poor resource areas. Hopefully through these and other efforts NGO's, governments, regional and local health institutions, and other important organizations will also become interested and active in improving treatment and prevention of infertility in the non-Western world.

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