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Biomedical infertility care in low resource countries: Barriers and Access

Introduction

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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 Cytoplasmic 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 attention 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 constantly 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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