

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/ km² 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 utmost 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 rooted 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. "Pharonically" 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 infer-

tility 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 determinants 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 child-birth. 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 fluctu-

ating 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.

References

- Ahmed M, Mansour M, Khalid K et al. Semen Analysis of Infertile Sudanese Males in Gezira State Central Sudan. *Sudanese J Public Health*. 2009;4(3):340-4.
- Almroth L, Elmusharaf S, El Hadi N et al. Primary infertility after genital mutilation in girlhood in Sudan: a case-control study. *Lancet*. 2005;366(9483):385-91.
- Blyth E. Guidelines for infertility counseling in different countries: Is there an emerging trend? *Hum Reprod*. 2012; doi:10.1093/humrep/des112. <http://www.ncbi.nlm.nih.gov/pubmed/22493028>.
- El Safi A. Traditional Sudanese medicine: a primer for health care providers, researchers, and students: AZZA House. 2007.
- Elussein EA, Magid YM, Omer M et al. Clinical patterns and major causes of infertility among Sudanese couples. *Trop doct*. 2008;38(4):243-4.
- Gaily ZM, Elhoussein EE, Karar Z et al. Short-term Outcome of In-vitro Fertilization Babies (IVF) In Sudan. *Sudanese J Paediatr Child Health*. 2010;10-10:40.
- Habbema JDF. Is affordable and cost-effective assisted reproductive technology in low-income countries possible? What should we know to answer the question? *ESHRE Monographs*. 2008;1:21-24.
- Hakim LZ, Newton C R, MacLean-Brine D et al. Evaluation of preparatory psychosocial counseling for medically assisted reproduction. *Hum Reprod*. 2012; doi:10.1093/humrep/des129.
- Khan A, Colon J, Palta V et al. Assisted Reproductive Technology for men and women infected with human immune deficiency virus type 1. *Clinical Infectious Diseases*. 2003; 36(2):195
- Larsen U. Primary and secondary infertility in sub-Saharan Africa. *Int J Epidemiol*. 2000;29(2): 285-91.
- Nadel SF. The Nuba: an anthropological study of the hill tribes in Kordofan. AMS Press. 1978.
- Osman AA. Management of Infertility within Primary Health Care program in Sudan. *Asian J Sci Res*. 2011;4(2):158-64.
- Serour GI. Islamic Developments in Bioethics. *Bioethics Yearbook: Volume 5-Theological Developments in Bioethics*. 1997; 1992-1994, 5:171.
- Serour GI, Aboulghar MA, Mansour RT. Bioethics in medically assisted conception in the Muslim world. *J Assist Reprod Genet* 1995;12(9):559-565.
- Serour GI, Omran AR. *Ethical Guidelines for Human Reproduction Research in the Muslim World: International Islamic Center for Population Studies and Research, Al-Azhar University*. 1992.
- Vayena E, Peterson HB, Adamson D et al. Assisted reproductive technologies in developing countries: are we caring yet? *Fertil Steril* 2009;92(2):413-416.
- World Health Organization. Strategy to Accelerate Progress towards the Attainment of International Development Goals and Targets Related to Reproductive Health: Approved by the World Health Assembly. *Reproductive Health Matters* 2005;11-18.