FACTS, VIEWS & VISION
Issues in Obstetrics, Gynaecology and Reproductive Health
in ObGyn

Expert meeting

Genk – Belgium, 13 to 15 December 2009

Organized by the ESHRE Special Task Force "Developing countries and infertility" and the Genk Institute for Fertility Technology

Social Aspects of accessible infertility care in developing countries



Content

The Social and Cultural Consequences of Being Childless in Poor-Resource Areas
Frank van Balen (the Netherlands) 1

Considerations regarding government funding of assisted reproductive techniques in low-resource settings
Silke Dyer (South Africa) 17

Male perspectives on infertility and assisted reproductive technologies (ART) in sub-Saharan contexts
Viola Hoerbst (Portugal) 22

Misery of Empty Laps: Life of childless women in Bangladesh
Papreen Nahar (Bangladesh) 28

Fertility treatments under semi/occupation: The case of East Jerusalem
Daphna Birenbaum-Carmel (Israel), Ronit Kochman-Haimov (Israel) 35

Healers, nurses, obsgynecologists dealing with women in the quest to become pregnant in the south of Mozambique
Esmeralda Mariano (Mozambique) 43

Negotiating boundaries: Accessing donor gametes in India
Anjali Widge (India), John Cleland (United Kingdom) 51

Infertility and Treatment Seeking in India: Findings from District Level Household Survey
Sayeed Unisa (India) 59

Summary of an Expert meeting on "Social Apects of Accessable Infertility Care in Developing Countries"
Willem Ombelet (Belgium), Frank van Balen (the Netherlands) 66

Introduction

Frank Van Balen[1], Willem Ombelet[2,3]

[1]Faculty of Social and Behavioural Sciences, Department of Education, University of Amsterdam, the Netherlands.
[2]Coordinator of the ESHRE Special Task Force on "Developing countries and infertility"
[3]Genk Institute for Fertility Technology, Department of Obstetrics and Gynaecology, ZOL, Genk, Belgium.

December 2008 the ESHRE Special Task Force on "Infertility in developing countries" chaired by Willem Ombelet, organized its first international conference in Arusha (Tanzania). On this conference representatives of all the major international medical organizations in the field of infertility (FIGO, IFFS, ESHRE, ISMAAR) were represented. Also, the European Union, the World Health Organization, the Tanzanian governement, and other authorities, as well as journalists, were present. The conference was multidisciplinary and included infertility specialists, biologists, economists, sociologists, psychologists, ethicists, and so on. On this conference it was decided to create several working groups and study groups in order to realize afffordable and accesible infertility care, including low cost IVF. Among these groups was the social science, law and ethics study-group, which was especially created to look into the local circumstances regarding infertility care, the psychological wellfare of patients, the social situation of infertile people and the repercussions of treatment, as well as ethical and legal problems of the topic.

As a first step in realizing affordable fertility centers it was decided to start with a few pilot projects in different areas. Regarding the pilot projects the social and psychological side had to be included. For instance education on infertility and its treatment is considered necessary for patients as well as the general public. Also, the special circumstances regarding male infertility within various cultures had to be addressed. In addition to this, there is the case of traditional healing compared to biomedical treatment. Furthermore it is important to include infertility care within the framework of reproductive health. Finally it appears necessary to assess the pilot projects of affordable treatment: is information to patients sufficient, how are treatments assessed (medical and psychological), what are the social repercussions of having treatment, and how to go on after succesfull or unsuccesfull medical treatment.

In order to work out these aspects, it was decided to organize an expert meeting of involved medical professionals, and diverse social scientists (antropologists, sociologists, psychologists ethicists, and lawyers). This meeting took place December 2009 in Genk (Belgium).

Several of the participants agreed to write a paper regarding the topics raised considering affordable and accessible care in resource-poor areas. All these papers are presented in this Monograph. Further on in this Monograph you can also find a summary of the discussions held at the Genk meeting.

The social and cultural consequences of being childless in poor-resource areas

Frank van Balen[1,2], Henny M. W. Bos[1]

[1]*Faculty of Social and Behavioural Sciences, Department of Education, University of Amsterdam, the Netherlands.*
[2]*Frank van Balen Research, Warder, the Netherlands.*

Correspondence at: Frank van Balen, Faculty of Social and Behavioural Sciences, Department of Education, Nieuwe Prinsengracht, 1018 VZ Amsterdam, the Netherlands. E-mail: F.vanBalen@uva.nl

Introduction

Approximately 70-80 million couples world wide are currently infertile (Bos *et al.*, 1995; Boivin *et al.*, 2007) and it can be estimated that tens of millions of couples are primary infertile or childless. For most people, having children is immensely important; not being able to have children is a major life problem. There is also a large group of women and men, who have children, possibly form a previous relationship, who desperately wants to have another child. A considerable body of research in Western countries has shown that involuntary childlessness has strong psychological consequences (see for reviews: Greil, 1997; Brokvich and Fisher, 1998). Most of the studies carried out in this domain are quantatitative and some are qualitative. Both kind of studies, point in the same direction: there are various psychological and psychosomatic effects, and especially women are affected. The most frequently mentioned effects are distress, raised depression and anxiety levels, lowered self-esteem, feelings of blame and guilt, somatic complaints, and reduced sexual interest. For a small minority of women and men in the Western world these effects are at a clinical level or can be considered extremely serious (Greil, 1997).

It is interesting that social and cultural consequences are seldom mentioned in the reports on these studies. When these aspects are considered, they are often related to studies about elderly people without children, regardless of the reason for being childless. It is stressed in the reports of these studies that frail old people without children have less social support (cf., Johnson, 2006) and a less robust network for independent living compared to old people with children (cf., Wenger *et al.*, 2009). Wirtberg and co-workers (2007) however, carried out a study that is unique in the sense that it aims at elderly involuntarily childless women. They reported on 14 women, and described that in all cases but one sexual life was affected negatively and that half of these elderly childless women were separated.

Some studies, report the difficulty that childless couples have in communicating with friends who do have children. They describe negative (although sometimes well-meant) remarks within the couples' social worlds, for instance at birthday parties and other social gatherings; however, supportive reactions are also mentioned very often (Greil, 1991; van Balen *et al.*, 1996; Schmidt**,** 2006). It is possible for childless couples to participate in the 'world of children', especially if couples have good friends or relatives who have children. They are able to participate in the lives and activities of the children of their friends and relatives by, for instance taking care of the children for a part of the week or when the parents are on holiday; taking the children to school, music lessons or sports activities; or going to games or shows in which the children participate. An early study on childlessness found that about ten per cent of couples had chosen this strategy as a way of coming to terms with their childless life (van Balen, 1991) Also, recently Wirtberg and colleagues (2007) described this as typical coping strategy for childlessness. It appears that in the West childless people are not formally excluded from being involved with raising children.

In the 1990s, studies were published about the effects of childlessness in developing countries. The focus of these studies was different from studies carried out in the West. Although psychological effects are described, the main concerns are social and cultural effects (van Balen and Inhorn, 2002). This paper presents a review and an analysis of the results of the studies done to date in poor-resource areas regarding the social and cultural effects of being childless.

Methods

Literature search

To collect the studies, four Internet online databases were searched. These were Web of Science, Academic Search Premier, Science Direct and PiCarta. The following search terms were used on subject areas: 'childless/childlessness' combined with 'consequences/effects' and 'infertile/infertility' combined with 'social consequences/effects'. In addition, chapters were collected from three edited volumes, namely Social Science Research on Childlessness in a Global Perspective (2000), Women and Infertility in sub-Saharan Africa (2001) and Infertility Around the Globe, New Thinking on Childlessness, Gender and Reproductive Technologies (2002). Finally papers that were possibly additional to the Internet search, were collected from special issues of journals on the topic of infertility in poor resource areas, viz: Patient Education and Counseling (1997, 2005), Reproductive Health Matters (2002), Journal of Infant and Reproductive Psychology (2004), Journal of Psychosomatic Obstetrics and Gynaecology (2007). By using the search term infertile/infertility (which may comprise secondary infertility) studies that involved women or men who want to have another child, were included in the database.

Interpretative phenomenological analysis

A method based on interpretative phenomenological analysis (IPA; Smith and Osborn, 2004) was used to order the results reported in the studies. IPA is especially useful in exploring and ordering new topics (Chapman and Smith, 2002). This method is normally used in empirical studies, in this case however it was adapted for application to a literature review. The adaptation process started from a certain framework of analysing and grouping results, followed by recoding and regrouping of the results, adapting the framework definitions of concepts, and then reassessing and improving the way the findings of the various studies were ordered so as to establish the final framework and definitions of concepts and to locate the results in the categories and levels. To improve coherence and consistency, the co-author also coded categories, levels and frequency indications of a quarter of the studies and evaluated the concepts and assessed the framework. In this way, the results reported in the various studies were ordered into categories, intensity levels and frequency ranges.

Categories of consequences

Consequences were initially categorized according to four fields in which effects are mentioned in the various reports, namely the social, economic, legal and religious fields. While carrying out the rounds of IPA described above, it appeared more feasible to adapt these four categories. In-law effects were added to the 'economic' category because there were often essential economic effects attached to problems in the relationship with the in-laws. Couple relationships with extended family appeared to be a separate issue from 'within couple effects' which were coined 'marriage effects'. Marriage effects, such as marital instability and possible divorce, often appeared to be associated with other legal effects and were therefore added to the 'legal' category. Social effects were renamed 'community effects', in order to disentangle them from the more general use of the term social (e.g. 'social sciences' or 'social life'). The category 'religious' was augmented with the aspect 'spiritual', because this aspect was mentioned in some of the studies.

Intensity of effects

Several levels of intensity within each category were used to describe the effects. It was convenient to consider four levels for each category and to include in each category effects that have roughly the same intensity.

Community effects (from lowest to most intense level): (i) status loss, including no respect and being a social failure; (ii) ridicule, including insults and verbal abuse; (iii) stigmatization or recognizable marginalization; and (iv) isolation, including exclusion (from ceremonies and social gatherings), rejection, being an outcasts and physical abuse perpetrated by community members.

Economic and in-law effects (from lowest to most intense level): (i) costs of treatment (biomedical or traditional); (ii) no economic security, including no care in old age, no economic support from others, unable to find work, no connections and restricted land use; (iii) harassment, pressure and rejection by in-laws; and (iv) exploitation and abuse perpetrated by in-laws.

Legal and family aspects (from lowest to most intense level): (i) inheritance restrictions, including other legal restrictions such as property rights and burial rights; (ii) marital instability, including fear of the husband taking a second wife or divorcing the childless woman; (iii) the husband actually having a second wife; and (iv) divorce, including also expulsion from the home and physical abuse and violence perpetrated by the partner.

Religious and spiritual effects (from lowest to most intense level): were ordered as follows (i) effects perceived by oneself: not to have children in order to fulfil religious obligations; (ii) diverse forms

of witchcraft attributed to the infertile person; (iii) having the 'evil eye' or being a considered a person whom it is better not to touch; and (iv) being considered a person who brings illnesses and disasters to the community.

Frequency of effects

Because most of the studies that were collected were qualitative in character, the effects are often reported in descriptions, like 'almost all', 'common', 'frequently', and 'a few ', 'one case'. It appeared most feasible to use three frequency ranges: (1) all, almost all, majority, most; (2) many, frequent, often, common, not uncommon; and (3) some, a few, one (in small samples). In some of the reports clear indications of the frequency of some or all findings are absent. However, it could be deduced from the context whether the effect could be ranked in one of the three levels. Nevertheless, in a considerable number of papers this appeared not possible and therefore the effects were not quantified for these studies.

Results

The studies

Thirty-nine studies into various social effects of childlessness in poor-resource areas were collected. Of these, 19 concerned areas in sub-Saharan Africa, and 13 concerned areas the Indian subcontinent (India, Pakistan, Bangladesh, Sri Lanka). Just two studies were found concerning North-Africa and the Near East and only one concerning a Latin American country.

Some studies were sociological in character, based on a large survey and presented quantatitive data (Sundby 1997/1998; Unisa, 1999; Mulgoankar 2000a/2000b). In one of these (Sundby 1997/98), more sensitive issues were reported, that were collected through in-depth interviews in a smaller subsample. Four studies started with a psychological perspective (Denga, 1982; Fido and Zahid, 2004; Wiersema *et al.*, 2006; Donkor and Sandall, 2007). Donkor and Sandall (2007) and Wiersema and coworkers (2006) used a quantitative methodology to collect psychological and social data, while in the last authors also carried out semi-structured interviews on a subsample regarding socio-cultural aspects. Denga (1982) and Fido and Zahis (2004) reported on social effects but described only the methods used to collect psychological data.

The other studies had an anthropological approach, and employed various qualitative methods, mostly in-depth interviews with infertile people (see table 1). A few of these were based on a limited number of cases. The study by Riessmann (2000a/2002) used narrative analysis on three cases. Hollos (2003) and Hörbst (2008) performed out a qualitative analysis based on six, respectively two life histories. The report by Jenkins (2002) is a case study written in a novel-like style.

In several studies the number of the sample of infertile persons interviewed was absent (Neff, 1994; Boonmongkong, 2000; Feldman-Savelsberg, 2002). Also, in reports that used various sources of information, it is not always clear which source was the origin of the various results (Neff, 1994; Feldman-Savelsberger, 2002; Handwerker, 2002). Furthermore, a number studies were based not on information provided by infertile persons themselves but, for instance, on key-persons and focus group discussions (Okonufua *et al.*, 1997), attitudes in the general population and key Churchpersons (Pearce, 1999) or stories in newspapers and movies (Meyer, 1994). Only a few studies focused specifically on men (Dyer, 2004; Hörbst 2008). In the studies that included men, the focus was mainly on women (Bharadwaj, 2000; Nahar, 2000; Wiersema *et al.*, 2006).

Some papers had a limited perspective to start with and included only some aspects of childlessness, such as marital relational aspects (Denga, 1982), religious and spiritual effects (Meyer, 1994). Other studies were specifically focused on stigma (Apte *et al.*, 2004; Donkor and Sandall, 2007), identity, social construction and meaning (Neff, 1994; Kielman, 1998; Mariano, 2000/2004), treatment technology (Handwerker, 2002) and sexual dysfunction (Nene *et al.*, 2005). Most studies however, were not explicitly limited in focus with respect to the various social effects of childlessness. Sixteen of the reports listed at least effects in three of the social categories of effects, while 11 reports do so in two categories.

Regarding the settings, about half of the studies (18) were carried out within a community or were based on surveys in the community or the country. About the same number (15) were carried out in a medical setting or started out from a sample collected through clinics, gynaecologists and other health personnel. Two studies (Bahti *et al.*, 1999; Riessman, 2000b) used samples from a medical as well as a community source. Another report (Boonmongkong, 2000) did not specify the origin of the sample (see table 1).

The large majority (28) of studies concerned persons who were childless or primary infertile (never been pregnant). However, this is not always clearly specified in a methods section or the introduction, but could be deduced from the description and the results (or by implication), and in one case based on

Table 1. — Social effects; reported in studies (in brackets indication of frequency reported; ni = no indiciation).

Study	Area/ culture/ class	Community effects	Economic and in-law relation effects	Legal and marriage effects	Religious/ spirit effects	Sample, and Methods	Setting and Focus Limitation (if explicitly mentioned)
SUB-SAHARAN AFRICA							
Sundby, 1997/ 1998	The Gambia Islam National	Verbal abuse (some) Stigma (ni)	–	Inheritance restricted (all) Marital instability (many) Fear of extra wife (often) Extra wife (some) Divorce (some)	–	243 infertile women questionnaire; 17 women and 2 men unstructured interview; 4 women in-depth interviews and keypersons	Countrywide survey Primary and secondary infertility
Meyer, 1994	Ghana Christian/ spirits	–	–	–	Evil eye (ni) Witchcraft (ni)	Analysis based on stories in media	Newspapers, magazines and movies Having no children Limited to: Spiritual aspects
Donkor and Sandall, 2007	Ghana Urban and rura	Stigma (majority)		–	–	615 women waiting for treatment; Questionnaire based survey	Medical setting Primary and secondary infertility Limited to: Stigma
Denga, 1982	Nigeria Christian Urban	–	–	Marital instability (common) Extra wife (common) Divorce (common)	–	40 childless women and 40 controls: but no information about collection of social effects	Gynaecologists records Childless women Limited to: Marital relationship
Okonofua et al., 1997	Nigeria Yoruba Patrilocal	Outcasts (ni)	No economic security (often)	Inheritance restricted (often) Expulsion of the husbands house (common) Divorce (common)	Witchcraft (often)	Focus group discussions with key persons	Community setting Primary and secondary infertility
Koster-Oyekan, 1999	Nigeria Urban Patrilocal	Stigma (ni)	No economic security (common) Old age (common) Harassment by in-laws (ni) Exploitation (abuse) by in-laws (ni)	Fear of extra wife (ni) Fear of divorce (ni) Divorce (some)	Being a witch (ni)	In-depth interviews with 25 women confronted with infertility and several keypersons Questionnaire of school youths Semi-structured questionnaire among other women visiting traditional healers	Community-based Childless (barren) women

Pearce, 1999	Nigeria Yoruba	No respect (many) Ridicule (many) Stigma (margin) (many) Outcast (many) Exclusion ceremonies (all)	Old age (ni) No connections (all)	Burial rights (ni)	–	Based on 2 previous studies: attitudes of 104 men and women, and interviews and participant observation charismatic churckeypersons	Community attitude about childlessness Being childless
Hollos, 2003		Nigeria Village Patrilocal	No respect (all) Stigma (margin) (all) Physical abuse (some) Exclusion (all)	No economic security (some)	Divorce (all) No right of residence (expulsion) (all)	–	6 women aged 30-80: life histories
Community based, household survey Childless (barren) women	Leonard, 2002	Chad Patrilocal Christian Urban	Ridicule (ni)	Rejection by in-laws (ni)	Marital instability (ni) Divorce (often)	–	Conversations with 21 self-defined infertile Women
Based on household survey (170 interviews) Self-defined infertil-	ity	Hörbst, 2008	Mali Urban	Status loss (ni) Verbal abuse (ni) Stigma (ni)	–	–	
2 males with infertility (results based on one case) Participant observation and in-depth in-	terviews Medical setting Having no child	Feldman-Savelsberg, 2002	Cameroon Rural poor		Less gifts and less land (ni)	No property after divorce (ni) Fear of divorce (ni)	Witchcraft (ni)
Participant observation, and interviews with infertile women, husbands and keypersons No numbers given	Community level and medical personnel Childless (by implication)	Kielman, 1998	Tanzania Islam Villages	–	–	Divorce (often/ common)	–
25 interviews with selfdefined infertile women	Based on local health clinics Self-defined infertil-	ity Limited to: Identity of infertile women Gijsels *et al.*,	2001	Tanzania Urban district	No respect (ni)	Old age (ni) Child labour (ni)	Marital instability (mostly) Extra wives (few) Divorce (most)
–	30 life histories of infertile women	Medical setting Primary and secondary infertility	Hollos and Larsen, 2008	Tanzania Urban	No respect (all) Verbal abuse (all) Stigma (all)	Harassment by in-laws (often)	Marital instability (often)

–	25 infertile and 23 fertile women; In-depth Interviews	Based on household survey Childless women	Gerrits, 1997/2002	Mozambique Rural Matrilineal	Stigma (all) Isolation (all) Exclusion (ceremonies) (all)	Lack support old age (almost all)	Fear of divorce (some)
–	Snowball 25 infertile women, 9 cured, 10 fertile, and keypersons;	Semi structured interviews Snowball starting from community	level Childless women	Mariano, 1999/2004	Mozambique Rural Patrilocal	Stigma (fringe) (ni)	–
Fear of divorce (ni)	–	18 infertile women; informal interviews (3 cases reported on)	Community level Childless women Limited to: Meaning of childlessness	Upton, 2001	Botswana village area	Status loss (ni) Ridicule (ni) Islolation (ni)	–
–	–	Participant observation, Interviews and discussion with in-	fertile persons, community leades (no numbers given) and 17 traditional	healers. Two case studes described	Community setting Primary and secunday infertility	Dyer, 2002	South Africa Urban
Status loss (some) Verbal abuse (many) Stigma (many)	–	-	–	27 men seeking treatment; In-depth interviews	Infertility clinic Partly men with child (secondary infertility) Dyer, 2002	South Africa Urban	Ridicule/ verbal abuse (many) Stigma (many) Outcasts (many)
–							
Marital instability (many) Fear of divorce	(many) Physical abuse by partner (few)	–	30 women seeking treatment; In-depth interviews	Infertility clinic Partly women with child (secondary infertility)	**INDIAN SUB-CONTINENT**	Bhatti *et al.*, 1999	Pakistan Low income Urban
Isolation (one)	Pressure by in-laws (one)	–	–	17 infertile women; In-depth interviews	Clinic and community based Having no children	Neff , 1994	India Tribe
Stigma (margin) (ni)	–	–	–	Anthropological field-work and case study (no numbers mentioned)	Community based No indication of kind of infertility	Limited to: Social construction of infertility	Bharadwaj, 2000

India Several big cities	Stigma (almost all) Isolation (ni)	Harassment by in laws (ni)	–	–	45 semi structured interviews in IVF clinics (women and men)	IVF clinics Primary infertility (by implication)	Mulgoankar, 2000a/2000b
India Urban slum	Status loss (ni) Verbal abuse (ni) Stigma (ni)	Cost of IVF (some) Harassment by in-laws (ni)	Fear of divorce (ni)	–	225 childless couples semistructured interviews (results based on women's reports)	Community based on household survey Being childless	Riessman, 2000a/2002
India Middle class	–	Harassment by in-laws (all) Exploitation by in-laws (one)	Fear of divorce (some)	–	Narrative analysis 3 childless women of upper class; In-depth interviews	Community based Childless women	Riessman, 2000b
India rural Kerala	Status loss (almost all) Ridicule (often) Stigma (all) Outcasts (some)	Pressure by in-laws (all)	Fear of divorce (some)	–	31 in-depth interviews with infertile women, participant observation	Infertility clinic and village based childless women	Unisa,1999
India Villages	No respect (some) Verbal abuse (some) Stigma (common) Isolation and	Exclusion (ceremonies) (frequently)	–	Fear of divorce (few) Extra wife (some) Physical abuse husband (some)	–	332 childless women: questionnaires; 60 childless women: semi structured interviews (not	reported on)
Community based on household survey Childless women	Apte *et al.*, 2004	India Sex workers	Stigma (all)	–	–	–	107 childless female sex workers; Interviews and group discussion
Data collected in workplace area (community) Childless women Limited to: Stigma	Meera Guntupalli and Chenchelgudem, 2004	India Tribe	–	–	Divorce (some)	–	5 infertile, 22 cured and 11 fertile women. Participant observation, in- depth interviews, and informal interviews

Community based Childless women	Nene *et al.*, 2005	India Urban	Stigma (distinction) (almost all) Rejection (humiliation at	gatherings) (almost all)	Harassment and rejection by in-laws (many) Exploitation by in-laws	(very common)	–
–	40 couples with sexual dysfunction; Semi structured and in-depth interviews	Fertility clinic Childless couples with sexual dysfunction	Widge, 2005	India Middle class Urban	Verbal abuse (many) Stigma (many)	Cost of IVF (all) Rejection in-laws (some)	–
–	4 couples and 18 women in treatment; In-depth interviews	Infertility clinic Being childless	Nahar, 2000	Bangla Desh Poor urban	Status loss (many men) Ridicule (ni) Stigma (all women) Physical abuse (ni) Rejection (all women)	No work (many women) Rejection by in–laws (some women) Exploitation by in-laws (some women)	Fear of divorce (frequent women) Rejection by husband (many)
Not to touch (all women) Responsible for illnesses (one woman)							
20 infertile women; In-depth interviews, and 60 men and	women general population	Community based Being childless	Nahar, 2007	Bangla Desh Poor rural and middle class big city	Social failure (often) Stigma (all) (especially in rural area)	Mobility restriction (Rural: mostly) Isolation (all)	Cost treatment (almost all) Old age (rural: mostly) Social Support (especially:
rural) Child earnings (rural: mostly); Rejection in-laws (common)	Inheritance restricted (all) Fear of divorce (all) Fear of extra wife	(all) Extra wife (rural: common)	–	Rural: community based Urban: personal network and snowball method	20 rural poor women, 11 urban middle class women and keypersons; Life story interviews	Community based and social network Being childless	**OTHER AREAS**
Inhorn, 1994	Egypt Islam Urban poor	Stigma (ni) Rejection (ni) Exclusion (ni)	–	Fear of extra wife (ni) Fear of divorce (ni)	Evil eye (ni) Witchcraft (ni)	100 infertile women and 90 fertile women; Semi structured interviews	Hospital based Being childless
Fido and Zahid, 2004	Kuwait Islam Litterate and Illetrate	Stigma (all)	–	Fear of divorce (some) Fear of violence (some)	–	120 women and 125 controls: but no information on collection of social effects	Hospital based No indication of kind of infertility Limited to: Psychological

distress	Handwerker, 2002	China Big city	Social failure (ni)	–	–	Pious duties (ni)	100 women in treatment by questionnaire, 50 other women and 5 men semi-structured interviews, and interviews with various keypersons
Hospital based No child (by implication) Limited to: IVF as a	new technology	Pashigian, 2000/2002	Vietnam Rural	Social failure (no respect) (some) Insults (some)	Treatment costs (ni) Old age (ni) Harassment by in-laws (ni)	Fear of divorce (some) Fear of extra wife (some)	Pious duties (ancestor) (frequently)
39 women in treatment, and 10 women with one child; Ethnographic interviews	and life histories	Interviews in hospital Having no child	Wiersema *et al.*, 2006	Vietnam Big city	–	Cost of treatment (some) Old age (many) Pressure by in-laws (some)	Fear of divorce (frequent) Marital instability (not uncommon)

state politics (Handwerker, 2002). This last mentioned paper was based on interviews with infertile women in China, at a time and in an area where a strict one child policy in force. Seven studies included primary and secondary infertility (having been pregnant before), or people who had a child in the current or previous relationship. Two reports used the concept of self-defined infertility; that is the woman defines her situation as infertile, irrespective of the medical or social definitions (Kielman, 1998; Leonard, 2002). In two papers the term 'infertile' was used without there being sufficient information to decide whether or not this included women with children (Neff, 1994: Fido and Zahid, 2004).

Social effects

Community effects are mentioned in almost all reports (32). Stigma was mentioned the most (in 25 reports), while the highest intensity of community effects (isolation, rejection and exclusion) is mentioned in 14 reports. Status loss, social failure and no respect are also mentioned in 14 reports, as are ridicule and verbal abuse.

Economic and in-law effects are mentioned in most studies (21). In five of these, the effects concern the costs of infertility treatment, by either modern biomedicine or traditional medicine (e.g. healers or herbs). In 11 cases, economic insecurity is mentioned, for example no support in old age, receiving fewer gifts and less land, and having fewer relations. Harassment and feeling rejected by in-laws are mentioned in 15 reports, in four reports this was at the level of exploitation and abuse.

Legal and marriage effects were are reported in 26 of the reports. In five cases, the effects concerned inheritance restrictions and restricted burial rights. Many (21) of the reports mention marital instability, fear of divorce or fear of the husband taking an extra wife. Five of the reports state that husbands had actually taken a second wife. Divorce, expulsion from the home or physical abuse perpetrated by the husband is mentioned in 11 reports.

Religious and spiritual effects are mentioned in a few (8) of the reports. In two reports these had to do with the thoughts and feelings of the infertile person, namely fearing that pious duties could not be carried out after one's death. The other cases concerned accusations of witchcraft: diverse forms of witchcraft were mentioned five times, having the evil eye or being considered a person one had better not touch three times, and considered someone who brings illnesses and disasters to others in one paper (see figure 1).

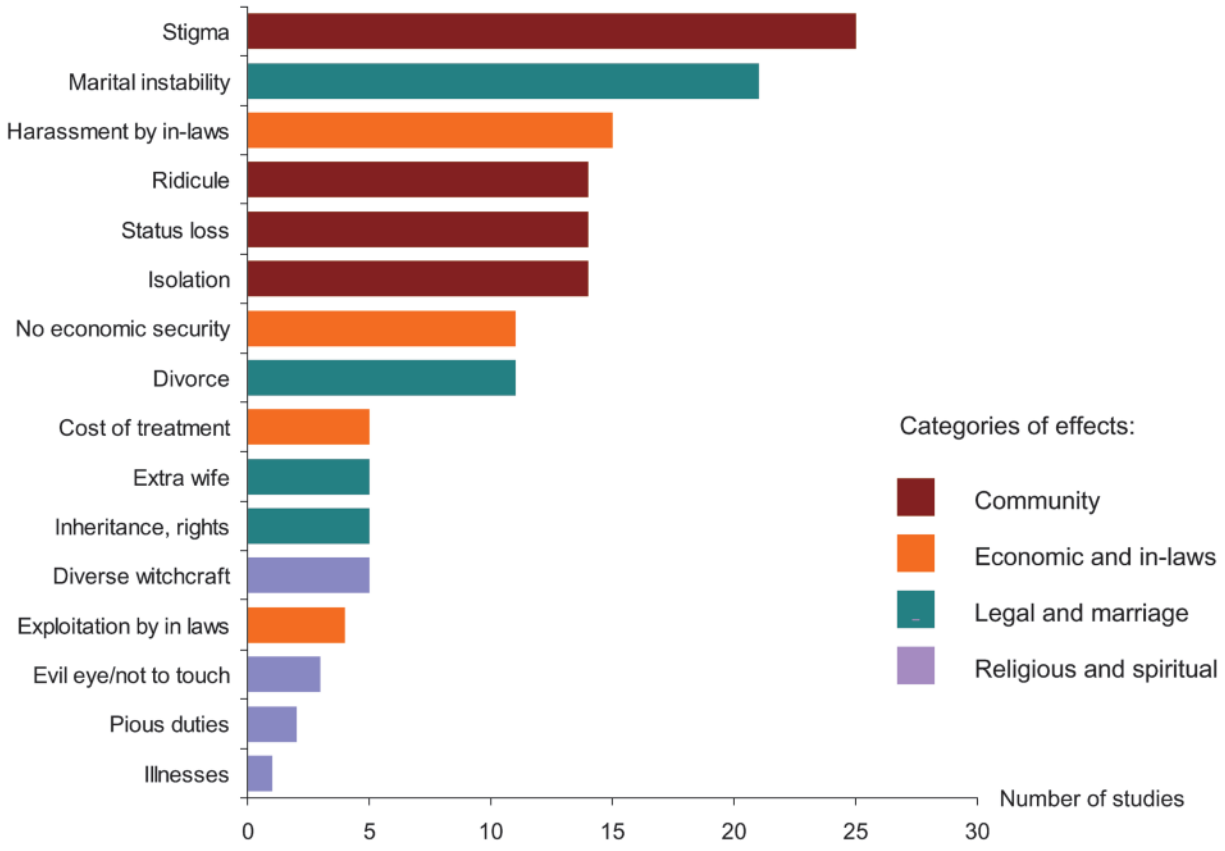

Fig. 1. — Number of studies in which diverse effects are mentioned

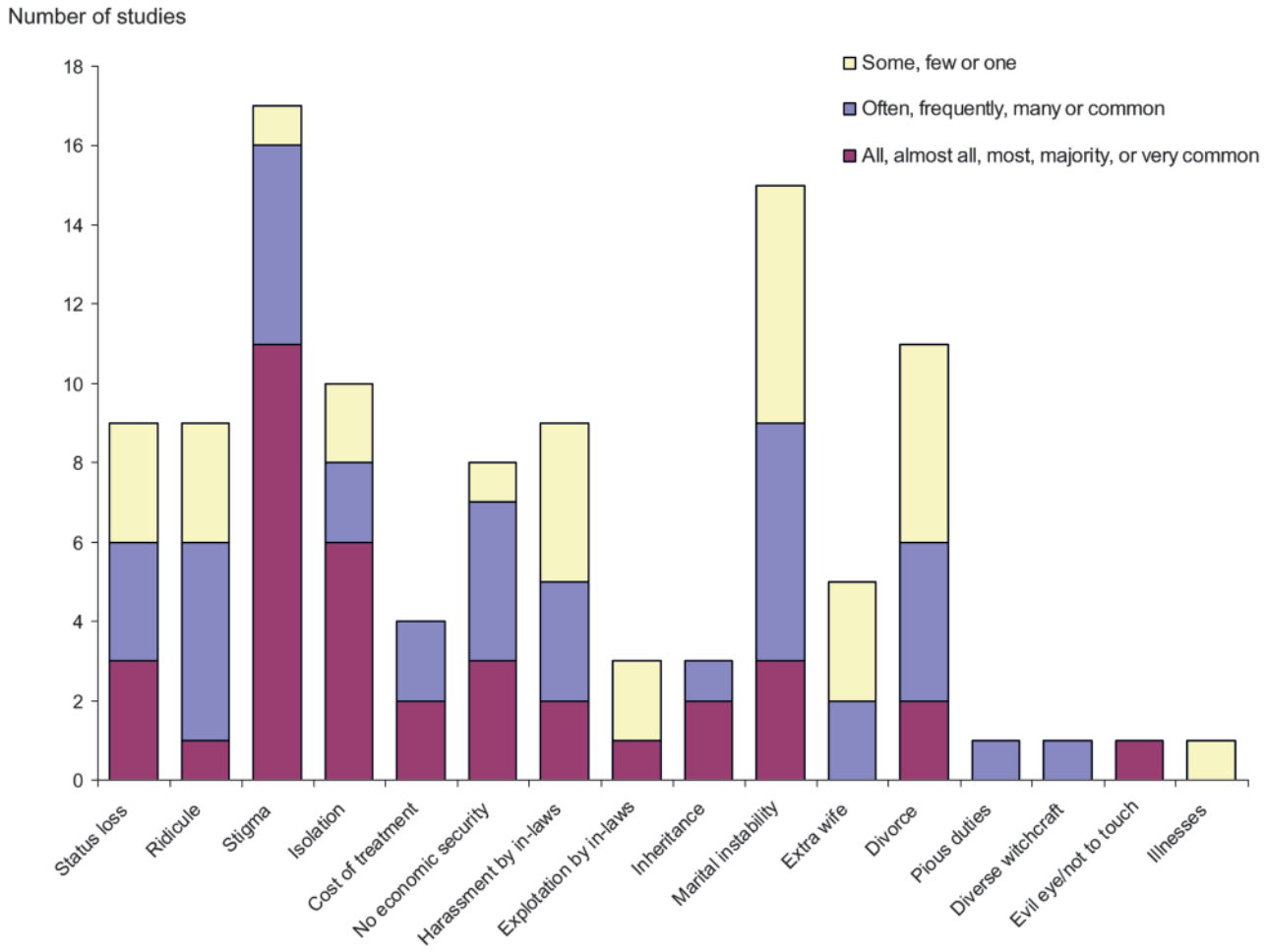

Fig. 2. — Frequency of effect if mentioned in studies

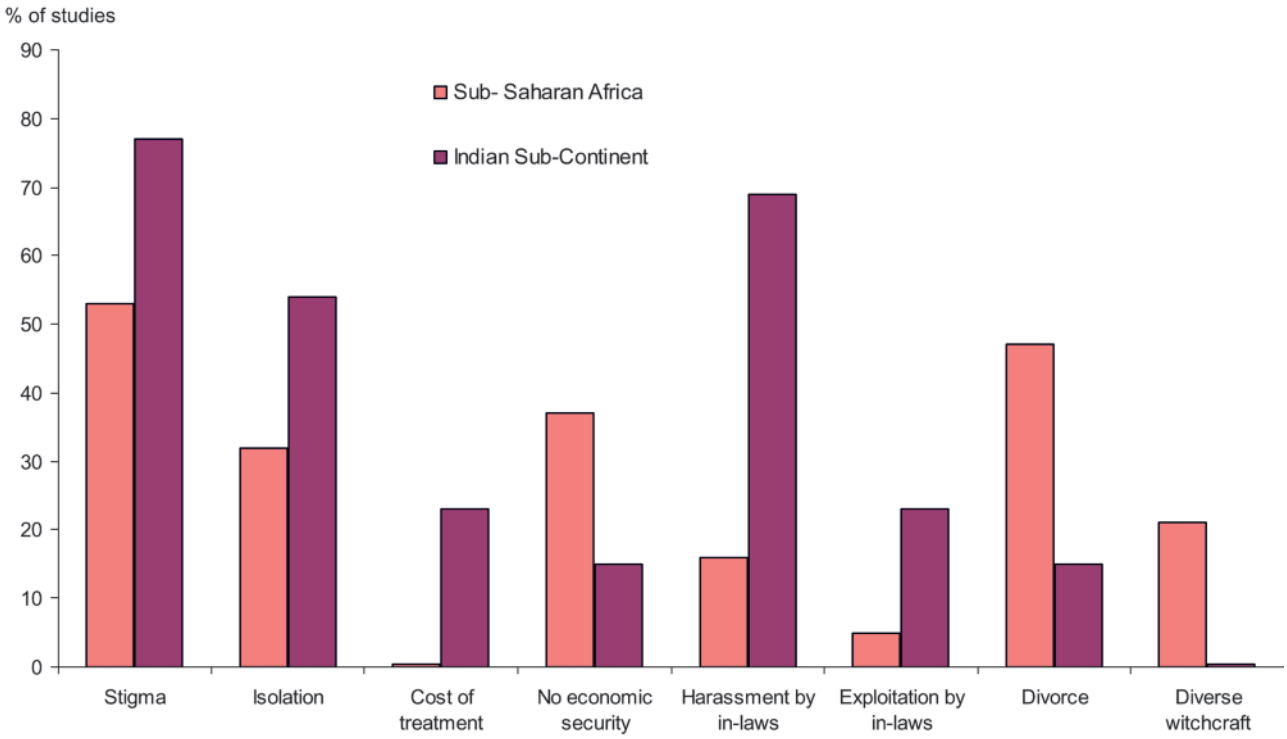

Fig. 3. — Comparison of Sub-Saharan Africa and Indian Sub-Continent: Percentages of studies in which effect is mentioned (effects with a differences of 20% and more are mentioned.

Frequency of incidence

The frequency of incidence of at least one of the social effects of being childless was indicated in 30 of the reports. More than half of these reports mention status loss and ridicule as happening frequently or always. The majority of the papers indicate that stigma and isolation are happening to most of the infertile persons. Several of the other social effects, such as no economic security, harassment by in-laws and marital instability were reported in about half of the papers as happening often. In the papers that mentioned the frequency in which husbands have actually taken a second wife or actually divorced their wives this was described in about equal numbers as happening in a few cases or happening often (see figure 2).

Comparison of sub-Saharan Africa and the Indian subcontinent

A comparison was made regarding the two regions in which most of the studies were carried out, namely sub-Saharan Africa (19 studies) and the Indian subcontinent (13 studies). The studies performed in the Indian subcontinent reported the most severe level of community effects (isolation) more frequently than the studies carried out in sub-Saharan Africa (54% vs 32%). Also, stigma was reported more often in the studies performed in the Indian subconinent compared to these in sub-Saharan Africa (77% vs 53%). Harassment (69% vs 16%) and exploitation (23% vs 5%) by in-laws were also reported much more in studies carried out in the Indian subcontinent compared to these performed in sub-Saharan Africa. On the other hand, actual divorce as a consequence of being childless was more frequently reported in sub-Saharan Africa than in the Indian subcontinent (47% vs 15%). Also a a lack of economic security was more often reported in the sub-Saharan studies compared to these in the Indian subcontinent (37% vs 15%) (see further figure 3).

Discussion

Over the last decade, a substantial number of papers have been published about the social consequences of being childless in poor resource areas. This subject is thus getting at least some of the attention that was promised in the action plan of the International Conference of Population and Development in Cairo (ICPD, 1994), which for the first time included infertility care in its goals for reproductive health. However, it is remarkable that most of the studies were carried out in sub-Saharan Africa and the Indian subcontinent. Almost no papers have been published about Latin America or North Africa and the Near East. The majority of the studies in sub-Saharan Africa were carried out by Western anthropologists. It can be speculated that sub-Saharan Africa is still a very accessible area for Western anthropological research, and this is helpful in publishing in international (English–language) journals. The studies performed in the Indian subcontinent were mostly undertaken by scientists indigenous to the area. In the Indian subcontinent, in contrast to many other areas, English is both still an official language and language that scientists use to communicate, which is an advantage as regards getting papers published in international journals. These factors may be partly responsible for the relatively large body of papers concerning the two areas that are published in international journals.

Regarding the few papers published about areas in North Africa and the Near East, one can speculate that the rather prominent separation between the world of men and that of women in many Arabian and Islamic areas might hamper research in this field, especially because of the difficulties in getting access to women in the home. Regarding the few studies carried out in Latin America, social consequences of childlessness might be less intense, because of the same cultural and economic forces that might explain the lack of serious social consequences in Western societies. Some cultural researchers state that Latin America has much in common with Western Europe and could possibly be considered a sub-civilization within Western civilization (Huntington, 1997) or is closely linked to Western culture and especially to that of Catholic Europe (Inglehart 1997).

The most frequently mentioned serious consequences of being childless are in the realm of community effects, in-law effects and effects on marriage. These severe effects concern almost exclusively women. This might be partly caused by still prevailing ideas that infertility is a woman's 'fault' or the denial of the existence of male infertility. It is remarkable that the most severe community effect, namely isolation and exclusion, is mentioned in ten reports. This situation creates an extremely difficult life for childless women, especially in communities in which people are well known to each other. But also stigma or being marginalized (mentioned in 24 reports), makes life very difficult in a village or quarter in which community life is the centre of most human interactions. The reactions of in-laws, and especially the mother in-law, also make childlessness difficult to bear: harassment and rejection by in-laws is reported in 14 studies, while exploitation of the childless woman by the in-laws (husbands' family) is reported four times. In addition and often also

influenced by in-laws, childlessness may lead to marital instability as described in 20 reports. Five reports state that husbands have actually taken another wife, and 11 state that husbands have divorced their childless wives. These effects on marriage are not so different from those reported by a recent study among elderly involuntary childless women done in the West (Wirtberg *et al.*, 2007). However, positive marriage effects have regularly been reported in studies in Western countries on couples in treatment or during reproductive life (Van Keep *et al.*, 1973; Callan, 1987; Baram *et al.*, 1988; Schmidt *et al.*, 2005). These effects are supposed to be associated with the shared experience of husband and wife of having to adapt to infertility and treatment. In contrast to marriage effects, accusations of witchcraft, including having the evil eye or being responsible for illness, are not mentioned very often (six studies) but this may indicate that community members try to avoid and exclude childless women as much as possible.

In studies carried out in the Indian subcontinent, community effects and especially in-law effects are reported more often than in studies performed in sub-Saharan Africa. This might be explained by the possibly greater importance of in-laws in the lives of married women and their nuclear families, in the areas were the studies have been carried out. Actual divorce is mentioned more in the sub-Saharan studies. Here, a role may be played by local customs related to marriage and divorce that makes dissolution of the marriage easier and more common. However, in describing these differences it is necessary to remark that there are of course large differences in cultural and economic circumstances within both these parts of the world, and this makes overall conclusions very preliminary and rather imprecise. This applies especially to the comparison between sub-Saharan Africa and the Indian subcontinent.

A considerable number of the studies were limited in focus and did not take into consideration all discerned types of social effects, thus effects might be unreported or under-reported. Some of the studies included research among childless persons as well as among women and men who already had a child. Assuming that the effects of not having a child at all are greater than the effects of not being able to have another child, there might be also under-reporting on severity of effects. Furthermore there are some considerable uncertainties in the reports that make the results difficult to interpreter. Some of the studies did not report very well on the numbers of respondents or the frequency of effects. Social effects were sometimes described without revealing the sources of this knowledge. In other cases, in which different methods for information gathering were used, it is not always clear on which source the various results were based. In addition, about half of the studies were based on samples of women or couples who were looking for treatment or were having treatment, and thus those who did not visit hospitals, clinics or other health-care centres were not included. According to the study by Boivin and colleagues (2007), this number might be about half of the infertile populations in the areas concerned.

Most studies were qualitative, used small samples and were very local. Although qualitative research is very useful in exploring new areas and new issues, quantative studies could help to corroborate the findings. Moreover, it would allow for statistical analysis, in particular it would be possible to analyse the relationships between the social effects of childlessness and the socio-economic and cultural variables.

Of course, whether or not one has a child is not the only factor that influences one's status and one's well-being; for instance, Donkor and Sandall (2007) showed that infertile women in Southern Ghana with a relatively high status in the community that is derived from other factors (e.g. education), were less stigmatized than other infertile women. Nahar (2007) also described that childless women from poor rural families suffered much more than childless women from the urban middle class in Dacca. Also, Riessman (2000b) described a lesser ferquency of insults and ridicule among economically priviliged childless women than among poor childless women in rural Kerala.

In contrast to most Western studies on childlessness and infertility few studies in poor resource areas have focused on psychological effects. It might be expected that the often intense social consequences described above may exacerbate the psychological consequences (e.g. stress, anxiety, depression and health complaints) much more than in the West. Indeed, a study by Dyer (2005) into the psychological distress of infertile women in a local community of Cape Town showed that women who reported intense social effects (i.e. physical abuse perpetrated by their husbands) suffered considerably more stress than infertile women in non-abusive relationships.

Finally, it can be asked whether economic and social development will ameliorate the often immensely serious consequences of being childless. In the rich Western countries, these social effects are seldom found. It is possible that some of the economic consequences regarding for example, care in old age and lack of economic security will diminish as economies develop further. Couples will be much less dependent on their children for their income. In Western countries, on a lifetime basis children cost more than they deliver. Economists have calculated that in the West a woman who has children will earn about EUR

100,000 less than a woman who does not have children (Mertens *et al.*, 1995; Pott-Butter, 1997). The Dutch 'household budget' institute recently stated that one child costs about 17% of the mean annual family income, and two children about 26% (Nibud, 2009). Across the Atlantic, the US Department of Agriculture stated in an Internet release that to raise a child to the age of 17 costs USD 150,000-300,000, depending on the family's social class (USDA News Release 0023.09). It might be argued that also in developing areas the balance between earnings and costs of having children is changing, because in the last decades the mean number of children per couple in many developing areas has decreased dramatically, especially in Asia, North Africa and the Near East (Population Studies, website 2009). Associated with this it appears that the nuclear family is becoming more and more the ideal family form (Pashigian, 2002; Nahar 2008), which may result in less influence from in-laws, and consequently less harassment by them. Improvements and developments in schooling that lead to more knowledge and information about the causes of infertility may mitigate the negative views of people in the community towards people who do not succeed in having a child and especially towards the end of blaming women for infertility. In this respect, active resilience among some of the childless women as described by Riessman (2000b) and by Nahar (2007) may help to diminish discriminatory behaviour. However, in many areas of the world there is still a pronatalist culture in which, besides the marginalization of involuntarily childless couples, the phenomenon of being voluntarily childless or postponing of having children is not well received (Feldman-Savelsberger, 2002; van Balen and Inhorn, 2002; Kagitbasi and Ataca, 2005). The social acceptance of couples who do not want to have children may be a sign of the disappearance of the stigmatization of being childless. Childless couples will probably continue to suffer negative social consequences as long as under the prevailing cultural forces they are considered less worthy than other couples.

References

Apte H, Mali L, Navle M, Revle S. Womanhood first: sex workers and infertility in Pune city. J Reprod Infant Psychol. 2004;22:271-8.

Baram D, Tourtelot E, Maecher E, Ko-Fen H. Psychosocial adjustment following unsuccesfull in vitro fertilization. J Psychosom Obst Gyn. 1988;9:191-198.

Bharadwaj A. Infertility and gender: a perspective from India. In: Van Balen F, Gerrits T and Inhorn M (eds). Social science research on childlessness in a global perspective. University of Amsterdam, Amsterdam, the Netherlands 2000, 65-74.

Bhatti LI, Fikree FF, Khan A. The quest of infertile women in squatter settlements of Karachi, Pakistan: a qualitative study. Soc Sci Med. 1999;49:637-49.

Boivin J, Bunting L, Collins JA, Nygren KG. International estimates of infertility prevalence and treatment-seeking: potential need and demand for infertility medical care. Hum Reprod. 2007;22:1506-12.

Boonmongkon. Living through infertility: from loss to resolution of the life course of Thai women. In: Van Balen F, Gerrits T and Inhorn M. (eds). Social science research on childlessness in a global perspective. University of Amsterdam, Amsterdam, the Netherlands 2000, 28-34.

Bos HMW, Van Balen F, Visser A. Social and cultural factors in infertility and childessness. Patient Educ Counsel. 2006;59: 223-225.

Brkovich AM, Fisher WA. Psychological distress and infertility: Forty years of research. J Psychosom Obst Gyn. 1998;19: 218-28.

Callan VJ. The personal and marital adjustment of mothers and voluntary and involuntary childless wives. J Marr Fam. 1987;49:847-856.

Chapman E, Smith JA. Interpretative phenomenological analysis and new genes**.** J Health Psychol. 2002;7:125-30.

Denga DI. Childlessness and marital adjustment in Northern Nigeria. J Marriage Family. 1982;44:799-802.

Dyer SJ. Infertility in South Africa: women's reproductive health knowledge and treatment-seeking behavior for involuntary childlessness. Hum Reprod. 2002;17:1657-62.

Dyer SJ, Abrahams N, Hoffman M, Van der Spuy ZM. Men leave me as I cannot have children": women's experiences with involuntary childlessness. Hum Reprod. 2002;17: 1663-8.

Dyer SJ, Abrahams N, Mokoena NE, Van der Spuy ZM. You are a man because you have children": experience, reproductive health knowledge and treatment-seeking behaviour among men suffering from couple infertility in South Africa. Hum Reprod. 2004;19:960-7.

Dyer SJ, Abrahams N, Mokoena NE, Lombard CJL, Van der Spuy ZM. Psychological distress among women suffering from couple infertility in South Africa: a quantitative assessment. Hum Reprod. 2005;20:1938-43.

Donkor ES, Sandall J. The impact of perceived stigma and mediating social factors on infertility-related stress among women seeking infertility treatment in Southern Ghana. Soc Sci Med. 2007;65:1683-94.

Feldman-Savelsberg P. Is infertility an unrecognized public health and population problem? The view from the Cameroon Grassfields. In: Inhorn MC and Van Balen F (ed). Infertility around the globe. New thinking on childlessness, gender, and reproductive technologies. UCLA-press, Berkeley, LA, USA 2002, 215-32.

Fido M, Zahid MA. Coping with infertility among Kuwaiti women: cultural perspectives. International J Soc Psychiatry. 2004;50:294-300.

Gerrits T. Social and cultural aspects of infertility in Mozambique. Patient Educ Counsel. 1997;31:39-48.

Gerrits T (2002) Infertility and matrilineality: the exceptional case of the Macua of Mozambique. In: Inhorn MC and Van Balen F (ed). Infertility around the globe. New thinking on childlessness, gender, and reproductive technologies. UCLA-press, Berkeley, LA, USA 2002, 222-46.

Gijsels M, Mgalla Z, Wambura L. No child to send: context and consequences of female infertility in northwestern Tanzania. In: Boerma JT and Mgalla Z (eds). Women and infertility in sub-Saharan Africa: a multi-disciplinary perspective. Royal Tropical Institute, Amsterdam, the Netherlands 2001, 203-22.

Greil AL. Not yet pregnant, infertile couples in contemporary America. Rutgers University Press, New Brunswick, USA 1991.

Greil AL. Infertility and psychological distress: A critical review of the literature. Soc Sci Med. 1997;11:1506-12.

Handwerker L. The politics of making modern babies in China: reproductive technologies and the new eugenics. In: Inhorn MC and Van Balen F (eds). Infertility around the globe, new

thinking on childlessness, gender and reproductive technologies. UCLA-press, Berkeley, Los Angeles, USA 2002, 298-314.
Hollos M. Profiles of infertility in Southern Niheria: women's voices from Amakiri. Afr J Reprod Health. 2003;7:46-56.
Hollos M, Larsen U. Motherhood in sub-Saharan Africa: the social consequences of infertility in an urban population in northern Tanzania. Cult Health Sex. 2008;10:159-73.
Hörbst V. Male infertility in Mali, kinship and impacts on biomedical practice in Bamako. In: Brockopp J and Eich T (eds). Muslim ethis; theory and practice. South Caroline University Press, South Caroline, USA 2008, 118-37.
Huntington SP. The clash of civilizations and the remaking of the world order. Simon and Schuster, New York, USA 1997.
ICPD. ICPD Plan of Action. UNICPD secretariat, New York, USA 1994.
Inglehart R. Modernization and postmodernization. Princeton University Press, Princeton, USA 1997.
Inhorn MC. Quest for conception, gender, infertility and Egyptian medical traditions. University of Pennsylvenia Press, Philadelphia, USA 1994.
Jenkins GL. Childlessness, adoption, and Milagros de Dios in Costa Rica. In: Inhorn MC and Van Balen F (eds). Infertility around the globe, new thinking on childlessness, gender and reproductive technologies. UCLA-press, Berkeley, Los Angeles, USA 2002, 171-90.
Johnson JW. In home care for frail childless adults: getting by with a little help from their friends? Urban Institute, Washington, USA 2996.
Kagitcibasi C, Ataca B. Value of children and family change: a three-decade portrait from Turkey. Appl Psychol Int Rev. 2005;54:317-37.
Kielman K. Barren ground: contesting identities of infertile women in Pemba, Tanzania. In: Lock M and Kaufert PA (eds). Pragmatic women and body poltics. Cambridge University Press, Cambridge, UK 1998, 127-63.
Koster-Oyekan W. Infertility among Yoruba women: percepetions on causes, treatments and consequences. Afr J Reprod Health. 1999;3:13-26.
Leonard L. Problematizing fertility: "scientific" accounts of Chadian women's narratives. In: Inhorn MC and Van Balen F (eds). Infertility around the globe, new thinking on childlessness, gender and reproductive technologies. UCLA-press, Berkeley, Los Angeles, USA 2002, 215-32.
Mariano E. Conceptions about woman's childlessness and land's infertility in a Rhonga community in the South of Mozambique. In: Van Balen F, Gerrits T and Inhorn M (eds). Social science reearch on childlessness in a global perspective. University of Amsterdam, Amsterdam, the Netherlands 2000, 136-39.
Mariano E. Involuntary childlessness among the Shangana (Mozambique). J Reprod Infant Psychol. 2004;22:261-70.
Meera Guntupalli A, Chenchlgudem P. Perceptions, causes and consequences of infertility among the Chenchu tribe of India. J Reprod Infant Psychol. 2004;22:249-60.
Mertens N, Schippers J, Siegers J. Career interruptions and women's life-time earnings. Europ J Women's Stud. 1995; 2:469-91.
Meyer B. Satan, slangen en geld: bekentenissen over duivelse rijkdom in christelijk Ghana (Satan, snakes and money: confessions about devilish richness in christian Ghana). In: Driessen H and De Jonge H (eds). In de ban van betekenis, proeven van symbolische antropologie (Under the spell of meaning, essays of symbolic anthropology). SUN, Nijmegen, the Netherlands 1994, 170-97.
Mulgaonkar V. Treatment seeking behaviour of childless couples in the slums of Mumbai. In: Van Balen F, Gerrits T and Inhorn M (eds). Social science reearch on childlessness in a global perspective. University of Amsterdam, Amsterdam, the Netherlands 2000a, 95-101.
Mulgaonkar V. A research and an intervention programma on women's reproductive health in slums of Mumbai. Sujeevan Trust, Mumbai, India 2000b.
Nahar P, Sharma A, Sabin K, Begum L, Ahsan SK, Baqui AH. Living with infertility: experiences among urban slum populations in Bangladesh. Reprod Health Matters, 2000;8: 33-44.
Nahar P. Childlessness in Bangladesh, suffering and resilience among rural and urban women. University of Amsterdam, Amsterdam, the Netherlands 2007.
Neff DL. The social construction of infertility: The case of the matrilineal Nayars in South India. Soc Sci Med. 1994;39: 475-85.
Nene UA, Covaji K, Apte H. Infertility: a label of choice in the case of sexual dysfunctional couples. Patient Educ Counsel, 2005;59:234-8.
NIBUD Nationaal Instituut voor Budgetvoorlichting. Hoeveel kost uw kind? (How much costs your child). Downloaded http://www.nibud.nl/uitgaven/kinderen/kosten-van-kinderen.html at 3-6-2009.
Okonofua F, Harris D, Odebiyi A, Kane T, Snow RC. The social meaning of infertility in Southwest Nigeria. Health Transition Rev. 1997;7:205-20.
Pashigian MJ. Infertility and the politics of marriage in Northern Vietnam. In: Van Balen F, Gerrits T and Inhorn M (eds). Social science research on childlessness in a global perspective. University of Amsterdam, Amsterdam, the Netherlands 2000, 127-8.
Pashigian MJ. Conceiving the happy family, infertility and marital politics in Northern Vietnam. In: Inhorn MC and Van Balen F (eds). Infertility around the globe, new thinking on childlessness, gender and reproductive technologies. UCLA-press, Berkeley, Los Angeles, USA 2002, 134-51.
Pearce TO. She will not be listened to in public. Perceptions among the Yoruba of infertility and childlessness in women. Reprod Health Matters. 1999;13:69-79.
Pott-Butter. Uitgesteld ouderschap: wiens keus, wiens kosten (Late parenthood, choices and costs). In Beets G, Bouwens A and Schippers J (eds) Uitgesteld ouderschap (Late parenthood). Thesis, Amsterdam, the Netherlands 1997.
Riessman C. Positioning gender identity in narratives of infertility: South Indiam women's lives in context. In: Van Balen F, Gerrits T and Inhorn M (eds). Social science research on childlessness in a global perspective. University of Amsterdam, Amsterdam, the Netherlands 2000a, 35-43.
Riessman C. Stigma and everyday resistance practices, childless women in South India. Gender Society, 2000b;14:111-35.
Riessman CK. Positioning gender identity in narratives of infertility: South Indian women's lives in context. In: Inhorn MC and Van Balen F (eds). Infertility around the globe, new thinking on childlessness, gender and reproductive technologies. UCLA-press, Berkeley, Los Angeles, USA 2002, 152-70.
Schmidt L, Holstein B, Christensen U, Boivin J. Does infertility cause marital benefit? An epidemiological study of 2250 women and men in fertility treatment. Patient Educ Counsel. 2005;59:244-251.
Schmidt L. Social and psychological consequences of infertility and assisted reproduction – what are the research priorities? Hum Fert. 2009;12:14-20.
Smith JA, Osborn M. Interpretative phenomenological analysis. British Psychological Society, Leicester, England 2004.
Sundby J. Infertility in the Gambia: traditional and modern health care. Patient Educ Couns. 1997;31:29-37.
Sundby J, Mboge R, Sonko S. Infertility in the Gambia: frequency and health care seeking. Soc Sci Med. 1998;46: 891-9.
Unisa S. Childlessness in Andhra Pradesh, India: treatment-seeking and consequences. Reprod Health Matters. 1999; 7:54-64.

Upton RL. 'Infertility makes you invisible': gender, health and the negotation of fertility in Northern Botswana. J South Afr Stud. 2001;27:349-62.
USDA United States Departement of Agriculture. News release no. 0023.09. Downloaded from http://www.usda.gov/wps/portal/usdahome on 10-06-2009.
Van Balen F. Een leven zonder kinderen, ongewilde kinderloosheid: beleving, stress en aanpassing. (A life without children, involuntary childlessness: experience, stress and adaptation). Dekker & van de Vegt, Assen, the Netherlands 1991.
Van Balen F, Trimbos-Kemper T, Verdurmen J. Perception of diagnosis and openness of patients about infertility. Patient Educ Counsel. 1996;28:247-52.
Van Balen F, Inhorn MC. Interpreting infertility a view from the social sciences. In: Inhorn MC and Van Balen F (eds). Infertility around the globe, new thinking on childlessness, gender and reproductive technologies. UCLA-press, Berkeley, Los Angeles, USA 2002, 3-32.
Van Keep PA. The involuntary sterile couple. World Health Foundation, Geneva, Switzerland 1973.
Wenger GC, Dykstra PA, Melkas T, Knipscheer KCPM. Social embeddedness and late-life parenthood, community activity, close ties and support networks. J Fam Issues. 2009;28:1419-56.
Widge A. Seeking conception: experiences of urban Indian women with in vitro fertilization. Patient Educ Counsel. 2005;59:226-33.
Wiersema NJ, Drukker AJ, Tien Dung MB, Hyunh Nu G, Than Nhu N, Lambalk CB. Consequences of infertility in developing countries: results of a questionnaire and interview survey in the South of Vietnam. J Translational Med. 2006;4:54-62.
Wirtberg I, Moller A, Hogstrom L, Tronstad S-E, Lalos A. Life 20 years after unsuccessful infertility treatment. Hum Reprod. 2007;22:598-604.

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

Silke J. Dyer[1], Guido Pennings[2]

[1]*Department of Obstetrics and Gynaecology, Faculty of Health Sciences, University of Cape Town, South Africa.*
[2]*Bioethics Institute Ghent, Ghent University, Belgium.*

Correspondence at: Silke.Dyer@uct.ac.za

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

Introduction

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

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

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

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

Psychosocial consequences of infertility

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

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

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

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

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

Lastly, infertility may impact on funeral rites, which are highly regarded in most societies but especially in some developing countries. Examples for the lost dignity in death (level 6) include among others the burial of infertile bodies outside community land (in the belief that these bodies may reduce the fertility of the soil), and burial with a marker to inform gods or ancestors of the unproductive status of the dead (Leonard, 2002; Hollos, 2003; Mariano, 2004).

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

Measuring the burden of infertility

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

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

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

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

Infertility treatment competes not only with other diseases for public money but also with infertility prevention. Generally speaking, prevention should have priority (Ombelet, 2008; ESHRE Taskforce on Ethics and Law, 2009). The main reasons in favour of prevention are that prevention is less expensive and benefits a greater number of people and that the measures used to prevent infertility simultaneously improve the health status of women. Access to maternity care and safe abortions, for example, contribute to the prevention of infertility and secure other rights of women such as reproductive health and family planning. However, this is not an all or nothing debate. There are very good reasons to reserve at least some money for treatment, especially when this is low cost treatment (Pennings, 2008). The main argument here is that sick people normally have priority on healthy people based on medical need. The plight of people who already attracted a disease or became infertile should not be ignored or dismissed. In the rest of this paper, we will look at some problems arising when this is accepted.

ART in low-resource settings

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

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

Prioritizing infertile patients for treatment

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

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

A second criterion for selection is chance of success. In circumstances of relative wealth, every person should have equal access to medical treatment. In times of great scarcity, however, the rules may have to be adapted in order to increase the total benefit and to improve efficiency. In such circumstances, 'wartime triage' may be applied, whereby the people who have the lowest chance of becoming pregnant are excluded (Rhodes *et al.*, 1992). An alternative is a threshold system which tries to find a compromise between the principle of justice (the equality of opportunity) and the principle of utility (the maximisation of outcome in terms of pregnancies) (Pennings, 2001). The trade-off includes two steps: firstly, the minimal threshold of success is determined. Secondly, no interpersonal comparisons of success are made above that threshold. The biggest problem, obviously, is to determine how small the chance of success should be to deny access to treatment.

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

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

Summary

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

References

Ali TS, Bustamante-Gavino I. Prevalence of and reasons for domestic violence among women from low socioeconomic communities in Karachi. East Med Health J. 2007;13: 1417-26.

Ameh N, Kene TS, Onuh SO *et al.* Burden of domestic violence amongst infertile women attending infertility clinics in Nigeria. Nig J Med. 2007;16(4):375-7.

Chachamovich JR, Chachamovich E, Zachia S *et al.* What variables predict generic and health-related quality of life in a sample of Brazilian women experiencing infertility? Hum Reprod. 2007;22(7):1946-52.

Collins JA. An international survey of the health economics of IVF and ICSI. Hum Reprod Update. 2002;8(3):265-77.

Daar AS, Merali Z. Infertility and social suffering: The case of ART in developing countries. In Vayena E, Rowe PJ and Griffin PD (eds) Current Practices and Controversies in Assisted Reproduction. World Health Organization, Geneva 2002, 15-21.

Devlin N, Parkin D. Funding fertility: issues in the allocation and distribution of resources to assisted reproductive technologies. Hum Fertility. 2003;6: S2-S6.

Dyer SJ, Abrahams N, Hoffman M *et al.* Men leave me as I cannot have children: women's experiences with involuntary childlessness. Hum Reprod. 2002;17:1663-8.

Dyer, SJ. The value of children in African countries – insights from studies on infertility. J Psychosom Obstet Gynaecol. 2007;28: 69-77.

ESHRE Taskforce on Ethics and Law including Pennings G, de Wert G, Shenfield F *et al.*. Equity of access to assisted reproductive technology. Hum Reprod. 2008;23(4):772-4.

ESHRE Taskforce on Ethics and Law including Pennings G, de Wert G, Shenfield F *et al.* Providing infertility treatment in resource-poor countries. Hum Reprod. 2009;24:1008-11.

Favot I, Ngalula J, Mgalla Z *et al*. HIV infection and sexual behaviour among women with infertility in Tanzania: a hospital-based study. Int J Epidemiol. 1997;26(2):414-9.

Gerrits T. Social and cultural aspects of infertility in Mozambique. Patient Educ Couns. 1997;31(1):39-48.

Hollos M. Profiles of infertility in southern Nigeria: women's voices from Amakiri. Afr J Reprod Health. 2003;7(2):46-56.

Ikechebelu JI, Ikegwuonu SC, Joe-Ikechebelu NN. HIV infection and sexual behaviour among infertile women in south-eastern Nigeria. J Obstet Gynaecol. 2002;22(3):306-7

Inhorn MC, Buss KA. Infertility, infection, and iatrogenesis in Egypt: the anthropological epidemiology of blocked tubes. Med Anthropol. 1993;15(3): 217-44.

Inhorn M. Right to assisted reproductive technology: Overcoming infertility in low-resource countries. Int J Gynecol Obstet. 2009;106:172-4.

International Committee for Monitoring Assisted Reproductive Technology (ICMART):de Mouzon J, Lancaster P, Nygren KG *et al.* World Collaborative Report on Assisted Reproductive Technology, 2002. Hum Reprod. 2009;1(2):1–11.

Jelsma J, Chivaura VG, Mhundwa K *et al.* The global burden of disease disability weights. Lancey.2000;355:2079-80.

Leonard L. "Looking for children": the search for fertility among the Sara of southern Chad. Med Anthropol. 2002;21(1):79-112.

Mariano EC. Involuntary childlessness among the Shangana (Mozambique). J Reprod Infant Psychol. 2004;22(4):261-9.

Ombelet W. False perceptions and common misunderstandings surrounding the subject of infertility in developing countries. Hum Reprod. 2008; Monograph:8-11.

Orhue A, Aziken M. Experience with a comprehensive university hospital-based infertility program in Nigeria. Int J Gynecol Obstet. 2008;101:11-5.

Pennings G. Postmenopausal women and the right of access to oocyte donation. J Applied Phil. 2001;18(2):171-81.

Pennings G. The physician as an accessory in the parental project of HIV positive people. J Med Ethics. 2003;29: 321-4.

Pennings G. Ethical issues of infertility treatment in developing countries. Hum Reprod. 2008; Monograph:15-20.

Ragni G, Mosconi P, Baldini MP *et al.* Health-related quality of life and need for IVF in 1000 Italian infertile couples. Hum Reprod. 2005;20(5):1286-91.

Rhodes R, Miller C, Schwartz M. Transplant recipient selection: peacetime vs wartime triage. Cambridge Quarterly of Healthcare Ethics. 1992; 4:327-31.

Russel S. Ability to pay for health care: concepts and evidence. Health Policy Planning. 1996;11(3):210-37.

Shukla GD, Verma BI, Mishra DN. Suicide in Jhansi City. Indian J Psychiat. 1990;32(1):44-51.

Van Balen F, Trimbos-Kemper TCM. Factors influencing the well-being of long-term infertile couples. J Psychosom Obstet Gynecol. 1994;15:157-64.

Van Balen F, Gerrits T. Quality of infertility care in poor-resource areas and the introduction of new reproductive technologies. Hum Reprod. 2001; 16(2):215-9.

Van Balen F, Bos HMW. The social and cultural consequences of being childless in poor-resource areas. F,V&V in ObGyn.2009;1(2):106-21.

Van Zandvoort H, de Koning K, Gerrits T. Viewpoint: medical infertility care in low income countries: the case for concern in policy and practice. Trop Med Int Health. 2001; 6(7): 563-9.

Widge A. Seeking conception: experiences of urban Indian women with in vitro fertilization. Pat Educ Counsel. 2005;59:226-33.

Male perspectives on infertility and assisted reproductive technologies (ART) in sub-Saharan contexts

Viola Hörbst

Centro de Estudos Africanos (CEA-ISCTE-IUL), Av. das Forcas Armadas, 1469-026 Lisboa, Portugal.

Correspondence at: viola.hoerbst@iscte.pt

Abstract

To date social science studies on male views of infertility in developing countries are rare. Concerning treatment seeking, literature assessing men´s behaviour from a biomedical point of view underlines bad male compliance with diagnosis and treatment, particularly if men are assumed to be the reason for unwanted childlessness. Summarizing the results of an anthropological research project on infertility and ART in Mali with regard to men this article shows that infertility is a complex problem configuration. Various factors such as the prevailing popular narrative to blame women for involuntary childlessness, alternative social solutions (polygyny), the double threat of demasculisation by male factor infertility and the reproductive aim to continue the patrilineage prefigure which options seem better or worse for men. Given this Malian background, on the one hand, biomedical infertility care renders men vulnerable for public disgrace due to possible evidence of male infertility causes, and thus block avenues for social solutions. On the other hand, biomedical means especially ART increase hope for own biological children, but the outcome of these cost intensive options even if available are not at all certain. In such situations men may prefer not to be involved in biomedical treatments at all and to hide behind the stigmatization of their wives, in order to avoid the risk of being exposed to public disgrace and double demasculinisation in terms of sexuality and of authority over women.

Key words: Infertility, male infertility, assisted reproductive technologies, sub-Saharan Africa, Mali.

Introduction

Most developing countries are pro-natalist societies, where children are a necessity in order to be acknowledged as a full social adult being (van Balen, 2008). Infertility and childlessness are often looked at as a predominantly female problem. Yet, scarce literature on male infertility in developing countries shows that not only women, but also men are in need of own (marital legal) offspring to proof their bodily capacity to produce children and thus their manhood (Dyer *et al.*, 2004; Hadolt and Hörbst, 2009). In addition, both women and men need children for various other reasons, such as to support them when they are old and/or sick, to provide them with persons of confidence and trust and in order to guarantee the continuity of their family lineage (Inhorn and van Balen, 2002; Gerrits 1997).

To date social science studies on male infertility in developing countries, including studies on male perspectives, their experiences of their wives infertility and/or of male factor infertility, are rare (for exceptions see e.g. Dyer *et al.*, 2004; Hörbst, 2008). Yet, a number of other studies, while not focusing on male infertility per se, have provided preliminary insights into the meaning and implications of infertility for men in various socio-cultural contexts and into the ways men are involved in seeking a solution for a couple's fertility problem (Bharadwaj, 2000; Bhatti *et al.*, 1999; Gerrits, 1997, 2002; Gerrits *et al.*, 1999; Inhorn, 1994, 2003, 2005, 2006; Mgalla and Boerma 2001; Nahar *et al.*, 2000; Nahar, 2007; Schuster and Hörbst, 2006, 2009; Sundby, 1997).

Literature emphasizes that main stream public narratives predominantly blame women for involuntary marital childlessness, while they hardly acknowledge male factor infertility (Sundby *et al.*, 1998; Nahar *et al.*, 2000; Nahar, 2007). Subsequently, the major and public part of the devastating infertility drama has to be shouldered by women, in terms of social ostracism, stigmatization, and social exclusion. Only few studies have shown that childless men are not treated equally like men with children and may suffer stigmatization and loss of

social status as well (Dyer *et al.*, 2004; Gerrits *et al.*, 1999; Hörbst, 2008; Inhorn, 1994; Mgalla and Boerma, 2001; Nahar *et al.*, 2000; Yebei, 2000).

Concerning treatment seeking, both in traditional and biomedical health care settings, women are found to bear the major part of the burden as well (see e.g. Inhorn, 1994; Gerrits, 1997; Nahar *et al.*, 2000; Nahar, 2007). Studies which assess men's behaviour from a biomedical point of view, underline the problem of bad male compliance with biomedical diagnosis and treatment, above all if men are assumed to be the reason for unwanted childlessness of the couple (Sundby *et al.*, 1998; Bhatti *et al.*, 1999). In particular, men are found not to be willing to hand in their semen for analysis, and in some cases this has to do with men's resistance to 'produce' semen by masturbation (see e.g. Dyer *et al.*, 2004). From the biomedical point of view, when thinking of setting up comprehensive infertility care in developing countries, major questions of concerns are threefold, namely: How to get men of infertile couples into the hospital? How to get them being diagnosed? How to get them to follow and support the treatment?

In this article I will summarize some of the findings on men`s perspectives from a long-term anthropological research on infertility and assisted reproductive technologies in the capital of Mali, Bamako[1]. From an anthropological point of view the problem of infertility has to be seen as complex problem configuration, where various socio-cultural and structural factors impact on what seems to be a better or a worse solution for men. This background serves as a basis to turn around the above noted questions and to analyse the situation along two alternative ones: What is at stake for men with regard to female or male factor infertility, what can biomedical treatments (including ART) offer to men and which avenues for solutions do such diagnostics constrain for men?

Infertility in Mali – a multiple problem configuration

To get children in Mali is a self-evident part of the anticipated biography and is neither for women nor for men a question of individual decision. The necessity to have children does not only derive from the couple or the single partners but also from the extended family as well as from society as a whole. After marriage the social pressure to procreate is high and if children fail to appear, first and foremost women are made responsible – due to the prevailing popular narrative in Bamako which blames women to be the cause of infertility. Although biomedical knowledge on male causes for infertility is increasingly disseminated through national and accessible international media, male factor infertility causing marital childlessness is hided from the public; it is equated with a source of shame and disgrace for a man. In consequence, foremost women are stigmatized to different degrees from members of their husband's extended families, but also from the wider social surrounding (neighbours and peers), e.g. at the frequently held baptisms and marriage ceremonies. To avoid shame, to maintain and to increase personal prestige are attributes highly valued by Malian men. In order to achieve these aims, they have to be treated with respect by other men and particularly by women. Children are essential for being acknowledged as a full social adult within Malian society – a quality which is predominantly connected to proof the bodily capacity to make children (Hadolt and Hörbst, 2009). The lack of children, as the socially visible sign of sexual capacity, is easily equated with impotence. Moreover, sexual potency and procreative ability are core factors for male authority over women (and other men). If children are missing, the respectful behaviour of women is endangered, too. To be taken for impotent and losing the authority over women equates a double threat for masculinity. Given this background, sub- or infertile men affirmed that they have no sexual problems and that no one in their social environment dares to insinuate them with regard to their or their wives` "infertility". Friends might tease them or make allusions such as "when will we go to a baptism in your house" or bother them with recommendations to marry another wife. The infertile diagnosed men stated that they enjoy enough respectability and authority in order to silence these voices quickly. Only a few men disclosed singular and shameful events to me, in which their family members or neighbours dared to directly accuse them as being the cause of their marital childlessness. The mainstream narrative which blames women in combination with men`s higher position seems to shield men (at least in many cases) from being suspected or even accused for male-factor infertility. Nevertheless, some also told me that their

[1] The field research in 2004 and 2005 was financed by a scholarship from the women's representative at Ludwig-Maximilians-University in Munich within the *University and Science Program (Hochschul- und Wissenschaftsprogramm)* and completed by a donation from the *Friends of the Ludwig-Maximilian-University of Munich (Freunde der LMU München).* The research from 2006 until 2008 was financed by the German Research Foundation (DFG) . I want to thank these three institutions as well as those people who worked for me during these research periods. Last not least I am most grateful to all women, men, institutions and practitioners, with whom I worked during my research in Bamako and partially Dakar and Lomé.

marital childlessness stopped them from having a higher rank in the family hierarchy and/ or blocked them off from receiving a higher post in their job.

Social options for solution

As usually women are taken to cause childlessness, the ideal solution for many extended families is seen in polygyny. Polygyny is a widespread phenomenon in Malian society, where the majority of around 90 % at least officially is Muslim (Esposito, 2003), which allows men to marry up to four women. Thus men living in (yet) childless marriages are urged by members of their patrilineage to marry a second wife in order to find a solution. For men who didn't undergo biomedical diagnostics, this might be seen as a realistic solution. On the one hand, many men have internalized the public narrative to such a degree that they simply don't imagine they really could be the cause for marital childlessness, on the other hand, many seem to avoid diagnostics because they are afraid and they don't want to know it for sure. For some of these men as well as those whose wives are diagnosed as sub- or infertile, polygyny might become a realistic loophole in the end. Nevertheless, many men try to solve the problem with their first wife for several years. Whatever avenues for a solution are approached: if they are not successful in helping to conceive a child, the pressure and the attractiveness to marry a second wife will increase. But for those men who are themselves diagnosed as sub- or infertile, this pressure by family members and peers is complicating the situation tremendously. Besides creating in many cases problems with their first wives, a second wife would substantially augment the risk of disclosing the men's secrets in case a pregnancy of the second wife would not be achieved neither.

All infertile men in my research informed their wives about their diagnosis. Some also informed selected persons, mostly their fathers, family chiefs and/or younger brothers. Their wives in turn informed either no one at all or only their mothers, a close friend or a younger sister. Most of the wives believe that their husbands would not stand the stigmatization and don't want to leave them over to public disgrace. The mainstream narrative to blame women for childlessness allows to weave a web of secrecy around the diagnosis and the situation, in order to protect the infertile man (and his patrilineage) from shameful situations, to hide his condition and to leave it to their wives to shoulder the bigger part of insinuations and marginalisation in daily life.

Whether the situation intensifies, disrupts or brings dramatic turbulences to the couples internal relations depend on many specific and individual aspects like love and emotions, living situation as well as resources available, but also on such facts as who is diagnosed infertile, the length of time the problem is already persisting, the number of unsuccessful treatments already undergone and the amount of money already spent. With regard to infertile diagnosed men, to share such secrets and the search for a solution seems to intensify couple relationships and many couple try to protect their relation against interfering interests and influences of the extended patrilineage – at least as long as there is hope for both partners that one day they will achieve to get a child together. Most of the men are eternally grateful to their wives who accept the men with their deficit, keep their secret and grant them respect in public life.

Biomedical treatments

However, mostly the wives initiate biomedical treatment, as they shoulder the bigger part of the stigmatization, they fear family's pressure for a second wife and they are in need of getting pregnant, in order to achieve the socially visible sign of their bodily capacity to produce children and thus to end their stigmatization. Men will profit from pregnancy as all children of their wives count as their legitimate biological ones. But with making children men link the duty to guarantee the continuity of their patrilineage - an aspect which comes to the fore when this aim is disrupted by a male-factor infertility diagnosis. Otherwise, the mainstream narrative which declares women as responsible for infertility and the simultaneous fact that all children born by the wife are taken as the husband's biological children shields men eventual incapacity to continue the lineage. Even if the husband himself or a family member might doubt the children's biological origin, there is no clear proof (besides genetic testing) and thus, the possibility is always left that the children in question are in deed his biological children (Hörbst, 2008).
Once biomedical diagnosed this aim to continue the lineage requires the transmission of male substances to the children in other ways. Therefore it is of central importance whether the cause for childlessness is diagnosed in the woman (which leaves social options as well as biomedical options open) or in the man, which closes alternative social options and requires the transmission of their substances in another way. All infertile men were open to homologue ART with the partners` gametes, but not for heterologue ART via sperm donation – except one. After two failed attempts with homologue IVF this man, belonging to a Christian denomination, had finally accepted IVF with sperm donation, as in his opinion it was the last option for his wife to get a

child within their marriage. The other men argued that such a child would not continue their patrilineage. Instead, they prefer to take foster children from a brother or a cousin. Although such a child would neither be their own biological offspring, it would be at least a child originating from the patrilineage via a family member (Hadolt and Hörbst, 2009). Many infertile men supposed to their wives to live as a couple without children, and all promised to never ever marry a second wife. But all wives regarded both propositions as being totally unrealistic for living in the Malian society. Instead, many wives of infertile diagnosed men at least try to pressure to achieve a biomedical solution. As neither foster children nor formal adoption allow the women to become pregnant, they are no appropriate solutions for them. Thus, in contrast to their men women in Mali were found to be more open for heterologue ART, even by ova donation - at least as a last means to overcome their childlessness. Nevertheless, they evaluated such an option as worse than sharing a common biological child with their partners.

These multiple and partially contradicting aspects, such as the need to get a child, contrasting gender specific aims, different available ways to achieve a solution are argued and/or negotiated within the couples. They potentially trigger despair and emotional turbulences adding to the already high burden of suffering from infertility, in particular in connection to financial feasibility.

Costs of ART treatments in Mali

Without a comprehensive health insurance system in Mali, biomedical treatments for most infertility ailments are quite cost intensive for the patients. Besides quite low fees in public hospitals, treatments, drugs and materials needed (e.g. needles, anaesthetics for operations etc.) have to be paid by them and cases of under-desk fees are reported. Concerning ART, which are particularly expensive, these interventions are only provided in a private clinic. No nationally nor internationally supported fond is (partially) taking over the costs for ART. For the patients in Mali one attempt for IUI roughly adds up to between 1,100 to 1,800 Euros (400 Euro for doctoral attainment, 200 Euros for analysis etc, between 500 to 1,300 Euros for pharmaceuticals); one IVF cycle costs in between 2,400 and 2,900 Euros (doctoral attainments 1,300 Euros, around 200 Euros monitoring and 900 to 1,400 Euros for medication); and for one attempt of ICSI expenses range between 3,000 to 3,600 Euros (1,900 Euros for doctoral attainment, 200 Euros for monitoring, 900 to 1,400 for medication). Although the fees for these interventions are in general lower compared to costs in Europe[2], and the local availability of ART makes these interventions feasible for a broader part of society, as travel and accommodation dispenses for two persons do not have to be reckoned, regular employment (to get credit) and/or good (additional) income from activities in the informal sector, as well as good relationships to affluent family members or to migrants abroad, who eventually contribute to manage costs, are necessary to undergo ART even when carried out in Mali. Beyond, even if couples have considerable financial sources at their disposition, whether such high amounts are spent on ART is influenced and linked to various competing needs and demands in the extended family (like paying school fees or health treatments for family members, lending money for investing in business etc.) The majority of Malians suffering from involuntary marital childlessness cannot afford ART treatments.

Conclusion

As the Malian situation outlined shows, infertility is a field of specific problem configurations where various socio-cultural, structural and economic factors prefigure what for men seems a better or a worse option to handle their situation. Although to get a child forms the ostensible key problem, this problem is intimately linked to diverging constellations, in which involuntary childlessness forms part of other problems (such as social respectability, position in family hierarchy, popular narrative, proof of sexual capability, family pressure for a second wife, social solutions, costs) and vice versa. These constellations prefigure those objectives affected men (and women) try to achieve simultaneously when trying to have a child. These purposes are multiple and appear as a meshwork or network of aims (Hadolt and Hörbst, 2009), and, in a synoptic way, attribute some solutions as better and some as worse at a specific time and situation. Based on this background, the question what is at stake from men's point of view with regard to biomedical diagnostics and what biomedical treatments (including ART) offer to men's problems configurations can be approached.

[2] For comparison in Germany an attempt for IUI (if not covered by health insurance) costs on average between 650 and 1,600 Euros (600 to 850 Euro for doctoral attainments, between 50 and 750 Euro for pharmaceuticals); for one IVF attempt an average of 4,600 Euro (3000 Euro for doctoral attainments and 1,600 Euro for pharmaceuticals) while one attempt of ICSI will cost on about 7,200 Euro (5,600 doctoral attainments and 1,600 Euro for pharmaceuticals), information given by the *Bundesverband Repromedizinischer Zentren* of Germany, 22.03.2010.

On the one hand, biomedical infertility care renders men more vulnerable, as the predominant narrative of female responsibility of marital childlessness is broken up. When undergoing analysis, men have to reckon with the possibility of being indeed diagnosed with male factor infertility. Although they know it is not true, many men have internalized the prevailing narrative that only women are the cause for involuntary childlessness to such a degree that receiving a divergent diagnosis is an emotional shock for them. Many have to struggle hard with this internally felt devaluation of their manhood and being robbed of what seems for many men a normative right. Moreover, via biomedical diagnostics men run a higher risk for public disgrace and shame, which includes a double demasculinisation, concerning sexuality and authority over women. Such a diagnosis bounds them to their wives' capacity and willingness of keeping the secret maintained. Thus the option to hide their handicap from getting publicly known is weakened.

Moreover, through biomedical diagnosis of male factor infertility different social solutions (wives conceiving via extramarital sex (with a family member), marriage of a second wife) are rendered more difficult. These avenues for solutions ask for an atmosphere of uncertainty, a situation of not exactly knowing, and not having a proof at hand. When the men know their own inability to produce children, it becomes more difficult for them to accept such means, as they contradict personal emotions and moral or religious values concerning female faithfulness and adultery. Further on, extramarital sex with a non-family member contradicts also the men's aim to continue the patrilineage.

On the other hand, biomedical treatments offer men hope for curing bodily and social impairments (e.g. increase of sperm quality and quantity via hormonal treatments). Sophisticated biomedical treatments, IUI (in combination with hormonal increase of sperm quality) and particularly ICSI heighten the hope to achieve an own biological child in the future. But the knowledge that biomedical doctors in principal could provide treatments for achieving a solution is rendered merit less, when many men hear the prices and know that the financial means necessary for such interventions won't ever be achievable for them. Thus, biomedical potentials can become a bitter and frustrating pill. Even if an IUI or ICSI is affordable, yet the outcome is highly uncertain, as success rates of ART are in general relatively low (around 35 % per cycle at its best and around 20% in sub-Saharan Africa). Moreover, highly featured accumulating effects can only develop its benevolence if several cycles are feasible and affordable. If only homologue IVF or ICSI are offered, the chance to realize the reproductive aim of continuing the lineage via own biological/genetic offspring is less achievable for many men diagnosed with azoospermia. Other options, such as taking foster children of a brother, might seem then more adequate to men, even if they do not allow their wives to achieve their reproductive aims (Hadolt and Hörbst, 2009). Increased commodification and commercialisation of biomedical health care in the last decades add to the fact that biomedicine is seen similar to other economic negotiations where money is exchanged for a specific product. In case of attempts without success many feel being "robbed" money without having received the "paid for" product.

In such situations, some men hand their fate over to Allah, some take after years a second wife, waiting for 'Abraham's miracle', others seem to compensate their handicap by various extramarital partners, rendering them vulnerable for acquiring sexual transmitted diseases. If confronted with the possibility to stay without children for the rest of their lives – even when ART are offered - men may prefer not to be involved in biomedical treatments at all. Men may rather hide behind the social stigmatization of their wives in order not to risk to be exposed to demasculinisation. Without financial assistance by the Malian state or by trans- and international organizations, only a rather small minority of the Malian population can benefit from locally provided ART. The great majority of infertile Malian couples rests without these options. Most of them keep on beating the traditional and classical biomedical ways to find conception, while taking the risk to even exacerbate their condition through incompetent treatment or poor hygienic handling – both in traditional and biomedical spheres. For less affluent sufferers from infertility the lack of own adequate financial means for a solution in combination with no help from the Malian state and the international community triggers frustration and desperation which in turn enhances loss of confidence concerning the state's power to care for the health of its citizens.

Perspectives

From the complex constellation which infertility presents for couples and from men's perspectives in Mali it can be generalized that bad male compliance with regard to biomedical infertility diagnosis and treatments is part of this specific problem configuration. Even so men might undergo biomedical diagnostics, the treatments necessary might be out of reach for them, due to lack of financial means. The mere existence of biomedical diagnosis and promising treatments not necessarily makes men's aims easier achievable for them, but even might

diminish them in their view. To the contrary, it might render for many men their emotional and social lives as well as their relationships more complicate, and, in cases their aim to biologically continue the patrilineage might get questioned, biomedical diagnosis and treatment might fundamentally contradict their objectives. While further social science research, focusing on male views with regard to infertility and its treatments (including ART) in different socio-cultural contexts is necessary, the concept to understand infertility as being a complex problem configuration might be a fruitful approach. Together with the outlined risks for men in Mali, it has the potential to advance the understanding for non-complying men. To see men and their doings embedded in complex social, structural and economic entanglements may serve as a starting point for further attempts to increase male compliance with biomedical infertility care in developing countries.

References

Bharadwaj A. Infertility, gender and technologies of procreation: a perspective from India. In Balen van F, Gerrits T, Inhorn M (eds) Social science research on childlessness in a global perspective. University of Amsterdam, Amsterdam, Netherlands, 2000: 65-74.

Bhatti LI, Fikree FF, Kahn A. The quest of infertile women in squatter settlements of Karachi, Pakistan: a qualitative study. Social Sci Med. 1999;49:637-49.

Dyer SJ, Abrahams N, Mokoena NE, van der Spuy ZM. "You are a man because you have children": experiences, reproductive health knowledge and treatment seeking behaviour among men suffering from couple infertility in South Africa. Hum Reprod. 2004;19,4:960-7.

Esposito JL (ed). Oxford Dictionary of Islam. Oxford, Oxford University Press, 2003.

Gerrits T. Social and cultural aspects of infertility in Mozambique. Patient Education Counsel. 1997;31:39-48.

Gerrits T. Infertility and matrilineality. The exceptional case of the Macua. In Inhorn MC, Balen van F (eds). Infertility around the globe: New thinking on childless, gender and reproductive technology. Los Angeles: University of California Press, USA, 2002: 233-46.

Gerrits T, Boonmongkon P, Feresu S *et al.* Involuntary childlessness: a neglected problem in poor-resource areas. ESHRE Monogr. 2008: 25-8.

Involuntary infertility and childlessness in resource-poor countries. Current Reproductive health Concerns. Amsterdam, Het Spinhuis, Netherlands, 1999.

Hadolt B, Hörbst V. Problemlagen, Anwendungskontexte, Nutzungspraktiken: Assistierte Reproduktionstechnologien in Mali und Österreich. In: Dilger H, Hadolt B (eds). Medizin im Kontext: Krankheit und Gesundheit in einer vernetzten Welt. Frankfurt am Main, Peter Lang Verlag, Germany, 2009: 89-110.

Hörbst V. Focusing Male infertility in Mali: Kinship and Impacts on Biomedical Practice in Bamako. In Brockopp J, Eich T (eds). Muslim Medical Ethics: Theory and Practice. South Carolina, South Carolina University Press, 2008: 118-37.

Hörbst V. Islamische Grundsätze und die Handhabung assistierter Reproduktionstechnologien in Bamako, Mali. In: Eich T (ed). Reproduktionsmedizin bei Muslimen: säkulare und religiöse Ethiken im Widerstreit? 2009: 48-64. http://www.heceas.org/media/Islam_Medizinethik_08.pdf [10.11.09].

Inhorn M. The Quest for Conception. Gender, Infertility, and Egyptian Medical Traditions. University of Pennsylvania Press, Philadelphia, USA, 1994.

Inhorn M. Global infertility and the globalization of new reproductive technologies: illustrations from Egypt. Soc Sci Med. 2003:1837-51.

Inhorn M. Religion and Reproductive Technologies. IVF and Gamete Donation in the Muslim World. Anthropology News. 2005;44:14-8.

Inhorn M. 'The worms are weak': male infertility and patriarchal paradoxes in Egypt. In Lahoucine O (ed). Islamic masculinities. London, ZED books, Great Britain, 2006: 217-37.

Inhorn M, Balen van F (eds). Infertility around the globe. New thinking on childlessness, gender, and reproductive technologies. Berkeley, University of California Press, USA, 2002.

Mgalla Z, Boerma JT. The discourse of infertility in Tanzania. In Boerma JT, Mgalla Z (eds). Women and infertility in sub-Saharan Africa: A multi-disciplinary perspective. Amsterdam, KIT Publishers, Netherlands, 2001: 189-200.

Nahar P. Childless in Bangladesh. Suffering and resilience among rural and urban women. Amsterdam, University of Amsterdam, Netherlands, PhD thesis, 2007. http://www.sjaakvandergeest.nl/pdf/PhDs/nahar_dissertation.pdf [28.04.2010]

Nahar P, Sharma A, Sabin K *et al.* Living with infertility: experiences among urban slum population in Bangladesh. Reprod Health Matters. 2000;8:33-44.

Schuster S, Hörbst V. Introduction. In: Hörbst V, Schuster S (eds). Reproductive Disruptions: African Perspectives. Thematic Issue. Curare. 2006;29:5-16.

Sundby J. Infertility in the Gambia: traditional and modern health care. Patient Educ. Counsel. 1997;31:29-37.

Sundby J, Mboge R, Sonko S. Infertility in the Gambia: frequency and health care seeking. Soc Sci Med. 1998;46: 891-9.

van Balen F. Involuntary childlessness: a neglected problem in poor-resource areas. ESHRE Monograph. 2008: 25-8.

Yebei VN. Unmet needs, beliefs and treatment-seeking for infertility among migrant Ghanaian women in the Netherlands. Reproductive Health Matters. 2000;8:134-41.

Misery of Empty Laps: Life of childless women in Bangladesh

P. Nahar

Research Fellow, Department of Anthropology, Durham University, Durham, DH1 3LE, United Kingdom.

Correspondence at: papreen.nahar@durham.ac.uk

Abstract

This research deals with the experience of childless women of Bangladesh, who are marginalised by a culture which idealises motherhood and are excluded from the mainstream discussion on women's health. By presenting the lives of these childless women through my research I hope to bring their hidden suffering to the surface and make their voices heard. The research was conducted with an ethnographic approach with feminist views. The study reveals that rural people view infertility more as a social rather than a health problem, such that not having children determines a woman as stigmatised, insignificant in a patriarchal society like Bangladesh. My study also reveals that these women are suffering alone – socially, psychologically, as well as economically. No public service is available for the rural poor. Predominantly rural women are in the hunt for treatment from various traditional healers, where mystery and miracle plays an important role. Only private sector provides expensive reproductive infertility interventions in the urban areas for the middle class in which success rate and quality of services are not monitored adequately. Both urban and rural women experience bodily harm, negative psychological effects and exploitation as treatment consequences. Neither health authorities nor legal bodies are concerned about the childless women's wellbeing. Yet the women resist this negligence towards them, for in various ways they create a space for themselves to survive in their families and in society. However, compared to the extreme scale of hampering wellbeing the everyday form of resistance among childless women is trivial.

Key words: Infertility, childless, Bangladesh, resilience, consequence, women.

Introduction and Background

This is a summary of my PhD thesis (Nahar, 2007). The study is about childless women in Bangladesh. It describes childless women's suffering and their resilience. Childlessness is the result of a complex interaction of biological and cultural factors and has social and emotional consequences (Greil *et al.*, 1989. Greil, 1997; Inhorn, 1994; Wiersema, 2006; Schmidt, 2009; Van Balen, 2008). In every culture infertility is explained in it's own way influenced by different social and cultural values and beliefs, which do not always match with biomedical explanations (Pearce, 1999). For women, it can result in role failure and social stigmatisation within the household and may lead to physical and psychological abuse in some cases life threatening medical interventions (Gerrits *et al.*, 1999; Inhorn, 1996; Van Balen, 2008; Van Balen & Inhorn, 2002). In many Developing countries including Bangladesh in the absence of a state level welfare system, children are necessary to secure parents' and families' survival and they serve as a valuable power source (Ahmad, 1991; Dyer, 2007; Nahar, 2000; Zulfiquer, 2004). Moreover, 'motherhood' if not only, is the primary culturally available identity for a woman in Asia (Gupta, 2000; Widge, 2001). Fertility control is the main focus of state level health policies in many developing countries (Bergstrom, 1992; Rowe, 1999; Ombelet, 2008). Which is again influenced by different global interest groups (Akhter, 1992; Rowland, 1996; Simon, 1986). No wonder that in Bangladesh, an overpopulated country where fertility control is the main focus of health policy (Akhter, 1992; 1994). As a result infertility never received attention as a public health problem (Nahar, 2007; Rashid, 2007). Consequently solution for infertility problem remain complex in such contexts. The people who are considered undesirable and unacceptable by society fall into the 'process of exclusion' (Reid, 2004). I

argue that in a resource poor, Muslim society like Bangladesh childlessness may be much more than medically defined infertility. Hence, infertility/childlessness in Bangladesh deserves special attention.

Aim of the study

The study intends to give a voice to the childless women and takes women's agency as point of departure, where women are not only the passive victims of body politics, but rather are actively engaged in a process to protect themselves from socio-cultural and political retribution.

Through my research, which to my knowledge is the first of its kind in Bangladesh, I explore aspects of infertility on various levels including the personal and community level, as well as the national and international policy level. On the personal level I explore the embodied experiences of infertile women from both urban and rural settings. On the community level I study the perceptions and attitudes of rural community people about infertility, and on the national and international level I explore the views of national health policy makers, program managers and health care providers, donors, including the international level population discourse.

Methodology

The research was conducted using an ethnographic approach. A critical medical anthropological perspective with a feminist view is the basis of analysis of the study. The term research approach is used here to indicate the epistemological viewpoint about the nature of the enquiry, the kind of knowledge that was discovered and kind of methodological strategies used (Holloway & Todres, 2005). My research is centred on the experience of infertile women in Bangladesh. It has two main centres of attention, one being infertile and the other women. Since infertility is both a health and a cultural issue I take the medical anthropological perspective. However a medical anthropological perspective is not necessarily gender sensitive. Because the sufferings of infertile women are another centre of attention for my study, it is inspired by the feminist perspective as well. The purpose of my research is to make Bangladeshi infertile women's voices heard as their 'sufferings' have never before been captured and have been systematically ignored by the authorities. This has put them in a marginalised position in society. A feminist perspective was therefore called for. Acker (1994) listed some of the core assumptions in the feminist perspective which I follow, "...Feminist research involves an acute state of awareness of the injustice women suffer from because of their sex, The purpose of this research is to improve women's lives, ...Women's experience in patriarchal society is the starting point for research: the statement 'the personal is political' is valid". Various qualitative research tools have been used for data collection for example life-history, free listing, pile-sorting, severity-ranking, body mapping, focus group discussion and key-informant interview.

Result

Through the exploration of community level socio-cultural constructions of infertility, local definitions and vocabularies of infertility were shown to establish a hierarchy in society where women must bear the burden of childlessness. Gender difference in valuing childlessness is clearly evident here. The study shows that rural community people view infertility more as a social problem than a health problem, such that not having children determines a woman as insignificant or useless and stigmatised. In the rural setting, mystery and miracle played an important role in explaining infertility.

Being childless has a wide range of negative consequences for rural Bangladeshi women, be they personal, psychological, economic or social, with the essence of these consequences being 'suffering'. Rural childless women experience strong stigma as their identity is devalued for not being able to produce children; they are blamed for their childlessness and as a result develop a sense of guilt. They are also socially isolated, and sometimes suffer abandonment by their families. They live a life full of fear and insecurity related to marital disruption. Women also experience increased poverty due to childlessness, as childless women's mobility is more restricted or their husbands are demoralised to earn. Rural infertile women's treatment seeking behaviour follows the logic of indigenous causation, although it is also based on pragmatic reasons. Local healers in the informal sector were found to be the most popular treatment option among the rural childless women. The factors for utilising them included low costs, same gender of the provider, having a shared explanatory model with the healers, easy availability and accessibility of the treatment and the value of rituals in the folk healing system.

The urban childless women, like their rural counterparts, suffer from guilt and feelings of role failure, and experience social isolation, loss of self-esteem and stigma. Insecurity and disruption in their relationships with their husbands were, however, less intense than among rural childless women. The results demonstrate that in the life of affluent, literate urban women there is little room for mystery and miracles surrounding infertility as there is for illiterate, poor

rural women. Unlike their rural counterparts, urban women predominantly seek expensive assisted reproductive technology (ART) treatment which is available only in the formal sector, in private services. Access to biomedicine is, in a way, a disadvantage for the urban women. By doing a diagnostic test which declares their infertile status they confirm their identity as 'deviant', whereas by not having the opportunity for the test, rural women may maintain hope until menopause. However, despite their affiliation to modernity, urban women still believe, like their rural counterparts, that the remedy for childlessness ultimately depends on Allah. As a result, in addition to biomedical treatment, many return or simultaneously pursue various traditional, spiritual or folk treatments. Significantly, both urban and rural women experience bodily harm, negative psychological effects and exploitation as treatment consequences. In case of suffering due to infertility treatment modern biomedical or traditional healing system does not make much difference.

It is, however, important to recognise that regardless of the negative psycho-social consequences, childless women both in rural and urban settings follow various overt or covert strategies to contest their stigmatised identity. They develop various strategies to make themselves acceptable in the family and community. They protect their marriage and prevent abandonment by their husbands and in-laws. I argue that both rural and urban childless women are not just passive sufferers of stigma and social-familial abuse, they are agents who fight against their socially sanctioned identity. They are not agents in the sense that they transform their identity or make big changes in society regarding the establishment of their rights. But if we put this in context it becomes evident that the efforts of the childless women are not only aimed at becoming pregnant but also at protecting their marriage and preventing them from being abandoned by husbands and in-laws. In an extremely patriarchal and hierarchical society like Bangladesh (Islam, 1994), where women's empowerment is far from reality, and where collective women's rights activism is limited, these childless women, by their everyday forms of resistance like independent, pragmatic, succeed in achieving their goal, namely averting abandonment. Instead of being martyrs of the system they manage to create a space in society through their innovative actions. However, resistance of childless women is insignificant compare to their sufferings.

In order to contextualise the lives of infertile women, I have tried to highlight some of the macro level factors affecting infertile women's lives in Bangladesh. The study revealed, approach of public health is still in its traditional form with an emphasis on morbidity and mortality. The issue of women's 'wellbeing' is excluded from the public health discourse in Bangladesh in many cases. My study also show that infertile women's lives have not been seen, known and identified in the macro level conceptualisation of women's health. Invisibility of infertile women's lives at both micro and macro level discussions on women's health in Bangladesh is observed.

In our studies, it is clearly shown in my study how, in a resource poor country like Bangladesh, health policies are influenced by various ideologies of resource rich countries and powerful international bodies, including funding agencies. I argue that the discussion and concern of 'population control' that was generated in the West, with Western interests, has shaped the reproductive health policies of Bangladesh. As a result, infertile women are systematically ignored in the health policies and programs. I therefore argue that it is not only a matter of resource constraint that prevents the public health sector from addressing the problem of infertility, but also the 'process of exclusion' in the international level discussion about the health of developing countries, which keeps the issue of infertility out of dialogue in health policy and action in Bangladesh.

Case-reports

Two cases are presented, one urban and one a rural childless woman's voice of their treatment seeking pathways. The life histories of these two women are presented more extensively and elaborately in the thesis. Here I have presented them in a condensed form.

Case-report 1

Podma's (an urban middle class childless woman) lonely travel to the destiny of motherhood:

Podma (40) is a lawyer by training now involved with her father-in-law's business. Her husband is a 'rich' businessman in Dhaka and the only son of affluent parents.

After one year of her marriage she was diagnosed with a tubal knot and the doctor gave her a medicine called 'clomid' (clomiphene citrate). After taking the medicine she had severe pain in the abdomen during menstruation, which made her roll on the floor. She changed her doctor and visited two of the best gynaecologists in the country. They also asked her to continue the medicines and have frequent intercourse. They too did not pay much attention to her complaints about the pain. They did some more diagnostic tests but were not sure about her problem. Several years passed. Podma and her husband

became dissatisfied with the doctors. Her severe pain during menstruation continued. Podma's sister (living abroad) then suggested that she should go abroad for treatment, saying, "Bangladeshi doctors will kill you". Only her family and her in-laws knew of this. Podma said,

> *I never told anyone about my treatment. Only my family and my in-laws knew about this. I did not share this with anyone else. I always used to think, 'how can I tell people that I do not have children?' Moreover, I could not accept the idea that I would not have a child. I used to hide everything from others; I did not want to share the fact that I was incapable of producing a child. I thought I will definitely get a child through treatment some day.*

But relatives became suspicious and started making comments. Neighbours would ask, "Hi, why are you not getting a child?" She overheard someone saying, "The years are passing, so and so's wife is not getting pregnant, she must be suffering from something". Some used to give her addresses of different *Hujurs* (religious/spiritual healers) who are said to be able to help women have children through spiritual means.

Podma gradually began to isolate herself from other women; she thought that she was not like them. But she still did not accept her childless identity. She was desperate to have a child.

Podma decided to go to Singapore for treatment; money was not a problem, and her husband was rich and supportive. Her father was also well-off and wanted to bear all the costs of her treatment. So they decided to go to Singapore, not telling people about their treatment plan except for some close relatives. To others she said that they were going abroad for a tour.

Podma went to Singapore and underwent treatment for as long as nine months. The hospital did several tests in different stages. The doctors finally gave her medicine that she was supposed to take four times a day. But after taking the medicines for a few weeks she started having severe bleeding. The doctors then did a Dilation and Curettage (D&C), which meant that the treatment had failed. Podma said, "It was such a distressing experience. During my stay in Singapore for nine months I didn't go shopping for a single day. My husband wanted to take me for outings, the hospital staff also told me to go out, but I didn't. My focus was only to get pregnant. Those nine months were a waste of time. That is when for the first time I started to think about myself as childless".

With a broken heart the two returned to Bangladesh. Podma was upset. She said, "I was very depressed and sad. I felt particularly sad for my husband and the in-laws. It is because my husband is the only child of his parents. I felt guilty, as it seemed that because of me the family will not have any offspring. Although my in-laws didn't blame me, still I felt guilty. My family also felt guilty about it. That is the reason that my father paid the entire treatment costs, although my father-in-law is richer than my father. The treatment was expensive there; you need to pay in US dollars. Moreover there were costs involved in living and accommodation".

When they returned from Singapore the doctors advised them (over email) to go for a test tube baby. After a year, Podma began to think about the option. Her father encouraged her and said he would again bear the costs. Her husband was also supportive. Podma was desperate to have a baby so she decided to go for it. She returned to Singapore. Another long journey in the quest for a baby had begun.

When I asked Podma to tell me her experience trying for a test tube baby, she took a deep sigh and said, "Oh! What a horrible experience that was. I don't know how I can describe that…" She continued:

> *[It was] as if it was a terrible game, a lottery. We, a group of twenty women, started this test tube game in the hospital. Every day we had to go through several tests. Every day they took blood; they measured our blood pressure and did many things in our bodies including watching reactions to medicines. And after the test results, every day they used to declare that so and so is not eligible for further treatment. So that person was out of the game. There was always tension, who would be the next to be thrown out. Each day I had to pass with this horrible tension, that I might be dropped out next. After fourteen days only five of us were left who were finally selected for the treatment. This whole process was very tough, painful and miserable. Finally after fifteen days doctors told me that it is time for me. Every day they were checking the ovum, they were checking how big it has become and other things. When the ovum comes in an exact measurement then they do the retreat. The process was very painful, both mentally and physically. Every day one doctor would push the injection then the other would do the scanning. They were scanning the ovum and the scanning was very painful. After fourteen days one is supposed to go for a special procedure. At twelve noon I took one injection, and exactly after twelve hours they took my ovum and the next day the replacement took place. In my case I used to produce many ova. The doctors were very hopeful about me, as I was young compared to other patients, still below thirty-five. Doctors implanted three embryos that grew well and they found heartbeat in three of them. But in between, other complications developed. Normally the medicine dose was the same for every one. But in my case as I produced*

too many ova, I did not need that strong dose, and hyper stimulation occurred. After four weeks, there was water all over my body and in the heart as well. One night, seven days after the implantation, I was feeling terribly bad but still I walked to the hospital from my residence, which was nearby. That day I was feeling that I was going to die. I collapsed. The doctors did not feel my pulse any more, the blood pressure was very low. They told me to lie down on the bed and within ten minutes I saw many doctors around me. They were giving me injections and were very tense. Doctors were running everywhere. I was conscious. At that moment when doctors wanted to do the X-ray I said no. Because at that time I knew that I am pregnant and I knew that if at this stage an X-ray is done it can harm the foetus. That night I could not breathe properly. I was alone, in that country they don't allow anyone to stay with the patient in the hospital. They were afraid that anything might happen in the night. In the morning, the heart specialist came and I was taken to the intensive care unit. I stayed there for four days. For two nights I could not sleep for a single moment. After three days I became bit stable. After four days they scanned and found that out of three ova two were growing very well but one had stopped growing.

The doctors decided that Podma should not move from the hospital during the first four months of pregnancy. The pregnancy continued for four months. During this period she stayed continuously in the hospital bed and was not even allowed to change the side she lay on. Both her hands turned blue, due to constant use of saline and injections. After fourteen weeks the doctors found that a clot had developed in the placenta. Then they took her to do the scan. They found the clot was big and the foetus was small. The doctors said to Podma that sometimes it happens that the clot comes out on its own, but that the foetus may or may not come out as well. They told her, "Now it is not in our hands. Sometimes the uterus's mouth opens due to pressure and the foetus might come out. We can't do anything about this". The doctors suggested to her to go back home. Podma said:

Just imagine my mental state at that time. I said to the doctors that after four months of all these sufferings you are saying that now this is not in your hands? The doctors told me that they couldn't do anything now. It's now my fate whether the foetus will stay or come out. Allah will decide if He wants me to be a mother or not. And the foetus came in the sixteenth week. I started feeling tremendous abdominal pain. I still remember, it was 8:30 in the morning that a blood clot came out. And my two children to be came out with that. That was the end of my dream.

Podma undertook the same journey a further two times, but no dream came true for her.

Case-report 2

Fulobala's (a rural poor childless woman) lonely travel to the destiny of motherhood

Fulobala is only forty-two, never went to school and does not have any income of her own. Her husband is a farmer. She got married at the age of twenty. Fulobala never became pregnant. In their early years of marriage her husband threatened that he would remarry if she could not produce a child, but he did not, which Fulobala thinks is due to her mother-in-law who did not allow it. She thinks that her mother-in-law is an exceptional person. Below is the journey Fulobala undertook to have a child:

At first, I took enchanted water (pani pora) from a religious leader (Hujur). I drank pani pora from an Islamic religious leader. He said that after four to five days of menstruation I would conceive. My menstruation continued for several months but I didn't conceive. I paid to many providers whatever money they wanted, from 50 to 300 taka [50 cents to 3 Euros].

I took some herbal medicines from a Fakir (spiritual healer). She gave the medicine periodically. I had to pay her a brass spoon, a chicken and six kilos of rice. It did not work. Then a female Kabiraj (herbalist) came. I gave her an old saree and she gave me medicines and pills for three months. I had to take the medicines at noon (exactly when the sun is in the middle of the sky) standing in the pond water after taking a bath. I went to some other Kabiraj as well with my mother. All of them told me that I had this childlessness due to my menstrual problem.

There is another kind of provider called baidda (gypsy, snake charmer). I trusted one of them; I gave many of my favourite things like a saree that I was wearing, a bangle from my hand, a spoon, a bottle of cooking oil and so on. But they were frauds. The result was zero. Again I took another baidda's medicine. She gave me oil to massage on the stomach and a pill which had a very bitter taste. She said she would come after three months with an enchanted banana, she never showed up. I have taken all sorts of medicines to get rid of joha-juhi (an indigenous ethno-physiological creature) as people suggested, but, finally, I could not give birth. Joha-juhi did not disappear. Afterwards I again had some Kabiraj medicines. At the same time I also had contraceptive pills as a remedy, since the health worker asked me to take them. Then I went to a homeopathic doctor who gave me medicines for two months. Every month I used to pay him 125 taka but that also didn't work.

I went to another Kabiraj who lives far away from our village. The rule to meet the Kabiraj was that I should go to her before sunrise and should be in a wet dress because the medicine had to be taken in a wet dress. I and my husband went to that Kabiraj for seven days before sunrise. My husband just accompanied me. After we reached there the Kabiraj gave me banana and some roots and herbs to eat with the wet dress on. I went there for seven days. Every day I used to eat one banana. First after waking up from sleep I took a bath, then went to the Kabiraj and then took her medicines. My husband didn't have to do anything. After taking the medicines I changed my dress to a dry dress and came back. We have to pass a bazaar and even in the early morning there are men, so I felt embarrassed to cross the bazaar with a wet dress. She asked me to go there after having sex the night before we visited her. The Kabiraj asked us to start her medicines from the first day of menstruation and have sex from the third day of menstruation and we had to continue having sex for the next five days. The total course lasted seven days as menstruation stays for seven days. But I menstruated only for two days. The Kabiraj asked us to have sex during menstruation but we could not do that. We had sex from the third day onwards; I was not menstruating at that time. But I didn't say anything to the Kabiraj. These were matters of shame (shorom). I paid her 60 taka. The next month we had to go through the same process. She asked me to come again but I gave up because the herbal medicines she gave were very strong, (tukkar oshud to kodhin). I was having problems, dizziness, headache, vomiting, and stomach ache. I felt I was dying. After feeling better after two months I went there again and had the medicines again but this time I felt worse. She gave more roots this time and some medicines we had to buy from the shop, all costing a lot. I finally stopped that treatment.

I was taken to a Fakir by one of my sisters-in-law to check if I am possessed by algaa batash (evil air/spirit). He thought I was. He put water in a metal plate and asked me if I saw myself double. I did see two of me, which meant I was possessed by algaa. He thought during my young age the algaa caught me from the pond and since then I am having menstrual problems. The Fakir treated me afterwards. He did blow on me with magical verses, gave me an amulet and asked me to buy an expensive stone and make a silver ring out of it. I was never able to buy that stone. So I cannot say that I took his treatment. I did not get cured. Actually, in most cases I took half of the treatment because I couldn't complete the course.

I went to many other places as well to have a child, for example to the shrine (mazar), where the jaree (a kind of group song) songs are performed throughout the night. They throw rice pop (khoi) all over the shrine and believe that a childless woman will conceive if she collects the khoi and eats with the intense wish to get pregnant. The belief is that the child is in one of these khoi, and a childless woman will find the proper one, if she is pure and loved by God. It was necessary to stay at night to listen to jaree songs. I did that but the khoi caused a burning sensation throughout my body.

One day a stranger with one leg came to our village and claimed to be a Kabiraj. He advised me to give away two cooking pots to the river in order to get a child. I had to pay him 2 taka, some sugar and bread. I drank river water for seven days. No result. Once a Kabiraj gave me a medicine made of seeds of jute which is the most common pill for the childlessness treatment. After taking the medicines I started vomiting and felt extremely sick. So many medicines entered into my stomach, but 'unkind' (nidoya) Allah has not fulfilled my wish!

This way, I have been trying with different providers for the last nineteen years. It is only in the last two years that I went to a pharmacy shopkeeper. The doctor [shop keeper] over there told me that something happened in my womb for a long time due to taking herbal medicines. The doctor also said that I have a tumour in my stomach. He asked me to do an ultrasound. I couldn't do that due to money constraints. The doctor asked me to use two injections but those two were very expensive medicines. Each 400 taka (4 Euros). Still I bought those two medicines. Unfortunately it did not work.

I took so many things from different providers. I went to all sorts of providers. I wanted to check whether there is at all any fruit (phol) in my stomach or not. I finally decided to go to a town [sub-district] specialist doctor. In order to bear the cost I sold the golden bangles that my mother had given to me during my marriage. Everybody said that I will have a baby after having a treatment and test by the town doctor. She tested my abdomen, chest etc. but nothing happened. Moreover, the doctor could not solve the problem of menstrual pain that started again after a few years' interval.

Now I have left everything to Allah. I did my best. I think I should not take any more. These medicines are strong (kora). If I take more medicines my body will be destroyed. I already spoiled my body, my stomach. I am praying to Allah and doing manot [promise prayer: paying to the shrine in order to fulfil the wish] to have a child. If I am able to bear a child, I will distribute sweets for the children (batasha) at the mosque or will arrange a Khatam of the Holy Quran at the mosque [where an official religious person recites the Quran in one sitting and food is distributed afterwards]. Some people said that Sura Yasin and Mobin Quaranic verses help to have a child. I cannot pray Arabic but I asked my neighbour to pray for me. I listen to her recitations so that God would consider me as if I read them.

I console myself and keep silent. People, ask me why I don't have a child. Sometimes I ask Allah why

He does not give me the blessing. Why is the suffering only for me?

The above two cases provide an impression of childless women's journey for their treatment seeking for both in urban and in rural Bangladesh.

Conclusion

In conclusion, this research deals with the experience of a minority population of Bangladesh namely childless women, who are marginalised by a culture which idealises motherhood and places a high value on children, and who are excluded from the mainstream discussion on women's health. My study reveals that these women are suffering alone – privately, socially, psychologically, as well as economically. Neither health authorities nor legal bodies are concerned about their wellbeing, which is greatly threatened. Yet the women do not give up. Although it may seem minor, they resist this negligence towards them, for in various ways they create a space for themselves to survive in their families and in society. However, compare to the extreme scale of hampering wellbeing the everyday form of resistance among childless women is trivial. By presenting the lives of these childless women through my research I hope to bring their hidden suffering to the surface and make their voices heard.

References

Acker S. Is research by a feminist always feminist research? In: Acker S. (Ed.), *Gendered Education: Sociological Reflections on Women, Teaching and Feminism.* Buckingham: Open University Press. 1994:55-71.

Ahmad A. *Women and Fertility in Bangladesh.* New Delhi, London: Sage Publications. 1991.

Akhter F. Reproductive rights: A critique from the realities of Bangladeshi women. In: Jahan R. *et al.* (Eds.), *Reproductive Rights and Women's Health* (pp. 41-58). Dhaka: Women for Women. 1994.

Akhter F. *Depopulating Bangladesh: Essays on the Politics of Fertility*. Dhaka: Narigrantha Prabartana. 1992.

Bergstrom S. Reproductive failure as a health priority in the third world: A review. East Afric Med J. 1992;69:174-80.

Dyer SJ. The value of children in African Countries - Insights from studies on infertility. Journal of Psychosomatic Obstetrics and Gynecology. 2007;28:69-77.

Gerrits T, Pimpawun B, Feresu S *et al.* Halperin. *Involuntary Infertility and Childlessness in Resource-Poor Countries.* Gender, Reproductive Health and Population Policy Project Series. Amsterdam: Het Spinhuis. 1999.

Greil AL, Poter KL, Thomas AL. Sex and intimacy among infertile couples. Journal of Psychology and Human Sexuality. 1989;2:117-38.

Greil AL. Infertility and psychological distress: A critical review of the literature. Social Science and Medicine. 1997;45:1679-1704.

Gupta J. *New Reproductive Technologies, Women's Health and Autonomy: Freedom or Dependency?* New Delhi, etc.: Sage. 2000.

Holloway I, Todres L. The status of method: Flexibility, consistency and coherence. In: Holloway I. (Ed.), *Qualitative Research in Health Care* (pp. 90-102). Maidenhead Berkshire: Open University Press. 2005.

Inhorn MC. *Quest for Conception: Gender, Infertility, and Egyptian Medical Traditions.* Philadelphia: University of Pennsylvania Press. 1994.

Inhorn MC. *Infertility and Patriarchy: The Cultural Politics of Gender and Family Life in Egypt.* Philadelphia: University of Pennsylvania Press. 1996.

Islam M. *Whither Women's Studies in Bangladesh.* Dhaka: Women for Women. 1994.

Nahar P, Sharma A, Sabin K *et al.* Living with infertility: Experiences among urban slum population in Bangladesh. Reproductive Health Matters. 2000;8:33-44.

Nahar P. Childless in Bangladesh: Sufferings and Resilience Among Rural and Urban women. PhD thesis, Medical Anthropology Unit, University of Amsterdam. The Netherlands. 2007.

Ombelet W. False perceptions and common misunderstandings surrounding the subject of infertility in developing countries. ESHRE publication. www. Eshremonographs.oupjournals.org 2008; ISSN 0268-1161.

Pearce TO. She will not be listened to in public: Perception among the Yoruba of infertility and childlessness in women. Reproductive Health Matters 1999;7:69-79.

Pennings G, de Wert G, Shenfield F *et al.* Providing infertility treatment in resource-poor countries. Human Reproduction. 2009;24:1008-11.

Rashid SF. Kal dristi, stolen babies and 'blocked uterus': Poverty and infertility anxieties among married adolescent women living in a slum in Dhaka, Bangladesh. *Anthropology and Medicine* 2007; Vol. 14, No. 2, pp. 153-66.

Reid C. *The Wounds of Exclusion: Poverty, Women's Health and Social Justice*. Edmonton, Elberta: Qual Institute Press, 2004.

Rowe PJ. Clinical aspects of infertility and the role of health care service. Reproductive Health Matters. 1999;7:103-11.

Rowland R. *The advancement of reproductive health in the Asia/Pacific region: Redefining the basis*. Proceedings of the conference, 'The Third Asia and Pacific Conference on the Social Science and Medicine', February, 1996, Faculty of Health and Human Science, Edith Cowan University. Perth: Western Australia.

Schmidt L. Social and Psychological consequences of infertility and assisted Reproduction, what are the research priorities? Human Fertility. 2009;12:14-20.

Simon JL. *Theory of Population and Economic Growth.* Blackwell: Oxford, 1986.

Sundby J. Sad not to have children, happy to be childless: A personal and professional experience of infertility. Reproductive Health Matters. 1999;7:13-9.

Van Balen F, Inhorn MC. Introduction. Interpreting infertility: A view from the social sciences. In: Inhorn CM, Van Balen F. (Eds.), *Infertility Around the Globe. New Thinking on Childlessness, Gender, and Reproductive Technologies* (pp. 3-33). Berkeley: University of California Press, 2002.

Van Balen F. Involuntary childlessness: a neglected problem in poor-resource areas. ESHRE publication. www. Eshremonographs.oupjournals.org 2008; ISSN 0268-1161

Widge A. *Sociocultural attitudes towards infertility and assisted reproduction in India.* Web: www.who.int/reproductive-health/infertility/11.pdf#search=%22Anjali%20Widge%20India%22. (Accessed September 18 2006), 2001.

Wiersema JN, Drukker A, Dung MBT *et al.* Journal of Transnational Medicine. 2006;4:54.

Zulfiquer MH. *Country paper on child labour*. www.cwa.tnet.co.th/booklet/Contents.htm (Accessed November 4 2004), 2004.

Fertility treatments under semi/occupation: The case of East Jerusalem

Daphna Birenbaum-Carmeli, Ronit Kochman-Haimov

[1]*Faculty of Social Welfare and Health Studies, University of Haifa, Haifa, Israel, 31905.*
[2]*Department of Obstetrics and Gynecology, Hadassah University Hospital, Mt. Scopus, Jerusalem.*

Correspondence at: Faculty of Social Welfare and Health Studies, University of Haifa, Haifa, Israel, 31905. E-mail: daphna@research.haifa.ac.il

Abstract

The state of Israel funds unlimited fertility treatment to any of its female citizens. Palestinian residents of East Jerusalem, whose area has been annexed to Israel after its occupation in the 1967 War, are also entitled to these services. Whereas this occupied population indeed benefits from the state funded treatment, East Jerusalem women face particular difficulties that arise primarily from linguistic and political barriers. The difficulties are especially pronounced when the husband is a resident of the West Bank and as such, requires a special permit to enter the city. The article depicts this mixed picture, in which medical privilege merges with political exclusion.

Key words: Israel, Jerusalem, Palestinian, fertility treatments, reproductive policy, IVF.

Introduction

Israel's public funding of fertility treatments is unparalleled worldwide. Treatment is offered for a modest user contribution – roughly 100 US Dollars per IVF cycle – to practically any Israeli woman, without screening and irrespective of her family status, sexual orientation, education, financial situation or mental wellbeing, to the age of 45 – or 51 if she uses a donor egg – until she has two children with her present partner (where applicable). The number of treatment cycles is not limited and some women indeed undergo as many as twenty five cycles or more (Birenbaum-Carmeli and Dirnfeld, 2008). These exceptional policy and practice have generally been attributed to three major sources: the Biblical prescription, the Holocaust trauma and demography politics. The biblical commandment 'Be fruitful and multiply' (Genesis, 1: 28) has historically identified individual with collective survival, rendering reproduction a collective mission (Swirski, 1976; Haimov-Kochman, 2008). In more recent history, childbearing was constituted as a symbolic response to the Nazi extermination and a rehabilitative act for individual survivors. This pronatalist reaction was also encouraged by state bodies that aimed to enlarge the local Jewish population, hence defined high fecundity as part of the Zionist nation-building effort (Stoler-Liss, 2003).

These political connotations of fertility charge the entitlement of Palestinians who are Israeli citizens to funded fertility treatment with sensitive meanings and contradictions (Kanaaneh, 2002). Within this category, the case of East Jerusalem is especially pronounced. In order to elucidate the particularity and its practical consequences, we start with an overview of the political and economic circumstances within which East Jerusalem Palestinians receive fertility treatment. We precede the overview with a brief methodological section.

Methodology

The present paper is based on the participant observations of the second author (R K-H), who is a fertility expert at the Sheikh Jarrah women's health clinic and at the IVF unit at the Mount Scopus Hebrew University Hadassah Medical Center. The observations were supplemented by semi structured interviews with three additional doctors in

the IVF unit, which were conducted by the first author (D B-C).

The description of the political context is based primarily on published reports. The reports are produced mainly by the United Nations Relief and Works Agency (UNRWA) and the United Nations' Office for the Coordination of Humanitarian Affairs (OCHA). Additional sources are reports generated by Israeli bodies: (1) *Btselem*, which is the Israeli Information Center for Human Rights in the Occupied Territories, documenting human rights violations in the Occupied Territories, (2) ACRI, The Association for Civil Rights in Israel, and (3) Jerusalem Institute for Israel Studies. The heavy reliance on reports rather than academic studies encapsulates the scarcity of academic research on occupation-related subjects.

Jerusalem's Palestinian residents who are not Israeli citizens

Until the 1967 war, the Israeli section of the city of Jerusalem spanned across 38 sq kilometers (Yanay, 2007). Following the occupation of the West Bank in the war, Israel annexed 70 square kilometers. Today, following various changes, the city's jurisdiction is 126 Sq. kilometers (Hoshen and Korach, 2009). Of this territory, one square kilometer comprises the historical Old City of Jerusalem. The rest of the land was a new addition to the city's jurisdiction. Under its rule, the State of Israel has confiscated some 30% of the annexed territory. On this land, it has constructed various government buildings (e.g., the Ministry of Public Security, the Ministry of Housing, the Ministry of Justice, the Jerusalem district court), and supported the construction of 64,870 dwellings for Jewish Israeli settlers. In contrast, the Palestinian residents of the area were allowed to build only 8,890 dwelling units during over four decades of Israeli rule. At present, following the erection of the separation barrier that cuts through the Palestinian metropolitan area, about 50,000 Palestinian residents have become isolated behind the barrier, cut off from essential services, including medical care. Many of these residents, who have formerly moved to the city's outskirts, have returned to central city neighborhoods, out of fear of losing their civil status and in order to gain easier access to essential services. Crowding has consequently mounted to 1,054 persons per square kilometer in 2007, the highest figure in the West Bank (UNRWA, 2010). The housing density among the Palestinian residents is also the highest within the city (Table 1). Moreover, owing to Israel's policy of severe restrictions on development and construction in the Palestinian neighbourhoods, East Jerusalem Palestinians are practically unable to obtain formal construction permits from the Israeli authorities. As a result, thousands of Palestinians in the city are under threat of house demolition, eviction or displacement. According to the United Nation Office for the Coordination of Humanitarian Affairs, the figure is roughly 60,000 residents (OCHA 2009), representing just under a quarter of the city's Palestinian residents (Hoshen and Korach, 2009).

In terms of civil status, the majority of East Jerusalem inhabitants – 93% - are defined as permanent residents of the state of Israel. (5 % are citizens and 2% are negotiating their status; Hoshen and Korach, 2007). In this respect they differ from Palestinians who live in the West Bank and the Gaza Strip, who have no civil status in Israel. Being defined as permanent residents, East Jerusalem inhabitants are entitled to most civil rights in Israel, but are denied basic political rights like voting to the Knesseth (Israel's parliament) and eligibility to Israeli passports. As of 2003, an Israeli resident – or

Table 1. — The Palestinian vs. Jewish Sector in East Jerusalem.

	Jewish sector	Palestinian sector
Population	495,000 (65%)	269,000 (35%)
Percent of the city's poor	33%	67%
Beneath the poverty line (families)	23%	67%
Beneath the poverty line (children)	48%	74%
Unemployment	9%	13%
Person per room	1.0	2.0
Sq. meter per capita	24	11
Public parks	1,000	45
Swimming pools	34	3
Libraries	26	2
Sport facilities	531	33
Total fertility rate	4.0 (7.7 among orthodox Jewish women)	4.1

Source: Btselem, withholding investments in East Jerusalem, n.d; Hoshen and Korach 2009).

citizen, for that matter – who marries a resident of the occupied territories or a neighboring Arab country, is not allowed to apply for Israeli status for the spouse. This amendment to the Citizenship Law – which has immediate implications on fertility treatments, as will be shown below – has been introduced presumably as a security measure, but was then extended on 'demographic grounds.' The problematic stance of the amendment is implied in its yearly revalidation and the continued Supreme Court debate about its legitimacy. The sharp contrast to the Law of Return, which grants every Jewish person and their spouses, full citizenship upon arrival in Israel, is self evident.

Residents of East Jerusalem do have a right to work and travel in Israel. They pay Israeli tax and are eligible to healthcare and social benefits. This entitlement is, however, fragile. As of 1995, East Jerusalem residents who leave their homes and travel abroad for a longer period of time, e.g., to study, lose their residency status (Golan 2009), thereby losing, among other things, their civil rights in Israel. Between 1967 and 2007, the Ministry has revoked the permanent residence status of 8,558 East Jerusalem Palestinians (Btselem, revoking civil status). Notably, in the subsequent year, 2008 alone, it has revoked this status from 4,577 Palestinian residents of East Jerusalem (Hasson, 2009). Generally, East Jerusalem residents, who want to materialize their Israeli civil rights, need to positively prove – unlike any other Israeli – that they have resided in the city continually for years. Investigation is carried out whenever a new claim is being filed (Btselem, revoking social rights).

The reluctance towards East Jerusalem residents manifests in discrimination in other spheres of life as well. In education, approximately 5,500 school-age children, comprising 5.84% of total school-age population, are not registered in any educational institution (ACRI and Ir-Amim, 2009). Of the 645 classrooms that the Israeli Supreme Court has ordered Jerusalem municipality to construct, less than 100 have been built. The gaps in comparison to the Jewish sector are enormous (Table 1). Though they comprise a third of the city's inhabitants, the Palestinian residents of Jerusalem are allotted a mere 14% of the municipality budget (Golan, 2009). The condition of the Eastern part of the city has been described as 'general neglect' (Eldar, 2009).

In terms of economic status, Jerusalem's population in general is poorer than that of other main cities in Israel (owing to the high percentage of impoverished Palestinians and orthodox Jewish families in which the man attends biblical institutes and is not gainfully employed). Within this landscape the Palestinians are still the poorest (Table 1).

This disparity is commonly attributed to Israel's interest in creating and maintaining a Jewish majority in the city. Informally, the concerted effort to drive Palestinian residents outside Jerusalem has sometimes been entitled 'the silent transfer'. More generally, East Jerusalem residents are perceived as part of the entire Palestinian minority living within the borders of pre-1967 Israel, which is often referred to as 'the demographic problem' or 'threat.' Noticeably, the birth rate of Jewish Orthodox women in Jerusalem is 7.7 as compared to 4.1 among the city's Palestinian residents (Hoshen and Korach, 2009). It is this political climate that charges the entitlement of East Jerusalem residents to unlimited state funded fertility treatments with heightened sensitivity.

The clinic at hand is located in Sheikh Jarrah, a residential neighborhood in the Palestinian section of Jerusalem. On account of property dispute regarding houses that had belonged to Jewish owners prior to the 1948 war – namely, before the founding of the state of Israel – some Jewish settlers have reclaimed allegedly Jewish-owned properties and their alleged right to 'return' to the neighborhood and gained Court approval to their demand. Since last August (2009), four Palestinian families – 51 people – were evicted from their Sheikh Jarrah homes by Court order, and their emptied houses were captured by Jewish settlers. The motion has stirred loud criticism, mostly from abroad, underscoring the denial of the Palestinians' respective right to reclaim their own confiscated and abandoned property that is scattered throughout West Jerusalem and the whole of Israel (Medzini and Weiss, 2009). In the context of the present article, we note that Sheikh Jarrah dispute, addressing the locality in which the Palestinian residents meet the mostly Jewish medical staff, features constantly in the media owing to weekly demonstrations in the neighborhood.

Health and Healthcare in East Jerusalem

In 1995, Israel has ratified the national Health Insurance Law that entitled all Israeli citizens – and permanent residents – to public health care. The payment for the services is collected by the National Insurance Institute, as a progressive tax, in proportion to one's income. The services are provided by the four HMOs that have been operating in the country in the decades that preceded the Health Insurance Law. Individuals can join or change membership from one HMO to another according to their preference.

The HMOs' budget is allocated on a per capita basis, according to the insured population's age. As a result, the competition is especially fierce when the

population at hand is young, i.e., relatively healthy. With a mean age of 19 years, as compared to 25 among the city's Jewish population, East Jerusalem's Palestinian residents, who became eligible to health insurance when the national Health Insurance Law came into effect, make an attractive audience for the HMOs. The competition that evolved among the HMOs brought about a swift improvement in health services in Jerusalem's Palestinian sector.

Consequently, healthcare is a relatively equitable life domain in the underprivileged lives of East Jerusalem Palestinians. An indication, if ambiguous, to this state of affairs can be found in the infant mortality rate. Starting out from 45.2 per 1,000 live births in the 1970's, infant mortality rate among Palestinians in Jerusalem has declined to 6.0 in 2004-2006. Improved as it is, however, this figure is still more than twice higher than the respective figure among the city's Jewish residents: 2.9 per 1,000 births (Hoshen and Korach, 2009). Part of the gap is attributed to the prevalence of congenital malformations due to consanguineous marriage (Amitay, 2005). The remaining difference, however, probably reflects the educational and economic disadvantage of this population.

Clalit is Israel's largest HMO, serving over fifty percent of the country's population. The majority of the Palestinians in Israel are also insured in this HMO, so are most East Jerusalem residents. The women's health clinic in Sheikh Jarrah that we will describe below, is *Clalit*'s main ob/gyn clinic in East Jerusalem, serving practically only Palestinian women.

In addition to Israeli service providers, the city has nine Palestinian hospitals and 134 UNRWA primary care clinics, providing mother and child healthcare, family planning and preventive medicine services (UNRWA, 2009). These medical centers are not funded by the Israeli system and serve primarily West Bank and some Gaza Palestinians who are not eligible to Israeli health services. We will not go into the details of this subject as it is beyond our present scope.

Fertility treatment in East Jerusalem

Infertility is highly aggravating for affected couples everywhere. In the Middle East, where childbearing is crucial for one's self accomplishment and social standing, the implications are especially pernicious, stigmatizing both men and women (Inhorn 2004, 2009; Haimov-Kochman, 2009; Serour, 2008). The thorough medicalization of the impairment may have somewhat alleviated its stigma (Birenbaum-Carmeli and Inhorn, 2009). Still, childlessness comprises a major social problem and an injury to individuals' self-perception. The impact on the woman, her dignity, moral identity and psychological wellbeing, is devastating (Inhorn and Van Balen, 2002; Haimov-Kochman, 2009). Often, the woman is blamed for the barren marriage even when its source actually lies in her partner's body (Serour, 2002). The unacceptability of adoption in most Muslim circles rules out this solution to childlessness (Birenbaum-Carmeli and Inhorn, 2009). Equally inconceivable in this setting is the notion of voluntary childlessness, a popular mode of camouflaging infertility in industrialized countries (Inhorn and Van Balen, 2002: 8). Resolving infertility is therefore crucial to the life of infertile couples, and the availability of funded treatment is considered a great relief. Poorer families – and East Jerusalem families largely fall into this category – are especially dependant on public funding. Having said that, we need to remember the state's interest in reducing the city's Palestinian population, which is the broader context of the medical encounter that will be depicted now.

The community clinics. *Clalit's* women's clinic in Sheikh Jarrah operates since 1989, serving *Clalit*'s Palestinian clientele five days a week. The clinic provides basic obstetric and gynecological services. Fertility treatments are provided mostly by three fertility specialists from the nearby Hadassah Hebrew University Medical Centre on Mount Scopus. The doctors, two men and a woman, are all Jewish. Only one of them speaks Arabic, though in years of work with Palestinian patients, the other two have acquired enough command of the language to enable basic communication. A Palestinian woman has been working at the clinic as a translator for over fifteen years. Her long acquaintanceship with fertility issues, alongside the doctors' knowledge of Arabic, if limited, ensures relatively smooth communication between the Hebrew speaking Jewish doctors and the Arabic speaking Palestinian patients.

At the Sheikh Jarrah clinic only basic tests and treatments can be conducted: Ultrasound follicular follow up and hormonal profiling. For other procedures, still quite elementary, e.g., sperm count or hysteroscopy, the patients are referred to the Jewish part of the city. Historically, the referral to the further laboratory was initiated in order to ensure that the Palestinian patients benefit from the same quality of service that the Jewish population enjoys. Moreover, the distance between Sheikh Jarrah and the West Jerusalem clinic is very short: a ten minute walk. Still, in practice, crossing the path on foot is uncustomary for Palestinian women by themselves, even when walking in pairs. The way thus requires a ride in two buses as there is no direct bus from the

Palestinian part of the city to the Jewish section. Once in the Jewish part of town, the women, identified as 'Arab' by their traditional clothes, are subject to suspecting by-passers' gaze. At the entrance to the clinic, the Palestinian patients, like all others, must undergo a security search, in which they are probably checked more thoroughly. In this clinic, there is no translator and many of the Palestinian patients cannot speak any Hebrew. The linguistic limitation adds to the surrounding tension.

The language-related difficulty requires some elaboration. Arabic is an official state language in Israel. It is the mother tongue of its twenty percent Arab minority. However, Arabic is not a compulsory subject in Jewish schools and only few Jewish Israelis can speak the language. Among Ashkenazi Jews – and most doctors in the IVF unit (and in Israel more generally) are of Ashkenazi descent – Arabic speakers are particularly rare. In Israel's Arab schools, however, Hebrew is mandatory. Palestinians who are Israeli citizens are therefore pretty fluent in Hebrew. This generalization does not apply to East Jerusalem residents, who do not follow the Israeli curriculum and are not required to learn Hebrew. While releasing East Jerusalem residents from a compulsory requirement, this 'freedom' leaves many local Palestinians devoid of communication capacity outside the Arab community. Women, who normally do not work outside their homes – a mere 13% of the Palestinian women in Jerusalem are gainfully employed (Hoshen and Korach, 2009) – have particularly meager Hebrew linguistic skills. Yet, for these underprivileged couples, most of whom make a living off the husband's work as a day laborer, taking a day off in order to accompany one's wife to the clinic and serve as a translator, is a luxury that most patients cannot afford. The woman thus usually arrives in the clinic together with a female relative and depends on the occasional presence of an Arabic speaking staff member.

Given the inconvenience and discomfort that these visits entail, many Palestinian patients prefer to approach a private laboratory or clinic in the familiar eastern part of the city, though this means paying out of pocket – if a relatively modest fee (e.g., 70 USD for laparoscopy) – for a service that they can obtain for free in the Jewish part of town. Moreover, the Israeli doctors do not always trust the professional quality of the East Jerusalem procedures and therefore often request a repeating test (e.g., sperm count) in a laboratory with which the doctors are better acquainted, i.e., one that operates in the Jewish part of the city. Problems that cannot be resolved in these clinics, primarily those that require IVF, are referred to the Mount Scopus IVF Unit in Hadassah Hebrew University Medical Center. As mentioned, all these treatments are provided with just a minimal patient financial contribution.

The hospital clinic and the predicament of geographically divided couples. Inside the examination room, in the Mount Scopus IVF clinic, the medical team offers Palestinian women and couples cutting edge fertility care. However, here too, surrounding factors position East Jerusalem residents at a disadvantage vis-à-vis their Jewish counterparts or even their Palestinian counterparts who are Israeli citizens (Palestinians living in those regions that have been included in the state of Israel prior to the 1967 war).

Roughly half the patients in Mount Scopus IVF unit are Palestinians. Nonetheless, linguistic barriers abound here as well. Of the five unit's nurses, only one speaks Arabic. The other nurses and the doctors use a mixture of Hebrew, Arabic and English in order to assure that their instructions are understood properly. Occasionally, however, a woman misunderstands, especially those instructions that are delivered on the telephone, and takes a wrong dose of medication or misses the prescribed time of an injection. Such mistakes may result in cancellation of a whole treatment cycle. Some women solve the problem by requesting a Hebrew speaking relative, in most cases, a man, to receive the instructions over the phone on their behalf, thereby compromising their intimacy and privacy. In the absence of a Hebrew speaking relative, the woman is invited to come back to the clinic, at midday, for the second time on the same day, in order to get the complicated instructions straight. All of these problems become more poignant when the treated spouses live on two sides of the separation barrier, namely, when one partner is an East Jerusalem resident and the other one lives elsewhere, most commonly, in the West Bank.

In 2002, Israel has decided to construct a Separation Barrier that would enable monitoring of all Palestinian movement from the occupied West Bank to Israel. In the Palestinian conurbation around Jerusalem, where life has previously flowed across the municipal boundaries – thereby facilitating the creation of geographically divided couples – the barrier seriously interrupts daily life. People living in neighboring streets and suburbs have been cut off, since entering Jerusalem now entails a long, formal process of permit application, the outcome of which is uncertain. The actual crossing into the city is another obstacle, as only four out of the 14 checkpoints between the city and its surrounding are open to Palestinians. Indeed, in some cases, mobility restrictions may render a couple's meetings – and intercourse – so rare as to prevent conception. A whole year can thus go by without a pregnancy,

making the couple eligible to infertility workup. Ironically, the state that prevents the partners from getting together would provide them with costly, as well as bodily taxing fertility treatments to help them conceive.

As in other Middle Eastern populations, infertility is extremely high among Palestinian men in Israel, implicating 80-85% of the infertile couples seeking medical assistance (Mount Scopus clinic estimates; See also Inhorn 2004, 2009). The common practice of attending to the man's infertility by treating his wife's body is endorsed in the Mount Scopus IVF unit as well. At this point, the question which spouse is an East Jerusalem resident, i.e., which partner is entitled to free treatment, becomes crucial, as the state funds fertility therapy, including IVF, only to the woman, who is the actual clinic patient. This means that if the woman is an East Jerusalem resident, she is entitled to treatment even if the problem is primarily her husband's. However, a West Bank wife of an infertile East Jerusalem resident is not eligible to treatment, even though she would have been treated in order to resolve his impairment. Such couples, in which the wife is not an Israeli resident, have to approach a West Bank fertility clinic and pay for their treatment. The notion that is commonly cited by fertility experts, that in the treatment of infertility, it is the couple – rather than one partner or the other – who is 'the patient', apparently collapses when we look at these Palestinian couples who live on two sides of the barrier.

In the more favorable cases, when the wife is entitled to healthcare, she can start treatment. She needs, however, to resolve the problem of her husband's probable inability to arrive in the clinic at a prescribed day. Both, obtaining an entry permit and crossing the barrier are especially difficult for young men who are perceived as the greatest security threat. The Palestinian men whose wives undergo fertility treatment in the Israeli system belong almost invariably to this category.

The husband's absence on the day of ovulation normally results in losing the whole cycle. In one such case, the husband managed to provide the semen in some improvised spot near the checkpoint and then transferred the sample to a relative who was waiting on the other side. However, this resourceful solution was an exception. In most cases, the cycle was lost.

Losing a cycle was especially painful in the case of IVF. Trying to resolve the problem of having many mature oocytes and no sperm for fertilization, the doctors started exploring the option of oocyte freezing (Table 2). Today, Mount Scopus embryologists are considered Israel's leading team in this technology.

Having realized that the husband's inability to arrive in the clinic on the prescribed day was in fact rather common, the IVF team started requesting a frozen semen sample from every men living behind the barrier. The man thus comes over from the West Bank to the Mount Scopus IVF unit whenever he can and freezes semen for later use. This practice has become a routine component, indeed, a requirement, for treating geographically split couples. If the man cannot obtain a permit to arrive at the sperm bank even once, in order to freeze a semen sample, fertility treatment will not start.

This solution is however, costly, entailing a fee of 700 NIS (nearly 200 USD). In a reality in which the real per capita income is 1,284 USD (Kawach, 2010) this sum amounts to some 15% of one's annual income. The inconvenience and costs drive some geographically divided Palestinian couples to seek treatment in the West Bank, despite the generally lower professional level, as compared to the treatment that the woman can obtain for free as an Israeli resident.

Discussion

By way of conclusion we can summarize that once inside the clinic, East Jerusalem Palestinians receive high quality fertility treatment, equal to that provided to Jewish Israelis. Yet, the medical encounter is surrounded with formal and informal obstacles and inequality. Palestinian patients suffer more inconvenience due to communication difficulties and restrictions on their movement, which also translate into extra costs. Whereas the doctors do not try

Table 2. — Egg freezing-thawing figures.

Time span	1999-2004
Number of women	24 women, of which -
	3 Jewish women
	21 Palestinian women [the first ten women were all Palestinian]
Numer of frozen-thawed eggs	120
fertilization rate	60%
pregnancy rate	31% per embryo transfer
oocyte survival rate	Rise from 30% to 70%

to alter the political limitations placed on their Palestinian patients, the IVF team does make active and creative efforts to resolve the various problems that individual patients encounter and to maximize the treatment's efficacy under the existing conditions.

A crucial voice that is missing from the depiction above is that of the patients. The doctors interpret the return of Palestinian couples for a second and third child, the gifts and sweets, as well as the babies' photos that they offer the staff as tokens of gratitude. Bringing the babies along is another indication of favorable attitude. Having said that and not necessarily in contradiction, the dialogue between the mostly Jewish staff and the Palestinian patients is carried out with great caution that suggests profound fragility. During decades of work with East Jerusalem Palestinians, both patients and staff consistently refrain – so the doctors testify – from any political comment, even at the height of the Intifada and the Israeli attack on the Gaza strip in the winter of 2009. Even the current struggle over the eviction of Sheikh Jarrah Palestinian families from their homes, and the weekly demonstrations in the neighborhood, which take place near the clinic and the patients' homes, and which are routinely reported in the media, is silenced in the clinic encounter. Another hint towards the underlying tensions is the failure of one doctor in the IVF unit to recruit patients for a qualitative study that aimed to give voice to their travail while undergoing fertility treatments in Israel. The doctor, a (non-Jewish) Russian woman married to a Palestinian man, who lives in East Jerusalem, who is fluent in Arabic and is now an observant Muslim, approached a few Palestinian patients of the unit and invited them to participate in the study. Though she assured the women that the descriptions would be anonymous and that all identifying details would be removed, all but one woman did not even consider participation. Eventually, this woman, too, has decided in the negative. The women's silence leaves us in the dark regarding their experience. Yet, their refusal to talk may represent a sense of insecurity. An interesting, if ironic counterpart to the women's silence can be found in the silence of Hadassah medical center, which intentionally leaves this exemplary Israeli-Palestinian cooperation away from the spotlight.

What does the description above add up to? Possibly, to conclude that owing to the HMOs economic interests in enrolling the Palestinian population, and the doctors' professional conviction, healthcare, and fertility care in particular, are a relatively less discriminatory sphere in the grim picture of Palestinian life under Israeli occupation. Yet, even here, the treatment is imbued with the politics of domination.

References

ACRI and Ir-Amim. Status Report: The Arab-Palestinian School System in East Jerusalem As the 2009-10 School Year Begins, The Association for Civil Rights in Israel, http://www.acri.org.il/pdf/EJeducation2009en.pdf 2009, accessed February 3, 2010.

Amitay Y. Infant mortality in Israel: National Figures – 2003, Ministry of Health, www.health.gov.il/Download/pages/tmuta2003_tinuk.doc, 2005, accessed January 31, 2010.

Btselem, East Jerusalem: Denial of Health Insurance and Social rights,
http://www.btselem.org/hebrew/jerusalem/social_security.asp, N.D. accessed January 15, 2010.

Birenbaum-Carmeli D, Dirnfeld M. The more the better? IVF policy in Israel and women's views, Reproductive Health matters. 2008;16(31):1–10.

Birenbaum-Carmeli D, Inhorn M. Masculinity and Marginality: Palestinian Men's Struggles with Infertility in Israel and Lebanon, Journal of Middle Eastern Women Studies. 2009;5(2):23-52.

Btselem, refraining from Investments in East Jerusalm. N.d. [Hebrew] http://www.btselem.org/Hebrew/Jerusalem/Infrastructure_and_Services.asp, accessed January 29, 2010.

Btselem, revoking civil status, [Hebrew] http://www.btselem.org/Hebrew/Jerusalem/Revocation_of_Residency.asp, N.D. accessed January 29, 2010.

Elder A. The Jerusalem Syndrome, *Haaretz*, November 23. http://www.haaretz.com/hasite/spages/1130036.html , 2009; Accessed January 29, 2010.

Feller O. Residents by force, *Ynet,* http://www.ynet.co.il/articles/0,7340,L-3718076,00.html, May 20, 2009, accessed January 15, 2009.

Foundation for Middle East. Jerusalem Statistics 2006, http://fmep.org/settlement_info/settlement-info-and-tables/stats-data/jerusalem-statistics-2006, accessed January 15, 2010.

Golan D. Anyone can drum, Haaretz, December 22 2009, http://www.haaretz.com/hasite/spages/1136721.html, accessed January 29, 2010.

Gordon N. Separate But Unequal: Jerusalem's Silent Conquest: By Denying Palestinians Equal Rights Israelis Expedite Palestinian Expulsion, Washington Report on Middle East Affairs, March 1999, p. 46.

Haimov-Kochman R, Rosenak D, Orvieto R, Hurwitz A. Infertility counseling for orthodox Jewish couples. Fertil Steril. 2010; 93(6):1816-9.

Haimov-Kochman R, Imbar T, Farchat M, Bdolah Y, Hurwitz A. Adolescent infertility – to treat or not to treat. Fertil Steril. 2009;90(5):e1-4.

http://www.washington-report.org/backissues/0399/9903046.html, accessed, January 6 2010.

Hasson N. Israel stripped thousands of Jerusalem Arabs of residency in 2008, *Haaretz*, December 2, 2009,
http://www.haaretz.com/hasen/spages/1132170.html, accessed February 2010.

Hoshen M, Korach M. Jerusalem Figures 2005/2006: Current situation and Upcoming Trends, Jerusalem Institute for Israel Studies [Hebrew] http://www.jiis.org.il/imageBank/File/articles/FACTS-2007-heb.pdf, 2007. accessed January 31, 2010.

Hoshen M, Korach M. Jerusalem Figures 2007/2008: Current situation and Upcoming Trends, Jerusalem Institute for Israel Studies [Hebrew] http://www.jiis.org.il/imageBank/file/publications/facts_2008_heb.pdf , 2007. accessed January 31, 2010.

Inhorn MC. Sexuality, masculinity, and infertility in Egypt: Potent troubles in the marital and medical encounters. Journal of Men's Studies. 2002;10:343-59.

Inhorn MC. Middle Eastern masculinities in the age of new reproductive technologies: Male infertility and stigma in Egypt and Lebanon. Med Anthropol Q. 2004;18:34-54.

Inhorn MC. Middle East Masculinities in the Age of Assisted Reproductive Technologies, in *Assisting Reproduction, Testing Genes: Global Encounters with New Biotechnologies*, D. Birenbaum-Carmeli and M. Inhorn (eds.), New York and Oxford: Berghahn Books, 2009.

Kanaaneh RA. Birthing the Nation: *Strategies of Palestinian Women in Israel*, University of California Press 2002.

Kawach N. Real per capita income of Palestine plunges, Emirate Business 24/7, http://www.zawya.com/pdfstory.cfm?storyid=ZAWYA20100117042130&l=042100100117, January 17, 2010, accessed January 30, 2010.

Medzini R, Weiss E. Confrontations yet again in Sheikh Jarrah: Twenty five Left Wing Activists detained, Ynet, December 18, 2009, http://www.ynet.co.il/articles/0,7340,L-3821875,00.html, accessed January 13, 2010.

Maoz M, Nusseibeh, S. (Eds.). *Jerusalem: Points of Friction and Beyond.* The Hague: Kluwer Law International 2000.

OCHA (United Nations Office for the Coordination of Human Affiars) 2009. Consolidated appeal for occupied Palestinian territory 2010: Humanitarian Appeal, http://ochaonline.un.org/humanitarianappeal/webpage.asp?Page=1823, accessed January 15, 2009.

OCHA West Bank Movement and Access Update, http://www.ochaopt.org/documents/ocha_opt_movement_access_2009_november_english.pdf, November 2009, accessed January 30 2010.

Serour GI. Attitudes and cultural perspectives on infertility and its alleviation in the Middle East area. In: Current Practices and Controversies in Assisted Reproduction – Vayena E, Rowe PJ, Griffin PD, eds. Geneva, Switzerland: World Health Organization. 2002,41-49.

Serour GI. Medical and socio-cultural aspects of infertility in the Middle East, ESHRE Monographs, 2008, 1:34-41, http://eshremonographs.oxfordjournals.org/cgi/content/full/2008/1/34, accessed January 2, 2010.

Stoler-Liss, Sachlav. 2003. 'Mothers Birth the Nation': The Social Construction of Zionist Motherhood in Wartime in Israeli Parents' Manuals. Nashim. 6: 104-18.

Swirski, S. 1976 Community and the Meaning of the Modern State: The Case of Israel, Jewish J Sociol. 18: 123-40.

UNRWA. UNRWA Fact Sheet, http://www.unrwa.org/userfiles/201001194213.pdf, 2009, accessed on January 29, 2010.

UNRWA. West Bank and Gaza Strip Population Census of 2007, Briefing Paper, http://www.unrwa.org/userfiles/2010012035949.pdf, January 2010, accessed January 29, 2010.

van Balen F, Inhorn MC. Introduction. Interpreting Infertility: A View from the Social Sciences. In: Inhorn M. and F. Van Balen (Eds.) *Infertility around the Globe*, Berkeley, University of California Press, 2002,3-32.

Yanay D. Forty year of Israeli Rule in East Jerusalem, Ir-Amim, http://www.ir-amim.org.il/?CategoryID=334, 2007, accessed January 6 2010.

Healers, nurses, obstetrics-gynaecologists dealing with women in the quest to become pregnant in Southern Mozambique

E. Mariano[1], M. Samucidine[2], I.B. Boaventura[3], C.P. Sousa[4]

[1]*Researcher and Lecturer at Faculty of Arts and Social Science – Dept. of Archaeology and Anthropology, at the Eduardo Mondlane University (UEM), PhD fellow at Catholic University of Leuven (KUL).*
[2]*Dept. of Obstetrics and Gynaecology, UEM, Maputo Central Hospital, P.O. Box 257, Maputo.*
[3]*Dept. of Obstetrics and Gynaecology, UEM, Maputo Central Hospital, P.O. Box 257, Maputo.*
[4]*Dept. of Community Health, Faculty of Medicine, UEM, P.O. Box 257, Maputo.*

Correspondence at: esmeralda.mariano@uem.mz or esmeraldamariano3@gmail.com

Abstract

People's expectations concerning progeny in southern Mozambique are not solely confined to individual's life as defined by the temporal dimension of the biological vital cycle. It interlinks with after – death and the relations between the individual and spirits of the ancestors. All members of the community aim at a number of symbolic systems and interweave relations with social expression that create in their interplay a universe where everyone may build his/her identity. To be childlessness is an unfortunate event that can disturb patterns of regularity and continuity with implications for the health and well being of individuals and the community. The traditional healers (*tinyanga*) in the community have the social task of addressing these felt needs by rendering continuous what is discontinuous, re-establishing the disturbed continuity, and recreating the conditions for recognition. Their assignment in caring for the individual and the community is accomplished through practices emerging from syncretism of customary knowledge and practice and premises from biomedical field. It is a dynamic area of interaction very close to common people and encompassing their understanding and positioning in daily social life with the *tinyanga* well placed to guide and influence. Therefore, the diagnostic and therapeutic practices of the *tinyanga* emerge as privileged instances in this investigation. Present paper describes *kutsamiwa* arising within the frame of failure in generating babies moving through levels of interaction and dialogue between hospital perspective and *tinyanga* and women's experiences.

Key words: tinyanga, diagnostic procedure, treatment, *kutsamiwa,* infertility.

Introduction

> *I would have liked to have children, sometimes my husband does not respect me, and he does not show/present his salary because I have no children. You may raise children of another woman (...), do everything [more than] a real mother [biological] could do but he will never say: you have done me good! No, you may do all you can, your husband may have fifty children but with you, because he sleeps with you [have sexual relations] he has to have a child that comes out of your belly and you also need to feel happy because you have your child. Having no child in this world is just not possible!* (Female healer, Maxaquene 2008).

Contrary to the policies in reproductive health that are based on the perspective of birth control, of population growth stabilisation and the reduction of maternal and neo-natal mortality, individuals without or with few children undergo severe biological, social psychological, and discriminatory practices (in society) that lead to depressive feelings, worries and sadness (Gerrits, 1997, Barden-O'Fallon, 2005). Childlessness brings to discussion gender and power relations in the couple and with relatives and the therapists. When a woman does not get pregnant she is the first to be pointed out for the lack of children and subject to seek for health care on her own. Non conception and children death are rarely perceived

as a health problem with hospital biomedical solution. Healers are the first choice for consultation and diagnosis. Only when traditional medicine attempts are ineffective then questioning on the lack of children turn to the biomedical sphere.

Since 2001 aspects inherent to infertility in Southern Mozambique (Maputo province) had been explored and identified the existence of *kutsamiwa* (Mariano, 2002) a physical disorder associated to lack of children, frequent occurrence of abortions, including the death of the husbands. This phenomenon though still very little studied was reported in a WHO study (2005-2007) on vaginal practices in Tete Province of Mozambique where is known as *masale* or *masungo,* and *vúmbá* among the Shona (Chapman 2006).

The present research on reproductive failure and sexual health problems in the context of different medical systems in Gaza and Maputo, that is currently developing[1], reveals in the traditional context three main etiologies of the inability to bear children: a) non compliance with *lovolo* and or its incorrect performance; b) *xilume* (pre-menstrual pains) and *xithethu* (non entrance and retention of sperm), and c) *kutsamiwa*. Within these etiologies we give particular attention to *kutsamiwa* for the following reasons: 1) it implies using an invasive procedure to remove a tissue, epithelia or warts in the genital and anal region; 2) a considerable number of women has been submitted or voluntarily submits to this type of intervention with scant evidence on its therapeutic efficacy relative to infertility; 3) literature on the phenomenon in Mozambique is scarce; and in association with the latter because it is a physical intervention that requires both traditional and biomedical approaches for its analysis and understanding.

Methods and research locations

This present research project has been approved by the Scientific and Academic Council of the Faculty of Arts and Social Sciences of the University Eduardo Mondlane (UEM) in September 2008, and by the Faculty of Social Sciences Committee of the Catholic University of Leuven (KUL) in Belgium in March 2009, and by the National Commission of Bioethics for Health of the Ministry of Health in Mozambique in the beginning of January 2010.

In an active and continuing way the research involves twelve traditional healers (*tinyanga,* and the herbalists known as *tinyangarhume*)*;* three obstetric-gynaecologists, one general practitioner, two registered nurses – one general and the other specialized in Maternal and Child Health (MCH), and three final year students in anthropology. All of them participate in the process of identification of individuals reporting fertility problems, and in the analysis and discussion of the phenomenon. The conversations took place in the *tinyanga* working places that is the *ndhumbha* = houses of spirits, or traditional healers cabinets that are privileged places for men and women to meet and exchange ideas and concerns on reproductive sphere.

Some patients, after consultations with *tinyanga* and conversations with me, have been referred to the biomedical health services (Xai-Xai Health Centre and the Provincial Hospital of Gaza, Magude Health Centre and Central Hospital of Maputo, the best equipped in the country), for clinical observations and interventions by the gynaecologists. This process only started in January 2010 due authorization of the Minister of health to undertake the study. In spite of the approval by the biomedical health system and its explicit acknowledgement of the importance of the study the involvement of the biomedical specialists is still limited and often they are not available for the required follow up anticipated in the study. In some consultations at the hospitals the patients were followed by the healer and me. The clinical observation using multidisciplinary lens allows for better understanding of what problem women and healers refer to and the location of the problem in the body of the woman.

The data here presented constitute the first notes of the conversations started by the end of February 2008 with the *tinyanga* both sexes though mostly women. Individual informal interviews were conducted with twenty-two women that bore a child but never got pregnant again and others that had never got pregnant. Group discussions were held with biomedical professionals–gynaecologists, nurses and traditional birth attendants in the Provinces of Maputo (Maputo city and Magude District) and Gaza. For the interviews with women who do not conceive and bear children we have adopted the method of narrative as in the experience of telling and interpreting the narrative is a mediator between the interior world of thinking and feelings and the outer world of actions and observable states (Garro and Mattingly, 2000). While the hospital doctor do not need narratives for its diagnosis as treatment is prescribing from data observable in a material body the traditional healers centres on its subject in the interaction with its family milieu and its social

[1]For PhD degree at Catholic University of Leuven (KUL) in Belgium in the context of DESAFIO-program VLIR-IUC-UEM.

relations acting as a mediator in the narratives. Fifteen cases were selected from the total narratives that illustrate the different experiences of infertility; causes of non conception and procedures in diagnosis and therapy to be followed during the research (until 2012).

The dialogue and structure of the conversations with the different informants was based in the application of topic guidelines and semi-structured interviews in Portuguese and Changana, the predominant language spoken among the participants in the areas of study and in the informal conversations.

The observation at the consultations (*lhalhuwa tinhlolo* = diagnostic procedure) conducted by the *nyanga* enabled the identification and understanding of the criteria for the attribution of aetiologies of reproductive failure in man and in woman.

Study findings

Even when traditional healers admit the responsibility of man over the fertility of the couple men are rarely directly involved in the therapeutic process. It is the women that often submit to traditional treatments. The husbands are involved in the therapeutic process mainly when cause the is attributed to non compliance with *lovolo,* or when the clinician prescribes some physiologic tests (blood, sperm). The apparent autonomy of woman in the management of her own body to render it proper for reproduction is put into question when she must negotiate and invite the husband to participate with her in the infertility consultations and find due solutions. It is in this context that his virility and her reproductive capacity are publicly open and put to discussion.

In conversations with four couples worried about their fertility the men's attitude was always to blame their wives as the main responsible persons for the couple's generative incapacity. Whenever we confronted them with the hypothesis of a need to visit the hospital for a check of their physical being they were willing to follow the doctor's recommendations. In practice men absence and their non involvement in the therapy is justified by their commitment to production outside the home (South Africa). In fact their involvement in the quest for solutions was based solely in entrusting and permitting their spouses the use of health services either traditional or biomedical. When asked women how they would conceive if their husbands are away they answered it was important to be ready and wait for the spouses even if for a brief period of time (one or two months) of intense sexual relations. The follow up of some cases during the research (some women have initiated treatment and hospital care) may give some indication over their generative ability.

The hospital is by excellence the place for treatment of physiological disorder but rarely used by individuals with reproductive problems either by lack of knowledge over type of services on offer or to lack in economic resources and the belief in traditional aetiologies. The following reports of a childless woman reveals in one hand the knowledge of reproductive technologies though not universally accessible, and at the same time demonstrate the capacity to live with infertility and attempt to adapt to the condition of being infertile.

> *"When my menstrual period started my late grandmother took that, I think she has hidden in the place that she (...) and she end up dying. (...) So it's better to kill that hope because nobody is going to say (...). There are people that are able to undergo treatment in the hospital (...) but for that you need money. Can you imagine what is to spend fifty millions, go to a hospital with your husband, because you have to go with your husband in South Africa? And you can come back pregnant. But pay attention, it is not 100% guaranteed. ... I start seeing it as preferable (...) as my brother; I have only one brother (...). He has done for me three children"* (Female healer, Maxaquene, 2008). The physical death of the grandmother represents the end of her reproductive capacity because it is believed that at the beginning of menarche some magical acts can be performed to reduce menstrual flow and to control sexuality and reproduction.

Social norms that influences fertility: Gender, power relations, marriage and reproductive roles

Physiological maturity - reproductive is represented by the woman transition from her family space to the sexual and reproductive space. The change in space is metaphorically indicated by her cloth (*dzovo*) she takes along, the cloth her mother wrapped tightly around to accommodate her as child on the back. To carry the child on the back means to raise, to educate. As her mother proved her reproductive capacity the cloth symbolizes fertility and these qualities are auspicious for its reproduction when the daughter is 'acquired' by her husband at the time of *lovolo*. *Male ya xisingu* (money of the first cloth that carry the child) is one of the most important steps to accomplish during *lovolo,* and is essential to secure fertility and harmony between the couple. It means that the woman upon leaving the father's home already grown up is unwrapped to be wrapped by the husband and his relatives therefore raising the need for compensation. The link thus established is not solely between the couple and towards family relatives but also with the spirits of their ancestors. During the deliverance of money in the act of *lovolo*, a parcel must be presented to the spirits of ancestors protecting the

individual. The spirits are informed that the daughter has already left the home through the elderly women (maternal aunties). "*The money of xisingu, is for the grand- parents to receive with the 'mhamba' that is required by the spirits of the home, (...) they must know that she is in a new family"* (Female healer, Maxaquene, 2009).

As the majority of women are economically dependent on men the access to conventional and traditional health care is also determined by the decision power of the husband. The source of income of men and family economy derived mainly from the migratory work in South Africa. The presence of man is a necessary condition to propitiate fecundity but because he is absent long periods and has expectations regarding the woman fertility he puts his sexual and reproductive health at risk. This way he reproduces in his wife the feeling of responsibility relative to the generative process as *"man's function is productive and that of a woman is reproductive"*. The material and biological dependence of woman regarding man exacerbates with his absence. In this case the mother in law engages in the role of the head of the household in managing the domestic chores inclusive those of the daughter in law reproductive sphere. The mother in law advises and sometimes seconds the daughter in law to the *nyangas*' consultations to identify and find solutions to the problem. The brief return of the husband to his home[6] constitutes an important occasion for the couple's sexual encounter, and for the resolution of family problems. Among patrilinear groups in Southern Mozambique (Maputo and Gaza study areas), social roles and the gender relations are remarked through matrimonial compensation, the *lovolo,* in which woman is attributed the reproductive function. The accomplishment of *lovolo*, as a complex and value-laden institution influences the reproductive process.

The knowledge of social norms is valued and explored in the wake of troubles. The norms prescribe individuals ought to practice different rituals in accordance to the physiological evolution. The *lovolo* for example, is a complex matrimonial practice that has implications in family, sexual and reproductive relations. Decision on marriage does not only depend on individual will, physical development, socially accepted/recognized age, but also the spirits will. There are "son-law spirits" with powers to choose women as spouses. One understands this way that sexuality and reproduction integrate the relations between individuals and spirits in a continuous process of conflicts, negotiations and agreements between ones and the others and between them. The value and the end reason of marriage centres in the regenerative process and include different stages. The non compliance of social norms may alter the body functioning and sexual relations and reproduction functions.

When spirits determine fertility

The consultations of *tinyanga* indicate the probabilities of traditional and hospital cure. When reproductive failure does not result from the intervention-choice of a spirit, the *tinyanga* consider they capable of curing the main physical causes (*xithethuxilume* and *kutsamiwa*).

"*I have an example from an urban lady almost forty years of age that could not conceive. After several attempts and differentiated therapies in hospitals she opted for traditional cure with me, she finally solved her problem and has had a child. Her problem could not be cured in a hospital because it was related to spirits"* (Female healer, Xipamanine 2008). There is no contradiction between intervention-choice of a spirit and an illness related to the spirits. In this case we refer to the woman chosen by the spirit to become a *nyanga*, the spirit being the one that determines the sexuality and reproductive capacity of the woman. Their fertility results from a process of negotiation between the woman who accepts becoming *nyanga* and the spirit that confer her the power to have children biological ones or not biological ones (Mariano, 2002). The spirits are associated with ambivalent forces which may be both life-threatening and life-given (Devisch, 1993).

The diagnostic procedure in traditional medicine

Devisch (1993) remarks that in the context of traditional medicine, more than diagnosis and hermeneutics it is an anamnesis and causal or moral inquiry of disorders. Diagnosis is an attempt to describe on the origin of disease or illness, locate and to render objective its causes. It is also an effort to invoke an effective reaction (Good, 1999). Considering the dynamic and holistic view of traditional medicine we adopt diagnosis and diagnostic procedure. The different modalities and forms of traditional diagnosis include: intuitions, dreams, possession trance, sniffing and divination centring on the individual's experience in the interaction with the protective spirits and the family and social milieu.

In reading the *tinhlolo* (divinatory bones) during infertility consultations one observes that each element is polysemantic and with multiple functions

[2]The majority of men visit their relatives at least twice or more a year.

that can vary according to its position, shape, chromaticism etc. It differentiates man from woman by its shape, for example in the turtle shells the ones that have a shape larger and open represents woman while the more slender and longer is the male equivalent.

The interpretation of the *tinhlolo* is one of the diagnostic procedures most spread in the southern Mozambique; this procedure is also called *bula* that is to speak, to reveal. It is the spirit that guides the interpretation of the pieces during the consultation but the capacity to read the pieces in its different combinations depends on the degree of knowledge and the school of initiation of each *nyanga*. In the infertility consultations over the shell of a female turtle (Fig. 1) one overlay another plant element called *ntima* meaning black in Tsonga, darkness or shadow. A *nyanga* reveals it is *kutsamiwa*. Having a shadow in the case of *kutsamiwa* is equivalent of harbouring a bad spirit that prevents conception. A black colour indicates illness and death.

The observation of the consultations of oracles[7] through the bones, (*hlalhluva tinhlolo*) among *tinyanga* as enabled me to analyze the meanings of the pieces in use that indicate the health status and illness. The ill individual has weak blood and is represented by a reddish stone. This element also indicates the consistency of the sperm (weak and watery), metaphor of an infertile man or woman. Strong blood and or weak also define sex and somatic characteristics of children. In case of doubt of biological paternity some pregnant women undergoes the scrutiny of traditional healers. The good or bad quality of blood is observable through a mix or exchange of blood fluids between the couple during sexual intercourse; the mix is compatible when pleasurable and with generation as aim. As also revealed in the study undertaken in the Province of Tete in Central Mozambique, well being is defined as a function of the preparation for sexuality and in the perspective of having a pleasurable and well succeeded sexual relation that culminates in the conception and birth of a child. However, it does not mean that every sexual intercourse shall necessary engender a child but preparation for success implies the existence of conditions for its occurrence (Bagnol and Mariano, 2009).

Diagnosing sexual fluids: Male infertility

The sexual attraction and sexual desire among a couple indicate blood affinity. The absence of sexual desire is the first sign of anomaly in the blood. "The desire and pleasure that the partners incite in the other reflect and reinforce the excitation and the reciprocal giving in sexual union" (Devisch, 1993). The incapacity to generate indicates the bad quality of blood. In secret and in agreement between the woman and the *nyanga,* the physiological observation of male fertility is conducted through the analysis of the sperm consistence. After the sexual intercourse the woman alone and in secret analyze the quality of the seminal fluid; if it sticks on the woman's body it is a sign of fertility. Another method with the man consent with the presence of relatives of the man and the woman is the test of generative capacity using the seeds of millet or maize put in two different recipients containing the man and woman urine. If the seeds germinate it is a sign of fertility, otherwise the man shall submit to a treatment.

Lack of children is considered an illness of women: aetiology and therapeutic devise

The *tinyanga* refer that mainly women look for the inability to have children treatment though they recognize the existence of male reproductive failure. Men rarely present themselves to the *nyanga* on their own to consult for their eventual inability to reproduce. They only look for treatment upon the wife demand, doctors or by the *nyanga*, as women take initiative on this matter.

When an organic dysfunction is present due to vaginal discharges or itching in the genitals, the feeling of physical discomfort is referring; by order from the traditional to the biomedical sphere. The collective and holistic vision of the body gives way to the individual-organic body. Such a process evolves and is re-directed to the state of physical disorder when classified and legitimized by the institution that heals. The hospital is chosen to the analyses to know the "truth" about something that is not visible in the traditional domain. However, clinical results may not always imply ensured biomedical therapeutic efficacy. Sometimes the therapeutic process must start from the reconciliation and re-establishment of social relations with spirits of the ancestors and of practice of certain acts as complementary.

Xilume refers to pre-menstrual pelvic pain and *xithethu* or *nthelelu* to disturbances that prevent the retention of sperm. The non entrance of sperm means that it has not gone in. Both are considered female physical disorders the first having to do with the menstrual cycle and it is sustained that the one that

[3]Divination is the process of using ritual means to reveal things hidden to ordinary perception, such as information about sources of illness.



Fig. 1. — Divinatory pieces that indicate disturbances related to reproductive problems.

has *xilume* rarely has the capacity to retain sperm and consequently may not get fecundity and conception. The woman does simultaneous treatments; intake of medicinal decoctions for *xilume* and the vaginal insertion of plant preparations in small balls to treat *xithethu.* The little balls also termed marbles serve the purpose of absorbing the vaginal secretions and clean the passage of the sperm removing the whitish and foul odour "dirtiness". This treatment has triple action: a) to remove the "dirtiness' and eliminate disease; b) to close and narrow the vaginal opening (Bagnol and Mariano, 2005; Bagnol and Mariano, 2008, Martin *et al.*, 2009); and finally retain and prevent the leaking of sperm to enable conception. Therapeutic efficacy is observed when the woman gets pregnant.

Kutsamiwa contrary to *xilume* and *xithethu* is a disorder affecting both man and woman that does not prevent fecundity, conception and pregnancy but causes abortions and the death of children. This anomaly is described as being extremely dangerous that "germinates" in the male and female genital organs. *Kutsamiwa* is also called *vùmbà*[8], and due to its negative effects is the equivalent of witchcraft. The itch in the genital organs, abortion, death of children and husband, woman repudiation by husbands or sexual partners are signs of *kutsamiwa* state. The elimination of this evil is a necessary condition for the survival of the individual. The treatment of *kutsamiwa* is not performed only by traditional doctors; any person may learn how to cure this evil.

Removing the poison and evil from the body

Traditional medicine practitioners call the attention for the need to linguistic and terminology clarification relative to the treatment of *kutsamiwa*. In spite of the use of a razor /blade it is not about cutting, it is about excision or removal of a poison. It is more appropriate to talk about "take out" or extract the cause of the inability to bear a children, because cutting implies pain and as consequence women would express pain by crying that can lead to withhold from treatment. Women that have undergone

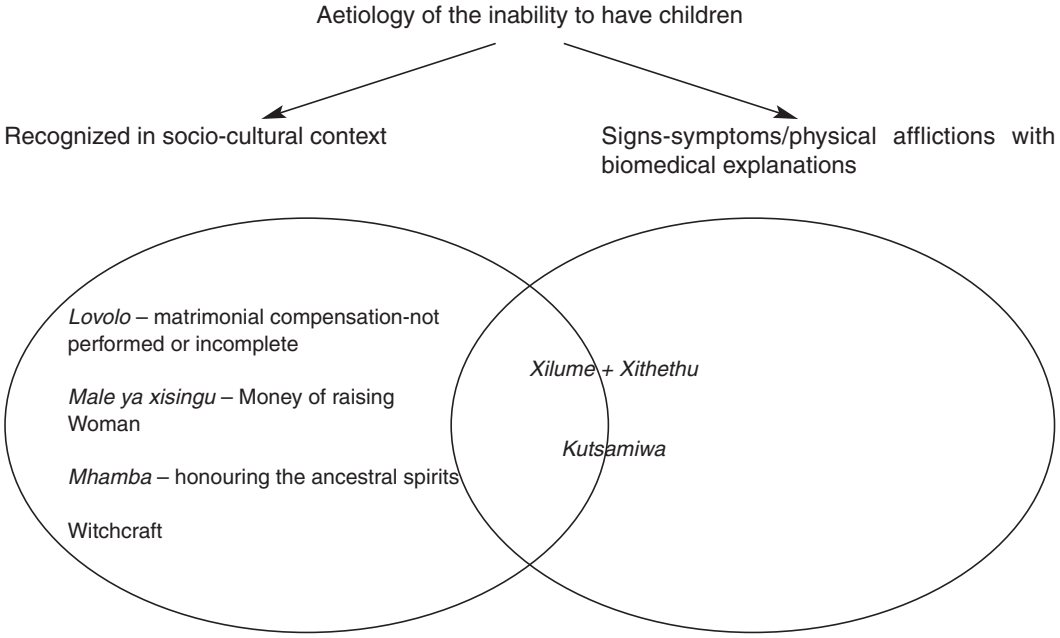

Fig. 2. — The main etiologies of the inability to have children

[4]Attributes of person whose children died in a early age.



Fig. 3. — Vaginal balls to treat the rejection of sperm



Fig. 4. — Removing the alien substances - *kutsamiwa* that prevent fertility.

COLOR PRINT ?

this experience sustain that taking it out leave no traces while cuttings leave behind scars.

Traditional vaccines or incisions largely practiced in Mozambique, in spite of being scarcely documented, are being referred to in the literature because of its invasive procedures and the use of instruments not subject to previous sterilization (West, 2009). The interest on the analysis of traditional incisions emerges in the context of HIV and AIDS, and as strategy of prevention and control of blood contamination among the traditional medicine practitioners. As to incisions (small parallel cuts in different parts of the body) made with a razor, a medicinal mixture is spread on the skin with the fingers for it to penetrate the body.

Fieldwork has revealed that vaccine-incisions compared to poison removal-*kutsamiwa*, are less invasive procedures and done in less sensitive body parts. The treatment of *kutsamiwa* consists in the excision of tissues or warts in the interior of vaginal labia and in the perinea area (between the anus and the vagina), by means of razors (Mariano, 2001, 2004; Bagnol & Mariano, 2005; Martin *et al.*, 2009). Depending on practitioners and regions before or after the treatment of *kutsamiwa,* besides the removal of the anomaly incisions are made in various parts of the body to prepare or conclude the treatment.

What traditional healers conceive as anomalies the salience of membranes they consider detrimental to the woman well being and her sexual and reproductive health is viewed as normal and functional by obstetric-gynaecologists. In the genital area what is indicated as *kutsamiwa*, corresponds in biomedical language to *fúrcula* that is, prolongation of the external vulva great lips (labia major) and *caruncu-lous multiform* that is, remnants of the hymen rupture (internal), while in the anal regional corresponds to haemorrhoidal. In various occasions obstetric-gynaecologists referred to their clinical experience of patients or pregnant women that had cut haemorrhoidal.

In a training session on "Strategies for a sustainable articulation between traditional medicine and biomedicine relative to sexual and reproductive health, STIs and HIV and AIDS", the use of anatomical illustration of the genitals enabled the indication and classification of the body parts. Traditional healers argue that it is not haemorrhoidal (known as *mudidi*), which is different from *kutsamiwa* (Fig. 4). In the hospital at the gynaecology consultation both traditional and biomedical doctors after the observation of woman's body they present discordant interpretations and knowledge. Contradiction between professionals over the signs in genitals stemming from images lead biomedical to suspect that *xilume*, *xithethu* and *kutsamiwa* may be consequences of sexually transmitted infections (*condilomas* and genital ulcers).

Discussion and conclusion

The cases so far observed and analyzed are limited for generalizations and large theoretical elaborations. Therefore there is need to extend the discussion between biomedical and traditional healers avoiding rush in pretentious attributions of truths between the different knowledge systems. The possibility to explore and deepen is based on an attitude of knowing deeply the phenomenon in the first place; identifying what is being effectively talked about and only thereafter moving to the analysis of the attributed meanings.

The primary and most feared aetiology of the inability to bear children is the presence of an

"anomalous body" in the body called *kutsamiwa* or *vúmba* (Mariano 2002, Chapman 2006). Genitals are considered the parts of the body where this most dangerous kind of (alien substance) may be settled. Devisch (1993) points that corporeal orifices act as a juncture between various orders, represent destruction and regeneration. Therefore, manipulation of skin and bodily postures may become means of healing.

During the research very often women said *"I am just tired of being cut"*. Or the *nyanga* had commenting over the body of a woman full of vaccine scars in her search for life (*wutomi*). *Wutomi* is life and also it is health, well being and to a certain extent it emanates from *nthumbuluku*, as a sort of vital force (Ferré, 2008). To what extent removal is effective and is it necessary? The will to bear children transcend the operation pain as woman is prepared to sustain pain for if she cries the treatment won't have its effect and will never conceive. *"You have to keep your heart tight as if you were delivering a child"* (Female healer, Magude, 2010)*."*

In the main national newspapers there are often advertisements of traditional healers selling their competences in treating life, health and illness. Their abilities are described in either biomedical or traditional language when talking of infertility, being sterile, sexual impotency, "being tight" etc. It means that life, health and physical afflictions are not rigidly bounded and there is room for the sensitive and emotional aspect of experience in the perspective of the individual though at the level of physiological functioning the objective also counts. While the biomedical paradigm bases on objectivity – disease in the individual the traditional medicine practitioners have a holistic perspective of ill being, the body is physical and spiritual and the individual is a social and collective human being. This is why this research is mainly about individual experience that is subjectivity and the senses.

References

Augé M. Antropologia, cultura, medicina, In: Il Sapere della Guarigione, (Eds): Pino Donghi, Laterza.1996, p. 15-23.

Bagnol B, Mariano E. Género, Sexualidade e Práticas Vaginais - na Província de Tete - Moçambique. Maputo: OMS, ICRH, CRDS-MISAU. 2005.

Bagnol B. Lovolo e espíritos no Sul de Moçambique, In: Análise Social, 187 Vol. XLIII (2º), ICS.2008. p. 251-272.

Barden-O'Fallon J. Unmet Fertility Expectations and the Perception of Fertility Problems in a Malawian Village, African Journal of Reproductive Health 9 (2):2005. p.14-25.

Chapman RR. Chikotsa - Secrets, Silence, and Hiding: Social risk and reproductive vulnerability in central Mozambique, Medical Anthropology Quarterly, Vol. 20, Nº 4. 2006. p. 487-515.

Devisch, R. Weaving the Threads of Life: The Khita Gyn-Eco-Logical Healing Cult Among the Yaka, 1993 The University of Chicago Press.

Devisch, R. Mediumistic Divination among the Northern Yaka of Zaire: Aetiology and Ways of Knowing. In: African Divination Systems. Ways of Knowing. Peek, M. Philip (eds.) Bloomington: Indiana University Press. 1991. 112-32.

Dijk R van, Reis R, Spierenburg M. The Quest for Fruition Through Ngoma. Political Aspects of Healing in Southern Africa. Cape Town: David Philip. 2000.

Farré A. Vínculos de sangue e estruturas de papel: ritos e território na história de Quême (Inhambane), In: Análise Social, 187 Vol. XLIII (2º), ICS2008. p.393-418.

Gerrits T. Social and cultural aspects of infertility in Mozambique. Elsevier, Patient Education and Counselling. 1997. 31: 39-48.

Granjo P. Dragões, régulos e fábricas: espíritos e racionalidade tecnológica na indústria moçambicana, In: Análise Social, 187 Vol. XLIII (2º), ICS. 2008. p.223-49.

Green E, Jurg A, Dgedge A. Sexually transmitted diseases, AIDS and traditional healers in Mozambique, Medical Anthropology. 1993. 15: 261-81.

Green E. AIDS and STDs in Africa: bridging the gap between traditional healers and modern medicine. Boulder, CO. Oxford, Westview Press. 1994.

Good J. Narrare la malattia - Lo sguardo antropologico sul rapporto medico-paziente, Edizioni di Comunità, Torino. 1999.

Honwana A M. Espíritos vivos, tradições modernas Promédia, Maputo. 2002.

Janzen J.M. Ngoma - Discourses of Healing in Central and Southern Africa**,** University of California Press. 1992.

Martin H, Hull A, Preston-Whyte TH et al. A cross cultural study of vaginal practices and sexuality: Implications for sexual health, Social Science & Medicine 70, (2010) 392-400.

Mariano, E. "Involuntary Childlessness among Shangana (Mozambique)"Journal of Reproductive and Infant Psychology. 2004. 22 (4): 1-9.

Mariano E, Paulo M. Infertilidade, Fertilidade: áreas escondidas do nosso quotidiano? KULA, Maputo. 2009. p. 17-57.

Mattingly C, Garro C. Narrative and the cultural construction of illness and healing. University of California Press, Berkeley, Los Angeles, London. 2000.

Meneses MP, Fumo J, Mabilana G et al. As autoridades tradicionais no contexto do pluralismo jurídico. In: Santos, B. S. e Trindade, J. C. (eds.). Conflito e transformação social: uma paisagem das justiças em Moçambique. Porto: Afrontamento. Cap. 2003. 20. p. 341-427.

Ombelet W. False perceptions and common misunderstandings surrounding the subject of infertility in developing countries. ESHRE publication. www. Eshremonographs.oupjournals.org 2008; ISSN 0268-1161.

Pool R. Dialogue and interpretation of illness, Health, Culture and Society. 2003.

Thornton R. The transmission of knowledge in South African Traditional Healing, Africa 79 (1). 2009.

Van Balen F, Inhorn M. Interpreting infertility: a view from the social sciences. In: M.C. Inhorn & F. Van Balen (Eds), Infertility around the globe: new thinking on childlessness, gender, and reproductive technologies. 2002. p. 3-32. Berkeley: University of California Press.

West HG. O Poder e o invisível em Mueda, Moçambique, ICS. 2009.

Woulputte SV, Devisch R, Le Roy J *et al.* Medical pluralism and lay therapy management in Kinshasa, ULRICA. 2002.

Negotiating boundaries: Accessing donor gametes in India

Anjali Widge, John Cleland

Centre for Population Studies, Department of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, London, United Kingdom.

Correspondence at: anjali.widge@gmail.com

Abstract

Background: This paper documents how couples and providers access donor materials for conception in the Indian context and perceptions about using them. The objective is to facilitate understanding of critical issues and relevant concerns.
Methods: A postal survey was conducted with a sample of 6000 gynaecologists and in-depth interviews were conducted with 39 gynaecologists in four cities.
Results: Donor gametes are relatively more acceptable than a few years ago, especially if confidentiality can be maintained, though lack of availability of donor materials is sometimes an impediment to infertility treatment. Donor sperms are usually accessed from in-house or commercial sperm banks, pathology laboratories, IVF centres, professional donors, relatives or friends. There is scepticism about screening procedures of sperm banks. Donor eggs are usually accessed from voluntary donors, friends, relatives, egg sharing programmes, donation from other patients, advertising and commercial donors. There are several concerns regarding informed consent for using donated gametes, using relatives and friends gametes, the unregulated use of gametes and embryos, record keeping and documentation, unethical and corrupt practices and commercialisation.
Conclusion: These issues need to be addressed by patients, providers and regulatory authorities by providing information, counselling, ensuring informed consent, addressing exploitation and commercialisation, ensuring monitoring, proper documentation and transparency.

Key words: Infertility, India, donor, gametes, assisted reproductive technologies, ART.

Introduction

The 'mothering role' of women is seen to be central in many traditional societies, including in India where there seems to be no space for infertile couples as part of the governing definition of the family. The system of patriarchal descent, patrilocal residence, property inheritance, lineage and caste are responsible for the extreme importance given to fertility in Indian society. Childlessness is a life crisis for many couples, with many visible and invisible losses. Infertility affects more than 80 million people worldwide (Daar and Merali, 2002). In India the estimates of primary and secondary infertility are 3% and 8%, but expected to be higher as this evidence is dated (WHO, 1980). Infertility affects women's identity, status and security and they experience stigmatisation, isolation and powerlessness. Childless women are more vulnerable to blame, mental and physical violence, threats of abandonment, divorce and social exclusion (Singh, Dhaliwal and Kaur,1996). They are under psychological, familial and community pressure to have their own biological child (Singh and Dhaliwal,1993; Widge, 2001). They seek treatment, including assisted reproductive technologies (ARTs), if affordable. Adoption is not popular though some couples grudgingly adopted before ARTs were introduced (Bharadwaj, 2003). Surrogacy is still uncommon in India, though some couples are using this option nowadays.

The first scientifically documented IVF baby was born in India in 1986 which heralded the growth of ARTs, mostly in the private sector. Treatments are expensive, the sector is highly commercialised and

the market thrives on couples' desperation to have their own 'biological' child. ARTs could involve the use of donated gametes and couples may have to use donated sperm, eggs or embryos to facilitate reproduction. This paper focuses on how couples and providers access donor materials for conception in the Indian context and perceptions about using them. Specifically it focuses on general concerns about using donated gametes, how they are accessed, informed consent, costs, concerns of providers and couples, ethical dilemmas and unethical practices. It originates from a study inspired by earlier research that explored women's experiences of childlessness and ARTs in India (Widge, 2001). As these issues have been mostly addressed by the media in India, this paper is an initial step in the exploration and documentation of these issues and could facilitate our understanding of critical issues and relevant concerns.

Gamete and embryo donation is a sensitive subject especially in societies where extreme social and cultural importance is given to genetically related children (Kirkman, 2008). Health professionals and regulatory bodies are important collaborators in this venture to address ethical aspects and other concerns. The issues that have been debated till date globally are socio-psychological responses and attitudes of recipients and donors, donor anonymity, payment to donors, commercialisation of gametes and embryos, proper recruitment and screening of donors, quality of the gametes and limiting the use of donors to reduce the risk of consanguinity. Some other issues have also included assessment and screening of recipients, avoidance of transmission of genetic diseases to the recipients and offspring, the information given to and welfare of the future child, informed consent, conflicts of interests between the various actors and appropriate regulatory mechanisms (ESHRE, 2002; Dickens, 2002). Recently the United Kingdom's HFEA scheme on payment for egg sharing for stem cell research has raised concerns among clinicians and activists (Roberts and Throsby, 2008).

Ideally couples would like to have their own biological child but sometimes it is not possible to have a completely genetically linked child and patients have to accept a partial genetic link or a gestational link (Halman *et al.*, 1992). Couples also have to deal with a shortage of gametes in most societies but providers and patients find ways to overcome this shortage (Fathalla, 2002).

In some societies religion and law prevent couples from using donated gametes but in many they are ethically and legally accepted and in some the restrictions are ignored in the desperation to have a child (Borrero, 2002; Inhorn, 2002). Some couples travel abroad to access donor gametes and ARTs that are not accessible in their own, for legal or other reasons (Dickens, 2008). It is broadly understood that gamete and embryo donation are safe, cost effective and beneficial for infertile couples. But their use has given rise to contentious issues and an understanding of the science, guidelines, ethical and legal and social implications of these procedures is required for them to be used safely and effectively (Borrero, 2002). So far it has been difficult to find an international consensus on how to deal with these issues as there are social, cultural, religious differences, but each society needs to develop and implement its own statutes.

a) Sperm donation

The majority of sperm donors are men between the ages of 18-40 who donate anonymously or are known donors either altruistically or for a financial incentive (HFEA, 2007). Some donors donate at different sperm banks or via the internet but there are concerns that using the same donor sperm may lead to recessive, disease-causing genes and unrealised consanguinity. Known sperm donors donate to relatives and friends. The laws regarding sperm donation vary in different countries. Sperm donors and recipients are usually anonymous to each other. However, a recipient may receive non-identifying details about the donor such as height, weight, hair colour and education. Recipients have concerns regarding physical attributes, health status, education, occupation, family background and interests of donors (Purdie, 1992). Recently the law in certain countries has given rights to people conceived through sperm donation to access varying levels of information about their biological father, after a certain age. The morality and ethics of sperm donation has caused much heated debate but despite these issues, sperm donation has been acceptable because it enables couples to have children There are shortages of sperm donors and banks struggle to access donors (National Gamete Donation Trust, 2008). Shortages have let to men offering free sperm on the internet (which not recommended for health reasons and the possibility of exploitation, women going abroad and a smaller donor pool (Collier, 2010).

b) Egg donation

Egg and embryo donation has been used to treat infertility for a variety of conditions. Sources of donated oocytes include donations from infertile women usually between the ages of 25-35 years, already undergoing egg collection, altruistic donations from relatives or friends or commercial donations from non infertile women or from egg sharing

programmes in IVF clinics (Leeton *et al.*, 1986). Use of egg donors is regulated in many countries but the high demand for donors has led to waiting lists and shortages. The increased international demand for donor eggs has triggered a surge of egg donation and even international travel for fertility treatment (Storrow, 2005) and even mail order oocyte donation, which raises ethical issues of possible exploitation of underprivileged women (Heng, 2006). Egg donation is a cumbersome procedure and for some, it goes against socio-cultural norms. There are also be cultural differences in the willingness to donate oocytes (Purewal and Akker, 2005). Payments to donors has been considered as ethically acceptable but there are arguments against payment that consider inequality, co modification and exploitation of donors (Steinbock, 2004; Shanley 2002).

c) The Indian context

Using donated sperm in India is usually a matter of secrecy as couples do not want their infertility revealed and disturb the social and biological connection between the mother, father and child (Bharadwaj, 2003). It has been suggested that the use of donated gametes is taken lightly by the medical community and there are practices like sperm mixing, transplantation of embryos without consent or the discarding of embryos by mistake in India (Aquil, 2006). Donor sperm being used in artificial insemination and IVF without the couple's knowledge have also been reported (Srinivasan, 2004).

The Indian Council of Medical Research in its guidelines for regulation of ART clinics in India, states that no ART procedure will be done without the spouse's consent; use of sperm or eggs donated by a relative or known friend of either the wife or husband shall not be permitted; the ART clinic will be responsible to obtain sperm from appropriate banks and eggs and provide the couple with information on height, weight, skin colour, educational status, profession, family background, freedom from known diseases like Hepatitis B or AIDS, ethic origin and the DNA fingerprint (if possible). They also state that semen mixing is not permitted; the ART clinic cannot be party to any commercial element in donor programmes or gestational surrogacy and that the child has the right to seek information about the genetic parent or surrogate when the child reaches the age of 18, but the donors identity will not be revealed until then. According to the Ministry of Health and Family Welfare, these guidelines have been formulated to protect patients as they believe that several ART clinics are functioning without adequate infrastructure to deliver these services and these services are 'highly questionable' (ICMR, 2005).

Methods

This research was funded by grants from the Ford Foundation (India), UNFPA (India) and Soros Foundation and conducted with members of the Federation of Obstetricians and Gynaecological Societies of India (FOGSI), which is a large specialist organisation with 16,000 members. The research was approved by the ethics committees of the London School of Hygiene and Tropical Medicine and FOGSI in India and informed consent of all interviewees was obtained.

In the first phase a postal survey was conducted with a nationally representative sample of 6000 gynaecologists practicing in the public and private sectors randomly selected out of a list of all FOGSI members. The purpose was to explore the range of infertility services that are being offered in these sectors. The survey focussed on background information, services offered (including donor related), referrals for ARTs and adoption and impediments to effective infertility treatment. Despite reminders, the final response rate was 8% yielding 470 responses: 365 (78%) from the private sector, 55 (12%) from the public sector and 49 (10%) from those who practice in both. This was sufficient to sustain rudimentary statistical analysis, though obviously the achieved sample may not be representative. The data ware analysed using SPSS, frequency tables were generated and tests of significance were conducted for some variables.

In the second phase, in-depth interviews were conducted with 39 providers (27 from the private and 12 from the public sector respectively) in two major cities (New Delhi and Mumbai) and two medium cities (Agra and Nashik) in India. These providers were randomly selected from those who responded to the survey and agreed to be interviewed. In-depth interviews were conducted and taped with informed consent and categories of responses were coded and analysed using thematic content analysis with the help of excel worksheets. Relationships between themes were then analysed. The interview guides focused on the following: patient related information; barriers to prompt care seeking for women/couples; quality of treatment; screening process; cost and affordability; patients information on infertility and information provided to patients; informed consent procedures; sex preference; strengths and weaknesses of ARTs and opinion of ART practitioners; reasons for rejection; success rates; coping strategies of patients; adoption and problems associated with infertility services. They also focussed on donor issues: access, screening, choices of donors, reasons for acceptance or rejection of donated materials, transactions between donor and recipient, third

party donation issues of concern, number of embryos transferred, use of spare embryos; access to and use of surrogates and perception of regulatory guidelines regarding donated materials. The paper focuses mainly on the information from the in-depth interviews on the above mentioned donor related issues.

Results

A quarter of the providers surveyed said that they have a donor programme at their facilities. 68% of providers offered artificial insemination by husband at their clinics, less than 1% offered artificial insemination by donor, 19% offered oocyte donation, 23% have sperm banking facilities, less than 1% offer embryo donation and 12% allow surrogacy arrangements.

Most providers felt that donor gametes are acceptable to two thirds of the cases of those who need to use them. But acceptability is usually after counselling and reflection on the available options. 44% of the providers surveyed said that donor insemination was acceptable to their patients, whereas 37% felt that there was a negative attitude towards donor insemination. A quarter of the providers felt that lack of availability of donor materials was one of the impediments to infertility treatment.

a) Accessing donor sperm

Most gynaecologists said that they access donor sperms from sperm banks or pathology laboratories, or ask their patients to access them directly and some collaborate with IVF centres to access them. A few providers were uncomfortable with patients accessing their own samples from a laboratory, a relative, friend or from anyone known to the patient though this was acceptable to some others. Most ART specialists said that they access their samples from commercial sperm banks or have their own banking facilities. Some allow patients to access their own donors or samples, some have access to professional donors and some use spare samples from current patients and/or from health workers in their facility.

Most providers were of the opinion that patients sometimes want their own family members to donate sperm. Many reported that they were approached by patients to use the father or brother-in-law's sperm because of caste, lineage and property concerns. This was usually unacceptable to providers as they felt it could create future inter-generational problems or confusions about parentage. Some felt that donor sperm of a distant relative, friend or brother was acceptable if they worked out a mutual arrangement between them. They expressed concern that some providers are not apprehensive about using sperm from any source as there are no checks. Several providers reported the practice of using fresh or mixed semen and expressed concerns about the medical status of the donor and the quality of the sperm in such a context. They also reported that the repeated use of the same sperm donor in the same geographical area was a problem as it could have cross-genetic implications.

An ART specialist reported a case of what she called *ART incest* where the clinic was approached by a couple who had lost their son and wanted to use their daughter's eggs and the father's sperm to have a son. Besides genetic implications, she felt this would create major kinship dilemmas for the couple and the future child.

b) Sperm bank protocols

Some providers were sceptical about protocols followed by sperm banks, quality of sperm samples and checks and audits. Some reported that screening procedures were adequate but those who were unsure about their protocols have their own sperm banks and prefer to conduct their own screening for general infections, biochemistry, family, sexual and drug history, allergy, thalassemia, HIV, Hepatitis B, and VDRL.

c) Accessing donor eggs

Providers suggest that most couples access eggs from commercial donors (some providers have a donor list and the patients can choose on the basis of criteria such as colour, height etc.), voluntary donors (e.g. employees of the hospital or clinic), friends and/or relatives, through egg sharing programmes in IVF clinics, donation of spare eggs or embryos by patients and through advertising on the internet (one of the ART specialists has photographs and profiles of egg donors on his website). Some providers encourage patients to arrange their own donors. There are usually few voluntary anonymous donors. Some ART specialists expressed concerns about egg sharing as that may reduce chances for both the donating and recipient couple. There is a huge demand for eggs and supply is usually a problem as egg retrieval is a physically and medically complicated procedure. Commercial egg donation is a new concept in India, and some providers expressed concern about exploitation of such donors. Currently only few centres in major cities have access to such donors.

d) Use of spare embryos

Most providers transfer three embryos and either cryo-preserve spare ones, discard them, use them for another couple or for research.

e) Acceptance of donor gametes: relevant concerns

Providers reported that couples' main apprehension about using donor sperm was the lack of a genetic link and the man's concern about his status in the joint family. A provider shared a case of a couple where the husband, even after agreeing to using donor sperm, abandoned his wife. Though most providers felt that there has been a change in attitude towards using donated gametes, especially if secrecy can be maintained, the use of donated materials is still perceived as socially unacceptable. Some felt that couples did not focus as much on caste and colour as before, in the desperation to have a child. But concerns are expressed about education, professional status, religion and medical history of the donor. One of the providers explained...

> *....couples are so hardened by the process of going through infertility testing and treatment that they usually don't ask too many questions about the donated sample and they will be ready for donor eggs, donor semen, donor 'everything'.*

A few providers maintained that that donated materials are not accepted easily by uneducated and conservative patients and if they do, it is usually a time consuming process. There are some patients who prefer to remain childless or choose not to use donated materials due to religious concerns.

Concerns regarding donor eggs are fewer though patients are worried about religion, physical characteristics, background, family, medical history and some about caste. One of the ART providers offers information on seven criteria i.e. height, built of the patient, colour of eyes, colour of hair, blood group, social background and educational status. If recipients require more information they are provided with information about marital status, number of children and husband's status.

f) Costs of gametes

Most providers said that the cost for donor sperm range between Rs. 200-600 (5-15 USD) per sample but it has also been reported in the media that sperm donors receive up to Rs. 5000 (125 USD) and an egg donor between Rs. 10000-20000 (250-500 USD) per sample, which doctors disguise as travelling expenses (Dutta, 2002). Patients acquire sperm samples directly form the banks or pay the providers. If couples are willing to participate in the clinic's egg-sharing programme, the costs are reduced by Rs. 10000-20000 per IVF cycle for the woman who is donating the eggs. As egg donors are not easily available and commercial donors are few, most clinics encourage egg sharing. If donors are from the family or friends, they make their own monetary arrangements, if any.

g) Providers' perceptions about using gametes from relatives and friends

More than half of the providers, who allow the use of donated material in their practice, felt that the recent guidelines by the ICMR that do not allow the use of relatives or friends gametes, were acceptable as the use of such materials may lead to problems within the families about paternity and property. A private provider shared her opinion.

> *...I am not sure of using a friends sperm is acceptable as there could be problems later. A woman I know was deserted by her husband as he started living with the woman who had a child with his donated sperm.*

Some providers disagreed with the guidelines as they felt that lineage and shortage issues can be taken care of if relatives' sperm and/or eggs are used.

h) Ethical dilemmas/unethical practices

Most providers said that the use of relatives' sperm and secrecy about the use of donor sperm from either the husband, wife or the family, was an ethical dilemma in their practice. A provider expressed one such dilemma:

> *I was approached by someone who wanted me to conduct the test on his friend as he was azoospermic, so that his in laws don't doubt his fertility.*

Some providers felt that the practice of using spare eggs and embryos without informed consent of couples and the use of untested fresh or mixed semen was unethical. They felt strongly that that ARTs may become a racket because of the unethical use of donated gametes. Recently subsidiary businesses supporting the ART industry have emerged, for e.g. consultants (who may not have clinical and practical knowledge), offering services to set up a gamut of infertility services including supply of technical personnel and professional donors (persn. comm. with provider).

i) Other concerns

In general, providers expressed concerns about the unregulated use of gametes, embryos and stem cells, lack of or incomplete informed consent, record keeping and documentation. Some providers allowed the free use of donor gametes irrespective of the guidelines. Most suggested a strong regulatory mechanism to monitor and discourage unethical practices, but some felt that providers should practice self-regulation. The need for a national law on sperm banking

was expressed and some disapproved of the guidelines regarding keeping DNA records for 40 years and access to donor information to the child after 18 years of age. They felt record-keeping is cumbersome and revealing the identity to the child maybe difficult in Indian society as children may find it socially unacceptable that they have two parents. Donors who have donated several times may find themselves in an awkward situation and donation of gametes may be reduced.

Discussion

Most concerns with the use of donated gametes discussed in other contexts are emerging in India. Data from this study indicate that ICMR's guidelines are not being followed adequately as providers are guided by the desperate need of their patients and their demands, profit motives and the decreasing supply of gametes.

The boundaries between who is an acceptable child (biologically related or not) and who is an acceptable donor and what is morally and ethically acceptable seem to have blurred in the desperate need to have a child. Couples seem to have fewer concerns about using donated gametes and are less focused that before on issues of caste and colour. Having a child is relatively more important over donor gamete related complications and recipients are so overwhelmed by the current situation of childlessness that they are unable to think clearly about the personal and social consequences of their decisions**.** Providers objections regarding guidelines on anonymous gamete donors include consequences of shortage of gametes, commercialisation and corrupt practices Though there are arguments for and against donor anonymity, they feel it is tempting to accept donor anonymity (Dickens, 2002; Pennings, 2000). It could be hard to judge whether known donors are motivated by pressure or financial motivation in the context of the commercialised and unregulated private health sector care in India where there is inadequate counselling and informed consent. On the other hand it has been argued that donor anonymity would lead to a vicious cycle of paid donation and result in the exploitation of donors and recipients in India (Dutta, 2002). In some countries new systems of recruiting gamete donors are being tried out like the mirror exchange system where the male partner donates sperm and is guaranteed a reduced waiting time for donor oocytes. This could also work the other way and may avoid ethical objections raised against other incentives to attract donors (Ferraretti *et al.*, 2006).

Regarding the use of relatives' gametes, there are arguments for and against it , about securing the stability of the family, fear of the unknown origin of the genetic material versus creating complications of paternity, later rejection by a partner, accusations of adultery, and family tensions. In such a context there are many issues to consider (Nikolettos *et al.*, 2003; Frith, 2001; Marshall, 2002). Using the father-in-law's sperm could possibly create confusion in kinship structures and conflict within relationships and the family. Patients seem to be unaware of such consequences and sometimes may succeed in negotiating with providers they are usually focused on having a child. Besides there are issues of inequality in the family regarding gender and property or using a relatives' sperm in the present may result in the husband's rejection of a wife in the future or in accusations of adultery. But using a relative as a egg donor could be a positive option, for example, most women would feel comfortable using their sister's eggs. The issue is difficult to resolve and needs further exploration in the specific context of the family dynamics in India. Currently the situation requires that patients are provided with adequate counselling and made aware of consequences that may impinge on their or their future child's life.

The proper recruitment and screening of donors could avoid transmission of genetic diseases and HIV to recipients and offspring. Using low quality gametes are of concern as some sperm banks, and providers may not be following protocols. Practices of using fresh or mixed sperm have been reported, which are medically unacceptable. It has also been suggested that there is a semen racket in India asmany banks do not have adequate facilities of preservation, screening and many do not follow WHO guidelines (Ghosh, 2006). Sufficient screening procedures minimise risks for the receiver and the offspring and need to be followed (Garrido, 2002). Recruitment and counselling of gamete donors has to be done in an open and transparent and informative manner. Unless guidelines are implemented with proper monitoring, these practices are likely to continue. Proper record keeping is key because of the repeated use of the same donor samples, as that increases the risk of consanguinity. Information provided to recipients about the donors may be misleading or inadequate and donor gametes could be used without informed consent of the wife and/or husband. Therefore it is critical that complete and transparent information is provided and informed consent of the involved parties is obtained.

Conclusion

ARTs have the capacity to alter established family structures and bring to fore many emotional and ethical issues. The definition of the traditional family

has changed in many parts of the world and the boundaries are being expanded to include arrangements for parenting that are accompanied by complex social and ethical issues which need to be considered (Seibel, 1996). The above mentioned issues need to be addressed by patients, providers and regulatory authorities by providing information, counselling, ensuring informed consent, addressing exploitation and commercialisation, ensuring monitoring, proper documentation and transparency. Proper regulation of ARTs may restrict choices for couples and providers but is critical in protecting vulnerable users. It is important that the current specific social and cultural context be kept in perspective, democratic values respected, and to find a way of using these technologies wisely as they affect current and future generations.

Acknowledgements

The authors would like to thank the all the interviewees, Sunetra Deshpande and Emma Slaymaker who helped with the analysis, the Federation of Obstetricians and Gynaecological Societies of India, the Ford and Soros Foundations and UNFPA/India.

Funding

Funding for the research was provided by the Ford Foundation (India), UNFPA (India) and the Soros Foundation. Besides dissemination of the grant their role was to provide feedback if any, on the narrative reporting on the study. There are no competing interests with those mentioned above.

References

Aquil S. Artificial reproductive techniques: Medico-legal and ethical issues, Indraprastha Technology Law Journal. 2006;1:145-152.

Bharadwaj A. Why adoption is not an option in India: the visibility of infertility, the secrecy of donor insemination, and other cultural complexities. Soc Sci Med. 2003;56:1867-1880.

Bhasin P. Government guidelines on IVF raises concerns. http://www.ndtv.com/convergence/ndtv/defaultndtv. aspx. 2006.

Borrero C. Gamete and embryo donation In: Vayena E, Rowe PJ and Griffin PD (eds). Current Practices and Controversies in Assisted Reproduction. World Health Organization, Geneva, Switzerland 2002, 166-176.

Collier R. Sperm donor pool shrivels when payments cease. Can Med Journal. 23;182(3):233-4.

Daar AS, Merali Z. Infertility and social suffering: the case of ART in developing countries. In: Vayena E, Rowe PJ and Griffin PD (eds). Current Practices and Controversies in Assisted Reproduction. World Health Organization, Geneva, Switzerland 2002, 15-21.

Dickens B. Ethical issues arising from the use of assisted reproductive technologies In: Vayena E, Rowe PJ and Griffin PD (eds). Current Practices and Controversies in Assisted Reproduction. World Health Organization, Geneva, Switzerland 2002;332:348.

Dickens B. Legal developments in assisted reproduction. Int J Obst Gyn. 2008;101:211-5.

Dutta R. ICMR's proposed prohibition creates furore, Express Healthcare Management http://www.expresshealthcaremgmt.com/20020715/cover1.shtml, 2002.

ESHRE Task force on ethics and law: Gamete and embryo donation. Hum Reprod. 2002;17:1407-8.

Fathalla M. Current challenges in assisted reproduction In: Vayena E, Rowe PJ and Griffin PD (eds). Current Practices and Controversies in Assisted Reproduction. World Health Organization, Geneva, Switzerland 2002: 2-12.

Ferraretti AP, Pennings G, Gianaroli L *et al.* Semen donor recruitment in an oocyte donation programme. Hum Reprod.2006;21:2482-5.

Frith L. Gamete donation and anonymity: the ethical and legal debate. Hum Reprod. 2001;16:818-24.

Garrido N, Zuzuarregui JL, Meseguer M *et al.* Sperm and oocyte donor selection and management: experience of a 10 year follow-up of more than 2100 candidates. Hum Reprod. 2002;17:3142-8.

Ghosh A. Compromised semen racket unearthed. The Times of India, Delhi, 2006; Dec 12.

Hallman J, Antonia A, Frank A. Attitudes about infertility interventions among fertile and infertile couples. Am J Public Health. 1992;82:191-4.

Heng BC. Ethical issues in transnational "mail order" oocyte donation. Int J Obst Gyn. 2006;95:302-4.

Human Fertilisation and Embryology Authority SEED Report: A report on the Human Fertilisation and Embryology Authority's review of sperm, egg and embryo donation in the United Kingdom. HFEA, UK, 2007.

Indian Council for Medical Research and National Academy of Medical Sciences National guidelines for accreditation, supervision and regulation of ART clinics in India, New Delhi, 2005.

Inhorn MC, van Balen F. Interpreting infertility: a view from the social sciences In Inhorn MC Balen FV(eds) Infertility around the globe: new thinking on childlessness, gender and reproductive technologies. University of California Press, Berkeley, 2002.

Kirkman M. Being a 'real' mum: motherhood through donated eggs and embryos. Wom Stu Int for. 2008; 31:241-8.

Leeton J, Caro C, Howlett D *et al.* The search for donor eggs: a problem of supply and demand. Clin Reprod Fertil. 1986;4:337-40.

Marshall LA. Ethical and legal issues in the use of related donors for therapeutic insemination. Urol Clin North Am. 2002;29:855-61.

National Gamete Donation Trust Egg donation. http://www.ngdt.co.uk/egg-donation/; 2008.

National Gamete Donation Trust Sperm donation. http://www.ngdt.co.uk/sperm-donation/; 2008.

Nikolettos N, Asimakopoulos B, Hatzissabas I. Intrafamilial sperm donation: ethical questions and concerns. Hum Reprod. 2003;18:933-6.

Pennings G. The right to choose your donor: a step towards commercialization or a step towards empowering the patient? Hum Reprod. 2000;15:508-14.

Purdie A, Peek JC, Irwin R *et al.* Identifiable semen donors – attitudes of donors and recipient couples. N Z Med J. 1992;105:27-8.

Purewal S, Akker VD. British women's attitudes towards oocyte donation: ethnic differences and altruism. Pat Edu and Co. 2006;64:43-9.

Roberts C, Thorsby K. Paid to share: IVF patients, eggs and stem cell research. Soc Sc Med. 2008;66:159-69.

Seibel MM, Zilberstein M, Seibel SG. Gamete donation mirrors society. Hum Reprod. 1996;11:941.

Shanley ML. Collaboration and co modification in assisted procreation: reflections on an open market and anonymous donation in human sperm and eggs. Law & Society Review. 2002;36, 257-84.

Singh AJ, Dhaliwal LK Identification of infertile couples in a rural area of northern India. Indian J Med Res. 1993;98:206-8.

Singh AJ, Dhaliwal LK, Kaur A Infertility in a primary health centre of northern India: A follow up study. J Fam Welfare. 1996;42:51-6.

Srinivasan S. Selling the parenthood dream. In Rao M (ed) The unheard scream: reproductive health and women's lives in India. Zubaan and Panos Institute, New Delhi, 2004;45-66.

Steinbock B Payment for egg donation and surrogacy. Mt Sinai J Med. 2004;71:255-65.

Storrow R Extraterritorial effects of fertility tourism arising from restrictive reproductive laws: what should national parliaments consider? Hum Reprod. 2005;20: 48-9.

Widge A. Beyond natural conception: a sociological investigation of assisted reproduction with special reference to India. Thesis. Jawaharlal Nehru University, New Delhi, 2001.

Widge A Socio-cultural attitudes towards infertility and assisted reproduction In: Vayena E, Rowe PJ and Griffin PD (eds). Current Practices and Controversies in Assisted Reproduction. World Health Organization, Geneva, Switzerland 2002: 60-74.

World Health Organization Ninth Annual Report, Special programme of research, development and research training in human reproduction, Geneva, 1980: 107.

Infertility and Treatment Seeking in India: Findings from District Level Household Survey

Sayeed Unisa

Department of Mathematical Demography and Statistics, International Institute for Population Sciences, Deonar, Mumbai 400088, India.

Correspondence at: Tel.: +91 22 42372430; fax: +91 22 25563257; e-mail: unisa@iips.net

Abstract

Introduction: The purpose of the present paper is to give an estimate of prevalence of infertility and proportion of women seeking treatment for fertility in India by different socio-economic characteristics. An attempt is made to compare lifetime infertility, current infertility and childlessness.
Methods: District Level Household Survey is one of the largest cross-section survey covering 643 944 ever married women. In this survey, for the first time, a module on infertility was kept to examine the past and current problem of infertility in India.
Results: Estimates of lifetime primary/secondary infertility for currently married women aged 20-49 with at least two years marital duration is found to be 8.8%. Three-fourth of those who reported lifetime problem of infertility suffered from primary infertility. Childlessness and current primary infertility are found as 3.7 and 2.3% respectively among women. On average, the percentage of childless women are found to be 1.4% higher than infertility showing that voluntary childlessness is negligible in India.
Childlessness and primary infertility are also estimated removing the subset of population who are currently pregnant or using contraceptive, then the prevalence is found to be 8.9 and 6.4% respectively. Percentage of women seeking treatment for lifetime primary and current primary infertility are around 83%. A higher number of women are now going for allopathic treatment for current infertility problems in comparison to lifetime primary infertility. Although the prevalence of current infertility is 2%, there is huge demand of fertility services in actual number in India.

Key words: Childlessness, India, infertility, lifetime infertility, prevalence, socio-economic.

Introduction

Infertility is included in ICPD as one of the components of reproductive health. Many developing countries have not included in their programme this component for services as these countries are facing population problems (Berer, 1999). Moreover, there is a lack of data to show the demand of fertility services in developing countries and to some extent in developed countries too (Sundby *et al.*, 1988; Van Balen *et al.*, 1997; Unisa, 2001, Che and Cleland, 2002; Boivin *et al.*, 2007). Attempts were made to estimate infertility indirectly from the information on childlessness from the census and survey data (Pathak and Unisa, 1993). Some researchers have also estimated infertility from Demographic and Health Surveys (WHO, 1991; Rutstein and Shah, 2004). In case of India too, reliable estimates of infertility and demand of medical care are not available except for as few localized surveys (Zarger *et al.*, 1997; Unisa, 1999). No comprehensive measures of the prevalence of infertility in India have been carried out, nor have there been any reliable measures of infertility trends. Availability of fertility drugs and reproductive technologies, media attention, less secrecy about the issue of infertility gives an impression that infertility has increased over the period. Moreover, environmental and occupational exposure to chemicals, life style, late marriages, stress and psychological factors, are also found to contribute in increasing prevalence of infertility (Evers, 2002; Foresta *et al.*, 2002; Oliva *et al.*, 2001; Winder, 1989; Olsen *et al.*, 1983).

In order to set up adequate fertility services and to meet the challenges one must know the potential need and demand for medical services in the country. The aim of the present paper is to address two questions: (I) what is the prevalence of infertility in India, and (II) what proportion of couples seeks and/or receive medical care for fertility difficulties? Answers to these questions may empower people with fertility problems and efforts to persuade organizations and government to allocate resources and services for easing the burden of infertility.

Materials and Methods

A seperate module was designated on infertility for the first time in the District Level Household Survey (DLHS-3) and the present study is based on this data. The primary objective of this survey is to provide reproductive and child health outcome indicators at the district level in order to monitor and provide corrective measures to the national programme (IIPS, 2010). A multi-stage stratified systematic sampling design was adopted for DLHS-3. In each district, 50 primary sampling units (PSUs), these are census villages for rural areas and wards for urban areas, were selected in the first stage by systematic probability proportional to size (PPS) sampling. In rural areas in the second stage of sampling, households were drawn from the selected villages (PSUs) after house listing. Whereas, in urban areas the second stage of sampling is the selection of Census Enumeration Blocks (CEBs) followed by selection of households in the third stage of sampling. Circular systematic sampling was adopted for selection of households.

The DLHS -3 survey is one of the largest ever demographic and health surveys carried out in India, with a sample size of about seven hundred thousand households. Fieldwork was conducted during December 2007 to December 2008 covering 611 districts in the country, gathering information from 643,944 ever married women in the age group 15-49 years. Overall household response rate was 94 cent with 89 per cent for ever married women. The ever-married women's questionnaire contained information on women's characteristics, maternal care, and reproductive health including module of infertility. All household level questionnaires were bilingual, with questions in both regional languages and in English.

The module of infertility consisting of seven questions was canvassed to all ever-married women to gather information on infertility status and treatment seeking in DLHS-3. In this survey, treatment sought and type of treatment (allopathic or other) is also asked to those women who reported problems in conceiving.

Following definitions are used in the paper:

Lifetime infertility: Ever had/have problem in getting pregnant

Lifetime primary infertility: Ever had/have problem in conceiving for the first time

Childlessness: Never had any live birth till interview date

Current primary infertility: Never had any live birth till interview date and reported problem in conceiving for the first time

Estimation of lifetime infertility is based on the question – whether women ever had a problem in getting pregnant (first question of module in the DLHS). Lifetime primary infertility is based on the first question and the timing of this event that is problem in conceiving for the first time (second question of module). Estimation of childlessness is based on the information of the birth history question – women ever had live birth (No). Current primary infertility is based on the birth history information that is no live birth until interview date along with the first two questions of the infertility module about problem of getting pregnant for the first time. For all the above indicators, currently married women in the age group 20-49 with at least two years marital duration are considered for this paper. Current primary infertility has also been calculated removing the subset of population who are currently pregnant or using contraceptive among the same age and marital duration women. Women of ages 15-19 are not considered here as they are in process of maturity and sometimes face adolescent infertility (Agrafiotis, 2007). In case of India, women after marriage frequently visit their parental house for religious and cultural reasons, hence, marital duration of two years is considered here to give sufficient exposure time of 24 months for conception (WHO, 2001).

Demand for medical care was defined as the proportion of couples who decide to seek any medical advice or care to resolve their fertility problems – the question in the module was" Have you or your husband consulted anyone for advice or treatment for infertility problem". The following question in the module of infertility was about the source of treatment (Government allopathic care, private allopathic care, AYUSH, herbalist, traditional healer, religious/faith healing). In the study, overall figures that include any type of care (general advice, diagnostic testing, treatment) and any type of services (allopathic, AYUSH-Indian System of Medicine) are used. However, separate estimate of demand for allopathic treatment are also provided adding government and private allopathic care.

The future number of expectedof infertile couples and services required are estimated using projected female population of India by age for 2011 and 2021

(Registrar General of India, 2006). The proportion of currently married women from 2001 census is kept the same for estimating currently married women in 2011 and 2021 considering that marriage dissolution over period will remain more or less same (any marginal increase in divorce will be compensated with marginal decrease in widowhood). Estimates of currently married women population of age 20-49 were multiplied by the proportion of women with corresponding lifetime and current primary infertility from the present analysis to get estimates of infertile women for 2011 and 2021. Estimated number of infertile women were then multiplied by the proportion of those seeking infertility medical care to get estimates of the number of infertile women seeking fertility treatment.

Results

Results of lifetime, current infertility and treatment are presented by socio-economic characteristics of women. The purpose of giving infertility rates by

Table 1. — Percentage of women aged 20-49 years with at least two years of marital duration who are childless/infertile according to selected background characteristics, India, 2007-2008.

Background Characteristics	Lifetime infertility	Lifetime primary infertility	Based on all women		Based on non pregnant and non contraceptive users	
			Childless	Current primary Infertility	Childless	Current primary Infertility
Current age						
20-24	9.4	7.3	10.6	4.6	14.6	7.9
25-29	8.7	6.4	4.2	2.8	9.3	7.0
30-34	8.8	6.4	2.6	2.0	8.5	7.0
35-39	8.7	6.6	2.1	1.7	7.3	6.3
40-44	8.7	6.8	1.8	1.5	5.7	4.8
45-49	8.8	7.0	1.7	1.5	4.4	3.8
Type of locality						
Rural	8.9	6.9	3.8	2.3	8.4	5.9
Urban	8.5	6.3	3.7	2.4	10.2	7.7
Age at consummation of marriage						
Below age 18	9.5	7.4	3.0	1.9	7.1	5.1
18 and above age	8.2	6.0	4.4	2.8	10.8	7.8
Education of women						
No schooling	9.4	7.3	3.4	2.2	7.3	5.4
Less than 5	9.2	7.1	3.2	2.1	8.3	6.2
5-9 years	8.6	6.4	4.0	2.5	10.6	7.6
10 or more year	7.6	5.5	4.4	2.5	11.7	8.0
Education of husband						
No schooling	9.3	7.1	3.4	2.3	7.2	5.4
Less than 5	9.3	7.1	3.3	2.3	8.3	6.3
5-9 years	8.9	6.8	3.9	2.4	9.4	6.8
10 or more year	8.3	6.2	4.0	2.3	10.0	7.0
Religion of the women						
Hindu	9.0	6.9	3.9	2.4	9.6	6.8
Muslim	8.8	6.8	3.3	2.3	6.2	4.8
Christian	6.2	3.9	3.1	2.0	6.5	5.1
Sikh	9.7	7.5	2.7	2.0	10.5	8.5
Buddhist	6.7	4.5	3.1	1.9	9.3	7.4
Caste of the women						
Scheduled Caste	9.5	7.3	3.8	2.4	9.4	6.7
Scheduled Tribe	7.2	4.9	4.1	2.4	8.3	5.8
Other Backward Caste	9.3	7.2	3.9	2.4	8.9	6.2
Other	8.7	6.6	3.3	2.2	9.2	7.0
Wealth index quintiles						
Poorest	9.8	7.6	4.4	2.6	7.5	5.2
Second	9.4	7.3	4.0	2.4	8.0	5.5
Middle	8.7	6.6	3.6	2.2	8.6	6.1
Fourth	8.6	6.5	3.6	2.3	9.9	7.4
Richest	8.2	6.0	3.5	2.3	10.4	7.8
India	**8.8**	**6.7**	**3.7**	**2.3**	**8.9**	**6.4**

socio-economic characteristics is to identify any specific group which is facing and how many of them effort to go for treatment.

Lifetime infertility

Estimates of lifetime infertility give an idea about how many women actually suffered with this problem that they might not be facing currently. This measure gives a better idea about potential need of fertility services in the country. Based on the question whether women have faced any time problem in conceiving (for the first time, after live birth/still birth, abortion), lifetime infertility rates are computed for currently married women in the age group 20-49 with at least two years marital distribution by socio-economic characteristics (Table 1). It is found that 8.8 percent women in India faced the lifetime primary/secondary infertility problem. Three-fourth of those who reported a lifetime problem in conceiving suffered from primary infertility. Age-wise lifetime primary/secondary infertility prevalence is the same for all age groups except for age group 20-24.

It is found that 6.7 percent women have faced or facing problem in conceiving for the first time (lifetime primary infertility). Those women belonging to poorest wealth quintile, Sikh religion, Scheduled caste, who got married before age 18 years, and not gone to school or have less than five years education have higher prevalence of primary infertility in comparison to their counterparts (above seven per cent prevalence).

Childlessness and Current Infertility

Childlessness is defined as how many women at present did not have any live birth whether this might be involuntary or voluntary. Whereas current primary infertility estimates gives an idea about the current problem in conceiving for the first time. The current primary infertility measure is also based on the question whether women have faced problem in conceiving for first time but it is computed only for those women who never had any live birth. Table 1 presents estimates of current childlessness and primary infertility for currently married women with at least two years marital duration by socio-economic characteristics. Childlessness and current primary infertility are found as 3.7 and 2.3 per cent respectively among women. A comparison of childlessness and infertility estimates gives an idea about voluntary childlessness in India. On an average, the percentage childless women is 1.4 percent higher than primary infertility showing that voluntary childlessness is negligible in India. Negative relationship between age and status of childlessness and primary infertility is found as it was expected. At the end of reproductive ages, both the rates are almost same and it may be noted that less than two percent remained primary infertile by the age 45-49.

Childlessness and primary infertility is also estimated removing the subset of population who are currently pregnant or using contraceptive then the prevalence is found as 8.9 and 6.4 per cent respectively. These estimated are found higher for women belonging to Sikh religion, five and above years of education, belonging to richest wealth quintile, and those women who got married after age 18 and living in urban areas.

Demand for medical services

In case of India along with allopathic system of medicine, other Indian systems of medicine, and alternative system of medicines (Ayurvedic, Yoga, Unani, Sidha, Homeopathy (AYUSH), herbal, traditional medicine, religious / faith healing) are also used by couples for infertility treatment (Kakar, 1983; Unisa, 2000). Women were asked about treatment, / diagnosis and / advice for infertility by any type of medical practitioner. Treatment for lifetime primary as well as current primary infertility behavior is presented in Table 2 only for currently married 20-49 age group women with at least two years marital duration. A very high proportion (around 83 per cent) of women sought treatment for lifetime and current infertility from any source of medicine. Except women who belong to poorest wealth quintile, scheduled tribes and never gone to school all other women have similar pattern of treatment from any source of medicine. More than 90 percent women belonging to Sikh religion and highest wealth quintile are undergoing treatment for lifetime and current infertility.

Seventy two percent and 66 percent women respectively were going for current and lifetime infertility treatment by allopathic system of medicine at all India level. Over all higher percentage of women are going for allopathic treatment for current in comparison to lifetime infertility. Although difference in treatment seeking from any source exists by socio-economic characteristic of women but large differences are found when it comes to women going for allopathic treatment for lifetime and current primary infertility treatment by socio-economic characteristics. There is 40 percent difference in poorest to richest wealth quintile, 26 per cent with no schooling to 10 and above years of schooling and 23 per cent in rural- urban areas among women who are going for allopathic treatment. Around 50 per cent women belonging to scheduled tribes and poorest wealth quintile women can afford to go for allopathic treatment. Most of the women who have undergone

Table 2. — Percentage of currently married women aged 20-49 years with at least two years marital duration who sought treatment for lifetime/currently primary infertility problem, according to selected background characteristics, India, 2007-2008.

Background Characteristics	Lifetime infertility treatment		Current infertility treatment	
	Any type of treatment	Allopathic treatment	Any type treatment	Allopathic treatment
Current age				
20-24	79.9	64.8	73.6	61.5
25-29	86.4	71.5	84.2	74.1
30-34	85.8	69.1	87.3	77.5
35-39	83.6	66.7	87.0	77.8
40-44	82.2	62.9	85.5	76.5
45-49	78.7	58.9	83.0	75.3
Type of locality				
Rural	81.4	61.7	79.0	66.3
Urban	87.7	77.4	88.7	83.4
Age at consummation of marriage				
Below age 18	81.6	61.7	79.7	67.6
18 and above age	85.4	72.2	83.9	74.9
Education of women				
No schooling	79.2	56.9	76.3	61.6
Less than 5	83.1	63.0	82.7	69.8
5-9 years	86.5	74.4	85.0	77.8
10 or more year	91.0	85.2	90.9	87.2
Education of husband				
No schooling	77.4	53.3	74.2	56.9
Less than 5	79.0	55.8	77.7	63.8
5-9 years	84.1	67.8	82.8	73.3
10 or more year	88.5	78.8	88.3	83.3
Religion of the women				
Hindu	82.4	65.5	80.9	70.8
Muslim	87.2	69.5	88.1	79.2
Christian	82.3	70.2	85.2	73.3
Sikh	96.4	83.6	95.2	87.2
Buddhist	74.0	63.1	75.3	65.2
Caste of the women				
Scheduled Caste	81.6	62.5	78.6	68.9
Scheduled Tribe	72.7	46.1	71.9	50.4
Other Backward Caste	84.3	69.2	84.0	75.4
Other	87.5	74.5	88.5	82.7
Wealth index quintiles				
Poorest	75.4	48.3	69.0	47.8
Second	79.4	57.0	75.5	61.1
Middle	81.5	63.1	81.3	71.1
Fourth	85.0	71.6	86.7	80.7
Richest	91.4	84.0	92.4	88.8
India	**83.3**	**66.4**	**82.2**	**71.9**

allopathic treatment have availed it from private sector, as complete diagnostic services and treatment are not available in most of the Government health service centres in India.

Future potential demand of medical care for infertility

In order to set up adequate fertility services and to meet the challenges one must know the potential need and demand for medical services in the country. Hence, number of infertile women and out of them how many are going for medical care is projected for 2011 and 2021. Projected female populations and proportion of currently married women are used from census statistics and prevalence rates of infertility and treatment seeking aret used from the estimates of DLHS-3. Table 3 shows the projected number of women of age group 20-49 for 2011 and 2021 respectively. Estimation of currently married women (couples) shows that there will be 184 and 239 million women respectively in 2011 and 2021. Sixteen and 21 million currently married women aged 20-49 have lifetime primary infertility in 2011 and 2021. Of these women, eight and 11 million go for allopathic treatment if the current rate of 66 per cent seeking treatment is used. Over the period, it

Table 3. — Projected figures of potential need and demand for infertility medical care.

Categories of estimation	2011 Estimated number (×1,000)	2021 Estimated number (×1,000)
Number of projected women of ages 20-49	228,840	296,365
Number of currently married women of ages 20-49	184,921	239,486
Number of currently married women who will have lifetime infertility (9%)	16,642	21,553
Number of currently married women who will have lifetime primary infertility (7%)	12,389	16,045
Number of currently married women who will go for allopathic treatment for lifetime primary infertility (66% - low)	8,543	11,064
Number of currently married women who will go for allopathic treatment for lifetime primary infertility (85% - high)	11,002	14,249
Number of currently married women who will have current experience of primary infertility problem (based on 2% prevalence - low)	3,698	4,789
Number of currently married women who will go for allopathic treatment for current primary infertility (85% - high)	3,143	4,071
Number of currently married women who will have current experience of primary infertility problem in 2011 (based on 5% prevalence - high)	9,246	11,974
Number of currently married women who will go for allopathic treatment for current primary infertility (85% - high)	7,859	10,178

may be expected that use of allopathic treatment will increase and at least 85 percent will seek allopathic treatment. Using 85 percent going for allopathic treatment potential demand of services is also projected and it is found that 11 and 14 million would undergo treatment. It is also projected and presented in table how many vurrent primary infertile (couple) there will, how many of them go for treatment.

Discussion

For the first time in India we have lifetime prevalence of primary/secondary infertility data from the District Level Household Survey that has included module on infertility. This estimate is valid insofar as DLHS-3 consists of a representative sample of whole population of India. The analysis shows not very significant variation by socio-economic characteristics in the prevalence of infertility. However, demand for infertility medical services varies largely by wealth quintiles, education and residence.

In the study conducted in the USA on the trend of infertility, it is found that rates stayed more or less the same over the period 1985-2002 (Stephen and Chandra, 2006). In contrast, in some of the African countries, prevalence was dropped drastically from exceptionally high level of 50 percent (Larsen, 2005). In India, the prevalence of infertility is similar to estimates derived for the developing countries (Boivin *et al.*, 2007). In this study too, similar to USA pattern of lifetime infertility, we are expecting lifetime infertility prevalence will remain more or less at the same level. Therefore, it is justified to use the same prevalence rates of 2007-2008 for projection of infertile women in India for 2011 and 2021.

Children and motherhood are important in developing countries for socio-cultural reasons and continuity of marriage (Berer, 1999; Unisa, 1999). However, among women belonging to low socio-economic strata only about half used allopathic infertility treatment. One of the factors for low demand is that people may not be motivated to seek treatment if fertility services are limited or unavailable in public health sector (Sundby *et al.*, 1998; Unisa, 2001; Bovin *et al.*, 2007). Couples have to spend considerable amount of money for fertility treatment which is difficult to manage in their available resources (Unisa, 2008).

A lot of medical research has been devoted for the advancement of procedures that can be offered as infertility services. Some of the fertility treatments range from relatively simple hormone treatments to highly complex and invasive procedure. The success rate of these procedures varies, but few are encouragingly high ones (Statistics of Human Fertilisation and Embryology Authority of the U.K., 1999). A

large proportion of women seeking infertility treatment have ovulation and reproductive tract infection (Norris, 2001). We need epidemiologic surveys to estimate demand for specific treatment services for infertility in India. However, basic low cost diagnostic and treatment services may be provided at community level health facilities in India as very large number of women going to be infertile in coming years. Looking at the potential demand of services, component of infertility may be included with more emphasis in the current policy of health services to women/men.

Funding Agency

Ministry of Health and Family Welfare, Government of India funded district Level Household Survey-3. International Institute for Population Sciences, Mumbai is nodal agency for this survey and author is one of the coordinator of this project.

Acknowledgements

I would like to thank all Technical Advisory Committee members of DLHS-3 especially Professor PM Kulkurni, (Late) Professor Mari Bhatt and Professor F Ram for their support for inclusion of module on infertility in the District Level Household Survey.

References

Agrafiotis GK. A stochastic model for estimating adolescent sterility among married women, Biometrical Journal. 2007; 28(8):1001-5.

Berer M. Living without children. Reprod Health Matters. 1999;7(13):6-13.

Boivin J, Bunting L, Collins JA *et al.* International estimates of infertility prevalence and treatment-seeking: potential need and demand for infertility medical care. Hum Reprod. 2007;22(6):1506-12.

Che Y, Cleland J. Infertility in Shanghai: prevalence, treatment seeking and impact. J Obstet Gynaecol. 2002;22:643-8.

Evers J. Female subfertility. Lancet 2002;360:151-9.

International Institute for Population Sciences (IIPS). District Level Household and Facility Survey (DLHS-3), 2007-08: IIPS, Mumbai, India. 2010 (In press). (See also http://rchiips.org)

Kakar DN. Traditional healers in North India: A case study. Nursing Journal of India. 1983;74(3):61-3.

Larsen U. Primary and secondary infertility in sub-Saharan Africa. Int J Epidemiol. 2000;29:285-91.

Norris S. Reproductive Infertility: Prevalence, Causes, Trends and Treatments. Parliamentary Research Bracnh, Library of Parliament, Canada, 2001.

Oliva A, Spira A, Multiger L. Contribution of environmental factors to the risk of male infertility. Hum Reprod. 2001; 16(8):1768-76.

Olsen J, Rachootin P, Schiodt A *et al.* Tobacco use, alcohol consumption, and infertility**.** Int J Epidemiol. 1983;12:179-84.

Pathak, KB, Unisa S. Estimation of primary and secondary infertility from children ever born data in K.B. Pathak and A. Pandey (eds.) Bio-Social Aspects of Human Fertility. New Delhi: B.R. Publishing Corporation, 1993.

Registrar General of India. Population Projections for India and States 2001-2006: Report of the Technical Group on Population Projections Constituted by the National Commission on Population. Office of the Registrar General & Census Commissioner, India.2006.

Rutstein SO, Shah IH. Infecundity, infertility and childlessness in developing countries. DHS Comparative Reports, No. 9, 2004.

Statistics of Human Fertilisation and Embryology Authority of the U.K., 1999. Available at www.hfea,gov.uk/patgde99/infert/range.htm

Stephen EH, Chandra A. Updated projections of infertility in the United States:1995 to 2025. Fertil Steril. 1998;70:30-4.

Sundby J, Mboge R, Sonko S. Infertility in the Gambia: frequency and health care seeking. Soc Sci Med. 1998;46: 891-9.

Unisa S. Childlessness in Andhra Pradesh, India: treatment-seeking and consequences. Reprod Health Matters. 1999;7: 54-64.

Unisa S. Sequence of fertility treatment among childless couples in Ranga Reddy District, Andhara Pradesh, India. Asia-Pacific Population Journal 2001;16 (2):161-76.

Unisa S. Longitudinal study of childless women in India: Success of fertility enhancing treatments. Paper presented at conference on Reproductive Health Challenges. 26-29 August, 2008; Oslo, Norway.

Van Balen F, Verdurmen J, Ketting E. Choices and motivations of infertile couples. Patient Educ Couns. 1997;31:19-27.

WHO. Infertility: a tabulation of available data on prevalence of primary and secondary infertility. Programme on Maternal and Child Health and Family Planning, Division of Family Health. World Health Organization,Geneva: 1991.

World Health Organization. Reproductive health indicators for global monitoring: Report of the second interagency meeting**,** 2001. Geneva: World Health Organization.

Zarger AH, Wani AI, Masoodi SR *et al.* Epidemiologic and etiologic aspects of primary infertility in the Kashmir region of India. Fertil Steril.1997;68:637-43.

Summary of an Expert meeting on "Social Aspects of Accessible Infertility Care in Developing Countries"

Willem Ombelet[1,2], Frank Van Balen[3]

[1]*Coordinator of the ESHRE Special Task Force on "Developing countries and infertility".*
[2]*Genk Institute for Fertility Technology, Department of Obstetrics and Gynaecology, ZOL, Genk, Belgium.*
[3]*Faculty of Social and Behavioural Sciences, Department of Education, University of Amsterdam, the Netherlands.*

Programme of the meeting

Theme 1: Education on infertility and its treatment

Introduction by **Geeta Nargund**

a) Present knowledge: sources of information (media) education (schools), medical training.
b) How to improve knowledge in poor resource areas about infertility, its consequences and its treatment?

Notes and summary by **Tamara Egede**

Theme 2: Male infertility

Introduction by **Viola Hörbst**

a) Recognition of male infertility (hidden cause, often kept secret)
b) Problems in getting males to (sperm) examinations (feasibility)
c) Participation in IVF, IUI and other treatments

Notes and summary by **Trudie Gerrits**

Theme 3: Accusable infertility care

Part 1: introduction by **Johanne Sundby**

a) Role of traditional healers compared to modern biomedicine: accessibility, costs, success-rate, norms and values
b) Limitations, hurdles, advantages and disadvantages of low-cost IVF and other treatments such as IUI

Part 2: introduction by **Sheryl Vanderpoel**

c) Infertility care in relation to other health priorities in the areas, incorporation within family planning, political considerations (acceptance of contraceptives)
d) Who will be able to come to treatments (and pay for it)?

Notes and summary by **Papreen Nahar**

Theme 4: How to assess the low-cost IVF pilot projects

Introduction by **Cora de Klerk**

a) Information to couples
b) Assessment of the treatment
c) Follow up after successful and unsuccessful treatment

Notes and summary by **Nathalie Dhont**

Conclusions:

Programme of action:
Advice and suggestions to the ESHRE special taskforce "Developing countries and infertility"
Countries and areas of potential success for improvement infertility care (education, treatments and methods)
Practical matters, things to work out, instrument development, next meetings.

List of participants

Willem Ombelet (Belgium)
willem.ombelet@telenet.be
Tamara Egede law England (Nigeria)
Egedeto@cardiff.ac.uk

Organized by the Social Study group of the ESHRE Special Task Force "Developing countries and infertility".

Genk, Belgium, December 11-12, 2009.

Trudie Gerrits (the Netherlands)
G.J.E.Gerrits@uva.nl
Johanne Sundby (Norway)
Johanne.Sundby@samfunnsmed.uio.no
Papreen Nahar (Bangla Desh)
Papreen21@yahoo.com
Viola Hörbst (Portugal)
Hoerbst@lrz.uni-muenchen.de
Frank van Balen (the Netherlands)
F.vanbalen@uva.nl
Geeta Nargund (United Kingdom)
geetanargund@gmail.com
Hassan Sallam (Egypt)
hnsallam@link.net
Sheryl Vanderpoel (WHO, Geneva)
vanderpoels@who.int
Carin Huyser (South Africa)
carin.huyser@up.ac.za
Cora de Klerk (the Netherlands)
C.deklerk@erasumusmc.nl
Anjali Widge (India)
Anjali.Widge@gmail.com
Nathalie Dhont (Rwanda)
Dinaluju@yahoo.com

Theme 1: Education on Infertility and its Treatment

Presentation by Geeta Nargund and notes by Tamara Egede

This document summarizes the discussion points on the theme - *Education on Infertility and its Treatment*. Presented by Geeta Nargund, Chief Executive, Health Education Trust UK and President- International Society for Mild Approaches in Assisted Reproduction (ISMAAR). The meeting based its discussions on the points of investigation raised in Nargund's presentation relating to the potential collaboration with NGOs, school curriculum, medical education, community programmes, joint funding applications and media campaigns. The key discussion points and conclusions are set out below.

Present knowledge and sources of information

1) The meeting exchanged views on the knowledge resources on infertility and its treatment highlighted in Nargund's presentation and expressed support for widening access of relevant resources to patients, clinics and communities in targeted regions for the pilot schemes.
2) The meeting considered the formulation of bespoke knowledge resources designed to meet local circumstances in targeted regions. The work of the Fertility Education Trust and other similar resources (referred to in the presentation) which provide tutorials, charts and materials on fertility and infertility were considered.
3) Participants further explored how current knowledge could be extended beyond infertility prevention and treatment to include tangible strategies and programmes that aim to tackle the social consequences of infertility in low resourced countries.

Medical Education and School Curricula

1) Discussions focused on the current status of infertility training in medical education and moved on to consider how the reproductive health curricula in low resourced countries could be further strengthened in the area of infertility training and its wider integration into the primary health care service as recommended in Nargund's presentation.
2) The meeting also considered the inclusion of infertility education in the reproductive health care curricula of secondary schools so as to create further awareness on infertility prevention and the impact of unsafe sex and abortions on fertility.

Media and Dissemination Campaigns

1) The meeting exchanged views on the appropriate information media to disseminate knowledge on infertility management. A range of media were considered, including the use of popular dissemination campaigns such as radio jingles, print media, television adverts, fliers, posters and the use of drama and film clips.
2) It was recommended that the intended materials be translated into local languages, particularly when targeted at rural communities and other patients groups with lower levels of education. Some participants pointed out that the local language component may not be relevant for middle income bracket patients situated in urban centres.

Availability of Information Technology in Low Resourced Countries

1) A related issue on effective dissemination tools had to do with the use of internet and social network web tools such as Face book and Twitter. While a number of the participants recognised the role of internet dissemination in creating awareness on infertility management; views diverged on the suitability of social network web tools considering that several of the targeted patients may come from low income brackets. Attention was however drawn to the evidence of the usage of social network web tools in urban centres of low resourced countries, but several participants maintained that local circumstances (e.g. internet connectivity) and the status of patients

were critical in determining what tools to include in the taskforce dissemination strategy.
2) The meeting concluded discussions on this point by recommending the use of the ESHRE website and other partner websites in highlighting the activities of the task force and pilot schemes.

Collaboration and Partnerships

1) Following from the presentation, the role of national governments, the civil society (non-governmental organisations (NGOS) and community leaders in supporting the taskforce's work was considered. While many participants expressed support for public–private partnerships (PPPs) in furthering the work of the taskforce within beneficiary regions, they saw the role of civil society as vital in ensuring accountability in regions faced with concerns of poor governance and corruption.
2) The meeting agreed with the recommendations raised Nargund's presentation that community leaders could be used as agents to change community attitudes on infertility.
3) The meeting further agreed that knowledge products from commercial IVF clinics which have patient recruitment as their sole objective may detract from the wider work of the taskforce which seeks not only to widen access to Assisted Reproductive Technologies (ARTs), but to improve the status of infertile patients who remain childless or pursue other alternative parenting structures such as adoption.

Gender Empowerment

The meeting also supported creating greater awareness on gender empowerment to reduce the social stigmatisation of childless women in resource countries. Again, the engagement with the civil society was underscored as crucial in championing empowerment and advocacy programmes aimed at uplifting the status of the infertile women in low resource countries.

Funding Opportunities

The participants also exchanged views on funding options to progress the work of the taskforce. While it was considered desirable that the taskforce continue to explore peer review grants and other customary funding opportunities, it was suggested that the taskforce consider alternative funding opportunities such as corporate social responsibility funding options as discussed in Nargund's presentation.

Alternative Options to Low Cost IVF Schemes

The meeting reiterated the importance of the work of the taskforce being wider than the provisioning of low cost IVF schemes and agreed that while there may be socio-cultural or religious barriers to child adoption in some regions; the option should still be included in the taskforce's framework for establishing adequate infertility care in poor resource areas.

Theme 2: Male infertility

Presentation by Viola Hörbst and notes by Trudie Gerrits

Introduction

Most of the developing countries are pro-natalist societies, where children are a necessity in order to be acknowledged as a full social adult being. Infertility and childlessness are often looked at as a predominantly female problem. Yet, scarce literature on male infertility in developing countries shows that not only women, but also men are in need of own (marital legal) offspring to proof their bodily capacity to produce children and thus their manhood. In addition, both women and men need children for various other reasons, such as to support them when they are old and/or sick and in order to guarantee the continuity of their family lineage.

To date social science studies on male infertility in developing countries, including studies on the male perspective and/or their experiences of infertility, are rare. Yet, a number of other studies, while not focusing on male infertility per se, have provided preliminary insights into the meaning and implications of infertility for men in various socio-cultural contexts and into the ways men are involved in seeking a solution for a couple's fertility problem.

Literature emphasizes that main stream public narratives predominantly blame women for involuntary marital childlessness, while they hardly acknowledge or even hide male factor infertility; only a few studies have also pointed to awareness of male factor infertility. Subsequently, the major and public part of the devastating infertility drama has to be shouldered by women, in terms of social ostracism, stigmatization, and social exclusion. Yet, at the same time studies have shown that childless men are not treated equal as fathers and those men may suffer from stigmatization and loss of social status as well. While thus social stigma for childless men exists and even may be high, men are also found to be able to disguise their problem by allowing their wives to have sex with another man (for example with a relative) or by claiming children elsewhere.

Concerning treatment seeking, both in traditional and biomedical health care settings, women too are found to bear the major part of the burden. Literature, assessing men's behavior from a biomedical

point of view, underlines the problem of bad male compliance with biomedical diagnosis and treatment, above all if men are assumed to be the reason for unwanted childlessness of the couple. In particular, men are found not to be willing to hand in their semen for analysis, and in some cases this has to do with men's resistance to 'produce' semen by masturbation. From the biomedical point of view, when thinking of setting up comprehensive infertility care in developing countries, major questions of concerns are threefold, namely: How to get men of infertile couples into the hospital? How to get them being diagnosed? How to get them to follow and support the treatment?

In order to get new ideas on how to approach these questions Viola Hörbst suggested in her presentation to turn these questions around and look at the problem of male infertility from afflicted men's perspective, thus putting two questions forward:

1) What is at stake for the men with regard to being diagnosed as infertile?

To understand what is at stake for men with regard to (potentially) being diagnosed as infertile, male infertility should be looked at as a field of problem configurations where assisted reproductive Technology (ART) is but one means - admits others - to find a solution. In her study on ARTs in Mali Hörbst found that various factors impact on what seems for men a better or a worse option, such as secondary gender specific reproductive aims (to continue the lineage versus showing pregnancy to stop stigmatization); main stream norms linked to masculinities, main stream narratives of infertility (female responsibility, secrecy), costs, couple relations, family pressure for alternative social solutions (polygyny, divorce), religion (Islam allowing to marry up to three women) and necessities in the enlarged family to spend the money needed (school fees, diseases of other members, etc.).

To get comprehensive and new insights on what keeps infertile men from complying with biomedical recommendations and infertility care, we then can ask the following question.

2) Which options are opened up or closed via biomedical treatment avenues? What does biomedicine – including ART – offer with regard to men's problem configurations when diagnosed infertile?

On the one hand, biomedical infertility care renders men more vulnerable, as the predominant narrative of female responsibility of marital childlessness is broken up. Thus, via biomedical diagnostics men are put at a higher risk for public disgrace and shame, which includes a double de-masculinisation, concerning sexuality and authority over women. Moreover, no secrecy web between the partners is any longer possible, and discrete social solutions (such as clandestine extramarital sex by their wives) are no longer acceptable to these men.

On the other hand, biomedical treatment offers men hope for curing bodily impairments (e.g. increase of sperm quality and quantity via hormonal treatments) and it offers the hope to conceive an own biological child in the future. Yet, the outcome of this option is insecure, as success rates of infertility treatments (including ARTs) are not very high, and particularly if only one treatment cycle is affordable to them. If only homologue IVF is offered, the reproductive aim of continuing the lineage via own biological/genetic offspring is not achievable for men diagnosed with azoospermia. Thus other options, such as taking foster children of a brother, might then seem more adequate to them to achieve their secondary reproductive aims, as Hörbst found in her study in Mali.

If confronted with the possibility to stay without children for the rest of their lives – even when ARTs are offered – men may prefer not to be involved in these treatments at all. They may rather hide behind the social stigmatization of their wives in order not to risk to be handed over to double de-masculinisation, in terms of sexuality and in terms of authority over women, and thus to social death.

While some points detected in Hörbst's research on ARTs in Mali can be generalized for many societies of sub-Saharan Africa, as well as for other developing countries, for future research and pilot projects of ART we have to keep in mind that there are always specific local contexts (in terms of sociocultural, structural, political aspects and international connections) impacting on the perception, handling and treatment of male infertility via assisted reproductive technologies.

Discussion

In the discussion a number of issues were brought up:

1) Diagnosis of female infertility may negatively impact woman's position

It was observed that if the results of fertility examinations of both partners of a couple shows that the woman is the cause of the couple's fertility problem, this may lead to a (further) decrease of the position and situation of the woman. As a result she may suffer more from her infertility problem and childlessness. The husband may divorce from her and/or find a new wife rather than paying for expensive treatments. In Mali Hörbst found that men seem to be less willing to pay when their wife was diagnosed to cause the infertility, as the social solution to marry

another wife (as allowed by Islamic regulations) was often seen as more attractive, and that they were more motivated when they themselves were to blame. (This is to a certain extent comparable to what Inhorn has observed in Egypt when ICSI was introduced in the country and wives of infertile couples were too old to bear their child. Even when in these cases the men were to blame for the childlessness of the woman.) In this case thus the result of introduction or application of assisted reproductive technologies may have a devastating effect on infertile diagnosed women rather than improving their situation. This is a serious ethical concern that should be very well considered before introducing ARTs in a new context.

Following the discussion of this concern it is suggested that a diagnosis should never be performed when it cannot be followed up by a form of treatment. This raises the question whether level one (diagnosis only) should then be skipped completely. This question was not really answered, though it was said that it is always good to know a cause.

2) Semen testing

The question whether people will be able to understand the genetic parts of fertility treatments was raised. This of course differs from place to place and from couple to couple. In general it should not be presumed that people in developing countries per se have low understanding of reproduction, as the people who will be able to afford (the low cost) ART will presumably belong to the mid-level and higher economic classes and many of them will be relatively well educated.

With regard to semen testing it is observed that in India and South-Africa men may hand in the semen of a relative instead of their own in order to avoid getting bad results and being blamed for the infertility problem. It is said that explaining the importance of handing in their own semen should be stressed to the men/couples in order to be able to make a good diagnosis (and thus follow it up with a proper treatment) and also because it is important to know the HIV-status of the man involved. Related to this it is mentioned that a first step in diagnosis and treatment should always be an extended intake session (this word was thought to be more acceptable in some cases than the word counseling). In addition, it was suggested – as is common practice in the clinic of the South-African participants as well as in Mali (Hörbst, forthcoming) – that men always are invited separately to get their test results.

During the above discussion of semen testing the issues of HIV/AIDS was raised, including also the question whether HIV+ people should be included or excluded from treatment. It was also questioned whether people will come if they know that they have to be tested for HIV/AIDS. Yet, it was observed that from PMCTC programs we have learned that (both) parents do come for testing. It is concluded that we cannot answer the question on inclusion/inclusion of HIV+ people in general terms: more information and insights are needed on transmission rates, testing behavior, safety measures and national guidelines, which are different in various places.

Besides IVF and ICSI, intrauterine insemination (IUI) should not be forgotten as this form of ART is cheaper, easier to perform and has a good acceptance with regard to patients. In Mali IUI provides good results and can be a first step in order to find a solution for couple infertility in low-resource settings.

Theme 3: Accusable infertility care

Presentations by Johanne Sundby and Sheryl Vanderpoel, notes by Papreen Nahar

First part of the theme

Introduction of the session done by Johanne Sundby. As per the programme, the sessions were divided in to two sections:
1) Role of traditional healers compared to modern biomedicine: accessibility; costs, success-rates, norms and values.
2) Limitations, hurdles, advantages and disadvantages of low-cost IVF and other treatments such as IUI.

Johanne Sundby started introducing the topic from the policy angle of ICPD and MDG as well as Human Rights Issues. With evidence she made it clear that in developing countries infertility is still no one's agenda. She brought up the issue of the role of traditional healers in infertility treatment and mentioned how various indigenous misconceptions regarding the causes of infertility can hinder proper infertility services. Sundby argued that infertility should be included with other family planning services in developing countries. She then gave examples of infertility issues from the African region. She mentioned that in Africa the health care is generally poor and there is lack of even basic services. Particularly infertility services are worst. As a result women suffer the most. Their sufferings are intensified because of marital disruptions. She also mentioned other social and emotional consequences of infertility. Finally she recommended putting effort in the creation of creative services for basic infertility treatment. She suggested addressing research into the cause of infections that may result into infertility. She also highlighted that the infertility services in developing countries should be affordable, accessible, user-friendly, and non-discriminatory.

Discussion

Discussions started by comparing the scenario between the African and South Asian contexts. Participants mentioned various similarities and dissimilarities between these two regions regarding infertility consequences and infertility service in the existing health system. Social science experts mentioned the lack of the integration of services between the Government, NGO's and Private Sector's especially in the Indian and Bangladeshi context. The group felt that a country-based guideline for infertility treatment from the WHO was needed. But a WHO representative made it clear that the WHO could not provide guidelines straightaway, because it has to be evidence-based. It has been discussed that for some countries (particularly ones with low income) infertility services will not be popular unless it is free. But for some countries it will be popular with low payment. Therefore average income countries were selected to start the initial activities of the project on IVF in developing countries.

Participants discussed the probable barriers in developing countries apart from financial constraints. In relation to this the issue of cultural acceptance of IVF was discussed. It was also mentioned that there might be resistance from the traditional as well as professional providers, since providing solution of infertility is their business. Moreover, there was some discussion on the ethical issues of IVF in the developing context, and a question was raised about how to deal with the failed cases of the IVF.

When the issue of adoption was suggested as a solution for infertility, the specialists retorted with the issue of existing laws, unpopularity and religious barriers regarding adoption.

Conclusion / Suggestions

Based on the discussion, the expert group concluded that the following issues need to be addressed to start infertility services in developing countries.

1) Quality of infertility service has to be ensured and maintained in developing countries.
2) Less expensive services must be available in developing contexts.
3) Social science experts suggested establishing a proper link between the Private – Public – NGO sectors. Apart from the Private Sectors other stakeholders like the Government and NGO's need to be involved in the process.
4) Some experts thought that most likely the IVF would not be accepted culturally at the initial stage but it was agreed that people would accept it pragmatically as the value of children in developing countries is enormous. Also traditional healers can be involved in certain contexts.
5) The IVF should target the middle income group/countries not the ultra-poor.
6) Poor laws discriminate the idea of adoption in developing countries and so the laws need to be addressed.
7) The social science expert group needs to discuss more about the ethical issues of non-effective treatment.

Second part of the theme

Sheryl Vanderpoel (WHO) in her presentation firstly wanted to say how infertility has been a neglected issue in the discourse of health, family planning and reproductive health issues in developing countries. She also discussed why infertility was not included in some countries health agenda. She has discussed the WHO initiation on the issues of infertility. WHO addressed infertility as 'disability'. To include DALY they have opened an envelope called infertility 'Disability burden'. Infertility appears to be hidden as a target within Family Planning. However, it must be included and integrated in a package of intervention of reproductive health, material care and child care. Family planning must address infertility. Moreover, infertility is linked with STD, TB and HIV. Therefore there is even more reason to include it, especially in poor recource countries. In education programmes infertility must be an important aspect. It might be an idea to give 'vouchers' of infertility treatment to the ones who cannot pay for it. Several issues and suggestions were raised in the discussion.

Discussion

1) Ethical issues like "only diagnosis and not providing treatment" are discussed as a problem.
2) Appreciation of sharing the evidence of nothing has been done on infertility issues.
3) Proposal to WHO on infertility treatment guideline for every region of the globe.

Suggestions

1) Cultural construction of infertility needs to be addressed more
2) The problem of fixing priority of public health problems needs to be addressed

Theme 4: How to assess the low-cost IVF pilot projects

Presentation by Cora de Klerk notes by Nathalie Dhont

It was discussed how we should assess/follow-up our pilot projects.

Some general principles were agreed upon:

Methods

1) It should involve a combination of qualitative and quantitative research methods.
2) We could make a visual analogue scale on which patients indicate their perceived burden of disease. This "internal" DALY could be compared with "external" DALY
3) Mobile phones could be used to contact patients for follow-up since most households possess at least one mobile phone.

Who will do the research?

1) Ideally we make a core questionnaire which is then adapted for each country taking into account the different socio-cultural settings.
2) These questionnaires will need to be designed in collaboration with local people but supervised by the ESHRE Task Force.

Population

1) Patients who participated in the low cost IVF cycles
2) Non-IVF patients, including the ones who remain childless. Little is known about what happens to these patients.

Informed consent

We need to think about illiterate people: a relative or another participant will need to explain the content of the consent form after which verbal consent can be obtained. (In Rwanda illiterate people put a dumb print instead of signature and the relative signs).

To do next

1) To make a general plan of what psychosocial research needs to accompany the project.
2) The design of the follow-up questionnaires for men and women (until 1 month after treatment).
3) The design of information leaflets for the participants.



For a
fertile
collaboration

FERRING PHARMACEUTICALS in GYNAECOLOGY. Help your nature.