

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

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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 task-force “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.

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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 homologous 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 socio-cultural, 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 resource 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.