Fertility options for Muslim people: acceptability & awareness among clients and health service providers

**ABSTRACT**

Objective: The available options for infertile Muslim couples are 1: remaining childless permanently; 2: Polygynous marriage; 3: Divorce; 4: Fostering an orphan legally; or 5: New reproductive technologies. In nearly 20 nations of the Muslim Middle East and Muslim people in non-Islamic countries, marriage is highly valued and they can not live happily without children. Authors have made an important point regarding deficient counseling concerning awareness, acceptability and offering of these options. To test the above fertility options awareness & acceptability among infertile couples & consultants.

Materials & Methods: 120 Muslim couples & 20 consultants were surveyed over a 6-months period were surveyed for their knowledge of fertility options awareness, acceptability and offering. It was hypothesized that less than 50% of the subjects had an adequate understanding of the available options.

Results: 33% (n=80) of subjects (for clients) had a score of 5 or more which was considered as having an adequate understanding of the available options, while less than 20% of doctors (n=4) offered other options during counseling. The hypothesis was accepted, giving reason for concern about the effectiveness of consumer education at all levels of fertility management.

Conclusions: In Muslim communities, fertility awareness is generally very poor among clients and consultants. The authors believe that there are many positive implications for promoting patient education about fertility awareness.

Keywords: Fertility options, Muslim, awareness, acceptability.

**INTRODUCTION**

Infertility as it was described by National Institute for Clinical Excellence NICE 1 is the state of inability to conceive after 2 years of unprotected intercourse. It is more than a physical problem, it has devastating social, psychological and economic burden 2, which go beyond childlessness, and women bear the major hurt of the burden and made to feel inferior and may be abused or even tortured by the family, even when the man is at fault3.

Although infertility is a global problem and estimates of its prevalence are not very uniform and vary from region to region, the available literature figures worldwide up to 8-12% 1 and estimated to be up to 13% in Egypt 4. In Nigeria where Muslims represent up to 65% of the whole population the prevalence up to 20-30% 5. In 1992 Islam had over 1.250 billion followers and this figure expected to increase to 2.5 billion by the year 2020. With the present rate of population growth 6. Extrapolation to the global population means that 29-44 million of these infertile couples are Muslims because of a relatively high prevalence of infertility among Muslims in developing countries. The rate of tubal occlusion in sub-Saharan Africa with its predominant Muslim population is over three times that in other regions, with the exception of the Eastern Mediterranean.

As most couples with sub fertility will conceive spontaneously or will be amenable to treatment, so that only 4% remain involuntarily childless 7 and facing a couple with Intractable infertility, although rare, is extremely distressing not only for the clients but also for the health service providers and alleviation of infertility even by proper counseling therefore becomes a necessity on many levels and it has been declared a public health issue by the World Health Organization (WHO) 8. So help from a counselor may be needed, people may be able to accept their position and see the opportunity to start a new life 9.

United nations declarations of Human Rights in Article 16:1 states that "Men and women of full age, without any limitation due to race, nationality or religion have the right to marry and found a family 10 and the reproductive health insists on the individual's right to reproduce and freedom to decide when and how often 11.

The most basic and desired goal in adulthood is achieving parenthood 10. The situation is the same in Muslim community as the clear message to Muslim spouses is to have as many children as they raise them suitably as the children are a divine gift to the spouses and the demand good care for them, educating and qualifying them to serve society 6. Based on
understanding of the Islamic teachings and looking to the local moral worlds of infertile Muslims as they attempt to make, in the religiously correct fashion, Muslim community is differ than western world. The former depends upon the presence of a non-binding but authoritative Islamic religious proclamations called fatwas that have profoundly affected the practice of many aspects in such field. Recently, many fatwas have been issued in Egypt and other Muslim countries. In western countries, the available options for a couple with intractable infertility are donation (egg, sperm, and embryo donation), adoption, surrogacy or accepting a child-free lifestyle. The available options in Muslim world is quite different and they include (1) remaining childless permanently; which is unthinkable in the Muslim communities to remain in a permanent childlessness; (2) divorce (or the wife divorce herself) which can only be performed after legal consultation and this is highly unacceptable by the wife; (3) to divorce if the cause is related to the husband and/or the wife which appears to be traumatic for both; (4) to adopt an orphan legally, which is rarely viewed as an acceptable option; or (5) to go through New reproductive technologies, including IVF and ICSI, to overcome infertility. So it can be concluded that the acceptable fertility options may vary according to couple’s culture, religious, moral beliefs, and the availability of such option.

It is observed that there is little published literature on the level of fertility awareness amongst customers attending fertility clinics in general and especially for special circumstances e.g. Muslim communities. Fertility awareness is generally very poor not only in couples attending a fertility clinic but also among heath service providers. Also, physicians offering the fertility services are different in their acceptability to all options.

As counseling concerning any treatment option for any other medical problems should be the first step it should have the same priority in the management of one of the most sensitive issues for the Muslim families which is infertility. From a patient’s perspective, the authors believe that there are many positive implications for promoting customer awareness and their education about the available fertility awareness and acquiring knowledge of different fertility options that are available in their communities can be a very empowering experience, and can ameliorate a potentially solvable problem. From a physician’s perspective, offering the options can be met with a valuable rate of acceptance.

It has been our observation for a long time that clients attending the infertility service clinics at our hospital and private sectors have an inadequate understanding of the available fertility options for intractable cases. Until analysis of the results of this study we do not know the root defect whether from deficient clients knowledge or lack of awareness and offering from the health service providers to their clients.

Recently there is a trend to increase the patient involvement in health care delivery, evaluate new treatments, as part of audit and also used to evaluate participant opinion of as part of the Continuing Professional Development (CPD) process. As the questionnaires can be used in a wide range of situations to gather opinion and collect information and attitude of consumers towards certain modality of treatment, so the present study used this technique to test the above fertility options awareness & acceptability from the infertile couples and offering the package by health care providers.

Materials & Methods

The study questions were does the Muslim people with infertility aware and /or accept all available fertility options? And does their health service providers aware /offering all these options during counseling? The study populations were two groups: the first one included hundred and twenty couples attending three tertiary infertility clinics (infertility unit of Obstetrics & Gynecology department, El-Menia faculty of medicine, El-Menia infertility center for research and treatment, El-Menia university, and private unit managed by the three authors) over a period of 6 months suffering from intractable infertility for infertility investigation and treatment were invited to participate in this study. All the couples had been attempting conception for at least 3 years and having been referred from a specialist. They were assessed initially as having intractable infertility. The second group included twenty consultants offering the service in these three clinics. Of them were male while 4 were female doctors. The technique followed in the selection of both groups called “purposive sampling”.

Prior to commencement of the study, the research proposal was approved by the ethical committee from the related department. A questionnaire was designed for this purpose (follow chart: 1). The protocol used in this study was to provide the information in advance to all invited Participants during the initial meeting and then asking them to indicate whether they wish to take part in a survey or not when they come back for the next visit, rather than asking them to fill the questionnaire in one sitting. The interval between the visits was accompanied with telephone reminder to improve the response rate. Clear contact details of the research coordinator (who is the second author) and main author in case of further enquires from the participants. Stress to all couples that their future health care will not be affected if a subject chooses not to participate in this study.

A separate questionnaire was designed by the authors for each participant (wife, husband & doctor). The questionnaires were different in the questions offered to suit each participant. Husband and wives were surveyed for their knowledge of fertility options awareness and acceptability that are already available and matched for their beliefs according to Islamic teachings. The doctors were also surveyed for their awareness and offering the above options for their clients. We used The Arabic language for writing the questionnaire for clients while for the consultants we used English one. The questionnaires were printed in a White paper to avoid taring of the eyes but marked for each participant category (i.e. red small circle for wives, blue for husband and green for doctors) for easy collections from the prepared boxes. Each questionnaire was labeled with a unique ID number so that easy to identify and also reminders are only sent to non-respondents.

Each questionnaire was composed of 12 questions which were designed to determine the participants’ level of knowledge regarding his/her awareness and acceptability of the different available fertility options and their use of this information to enhance their chances of conception. Eight of the questions were multiple choice and on further questions asked subjects to describe details of their concerns and possible causes of why they are not aware of not accepting a particular option. We used Likert scale [15] to ask the participants to rate the extent to he/she agree or disagree about a particular option. Questionnaire for the consultants was composed of also twelve questions but different contents. It covered certain areas as the duration of experience in this field, work load, awareness and offering the above options and why he/she think the reasons behind lack of awareness and lack of offering the available options.

Singing a written consent by each participant. Each author was dedicated to one group, the main author for the doctors while the second author for the husbands. As the third author is a female doctor so she dedicated for the wives participating in the study.

The questionnaire was completed before or after usual clinical visits anonymously by each subject (wife, husband & doctor) in a separate room and each participant was asked to put it in the prepared boxes that were collected from the three units after
completion of the survey. The questionnaire for the couples was graded into 3 classes:
(A) Level of awareness of each option (given one mark each).
(B) Level of accepting each option (given one mark each).
(C) Level of use such awareness & acceptability to enhance his/her fertility. Answered in open questions.

The questionnaire for the consultants was also graded into 3 classes:
(A) Level of awareness of each option.
(B) Level of offering to the treated couples.
(C) Level of use such awareness on offering during counseling. Answered in open questions.

The questionnaires were initially analyzed for characteristics such as age of the participants, years of attempting conception, previous visits to the clinic seeking for medical advice about their concerns, perceived cause of infertility, previous counseling about the options available.

These questionnaires were scored by 2 independent clerks. Scores ranged from 0 for subject who had no concept of fertility options awareness, acceptability and/or offering the options to 10 for those who were highly aware, accepting or offering. A cut-off of 5 or more was considered as having adequate fertility awareness. The percentage of clients and consultants with fertility awareness & acceptability and offering scores of 5 or greater were statistically analyzed for acceptance of the hypothesis using a chi square test.

All participants were promised to receive feedback if they wish to do so for the results of this study stressing on the anonymity of the information provided separately by each one of them and not all information disseminated. It was hypothesized that less than 50% of the subjects had an adequate understanding of the available options and acceptability.

RESULTS

The response rate in this interviewer-based survey was 78% for the clients (husband & wives), while for the consultants was 82%. The self-complete questionnaire technique which followed in this survey ensured confidentiality and anonymity of all participants. They were allowed to use a separate room to fill it with clarification of vague questions. The literacy level was sufficient to complete the questionnaire. The mean mean age ± SD was 27.4 ± 6 for wives while 32.3 ± 4.9 for the husbands.

For 43% of couples (both husbands & wives) it was their first visit to a tertiary referral infertility clinic. While 20% of the husbands sought medical advice separately in a tertiary units due to isolated male factors, 75% of wives sought medical advice in a tertiary units for surgical interventions before for improving their fertility options. Seventy percent had been trying to conceive for 3 years, 13% for 4-5 years, and 16% for greater than 6 years.

Fifty four percent of subjects recorded their understanding of the cause of their infertility as ‘unexplained’ or did not know at the time of their first visit to the clinic while twenty percent recorded the cause as male factor and twenty six attributed to female factors (figure 1). We found 33% (n=80) of subjects (for clients) had a score of 5 or more which was considered as having an adequate understanding of the different 5 available options for the Muslim people while 67% not aware with the full options available.

Surprisingly, not all the aware clients accept the options i.e. only 25% (n=60) of the clients of the available fertility options accepting these options as a treatment i.e. 8% although aware but still not accepting the available options. Analysis of consultant's questionnaire revealed that 85% (n=17) of the participating consultants were aware with all options and 15% of them not fully aware. Only three consultants (less than 20%) of those who are fully aware (n = 4) offering all the available options during counseling while the others concentrate only to counsel their clients for the available medical options only like surgical interventions or assisted reproductive techniques (figure 3).

The hypothesis that less than 50% of subjects have an adequate understanding of the available fertility options and acceptability accordingly for the clients and offering these options by the service providers was supported (Chi sq. test <0.01). Some reasons were given by the consultants for their lack of offering all options listed in figure 4.

Flow chart (1): Stages of questionnaire design

Flow chart (2): Administration of questionnaire

- Define research question &
  Define study population

- Who the questionnaire will be administered?

  - Formulation of questions
  - Formulation of responses

  - Design the layout
  - Pre-pilot the questions and layout
  - Design the coding scheme

  - Printing

- Are you aware with ALL fertility options?

  - Not All
    - Yes
    - No

  - Clients: Are you accepting all these options?
    - Not All
      - Yes
      - No

  - Consultants: Are you offering all these options?
DISCUSSION

The results obtained from this survey support the hypothesis of the authors that awareness and acceptability among clients and offering by service providers of different available fertility options in Muslim world is very poor giving reason for concern about the effectiveness of consumer education at all levels of fertility management.

The purposive sampling technique that was followed in the selection of the group study is useful because a wide range of possible views can be identified. We used self-complete questionnaire technique which ensured confidentiality and anonymity. Another advantage of this technique is being cheaper to administer. In this study we reported for the first time the area of significant deficiency in the first station in managing infertile couples not only in consumer education but also among service providers in the Islamic world. Of greatest concern is the proportion of couples (67%) and consultants (80%) who were scored as having no awareness or none offering of already available options.

We reported in this survey the majority of participants (71%) had been trying to conceive for 3 years, and the majority also (67%) were non-aware with different options until facing the consultants at the tertiary units who also not offering all options (only 20% of them). Therefore, it is important that during the initial visits with the general practitioners or even the consultants to establish if the couple aware with available fertility options that suits them or not. More importantly, are they accepting these options or not and why?

This study also exposed some misconceptions one is the restrictions of fertility options to one or more, the other big misconception is the lack of acceptance of many consultants to offer other solutions to manage infertility irrespective of client acceptance or not. The majority of the participant in this study were people from higher social groups and non-ethnic minorities (either the couples or the consultants) who are more likely to complete questionnaires than other groups which was clearly reflected in the response rate in all groups and poor response rates which lead to bias were avoided. Previous studies have shown that people are more likely to respond to questionnaires that cover issues that are relevant to them. As the questionnaire surveys are particularly reliant on the willingness of the participants to take part, considerable efforts were done by the authors to encourage subjects to take part so increasing the response rate e.g. clear explanation of the study proposal to all participants, stress the anonymity of the survey of the questionnaire filled by each participant, and appointing a female doctor to interview the ladies participated in the study who one of the authors. Other ways used to improve the response rates were reminding the couples before coming to think about the study and using attractive style for the questionnaire. No financial incentives were offered to participants as it's unethical to offer financial incentives to take part in healthcare surveys. Using two settings for introduction and filling the questionnaire with a telephone reminder had two advantages; the first was improving the response rate while the second advantage was low cost for the study. The cost of the study has been reduced by other measures like the use of self-complete questionnaire and non-use of interpreters as there is a single language practiced in the locality.

The number of first time attendees to a tertiary infertility clinic was 43% of couples (both husbands & wives) appear to correlate with the expected high proportion of subjects who either perceived their cause of infertility as unexplained or did not know (54%, figure 1). While 20% of the husbands sought medical advice separately in a tertiary unit due to isolated male factors, 75% of wives sought
medical advice in tertiary units for surgical interventions before improving their fertility options which reflect the lack of understanding on the part of women as wrongly believed that the only responsibility.

The data obtained showed that 33% only (n=80) of subjects (husbands & wives) achieved the passing score to be aware with the whole list of available options and thought to be fully understand what each option mean while the majority (67%) were not aware at all. Further analysis of these data showed not all subjects who were aware can accept these options. The reasons behind this were many e.g. educational status as the new reproductive technologies can only be accessed by a few rich couples, who make use of them through expensive private sector services that are increasingly available in many of developing countries where the majority of Muslim people there, social factors (to accept polygamous marriage or divorce). This leads to aggravation of the problem's magnitude.

Although all consultants were aware the full list of options, only 20% of them offering their clients with these options. Many reasons had been discovered e.g. In 55% of consultants, they thought that the clients have already know these options while in 20% the answer was it is not my job to offer non-medical options e.g. polygamous option. 5% of consultants adhered to the lack of offering to the clients themselves because they did not ask about the available option or even they can not reveal any cause for non explanation. Due to social circumstances, about 15% of consultants cannot offer some options e.g. divorce as it is may be traumatic to even both. One of major concern is the source of medical knowledge is coming from western curriculum rather than respecting the original culture and this is the responsibility of professionalism.

The authors think that there are many positive implications for promoting patient education about awareness of different fertility options in a special situation e.g. Islamic culture not only among customers but also among this service providers. It is very empowering experience to find list of options amid a very frustrating situation of intractable infertility from the patient's perspective. From the doctors' perspective, it enforces the relationship between them & their clients as the latter feel the former responsibility extend beyond medicine. The third merit is the resource and financial perspective; there are occasions where unnecessary or very expensive interventions are carried out instead of simple alternative options e.g. going through three trial of A.R.T.s is much cheaper than marriage itself from the economic point of view, irrespective of other emotional troubles among both clients. And marriage itself may be encouraged by the other partner to keep the bond stable as much as they can. If both clients and their health service providers have a clear understanding of what each option mean, it would be possible to more accurately select the suitable option in a short time which, of course, will give more meaningful results. Another application of this information is to know when to start and when to take off a particular option.

Other researchers have demonstrated that it is possible to successfully instruct 70% of regularly menstruating infertility patients in aspects of fertility awareness. So, incorporation of trained personal e.g. nurse, social worker or even Sheikh or Imam (a person who teach religion and the people trust into the tertiary referral units would be a logical step to rectify this highlighted lack of knowledge among clients. Running courses for the consultants also very empowering to highlight the deficient areas of counseling. The authors do not know the extent to which these results apply to other Muslim people in other communities as they conducted this survey among Sonia group in one of the Muslim countries; although we are very confident that will benefit similar category after application of national law. It is for communities to judge for themselves how valid the results for a given population.

There is little published literature on the level of fertility awareness amongst patients attending fertility clinics especially for special circumstance e.g. Muslim communities. Awareness with the available fertility options awareness for Muslim people is generally very poor among couples attending tertiary units. Offering these options by health service providers is also very poor. Also, physicians offering the fertility services are different in their acceptability to all options. The authors believe that there are many positive implications for promoting patient education about the available fertility options for Muslim people. From a patient's perspective, acquiring knowledge of different fertility options can be a very empowering experience, and can ameliorate a potentially solvable problem. From a physician's perspective, offering the options can be met with a valuable rate of acceptance.

There is urgent need to develop culturally sensitive guidelines respecting the moral and religious of the target population augmented with political willingness to relief the burden of infertility by offering more options from the counseling physicians to the clients. As majority of Muslim people living in developing countries, so tackling of infertility should focus on a stepwise approach beginning with the establishment of preventive services in all of these countries, through integrated infertility treatment at the primary and secondary care levels and ending up with well organized, referral units which should also develop and offer affordable assisted reproductive technology.

Support from friends, and family is vital for couples coming to terms with infertility and accepting a child-free lifestyle. Attendance of non-medical person e.g. sheikhs to the counseling sessions helping the doctors in offering all available options are very encouraging to improve the pregnancy rate through going through the assisted techniques. The authors also encourage the use of information leaflets that include these options either in Muslim countries or even for the Muslim minorities in non-Muslim countries. Finally, the role of media can not be neglected to overcome this poor awareness that will consequently reflect upon patient satisfaction.

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