Knowledge and attitudes of infertile couples about assisted reproductive technology

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Abstract

Background: Knowledge of infertile couples about assisted reproductive technology is a fundamental parameter to optimize the infertility treatment and conduct it cooperatively.

Objective: To evaluate knowledge and attitude of infertile couples about assisted reproductive technology we designed a descriptive cross-sectional study.

Materials and Methods: 400 infertile patients were investigated by a self-administered structured questionnaire about demographic data, infertility history, and several relevant variables in an outpatient infertility clinic of a university hospital.

The main outcome measurements included scoring the answers in the questionnaire regarding knowledge, and grouping the answers regarding attitude. Resulted data were analyzed in relation to patient’s gender and treatment history, and educational, ethnic and religious groups.

Results: Of 400 cases (251 women and 149 men) 167 patients (41.7%) were scaled to have good knowledge and 223 patients (55.7%) had a poor knowledge about ART. 74.6% of patients with advanced education and 30.3% of patients without advanced education were scaled to be good in knowledge. 45.6% of men, 43.4% of women and 64.8% of patients with a history of passing previous ART cycles had a good knowledge. The source of information was mentioned to be the ART centers in 73% of cases. 95% of patients disagreed to have sperm or ovum donation or to undergo surrogacy. 22% of all patients (27.5% of women versus 12.1% of men) agreed with embryo reduction. 94.5% of patients mentioned the ART expenses not to be affordable readily.

Conclusions: Less than half of patients presented to be knowledgeable about ART. Not a great portion of the patients agreed with sperm donation. ART expense is mentioned to be burdensome by nearly all of the patients.

Key words: Attitude, Knowledge, Assisted reproductive techniques

Introduction

Knowledge of infertile couples about assisted reproductive technology is a fundamental parameter to optimize the infertility treatment and conduct it cooperatively. On the other hand, different aspects of this technology lead to many serious socio-economic and ethical problems. Particularly for those who practice reproduction techniques, it is important to learn about the various public attitudes related to parental rights, legislation and available resources for assisted reproductive technologies (ART). Researchers have suggested that one has to take into account that these attitudes exert an influence on civil and medical authorities in the field of reproduction (1). Because of the subjective nature of treatment, pregnancy, and parenting, the objective measurement of the psychosocial, emotional, and attitudinal impact on the parents of the use of ART will be limited to capture.

In vitro fertilization has outgrown its infancy and the questions to be considered have expanded well beyond the basic interest in establishing normal development. Few studies have focused on the infertile couples beyond the scaffolding of the obstetric outcome and the physical, cognitive, and psychosocial development of their children. A study in Australia showed that 64.2% of people regarded egg donation to be a reasonable treatment for infertility (2). In another study in Canada 47%
of answerers confirmed embryo reduction (3). In a study done in the United States 71% of infertile couples mentioned no interest to a genetic evaluation and only 14% of them accepted the issue of egg donation as a solution to prevent genetic abnormalities (3).

The present study was designed to evaluate the knowledge of infertile couples about the facts of ART and their attitudes toward some of its related aspects.

Materials and Methods

During a descriptive cross-sectional study, all patients referring to infertility clinic of Vali-e-Asr research center from March 2000 were invited to fill a questionnaire. Case collection was extended until the cases reached to a total number of 400. Only in cases of illiterate patients the task was done by an interviewer in the clinic. The survey was developed by the authors and was reviewed for validity and clarity by reproductive endocrinologists experienced in ART field and then approved by a university review board. Questions covered the following areas: demographic information, current health status, infertility treatment and its result, knowledge about scientific facts of ART and the source used for, attitude toward genetic material donation, surrogacy, multiple fetal pregnancy reduction, the expense of ART and hopefulness about the outcome of ART. Responses were recorded in a multiple-choice format. In the session of knowledge assessment if the number of correct answers were less than 7 the patient was rated to be in poor knowledge group and the patients with 7-14 correct answers were counted to have a good knowledge. The religion was classified into Muslim and non-Muslim and the educational status categorized into 4 levels (illiterate = level I, primary school = level II, mid or high school = level III and university levels = level IV). Relating to their occupation, the cases were divided into two groups: health care workers and others. Financially the cases were rated as high and low income.

Statistical analyses were performed using SPSS package. Procedures included Chi-square test, Fisher's exact test, and Pearson's product-moment correlations.

Results

Background information

The demographic characteristics of the male (n=149) and female (n=251) cases revealed that the mean (±SD) age of them was 36±1.5 years, most of which were Muslim (99.5%) and they were predominantly (68%) from Persian tribe (Turkish: 22.5%, Kurdish:4%, Armenian: 0.5% and Lor: 5%). Less than 15% of patients had proper income comparing to more than 85% with moderate and low incomes (GDP of Iranians was about 1200 US$). 76.5% of the cases were in low income group (mean of monthly income= $110±30) so IVF could be considered financially burdensome for them. Causes of infertility in these couples were male infertility, female infertility, both and unexplained with ratios of 33%, 37.5%, 14.5% and 15% respectively. 85% of cases were in level III and IV of education. The duration of patients' awareness about ART had a mean of 3.42 (±1.5) years. Patients mentioned the source of their information about assisted reproduction to be ART centers in 73%, radio and television in 17.5%, their friends and families in 6% and publications in 3.5% of cases.

Knowledge about ART

Of 400 cases 167 patients (41.7%) were scaled to have a good knowledge and 223 patients (55.7%) had a poor knowledge about ART. The results of patients' answers to questions in knowledge assessment session are presented in table I. Most of the patients mentioned the ART centers to be their information source.

45.6% of men and 43.4% of women had answered correctly to more than half of the questions and so scaled to be knowledgeable.

There was no significant difference in good knowledge score regarding different infertility causes (33.2% and 36.9% in male factor and female factor respectively, p= 0.082). Health care workers had good knowledge in 79.16% of cases and others did so in 39.48% of cases (p<0.0001). The patients with levels III and IV of education were knowledgeable in 74.60% of cases and others in 30.29% of cases (p<0.0001).

64.5% of patients with a positive history of ART treatment and 42.14% of others had good knowledge (p=0.0080).

ART centers were mentioned by 73% of patients to be the source of their information about ART. Subsequently radio & television, friends and publications were pointed out by 17.5%, 6% and 3.5% respectively as information source for infertile patients.
Knowledge and attitudes of infertile couples about ART

Table 1. The results of patients’ answers to questions in knowledge assessment session.

<table>
<thead>
<tr>
<th></th>
<th>correct n (%)</th>
<th>incorrect n (%)</th>
<th>no answer n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>effect of age on ART success rate</td>
<td>280 (70)</td>
<td>39 (9.7)</td>
<td>81 (20.3)</td>
</tr>
<tr>
<td>effect of smoking on ART success rate</td>
<td>267 (67)</td>
<td>60 (15)</td>
<td>73 (18)</td>
</tr>
<tr>
<td>effect of age on genetic abnormality</td>
<td>262 (66)</td>
<td>48 (12)</td>
<td>90 (22)</td>
</tr>
<tr>
<td>risk of genetic abnormality in oligo/azoospermia</td>
<td>141 (35)</td>
<td>152 (38)</td>
<td>107 (27)</td>
</tr>
<tr>
<td>risks due to ovulation induction</td>
<td>47 (12)</td>
<td>41 (10)</td>
<td>312 (78)</td>
</tr>
<tr>
<td>risks due to ovum pickup</td>
<td>73 (18)</td>
<td>45 (11)</td>
<td>282 (71)</td>
</tr>
<tr>
<td>success rate of ART</td>
<td>166 (41)</td>
<td>56 (14)</td>
<td>178 (45)</td>
</tr>
<tr>
<td>risk of EP in ART</td>
<td>98 (24)</td>
<td>87 (22)</td>
<td>215 (54)</td>
</tr>
<tr>
<td>risk of multiple pregnancy in ART</td>
<td>181 (45)</td>
<td>42 (10.5)</td>
<td>177 (44.5)</td>
</tr>
<tr>
<td>risk of congenital abnormality in ART</td>
<td>85 (21)</td>
<td>70 (17)</td>
<td>245 (62)</td>
</tr>
<tr>
<td>development of ART children</td>
<td>103 (26)</td>
<td>29 (7)</td>
<td>268 (67)</td>
</tr>
<tr>
<td>IQ of ART children</td>
<td>103 (26)</td>
<td>28 (7)</td>
<td>269 (67)</td>
</tr>
<tr>
<td>altered IQ of children due to medication used in ART</td>
<td>360(90)</td>
<td>32(8)</td>
<td>8(2)</td>
</tr>
<tr>
<td>altered IQ of children due to ovum pickup</td>
<td>164(41)</td>
<td>216(54)</td>
<td>20(5)</td>
</tr>
</tbody>
</table>

Attitudes

In total, 98.7% of responders were opposed to sperm donation. Of 400 cases only 5 (1.3%) agreed with sperm donation all being women, Muslim, having at least one previous ART cycle in their history and all from Persian tribe. 4 of them had advanced education. Of all characteristic parameters positive attitude toward sperm donation was significantly related to sex, level of education and positive history of ART treatment.

The attitude toward egg donation was negative in 96% of cases. Of 17 patients who agreed with egg donation, 11 were women, 10 had advanced education, 2 had previously used ART and all 17 were Muslims.

14 patients (3.5%) confirmed surrogacy as a solution for infertility if indicated and all others disagreed with it. Of patients who agreed with surrogacy, 13 had advanced education, 12 had positive history of using ART and 8 were women. 87 (21.5%) patients agreed with embryo reduction in the case of high risk multiple pregnancies, of which 69 were women. Advanced education (50 of 87 patients) had a significant relation to this aspect of patients’ attitude.

387 of 400 patients (94.5%) mentioned the cost of ART to be burdensome.

Using SPSS software it was shown that of all attitudinal aspects mentioned above only those relating to sperm donation and embryo reduction were significantly related to sex, both being more positive in women.

Discussion

In the last two decades, advances in biomedical science and technology have given physicians, patients and their families a vastly expanded range of options, requiring people's ability to discriminate between health care choices and rising at the same time new ethical issues. Society’s concern for the ethical aspects of medical practice has led to a growing need for the medical profession to be fully aware of the public's views, not only on the patient-physician relationship, but also on how the new developments in medicine affect human rights, social structure, and health policy. Although the donation and receipt of gametes has become an integral part of infertility management, previous research in the field of social attitudes and intention to use medical technologies is limited. The first practice of pre-embryo donation was reported at the end of the 1980's. At present, the practice of pre-embryo donation still remains limited. Although the demand for ART is significant, there is still a legislative gap concerning these reproductive techniques. The findings of the present research should be given close consideration by policy makers and health education campaigns.

Our study revealed that the knowledge of answerers about ART was significantly related to all parameters of occupation, education, and history of previous cycles of ART, but there was no difference in knowledge between men and women.

The belief of patients about the success rate of ART is an important incentive for them to count it the proper step in their treatment. In our survey, 14% of answerers believed the success rate of ART to be more than 50% and 45% of them were not aware about the rate. For sure, the absence of a correct idea in this regard will impress them negatively in case of ART failure to agree with repeating the cycle or encouraging other patients if they are disclosed. The ART centers must have
strategies with a strong trend to disclose their existing potentials as honestly as possible, so they must have a precise statistical view of their success rate for sure.

Education is needed to make the general community aware of the various aspects of ART. As proved in our study, publications have shown a low contribution as the source of information.

Our study is limited by homogeneity of the geographic location of the clinics, race, socioeconomic status and religion.

In the session of attitude evaluation, there was an overall negative view to genetic material donation. The only patients who agreed with sperm donation were those who had at least one previous failed ART cycle. None of the men had a positive attitude towards sperm donation. Regarding men and women differences in attitude, another limitation of our study is that each of the spouses filled the questionnaire separately without the possibility to make a consensus, a reality which plays one of the main roles in couples’ decision making for practicing ART.

The reluctance of couples in our sample to consider gamete donation as an option to avoid transmitting a genetic disorder is very similar to findings from a survey of 245 carriers of recessive genetic disorders (4). In latter study, respondents clearly preferred the option of using prenatal diagnosis, or if possible, pre implantation genetic diagnosis to preclude the necessity of considering pregnancy termination, rather than forgoing the possibility of having their own genetic child. In mentioned study neither the out of pocket cost nor the technical difficulties of pre implantation genetic diagnosis were addressed in the information given to participants however. Thus, a session with a genetic counselor or mental health professional remains an important aspect of preparation for IVF when genetic risks are present. As health professionals, we must continue to offer guidance to couples and make sure they have the clearest understanding possible of genetic risks to the offspring. Future research should focus on methods of genetic counseling that can help couples more accurately to anticipate their future emotional reaction to a child born with a genetic abnormality.

The cost involved in medically assisted reproductive therapy is another problem faced by the infertile couple. So it should be clearly discussed with the couples that in case IVF is a financial burden or if IVF fails what other options to treat infertility should be considered by them. At the time of doing our survey the expense of one cycle of IVF including the medication and sonographic studies had a mean of 400 $ and at the same time 76.5% of our cases were in low income group (mean of monthly income= 110±30 $). Since in Iran there is almost no insurance coverage for infertility management, so IVF could be considered financially burdensome for patients. As shown by Fonnest et al (1991), religion and profession are determinants for the attitude towards several of the ethical controversies of ART and related subjects asked for in such studies (5).

Evans et al (1991) in their multi-center study found the attitude of an acceptance of selective termination in quadruplets or more fetuses and in multiple pregnancies bearing an anomalous fetus; reflected profession and religion. The highest acceptance was found among professionals in maternal-fetal medicine and Jewish respondents (6).

In our study although 181 patients (45%) had a good knowledge about the existing risks of multiple pregnancies, only 87 (21.5%) patients of which 69 were women agreed with embryo reduction and only in the case of high risk multiple pregnancies. Advanced education (50 of 87 patients) had a significant relation to this aspect of patients' attitude.

As mentioned previously, the homogeneity of religion in our cases infirmed us to evaluate the influence of religious affiliation on attitudinal aspects of the survey.

In regard to profession, 83% of health care workers and 12.4% of others had a positive attitude towards embryo reduction.

It is important to know whether the use of ART is a low priority for individuals particularly where resources are unavailable for costly biomedical technologies with questionable effectiveness and that these technologies, when effective, assist only a very few patients eligible to benefit from them. Public support for ART varies depending on the circumstances of its use. At present, the majority of countries in Europe do not have established legislation pertaining to the various aspects of ART practice (7). Many countries have undertaken governmental inquiries to propose legal conditions under which ART may be acceptable, and to set limits beyond which their use is unacceptable on ethical grounds. Similar inquiries have been conducted by the World Health Organization Guidelines for ART (World Health Organization, 1992), the Council of Europe and various medical societies to determine the conditions and limits of acceptable professional practice and scientific research, and respect for the dignity of the human being etc (8).
Conclusion

It seems, if not even late, it is the time for favorable attitudes towards legislative and financial measures to be adopted by the government for the promotion of reproductive technologies.

The results of this survey should help physicians and governing bodies to make informed decisions about the future directions of ART.

References