Infertility Definitions – Patients' Perspectives

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Abstract: Background: The patients' perspective of the definition of infertility may differ from the traditional medical definition.

Objective: To explore patients' perspectives regarding the definition and treatment of infertility.

Methods: 343 infertile patients attending the infertility and IVF unit completed anonymous comprehensive questionnaires.

Results: Time to conception of <1, 1, 2 or more than 3 years was defined as infertility by 6%, 54%, 22% and 18% of the patients, respectively. The time period by which primary infertility was defined was longer in the ultra-orthodox, compared to other less observant sectors: 1.9±0.9 and 1.5±0.9 years, respectively (p<0.001). The time period by which secondary infertility was defined was longer according to religious piety: 1.6±1.2; 1.8±1.0; 2.0±1.0 and 2.6±1.6 years in secular, traditional, orthodox and ultra-orthodox patients, respectively (P<0.001). The number of existing children after which couples will still wish to attend infertility treatment significantly correlated with the religious devotion: 2.4±1.9; 3.2±2.0; 4.6±2.5 and 5.5±2.3 children in secular, traditional, orthodox and ultra-orthodox couples, respectively (P<0.001). Regarding the number of miscarriages that requires medical evaluation and treatment, 15% defined it after one miscarriage, 51% after two, 27% after three and 7% after four times or more.

Conclusions: patients' subjective definition of infertility differs from the common medical definition, and correlates significantly with the degree of patients' religious devotion.

Keywords: Infertility, definition, perspective, miscarriages, religion.

1. INTRODUCTION

According to the international committee for monitoring assisted reproductive technology" (ICMART) and the world health organization (WHO) revised glossary of ART terminology, infertility is "a disease of the reproductive system defined by failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse" [1]. This classical definition is based on large studies such as Guttmacher's study of 5574 English and American couples practicing unprotected intercourse, of whom 50% conceived within three months, 72% conceived within six months, and 85% conceived within 12 months [2]. Similar figures were demonstrated by Gnoth *et al.* who found that the cumulative probability of conception at one, three, six and twelve menstrual cycles were 38%, 68%, 81% and 92%, respectively, and by Wang *et al.* who observed that more than 90% of newly married women will conceive within their first 6 cycles [3, 4].

However, the patients' perspective of the definition of infertility may differ from the traditional medical definition. Our aim in the present study was to investigate the infertility definition as perceived by an infertile population, and the correlation of the definition with patients' demographic and background. Moreover, since our study population was demographically highly heterogeneous, with different streams of devotion to religion, we also aimed to explore whether the population heterogeneity would correlate with diversity of the patients perspectives of definitions of infertility. These findings may assist in clarifying the most culturally appropriate approach to infertility evaluation, and treatment.

2. METHODS

The study population consisted of patients attending the infertility and IVF unit of Barzilai Medical Center, Ashkelon, Israel in years 2010-2012. The study was approved by the hospital's Clinical Research Committee. After a comprehensive explanation of the study goals, including explanation of protection of anonymity, participants completed a structured questionnaires. This included background data, such

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as age, number of siblings, duration and length of infertility, parity, obstetric history, nationality and religious sector (secular, traditional, orthodox and ultraorthodox). The patients were asked to define primary and secondary infertility and the number of consecutive miscarriages needed to warrant seeking medical evaluation. In addition, we asked the patients to designate the number of existing children in which they will still undergo infertility treatment. Questionnaires were available in Hebrew and Arabic as appropriate.

3. STATISTICAL ANALYSIS

The Pearson and Spearman correlation coefficients were calculated in order to assess the strength of the associations between pairs of quantitative variables. The comparison of quantitative variables between groups was carried out using the Mann-Whitney non-parametric test when two groups were compared and the Kruskal-Wallis non-parametric test when three or more groups were compared. The non-parametric tests were applied as the data compared between the groups was not normally distributed. The McNemar test was used for assessing differences between paired qualitative variables, and the paired t-test was used for assessing differences between paired quantitative variables. All tests applied were two-tailed, and a p-value of $\leq$ 0.05 was considered as statistically significant.

4. RESULTS

Three hundred and forty three patients were enrolled in the study. Their demographic and background parameters are summarized in Table **1**. Time to conception of less than a year, 1, 2 or more than 3 years was defined as infertility by 6%, 54%, 22% and 18% of the patients, respectively. The time period by which primary infertility was defined was longer in the ultra-orthodox patients, compared to other less observant sectors (secular, traditional and orthodox), 1.9±0.9 and 1.5 ±0.9 years, respectively (p<0.001). The time period by which secondary infertility was defined, was longer according to religious piety: 1.6±1.2; 1.8±1.0; 2.0±1.0 and 2.6±1.6 years in secular, traditional, orthodox and ultra-orthodox patients, respectively (P<0.001).

As many as 40% of the study participants thought that couples with secondary infertility should attempt conception for a longer period before accepting the diagnosis of infertility than those with primary infertility.

However, 15% thought that those with primary infertility should wait for a longer period before being diagnosed as infertile, while 45% of the patients, though that the time to conceive should be similar for primary and secondary infertile couples (P<0.001).

Table 1: Patients Demographics and Background Parameters

Patients' Age (yrs)	30±6.25
Mean number of children	1.1±1.6
Distribution of the number of children	0 – 50% 1 – 23% 2 – 13% 3 – 5% 4 – 9%
Duration of infertility (yrs)	2.8±2.3
Type of infertility	Primary –33% Secondary – 67%
Religious piety	Secular – 18% Traditional – 29% Orthodox – 24% Ultraorthodox – 29%

The mean number of existing children in which couples still wish to attend infertility treatment was 4±2.5. This correlated significantly with the religious piety, 2.4±1.9; 3.2±2.0; 4.6±2.5 and 5.5±2.3 children for secular, traditional, orthodox and ultra-orthodox couples, respectively (P<0.001) (Figure **1**). The mean number of children that the patient wished to have in their future family was 5±2.5 children. It is significantly lower than 6±3 children in the core families of the couples (P<0.001).

The number of previous miscarriages that requires medical evaluation and treatment, was defined as 1, 2, 3 and $\geq$4 in 15%, 51%, 27% and 7% of the study participants. No correlation was found between the aforementioned number of miscarriages and patients' religious identity.

The definitions of infertility did not differ between the Jewish and Arab population (consisting 85% and 15% of the study population, respectively). Patient's age, duration of infertility, number of children and number of siblings in the couples' families did not correlate with patients' definitions of infertility.

5. DISCUSSION

This study focuses on the patient's perspective and definition of infertility. A significant number of the patients defined infertility differently to the strict medical
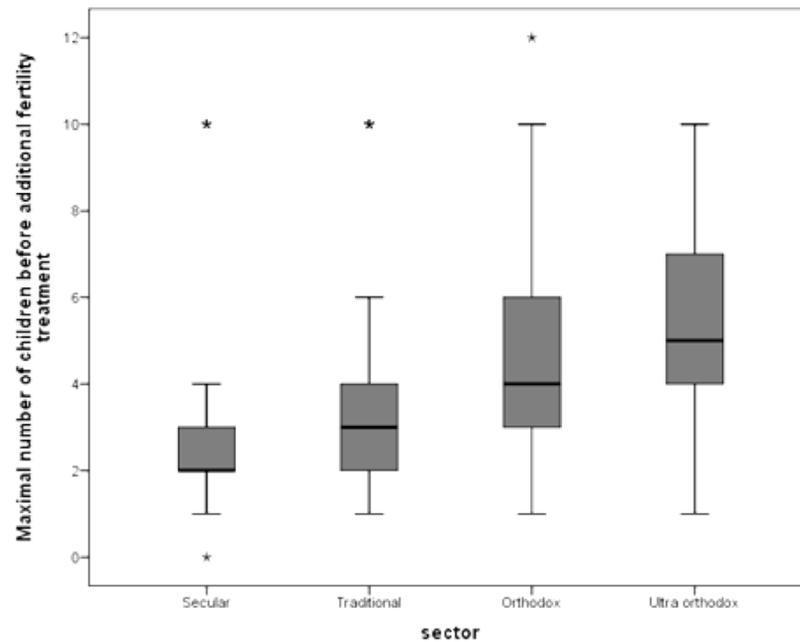
Figure 1: The mean number of existing children in which couples still wish to attend infertility treatment - according to their religious piety (P<0.001).

definition. The discordance between the medical facts and the lay patient's perception may lead to confusion regarding the appropriate time to seek infertility evaluation. This can lead to an unnecessary postponement, or alternatively, to patients demanding unwarranted and inappropriately premature evaluation and intervention.

Fifty four percent of the study participants defined infertility as over 12 months of failure to conceive despite unprotected sexual intercourse, in accordance with the medical definition. However, more than a fifth of the patients thought that two years were required and almost 20% believed that three or more years were required, in order to define infertility. These results are consistent with previous studies, such as Adashi *et al.* in which only half of the patients defined infertility similarly to the WHO definition, or Dick *et al.* which found that only 66% of all infertile women defined themselves as infertile [5, 6]. Van Balen *et al.* found that 38% of infertile couples defined infertility differently to the medical definition [7]. White *et al.* found that only 35% of infertile women defined themselves as infertile and only 40% presented for medical evaluation [8]. Daniluk *et al.* found that among 599 childless men, on the 20 knowledge questions, overall knowledge was limited, with more than 50% of the sample answering correctly only 4 of 20 knowledge questions [9].

On the other hand, Larsen examined the prevalence of infertility among the general female population [10].

They compared the rate of infertility according to the patient's perception and the WHO criteria. The infertility rate according to the patients' subjective definition was higher than the medical definition, 10.3% VS 6.8% respectively. Similarly, in an internet sample of women attempting to conceive, the average time that elapsed between completing a year of unprotected intercourse and the first medical consultation for infertility treatment was 7±9 months [11].

The main background parameter that correlated with the patients' definition of infertility in terms of the duration of failure to conceive was religious piety. We found that, as patients' religious piety increases, the duration that defined infertility was longer. A possible explanation is that faith and religious observance may give patients greater hope in conceiving naturally. Another possibility is that religious people are more conservative, and tend to postpone medical intervention. Interestingly, in our study population both Jewish and Arab patients were included. In both sectors, women define themselves as secular, traditional, orthodox or ultraorthodox .We could expect that in different cultural backgrounds – would find different results. However, in multi variant analysis we found no impact of the nationality and religion on the patient's opinion. This finding may emphasize that religion devotion, and not the nationality or specific religion, is the main factor related to patient opinion regarding infertility definition.

We found no correlation between patients' definition of infertility and either patient age or duration of infertility. This is not intuitive as one could expect that in the older patients it would take a shorter time to define infertility than in younger women. The patients' family size also did not correlate with their definition of infertility. This is in contrast to White *et al.* who found that low parity was associated with earlier presentation for fertility evaluation [8].

Almost half of our study patients thought that the type of infertility - primary or secondary - may have an impact on the definition of infertility in terms of duration. Approximately 40 percent of the study population believed that it should require a longer time to define secondary infertility then primary infertility. A possible explanation is that couples who have already had children have "proven fertility" status, and therefore more time and patience is required prior to infertility evaluation.

In the present study we used as reference the definition of infertility that was set by the ICMART and the WHO revised glossary of ART terminology [1]. This glossary was performed because of the wide variety and the lack of uniformity in the definition of infertility in the medical literature. Thoma *et al.* found differences in the prevalence of infertility in the United States according to the different infertility definitions [12]. Gurunath *et al.* found heterogeneity of criteria used to define infertility and critical differences between demographic and epidemiological definitions in their review on 39 studies. However, none of the included studies were evaluated the patient's subjective definition of infertility [13].

The discrepancy between the actual and desired family size - motivates couples to seek infertility evaluation. Barden-O'Fallon defined "child deficit" as the state when the desired number of children, exceeds the actual number of children, in couples who have been practising unprotected sexual intercourse for at least 5 years [14]. Child deficit was reported in around 50% of the study population in rural Malawi. This definition is unique, since it is based on the individual subjective perception of the ideal number of children in a family. Similarly, we found in our study that even after a mean of 4 children, women would still wish to attend infertility treatment to achieve an additional pregnancy. This extraordinarily high number may reflect the cultural predisposition of our study population. We found a significant correlation between the number of desired children and the patient's religious piety. As

expected, the more religious patients were likely to desire more children. These findings express a significant difference between the patients' desire for children and the public policy in our country that subsidises IVF treatment for couples who have up to two children.

Recurrent pregnancy loss is defined as the occurrence of three or more consecutive losses of clinical recognized pregnancies prior to 20th week of gestation. The American Society for Reproductive Medicine suggests a thorough evaluation only after three or more losses [1]. Even after three miscarriages the risk of an additional miscarriage is approximately 33% [15]. Nevertheless, most of our study population believed that two miscarriages justify medical evaluation and treatment. This may express the patient's perception of miscarriage, as a pathological event that should be evaluated relatively early. Interestingly, regarding miscarriage - religious piety did not correlate with patients' opinions.

In the present study we focused on the perception of the infertility definition by the patient. Sabarre *et al.* focused on the awareness of infertility risk factors among Canadian students. They found that the participants were generally familiar with infertility as a biomedical health problem, could identify sex-specific risk factors but overestimated fertility of women in their thirties and ART success rates [16]. Other studies found a limited knowledge of reproductive outcomes affected by obesity among women with infertility [17, 18].

The clinicians that treat the infertile couples may tend to concentrate in the medical aspect of the problem. However, our study demonstrates that being aware to the patient perception may facilitate the communication between the patient and the medical stuff and probably may improve the patient compliance. Rodriguez described the conceptual and analysis of female fertility, and concluded that an improved understanding of female fertility will enhance health care professionals' understanding of female fertility and improve communication with women and other health care professionals [19]. Lind *et al.* investigated young women's perceptions of fertility-related information when scheduled for ovarian cyst surgery with a possible impact on fertility. They found that almost half of women with reproductive desire had ovarian surgery without recalling a discussion of fertility issues and more than half of them (58%) recalled receiving information about the impact of surgery on fertility [20]. This may emphasize the importance of appropriate

communication between the clinician and the patient – especially in cases which may relate to infertility issues. Read *et al.* studied other aspect of infertile patient's perception. They found that infertile couples expressed numerous needs for psychosocial supports although most of them haven't got it [21]. Giving the patient the psychological support is important by itself and probably may facilitate the medical treatment.

In summary, we found a substantial difference between the medical and the lay patient definition of infertility. Patient religious identity was found to be a crucial factor in the patient's opinion, as well as primary VS secondary infertility definitions. Moreover, miscarriage was interpreted as a pathological event that should be evaluated relatively early. We believe that enhanced understanding of the patients' perspectives may contribute to more sensitive communication and less misunderstanding between patients and their clinicians.

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