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Study on psychosocial aspects and support of in vitro fertilisation programme in an Asian population

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ABSTRACT

Introduction: Undergoing in vitro fertilisation (IVF) treatment is an emotional and physical burden. Couples rate the experience of waiting for the outcome of the IVF treatment and an unsuccessful IVF treatment cycle as the most stressful. The outcome of treatment would affect how they feel about their IVF experience. Our survey aimed to increase understanding of how couples feel about the experience of IVF before and during IVF treatment so that strategies to improve their experience can be devised.

Methods: A prospective self-comparative study on the psychosocial aspects and support of patients undergoing an IVF programme was done. The questionnaire compared their responses before and during the IVF treatment.

Results: A total of 50 couples (100 respondents) participated in our survey. 78 percent were Chinese, 11 percent Malay and ten percent Indian. 64 percent have had tertiary education. 39 percent were married for three to five years, while 38 percent were married for six to nine years. 83 percent have no children prior to IVF treatment. Prior to counselling, 55 percent had some medical knowledge on types of treatment procedures, the treatment options and the risks of IVF. This increased to 81 percent after counselling. 80 percent found the medical counselling helpful. 80 percent found psychosocial counselling helpful in understanding the emotional issues involved in undergoing IVF treatment. 70 percent of couples felt that ongoing psychosocial counselling was useful, especially during the most stressful stage of IVF.

Conclusion: This study increased our understanding of the emotional aspects of IVF. Current strategies of providing medical and psychosocial counselling before IVF help prepare couples psychologically. Emotional support and psychosocial counselling before and during IVF were identified as important areas, particularly while waiting for the pregnancy test result.

Keywords: counselling, in vitro fertilisation, psychosocial support

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INTRODUCTION

It is clear that in vitro fertilisation (IVF) treatment is emotionally and physically stressful, and often financially demanding, for both the woman and her partner[1]. The outcome of IVF treatment would affect how they feel about the IVF experience. There are many studies where the couple gives evidence of the stress involved in undergoing treatment for assisted conception[1-3]. All couples at KKIVF Centre at the KK Women's and Children's Hospital, undergo one session each of medical and psychosocial counselling before their first assisted reproductive technique (ART) cycle. Ongoing counselling is provided on an ad hoc basis. The purpose of this study was to increase understanding of how couples feel about the experience of IVF before and during IVF treatment so that strategies to improve their experience can be devised.

METHODS

A prospective self-comparative study on the psychological aspects and support in 50 couples (100 patients) undergoing IVF programme was done from April to December 2004. The questionnaire compared their responses before and during IVF treatment. A self-administered questionnaire was used to collect the relevant information. An interpreter was used whenever the patient or partner did not speak or read English. The questionnaire consisted of 64 items divided into different sections. Both the husband and the wife received a questionnaire each

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and they were asked to fill in their responses individually without discussing with their respective spouses. We hoped to determine whether there were any differences in response with respect to gender.

Section 1 (items 1 to 10), "Information about you and your family", provided information on the patient's socio-demographical background. Section 2 (items 11 to 20), "Decision to try IVF/ART", explored how and why the patient made the decision of attempting IVF/ART treatment. Section 3 (items 21 to 30) and Section 4 (items 31 to 40) were administered before the patient went through the mandatory medical and psychosocial counselling prior to the IVF programme. Section 3, "Medical knowledge of IVF programme", provided information on the patient's level of knowledge before counselling by the medical doctor and nurse specialist. Section 4, "Psychosocial counselling by counsellor", explored the patient's expectations prior to counselling by the medical social worker, who is also our in-house counsellor.

Section 5 (items 41 to 49), Section 6 (items 50 to 52) and Section 7 (items 53 to 64) were administered after the patient had gone through the necessary counselling by the medical doctor, nurse specialist and medical social worker. The patient either had not begun her IVF programme proper or was in the midst of her IVF treatment. Section 5, "How do you feel about medical counselling session", enabled us to understand how much the patient had benefited from the medical counselling session. Section 6, "How do you feel about nurse briefing", enabled us to know how much the patient had understood regarding the practical aspects of the IVF programme, including the financial cost, the amount of time and logistics involved, and the injection procedures. Finally, Section 7, 'Psychosocial counselling by counsellor', explored the importance of such counselling as perceived by the patient.

The patients were asked to indicate their answers using the four-point Likert scale in the questionnaire for sections 2 to 7. A separate column labelled "No response" or "Not applicable" was available if the patients did not want to respond or felt that the question was not applicable to them. After completion of the questionnaire, the data was collected and analysed.

RESULTS

Section 1, "Information about you and your family", included demographical information and the findings are presented in Table I. The couples seeking IVF treatment were generally above 30 years of age (with the men older than the women). 64% of the couples had at least tertiary education and 84% of both partners earned a living. 88% were married for more than three years with 49% being married for more than six years. 83% had no children prior to IVF treatment.

Table I. Demographical information.

Age of women (years)	N=50
20–29	4
30–34	24
35–39	20
≥ 40	2
Age of spouse (years)	N=50
20–29	4
30–34	13
35–39	24
≥ 40	9
Ethnic group	%
Chinese	78
Malay	11
Indian	10
Others	1
First language	%
English	74
Chinese	19
Malay	2
Tamil/Hindi	5
Others	0
Highest education level	%
Nil/primary	2
O-Level	19
A-Level	14
College/university	64
Doing paid work	%
Both working	84
Husband only	16
Wife only	0
Both not working	0
Religion	%
Buddhism	47
Catholic/Christian	18
Muslim	10
Hindu	10
Others	15
Number of years married	%
≤ 2	12
3–5	39
6–9	38
≥ 10	11
Order of marriage	%
1st	95
2nd	5
3rd	0
Children prior to IVF	%
Yes, current marriage	14
Yes, previous marriage	3
No	83

Table IIa. Responses to "Decision to try IVF/ART".

Statement	SD + D (%)	A + SA (%)	NA (%)
It was primarily my decision to try IVF.	22	66	12
Both agreed to try IVF.	0	100	0
I felt pressurised by family and friends to try IVF.	69	17	14
The information provided by the doctor and the clinic was helpful when deciding to try IVF.	9	83	8
The expectations for women to become mothers influenced my decision to try IVF.	27	58	15
Deciding to try IVF posed some ethical dilemmas.	55	31	14
The financial cost of IVF was carefully considered before deciding to have treatment.	10	89	1
Deciding to try IVF was easy.	61	35	4
IVF treatment is acceptable by the society.	8	87	5
I felt poorly informed and unaware of what was involved when deciding to try IVF.	69	24	7

SD: Strong disagree; D: Disagree; A: Agree; SA: Strongly agree; NA: Not applicable

Table IIb. Gender differences in responses to "Decision to try IVF/ART".

Statement	A + SA (%)		p-value
	Women	Men	
It was primarily my decision to try IVF.	62	70	0.81
Both agreed to try IVF.	100	100	NA
I felt pressurised by family and friends to try IVF.	20	14	0.36
The information provided by the doctor and the clinic was helpful when deciding to try IVF.	82	84	0.73
The expectations for women to become mothers influenced my decision to try IVF.	64	52	0.72
Deciding to try IVF posed some ethical dilemmas.	38	24	0.12
The financial cost of IVF was carefully considered before deciding to have treatment.	92	86	0.48
Deciding to try IVF was easy.	32	38	0.53
IVF treatment is acceptable by the society.	84	90	0.15
I felt poorly informed and unaware of what was involved when deciding to try IVF.	22	26	0.60

In Section 2, "Decision to try IVF/ART", the patient was asked to indicate on a four-point Likert scale, "Strongly disagree", "Disagree", "Agree" and "Strongly agree", the degree to which they felt the ten statements applied to them. A separate column of "Not applicable" was available if they felt the statement was not applicable to them. The responses are shown in Table IIa. 66% felt that it was their own decision to start IVF treatment. All of them agreed with their partners before trying IVF. 83% felt that the information provided by the doctor at the clinic was helpful when deciding to try IVF. 89% carefully considered the financial cost of IVF before deciding to have the treatment.

A comparison was made between gender differences with respect to the response provided in this section and the results are shown in Table IIb. Although the differences were not statistically significant, more women felt that the expectation for women to become mothers influenced their decision to try IVF.

Section 3, "Medical knowledge of IVF programme", was administered before the couple began any medical counselling by the medical doctor and nurse specialist. On a four-point Likert scale, "No knowledge", "Little knowledge", "Some knowledge" and "A great deal of knowledge", the patient was asked to state how much knowledge they had with regard to the ten statements about IVF. A column labelled "No response" shows the percentage of patients who did not respond to that particular statement. The response is shown in Table III.

Section 4, "Psychosocial counselling by counsellor", was administered before the couple underwent the counselling session by the medical social worker. On a four-point Likert scale, "Strongly disagree", "Disagree", "Agree" and "Strongly agree", the patient expressed

Table III. Responses to "Medical knowledge of IVF programme".

Statement	NK + LK (%)	SK + GK (%)	NR (%)
The type of treatment procedures	52	48	0
The type of treatment options available	49	50	1
The risks of IVF procedures, e.g. multiple births, ovarian hyperstimulation syndrome	33	66	1
Information about drugs and possible side effects	61	39	0
Chances of taking home a baby	25	72	3
Understanding about possibility of miscarriage/ectopic pregnancy	40	59	1
Knowledge about alternatives to IVF, including child-free living and adoption	35	64	1
Knowledge about injection procedures	52	48	0
The average financial cost of IVF treatment	27	72	1
The time/duration needed to commit for one cycle of IVF	39	60	1

NK: No knowledge; LK: Little knowledge; SK: Some knowledge; GK: Great knowledge; NR: No response

Table IV. Responses to "Psychosocial counselling by counsellor".

Statement	SD + D (%)	A + SA (%)	NA (%)
Counselling helped me to understand the emotional issues involved in IVF.	19	70	11
I was unable to share my decision to try IVF with my family and friends.	38	50	12
I find it difficult to talk about infertility.	24	65	11
Counselling helped to identify useful coping strategies.	13	74	13
Ongoing counselling should be part of the IVF programme.	23	65	12
Counselling is needed for the most stressful stage of IVF, i.e., waiting for the pregnancy test result.	20	70	10
With counselling, I'm ready to cope with a bad result.	24	63	13
The nurse offered emotional support.	9	77	14
My doctor offered emotional support.	18	65	16
I myself can adjust my emotion.	9	81	10

SD: Strong disagree; D: Disagree; A: Agree; SA: Strongly agree; NA: Not applicable

their expectations of counselling in terms of providing emotional support and coping with stress. A separate column of "Not applicable" was available if they felt the statement was not applicable to them. The responses are shown in Table IV.

Section 5, "How do you feel about medical counselling session", and Section 6, "How do you feel about nurse briefing", were administered after the medical counselling session provided by the medical doctor and the nurse specialist. The statements related to the patient's satisfaction with the information provided. They rated their satisfaction with the information they received on a four-point Likert scale, "Not satisfied", "Somewhat satisfied", "Satisfied' and 'Very satisfied". A column labelled "No response" showed the percentage of patients who did not respond to that particular statement. The responses are shown in Tables V and VI.

Section 7, "Psychosocial counselling by counsellor", was administered after the couple had completed their psychosocial counselling by the medical social worker. They stated the extent of their agreement with the 12 statements about the counselling service and other support provided by the hospital on a four-point Likert scale of "Strongly disagree", "Disagree", "Agree" and "Strongly agree". A separate column of "Not applicable" was available if they felt any specific statement was not applicable to them. The results are shown in Table VII. 83% felt that counselling helped them to understand the emotional issues involved in IVF. 78% felt that ongoing counselling should be part of IVF treatment. 71% felt that counselling was needed for the most stressful stage of IVF, that is, waiting for the pregnancy test result.

Both medical and psychosocial counselling are mandatory for couples going through their first IVF/ART cycle in our unit at KKIVF Centre. Subsequently, further counselling, if required, will be provided on an ad hoc basis. 80% of patients felt that the overall medical and psychosocial counselling was helpful. 82% felt that the

Table V. Responses to "How do you feel about medical counselling session".

Statement	NS + SS (%)	S + VS (%)	NR (%)
Explanation of treatment procedures	10	85	5
The type of treatment options available	19	76	5
The risks of IVF procedures, e.g. multiple birth, ovarian hyperstimulation syndrome	16	82	2
Information about drugs and possible side effects	25	71	4
Explanation about the chance of taking home a baby	14	82	4
The possibility of miscarriage/ectopic pregnancy	13	83	4
Alternatives to IVF, including child-free living, adoption	21	62	17
This counselling session was helpful	15	80	5
This counselling session was of appropriate duration	13	82	5

NS: Not satisfied; SS: Somewhat satisfied; S: Satisfied; VS: Very satisfied; NR: No response

Table VI. Responses to "How do you feel about the nurse briefing".

Statement	NS + SS (%)	S + VS (%)	NR (%)
Explanation about financial cost	5	92	3
Explanation about time involved	7	90	3
Explanation about injection procedures	10	86	4

NS: Not satisfied; SS: Somewhat satisfied; S: Satisfied; VS: Very satisfied; NR: No response

Table VII. Responses to "Psychosocial counselling by counsellor".

Statement	SD + D (%)	A + SA (%)	NA (%)
Counselling helped me understand the emotional issues involved in IVF.	7	83	10
I was unable to share my decision to try IVF with my family and friends.	30	51	19
I find it difficult to talk about infertility.	30	56	14
Counselling helped to identify useful coping strategies.	8	78	14
Ongoing counselling should be part of the IVF programme.	16	70	14
Counselling is needed for the most stressful stage of IVF, i.e., waiting for pregnancy test result.	15	71	14
After counselling, I am ready to cope with a bad result.	6	81	13
The nurse offered emotional support.	4	83	13
My doctor offered emotional support.	10	77	13
I myself can adjust my emotion.	6	82	12
This counselling session was helpful.	6	80	14
This counselling session was of appropriate duration.	5	81	14

SD: Strong disagree; D: Disagree; A: Agree; SA: Strongly agree; NA: Not applicable

medical counselling was of an appropriate duration while 81% felt that the psychosocial counselling was of an appropriate duration.

A comparison was made on the pre- and post-medical and psychosocial counselling. This allowed us to determine the usefulness of either counselling and provided us with information regarding which item needed further elaboration and improvement. The results are shown in Tables VIIIa and VIIIb. There was statistically significant improvement in knowledge

Table VIIIa. Comparison of pre- and post-medical counselling responses.

Statement	Pre-counselling			Post-counselling			
	NK + LK (%)	SK + GK (%)	NR (%)	NS + SS (%)	S + VS (%)	NR (%)	p-value
The type of treatment procedures	52	48	0	10	85	5	<0.001
The type of treatment options available	49	50	1	19	76	5	<0.001
The risks of IVF procedures, e.g. multiple births, ovarian hyper-stimulation syndrome	33	66	1	16	82	2	0.006
Information about drugs and possible side effects	61	39	0	25	71	4	<0.001
Chances of taking home a baby	25	72	3	14	82	4	0.053
Understanding about possibility of miscarriage/ectopic pregnancy	40	59	1	13	83	4	<0.001
Knowledge about alternatives to IVF, including child-free living and adoption	35	64	1	21	62	17	0.143
Knowledge about injection procedures	52	48	0	10	86	4	<0.001
The average financial cost of IVF treatment	27	72	1	5	92	3	<0.001
The time/duration needed to commit for one cycle of IVF	39	60	1	7	90	3	<0.001

NK: No knowledge; LK: Little knowledge; SK: Some knowledge; GK: Great knowledge; NS: Not satisfied; SS: Somewhat satisfied; S: Satisfied; VS: Very satisfied; NR: No response

Table VIIIb. Comparison of pre- and post-psychosocial counselling responses.

Statement	Pre-counselling			Post-counselling			
	SD + D (%)	A + SA (%)	NA (%)	SD + D (%)	A + SA (%)	NA (%)	p-value
Counselling helped me to understand the emotional issues involved in IVF.	19	70	11	7	83	10	0.100
I was unable to share my decision to try IVF with my family and friends.	38	50	12	30	51	19	0.416
I find it difficult to talk about infertility.	24	65	11	30	56	14	0.257
Counselling helped to identify useful coping strategies.	13	74	13	8	78	14	0.256
Ongoing counselling should be part of the IVF programme.	23	65	12	16	70	14	0.234
Counselling is needed for the most stressful stage of IVF, i.e., waiting for pregnancy test result.	20	70	10	15	71	14	0.427
With counselling, I'm ready to cope with a bad result.	24	63	13	6	81	13	<0.001
The nurse offered emotional support.	9	77	14	4	83	13	0.143
My doctor offered emotional support.	18	65	16	10	77	13	0.073
I myself can adjust my emotion.	9	81	10	6	82	12	0.445

SD: Strong disagree; D: Disagree; A: Agree; SA: Strongly agree; NA: Not applicable

after medical counselling with regard to the type of treatment procedures, the treatment options, information about drugs and understanding about the possibility of miscarriage/ectopic pregnancy. There was also better understanding about the injection procedures, the financial cost of treatment and the time commitment for one IVF cycle.

Patients felt that they were able to cope with the emotional stress of IVF on their own. After psychosocial counselling, patients felt that they were more ready to cope with a bad result ($p<0.001$). They found that nurses were the best providers of emotional support followed by counsellors, then doctors.

DISCUSSION

IVF treatment is emotionally and physically stressful, and often financially demanding. There is a substantial emotional investment for the couple, as this treatment is usually the last resort after years of exhausting other avenues to try to have a family. For the women, there may be considerable physical pain and the time required to undergo treatment may interfere with other ambitions in life. To accurately quantify the stress involved in IVF is difficult since the couple would have experienced infertility-related stress prior to decision and commencement of IVF.

The most stressful time in an IVF treatment cycle is the wait after embryo transfer, to find out if the treatment has resulted in a pregnancy[1-4]. Other researchers have found that common reactions during IVF are anxiety and depression. 50% of our respondents found it difficult to share their feelings with family or friends and 65% found it difficult to talk about their infertility. After an unsuccessful IVF, feelings of sadness, depression and anger prevail[1]. After a successful IVF treatment, IVF parents experience more stress during pregnancy than "normal fertile" parents[1]. Mothers with children conceived by IVF express a higher quality of parent-child relationship than mothers with a naturally-conceived child[1]. It has been shown that ineffective coping strategies, anxiety and/or depression are associated with a lower pregnancy rate[1].

83% of our patients felt that counselling helped them to understand the emotional issues involved in IVF. Most women rate the physical stress, like injections and scans, to be less distressing compared to the emotional stress, like waiting to find out how many eggs had been fertilised[4]. Our study showed that the main stress of IVF is still waiting for the pregnancy test result. 70% of the respondents felt that counselling should be offered at this stage of their treatment.

The majority of our patients were educated with 78% of them having attained at least a high school/A-level education. Hence, they were quite well informed regarding IVF even prior to attending any medical counselling sessions conducted by our doctors and nurses. Despite this knowledge, 80% of them still felt the medical counselling was helpful. This was probably because they only had general knowledge regarding IVF and the medical counselling provided them with details of the IVF programme. 85% of the patients knew more about the types of treatment procedures compared to 48% before counselling ($p<0.01$). 82% understood the risks of IVF, e.g. multiple births and ovarian hyperstimulation syndrome, compared to 66% before counselling ($p=0.06$). 71% had more information about the drugs and possible side effects compared to 39% before counselling ($p<0.01$). They were also more aware of the technical aspects of IVF, including injection procedures and time/duration of one cycle of IVF, after counselling. There was a marked increase in knowledge to almost 90% after the counselling, highlighting the importance of including these topics in the counselling session. Hopefully, this information will enable the couple to make a better decision regarding IVF treatment.

Women were overly optimistic about their first attempt at IVF, with 70% being moderately to highly optimistic about success. Level of optimism generally declined with the number of attempts[2]. Both women and men tended to overestimate the chances of success of IVF[7], with some 25% grossly overestimating their chances of being successful[4]. In our study, 82% of respondents felt that they had greater knowledge of their own chances of a take home baby as compared to 72% of respondents prior to the medical counselling ($p=0.053$).

Women attributed their lack of success to a wide range of factors, including the low success rate, being anxious or stressed, bad luck, or problems associated with their condition and the procedure[2]. The major strategy most women used to cope with the programme was to adopt the attitude that they might be successful in the long run[2]. Other coping strategies included keeping themselves busy, staying calm and seeking the support of other IVF women and husbands[2]. Husbands were listed as the major source of emotional support, followed by other infertile women and nurses, counsellors and doctors[2]. Our study also showed that nurses provided better emotional support than medical social workers and doctors. This could be because couples had more contact opportunities with nurses during their treatment and only saw the medical social counsellor/worker during ad hoc visits. Nearly 80% of respondents found that the psychosocial counselling session helped them to develop coping strategies and 81% felt that with counselling, they were better equipped to cope with the bad results ($p<0.001$).

The vast majority agreed that ongoing counselling should be part of the IVF treatment[4]. Our study also reiterated this point. Henceforth, avenues for ongoing

counselling should be provided and made easily available to couples who need this service. The clinic can contact couples during and between treatments to enquire about the changing needs of the couple. This is especially so during the most stressful part of the treatment, waiting for the result of the pregnancy test. Treatment outcomes did not influence any change in attitudes towards IVF before and after treatment[5]. After treatment, the women's state of anxiety remained unchanged, while the quality of couples' relationships was enhanced[5]. We did not assess this aspect in our study.

Majority of patients (67%) agreed that it was primarily their own decision to try IVF, but only 35% felt that it was easy to make this decision. 89% felt that the financial cost of IVF was carefully considered before deciding to have the treatment and counselling allowed 92% of the respondents to better understand the average cost of IVF treatment. It is important for clinic staff to be aware of this, as the patient may be feeling particularly vulnerable at the time of starting treatment. Although 87% of our patients felt that IVF programme is acceptable by society, 50% of them felt that they were unable to share their decision to try IVF with family and friends, and 65% felt that it was difficult to talk about infertility. Studies have shown that secrecy and having to come up with excuses for absenteeism at work added to the stress of treatment[4]. Henceforth, psychosocial counselling should target this aspect to help couples cope with this issue as the majority of our couples (84%) are working for a living.

By including childfree options and adoption in the medical counselling, more respondents had knowledge about alternatives to IVF. In addition, couples should be counselled about the option of stopping treatment[4] as the decision to end treatment may help couples to come to terms with their unresolved infertility. Though this decision is difficult to make, it offers some women a way out of the emotional distress caused by IVF[6]. The ability to retain information varies greatly with individuals. Reading et al have shown that as much as 50% of information is forgotten as soon as five minutes after consultation, and that information processing can be inhibited by anxiety and how the information is presented[8]. Therefore, information needs to given repeatedly, again emphasising the importance of ongoing counselling as indicated by 65% of our respondents.

There was greater emotional distress for women compared to men in relation to infertility diagnosis and treatment. Women experienced more stress than men at a number of stages of treatment[3]. We found that the expectation of women to become mothers influenced more women than men to try IVF. However, almost equal numbers of women and men felt that it was primarily their own decision to try IVF and both partners were in agreement to try IVF in 100% of our respondents. This may be a biased figure because we interviewed infertile couples who had already registered to start IVF rather than infertile couples who had only begun to seek medical help and investigation.

Women experienced heightened anxiety during intake for IVF. In our study, fewer women felt that the decision to try IVF was easy compared to men. There is also a higher level of distress in women than in their male partners[7] as shown by the higher proportion of women in our study feeling "pressurised to try IVF" as compared to the men. This gender difference in symptoms could be due to women have a greater emotional investment in childbearing or a closer involvement in the process of IVF[7]. However, this could also be viewed as part of a wider pattern of gender differentials in reporting emotional distress[7].

This study increased our understanding of the emotional aspects of IVF in our population base. Continual emotional support during IVF was identified as important, particularly while waiting for the pregnancy test result. We need to provide more formal support for couples during this stage of treatment. The findings can be used by providers of IVF to implement strategies that may reduce stress and improve the patients' well-being.

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