RESEARCH ARTICLE

Accepting Finite Disappointments amidst Infinite Hopes—Treatment-related Concerns in Infertile Women Seeking Medically Assisted Reproductive Treatments: A Clinic-based Cross-sectional Study from India

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Abstract

Aim: The aim of this study was to devise a measure to estimate the treatment-related concerns in women seeking fertility treatments. We also aimed to compare the women with and without psychiatric morbidity in their treatment experiences.

Settings and design: This study has a cross-sectional design, and the survey was conducted on 300 participants visiting the study site.

Measures: The International Classification of Diseases (ICD) was used to assess for psychiatric comorbidity. Treatment concerns were assessed using the "treatment-related concerns scale for infertility (TRC-I)" devised by the investigators for this research.

Statistical analysis: Statistical Package for the Social Sciences (SPSS)—16 was used for descriptive data analysis, and Chi-square was used for univariate analysis to evaluate the associations between psychiatric comorbidity and treatment concerns.

Results: Our data suggests that women (especially those with psychiatric comorbidities) are considerably impacted by immediate physical, financial, emotional, and interpersonal outcomes from treatments.

Discussion: Women had serious concerns with lack of certainty of pregnancy, the side effects, fear, anxiety, and pain arising out of procedures, unmanageable emotional distress during intrauterine insemination (IUI)/*in vitro* fertilization (IVF) cycles, disturbances in their sexual functioning, financial strain, treatment continuation, and lastly the social implications of infertility. They were minimally bothered with the repeated blood tests and normalcy of the baby born. Those with psychiatric comorbidities were more concerned over repeated IUI/IVF cycles, recoveries, pain, fear, anxiety, and social stigma and voiced out to seek professional psychological support.

Conclusion: Flexibility in treatment planning, stability in clinical relationships, and staff support, along with psychological, informational, and spousal help, serve as important sources of positive treatment experiences.

Keywords: Assisted conception, *In vitro* fertilization, India, Infertility, Stress, Women.

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Introduction

Infertility distress stems from a complex interaction of several client-specific and treatment-specific variables.[1] Distress is known to elevate with medium to a long duration of infertility, repeated implantation failures, an increasing number of attempts, cost of investigations, and longer cures, and these factors contribute toward higher grief, longing, and frustration in men and women.[2–5]

The quality of care in infertility was traditionally assessed by tracking the treatment outcomes, such as cumulative live birth rates or complication rates, and by patient-centered feedback.[6] Patient-centric feedback is particularly useful in infertility, as it provides us cues into the subjective experiences of patients.[2,7] These feedbacks also provide the caregivers with essential targets for reducing treatment burden, discontinuation, and improvising the overall quality of services.[8–10] Existing literature on treatment-related concerns in infertility reveals about 50% of women seeking treatments are dissatisfied, hopeless, impatient, uncertain with the treatment process and 55% expressed that they were dissatisfied as the treatments overall emotional/financial/relational strain is unmanageable.[11–13] Reviews also suggest that as the live-birth rates in single cycle of intrauterine insemination (IUI)/*in vitro* fertilization (IVF) are lower than cumulative rates for three to six cycles, a large percent of patients visiting the clinics end up being treatment-repeaters.[14–16] Treatment repetition adds to their existing

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toll of emotional, physical and financial stressors, in both western and Indian setups.[17–20] Women also express worries emanating from the fact that treatments per se do not guarantee conception or the live birth of a physically and mentally normal baby.[21] Furthermore, factors such as repeated investigations (transvaginal scans and semen analysis), lack of opportunity for doubt clarification, negative doctor-patient interactions, lack of spousal involvement in treatment planning also leads to negative patient experiences.[22] Additionally, other barriers to treatment-seeking include factors such as procedural pain, safety and injection-related anxiety in infertile women.[21] The involvement of men in the treatment pathway and assisting women to a greater respect, autonomy, control over their treatment process also improves their experience.[22] Thus, in order to address the aforesaid patient concerns in infertility, a growing body of research mandates the application of "patient-centered care approach" in fertility care that ranges from services like assessing needs, answering common questions, providing information, support and documentary resources along with provision of cost-effective treatments, and access to support groups.[23–26] Accordingly, in a patient centered programs values like "respect, autonomy, and partner involvement" are highly appreciated and these are serve as strengths in fertility care.[24–26]

Research demonstrates that one-third of patients are given written information, and 78% continue to express a wish for more verbal explanation.[27] Another weakness cited by patients is the low collaboration in emphatic decision-making and inaccessibility of their medical records.[28,29] Another cross-sectional study concludes that about 40% of patients are never asked to bring their partners to a clinic, 86% reveal that emotional aspects of infertility are ignored, 47% report that a clear plan for the future is not provided, and 23% of those who had been given drug treatments received little or no information about it.[29]

Despite these facts and figures, investigations that examined the patient's subjective experience of undergoing recurrent ovulation induction (OI), IUI, and IVFs, especially from a nation such as India, are scarce.[19,30,31] To the best of our knowledge, a meticulous search of the empirical literature on this topic from the Indian setups leaves us with several gaps in the literature, with more questions unanswered than answered. This study is conceived in light of these lacunae. It is also planned in consideration of the fact that most of the research on patient experiences in infertility emergences from high-resource countries where treatments are technologically more advanced and have better success rates and where treatments are insured.[22,31,32]

Some researchers also emphasize the associations between patient dissatisfaction and depression or anxiety faced by infertile individuals.[21,22] Elevating distress is an established risk factor for psychiatric morbidity, particularly in women undergoing fertility treatment.[18–20] This is so as irrespective of the cause of infertility, females face a higher burden since they undergo most of the invasive procedures and investigations in IUI and IVF. This fact stands true for both time periods, that is, before and after conception.

The objectives of this study were to estimate the treatment-related concerns of women seeking fertility treatment and to examine the categorical differences in the severity of these concerns (minimal, moderate, and maximum) raised by the participants of this study. We also aimed to compare the women with and without psychiatric morbidity on their treatment concerns.

Materials and Methods

Study Participants

The sample of this cross-sectional study comprises 300 married infertile women (visiting the outpatient services at Department of Reproductive Medicine and Surgery based at Kasturba Medical College & Hospital, Manipal Academy of Higher Education, Manipal, Karnataka, India. They were referred for the study by the infertility experts at study cite. The data was drawn using convenience sampling. The inclusion criteria of the study were cases diagnosed with primary or secondary infertility or with recurrent pregnancy loss and consenting to participate. The consenting participants were administered the study measures described below. The study excluded those women who were unwilling to participate. The duration of the study was 5 months. The sample size of the study was restricted and time-bound as it was a part of a larger doctoral project.

Ethical clearance from the institutional authorities and Hospital Ethics Committee was taken before the conduct of this work.

Description of Study Measures

- Structured pro forma for sociodemographic details: This was a brief form compiled by the researchers for assessing each participant on variables like the participant's age, education, SES, occupation, diagnosis, duration of marriage, infertility, and treatment history.
- International Classification of Diseases (ICD)–10—Clinical Descriptions and Diagnostic Guidelines (CDDG) version: The World Health Organization proposed the International Classification of Diseases as a gold standard for reporting diseases and health conditions. It is extensively employed in clinical setups in India for diagnosis and monitoring of the prevalence of diseases, identification of health trends, and statistics at a global level. Chapter V (F) of the ICD contains guidelines and 100 categories for mental and behavioral disorders. The ICD is available in several versions, and for this study, the CDDG was used by the principal investigator (licensed clinical psychologist who was trained personnel for using the manual) to diagnose psychiatric morbidity.
- The development and validation of the "treatment-related concerns scale for infertility (TRC-I)": The questionnaire was a patient-rated measure constructed in four phases.

Literature Review

We initially reviewed the literature on available measures for assessing treatment concerns in women undergoing treatment. Measures like knowledge and beliefs about fertility treatment retrieved from the international decision-making study[33] "fertility experiences questionnaire,"[34] concerns with assisted reproductive treatments scale,[35] patient attitudes to medical and psychosocial care in fertility (COMPI, Copenhagen Multicentre Psychosocial Infertility Research Programme)[36] were present. However, a look at the later measures shows that each of these measures was devised for assessing the local needs of patients within certain clinical setups. These measures are useful tools, carefully constructed and translated into vernacular languages, and validated for use with specific patient populations; however, none of these were found to be a gold standard or cross-culturally valid tool for assessing infertility-related treatment experiences. Thus, they were not found suitable for use in the present study with the Indian population.

Patient and Staff Survey for Designing the Tool

Recent studies have also pinpointed the importance of developing tailor-made instruments to assess the quality of care and satisfaction using patient feedback forms in clinics, as these can be clinically useful in improving patient care and services.[37,38] Moreover,

we decided to conduct a small survey in which we interviewed experienced infertility doctors (junior and senior residents and professor grade doctors), infertility nurses, andrologists, and infertility counselors who participated in providing us details on their observation of usual issues, problems faced and complains made by patients during treatment times. Based on their suggestions and review of existing literature, the authors of this study comprised the initial scale consisting of 26 items to be answered by participants on a three-point rating scale (minimal = 1, moderate = 2, maximum = 3), in order to indicate their severity of concerns.

Pilot Test of Initial 26-item Measure

This initial measure was pilot tested on 30 consenting patients attending outpatient department services at Department of Reproductive Medicine and Surgery, Kasturba Medical College & Hospital, Manipal Academy of Higher Education, who were drawn using random sampling. The 26-item measure was tried out in two formats, out of which the 15 women answered it entirely on the basis of self-administration, and the rest of the women answered it based on a face-to-face interview with the principal investigator. Personal feedback was taken from all these 30 women regarding the adequacy of the scale, missing items, and their overall experience of fertility care. Based on this initial try-out and feedback, we improved and added certain items to the scale.

Expert Validation

The next step was expert validation. The scale was again administered to a panel of psychologists, social workers, doctors (junior and senior residents and professor grade doctors), nursing staff, and counselors working in this area to take their unanimous feedback and comments on the face validity, clarity, and adequacy of items in the scale. In this way, the final scale comprised 31 items that were considered to be high on informal consistency and expected to be answered by the participants on a 3-point rating scale (minimal = 1, moderate = 2, maximum = 3) and, in totality clubbed under five subdomains. Table 1 presents the final version of the scale.

Kannada Translation of the Final Scale

Kannada language version of the scale was found to be suitable for use in this study. The final scale was translated from English to Kannada and back-translated (from Kannada to English) by a bilingual expert in order to check for its accuracy.

Procedure

This study was a pilot work to a larger investigation, which was a doctoral project of the principal investigator on the "effectiveness of modified mindfulness-based cognitive therapy in distressed couples with infertility, undergoing intra-uterine insemination." After ethical clearances (IEC-275/2014 sort from institutional authorities and the Clinical Trial Registry: CTRI/2015/07/005973), the study was conducted in two phases. The first phase comprised the development and pilot testing of the "concerns with fertility treatment scale." In the second phase, the main study was conducted on 300 women diagnosed with infertility. They were included on the basis that they met the study criteria and were explained the purpose of the study and its implications. Informed written consent was obtained for their participation. The consenting women were interviewed to collect information on sociodemographic as well as clinical variables using a structured performa. Subsequently, participants were assessed for treatment-related concerns using the "TRC-I" that was constructed by the researchers for this particular study. All participants were guided by the principal investigator in completing the scale. The principal investigator was a licensed clinical psychologist and psychotherapist, and a doctoral scholar posted exclusively to carry out unbiased research at the study site. She was not involved as a staff at the infertility center or involved in any fertility treatment decisions or procedures at the study site. This was informed to all participants prior to their enrolment and written consent so as to ensure the exclusion of any reporting biases and honest reporting of their treatment-related experiences. After data collection, it was subjected to the following analysis.

Data Analysis

Data were analyzed using Statistical Package for the Social Sciences (SPSS)—15. Descriptive data analysis was carried out to evaluate the differences between mild, moderate, and high treatment concerns of women. A descriptive analysis followed by a Chi-squared test (as a measure of univariate analysis) was carried out to evaluate the differences between the treatment concerns of women with and without psychiatric morbidity with *p*-values fixed at 0.05. The odds ratio was calculated, as well as a measure of association between an exposure (presence or absence of psychiatric morbidity) and an outcome (various treatment concerns).

Table 1 presents the descriptive data on participants in the study. Table 2 presents the comparative analysis of the severity of treatment concerns reported by women on the "concerns with fertility treatment scale." Figure 1 depicts a plot of the most common and least common concerns reported by the study participants. Table 3 presents a comparative analysis of treatment concerns of women with and without psychiatric morbidity.

Discussion

The objectives of this study were to estimate the treatment-related concerns of women seeking fertility treatment and to examine the categorical differences in the severity of these concerns (minimal, moderate, and maximum) raised by the participants of this study. We also aimed to compare the women with and without psychiatric morbidity on their treatment concerns.

With respect to the primary objective, the findings of this study revealed that all participants were highly concerned over "fear or anxiety from procedures, lack of certainty that a pregnancy will result from treatment, worries related to the outcome of pregnancy (abortion, multiple pregnancies, and anomalies or complications of pregnancy or delivery), apprehension over "pregnancy results" in the month in which women have taken treatments, receiving sexual advice or preconception counseling, inabilities to relax in spite to trying hard enough, overall expenditure of treatment cycles, drugs, investigations, traveling, and accommodation and obtaining medical claim for same. About 70–80% of women were seriously bothered due to these issues. These findings are also supported by other researchers, who report that these women wanted their infertility distress to be recognized by others, to feel cared for, and to have confidence in health professionals in situations where outcomes are uncertain.[21,25,26] Negative effects of treatment on marital relationships and injection-associated anxiety[21,39] have been shown to be two major causes of stress in some studies.

Additionally, around half of the study participants (45–60%) expressed moderate levels of discomfort from repeated investigations (especially with HSA), worries over the side effects

Table 1: Descriptive data of the study participants

Characteristics		*Frequencies (%)*
Age of the women (in years)	20–25	57 (19%)
	26–31	177 (59%)
	32 and above	66 (22%)
Education of the women	Up till 10th	153 (51%)
	10th and above	147 (49%)
Marital years	1–4	129 (43%)
	5–7	99 (33%)
	8–10	21 (7%)
	Above 10	51 (17%)
Occupation	Semi-skilled	135 (45%)
	Skilled	132 (44%)
	Clerk/shopkeeper/business	21 (7%)
	Semiprofessional and professional	12 (4%)
Duration of infertility (in years)	1–3	126 (42%)
	4–6	120 (40%)
	6–12	54 (18%)
Years since taking fertility treatments (OI, IUI, IVF, ICSI)	1–2	63 (21%)
	3–4	138 (46%)
	5–6	84 (28%)
	>7	15 (5%)
Family income per month in Indian national rupees	8,000–12,019	84 (28%)
	12,019–16,019	144 (48%)
	16,020–32,049	30 (10%)
	>32,050	42 (14%)
Diagnosis of females	No abnormality	78 (26%)
	Mild endometriosis	27 (9%)
	Tubal defect	21 (7%)
	Fibroid	24 (8%)
	Polycystic ovarian disease	150 (50%)
Infertility type	Female factor	96 (32%)
	Male factor	78 (26%)
	Combined factor	84 (28%)
	Unexplained cause	42 (14%)

of drugs, repetition and cancellation of the treatment cycle, decisional doubts, and lack of clarity over treatment options, inadequate nutritional advise, anxiety from investigations to its findings (possibility of a defect being identified in them), elevated distress during treatment times, doubts related to disturbances in sexual activity, concerns that unmanageable stress might impede conception, elevated mood swings, during or after treatment times, taking repeated medical leaves, long recovery gaps and work interruption due to treatments and disturbances in normal life routines. Approximately two-thirds of participants reported the presence of a range of social stressors like unsolicited questions or advice from others over religious remedies, protecting sexual privacy, persistent negative social attitudes over undergoing unnatural means of conception, facing social stigma or discrimination, and vicissitudes of informational sharing, secrecy, concealment, and disclosure. The later findings find support in the literature,[19,21,40,41] where others have opined that lack of family and/or social support, worries about treatment safety, treatment stress, and disruption in social ties cause distress to couples.[42]

Intriguingly, women expressed bare minimal concerns with repeated transvaginal ultrasounds (TVS), concerns with the physical and mental outcome of the baby born out of such treatments, informational sufficiency, adequacy of patient support from infertility staff, spousal involvement in treatment phases, opting for treatment regularity, over seeking professional psychological support services in infertility clinic, revealing about ongoing treatments and its details to others and missing social functions or obligations due to ongoing treatment cycles. Such findings were contrary to those found in Western literature.[22,26,28,43] The latter findings could probably be attributed to the positive treatment environment and superior patient-centered care provided at the study site as it was a part of a medical college and primarily educational institution. In the current data, one of the factors that could have led to the adequacy of patient support could be that our patients were provided with an opportunity to have detailed discussions and well-timed information and a one-to-one dialog with the infertility experts regarding their condition during each phase of treatment (IUI/IVF). In this way, the perceived burden could have been negated as the informational needs and emotional expectations of the women were well-met. An extra effort was made by staff to ensure spousal involvement as much as possible, especially during anxiogenic phases of treatments such as

Table 2: Comparative analysis of severity of treatment concerns reported by women

Treatment-related concerns scale for infertility

Subject's ID: Age: Gender:

Date of assessment:
Clinical diagnosis/treatment history:
Current treatment plan:
Any other details:

Dear participant,
These questions ask about the effects that your infertility treatment may have on your life over the last 4 weeks**.** For each question, kindly check (tick the box next to it) for one response that most closely reflects your extent of concern. Please relate your answers to your current thoughts and feelings.
Some questions may relate to your private life, but they are necessary to holistically measure all aspects of your life that are impacted by infertility treatments.
Kindly note that:

- Your response needs to closely express your opinion.
- There are no right or wrong answers.
- Please mark each response very clearly and fill out all the questions.
- If you have any doubts, please clarify with the scale administrator.

I. Physical concerns with treatments		*1 = least concerned n (%)*	*2 = moderately concerned n (%)*	*3 = highly concerned n (%)*
P1. Repeated investigations	Blood tests	182 (60)	65 (22)	53 (18)
	TVS	79 (26%)	105 (35%)	116 (39%)
	Husband's semen analysis	54 (18%)	100 (33%)	146 (49%)
P2. Concerns of accommodation, hospital stay, traveling, and multiple clinic visits during treatments		85 (28)	101 (34)	114 (38)
P3. Concerns with two or more side effects of drugs and procedures (nausea, stomach upset, headaches, abdominal bloating, discomfort, mood swings, abnormal bleeding, chances of exaggerated ovarian response, weight change, etc.)		82 (27%)	69 (23%)	149 (50%)
P4. Pain from treatment-related procedures		49 (29%)	37 (12%)	176 (59%)
P5. Cancellation of treatment cycle due to slow or poor ovarian response, despite using appropriate drugs		76 (25%)	89 (29%)	135 (45%)
P6. Repetition of treatment cycles owing to limited margins of success		54 (18%)	131 (44%)	115 (39%)
P7. Lack of certainty that a pregnancy will result from treatment		43 (14%)	18 (6%)	239 (79%)
P8. Worries related to the outcome of pregnancy (abortion, multiple pregnancies, anomalies or complications of pregnancy or delivery)		32 (11%)	219 (73%)	49 (16%)
P9. Pregnancy will result in the delivery of a normal (physically and mentally healthy) child		159 (53%)	127 (42%)	14 (5%)
P10. Not having enough information about diagnosis, prognosis, and treatment process		176 (58%)	95 (32%)	29 (10%)
P11. Decisional doubts over various treatment options		44 (15%)	99 (33%)	157 (52%)
P12. Receiving adequate patient support from the infertility team		190 (63%)	96 (32%)	14 (5%)
P13. Concerns over treatment termination or discontinuation vs continuation		115 (38%)	132 (44%)	53 (18%)
P14. Nutritional advice for enhancing fertility and vigor		25 (8%)	136 (45%)	139 (46%)
II. Emotional concerns with treatments		*1 = least concerned n (%)*	*2 = moderately concerned n (%)*	*3 = highly concerned n (%)*
E1. Fear or anxiety from procedures		49 (16%)	35 (12%)	216 (72%)
E2. Anxiety of a possible defect being identified in them		34 (11%)	133 (44%)	133 (44%)
E3. Distress during treatments		33 (11%)	110 (37%)	157 (52%)
E4. Apprehension over "pregnancy results" after treatments		25 (8%)	48 (16%)	227 (76%)
E5. Distress related to disturbances in sexual activity		24 (8%)	120 (40%)	156 (52%)
E6. Obtaining sexual advice and preconception counseling for normal conception		16 (5%)	68 (23%)	216 (71%)
E7. Inadequate spousal involvement in treatments		233 (77)	50 (17)	17 (5)
E8. Concerns that "their levels of stress might impede conception"		82 (27)	30 (10)	188 (62)
E9. Inability to relax		31 (10%)	55 (18%)	214 (71%)
E10. Concerns over seeking professional psychological support services in infertility clinic		223 (74%)	43 (14%)	34 (11%)
E11. Concerns of elevated mood swings, frustrations, irritability, and anger outbursts during or after treatment times		61 (20%)	163 (54%)	75 (25%)

Contd…

Table 2: *Contd...*

III. Financial concerns about treatments	*1 = least concerned n (%)*	*2 = moderately concerned n (%)*	*3 = highly concerned n (%)*
F1. The overall cost of the treatment cycle (drugs, investigations, traveling, and accommodation)	9 (3%)	86 (29%)	205 (68%)
F2. Obtaining medical claims for treatments and drugs	20 (7%)	64 (21%)	216 (72%)
IV. Occupational concerns from treatments	*1 = least concerned n (%)*	*2 = moderately concerned n (%)*	*3 = highly concerned n (%)*
O1. Absenteeism from the workplace (self and spouse)	103 (34%)	140 (46%)	57 (19%)
O2. Taking repeated medical leaves (self and spouse)	56 (19%)	129 (43%)	115 (38%)
O3. Long recovery, work interruption due to treatments (self and spouse)	42 (14%)	158 (53%)	100 (33%)
O4. Disturbed daily chores and normal life routines (self and spouse)	73 (24%)	179 (60%)	48 (16%)
V. Social concerns with treatments	*1 = least concerned n (%)*	*2 = moderately concerned n (%)*	*3 = highly concerned n (%)*
S1. Social embarrassment of revealing treatment details to others	151 (50%)	79 (26%)	70 (23%)
S2. Missing social responsibilities or functions due to ongoing treatments	226 (75%)	70 (23%)	4 (1%)
S3. Unsolicited questions or advice from others over infertility and its cures	25 (8%)	94 (31%)	181 (60%)
S4. Protecting sexual privacy	47 (16%)	99 (33%)	154 (51%)
S5. Inadequate social support for treatment continuation	183 (61%)	100 (33%)	17 (6%)
S6. Persistent negative social attitudes over "undergoing unnatural means of conception"	40 (13%)	133 (44%)	127 (42%)
S7. Spoiled social image, stigma, and discrimination due to infertility	61 (20%)	89 (30%)	150 (50%)
S8. Concerns over the extent of secrecy, concealment, and disclosure	77 (26%)	92 (31%)	130 (43%)

insemination procedures in IUI, oocyte pick-ups, embryo transfers during IVF, and choosing donor treatment programs.

Furthermore, due to the high caseload at the infertility center, it was managed by a well-facilitated and adequate number of infertility staff. The onus of patient support and ensuring treatment satisfaction did not explicitly rest on the shoulders of the treating doctors. It was rather shared by all the infertility staff members. In personal interviews with the participants during the conduct of this work, they reported that the infertility nurse, sonologist, nursing heads, counselors, and even the junior nurses and receptionist at the desk were sources of invaluable personal assistance as well as support for the women. Patients also shared their stories and felt relief from peer support. Talking, sharing, and caring with women, sitting with them in the waiting areas, or receiving the same treatment (IUI/IVF) made the women feel validated. These findings were also supported by other investigations that go on to claim that personal knowledge and information provided by ex-patients, peers, partners, and midwives increase the satisfaction of patients undergoing treatments at fertility clinics.[8,10,43,44]

It is also important to note that the backgrounds of patients visiting the study site were diverse in nature. Each patient varied from the other in terms of demographic, sociocultural, and economic factors. This made uniform information exchange a complicated task for the infertility staff, as each time, it had to be matched with the patient's level of education, linguistic understanding, interest, and comprehension. Thus, a special effort was made at the study site to help all patients receive and understand fertility-related information, clarify, and be involved in open-ended verbal exchange to aid their decision-making. All such factors empowered the women, leading to better treatment experiences as found in our sample in comparison to those found in earlier studies. Likewise, emphasis on informational counseling has also been laid by other investigations.[45] Our results supported the existing evidence for the "patient–physician partnership model of fertility care." Information exchange is a vital component of this model. The format, content, and timing of the information provision have been considered very important.[27] Besides, these studies also report that factors such as clinic organization, provision of written informational details (on causes, cure, side effects, outcomes), diagnostic clarification, explanation on procedural aspects of IUI, IVF, an extension of emotional support (by staff, social worker or psychologist, peer group), doctor's attitudes (behavior, competence, compassion, trust, respect, listening skills, verbal explanations, and shared decision making) leads to positive patient experiences.[3,22,46] Most importantly, increasing the fertility staff's desire to change and their ability to work towards optimal quality improvement may also enhance treatment satisfaction.[23,43,44,47] Handling treatment burden increases patients' perceived behavioral control, continuity of care with the same physician, and benefits of planning for multiple cycles as well, making them more likely to attain their "wish-for" outcomes.[48,49]

With respect to the second objective, which was to compare the women with and without psychiatric morbidity on their treatment concerns. Our findings revealed that those with significant psychiatric morbidity are 32 times more concerned with pain, 22 times more concerned with repeated TVS, and seven to six times more worried over choices of treatments (continuation vs discontinuation) as well as afraid and anxious of the various procedures of IUI/IVF, in comparison to those without any significant psychiatric disorder. Also, those suffering from a major psychiatric condition were four times more likely to worry about the treatment results in the waiting periods and over long recoveries, as well as disruption to their occupational lives as a result of treatment. Such women were also more worried over treatment-induced stress and social embarrassment and three times more likely to voice out a need to seek professional social support.

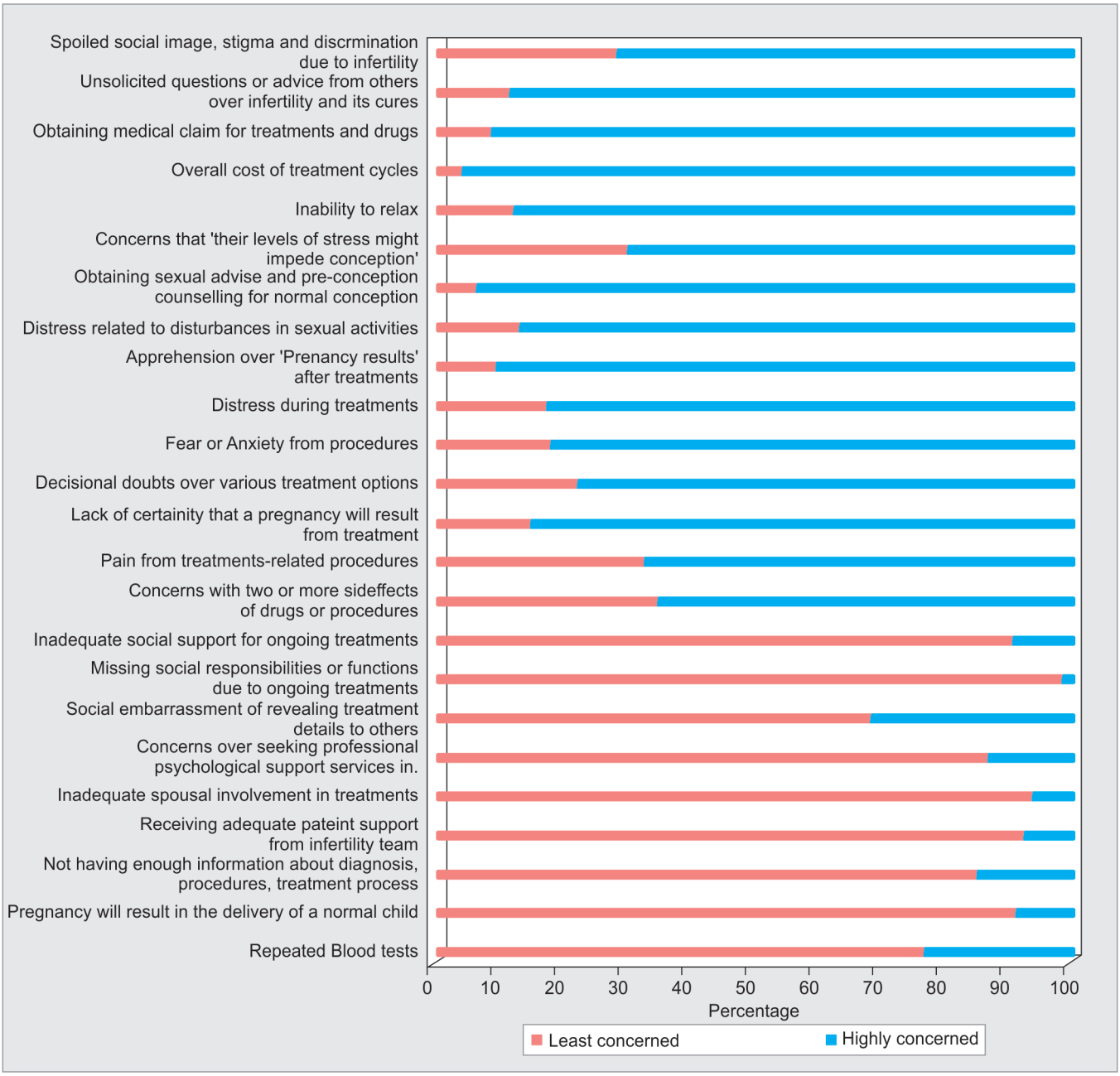

Fig. 1: A plot of the most common and the least common concerns reported by the study participants

Strength and Implications of the Study

To the best of our knowledge, this study is one of the first detailed investigations from India that documents the treatment experiences of patients undergoing OI, IUI, and IVF in a clinic-based Indigenous setting. Also, despite a large number of individuals taking up fertility treatments, this appears to be one of the first systematic investigations in which an in-house measure/self–report tool is made to tap their treatment-related experiences and expectations. For most parts of infertility treatments, women are more involved, are the sole arbiters, and are willing to take higher risks (independent of the likelihood of success) than men. In this way, medical treatments may be pursued to extremes by females.[50] It emphasizes the recent and the most influential perspective, which is the application of an integrated care approach to infertility to make this journey comfortable for them.[44,49,51] The study also emphasizes the need to tackle three sources of treatment burden, namely[44,49,51]:

- Patient-related outcomes (negative individual and couple attitudes, low emotional tolerance, psychological vulnerability, relational strains).
- Clinic-related outcome (infertility team-related, their attitudes, patient care, and technology and environment-related).
- Treatment-related outcomes (physical burden, disruption of social and work life, and low prognosis issues).

Limitations of the Study

As this has been a cross-sectional study, the cause-effect associations could not be ascertained in the present investigation.

Table 3: A comparative analysis of differences in treatment concerns of women with and without psychiatric morbidity

I. Physical concerns with treatments		*Psychiatric morbidity*		*Odds ratio with 95% confidence interval (CI)*
		Absent (n = 66)	*Present (n = 234)*	
Discomfort with repeated blood tests	Minimal to moderate concerns (*n* = 247)	51 (17%)	196 (65%)	1
	High concerns (*n* = 53)	15 (5%)	38 (13%)	1.51 (0.77, 2.97)
Discomfort with repeated TVS	Minimal concerns (*n* = 79)	50 (17%)	29 (10%)	1
	Moderate to high concerns (*n* = 221)	16 (5%)	205 (68%)	22.09 (11.14, 43.78)*
Discomfort with repeated semen analysis for the husband	Minimal concerns (*n* = 54)	29 (10%)	25 (8%)	1
	Moderate to high concerns (*n* = 246)	37 (12%)	209 (70%)	6.55 (3.45, 12.41)
Concerns about accommodation, hospital stay, traveling, and multiple clinic visits during treatments	High concerns (*n* = 114)	40 (13%)	146 (49%)	1
	Minimal to moderate concerns (*n* = 186)	26 (9%)	88 (30%)	0.92 (0.53, 1.62)
Concerns with two or more side effects of drugs and procedures (nausea, stomach upset, headaches, abdominal bloating, discomfort, mood swings, abnormal bleeding, chances of exaggerated ovarian response, weight alteration, etc.)	Minimal concerns (*n* = 82)	24 (8%)	58 (19%)	1
	Moderate to high concerns (*n* = 213)	42 (14%)	176 (59%)	1.73 (0.96, 3.10)
Pain from treatment-related procedures	Minimal concerns (*n* = 87)	38 (12.7%)	48 (16.3%)	1
	Moderate to high concerns (*n* = 213)	17 (5.7%)	196 (65.3%)	32.35 (14.52, 72.10)*
Cancellation of treatment cycle due to slow or poor ovarian response, despite using appropriate drugs	Minimal to moderate concerns (*n* = 165)	31 (10%)	134 (45%)	1.50 (0.76, 2.94)
	High concerns (*n* = 135)	35 (12%)	100 (33%)	1
Repetition of treatment cycles owing to limited margins of success	Minimal concerns (*n* = 54)	19 (6%)	35 (12%)	1
	Moderate to high concerns (*n* = 246)	47 (16%)	199 (66%)	2.29 (1.20, 4.37)*
Lack of certainty that a pregnancy will result from treatment	Minimal to moderate concerns (*n* = 61)	15 (5%)	46 (15%)	1.07 (0.48, 2.37)
	Moderate to high concerns (*n* = 239)	51 (17%)	188 (63%)	1
Worries related to the outcome of pregnancy (abortion, multiple pregnancies, anomalies, or complications of pregnancy or delivery)	Minimal concerns (*n* = 251)	55 (18%)	196 (65%)	1.25 (0.49, 3.17)
	Moderate to high concerns (*n* = 49)	11 (4%)	38 (13%)	1
Pregnancy will result in the delivery of a normal (physically and mentally healthy) child	Minimal to moderate concerns (*n* = 159)	33 (11%)	126 (42%)	1.16 (0.67, 2.01)
	High concerns (*n* = 141)	33 (11%)	108 (36%)	1
Not having enough information about diagnosis, prognosis, and treatment process	Minimal to moderate concerns (*n* = 176)	36 (12%)	140 (47%)	1.24 (0.71, 2.15)
	High concerns (*n* = 124)	30 (10%)	94 (31%)	1
Decisional doubts over various treatment options	Minimal concerns (*n* = 44)	6 (2.0%)	38 (12.7%)	1
	Moderate to high concerns (*n* = 256)	60 (20%)	96 (65.30%)	1.91 (0.78, 4.80)
Receiving adequate patient support from the infertility team	Minimal to moderate concerns (*n* = 190)	40 (13%)	150 (50%)	1.61 (0.66, 2.03)
	High concerns (*n* = 110)	26 (9%)	84 (28%)	1
Concerns over treatment termination or discontinuation versus continuation	Minimal concerns (*n* = 115)	98 (32.7%)	17 (5.7%)	1
	Moderate to high concerns (*n* = 185)	49 (16.3%)	136 (45.3%)	7.64 (3.99, 14.61)*
Nutritional advice for enhancing fertility and vigor	Minimal to moderate concerns (*n* = 161)	35 (12%)	126 (42%)	0.90 (0.56, 1.67)
	High concerns (*n* = 139)	31 (10%)	108 (36%)	1
II. Emotional concerns with treatments		*Psychiatric morbidity*		*Odds ratio with 95% CI*
		Absent (n = 66)	*Present (n = 234)*	
Fear or Anxiety from procedures	Minimal concerns (*n* = 49)	39 (13%)	10 (3%)	1
	Moderate to high concerns (*n* = 251)	27 (9%)	224 (75%)	6.83 (3.21, 14.51)*
Distress over a possible defect being identified in them	Minimal to moderate concerns (*n* = 186)	40 (13%)	146 (49%)	1
	High concerns (*n* = 113)	25 (9%)	88 (30%)	0.92 (0.53, 1.62)
Distress during treatments	Minimal concerns (*n* = 33)	14 (5%)	19 (6%)	1
	Moderate to high concerns (*n* = 267)	52 (17%)	215 (72%)	3.04 (1.43, 6.40)*

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Apprehension over "pregnancy results" after treatments	Minimal concerns (*n* = 25)	12 (4%)	13 (4%)	1
	Moderate to high concerns (*n* = 275)	54 (18)	221 (74%)	3.77 (1.63, 8.70)*
Distress related to disturbances in sexual activity	Minimal concerns (*n* = 144)	34 (11%)	110 (37%)	1
	Moderate to high concerns (*n* = 157)	32 (11%)	125 (41%)	1.19 (0.69,2.06)
Obtaining sexual advice and preconception counseling for normal conception	Minimal to moderate concerns (*n* = 84)	15 (5%)	69 (23%)	1.42 (0.74, 6.69)
	High concerns (*n* = 216)	51 (17%)	165 (55%)	1
Inadequate spousal involvement in treatments	Minimal to moderate concerns (*n* = 233)	50 (17%)	183 (61%)	1.09 (0.34, 3.48)
	High concerns (*n* = 67)	16 (5%)	51 (17%)	1
Concerns that "their levels of stress might impede conception"	Minimal to moderate concerns (*n* = 112)	25 (8%)	87 (29%)	1
	High concerns (*n* = 188)	41 (14%)	147 (49%)	1.20 (0.66, 2.19)
Inability to relax	Minimal concerns (*n* = 31)	16 (5%)	15 (5%)	1
	Moderate to high concerns (*n* = 269)	50 (17%)	219 (73%)	4.67 (2.16, 10.07)*
Concerns over seeking professional psychological support services in infertility clinic	Minimal concerns (*n* = 223)	39 (13%)	184 (61%)	1
	Moderate to high concerns (*n* = 77)	27 (9%)	50 (17%)	2.54 (1.42, 4.55)*
Concerns of elevated mood swings, frustrations, irritability, and anger outbursts during or after treatment times	Minimal concerns (*n* = 61)	39 (13%)	50 (17%)	1
	Moderate to high concerns (*n* = 238)	16 (5%)	45 (15%)	1.33 (0.69,2.56)
		Psychiatric morbidity		*Odds ratio with 95% CI*
III. Financial concerns with treatments		*Absent (n = 66)*	*Present (n = 234)*	
The overall cost of the treatment cycle (drugs, investigations, traveling, and accommodation)	Minimal to moderate concerns (*n* = 95)	15 (5%)	80 (27%)	1.76 (0.93, 3.33)
	High concerns (*n* = 205)	51 (17%)	154 (51%)	1
Obtaining medical claims for treatments and drugs	Minimal concerns (*n* = 20)	6 (2%)	144 (5%)	1
	Moderate to high concerns (*n* = 280)	60 (20%)	220 (73%)	1.57 (0.57, 4.26)
		Psychiatric morbidity		*Odds ratio with 95% CI*
IV. Occupational concerns from treatments		*Absent (n = 66)*	*Present (n = 234)*	
Absenteeism from the workplace (self and spouse)	Minimal concerns (*n* = 103)	23 (8%)	80 (27%)	1
	Moderate to high concerns (*n* = 197)	51 (17%)	154 (51%)	1.03(0.58, 1.82)
Taking repeated medical leaves (self and spouse)	Minimal concerns (*n* = 56)	16 (5%)	40 (13.3%)	1
	Moderate to high concerns (*n* = 244)	50 (16.7%)	194 (64.7%)	1.55 (0.80, 2.99)
Long recovery, work interruption due to treatments (self and spouse)	Minimal concerns (*n* = 42)	20 (7%)	22 (7%)	1
	Moderate to high concerns (*n* = 258)	46 (15%)	212 (71%)	4.17 (2.10, 8.26)*
Disturbed daily chores and normal life routines (self and spouse)	Minimal to moderate concerns(*n* = 252)	41 (14%)	211 (67%)	1
	High concerns (*n* = 48)	14 (8%)	34 (11%)	1.04 (0.52, 1.87)
		Psychiatric morbidity		*Odds ratio with 95% CI*
V. Social concerns with treatments		*Absent (n = 66)*	*Present (n = 234)*	
Social embarrassment of revealing treatment details to others	Minimal concerns (*n* = 151)	48 (16%)	103 (34%)	1
	Moderate to high concerns (*n* = 149)	18 (6%)	131 (44%)	3.39 (1.86, 6.18)*
Missing social responsibilities or functions due to ongoing treatments	Minimal concerns (*n* = 226)	53 (17%)	173 (58%)	1
	Moderate to high concerns (*n* = 74)	13 (5%)	61 (20%)	1.43 (0.73, 2.81)
Unsolicited questions or advice from others over infertility and its cures	Minimal to moderate concerns (*n* = 119)	21 (17%)	98 (33%)	1.54 (0.86, 2.75)
	High concerns (*n* = 181)	45 (15%)	136 (45%)	1
Protecting sexual privacy	Minimal to moderate concerns (*n* = 146)	28 (9%)	118 (40%)	1.38 (0.79, 2.39)
	High concerns (*n* = 154)	38 (13%)	116 (39%)	1
Inadequate social support for treatment continuation	Minimal concerns (*n* = 183)	45 (15%)	138 (46%)	1
	Moderate to high concerns (*n* = 117)	21 (7%)	96 (32%)	1.49 (0.83, 2.66)
Persistent negative social attitudes over "undergoing unnatural means of conception"	Minimal concerns (*n* = 173)	44 (15%)	129 (43%)	1
	Moderate to high concerns (*n* = 127)	22 (7%)	105 (35%)	1.62 (0.91, 2.88)
Spoiled social image, stigma, and discrimination due to infertility	Minimal concerns (*n* = 61)	30 (10%)	31 (10%)	1
	Moderate to high concerns (*n* = 239)	36 (12%)	203 (68%)	5.45 (2.95, 10.08)*
Concerns over the extent of secrecy, concealment, and disclosure	Minimal concerns (*n* = 77)	14 (5%)	63 (21%)	1.36 (0.71, 2.65)
	Moderate to high concerns (*n* = 222)	52 (17%)	170 (57%)	1

* is to denote Statistically Significant difference at 0.05 Confidence interval.

Additionally, as the study was a pilot work for a larger project, its sample size was limited and time-bound. This was not a randomized and controlled investigation, so our results should be interpreted with caution owing to the possibility of a certain margin of contamination and sampling bias, observer bias, and participant recall bias. Also, a disproportionately larger number of polycystic ovary syndrome patients were there in our sample, and this may serve as a confounding factor as well since these patients have greater mood swings, body-esteem image issues, and other psychological comorbidities. Additionally, some contamination biases could have crept in from the general patient-staff interactions of our participants as well, and this serves as a demerit. The tool developed for assessing treatment-related concerns (TRC-I) was invented for use as an "in-house measure" in order to tap the common experiences of patients visiting the study site. Its psychometric properties and standardization were limited and beyond the scope of this study, and this area may be worked upon by future investigators. This was a preliminary study, and validation of the measure, that is, TRC-I used in the study, could be carried out in a more scientifically standardized manner by other investigators. In the future, researchers working in similar areas can plan prospective cohort investigations with a mixed methods approach in order to tap the social and culturally specific needs, expectations and experiences of couples, and men and women seeking fertility treatments.

Conclusion

The present research supports that certain women undergoing fertility treatments are significantly concerned over 'fears or anxieties of various procedures, worried over pregnancy outcomes, tensed in post-procedure waiting periods, wish to receive sexual advice or preconceptional counseling, coping with treatment distress, overall expenditure of treatment cycles, drugs, investigations, traveling, accommodation and obtaining medical claim for same. Women with psychiatric morbidities were higher on their treatment concerns in comparison to those without it.

Our study supports that sensitivity to the overall characteristics of patients and matching those to their IUI/IVF treatments were perceived to be vital care elements for most infertile patients. Flexibility, stability, and honesty in patient–staff interactions are the usual expectations of stressed subfertile couples during treatment phases. Also, offering a multidimensional approach, that is, psychological counseling, lifestyle interventions, clear, informational exchange, continuity of the usual occupational activities of patients, and greater spousal involvement may serve as important sources of positive experiences for most treatment-seekers.

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