

Original Research Article

Two sides of a coin: women's experiences and providers' perceptions of assisted conception in urban India

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Received: 13 November 2021

Accepted: 20 December 2021

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ABSTRACT

Background: The uptake of assisted reproductive treatments has increased radically in urban India. We aimed to understand women's lived experiences of assisted conception, and ART providers' perception of their patients' experiences.

Methods: This study was cross-sectional and we used a qualitative approach and key informant interviews to understand the experiences of women and the treatment providers. Participants were ten women who had conceived through assisted reproductive treatment and ten ART providers. The data was analyzed using Braun and Clarke's thematic analysis method.

Results: During the treatment process, women felt consumed by their need to conceive. They reported that it was difficult for them to focus on other equally important aspects of their life. Stress, depression and anxiety associated with the uncertainty of their treatment outcome were prevalent. Women were also worried about miscarriage, safety and health of their baby, and forming an attachment with their fetus during the pregnancy. Providers' concurred that women experience significant mood fluctuations in the form of stress, anxiety and depression which impacts treatment adherence and outcome. Women who have adequate spousal and family support are able to navigate the ART process better than women who lack social support.

Conclusions: Findings imply the need for screening and brief psychological interventions at different stages of fertility treatment and during the antenatal and postnatal period to enhance women's emotional well-being.

Keywords: Psychological distress, Assisted reproductive treatment, Women, Providers, India

INTRODUCTION

Infertility has been ranked as one of the significant stressors in life, comparable to divorce and death in the family.¹ A household survey-3 in India found eight percent of women have an infertility problem, of which 6% women have primary infertility, and 2% have

secondary infertility.² Assisted reproductive technology (ART) has grown by leaps and bounds in the last few years. India has probably recorded the most significant growth in ART centers, and the number of ART cycles being performed in our country has steadily risen over the last decade.³

Stress during infertility treatment originates from three different aspects of the experience such as chronic stress caused by the threat of infertility and the loss of hope; stress from the prospect of the treatment itself, and the stress of the actual participation in the treatment with its daily injections, scans and invasive procedure.^{4,5} The process of going through fertility treatment is often challenging and impacts both the woman's physical and mental health.⁶

Even after successful assisted conception, infertility causes women to anticipate loss and consider their pregnancy as 'tentative'.^{7,8} Women who conceive after ART report higher levels of context-specific fears than women who conceive spontaneously, such as fear of the baby's death during pregnancy and/or childbirth and/or after childbirth, fears concerning diseases, malformation, prematurity and the possibility of the baby having to stay in a neonatal intensive care unit.⁹⁻¹¹ Higher levels of anxiety specifically focused on the pregnancy outcome were reported, especially during the third trimester, compared to spontaneous conception women, although state and trait anxiety were lower.¹¹

In the Indian setting, while most empirical studies have focused on assessing women's mental health after an infertility diagnosis, during ART treatment, and on the pregnancy outcomes of ART (low birth weight and pre-term birth), research on women's subjective experiences of ART and provider's perceptions is limited. Therefore, this study aimed to explore women's experiences of infertility, treatment process, and pregnancy achieved after successful assisted reproductive treatment, and the perceptions of their treatment providers.

METHODS

Data for this paper comes from the initial exploratory (qualitative phase) study undertaken before the prospective longitudinal cohort (quantitative phase) study to understand the impact of maternal mental health on attachment and competence. We aimed to understand women's experiences of assisted conception and ART providers' perception of their patients' experiences.

Research design

The study was cross-sectional and qualitative.

Participants

Research participants were recruited using purposive sampling from a pioneering and reputed obstetrics and gynecology hospital in Bengaluru, Karnataka, India. The participants were 10 women who had assisted conception and 10 ART providers. Data saturation determined the final sample size. The inclusion criteria were primiparous pregnant women with singleton pregnancy treated for primary infertility, aged between 25 and 45 years, at 7th

month of pregnancy, and ability to speak any one of the three languages Tamil, Kannada, and English fluently. Exclusion criteria were assisted conception through donor gametes (sperm/egg donation) and currently receiving psychotropic medication or any structured psychological intervention. The inclusion criterion for ART providers was at least ten years of experience as an infertility specialist.

Data collection

The study received ethics approval from the Institutional Ethics Committee and the fertility center where the study was conducted. The purpose of the study was explained and written informed consent was obtained from all participants who met the eligibility criteria. A semi-structured interview schedule developed by the researcher was used to guide key informant interviews. The interview mainly focused on understanding women's experiences of the treatment process, pregnancy achieved after successful assisted reproductive treatment, and ART providers' perception of their patients' experiences. A sample of open-ended questions used in the key informant interviews include: How has the journey been after deciding to undergo ART? What has been the most difficult aspect of this treatment for you? Can you tell me about the concerns you have had during pregnancy (after assisted conception)? The questions which were asked to the ART providers were as follows: What do women go through when an attempted ART method fails? How do you restore their hope? Can you tell me about the concerns women have expressed to you during their pregnancy (after assisted conception)?

Interviews were conducted one-on-one in a private room. Interviews on an average took 35-45 minutes with women, and 25-35 minutes with ART providers. All the interviews were conducted by the first author. Women, if found to be distressed were debriefed at the end of the interview. The interviews were audio recorded and transcribed for analysis.

Data analysis

All the interviews were analyzed using the thematic analysis method by Braun and Clarke.¹² The first step in TA was becoming closely familiar with the data by reading and re-reading the interview transcripts. Following this close reading, in the next step, the initial codes were generated. After generating codes, the researcher clustered them into ideas that are related. All the data relevant to each theme were extracted and ensured that all the relevant data are associated first with individual codes and then with the themes. Once themes had been identified, the next step involved defining and naming themes. Once each theme was clearly defined and described, each theme was illustrated with reference to the transcripts. This involved using extracts or quotes that capture the essence of the theme.

RESULTS

The mean age of women was 34.90 years (SD=2.23) at the time of interview. The cause of infertility was attributed to the woman (n = 6) and the man (n = 4). The average duration of undergoing fertility treatment was 4.80 years (SD=1.58). Different assisted reproductive treatment methods were used like Ovulation Induction (OI), Intrauterine Insemination (IUI) and In Vitro Fertilization (IVF) (Table 1).

The mean age of ART providers who participated in the study was 46.30 years (range=39-57 years and SD=5.65) at the time of interview and the average years of experience were 19.90 years (range=12-29 years and SD=5.30). Data relating to the women's experiences of

assisted conception and ART providers' perception of their patients' experiences were analyzed. The main themes and sub-themes that emerged when analyzing the interviews of patients and providers were discussed below. Quotations are used to illustrate each theme and are identified with a participant number, followed by the group to which they belong, "P" (Patient) or "PR" (Provider).

Women's experiences of assisted conception

Salient concerns about treatment

This theme refers to the major concerns of women during the assisted reproductive treatment process.

Table 1: Demographic characteristics of women who had assisted conception.

Particip- ant no.	Age (yrs)	Education level	Occupation Status	Duration of marriage (years)	Duration of infertility (years)	Cause of infertility	Duration of treatment (years)	Type of ART currently received	History of treatment failure (N)
1	33	Master's Degree	Employed	8	6	Male factor	3	IUI (3 rd attempt)	IUI (2)
2	34	Master's Degree	Employed	10	7	Female factor	4.5	IVF (4 th attempt)	IVF (3)
3	35	Master's Degree	Employed	11	8	Female factor	6.5	IVF (3 rd attempt)	OI (2) IVF (2)
4	36	Bachelor's degree	Unemployed	9	7	Female Factor	6	IVF (3 rd attempt)	IVF (2)
5	33	Bachelor's degree	Unemployed	8	6	Male Factor	4	IUI (3 rd attempt)	IUI (2)
6	38	Master's Degree	Employed	12	10	Female factor	7.5	IVF (5 th attempt)	IVF (4)
7	34	Bachelor's degree	Employed	9	6	Female factor	4	IVF (2 nd attempt)	IVF (1)
8	32	Master's Degree	Unemployed	7	5	Male Factor	3	IUI (3 rd attempt)	IUI (2)
9	39	Master's Degree	Employed	11	9	Female factor	6	IVF (3 rd attempt)	IVF (2)
10	35	Bachelor's degree	Employed	10	7	Male Factor	3.5	IUI (4 th attempt)	IUI (3)

Four sub-themes were identified: need to become pregnant taking precedence over everything, doubt and uncertainty, the waiting period and the decision to go for a second attempt.

Need to become pregnant taking precedence over everything

Participants reported that they had difficulty to focus or make any major decisions on other important aspects of their life since the need to achieve pregnancy became a priority.

“It was hard for me to decide whether to take up the team lead position or not, though my colleagues kept on insisting that it will help for my career growth...After few days, I did refuse the opportunity since all I wanted is to get pregnant at least in this attempt...” (3P)

“I was in a state of mind where I barely could focus on anything in my life other than getting pregnant at least this time ...” (6P)

Doubt and uncertainty

At some point of the treatment, participants were doubtful whether the treatment will result in pregnancy and felt difficult to cope with the feelings of uncertainty.

“All these years I was trying to become pregnant, but couldn't...I was really doubtful whether going through this attempt will help me to achieve pregnancy...” (2P)

“What if after going through the entire procedure, still I end up not becoming pregnant...I don't want to feel that way, but I couldn't help it....” (9P)

The waiting period

The two weeks gap between the embryo transfer and pregnancy test has been perceived as the difficult phase of the treatment since they could hardly wait any further to know their test results.

“I would have repeated several times in my mind: you waited for 6 years to become pregnant and it's just few more days left...Then again I used to have thoughts what if the result turns out to be negative ... Each and every day till the day of the pregnancy test, was so painful for me” (1P)

Decision to go for a second attempt

Some participants felt emotionally exhausted after the failure of first attempt. As going through another attempt did not guarantee any success in becoming pregnant, most of them had difficulty in deciding about undergoing the second attempt.

“I felt shattered after the first attempt failed... Though I know the only way to get pregnant is trying for a next attempt, I wasn't sure whether I'll be able to go through the treatment all over again. One part of me was like what if it fails again, but other part of me was like what if I become pregnant. I couldn't decide; it was really tough. It took me months to go for the second attempt” (4P)

Social support

This theme refers to the role of support system in instilling hope during the treatment process. Two sub-themes were identified: informational support and emotional support.

Informational support

Most of the women felt that adequate information was provided by their health care professional was motivating and helpful for them to engage in the treatment process.

“When we met Dr. X, she explained each step of the procedure in such a detailed manner. Only after that I gained some amount of confidence to undergo the IUI treatment... She is truly so patient enough in answering all the queries we had.” (1P)

Emotional support

Participants perceived their spouse and mother as the major source of emotional support during the treatment process.

“After 2 attempts failed, I lost my hope completely to continue with the treatment. But because of my mom and my husband I underwent 3rd attempt. My mom used to talk to me hours together over the phone every day and made sure I was doing okay and my husband was quite positive and supportive to me throughout the treatment” (4P)

“My mom left her job just to be with me during the treatment. I don't know how I would have managed to continue with the treatment without her being on my side” (7P)

Concerns after assisted conception

This theme refers to the common concerns expressed by women during their pregnancy after successful treatment attempt. Three sub-themes were identified: fear of miscarriage, difficulty in forming an attachment and fear about baby's safety.

Fear of miscarriage

Most of the participants were constantly worried about miscarriage till the end of first trimester and were hyper vigilant to their bodily changes.

“I was so happy when the test result came positive... After we reached home, I wanted to call and tell so many people that I became pregnant, but then suddenly I became worried what if something happens to my baby?... Will my pregnancy last...? We didn't tell anyone about my pregnancy till the 4th month....” (8 P)

Difficulty in forming an attachment

Due to multiple failures in conceiving, some participants experienced difficulty in bonding with their unborn child.

“I've noticed few of my friends who used to constantly massage their tummy or talk to their baby while they are pregnant.... I have never felt or tried to connect with my baby like that ...” (2P)

Fear about baby's safety

Despite baby's growth and development being normal, some participants were more worried about the safety and health of their baby during the childbirth.

“Till now all my scans showed that my baby is healthy, but there are times, I get worried what if something happens to my baby during the delivery. I know I'm in good hands, my doctor will take good care of my delivery process...but until I see my baby, I don't think I'll be able to get out of this feeling” (5P)

ART providers' perception of their patients' experiences

Unsuccessful treatment attempt

This theme refers to the impact of failed ART attempt on women who underwent the treatment process. Two sub-themes were identified: disappointment and exhaustion and taking a temporary break.

Disappointment and exhaustion

Most of the providers reported that patients tend to feel exhausted and gets disappointed when the treatment doesn't result in pregnancy.

“Many patients have financial concerns... After investing their energy and money into the treatment process, they hope for a positive result; but when an attempted IUI or IVF method fails, they feel both physically and mentally drained....” (2 PR)

Taking a temporary break

Providers reported that after a failed treatment cycle, most patients tend to take a break from their treatment process and focus on other aspects of their lives as an attempt to overcome their distress.

“Almost all the patients prioritize the treatment process over the other aspects of their life..... Failure of an

attempted cycle and its emotional impact on them makes them to take a complete break for few months and reinvest their time and energy on other things....” (7 PR)

Resilience during the treatment

This theme refers to women's ability to recover from the previous failures in conception and being firm to put up with the physical and emotional demands of the next attempt. Three sub-themes were identified: inner strength, family support and taking control over the treatment process.

Inner strength

Providers reported that though women go through a renewed cycle of grief every time after the failure of an attempted cycle, their inner strength makes them not to give up and prepares them to try for multiple attempts to achieve pregnancy.

“After first unsuccessful treatment attempt, some patients give up and may not return back...Some patients are so firm, hold on to their hope and actively get involved in the treatment process; what makes difference between them is their will power & mental strength.....” (9P).

Family support

Most of the providers reported that support from family members especially from one's spouse enables women to overcome the distress and continue with the treatment process.

“Having a good support system has a huge influence on women being positive throughout the ART process... At times when women feel unsure to go for a next attempt, their partner's involvement and motivation helps them to carry on with the treatment” (4P)

Taking control over the treatment process

Providers reported that patients try to have a better understanding about the process and makes necessary life style modifications as an attempt to have some control over the treatment which in turn enables them to endure any discomfort that occurs during the course of treatment.

“Some patients actively engage themselves by trying to know more about the nature of the treatment and have a realistic expectation about their chances of success per cycle... They gain a better sense of control over the process....” (6P)

Apprehensions after assisted conception

This theme refers to the apprehensions of pregnant women after assisted conception. Two sub-themes were identified: apprehensive about effects of medications on fetus and anxiety about survival of the fetus.

Apprehensive about effects of medications on fetus

Providers reported that women who had been in treatment for a longer duration and got pregnant after multiple attempts tend to worry about the effects of medications on their unborn baby especially during their first trimester. Providers also reported that women who had assisted conception tend to seek lots of reassurance about the wellbeing of the fetus during their monthly checkups.

“After the positive pregnancy test, patients with history of multiple failures in conceiving tend to worry about the medications effects on their baby... Such concerns are more frequently reported during their first trimester....” (3PR)

“Even after communicating that their genetic testing and other reports are normal, patients always seek reassurance about their baby’s growth and development...” (5PR)

Anxiety about survival of the fetus

Most commonly reported is apprehension about the survival of their baby such as fear of miscarriage during their first trimester and fear of any harm to their baby during the delivery process. Fear of baby’s safety during delivery process is more common during their third trimester.

“Many patients with assisted conception generally worry about having miscarriage..... They tend to be extra cautious until they enter the 4th month. Though some seem to be relatively confident about the progress of their pregnancy and about the childbirth, many patients do worry about the mode of delivery and baby’s safety during the delivery especially after 32 weeks of gestation” (4P)

DISCUSSION

The purpose of this study was to explore women’s experiences and ART providers’ perceptions about assisted conception in the Indian context in order to plan early screening and intervention efforts for vulnerable women.

Themes emerged during the analysis revealed that during the treatment process, women experienced difficulty focusing or making any major decisions on other important aspects of their life as the need to achieve pregnancy became a priority. These findings are line with previous research in which infertility treatment was viewed as having a major influence over their current lives, affecting all other decisions.¹³ Most pregnant women perceived aspects of the ART treatment as emotionally difficult for them to handle and experienced strong feelings of uncertainty about the outcome of the treatment. Infertility treatment experiences in previous

studies have reported it to be an emotionally painful journey filled with uncertainty and longing.^{8,14}

Studies have shown that women perceive the physical demands of ART process such as daily injections, oocyte retrieval and embryo transfer, as emotionally painful and unbearable aspects of the treatment.^{4,5} But in the current study, the psychological demands of treatment process such as 14 days waiting period between the embryo transfer and pregnancy test and making a decision about undergoing the second attempt after the first unsuccessful attempt were perceived as emotionally exhausting, most difficult aspects of the treatment. Thus, the finding indicates the treatment journey as a mentally straining process.

Support systems such as family members and the treating team were perceived as playing a major role in enhancing women’s hope throughout the treatment process in this study. These findings are in line with previous research in which positive interaction between couples and support from mother led to increasing hope and motivation, and the support and understanding offered by hospital staff as a helpful factor during the treatment process.¹⁵⁻¹⁷

Women reported significant worries related to miscarriage and the safety and health of their babies during childbirth. These findings are in line with previous research in which women who had conceived after the ART process had perceived their pregnancies as being riskier and demanding were afraid of miscarriage due to which they ended up checking for bleeding or spotting and had a fear of being threatened by an unexpected event during pregnancy.^{14,18,19,20}

Due to multiple failures in conceiving, it was evident that women had difficulty in forming an attachment with their unborn baby during the pregnancy. Previous research has reported that women avoided strong antenatal attachment with the unborn baby because of fear of losing the baby.^{20,21} Though the current study findings are in line with few other previous studies that infertility problems affect attachment in pregnancies following ART. Studies have also reported divergent findings that the attachment to the fetus is similar to other pregnancies.^{22,23}

ART providers perspective

ART providers viewed failure in the attempted treatment method led to disappointment and exhaustion and patients took a temporary break from their treatment process to focus on other aspects of their lives. Women who undergo infertility treatment report disappointment when the treatment fails since so much energy, hope and money have been invested in the process.¹³ A Previous study has also shown that women temporarily step away from the cycle of attempting pregnancy, when they feel they had reached a limit where they had exhausted their emotional and practical resources or felt as though they had lost themselves in the treatment process.²⁴

The themes that emerged during the analysis revealed that women's inner strength, support from family, and their ability to take control over the treatment process helped them overcome the distress. It also enabled them to endure any discomfort which occurred during the treatment. The current study findings emphasize the significant role of women's resilience in treatment continuity. Women have reported that drawing on their support, enabled them to maintain the emotional strength and positivity needed to carry on with the subsequent attempts.²⁴

Findings suggested that women who had been in treatment for longer duration and got pregnant after multiple attempts were anxious about the effects of medications on their unborn baby, sought reassurance frequently about the wellbeing of the fetus, and were apprehensive about the survival of their baby. Based on their experience, providers felt that these apprehensions were expressed by women more commonly during their first and third trimester of pregnancy. Previous studies have shown pregnancy specific anxiety in IVF mothers, such as anxiety about the survival and normality of their unborn babies and damage to their babies during childbirth.^{10,25}

To the best of our knowledge, this study is the first to explore the women's experiences of assisted conception and ART providers' perception of their patients' experiences in the Indian setting. The findings of the study have led to the understanding that the previous negative experiences in conception affect the way women experience their pregnancy achieved through assisted conception. Findings also indicate that it is essential to pay attention to their psychological concerns during the fertility treatment and throughout the pregnancy period.

Despite these strengths, the limitations include a small sample size and not exploring the spouse's experience which may differ from that of the women's experiences. However, the small sample size is justified considering that this is an exploratory study of prospective longitudinal cohort study and the qualitative approach chosen for the same. Further, we achieved data saturation in this sample. The current findings have important implications for early screening and intervention for vulnerable women receiving ART.

CONCLUSION

Women perceived the psychological demands of the ART process as the most emotionally difficult aspect of their treatment journey. It is evident that a successful treatment outcome does not necessarily put an end to the psychological ramifications of infertility and its treatment on women. Thus, the current study finding implies the need for psychological screening and providing brief psychological interventions at different stages of treatment and during pregnancy to ameliorate the potential long-term effects of infertility and to enhance

women's emotional well-being. Further research should aim to also understand the spouse/partner's experience of fertility treatment and the challenges and concerns they experience in this journey.

ACKNOWLEDGEMENTS

The authors would like to thank all the pregnant women and the ART providers for their cooperation and willingness to participate in the study.

Funding: No funding sources

Conflict of interest: None declared

Ethical approval: The study was approved by the Institutional Ethics Committee

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Cite this article as: Saravanan V, Desai G, Satyanarayana VA. Two sides of a coin: women's experiences and providers' perceptions of assisted conception in urban India. *Int J Community Med Public Health* 2022;9:195-202.