

Experiences of Women Undergoing Treatment for Primary Infertility – A Qualitative Study (Preliminary Assessment)

Supriya Pottal Ray¹, Dr Nilima Bhore²

¹Ph.D. Scholar, Asst. Professor, Bharati Vidyapeeth University, College of Nursing, Pune

²Principal, Bharati Vidyapeeth University, College of Nursing, Sangli

Abstract: *Introduction:* This article describes the women's experience during the period of treatment for infertility. *Methodology:* A total of 15 samples were interviewed through a semi-structured interview guide, the responses to which were tape recorded. *Inclusion criteria:* samples who were diagnosed with primary infertility after one year of marriage and registered for treatment. *Responses:* were content analyzed by both the researchers along with the language expert. *The analysis yielded agreed upon 40 codes clustered into 5 themes: quality of life, burden of the disease, reaction, foundation/support, adoption.* *Results:* The findings discuss the psychological stress these women undergo during the course of treatment, they carry with the burden of the treatment in terms of time investment, financial resources, societal reaction which they have to confront daily. *The feeling to be heard for and to ventilate their thought processes needs to be taken into account. Treatment modality calls for the involvement of counselling sessions for the entire family of these women to help them cope up with course of treatment.* *Conclusion:* The study emphasizes that women undergoing treatment for infertility undergo stress in various spheres and need to ventilate their feelings, in long term this may have an effect on the treatment outcome.

Keywords: Infertility, treatment, women's experience

1. Introduction

Human life is a gift from almighty and the cycle continues because of reproduction. Pregnancy and childbirth are naturally and typically associated with happy feelings and emotions (Geller, 2004). The whole essence of marriage is seen in the view of producing children. The eventual conception of children is not viewed by most couples as a question of if, but when. (Peterson 2010.) The International Conference on Population and Development, ICPD (1994) has declared the reproductive and sexual health as the fundamental rights to individuals, couples and families all over the world. They declared that infertility is one of the basic issues of reproductive health care in their „Program of action“ which should be reached for all by the year of 2015. The WHO has estimated that 8–12% of couples around the world experience difficulty in conceiving a child. One in five (20%) couples will experience infertility – or the inability of a couple to conceive or carry to live birth a pregnancy after one year of regular sexual relations without the use of contraceptives. The present study aims to study the experiences of woman suffering from primary infertility such data are needed to complete the social science literature on this reproductive problem and to provide evidence-based data to guide the formulation of policies.

2. Objective of the Study

To explore experience of women undergoing treatment for primary infertility

3. Materials and method

Qualitative research approach with the method of inquiry being Hermeneutic Phenomenology. 15 women who were

seeking treatment for primary infertility were interviewed with a semi structured interview guide, the responses to which were tape recorded. The data were transcribed, coded, arranged and analyzed for categories and themes. **Inclusion criteria:** women diagnosed with primary infertility and are seeking treatment since one year. **Exclusion criteria:** women who have adopted child/children **Description of tool:** It consisted of two sections, Section I – demographic data, which included age, duration of marriage, duration of seeking treatment, education status, occupation and history of Consigamous marriage. Section II: A semi structured tool with questions regarding their experience during the treatment phase

4. Data Analysis

Written responses provided by participants were coded by a team of three researchers. Initially, each researcher coded the responses independently; then codes were compared and discrepancies resolved by consensus, leading to the construction of a codebook. In the second phase of “axial coding”, hypotheses about relationships among the original codes were formulated inductively (i.e., how codes were associated with each other and with the research question) leading finally to the identification of core themes and the construction of a model regarding the links between the themes.

5. Results

Essential Themes:

- 1) Quality of life:
- 2) burden of the disease
- 3) Reactions
- 4) Foundation /support

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5) Adoption

Thematic Codes/Statements

- Long treatment schedule
- Long waiting hours
- Distance
- Negative psychosocial consequences
- Self blame
- failure of treatment
- Commitment to treatment
- Finance
- Emotional
- Spiritual
- Social
- Spouse
- Family
- Mixed feelings

1) Quality of life

The quality of life surely gets affected in the clients as they always need to devote time for the treatment process. There are schedules to be maintained and instructions to be followed for specific days, which consumes a lot of time and attention. It disrupts the daily planning, one needs to manage work commitments, family unit, social life etc.

Long waiting hours Waiting hours are not only in the terms of waiting in a queue for your turn to seek the information about your progress, but it also means waiting for the results, speculating whether it's a win – win situation for you, or if you are left waiting for the next time

"You now changing doctors many times its difficult. It starts from all over again, its very stressful. We need to discuss everything all over again, I know it is for us, so that we benefit but it's difficult. to adhere to the treatment schedules, to be on time for treatment process, to follow the plans, along with this we need to wait so long"

"I am taking the treatment since 8 years, it's a long period. I have been to too many places and numerous doctors that, followed all what was said. It's been 10 years since I am married. There are many problems that I have to face, while undergoing the treatment process."

"I as taking treatment since 10 years, basically I am from Allahabad, but we have shifted here since 4 years" The doctors assured us that with some treatment modalities the defect will be treated and everything will be fine. Since I had to take further treatment and we had to be together, we took a decision to come here, and from then on we are seeking the treatment in Pune.

What I feel is if the doctors have assured us then the defect in me i.e. uterus will be rectified and I will be all fine, but I do not know how much time will be required more for this, even I have not asked them, that when will I be able to conceive."

Distance: Women reported that they choose to visit obstetricians who were preferably not in their vicinity but

eventually when fellow patients would give them references of other doctor's positive results they would divert to them. In any case they had to travel a distance. And this would also become a hindrance or a factor for seeking treatment

"After this we decided to go in for IUI, three IUI'S were done at Dr.---- clinic. Even after 3 IUI'S we did not get any results, it was not fruitful. All the hospital staff members supported us throughout; but somehow it did not work out in our favour.

Hospital is too far from our place; we have to go regularly for taking injections. Wait for the doctor's appointment, there are long queues, a lot of time is wasted." We have been to many places but did not get the results, these hospitals were also far from our place but we managed, the whole day is occupied"

"I have to juggle work and go for the treatment, it is difficult to travel so far every time, but I need to do it"

Negative Psychosocial consequences: *"The treatment process is physically and psychologically very painful. The procedure are to be followed strictly; there are days specified by the doctors to have coitus which is something very personal but needs to be followed; regular visits, follow ups, I have been to so many doctors, it takes a lot of time, the distance and time matters."*

"When I attend birthday parties, naming ceremonies, when I see other children, I do feel bad about myself, but then its temporary, this is what everyone feels."

"People have asked me after 2 years of marriage; they were eager to know when I'll give them good news, and they suggested that I should not be so relaxed and take treatment if necessary. They even said that I am enjoying my life after marriage; they questioned me whether I am planning about my family; according to them at this age at least I should have one child and then plan, if I want to..."

"In my opinion all these women like me, no one should remain like me; they all should conceive. I would like to share this, it was just recently, I mean few years back with every one consent, we were to adopt my husband's brother's child for which everyone has agreed; we filed in our papers in the court; and received the token and date for the custody of that child.

We all were waiting in the courtroom for my brother –in-law and his wife with the child; to my surprise no one turned up, I was devastated. My BP shot up and was admitted."

Yes I do feel bad or bad for myself that I do not have my own child; when I go for marriages or birthdays or naming ceremonies they keep on asking and I have no answer. I always think that I would have bought so many things for my child, but only if I had one. Though I do it for my brother-in-law's children, my sister's children but....."

Frustration

Women seeking treatment have thoughts which they fail to express resulting in mounting pressure on themselves, and

may even affect the treatment outcomes. They reported that they had uncertain outcome of the course of treatment, the question which always looms over is how long?

"Let's see what's my destiny .We have not yet thought of "adoption" because we have been assured by everyone that it will happen ;" you don't worry, it will happen", " it will work out for you". I have not yet thought of it."

As my age is also advancing I cannot say how long will continue with the treatment, and it all depends upon the doctors according to what they say we will proceed.

"Actually I do not even want to know how will it be done, how long should I wait, because with every test, if the results are not in our favour, I feel shattered my enthusiasm for further treatment schedules is dampened."

It's my destiny, if the one above has written. It is my destiny then let's see. Off course I keep thinking a lot that if nothing favours me what will I do, I had not eaten anything since 2 days; but I realized it was affecting my health and my treatment plan; I am fine now."

"I have to undergo immense mental stress, it's just yesterday that i was operated and i wanted my daughter to stay with me but she was sent to my sister (her biological mother). My treatment is going on since 7 years. In that this is the second time i have tested positive for TB, all the other reports were normal.

But now I am tired, my capacity is over to undergo the process all over again, I want to ask the doctors finally that whether it's Yes/No for my conception."

2) Burden of the Disease

Struggle: It sure is a struggle as described by the clients, they felt that for others it was a blessing to have children but in their case it was a struggle. Following instructions on matters which are very personal, feeling that they are differently treated, financial burden, to choose from various treatment options, societal reactions. All these events may them ponder over the situation they in.

They said after the reports everything is normal in both of us. We were given specific instructions regarding coitus we did follow that but were not successful. It's tough to follow instructions to have coitus on specific dates it goes on in my mind but at the end it results in failure. Stress is up to maximum, now after so many years of trying i am aware that i have crossed my age but during earlier days i used to feel bad for myself.

"I am always separated or else at least I feel like that, it's very different with people like us; who does not feel that they should have their own child?; when I go for functions, naming ceremonies I always think what is it that I have done," because of which I don't have my own child. As long as I can try, as long as I can, I will continue with my treatment till the time there will be any difference or it works in my favour I will continue."

"Till recently I have under treatment but now I have stopped. I even get that feeling " so much money I have spent still I was not successful have immense faith in god; I have been praying to him; now even after the treatment is stopped, I am sure I will conceive."

"Doctors have given me treatment options and laparoscopy was one of them, everything was explained, but I did not turn up for the scopy. No one blame me such but what happened is every time I thought of visiting the doctor I was entangle with family responsibilities and everyone has overseen this."

Failure of Treatment

Probably this fear of "failure of treatment" is from the very beginning in these clients as it is uncertainty which they have face at every step .Continuous monitoring of all the procedures, visiting the clinic whenever required takes a toll on them.

"I have stopped going to any doctor. I feel 20 years has been a long waiting period."

"now after so many years of trying I am aware that I have crossed my age but during earlier days I used to feel bad for myself."

"will continue with my own treatment I may not be able to tell you how long will i be able to continue my treatment. I may succeed somewhere that's why i am investing so much."

Commitment to Treatment

This is the one of the important factor expressed by the clients .They verbalized that it is difficult to adhere to the treatment schedules .some reported that distance created problems , some said that changes doctors which was followed by the beginning of the process all over again , some others who were working found it difficult to apply for leave regularly , few of them had family commitments , some had to complete job responsibilities .All these factors made their commitment to the treatment challenging.

"You know changing doctors many times its difficult .It starts from all over again, it's very stressful. We need to discuss everything all over again, I know it is for us, so that we benefit but it's difficult. To adhere to the treatment schedules, to be on time for treatment process, to follow the plans, It becomes difficult for us to practice act when instructed on a particular day by the doctors, it's even embarrassing at times"

"It's tough to follow instructions to have coitus on specific dates it goes on in my mind but at the end it results in failure"

"I have to take leave from work place for treatment if I miss one appointment its all over again"

I missed treatment plan due to examinations (school), then my brother in laws wedding even these are important or else we get to hear for this too"

"Our office timings are different we hardly get time to spend with each other, then there our treatment plans which take a back seat"

FINANCE: Yet another important aspect in their experience was finances. Many of them had shelled out whatever savings they had for the treatment; few of them were supported by their family members. Some of the clients were referred to places who charged reasonable. Some doctors did not charge their fees; some clients were working so they manage their expenses. It has been seen that even if the clients were burdened financially, the want of a child made them arrange and manage for their expenses.

"Financially we need to manage our expenses and save for our treatment we've invested much during these three years; since both our working we can afford it. IVF is expensive, but we will manage, we won't let that affect us. Our parents are more than willing to help us through."

They (In laws) support us financially they have been helping us since the past 6 years and 6 years is quite a long time We have invested a lot; whatever land, farm, and crop we had, we have sold out everything for this treatment; we have undergone a lot of treatment options."

"I was lucky that when sir referred to his clinic he did not charge me anything; he continued my treatment free of cost, having said that the medicine were very costly which I had to purchase on my own; and in that bargain I have even sold my gold jewellery. Since I am working I don't asked my parents or my husband for money for treatment schedule."

3) Reactions

Emotional: Though these women undergo a lot of stress, but they are emotionally strong, they adopt different coping strategies to overcome them, they need to ventilate their thoughts, channelize their thoughts so that they do not keep thinking about it.

"Not that anyone treated me that way, but it is a kind of stress that keeps on ringing in my mind."

I just try to walk away, read something, surf TV channels for these thoughts to go away. But it's difficult."

Whatever interview you are taking though it is for your study purpose but it has helped us to vent out our thoughts at least through this your blessings, we may bear the fruit in our womb.

In my opinion all these women like me, no one should remain like me; they all should conceive.

If I have to share my experience with you, I would frankly tell you that "I feel very bad about myself"; If I am struggling so long to conceive somewhere even I feel that I should gain the fruitful results; I feel bad for myself "self pity"; after all my struggle still, I mean why success is not knocking at my door.

Spiritual: All the clients gained solace from spiritual strength, they trusted in God completely, none of them ever blamed, rather they all believed that he would provide their needs in his time. They also said that they wished that no one faces what they are undergoing.

"I do trust God, hmmm, yes I do trust in God, whatever is in my destiny or whatever is planned by him for me."

"God is there he will help us out.. I have been to various spiritual places, I even fast and meditate."

"I trust God for this I have faith in him as well as faith on myself as I am trying hard for this. I find peace in chanting prayers, I do fast for my wishes"

"I feel that god should give at least one child to all the married couple; there should be no one like me in the entire universe. Now that the girls conceive out of....., its not acceptable in society nor spiritually. Still even they conceive why not me."

"I trust and trust in god alone, my reports and his reports all are normal so that's why I say it all depends on him. I fast Tuesdays and Fridays and this is the reason why I fast."

"I know my Lord is going to provide my needs, in his time he will give me"

"I pray to god I fast twice a week, I fast for 10 days during Navratra, in fact I am fasting today also; I have faith, I trust in god, if he feels I should have one he will definitely give. It is hope and faith that we will, I am 40, and I know that I have crossed my age but I have also heard of miracles."

4) Foundation / Support

Spouse/Family: Women said that they could this far only due to the support of their spouse and family members, contrary to the belief that it the family members who are more interested in having a heir to their legacy. Their spouse supported them unconditionally and would accompany them whenever they had a visit scheduled.

"My family members are very supportive towards me they have not questioned regarding my conception, and I am sure even in future they not let me feel so, they are very understanding."

My in laws are like my parents they have treated me more like a daughter rather than a daughter in law. Like how daughter would have stayed with her parents that's the way I am treated."

"My mother encouraged me for this and advised me to follow the instructions of doctors and get all the investigation done as told by them. She said "trust in God and if he's written it in your destiny you even conceive within a month, if not may be within 6 months we'll see what has to be done."

My in-laws also help us, but things are expensive; finally if we are not left with anything, then..... from where will get..

"I have no from my in-laws, parents; not even my husband; they have never forced me for the treatment."

"I and my husband its just the two of us staying here; so i ask god to keep us in good health and take care of our worries. My sister is come to stay with us since 2 months, as I have to get admitted every now and then, so she takes care, cooking etc.. My mother cannot come here as I have 2 more sisters to take care off."

My mother and mother in- law are very supportive; they keep taking turns to come and stay with us and they do support us.

"I was never pressurized for having a child, neither by my parents nor from my in-laws.

"My husband understands me well, even when my menstrual cycle was not regular he never blamed me for anything, never found fault in me."

"My bond with my husband is grown stronger, he says even if we don't have a child it is fine. He accompanies me to all my settings he manages work and takes leave"

5) Adoption

Adoption gained a mixed reaction from the women , some wanted to continue the treatment and were sure they will conceive , few others had already gone through the process were not successful .some of them were sure that they will never adopt.

"Adoption we have not thought of, we will continue to try for other treatment options"

"Though everything was done with everyone's consent and understanding following the government rule, we were left dishearten. That's why I have lost faith in adoption too."

"No I will never adopt I will continue with my own treatment i may not be able to tell you how long will I be able to continue my treatment. I may succeed somewhere that's why I am investing so much."

"I would want to see my own child grow, I want to experience that."

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