

EXPERIENCES OF WOMEN WITH INFERTILITY AND THEIR TREATMENT SEEKING PRACTICES: A QUALITATIVE STUDY

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ABSTRACT

BACKGROUND: Infertility imposes profound psychological and social impacts on those with the problem. The financial burden is also immense. The World Health Organization has labeled infertility as a disabling health problem. This study examines the experiences of women with infertility and their treatment seeking practices.

METHODS: We conducted a qualitative study with phenomenological approach. Data were collected using an in-depth interview and observations among eight purposively selected women who were being seen at Saint Paul Hospital Millennium Medical College (SPHMMC), Department of Gynecology and Obstetrics, infertility clinic from September 2015 to November 2015. The interviews were conducted by the investigator using a semi structured questionnaire discussion guide. The interviews were taped, then transcribed and translated into English. A bottom up approach was used to identify themes and sub themes.

RESULTS: Five themes and six sub themes were identified. Diverse negative emotional and psychological effects were reported. Both supportive and destructive changes were seen with relatives and friends. Treatments by in-laws and neighbors were largely negative. The women were constantly visiting different health facilities because of lack of definitive management. Religious activities were common.

CONCLUSION: Infertility deeply affects the life of infertile women with various emotional and social effects. The health system and health care providers should consider addressing managing the psychosocial aspects as well as providing advanced infertility treatment options. Further studies in exploring the life experiences are important preferably at community levels.

KEYWORDS: Infertility, experiences, treatment.

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INTRODUCTION

Infertility is defined by the World Health Organization as a failure to achieve a clinical pregnancy in childbearing age after 12 months or more of regular unprotected sexual intercourse¹. Globally the magnitude is estimated to be 15% of married couples. The incidence varies between and within countries². It appears to be a neglected problem in many developing countries. It is not a killing disease and so is not given a priority among other compelling health problems. However, the negative psychosocial consequences of this problem are quite profound. Perceptions in the community about the causes and treatment of infertility are by large deficient and wrong.

A study done in West Ethiopia showed that the perceptions as to the causes and treatment are mistaken³. Infertility is a neglected health problem in many developing nations. The concern of these countries is more on ways of controlling the fertility potential of individuals as the rise in population size is challenging their economic status and the limited resources they have. They are working actively on promoting and expanding the use of contraceptive methods. The total fertility rate (TFR) of these countries is large. Whatever the TFR is, it would mean nothing for the infertile couples, because they are badly in need of at least one child or one more child in their home. Ignoring this problem definitely makes reproductive health services incomplete as family planning by definition addresses not only those who are fertile but also the other side of failing to attain this capacity.

Infertile couples go to many different places and persons seeking treatment for their problem. Studies done in Africa show that couples prefer to go to sites for treatment according to the perception they have as a possible cause of the infertility. These places and persons include spiritualists (churches), traditional

healers, witchcrafts, and finally modern medicine (health facilities)^{4,5}.

Individuals are also forced to go for extra marital sex as a test for fertility and remedy for their infertility even if the issue is not openly spoken. This may further complicate the problem by acquisition of STI's. Women are also known to be abused in seeking treatment from traditional healers and witchcrafts including forced sexual intercourse as part of the treatment, and a price to be paid to keep their problems secret^{4,5,6}.

Understanding the health seeking behavior of couples with infertility will lead to identification of the perception of communities as to the causes of this problem and help in addressing the gaps prevailing in the community. It also helps to disseminate health information on the timely evaluation and treatment of individuals. Knowing the impacts of infertility will also help a lot in designing strategies to mitigate the negative consequences and help focus on the prevention of infertility as well as its impacts.

As to the knowledge of the investigator, there are no studies done in our country on the experiences of women with infertility and their health seeking behavior. This study tries to explore these issues among women coming with this problem to a teaching hospital in the capital Addis Ababa.

METHODOLOGY

Study setting: The study was conducted at SPHMMC, a teaching hospital in the capital Addis Ababa from September 2015 to November 2015. The department of Gynecology and Obstetrics has a specialized infertility clinic which is functional two days each week.

Study design: This was a qualitative study with a phenomenological study design using an in-depth interview with women diagnosed with infertility. The study assessed the lived experiences in their life due to this problem.

Study population: The study population comprised of individuals coming to the specialty clinic of infertility in the department of Gynecology and Obstetrics. Women coming to the infertility clinic for infertility treatment were the study subjects.

Sample size and Sampling: Sampling was determined by the level of saturation during data collection. Sampling was purposive. The duration of infertility was taken as a reason for the purposive sampling. The duration of the problem in women with infertility was assessed by the investigator. Women with longer duration of the problem on presentation were given the chance to participate. Inclusion criteria included fulfilling the operational definition for infertility for this study, willingness to participate in the study, and being able to give consent.

Data collection: Information was collected using an in-depth interview guide. The interview guide was developed based on the relevant areas necessary to address the study objective. The guide was used to lead the discussion. The issues addressed included when the woman and her partner came to know their inability to conceive, about the causes she believes/knows for this problem, what she feels and did about the problem, and what was done for her. Changes she had in her relationships with her partner, her own and her partner's relatives, friends and in the community, were also addressed. The information also included the situation under which she came to know and decide coming to this hospital and her expectations from the hospital.

Open ended questions were used. Data were collected as an exit interview. This was done by the investigator in a separate office where auditory and visual privacies were attained. The timing of data collection was determined on the convenience of each study participant. Each interview took between 35 to 55 minutes. Data was collected after getting informed written consent from the study participants. Seven

were interviewed in the hospital and one outside the hospital at her convenience.

The interviews were recorded by an audio recorder. Some responses and expressions were also noted and recorded manually in a note book. No one had an access to the audio taped interview except the investigator and once the interviews were transcribed, they were deleted. The transcriptions were given codes known only by the investigator. Data collection was continued till saturation of information was reached. **Data analysis:** Data analysis was done concurrently with data collection. The interviews were transcribed into text by the investigator shortly after the interview and then translated to English by a translator. They were then analyzed by the principal investigator using thematic analysis by a bottom up method. The translations were read and reread by the investigator repeatedly and points identified in each interview. This was done by condensing the interviews into shorter phrases capturing the lived experiences of the participant. Categories were then identified. Once this was done, related categories were used to identify major themes and sub themes. This was done manually.

Ethical considerations: Participants were provided with an information sheet explaining the summary of the study. The participants read it and further explanations were given for their questions. The participants gave a written consent to participate in the study. Their right not to participate in the study or withdraw from the study including not responding to some of the questions if they participate were fully explained and respected. There was no payment for participating in the study.

Participants' names were not used during data analysis, and each participant was assigned a code which is known only by the investigator. Data were kept confidential and no one had an access except the principal investigator.

Ethical clearance was obtained from the IRB of Addis Continental Institute of Public Health/University of Gondar, and the IRB of SPHMMC.

OPERATIONAL DEFINITIONS

Infertility: the inability to conceive after twelve months or more of unprotected sexual intercourse. Unprotected sexual intercourse implies the use of no contraception.

Experience: events encountered in personal and social life in association with infertility.

Treatment: any action/measure taken to get a solution for the perceived problem of infertility.

RESULTS

Demographic description

Eight women were interviewed in this study. Their age was between 25 and 37 years. Seven of them were from Addis Ababa while one was from outside of Addis Ababa. One is divorced and the others are married. Two of the participants were Muslims while the rest were Christians. One of them was a graduate from a college, and the other seven learnt till grade 9-12. Four of them were housewives, one was employed in a private firm and the other three had their own small-scale businesses – shops.

Six had primary infertility while two women had secondary infertility.

The results are compiled under 5 major themes and six sub themes (Figure 1).

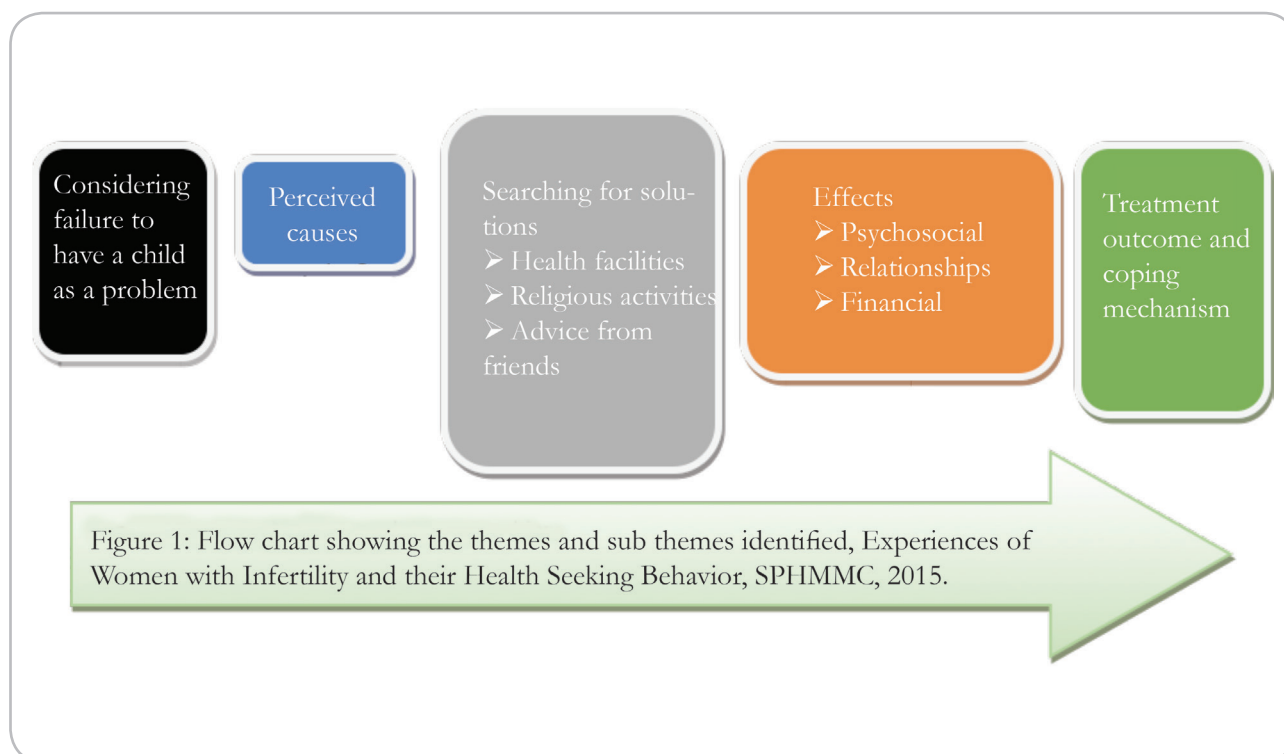


Figure 1: Flow chart showing the themes and sub themes identified, Experiences of Women with Infertility and their Health Seeking Behavior, SPHMMC, 2015.

1. Considering failure to have a baby as a problem

The participants responded that failure to have a child after marriage should be considered as a problem and some help should be sought within a period of less than 2 years. They have duration of failure to have a child ranging from 2 ½ years to 10 years. All started to go for treatment after one year but not beyond the second year. All, except one who is currently pregnant, are still seeking a solution since then, one of them for 10 years and another two for more than 5 years.

Regarding this issue P1 and P3 replied “it is preferable to go to health facilities at least after one year.”

P7 and P8 said it should not be more than 2 years.

2. Causes of failure to have a child

Some of the participants mentioned age as an important factor as a cause of this problem explaining it as determinant factor if they do not get a solution to their problem.

P1 reported “as age increases, the problem also advances..... being late....age is determinant. I feel I may have passed my age of getting a child while working”

P2 stated that “the age [reproductive] of a woman is limited..... I heard a treatment called IVF. I wanted to make use of it with my age”

Anxiety as a possible cause of failure to have a child was mentioned by the participants.

P1 said “ I had some stresses, for I was thinking on some issues..... I had anxiety..... I feel anxiety itself has some association with the womb i.e. by myself. I was very eager to have a baby after marriage.... when this did not happen after months, I started to be anxious....also in my work.....private.... I was being angry by it....and I thought that was the case.”

P7 also said “it can be an internal pressure, there are effects arising from anxiety... anxiety can be

the cause of this problem..... you have many problems inside.”

The widely held belief in the participants is the use of contraceptives as a cause for this problem.

P2 replied “I assume that it is the medicine [injectable contraceptive] that caused my problem.... Also I heard that it makes a woman infertile. I also think - has this happened to me? But many doctors told me that it does not make so..... I do not know.”

P3 said “when contraceptives are taken for long period pregnancy does not happen, it is not created..... the tablet, those that are buried..... they bring problems like this.”

P4 remarked “taking injections before giving birth causes this problem.”

Possible problems in the male were mentioned as causes by two of the participants.

P3 described that an STD a woman gets during pregnancy can be transmitted during intrauterine life resulting in infertility in the growing baby - as her mother had an STD while she was pregnant of her.

She described “ my mother told me that ‘after conceiving you I had an STD’..... she was not treated by then. She gave birth to three... I have two after me..... what did she say..... ‘that STD can be the reason for your problem’that is always my tension”

Abortion, single or repetitive, STD’s, and pelvic infections were described by many as possible causes.

P5 said “The causes....as I understood, STD’s, infections of the womb. If an STD is not treated early...”.

Medications or treatments taken for a long time for any medical reason are also described as a cause.

P7 described “medicines taken for a long time.... Ah.....me for example.....what I think hurt me is.....do you know? I have taken anti-TB treatment for a long time.....and I think that is the reason..... I took the medication for more than one year”

None of them believed it can be a hereditary problem or due to God's wrath.

P7 said "I do not think it is hereditary, you know why? As I told you this [getting children] is a gift from God. God does not create a woman sterile.....people may think it is hereditary. I do not believe that."

P5 reported "my in-laws say such a thing [from God's wrath] but this does not happen because of God's wrath. God created me for He loves me..... heredity...you know? I have many relatives who have given birth to twins....they are three..... I have such relatives. What brings such a problem to me among them? I do not think so."

3. Searching for solutions

Health facilities

All the participants have gone to at least 3 or 4 different health facilities. Two have visited at least 10 facilities. The types of facilities include health centers, family planning clinics, private maternity centers, private clinics, private hospitals, and public hospitals. Some visited these through referrals and the majority by their own will and efforts to get solutions.

P7 explained "every place in Addis Ababa, known or said to be good with infertility services, I have been there."

Religious activities

Some of the Christians said that they pray a lot and frequently and go to churches for this purpose. They take "tsebel" to their house with a container and drink it for many days. There are special ceremonies and prayers in the Orthodox Christian church held for people with difficulty of getting a child, and some attend these events. Travelling to different churches outside of Addis Ababa and staying there for 1-2 days was also reported.

Muslims also tell other people and their friends to pray for them.

P7 stated "as I told you, I am an Orthodox Christian.....and I go to 'tsebel's'....eeh.....there

are things that the church orders for people who have no children.....there is a prayer.... And I participate in those prayers.....to your surprise, I came to you after such a ceremony [this morning]"

Advices from friends

Women talk about the problem with their friends and advices from friends include trying to be happy as much as possible because it is during this time that the woman's egg is going to be prepared, lying flat on the back after coitus, avoiding douching and bathes after coitus.

P1 said "And when I was asking advices from people.....they told me to try to be happy as much as possible. Have sex by that time and if you do that you will get pregnantand I tried that, it was not successful. Ah....and how I should make sex..... lying flat on the back after coitus, avoiding douching and bathes after coitus.....all these were when I was discussing with my friends... I tried all these, but....."

There is no reported purposeful visit to traditional healers. P3 had an unintentional visit to a traditional healer but abandoned it immediately, for she did not have the belief in what they were questioning her.

4. Distress due to the problem

Psychosocial consequences

These were quite diverse.

All the women were crying when expressing what they felt about the problem, and were speaking in slow and soft voices. I had to give them time to cry and get settled, always with some kind words. These feelings were shared almost by all women whether they had support from their partners, relatives and friends or not.

Social effects included:

- disrespect by husband and relatives
- divorce
- neglect by in-laws
- robbery
- lack of love

Anxiety was experienced by all participants.

They also have a feeling of jealousy when they see children of their friends.

P1 also said “I do not have a bad feeling for they have children, but....you know....if I had my own also....it is seeing yourself, or else what is the most interesting thing in marriage? It is having a child...I lost the meaning of getting married. I mean it! Why did I have it if I am not able to give birth?”

Additionally, many other feelings were described by the participants including sense of inferiority and fear of divorce, being easily annoyed with emotional lability, depression, lack of sleep and appetite, feeling of being alone, avoiding meeting people, bad feeling of home, shopping without purpose, and low self-esteem.

Relationships: husband and relatives

All the women discussed the problem with their partners. In half the husbands were supportive while in the others they had a negative effect.

In the majority of women there are ill feelings from the relatives of their husbands, for there is no child in the marriage. These are expressed in two forms: directly to the woman and indirectly thorough her partner.

P8 stated “relatives of my husband say.....you [the husband] married an old woman...that is why she does not give birth.... But I am the 3rd for my parents and my elder sister gave birth recently.” She continued “the respect he has for me before and now are not the same. He becomes angry at me easily.... he is not happy when he gives me money for household expense; of course, I have my own income. He is not happy in anything.”

P6 also said “he always tells me that his relatives want to see a child. I get disturbed. They do not directly come and talk to me about the issue.”

The women are aware of these facts from what they observe, the way their in-laws look at them and changes in talks. The major part of the dismay is explicitly, fully and clearly told to the husband and he is the one to tell the woman what has been said to him about her and

the marriage. In some this goes to the extent of divorce and marrying another woman. This has created a profound emotional disturbance in the women.

In half of the women the relationships with relatives and their husbands were good and supportive.

P1 said “he makes me feel strong. He says ...it will happen, if not, it is possible to live without children. The main issue is the love between us..... He supports me a lot. It is me who gets annoyed, he is good. He was treating me well.” She added “people ask.....my and his relatives advise us to go to a medical care.”

P7 commented “his relatives were asking why we did not get a child. To your surprise, he has a very nice mother. It is his mother who is playing a major role to keep our marriage from divorce [she was crying]. Nobody from the relatives has treated me badly.”

Relationships: friends, working areas and neighbors

Effects from neighbors, friends, working area and the relatives of the women are more direct. These express their good or bad feelings directly to the woman.

P4 stated “I have left my job.... because at the work area they ask me why I am not having a child and so on.... I hated it and left the job. I was working in a private organization.....my neighbors... they insult me, directly and indirectly.”

Financial burden

There were some unpleasant feelings on household expenditures.

P5 explained “initially he was giving me money, but now....to speak the truth, I do not remember the time he gave me money.....”

P8 said “he is not happy when he gives me money, but I also have my own income.”

The financial expense for medical care has been immense.

P5 described “you go somewhere, you sell your gold, you sell something, you borrow from people....you ask, you go...go...there is nothing.”

5. Treatment outcomes and Coping mechanisms

One respondent is currently pregnant from treatment and said she is relieved a lot from the feelings of this problem. She was 3 months pregnant by the time of the interview. She was treated by a medication with ultrasound follow up and timed intercourse.

She said “what gives you happiness after marriage except having a baby? Oh, oh. God has given me what I loved, what I wanted.”

The rest are still going to health facilities for different reasons.

Some know the treatment is not available for them here in Ethiopia.

P8 said “they told me the treatment is by[IVF] or surgery, but also said the tube can be closed again after surgery. I tried a lot, tried and tried, no change.”

P5 said “your hospital, if you were able to go to the possible last alternative to help us-those to whom child bearing has been a problem.”

Because of lack of successes in getting a child, despite a lot of efforts in investigation and treatment, women have different explanations and suggestions in accepting the problem substantiating that it is totally out of their control.

P5 said “God has His own reason not to give me a baby.”

P7 stated “God gives babies. I am sure that I will have one in the future. May be the time is not now.”

Three women said “Let my husband marry another woman and have a child, or let him bring a child from another woman and I will take care of the baby.”

Interestingly no one talked about adoption.

DISCUSSION

Women have a good judgment of timing in considering failure to get a child as a health problem after an active trial. They responded a woman should be seen in not more than 2 years. This appears to be a very good health behavior so that problems can be identified early and early treatment options can be entertained.

The outcome of infertility treatment is greatly affected by the duration of the problem in addition to other factors. The problem seen is largely the lack of appropriate treatment which has resulted in repetitive and desperate measure of unnecessary visits even if the treatments for this problem are not widely available in the country. Some of the women were told about the unavailability of the treatment in the country, and are still going for help despite this information.

This shows the importance of improved and advanced treatment options to address the problem in the majority of women.

The emotional feelings identified in this study are profound and diverse. The psychological consequences in this study include anxiety, crying alone at home, lack of sleep, low self-esteem, depression, emotional lability, lack of sleep, loss of appetite, becoming easily upset, feeling of being alone, getting annoyed, and fear of divorce. These have also been described in other studies 4, 5, 7, 8.

Social effects include disrespect by husband and relatives, divorce, neglect by in-laws, being robbed of their property. These are similar in a study done at Oyo state in Nigeria⁴. Some supportive roles were offered by the relatives of the woman families especially from mothers and sisters. Some friends as well had such roles.

Health care providers should address these emotional disturbance s and problems in the evaluation of such women. Consultations with a psychologist or

psychiatrist should be considered to improve the quality of life of such women.

A huge gap is seen in the knowledge of the women as to the possible causes of infertility. Most of the mentioned reasons were not right or they do not have a direct association with the problem, except for STI's. The lack of appropriate knowledge will have its own impact in the prevention and treatment activities associated with the problem. Efforts need to be done to make people aware of the possible causes, so that preventive health behaviors can be practiced.

The above points demonstrate that infertility work up and treatment should include information, health education and counseling.

In contrast to other studies^{3, 5, 9, 10} infertility was not attributed to curse, an act of witchcraft or mystical power or as a punishment by God in this study. This may be because the respondents themselves were the victims of the problem and do not want to accept these as possible causes. It may as well be because of their relatively good status of education.

All women have been to many health facilities seeking for solutions. Some had attended religious ceremonies. There was no intentional visit to traditional healers. This is in contrast to other studies^{4, 5}. This can be due to 'social desirability' or 'courtesy' bias as the issue raised is quite sensitive, and the investigator being the provider of the health care service for these women.

Interestingly none of them mentioned adoption as an alternative, probably that may degrade their womanhood in frankly revealing their inability to reproduce through the biological means. It has been shown by many studies that adoption is not accepted as a solution for infertility in many African communities^{4, 5, 6, 10}.

Some of the women have explained their willingness for their husband to have a child from another woman,

even a divorce for that and also to take care of the baby if he can bring one from outside with the marriage in place. This is not mentioned in other studies.

CONCLUSIONS

The knowledge as to the possible causes of infertility has a wide gap. Measures to improve the awareness of the community on the possible causes of infertility are important.

The psychological and social consequences of infertility are diverse and profound. Women are going to many health facilities for lack of definitive treatment. Advanced methods of treating infertility should be made available if the problems associated with infertility are to be alleviated.

Health providers should address the emotional and psychological effects of infertility in the care they provide to these women. Further studies, preferably at the community level, are important to fully understand the wider consequences of the problem in society.

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