



LIVED EXPERIENCE OF WOMEN WITH INFERTILITY

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ABSTRACT

Introduction: Infertility is a medical condition which affects all dimension of life, including sexual, marital, social and personal aspects. It can cause painful emotional experience throughout a women's life. The social consequences of infertility include exclusion, verbal and physical abuse, divorce and stigma. Couples facing reproductive challenges often experience high level of psychological stress. **Methods:** Descriptive phenomenological research design was used to explore the lived experience of women with infertility who were currently seeking treatment. Nine women with infertility were selected through non probability purposive sampling. In-depth face to face interviews were conducted, audio recorded on a voice recorder, transcribed, and translated into English. Field note were maintained to capture additional relevant information. The data was analyzed manually. Audio records were listened to multiple times, and verbatim transcription were made. The data were then thematically analyzed using Colaizzi's (1978) methods. From the data individual meaning was coded and once the pattern began to emerged, codes were grouped and consolidate into common themes. **Result:** Two main themes emerged **Experience of infertility** and **Consequences of infertility**. The sub-theme included social stigma, the therapeutic journey, social consequences and emotional consequences. The studies found that infertility has a profound psychological and social impact on women's life. It effects couples through social exclusion, family dispute, verbal abuse and the risk of marital disharmony. Psychological impacts consisted self-imposed isolation, low self-esteem, hopelessness and feeling of inadequacy, often leading to emotional breakdown. To cope with infertility, most participants sought help from traditional healers and used homeopathic remedies alongside allopathic treatments. **Conclusion:** The study highlights the emotional pain of women with infertility- feeling undervalued, facing negative stereotypes, and experiencing pressure to bear children. It underscores the importance of healthcare providers understanding infertility from a more empathetic perspective.

KEYWORDS: Infertility, experience, Phenomenology, woman.

INTRODUCTION

Infertility is defined by the World Health Organization (WHO) as "a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse." Infertility is a reproductive health issue, and its prevalence is increasing particularly in developing countries. While one in six women in developed countries remain infertile, in developing countries one in every four women experience infertility.^[1] In Nepal, approximately 13-15% of married couples struggle with infertility, with at least six new cases reported daily at a leading infertility center.^[2]

Although infertility affects both men and women, previous researchers have suggested that women are more adversely impacted than men.^[3] Women who have never had children or are currently childless are more likely to experience divorced or separation. Childlessness and infertility can significantly affects a woman's ability to maintain a stable marital relationship.^[4]

Women with infertility tend to experience more stress than men facig the same condition. Infertility can lead to chronic stress and eventually a variety of psychological difficulties. More recently, published evidence suggests

that stress itself may influence the outcome of infertility treatment.^[5]

In Nepal, there is a limited number of studies done on infertility. The most common terms used for infertile women in Nepal are:= “Bahila”, “Banjhi” and “Aputri” and for infertile men:= “Aputro” and “Namarda”. These terminologies are based on the perception of infertility shaped by socio-cultural and traditional context of Nepal.^[6]

In the Nepalese community, children are valued as a form of socio-economic security and parenthood is considered culturally essential. Qualities of couple’s marital life are judged on the basis of their parenthood.^[6]

Infertility-based discrimination and prejudice have psychological impacts on women. Infertility stigma may contribute to people hiding information about their diagnosis from friends or family, and delaying or avoiding treatments. Despite the facts that infertility is relatively common, there is no adequate information regarding the problem faced by infertile women.⁷

Only a few studies in Nepal have explored the experience of women with infertility. The existing research has mostly focused on causes and treatment of infertility, with limited attention given to the social and emotional aspects of the condition. Due to the limited number of qualitative studies in this field, the present study was conducted to explore the lived experiences of women with infertility.

OBJECTIVES OF THE STUDY

To explore the lived experience of women diagnosed with infertility who are currently undergoing treatment.

METHODS

Research design: A descriptive phenomenological research design research design was used for this study.

Setting: The research was conducted within the indoor unit of Paropakar Maternity and Women’s Hospital, Thapathali. Those units were infertility out patient department and family planning clinic. (family planning clinics are only used for interview).

Population: Woman diagnosed as infertility was enrolled in the study.

Sample size: Participants were selected until the data saturation. Data saturation was achieved after interviewing 9 participants, There is one guiding principle in selecting the sample for a phenomenological study: all participants must have experienced the phenomenon and must be able to articulate what it is like to have lived that experience.^[8] Creswell (1998) recommends 5 – 25 while Morse (1994) minimum of six. The sample size of 8-12 participants is considered adequate.^[9]

Sampling technique: A non probability purposive sampling technique was used.

Inclusion criteria: Women who were diagnosed as infertility were enrolled in the study. Those participants who were easily accessible i.e., residing within Kathmandu Valley and who were able to verbally communicate well in Nepali language.

Data collection periods: Data were collected from 2077/09/05 to 2077/10/03.

Instruments: Data was collected using an in-depth interview guideline question which was developed based on literature review and after consulting subject experts. A tape recorder was used to record the interview.

Part I: Question related to socio-demographic information.

Part II: Interview guideline related to lived experience of women with infertility.

Ethical consideration: Approval was taken from IRB NAMS and Paropakar Maternity and Women’s Hospital.

Data analysis: Data analysis was started on the same day of interview. Code numbers was assigned to each participant and recorded data was listened to repeatedly until the actual meaning could be drawn from it.

Trustworthiness

Based on Lincoln and Guba (1985) criteria, trustworthiness was determined using five criteria such as credibility, transferability, dependability, confirmability, reflexivity.^[10] To ensure credibility, the researcher conducted in-depth interviews, transcribed data, and consulted experts. Transferability was supported by providing detailed descriptions of the participants' experiences. Confirmability was maintained by recording interviews and creating an audio trail. Dependability was achieved by continuing data collection until no new information emerged. Finally, reflexivity was maintained through regular self reflection and memo writing throughout the research process.

After transcription data were analyzed thematically using the steps outlined in Colaizzi’s (1978) method

- Reading the transcripts to develop an understanding of what the participants meant.
- Extracting significant phrases and formulating meaning for each significant phrase and statement.
- Organizing the meaning from each interview into themes.
- Validating themes by comparing them with the participants’ original descriptions and incorporating them into the original text.
- Developing an exhaustive description of the themes.

During data analysis, individual meaning was coded and when pattern began to emerge, these were combined and consolidated into common themes.

Cluster of Themes: The study's results revealed significant statements, which were categorized by

meaning. Similar findings from the in-depth interviews were grouped into two main themes:

Perceived experience of infertility and Perceived consequences of infertility

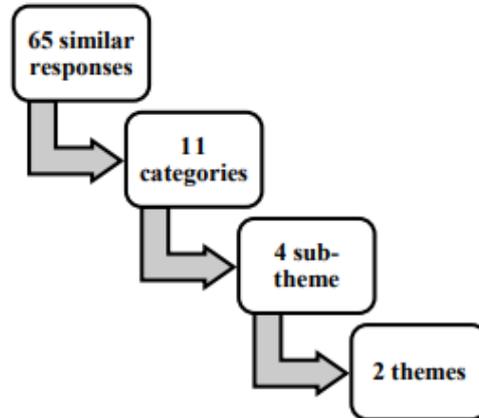


Figure 1: Generating response, categories, sub theme and themes.

RESULTS

The lived experience of the women with infertility are presented under two major emergent themes. Integrating codes and categories from all transcript produced a

master table themes with their sub theme and categories. It contains 2 themes with four subtheme and 11 categories.

Table 1: Emergent Themes with their Sub-themes and Categories.

| S No. | Categories | Sub themes | Emergent Themes |
|-------|--------------------------------|---------------------------------------|-----------------------------|
| 1. | Perceived discrimination | Social Stigma | Experience of infertility |
| 2. | Disclosure | | |
| 3. | Cause of Infertility | | |
| 4. | Economic hardship | Experience of the therapeutic process | |
| 5. | Alternative treatment approach | | |
| 6. | Treatment struggle | | |
| 7. | Social isolation | Social consequences | Consequences of infertility |
| 8. | Family relationship | | |
| 9. | Marital relationship | | |
| 11. | Self-perceived abuse | Emotional/ Psychological consequences | |
| 12. | Poor mental health | | |

Interpretation of the in depth interview

Each theme is described by their sub theme and categories, which are supported by quotation from the interview for the purpose of catching multidimensional aspect of the experience of the study participants. Verbatim quotes from data are italicized.

Theme 1 Experience of infertility

This emergent theme is explained under the sub theme **stigma** and **treatment journey**. The sub theme stigma has further three categories **discrimination**, **cause of infertility** and **concealment**. Similarly, the sub theme treatment journey has further three categories **burden**, **alternative approach** and **treatment struggle**.

Category: Perceived Discrimination

In this study, participants expressed range of views regarding discrimination they faced. One participant, Mina 34, said *“When my friends get pregnant, they*

gradually stop talking to me. Most of my close friends also do that to me. I can feel it, maybe they are scared to talk to me. Even my close friend did this to me. There is belief in our area that when you touch infertile women during your pregnancy then you may suffer from miscarriage or abortion”

In the same way Juna 29, said people consider her as heart less and Sita 33 has similar experience as Sita 33 says *“When I could not care for kids my friends once said byayeko gai lai po thaha huncha nabyayeko lai k thaha?”* People have belief that, only those who have children truly understand how to care, and it is often parenthood that brings greater sensitivity and maturity.

Almost all of the participants reported that they face some kind of discrimination from family, relatives, neighbors and from friends.

Category: Disclosure

Women expressed that they are not comfortable sharing their infertility related problems to people around them because of the negative attitude of the people. They rarely ventilate their suffering to their friends fearing gossip about them which resulted in concealment.

A participants expressed *“No, I haven’t told anyone. I fear I might be humiliated if I tell them. I haven’t talked about the treatment with my in-laws as well.” Sita 33.*

Similarly, Ganga 41 and Juna expressed similar views as Juna 29 responded *“No, I did not tell anybody about it, and if someone asked, I would not share. People just need reason to humiliate you. You know. They gossip a lot if we tell them about our problem.”*

Majority of the participants explain they don’t want to share with family and friend about their infertility because it makes them feel inadequate and lagging behind.

Category: Belief regarding cause of infertility

Two women blamed the evil power and three of them mentioned that it’s their fate being infertile. Two women mentioned that they had no knowledge about the exact cause of infertility even though there is a medical problem such as hypothyroidism, hormonal cause and which is confirmed by checkup.

Sita 33 has a different perception about the cause of infertility. She says *“I usually get bad dreams, lots of women to my dream and demand my child they compelled me to remove my patuki (a local cloth use for support of abdomen), so i am 100 percent sure that someone has cursed me with evil spirit (Malai arule Bigar gareko le Yesto bhayeko ho), That’s why I visit many janne (local healer) to remove the bad eye but the evil spirit is so strong that that cannot remove.”*

Likewise, Anu 38 said *“Things were fine for the first one to two years of marriage but one day my mother-in-law give me pustakari (a local sweet) to ea. That day, i felt slight discomfort, and I believe that was the day she possessed me with a bad spirit. She is a witch, and she sacrifices my children to pay for her demonic education.”*

Sub theme: Experience of therapeutic process**Category: Economic Hardship**

Treatment costs are usually covered of pockets. Multiple hospital visits and several treatment including Assisted Reproductive Techniques are the main factor for expenses. Most women stated that it is impossible to continue treatment because of the frequency of catastrophic expenditure. Lengthy treatment is emotionally, physically and financially enervating. This reflects participant’s struggle to manage finance and economic burden.

Ganga 41 said *“I went to X hospital for infertility treatment and tried there for 2 years. After that we came here in the hope that something will happen. I visited lots of hospitals like some private ones and now I came here. I am spending lot of time and money for this (Long sigh of despair). It’s hard to earn enough to bear the cost of treatment as I spent all my earning for treatment.”*

Category: Alternative treatment approach

All of the participants agreed that they sought traditional methods of treatment for their infertility. Most of them sacrifice goats, metal plates and visit local traditional healers like dhama jhakri, mata ji in the hope of getting pregnant. Worshipping to God and following certain ritual were very common. While seeking treatment most of them spent huge amount of money on traditional healers.

Mina 34 said *“I went to see lots of traditional healers. In the village, they take little money but in Kathmandu, Dhama Jhakri takes a lot of money. I paid Rs 23,000 to the Jhakri of Kapan. When I asked him to reduce the money, he said I should come with a big heart {Hatti ko Mann}. Lady from Bhaktapur took Rs. 1 lakh. but no result.”* Women shared that they spent significant amounts of money on traditional helers and religious offering in hopes of becoming pregnant.

Anu 38 said. *I made so many promises (bhakal) to offer something to Santaneshwor temple, Pathibhara temple.*

Category: Treatment Struggle

Infertility treatment can be emotionally draining and physically uncomfortable, involving lengthy processes that lead to ongoing hopes, fears, and increased suffering for many women.

Ganga explains- *“I am receiving treatment. We are trying continuously. I underwent surgery last year (Bhadra) to remove lumps (Mass) inside my uterus. I have tried artificial reproductive technologies (IUI) 3 times prior to surgery and 3 times after that. I am spending a lot of time and money on this. Since I work in a NGO office in Dhading it is very hard for me to manage leave.*

As Anu further illustrates *“What to say!! I have been visiting hospitals for so long and underwent IUI three times. When I came here for the second time for IUI I thought I was conceived. We were really dazed. But after three months miscarriage happened and admitted in the same hospital to be curated. At that time, I felt to commit suicide from third floor of this hospital. I really got afraid when I saw tiny people from the 3rd floor. (She cried again covering her face for about seven minutes). Doctors are planning for another cycle of IUI but I am really hopeless.”*

Theme 2 Consequences of infertility**Subtheme: Social consequences, Categories: Family relationship**

Infertility is a significant issue for women and their families. Many women reported feeling unsupported by their families, facing criticism from their husband's relatives due to their childless status, and experiencing strained relationships, particularly with in-laws.

Reena 23 illustrates that, *“My in-laws told my parents that I might not be having a uterus. There is a rumor that I lack female organs and my family is suspicious about that. Then we had lots of fights in our home. Then my husband decided to leave the village to stay in Kathmandu. I never got support from my in-laws.”*

As one participant Ganga says, *“They don't eat what I cook, do not talk to me, and complain about each and everything even in small things. They say my son has no one to inherit his property.”*

Categories: Social isolation

According to the study participants reflect that they avoid social gathering with family, friends to avoid inevitable questions and comments regarding their childless state.

Sita expressed *“My friends and relatives invite me to their parties but I don't feel like going. Once my husband's friends joked about it and made fun by telling him that his power is not enough”.*

Participants express they feel a lack of confidence when around friends and regularly decline social gatherings especially birthdays and rice feeding ceremonies claiming they are busy.

Categories: Marital Relationship

Seven out of nine woman spoke about marital conflict because of their infertility and describe marriage of stress, neglect, disagreement and fear of marital disruption as most of the women are dependent on their husband economically and emotionally.

Reena expressed with tear in her eyes, *“A lot of fights! My husband nowadays says if we don't have a child after 6..7 years of trying, its not worth trying. I won't trouble you; I would rather get married again and have a child. I will take care of you even after that”. I have lost faith these days. I think a man can change his mind anytime he wants! (Keta manche ko maan na ho) Cries....*

Sub-theme: Emotional Consequences, Categories: Self Perceived abuse

One participant, Devi, says *“once I heard my neighbor called me Papini (Sinner) She said one has to come with the written fortune to have a child. I cried so much because that hurt me for many days”*

Categories: Poor Mental Health

Anu 38 expresses *“I am really hopeless now a days even small things irritates me and it leads to dispute with people. I never used to respond with anyone whatever they said to me in the past but nowadays I can't tolerate it easily.”*

However, some women experienced a sense of relief while getting treatment and seeing many women suffering from the same problem.

DISCUSSION

The study explored women's experiences with infertility, highlighting the stigma, discrimination, and societal challenges they face. Some participants believed in myths about their condition. Many were reluctant to share their struggles due to fear of gossip, and experienced economic difficulties, along with physical and emotional strain from lengthy and often unsuccessful treatments- including costly alternative approaches.

The study explored women's experiences with infertility, highlighting the stigma, discrimination, and social challenges they encounter. Many believed in myths surrounding infertility and reluctant to share their struggles due to fear of gossips. Worthington et al. (2019) further reported that women with infertility experienced greater stigma than men. The stigma can strain relationships, lead individual to hide their diagnosis from friends and family, and delay or avoid seeking treatment which potentially resulting in a poorer prognosis.^[12]

Similarly, findings have been reported by Nagorriska M, Bartosiewicz A, Obrzut B, et al. (2019), where participants reported that embarrassing tests, longer procedure and difficulty in treatment were more troublesome which result in changes of the existing lifestyle.^[13]

Infertility also led to poor marital and family relationships, with many women isolating themselves and avoiding social gatherings. In this study they experienced rude comments from others, and infertility had a significant psychological impact, causing anger, guilt, sadness, low self-esteem, anxiety, and insomnia. Findings supported by Dierickx et al. (2018) and Liamputtong and Benza (2019) also concluded that women are more likely to face harsh social stigma related to infertility and childless women often viewed negatively.^[14,15]

CONCLUSION

Based on the findings of the study, it is concluded that childlessness has a profound financial, psychosocial, familial and marital impact on women's life. It is an instinctive biological behavior to have children and considered as an important milestone in Nepal. Therefore, being unable to achieve those has negative effects.

The results suggest that psychological counseling, and self-help groups, should be part of infertility treatment to help women manage emotional distress, as they often experience infertility as deep grief and feel isolated. The women's personal stories highlight the importance of support from family and husbands in managing the stress they experience.

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