

# **Narrative Medicine**

## Journeying infertility

Salik Ansari, MSc. Research Ethics

Former student, Centre for Ethics, Yenepoya (Deemed to be University), Mangalore

#### Corresponding Author:

Salik Ansari, Teaching / Technical assistant, Sangath, Bhopal - 462016.

Email: salik dot ansari at sangath dot in

Submitted: 25-Mar-2021 Accepted: 14-Jun-2021 Published: 13-Aug-2021

Fatima was around 40 years old and would assist my mother in sewing, ironing, and cooking. She was poor and was living hand to mouth by taking up small short-term jobs. I learned from my mother that her husband had divorced her for not being able to bear him a child. The man then married another woman and they went on to have a few children. Although I never spoke to Fatima personally there was something about her life that struck me even when I was a kid, and it keeps bothering me to this day.

Is having a child so important? Rather than abandoning her, shouldn't a good spouse be by the side of his wife no matter what? Couldn't they have just adopted a kid? What must it feel like to be in Fatima's shoes?

I raised some of these topics with my mother but did not get a convincing answer. In this narrative, I share anecdotes of the challenges associated with reproductive decisions and with infertility while also trying to join the dots of Fatima's story as I perceive it.

### Expectations

The moment a man and a woman enter into the union called marriage, there is an assumption that they shall one day start a family. Almost everybody around the couple expects it. The parents of the couple usually have a longing to see the faces of their grandchildren. Their colleagues keep asking 'when are you giving us the good news?' At first, the couple smiles and regards these questions as harmless and as well-intended curiosity. Then may come a time when they decide they actually want a child. Ideally, this should be a mutual decision between the couple but it may not be so. In this country, it is the man and his family who are often the key decision-makers on such issues. An anecdote was shared with us in one of our classes about a social science researcher who asked a female participant in her study whether she was using any contraceptive. She replied that she was using a Copper-T, a birth control tool. The mother-in-law overheard this exchange and slapped the woman asking her to get rid of the Copper-T. That is the extent to which the family members may be involved, or at least feel that they are entitled to be involved in the reproductive decisions of the couple.

#### Reality

Once the couple seeks conception, if within a few months there is no news of it, the panic starts. On the one hand, there is an urgency to see a specialist and find out what could be wrong, while on the other hand, they must keep up with the perpetual questions asked

Cite this article as: Ansari S. Journeying infertility. RHiME. 2021;8:90-2.

www.rhime.in 90

by others. These questions now no longer feel like well-intended curiosity but rather seem to be a reminder of one's inability. It is difficult to say how many couples actually go and seek an expert opinion. I do not know if Fatima ever went with her husband to a specialist. For many who do, there is no guarantee that the 'expert' is an actual 'expert.' It is not uncommon for conmen, pseudo-experts, or unqualified practitioners (quacks) to play with people's anxiety and drive their businesses; couples, irrespective of their educational status, can fall into the trap.

According to the Indian Council of Medical Research (ICMR) failure to conceive after at least one year of unprotected intercourse is the defining criteria for infertility,[1] while as per the Indian Society of Assisted Reproduction, approximately 10 to 14 percent of the Indian population is affected by infertility.[2] The accurate diagnosis of the cause of infertility is crucial not just so that the couple finds out what the truth is, but also to determine whether treatment of some sort is possible. However, diagnosis is particularly challenging because not one but two people are involved. Some cases of infertility can be associated with women, like ovulation disorders or cervical abnormalities; others can be associated with men, like abnormal sperm production or function or delivery; some causes may remain unidentified or are unknown.[3]

#### The Stigma

If the diagnosis of infertility is correct, it becomes established that the couple will not be able to have a child by 'natural' means. Their disappointment and sorrow are likely to peak. Sooner or later, as other people learn about this, they start to offer suggestions or judgments, or even taunts.

'You aren't trying hard enough.'

'It is because yours is an inter-caste marriage that you cannot bear a child.'

'Visit *Jaadu baba* (miracle monk) - he has the solution for everything!'

One's private life suddenly gets dragged into the common discussion on which anybody can comment. Beliefs like 'Children are a gift from God and not being able to have one is the sign of a curse' result in stigma and discrimination that is directed against a couple unable to start a family. They may be sidelined in important family decisions, not allowed to attend places of worship, boycotted in social circles, and so on. In some parts of India, having children is associated with having a greater authority. This is especially true for women who gain more power in the joint family structure because of their children (especially the male ones).

If the failure in conception is exclusively due to one partner, then the other may start blaming him/her. Even if there is no blame placed on one, they may still feel that it is because of their own shortcoming that their partner is being deprived of the joys of parenthood. It is perhaps this feeling of self-blame that makes a woman like Fatima succumb to the demands of the in-laws and of society, and give up her spouse for a reclusive life, unwilling or unable to find happiness moving forward.

I remember a conversation I overheard some time ago. It went like this:

'Hey, Mr. X doesn't have any children, right? Then why doesn't he marry again?"

This question was asked by a young woman to an older one. The older woman replied "Wo un mein hi kuchh kami hai (It is he who is lacking something)."

This conversation suggests that it is not only acceptable but also taken for granted (even by women) that a man will remarry another woman for the sake of fathering a child. However, it does not seem to apply the other way around, i.e., a woman abandoning her husband for the sake of bearing a child.

Is this a lack of empathy on the part of others? Is it ignorance? If one is educated to believe

www.rhime.in 91

that infertility can affect anyone, then will empathy automatically follow? Or will the desire to have children overpower the love and commitment to the spouse?

#### The Moral Imperative

The instinct to have one's own child and pass on the genes to continue the lineage is widely present in the animal kingdom. With complex creatures like humans, the failure of being able to fulfill this instinct can be devastating. Divorce, depression, suicidal thoughts can all be associated with infertility. As a child, these were among many things I did not understand. Now I think I know better, but on deeper reflection, I still do not understand it fully. Fatima is on top of my mind when I make this admission. A few years ago, Fatima became very ill and returned to her mother's home where she soon passed away. Her death has left a moral gap that I am still not certain how to fill.

The glorification and the necessity of parenthood (especially motherhood) is so profound that it has the potential to undermine the very life of an individual. In idolizing and glorifying motherhood, we imply that motherhood is an imperative for every woman, and we, thereby, curtail her autonomy. Such a

social insistence can marginalize women who may voluntarily or involuntarily not bear a child. These gendered notions deprive women of their basic human rights.

A while ago, I spoke to a senior social scientist who has worked extensively in the field of reproductive health. I asked her how we could get people to change their minds over important issues. She replied that we must engage with them, and bring as many people as we can into the conversation. Besides direct engagement, we may also encourage people who wish to share their experiences and stories, to bring them into the public domain. Newspapers (including regional language ones), the internet and social media, educational curricula have all got a role to play here. This could help in normalizing and humanising issues which are often ignored while many continue to be affected by them. When such stories find a space in public narratives, they may contribute towards changing the overall socio-moral landscape to become more inclusive and less discriminatory. They may also reach individuals like Fatima herself and inspire them. Perhaps that is the starting point to get over the stigma of infertility and its consequences. And that might also be a way we can honor the lives of people like Fatima.

### References

- 1. Indian Council of Medical Research. National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India. New Delhi: ICMR; 2005 [cited 2021 Aug 09]. Available from https://main.icmr.nic.in/sites/default/files/art/ART\_Pdf.pdf
- 2. Lal N. India's hidden infertility struggles. The

Diplomat. 2018 May 30 [cited 2021 Aug 09]. Available from https://thediplomat.com/2018/05/indias-hidden-infertility-struggles/

3. Mayo Clinic Staff. Infertility. 2019 Jul 25 [cited 2021 Aug 09]. Available from https://www.mayoclinic.org/diseases-conditions/infertility/symptoms-causes/syc-20354317.

Acknowledgements: Lakshya Arora, for his inputs on this piece, and Dr. Vina Vaswani, Director, Centre for Ethics, Yenepoya (Deemed to be University), for her support and encouragement.

Funding information: This narrative was written as a part of Yenepoya University Fogarty International Center's Research Ethics Master's Program for India that is supported by the NIH Grant No. 1 R25 TW010305. The content is solely the responsibility of the author and does not necessarily represent the official views of the National Institutes of Health

www.rhime.in 92