ijme

Indian Journal of Medical Ethics Vol VI No 3 July-Sept 2021

ARTICLE

Dispelling hope and leaving couples in a state of "inbetweenness": Moral dilemmas in infertility research

SUNU C THOMAS

Abstract

Infertility is a condition that has an inherent cultural significance. In India, married couples with infertility face the brunt of speculations and certain demeaning identities are assigned to the women. Care-seeking options for infertility are deeply gendered. The availability of technologically advanced treatments for infertility provides "hope" to couples, especially women, to resolve the demeaning identities assigned to them, related to infertility. The paper focuses on the moral dilemma faced by a medically trained public health professional while collecting data from women in Kerala who were unable to continue the suggested biomedical treatment. Infertility treatment is an entropic cycle of success and failure; thus, the women studied moved from one stage to another hoping for a resolution to their problem. They were also undergoing alternative treatments that were unlikely to succeed. The paper discusses the moral dilemma of choosing between explaining the poor likelihood of success and leaving them with "hope".

Keywords: *moral dilemma, hope, in-betweenness, infertility*

Introduction

Being diagnosed with infertility is often emotionally distressing (1) since it causes uncertainty regarding one's ability to start a family. In desperation, couples usually navigate the treatment options available to induce pregnancy (2). In infertility discourse, one cannot overlook the role of assisted reproductive technologies (ART), which are a source of hope (2) in the face of this uncertainty. Infertility treatment is emotionally and physically exhausting, because it can involve multiple failures at different points along the treatment curve for the couple, either individually or jointly. Therefore, the likelihood of abandoning treatment is high. Even though couples who do not meet with success usually give up treatment, overall, the number of couples opting for this technology continues to increase. Many women consider ART favourably and see it as a chance to achieve fertility despite the risks (3). Women's perspectives on the technology are demonstrated in Franklin's study, which stated that the women who were in the middle of the treatment cycle were full of "hope", even though they were not sure whether it was working for them or not (3). She added that the rationale for labelling this position as "full of hope" is because for the women, the desirable outcome was not necessarily a fruitful pregnancy but having given it a try. For these women, having attempted treatment was more important than its success. In this context, ending one's quest to have a child means the end of hope. The very "hope" that enabled them to persevere with the infertility treatment while overcoming multiple stressors, including their failure to conceive, also helps them deny their potential childlessness (4). Therefore, trying multiple treatment methods before giving up was of utmost importance. Franklin (3) also noted that the decision to abandon the hope of achieving pregnancy was a difficult one for couples since at each stage they revisited the decision and contemplated many "what if" questions. This means that when they decide to try a treatment, they are still holding on to the fine thread of "hope" that they may conceive a child with this particular treatment.

In this paper, I examine the moral dilemma associated with dispelling this "hope", which may play an important part in the day-to-day existence of couples with infertility. It calls for weighing the ethics of dispelling such "hope" against allowing couples to live with it. This dilemma is partly a consequence of who I am. I have therefore explained my positionality, ie, the world view that I hold. Moral dilemmas are part of the everyday practice of research (5), even though they are often not delineated as such. They are challenging because they pull a researcher in two or more equally compelling moral directions (6). A researcher interacts with various people in the field, and some of these interactions give rise to multiple obligations. It is difficult to choose between them when there is no clear moral hierarchy (7). Behavioural choices are usually determined by the context and the researcher's world view (8). Even after making a choice, the rejected alternatives remain unresolved, making moral failure an inevitable component of the resolution (9).

A study was undertaken to describe the care-seeking pathways of couples with infertility. This article explores the moral dilemmas I faced as a researcher while interviewing women who, at the time of the interview, were not pursuing the infertility treatment suggested by their doctor. The treatments suggested by the professional were the only possible methods that could offer a solution to their

Author: **Sunu C Thomas** (sunusarathomas@gmail.com), PhD Scholar, Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Thiruvananthapuram 695 011 INDIA.

To cite: Thomas SC. Dispelling hope and leaving couples in a state of "inbetweenness": Moral dilemmas in infertility research. *Indian J Med Ethics*. 2021 Jul-Sep; 6(3) NS: 229-233. DOI: 10.20529/IJME.2020.125.

Published online first on December 10, 2020.

Manuscript editor: Uma Kulkarni

Peer Reviewers: Supriya Subramani, Anindita Majumdar

problem. The couples had either abandoned all kinds of allopathic treatments or were trying other systems of medicine or alternate remedies.

Positionality of the researcher

First, I must state my position to enable readers to understand the dilemmas I faced. First and foremost, being a woman of reproductive age researching this particular problem, I was not able to detach myself from the experiences of the women I was interviewing. I could empathise with how much motherhood meant for those women. I am also a trained nurse and a public health doctoral student studying the care-seeking pathways for infertility; thus, I have an adequate understanding of infertility and its treatment. I am not a specialist doctor who can recommend a certain treatment over others; however, I do have a strong biomedical orientation due to my training and had approached the participants through the health system. Within the selected district in Kerala for the study, the accredited social health activist (ASHA) of that particular area was contacted first. I explained to them who I was and the purpose of my study and asked them to identify potential respondents for my study and for help in undertaking the interviews. I also asked the ASHA workers to ask the participants if they were willing to share their medical records with me. The ASHA workers were also informed by the office of the district medical officer to provide me with the necessary assistance. Hence, most of the participants were approached first by the ASHA worker, who informed them that someone wanted to talk to them about their treatment. I had carefully explained the study's objectives to the ASHA workers, who in turn explained them to the potential subjects; however, as they were approached by the ASHA and had their medical records examined, they may have assumed that there would be a review and treatment of participants. When I visited them for the interview, some of the women respondents expected me to offer some medical assistance. Hence, for the participants, I also embodied "hope" as someone who could help them in some way.

Ethics approval

The study was cleared by the Institutional Ethics Committee (IEC) of the Sree Chitra Tirunal Institute for Medical Sciences and Technology (SCTIMST), with the IEC clearance number is SCT/IEC/1112/JULY-2018, dated August 3, 2018. Written informed consent was obtained from all the participants before the interviews. The participants were first contacted through an ASHA worker and permission was sought for interviews. Only if the participant agreed, I visited them at their home. After explaining to them the purpose of the study and getting their permission, I started collecting the data.

Methods

The data were collected through a community-based survey. Women were the primary respondents, although the data was representative of the couples. This was because it was assumed that women would recall treatment details better than men, as in most cases, the treatment was directed at the woman's body. Thus, 604 women who were part of a couple seeking care for infertility (either one or both people in the couple had been diagnosed with infertility) were interviewed using a structured interview schedule. These women were either currently seeking care or had a history of seeking infertility care.

Care-seeking is defined in the study as including all methods adopted by couples to resolve infertility. This includes biomedical treatment, alternate systems of medicine, alternate methods like religious methods, faith-based and magic remedies, traditional medicine, etc. Treatment, in the case of this study, includes only modern medicine (Allopathy), Ayurveda and Homeopathy.

The study sample included women from three districts in Kerala – Thiruvananthapuram, Kottayam, and Malappuram. The 14 districts of Kerala were ranked based on the estimated level of infertility based on the Census 2011 data analysis. The districts were grouped into three categories based on their expected level of infertility as low, middle, and high levels of infertility. One district from each group was then selected for the survey. This ensured diversity in couples' infertility treatment-seeking experiences in terms of age at marriage, educational levels, and religious denomination. This study documents the various treatment options used to resolve infertility across the different types of centres ie, any institution visited by the couples, which offers Allopathy, Ayurveda or Homeopathy and the reasons, if any, for discontinuing treatment. The data analysis was done using R software version 1.2.1335. A descriptive analysis of the care-seeking pathways of couples was also carried out. This was done to understand the treatments suggested to couples and the reasons why they switched from one centre to another.

I used a feminist approach in this study; by centralising the women in the couples, I gained a better understanding of the negotiations that occur during care-seeking for infertility (1). Women's right to choose what happens to their body is often restricted in infertile couples due to their social and cultural context. The study is rooted in the understanding that infertility entails a social burden that is gendered. This means that even when the inability to reproduce is caused by male factor infertility, its burden must be borne by women. Reproductive technologies that offer solutions to couples with infertility burden women unequally when compared to men. Further, the fact that these services are concentrated in the private sector creates barrier in affordability for couples.

Care-seeking trajectory for infertility

A total of 604 women were interviewed regarding their treatment-seeking pathway, out of which 75.7% (457) of the women had no child at the time of interview and they were either continuing treatment (35.9%), had stopped treatment completely (24.1%), or were taking a break from treatment (36.8%). Others mentioned that the doctor had asked them to wait, that their partner was unwilling to continue treatment, or that they were trying religious methods (3.2%). Table 1 below shows the status of treatment for women who did not have a child at the time of interview.

The women had visited several centres, ranging from one to 11. Some continued to seek treatment, some had discontinued treatment temporarily, and others had stopped treatment permanently. They reported multiple reasons for quitting each centre. Some said that they abandoned treatment at a centre because they did not want to undergo

Table1: The status of treatment for women who did not have a child at the time of interview (n=604)

Status of women at the time of the interview		Continuing treatment	Stopped treatment completely	Taking a break from treatment	Partner unwilling to continue	Currently, no treatment suggested	Trying religious methods
No child	457 (75.7%)	164 (35.9%)	110 (24.1%)	168 (36.8%)	1 (0.2%)	12 (2.6%)	2 (0.4%)
Had a child/ pregnant	148 (24.5%)	-	-	-	-	-	-

the specific treatment suggested there. This was often the case when the suggested treatment was intra uterine insemination (IUI) or in vitro fertilisation (IVF). The respondents either went to another centre or stopped treatment altogether. The reasons given for stopping ART treatments were personal, ranging from the unacceptability of using donor sperm to financial difficulties. Couples did not exhibit the same level of reluctance with respect to using donor eggs when compared to donor sperms (10). This is because maternal relatedness was not considered as important as paternal relatedness in a patriarchal society (11). A study done to understand the perceptions of the use of donor sperm and eggs, reported that men and women felt that the use of donor sperm would lead to marital issues. The negative attitude toward the use of donor sperm can also be attributed to the shared experience of creating a child and societal opinions (11).

During the community-based survey, the researcher encountered couples in this category who had abandoned treatment when IUI or IVF was suggested, even though the treatment did not always include the use of donor sperm. They were reluctant to undergo these treatments due to a fear of using donor sperm, even when the option of using one's own sperm was available. They were of the impression that if the male partner has sperm, why did they have to undergo the ART procedure? In many cases, they also mentioned religious reasons as a factor that made them reluctant to use this technology. They reported that they continued to hope that pregnancy would happen in due course due to the presence of sperm. Many had abandoned modern medical treatments and were trying Ayurveda, homoeopathy and other alternative methods like religious or folk remedies to achieve pregnancy.

In the study, 32 couples (5.3%) were recommended IUI and 128 women (21.2%) were recommended IVF. Among this group, 115 (71.9%) did not want to take the treatment suggested by the doctor. Two-fifths of those who were suggested IUI (40.6%) and more than three-fifths of those suggested IFV (62.5%) did not pursue it as they did not want to adopt these treatments. The most common reason couples shift from one centre to another is a disinterest in undergoing the specific treatment that was suggested like IUI or IVF. They also tend to move from modern medicine to other alternative systems of medicine or alternate methods for the resolution of their problem. Table 2 shows the transition of couples from one centre to another.

A possible reason for not wanting to undergo IUI or IVF is that a donor sperm will be part of the treatment – they are either told that it will be or they assume that will be the case even when told otherwise.

A decision to stop treatment would mean exiting the care-seeking pathway and there would be no additional biomedical intervention to resolve the couple's infertility. The women in this situation remain in a state of limbo, in a state of "inbetweenness" according to Probyn (12) – they are without care and but have not entirely abandoned care-seeking. It is important for women not to abandon care-seeking as the onus of reproduction falls on them in the social contexts in which they live (13). The woman is left with no avenue to prove that her reproductive body is "normal" when her partner is the cause for infertility. This leads to couples trying alternate methods of care-seeking. This includes consuming different Ayurvedic formulations intended to improve semen parameters, folk remedies like consuming *naikarunaparippu* (velvet bean/*Mucuna pruriens*) powder in milk, and eating other "divinised" things like banana and ghee to achieve pregnancy, which are suggested as part of religious remedies.

The moral dilemma – to dispel or to leave them with "hope"

The social construction of infertility puts the onus of reproduction on women. Childless women are subjected to social ridicule and stigma (14). Thus, women become the primary reproductive agents in the couple, which is then threatened by the inability to reproduce. This idea of women's bodies as the bearers of reproductive impairment in a couple in the absence of pregnancy makes women embody the idea that the inability to reproduce is their "fault" (15–17). Thus women undertake every possible measure to prove that their bodies are functional and put themselves through a battery of invasive procedures. When one treatment fails, they hold on to "hope" that the next one may be successful. This is the reason they relentlessly go through rigorous treatment processes across multiple centres even though they are tired, both physically and emotionally, due to the invasiveness of the procedures and the absence of the desired results.

While conducting the survey, I encountered many women reporting that they had stopped modern medical treatment and were pursuing other systems of medicine or alternate methods to resolve infertility. The reasons cited included that they were (or their partners were or both were) uninterested in pursuing the particular treatment suggested by the doctor i.e., IUI or IVF specifically, among other things. They also reiterated that they were hopeful that the remedy they were using would be successful. They reinforced this by recounting anecdotes of people who had experienced a positive outcome using those means.

In these situations, I was confused about whether to explain to them that this was false hope and that they should seek

Table 2: The transition of couples from Centre 1 to Centre 2, when IUI or IVF is suggested as the treatment

	Another centre visited n = 604	Suggested treatment in this centre (Centre 1)		Discontinued because of the suggested treatment		Ayurveda or homoeopathy or alternate methods as the next point of care for those who were suggested	
		IUI	IVF	IUI (n = 5)	IVF (n = 11)	IUI (n = 5)	IVF (n = 11)
Yes	493 (81.6)	5 (1.0)	11 (2.2)	2 (40.0)	7 (63.6)	4 (80.0)	4 (36.4)
No	111 (18.4)	2 (1.8)	3 (2.7)	-	1 (33.3)	-	-

treatment or continue the treatment suggested by their biomedical doctor. I think my strong affinity towards modern medicine stemmed from the biomedical perspective that had shaped my training; hence my reluctance to acknowledge the positive effects, if any, of alternate systems of medicine. I did not have the scholarship to understand the workings of alternate systems. I also believed that alternative methods like religious practices or consuming traditional powders were not going to give them positive results. This belief was largely based on the biomedical training I had received where health professionals use an objective philosophy (18). So, at first, the only truth I believed in was that biomedical treatments could offer a definite solution to infertility. Any other method was not going to give the desired results. However, my public health training enabled me to discern that there was an "alternate truth". Through a reflexive analysis of my position vis-à-vis the problem, I was confronted with the question of whether it would be right to dispel the "hope" that makes them lead their life as it is?

In certain cases, couples were diagnosed with absolute male infertility and the use of donor sperm was the only available biomedical option. In these cases, I was sure that the participant would not undergo that treatment due to personal, cultural, and religious reasons. The dilemma that arose was whether it was worth dispelling the "hope" they lived with by providing accurate information about their situation from a biomedical perspective.

The second dilemma revolved around whether to inform the couples that the only solution was to undergo IVF, which is an expensive treatment and has a less than 40% (19) chance of success (while the mean live birth from one cycle and its subsequent cryo-cycles was only 33%)(19). A majority of the participants were of middle socioeconomic status; thus, it was not clear whether resorting to these treatments that do not provide 100% success would be worth their money.

I approached the participants from an assumed position of "knowing" (20); I was both knowledgeable about infertility and empathetic towards the women who were going through the related challenges. Being a woman of reproductive age enabled me to empathise with these women at a personal level and this made it difficult for me to dispel the one source of hope that they were holding on to. I was also in a position of power since I was talking to them from within the health system. Thus, I had to be cautious about my responses since the role I had assumed and what was expected of me by my participants would have jeopardised their "hope".

For the women, stopping care-seeking for infertility altogether meant that they could no longer dwell in hope, which is what gave them the strength to cope with childlessness and pursue exhausting treatments. It is also this "hope" that positions them between being able to achieve a pregnancy and being labelled as "barren" for the rest of their lives. This was true even when the infertility was due to the reproductive impairment of a partner. When there is a tendency to categorise everything into two groups (here: being infertile and fertile), belonging to the category of "infertile" is not desirable. When the ability to move to the category of fertile is hampered or delayed, one would like to stay in the space between the two categories. "Inbetweenness", as defined by Probyn (12), is a state between two possibilities that occurs when there is a desire to belong to one category. The state of 'in-betweenness' occurred in the women in the study when success through medical/scientific methods was not imminent but they needed to continue to think that alternate options hold promise. Thus, the women wished to be in this safe space of "inbetweenness" (12), where they found solace in not being labelled infertile (which is stigmatising), while still waiting to achieve the state of motherhood. Abandoning care-seeking here means an end to that "hope" and the many comforts that it offers. Even with regard to religious or astrological remedies, the women I interviewed believed strongly that they would get pregnant if they followed the remedies suggested. I was seen as someone who was there to secure their "hope", and not as someone who could dispel their belief. These alternative remedies are a part of the couples' socio-cultural milieu and their value system.

Dispelling their expectations came with the burden of knowing that there was no pragmatic solution to offer from my middle-class biomedical perspective. This was again a judgement call that I was making based on my own middle-class values – both judging their socioeconomic contexts and their biological options. Explaining the real nature of the problem and potential solutions meant taking away the only intangible thing that they lived with despite not achieving their desired goal of fertility, viz their hope. This hope is also intertwined with the value system that emerges from their culture. For couples with the dual problem – a lack of resources and the unacceptability of donor sperm – I chose to leave them in a state of "inbetweenness" in this context. When couples did not want to engage in assisted reproduction and chose alternate methods due to personal or other reasons, I held a different opinion. I believed that medico-scientific processes, including IVF, held a better chance of success than magico-religious belief oriented remedies. However, suspended as the women were, in a state of perpetual hope until their biological body refused to

respond, I chose not to reveal my views on the matter. This was because of the duality in the training I had received; my biomedical understanding of infertility and its treatment led me to objectively look at the problem and its solution independent of the context, but my public health training demanded that I look at the problem within the context because there were multiple truths, depending on one's standpoint. The reality of the everyday life of the participants transcended my truth that biomedical treatments were the only solution.

When confronted with a moral dilemma, a researcher may choose to act in a specific way or refrain from any action due to a moral choice. The premise for any moral dilemma faced by the researcher and the choice made by the researcher to resolve this is driven by their worldview (8).

So, after completing the interviews, I walked away, leaving the women in their state of "inbetweenness". The burden of living with that choice and not dispelling the information asymmetry between researcher and researched is my own.

Acknowledgements

I would like to thank to my PhD guide, Dr Mala Ramanathan, Professor, AMCHSS, SCTIMST, for reading the manuscript multiple times and correcting it. I would like to thank Dr. Rakhal Gaitonde, Professor, AMCHSS, SCTIMST, for his valuable comments, and my colleague, Ms Sapna Mishra, for identifying repetitive portions in the earlier drafts. Errors, if any, are entirely mine.

Declaration: *No competing interests. This research was carried out as part of my PhD thesis*

Notes

[1]Here, when I refer to IUI or IVF it also includes some cases where donor sperms were used for fertilisation.

[2]A term used by Elspeth Probyn to denote the "the constant way that one is always in between two languages, cultures, and histories."

References

1. Throsby K. *When IVF fails: feminism, infertility and the negotiation of normality.* 1st ed. Hampshire: Palgrave Macmillan; 2004.
2. Helén I. Health in prospect. High-tech medicine, life enhancement and the economy of hope. Sci Stud. 2004; 17(1):3–19.
3. Franklin S. *Embodied progress: a cultural account of assisted conception.* 1st ed. London and New York: Routledge; 1997.
4. Boden J. The ending of treatment: the ending of hope? *Hum Fertil.* 2013 Mar;16(1):22–5.
5. Guillemin M, Gillam L. Ethics, reflexivity, and "ethically important moments" in research. *Qual Inq.* 2004 Apr;10(2):261–80.
6. Arthur J. Famine relief and the ideal moral code. In: Cahn SM, Markie P, editors. *Ethics: history, theory and contemporary issues.* New York: Oxford University Press; 1998. pp. 807–20.
7. Lebus B. Moral dilemmas: Why they are hard to solve. *Philos Investig.* 1990 Apr;13(2):110–25.
8. McConnell T. Moral Dilemmas: The Stanford Encyclopedia of Philosophy. In: *Moral dilemmas.* Fall 2018. Metaphysics Research Lab, Stanford University; 2018[cited 2020 Nov 20]. p. 18. Available from: https://plato.stanford.edu/archives/fall2018/entries/moral-dilemmas/
9. Tessman L. *Moral failure: on the impossible demands of morality.* New York: Oxford University Press; 2015.
10. Gameiro S, Boivin J, Peronace L, Verhaak CM. Why do patients discontinue fertility treatment? A systematic review of reasons and predictors of discontinuation in fertility treatment. *Hum Reprod Update.* 2012 Nov 1;18(6):652–69.
11. Eisenberg ML, Smith JF, Millstein SG, Walsh TJ, Breyer BN, Katz PP. Perceived negative consequences of donor gametes from male and female members of infertile couples. *Fertil Steril.* 2010 Aug; 94(3):921–6.
12. Probyn E. *Outside belongings.* 1st ed. London and New York: Routledge; 1996.
13. Johnson KM, Fledderjohann J. Revisiting "her" infertility: Medicalized embodiment, self-identification and distress. *Soc Sci Med.* 2012 Sep; 75(5):883–91.
14. Riessman CK. Stigma and everyday resistance practices: Childless women in South India. *Gend Soc.* 2000; 14(1):111–35.
15. Clarke LH, Martin-Matthews A, Matthews R. The continuity and discontinuity of the embodied self in infertility*. *Can Rev Sociol.* 2008 Jul 14; 43(1):95–113.
16. Sandelowski M, Holditch-Davis D, Harris BG. Living the life: Explanations of infertility. *Sociol Health Illn.* 1990 Jun; 12(2):195–215.
17. Greil AL, Leitko TA, Porter KL. Infertility: His and hers. *Gend Soc.* 1988;2(2):172–99.
18. Wilson HJ. The myth of objectivity: is medicine moving towards a social constructivist medical paradigm? *Fam Pract.* 2000;17:203–9.
19. Gnoth C, Maxrath B, Skonieczny T, Friol K, Godehardt E, Tigges J. Final ART success rates: a 10 years survey. *Hum Reprod.* 2011 Aug 1; 26(8): 2239–46.
20. Pellatt G. Ethnography and reflexivity: emotions and feelings in fieldwork. Nurse Res. 2003 Apr; 10(3):28–37.