17 July 2020

To,

The Editor

IJME

Dear Sir/Madam,

I am submitting the revised version of the paper “**Between dispelling hope and leaving them in the state of ‘inbetweeness’: Moral dilemmas of research on infertility treatment seeking in Kerala**”. This has been revised in keeping with comments from the two reviewers who provided their comments. I would like to thank both the reviewers for the extensive comments which helped me refine the paper.

As the initial qualitative phase contributed to development of the tool for the quantitative survey and references to it were adding to the confusion in the presentation of the moral dilemma, I have removed references to it in the text. The present draft describes the community based survey data as this forms the context of the moral dilemma. I have clearly mentioned this in the response to each of the comments.

I am enclosing a reply to all the comments along with this.

Thanking You,

Sincerely,

sunu

Sunu C Thomas

PhD Student

AMCHSS, SCTIMST

Kerala, India

1. **Title: Between dispelling hope and leaving them in the state of ‘inbetweeness’: Moral dilemmas of research on infertility treatment seeking in Kerala.**

**RESPONSE TO REVIEWER 1**

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| S. No. | Reviewers’ comments | Author’s response |
|  | **Reviewer 1** |  |
| 1 | The paper does address issues relevant to the fields of bioethics and medical ethics in the developing countries, and is not too specialised for the journal. | I would like to thank the reviewer for this. |
| 2. | The information is new to some extent, especially the quantitative data being discussed. | Thank you. The quantitative survey is the context for the moral dilemma. |
| 3. | The interpretation needs to be developed further. Right now, the author has presented a simplistic interpretation of a mountain of data. There is need to pick on some data and reflect on findings through existing studies of IVF and infertility in India: Sama, Kalindi Vora, Unisa, Majumdar, Catherine Riesmann, Aditya Bharadwaj | The attempt here was to demonstrate the moral dilemma I felt while collecting the data. I have removed two of the tables that seemed excessive. I have read all of the papers referred to by the reviewer and have referred to Reismann’s paper. I felt the other authors did not have a direct bearing on the argument vis-à-vis the moral dilemma I faced. However, should it be necessary, I will include them.  The data from my thesis that I included from my thesis is to merely validate the arguments made here. |
| 4. | The paper is peppered with loose generalisations. What is care seeking? How is it different from infertility treatment? There is very little conceptual engagement with Franklin’s idea of hope technology though the author keeps calling her respondents hopeless. | Care seeking is defined in the study to include all the methods adopted by the couples to resolve infertility. It includes biomedical treatment, alternate systems of medicine, alternate methods like religious methods, faith based and magic remedies, traditional medicine etc. Treatment would include here only modern medicine and AYUSH. I have included the definition in page 4, lines: 135-138.  I understand the denigration involved in the usage of the word ‘hopeless’ and have removed all references to it in the paper. I have included an enhanced explanation of hope using Franklin’s ideas of ‘hope’ emanating from technology in the introduction section. |
| 5. | The concept of morality and ethics cannot be restricted to a paragraph long discussion of tangibility and intangibility. It seems fleeting and not in-depth enough. Also, the author’s self-reflexivity is not fully explored in the paper, except in the beginning. | This has been extended in the revised version of the paper, page 3. Lines: 80-88 under the section moral context. I am including the specific sentences below:  Moral dilemmas are part of the everyday practice of research(5), even though they are often not delineated as moral challenges. They are challenging because they pull a researcher in two or more equally compelling moral directions (6). In field situations a researcher tends to get mired in various interactions with individuals, some of which impose multiple obligations. It is difficult to make a choice across these multiple obligations as there is no hierarchy of morality surrounding these choices(7). The choice regarding which way to act is determined usually by the context in which the dilemma happens and the world view of the researcher (8). Even after making a choice, the rejected alternatives remain unfulfilled, making moral failure an inevitable component of the resolution (9).  I have discussed the dilemma by giving self-reflexive account in page 8, lines:274-281. I am including the specific sentences below:  I approached the participants with an assumed position of ‘knowing’ (15), I was both knowledgeable of the particular issue under study and I was also empathetic towards the women who were going through this whole infertility conundrum. Being a woman with a reproductive body enabled me to empathise with these women at a more personal level and hence it was difficult for me to cut their one fine thread of ‘hope’ that they were holding on to. And I also assumed a position of power in the field, because I was talking to them from within the health system. So I had to be cautious of the my responses since the role I assumed and the one assigned to me by my participants would have jeopardised their ‘hope’. |
| 6. | We get no idea of the questionnaire distributed to the 600 + women: what kind of questions were asked, what was the majority class, caste, religious background? How much money did individuals and couples spend on the treatment? These are important markers of hopelessness as well. | The revisions has been made in the methods section. Page 4, Lines: 145-147. I am including the specific sentences below:  The study documented the various treatment options used to resolve infertility across all types of centres and the reasons, if any for discontinuing treatment at specific centres.  Page 7, Lines: 267-270. I am including the specific sentences below:  Most of the respondents in the survey were of middle socio-economic status across all the three districts. Approximately 50 percent of the respondents were Hindu while 33 percent were Muslim and 17 percent were Christian. Majority of the respondents were educated more than high school level, and only 0.3 percent were illiterate.  The study did not explore the financial expenditure on spend on treatment. This information was dropped earlier during the piloting phase of the questionnaire as women found it very difficult to report. Therefore I am not able to add more to the narrative of the state of hopelessness by including details of expenditure. |
| 7. | The idea of ‘inbetweeness’ comes in at the end. It’s not completely articulated considering it appears so prominently in the title. If a theoretical conceptualization would help, then Janet Carsten’s article on children and inbetweeness might be useful. | I read Janet Carsten’s work on kinship and relatedness and I was unable to find any specific work on inbetweeness. However, my understanding of inbetweeness emerges in the context of the state of limbo in which women remain, not seeking specific treatments and not eschewing it altogether. The original reference to the state of ‘inbetweeness’ comes from Elspeth Probyn’s work ‘Outside Belongings’ [Probyn, E, 1996. Outside Belongings, Routledge Taylor and Francis Group, NewYork, pp90.]. I have therefore added the revisions in page8, lines: 288-295.  I am including the specific sentences below:  When the norm of the binding binary that is prevalent in most categorisations, the state of belonging to the category of infertile is not something one wants. When the ability to move to the category of not infertile is hampered or is delayed, one would like to remain in the space between the two i.e., between of the categories. ‘Inbetweeness’ as mentioned by Probyn (12)is the movement that happens when the wish to belong is there. So the women may wish to be in this safe space of “inbetweeness”[[1]](#footnote-1) (12), where they find the solace of not being labelled as something stigmatising while still waiting to achieve the state of motherhood. |
| 8. | Figure 1 is very convoluted and needs redrafting. | Thank you very much for pointing this out. The figure emerges from the confusion due to the multiple sources of information and does not add anything to the arguments being made. The figure has been removed. |

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. p. 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 [Internet]. Fall 2018. Metaphysics Research Lab, Stanford University; 2018. p. 18. Available from: https://plato.stanford.edu/archives/fall2018/entries/moral-dilemmas/

9. Tessman L. Moral failure : on the impossible demands of morality. Oxford University Press; 2015.

12. Probyn E. Outside Belongings. 1st ed. London and New York: Routledge; 1996.

15. Pellatt G. Ethnography and reflexivity: emotions and feelings in fieldwork. Nurse Res. 2003 Apr;10(3):28–37.

**RESPONSE TO REVIEWER 2**

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|  | **Reviewer 2:** | **Author’s response** |
| 9. | The present manuscript lacks an overall objective, and the stated aim of the paper is too specialized for the journal. However, most of the paper only describes the issue in a peripheral way. | Thank you for pointing this out. I have included specific sentences in the introduction to indicate what my objective is for writing this paper.  Page3, line 72-76, states: Here, I examine the moral dilemma in dispelling such ‘hope’, the ‘hope’ that could hold an important part in the day to day existence of couples with infertility. It calls for weighing dispelling such ‘hope’ against the alternative of allowing couples to live with it. This dilemma is partly a consequence of who I was. I therefore have included my positionality, ie., the worldview that I hold, in the discussion of the moral dilemma.  And page 4, lines 90-95, states: This article explores the moral dilemmas I faced as a researcher while interviewing women who at the time of interview were not pursuing the treatment for infertility suggested by the treating medical professional. The treatments suggested by the professional from a medical perspective was the only possible method that could offer a potential solution to their problem. The couples had either abandoned all kinds of allopathic treatments or were trying other systems of medicine or alternate forms of remedy. |
| 10. | The main arguments are not new nor are they well grounded. Detailed analysis and in-depth discussion is lacking | Thank you for pointing this out. I have made necessary correction in the revised draft. I have included detailed analysis in pages 5-7, lines 171-232 as the following:  Women visited any number of centres, ranging from to 1 to 11 centres, while some continued to seek treatment, some dropped out of treatment temporarily others stopped treatment permanently. They reported multiple reasons for exiting each centre. Among these reasons some said that they abandoned treatment at one centre because they did not want to undergo the treatment suggested at that particular centre. This was often mentioned when the suggested treatment was IUI or IVF[[2]](#footnote-2). The respondents either proceeded to the next centre or stopped the treatment altogether. The specific reason for stopping ART treatments were personal including the unacceptability of use of donor sperm and financial difficulties (10). Couples do not exhibit the same level of reluctance with respect to donor eggs when compared to donor sperms(11). The use of donor sperm was not acceptable compared to donor eggs because maternal relatedness was not considered as importance as a father’s in a patriarchal society (11). Men and women felt that use of donor sperm will lead to marital issues. The negative attitude to use of donor sperm was also attributed to an incomplete gestational experience, societal opinions.  During the community based survey the researcher encountered couples in this category who abandon treatment when IUI or IVF was suggested, even though the treatment did not always include use of donor sperm. The couples choose not to attemptIUI and IVF/ICSI, as they were reluctant to undergo such treatments due to the fear of using donor sperm, even when the option of using one’s own sperm was suggested.  They were confused by the understanding that if their partner has sperm, then why do they have to undergo the ART procedure? In many cases they also mentioned religious reasons as one of the factors hindering the use of this technology. They also reported that they continue to live with the hope that pregnancy will happen in the due course due to the presence of sperm. Many abandoned the modern medicine treatment to try Ayurveda or Homeopathy or other alternate methods like religious or folk remedies to achieve pregnancy.  In the study 32 (5.3%)women were suggested , and 128 (21.2%) were suggested IVF . Among this collective group, 115 (19.0%) did not want to continue the treatment suggested by the doctor. Two fifths of those 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 take up those treatment options.  When couples shift from one centre to another, the reason for transition can be disinterest in continuing the specific treatment that was suggested like IUI or IVF. This also means they tend to move from modern medicine to other alternate systems of medicine for treatment or alternate methods for resolution of their problem. This transition is demonstrated in table 2, when couples move from centre 1 to centre 2. Table 2 shows the transition of couples from one centre to another.  A possible reason for not wanting to undergo IUI or IVF is the assumption that a donor sperm will be part of the treatment or that they are told that donor sperm is part of the treatment options.  The decision to stop the treatment means that they will exit the pathway of care seeking and that there would be no additional biomedical interventions to resolve infertility for the woman. The women in this situation remain in a state of limbo, a state of ‘inbetweeness’ according to Probyn (12) without care and not entirely abandoning care seeking either. For women, to not to abandon seeking care is important as the onus of reproduction is seen to fall upon them in the social contexts they live in (13).  There is no avenue left to prove her reproductive body as normal in instances where her partner is the cause for infertility. This redirects the pathway into alternate methods of care seeking. This includes consuming different ayurvedic formulations sold under the guise for improving the semen parameters, folk remedies like consuming “naikarunaparippu” (Velvet Bean- Mucunapruriens) powder in milk, astrological remedies, eating other “divinised” things like banana, ghee to achieve pregnancy.  In the discussion on the issue in pages 7-9, lines 236-349, I have added:  I faced dilemma while conducting the survey where I encountered repeated accounts of women reporting that they had stopped modern medicine treatment and were pursuing other systems of medicine or alternate methods to resolve infertility. The reasons cited included among the other things, that they were (read as their partners were or both were) uninterested in pursuing the particular treatment suggested by the doctor i.e., IUI or IVF specifically. They also reiterated that they were hopeful of the success of the particular remedy they were using. This has been reinforced by them by pointing out anecdotal accounts of people who had a positive outcome by that means.  In these situations, I was confused as to whether to explain to them that this is false hope and they should seek treatment or continue the treatment suggested by their biomedical doctor. I think my strong affinity towards modern medicine stemmed from the biomedical perspective that shaped by my training. I came from the biomedical school, and hence my reluctance to acknowledge the positive effects if any of the alternate system of medicine. I did not have the scholarship to understand the working of this system. I also believed that the alternate methods like religious methods or eating some traditional powders were not going to give them positive results.  But on further reflection, I was confronted with the thought that whether it would it be right to dispel the ‘hope’ that makes them lead their life as it is? In certain cases, when the couples were diagnosed with absolute male infertility, the use of donor sperm was the only available biomedical option. I was sure in such cases that the participant was never going to undergo that treatment due to personal, cultural and religious reasons. The dilemma was whether it was worth dispelling the ‘hope’ with which people lived in or provide accurate information about their situation, of course from a biomedical perspective.  The second dilemma concerned the option of informing the couples that the only method is to undergo IVF which is an expensive treatment with less than 40% (14) chance of being successful( while the mean live birth from one cycle and its subsequent cryo-cycles was only 33%) (14). Many of those in these situations were of low socio economic status and it was not clear to me as to whether resorting to these treatments that do not provide 100% success is worth their money. Most of the respondents in the survey were of middle socio-economic status across all the three districts. Approximately 50 percent of the respondents were Hindu while 33 percent were Muslim and 17 percent were Christian. Majority of the respondents were educated more than high school level, and only 0.3 percent were illiterate. This was again a judgement call that I was making on the basis of my own middle-class values, both judging their socio-economic contexts and their biological options.  I approached the participants with an assumed position of ‘knowing’ (15), I was both knowledgeable of the particular issue under study and I was also empathetic towards the women who were going through this whole infertility conundrum. Being a woman with a reproductive body enabled me to empathise with these women at a more personal level and hence it was difficult for me to cut their one fine thread of ‘hope’ that they were holding on to. And I also assumed a position of power in the field, because I was talking to them from within the health system. So I had to be cautious of the my responses since the role I assumed and the one assigned to me by my participants would have jeopardised their ‘hope’.  Stopping the care seeking for infertility altogether means that they no longer can dwell in the ‘hope’ that gave them the power to stay in the state of childlessness and pursue the exhausting treatments. It is also this ‘hope’ that has pulled them together by a narrow thread between the state of being able to achieve a pregnancy and the potential of being labelled as barren for the rest of their lives, even when the infertility is contributed by the reproductive impairment of the partner. When the norm of the binding binary that is prevalent in most categorisations, the state of belonging to the category of infertile is not something one wants. When the ability to move to the category of not infertile is hampered or is delayed, one would like to remain in the space between the two i.e., between of the categories. ‘Inbetweeness’ as mentioned by Probyn (12)is the movement that happens when the wish to belong is there. So the women may wish to be in this safe space of “inbetweeness”[[3]](#footnote-3) (12), where they find the solace of not being labelled as something stigmatising while still waiting to achieve the state of motherhood.  The discourse of infertility emphases on the social construction of infertility (16) and how such a construction shapes the decision-making process for treatment and its effect on the men and women seeking treatment. This social construction of infertility puts the onus of reproduction on women and childless women are subjected to social ridicule and stigma(17). Thus, women become the primary reproductive agents among the couple and hence the inability to reproduce challenges their ability to do so primarily. This idea that women’s bodies as the bearers of reproductive impairment within the couple in the absence of a pregnancy makes the women embody the idea that inability to reproduce is their fault (18–20).  The idea that women may be having the reproductive impairment coupled with social ridicule and facing prying questions from family and friends regarding the pregnancy status, drives them into the treatment seeking pathway. They are also worried about their future, be it their problem or their husband’s problem, the burden of care lies with the women. Women are fraught within the whole infertility conundrum, where they have to take the ‘burden’ (of infertility and its treatment) and the ‘blame’. It is their bodies that pass through the scrutiny of the family, society and the medical tests and procedures (13,21). Men are able to detach themselves from the responsibility of the blame due to the social construction of infertility and from the invasive treatments due to the biology of reproduction.  This position of women makes it imperative to prove that their bodies are functional and hence put them through the battery of invasive procedures. Here ‘hope’ that is portrayed by the technology plays a role in helping the women to prove their bodies as capable of conforming to the social norm. This also is the reason for them relentlessly going through the rigorous treatment processes, making use of 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.  When they are unable to undergo a specific test they are advised due to the recalcitrance of their husbands they perforce resort to other measures to prove themselves as functional viz., the alternate methods. Abandoning care seeking here means an end to the ‘hope’ and the many comforts that it offers. Even if it is the religious or astrological remedies, the women I had interviewed talk with such unwavering belief that they will be able to get pregnant if they follow the remedies suggested. And I was seen as someone who was there to seal their ‘hope’ and not as someone who could dispel theirs. These alternative remedies emerge out of the socio-cultural milieu of the couples’ lives and the value system that they subscribe to.  Dispelling their expectations came with the burden that there was no pragmatic solution to offer from my middle class biomedical perspective. Explaining the real nature of the problem and the potential solutions meant losing the only intangible thing that they lived with in spite of not achieving their desired goal of fertility, viz. their hope. Moreover, this hope is also inter-twined with their value system that emerges from their culture. I chose the second option in this context, given the dual problem of lack of resources and the unacceptability of donor sperms for the couples. So, I walked away completing the interviews, leaving women in the state of ‘inbetweeness’. The burden of living with that choice and not dispelling the information asymmetry between researcher and researched is my own. |
| 11. | Analysis is not carried out with reference to important literature. | I am grateful to the reviewer for providing me with the references. In addition, I also looked up the references to moral failure as a consequence of resolution of moral dilemmas. I have referred to Lebus B. Moral Dilemmas: Why They are Hard to Solve. Philos Investig. 1990 Apr;13(2):110–25. ,  McConnell T. Moral Dilemmas: The Stanford Encyclopedia of Philosophy. In: Moral Dilemmas [Internet]. Fall 2018. Metaphysics Research Lab, Stanford University; 2018. p. 18. Available from: <https://plato.stanford.edu/archives/fall2018/entries/moral-dilemmas/> and Tessman L. Moral failure : on the impossible demands of morality. Oxford University Press; 2015. to enhance my understanding and included references to the same in the paper in pages 3 lines 80-88. These are included below:  Moral dilemmas are part of the everyday practice of research(5), even though they are often not delineated as moral challenges. They are challenging because they pull a researcher in two or more equally compelling moral directions (6). In field situations a researcher tends to get mired in various interactions with individuals, some of which impose multiple obligations. It is difficult to make a choice across these multiple obligations as there is no hierarchy of morality surrounding these choices(7). The choice regarding which way to act is determined usually by the context in which the dilemma happens and the world view of the researcher (8). Even after making a choice, the rejected alternatives remain unfulfilled, making moral failure an inevitable component of the resolution (9). |
| 12. | The paper has potential, but the present manuscript lacks logical coherence, depth and rigor in its presentation. | I thank the reviewer for enabling me to strengthen the paper. |
| 13. | The paper needs a complete revision to achieve its stated objective, along with rich analysis and engagement with existing literature and studies. Detailed comments for the author have been made in a separate document. | I thank the reviewer for providing detailed comments. This enabled me to implement line by line correction, revise the paper for cohesion and continuity and attempt to clarify the point I was making better. I am not sure if it is rigorous enough, but I have tried. |

**Reviewer 2-detailed review:**

General Comments

The author provides insightful field data on doctoral work on infertility. The main objective of the author is to present the dilemmas of the researcher while carrying out the research study, particularly during the data collection stage. The presentation of data about perspectives of infertility by women in itself is significant for health studies in India. It would be helpful for readers and be of important contribution to the field of healthcare and medical ethics if the researcher provides 1) in-depth analysis and engagement with existing literature and 2) direct the readers to major objectives or arguments, rather than briefly touching upon many themes (if that is the aim, it lacks depth and require much analysis of each theme). The main concern of the present manuscript is that it doesn’t achieve the intended objective of the paper with rich analysis and engagement with literature. Also, the mentioned objective about the researcher's dilemma can be discussed in detail without much reference to data descriptions or provide the narratives where necessary. However, an in-depth analysis of data with existing literature would greatly benefit and contribute to the medical ethics debates. Also, a detailed methodology and theoretical framework need to be added if the aim is to present the data. I suggest the author refrain from presenting qualitative data quantitatively, rather provide the interpretation and analysis with thick description.

As I understand, the author engages with moral dilemmas during the fieldwork. There are many well-established literature and studies on the researcher’s dilemmas, and the ways researchers navigate and justify the decisions. I strongly suggest that the author refer to such literature, particularly on reflexivity and epistemic injustice (I have provided below some suggested readings), as I could see the conceptual argument by the author around it.

**Specific comments**

**Comment 1: Page 3 & 4, Line 31-33, 1-17**

1. Before providing your position, please do provide the research context and the brief details about the study.

**Response: This is addressed in the revised draft manuscript, in the methods section. Pages4-5, Lines: 127-147.** These are included below:

The objective of the research study was to describe the care seeking pathway of couples with infertility. The study method was a community-based survey, where 604 women who were part of a couple seeking infertility treatment (one or both of the couple were diagnosed to have a problem) were interviewed using a structured interview schedule. These women were either currently seeking care or had a history of seeking care for infertility. Care seeking is defined in the study to include all the methods adopted by the couples to resolve infertility. It includes biomedical treatment, alternate systems of medicine, alternate methods like religious methods, faith based and magic remedies, traditional medicine etc. Treatment would include here only modern medicine and AYUSH.

The study sample included women from three districts of Kerala, Thiruvananthapuram, Kottayam and Malappuram. The 14 districts of Kerala were ranked based on the expected level of infertility. 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 selected. This brought in necessary variation in the infertility treatment seeking experiences in terms of age at marriage, educational levels and religious denominations. The study documented the various treatment options used to resolve infertility across all types of centres and the reasons, if any for discontinuing treatment at specific centres.

1. While discussing your position, it would be helpful and useful for readers to know more about the larger theoretical and conceptual framework you position your study and your analysis.

**Response: The revision has been made in the draft manuscript under the methods section, page 5, line: 152-157.** These are included below:

I looked at this study from a feminist perspective. The study is rooted in the understanding that there is a social burden to infertility and that it is gendered. This means, even when the inability to reproduce is caused by male factor infertility, its burden has to be borne by women. The presence of reproductive technology which offers solutions to couples with infertility burdens women unequally when compared to the men. That these services are more frequently located in the private sector creates additional barriers to access.

**Comment 2: Methods section**

If you are retaining the data description, then detailed methodology regarding sample, data analysis and theoretical framework needs to be provided.

1. Provide the reasoning for selecting districts.

**Response: The 14 districts of Kerala were ranked based on the expected level of infertility. 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 selected. The changes has been added in the manuscript in page 5, lines: 141-144.**

1. Why the structured interview schedule was incorporated given the qualitative phenomena was the focus?

**Response: There were two different phases for the study, the first phase was an exploratory study and the third phase had the community based survey which used the structured interview schedule. The moral dilemma that I discuss here is based on the community based survey. In this draft I have only explained the community based survey which was done using a structured interview schedule. I have therefore removed references to the qualitative phase which helped to develop the interview schedule.**

1. How was the sampling of participants decided? For instance, why the number of participants was 18, and why only 2 were husbands.

**Response: This section has been removed from the manuscript.**

**But I would like to clarify this question in the study women were the primary respondents and only if the women gave permission to interview the husbands were they approached for the interview. Hence, the numbers are varying for male and female respondents. This process, among other things facilitated development of the interview schedule. References to phase I in the write up tends to add to the confusion. I have therefore removed all references to it as it was partly instrumental in so far as tool development was concerned.**

1. Provide detailed data analysis approach and method, and theoretical framework.

**Response: Provided in methods section. These are available in page5, lines 141-157.** These are included below:

The data analysis was done using R software version 1.2.1335. A descriptive analysis of the care seeking pathway of the couples across 11 centers was done. This was done to understand the treatments suggested to the couples and the reasons for transition from one center to another.

I looked at this study from a feminist perspective. The study is rooted in the understanding that there is a social burden to infertility and that it is gendered. This means, even when the inability to reproduce is caused by male factor infertility, its burden has to be borne by women. The presence of reproductive technology which offers solutions to couples with infertility burdens women unequally when compared to the men. That these services are more frequently located in the private sector creates additional barriers to access.

1. Ethical considerations of the consent for interview, and how effectively it was carried as you mention they considered you as part of the medical team given that you contacted them through ASHA worker (Page 2, line 15). What were the ethical implications of that decision and were there possible ways you could have carried out the study?

**Response: The participants were first contacted through ASHA worker, they informed the participants that someone would like to talk to them about infertility treatments that they have sought. If they were willing I visited them at their home, I felt that since ASHA worker informed them about me prior, they considered me as a person from the health system. Also they thought I was someone who was there to propose a new treatment for them. But when I personally visited each participant, informed consent was taken explaining who I was and what was the purpose of my study. Only if the participant was willing to take part in the study after hearing the purpose of the study, the interview was started. This has been explained in the section on Ethics approval page 4 line 118-123. I include the specific sentences below:** The study was cleared by the Institutional Ethics Committee of SCTIMST, the IEC clearance number SCT/IEC/1112/JULY-2018 dated 03.08.2018. Written informed consent was obtained from all the participants prior to the interview. The participants were first contacted through ASHA worker and permission was sought for interview. Only if the participant gave permission I visited them at their home. After explaining to them the purpose of the study and getting their permission did I started collecting the data.

**Comment 3: Stages of care-seeking**

Page 7, line 2- Were all the 457 women planning a family or had planned to have a child and was accessing infertility treatment? **YES**

Why there is explicit focus only on women when the study focused on couples? Please provide details.

**Response: Infertility is a condition of the couples and hence the reference to the couples. But women were the primary respondents since the study started off with a gender focus of the effect of technology on women who are infertile. Also even if women did not had any problem and male infertility was the contributing cause for infertility since the treatment happens in the female body they tend to remember the different treatments done. This has been included in page 4, line 131-134. I repeat the sentences included below:**

Women were the primary respondents in the study although the data was collected for a couple. This was because of the assumption that women may be recalling the treatment details better than men, as in most cases some form of treatment may be happen on the women’s body.

**Comment 4: Findings and discussion**

Require in-depth analysis of data along with existing literature, particularly in the discussion section. Thick description of narratives is lacking.

**Response: This is added in the draft manuscript under the moral dilemma section, Line:234-349. I repeat the sentences below:**

**The moral dilemma – to dispel hope or to leaving them with ‘hope’**

I faced dilemma while conducting the survey where I encountered repeated accounts of women reporting that they had stopped modern medicine treatment and were pursuing other systems of medicine or alternate methods to resolve infertility. The reasons cited included among the other things, that they were (read as their partners were or both were) uninterested in pursuing the particular treatment suggested by the doctor i.e., IUI or IVF specifically. They also reiterated that they were hopeful of the success of the particular remedy they were using. This has been reinforced by them by pointing out anecdotal accounts of people who had a positive outcome by that means.

In these situations, I was confused as to whether to explain to them that this is false hope and they should seek treatment or continue the treatment suggested by their biomedical doctor. I think my strong affinity towards modern medicine stemmed from the biomedical perspective that shaped by my training. I came from the biomedical school, and hence my reluctance to acknowledge the positive effects if any of the alternate system of medicine. I did not have the scholarship to understand the working of this system. I also believed that the alternate methods like religious methods or eating some traditional powders were not going to give them positive results.

But on further reflection, I was confronted with the thought that whether it would it be right to dispel the ‘hope’ that makes them lead their life as it is? In certain cases, when the couples were diagnosed with absolute male infertility, the use of donor sperm was the only available biomedical option. I was sure in such cases that the participant was never going to undergo that treatment due to personal, cultural and religious reasons. The dilemma was whether it was worth dispelling the ‘hope’ with which people lived in or provide accurate information about their situation, of course from a biomedical perspective.

The second dilemma concerned the option of informing the couples that the only method is to undergo IVF which is an expensive treatment with less than 40% (14) chance of being successful( while the mean live birth from one cycle and its subsequent cryo-cycles was only 33%) (14). Many of those in these situations were of low socio economic status and it was not clear to me as to whether resorting to these treatments that do not provide 100% success is worth their money. Most of the respondents in the survey were of middle socio-economic status across all the three districts. Approximately 50 percent of the respondents were Hindu while 33 percent were Muslim and 17 percent were Christian. Majority of the respondents were educated more than high school level, and only 0.3 percent were illiterate. This was again a judgement call that I was making on the basis of my own middle-class values, both judging their socio-economic contexts and their biological options.

I approached the participants with an assumed position of ‘knowing’ (15), I was both knowledgeable of the particular issue under study and I was also empathetic towards the women who were going through this whole infertility conundrum. Being a woman with a reproductive body enabled me to empathise with these women at a more personal level and hence it was difficult for me to cut their one fine thread of ‘hope’ that they were holding on to. And I also assumed a position of power in the field, because I was talking to them from within the health system. So I had to be cautious of the my responses since the role I assumed and the one assigned to me by my participants would have jeopardised their ‘hope’.

Stopping the care seeking for infertility altogether means that they no longer can dwell in the ‘hope’ that gave them the power to stay in the state of childlessness and pursue the exhausting treatments. It is also this ‘hope’ that has pulled them together by a narrow thread between the state of being able to achieve a pregnancy and the potential of being labelled as barren for the rest of their lives, even when the infertility is contributed by the reproductive impairment of the partner. When the norm of the binding binary that is prevalent in most categorisations, the state of belonging to the category of infertile is not something one wants. When the ability to move to the category of not infertile is hampered or is delayed, one would like to remain in the space between the two i.e., between of the categories. ‘Inbetweeness’ as mentioned by Probyn (12)is the movement that happens when the wish to belong is there. So the women may wish to be in this safe space of “inbetweeness”[[4]](#footnote-4) (12), where they find the solace of not being labelled as something stigmatising while still waiting to achieve the state of motherhood.

The discourse of infertility emphases on the social construction of infertility (16) and how such a construction shapes the decision-making process for treatment and its effect on the men and women seeking treatment. This social construction of infertility puts the onus of reproduction on women and childless women are subjected to social ridicule and stigma(17). Thus, women become the primary reproductive agents among the couple and hence the inability to reproduce challenges their ability to do so primarily. This idea that women’s bodies as the bearers of reproductive impairment within the couple in the absence of a pregnancy makes the women embody the idea that inability to reproduce is their fault (18–20).

The idea that women may be having the reproductive impairment coupled with social ridicule and facing prying questions from family and friends regarding the pregnancy status, drives them into the treatment seeking pathway. They are also worried about their future, be it their problem or their husband’s problem, the burden of care lies with the women. Women are fraught within the whole infertility conundrum, where they have to take the ‘burden’ (of infertility and its treatment) and the ‘blame’. It is their bodies that pass through the scrutiny of the family, society and the medical tests and procedures (13,21). Men are able to detach themselves from the responsibility of the blame due to the social construction of infertility and from the invasive treatments due to the biology of reproduction.

This position of women makes it imperative to prove that their bodies are functional and hence put them through the battery of invasive procedures. Here ‘hope’ that is portrayed by the technology plays a role in helping the women to prove their bodies as capable of conforming to the social norm. This also is the reason for them relentlessly going through the rigorous treatment processes, making use of 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.

When they are unable to undergo a specific test they are advised due to the recalcitrance of their husbands they perforce resort to other measures to prove themselves as functional viz., the alternate methods. Abandoning care seeking here means an end to the ‘hope’ and the many comforts that it offers. Even if it is the religious or astrological remedies, the women I had interviewed talk with such unwavering belief that they will be able to get pregnant if they follow the remedies suggested. And I was seen as someone who was there to seal their ‘hope’ and not as someone who could dispel theirs. These alternative remedies emerge out of the socio-cultural milieu of the couples’ lives and the value system that they subscribe to.

Dispelling their expectations came with the burden that there was no pragmatic solution to offer from my middle class biomedical perspective. Explaining the real nature of the problem and the potential solutions meant losing the only intangible thing that they lived with in spite of not achieving their desired goal of fertility, viz. their hope. Moreover, this hope is also inter-twined with their value system that emerges from their culture. I chose the second option in this context, given the dual problem of lack of resources and the unacceptability of donor sperms for the couples. So, I walked away completing the interviews, leaving women in the state of ‘inbetweeness’. The burden of living with that choice and not dispelling the information asymmetry between researcher and researched is my own.

**Comment 5: Moral dilemma**

The objective of this paper is about the moral dilemma of the researcher, however, the author has not provided rich analysis and in-depth discussion regarding the researcher’s positionality and the ethical implications within the research study. I strongly suggest the author engage with existing literature on reflexivity and the related themes around the emancipation and empowerment as well as a critical theoretical approach which suggests ways of doing ethnography. The author’s moral decision and positionality needs to be situated and discussed in the background of context and ethical arguments.

**Response: A section on the moral context is added and positionality is also added in the draft manuscript.**

**Line:80-114. I am including those sentences below:**

**Moral Contexts**

Moral dilemmas are part of the everyday practice of research(5), even though they are often not delineated as moral challenges. They are challenging because they pull a researcher in two or more equally compelling moral directions (6). In field situations a researcher tends to get mired in various interactions with individuals, some of which impose multiple obligations. It is difficult to make a choice across these multiple obligations as there is no hierarchy of morality surrounding these choices(7). The choice regarding which way to act is determined usually by the context in which the dilemma happens and the world view of the researcher (8). Even after making a choice, the rejected alternatives remain unfulfilled, making moral failure an inevitable component of the resolution (9).

This article explores the moral dilemmas I faced as a researcher while interviewing women who at the time of interview were not pursuing the treatment for infertility suggested by the treating medical professional. The treatments suggested by the professional from a medical perspective was the only possible method that could offer a potential solution to their problem. The couples had either abandoned all kinds of allopathic treatments or were trying other systems of medicine or alternate forms of remedy.

**Positionality of researcher**

It is important here to state my position as that would enable readers understand the dilemmas I faced. First and foremost being a woman researching this particular problem, I was not able to detach my reproductive body from the women I was interviewing. I could feel for myself how the meaning of motherhood resonated with those women. I am also a trained nurse and a public health doctoral student studying the infertility treatment seeking pathway of couples. As a trained person in modern medicine and a researcher looking into the infertility treatment seeking pathway, I have sufficient understanding of infertility and its treatment. But I was not a specialist doctor who would have been able to suggest with definite authority that a certain treatment was better than the other for the participants in my study. I do have a strong biomedical orientation due to my training. I had approached the participants of the study through the health system and most of my participants were informed of my research topic by the health system representative, the Accredited Social Health Activist (ASHA worker). She in turn had informed them that someone will be coming to talk to them about their care seeking for infertility. Hence for the participants, I also embodied ‘hope’ as someone who could offer them some sort of help to bring in resolution to their problem.

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1. A term used by Elspeth Probyn to denote the “the constant way that one is always in between two languages, cultures, and histories ” [↑](#footnote-ref-1)
2. Here, when I refer to IUI or IVF it also includes those using donor sperms for fertilization in some cases [↑](#footnote-ref-2)
3. A term used by Elspeth Probyn to denote the “the constant way that one is always in between two languages, cultures, and histories ” [↑](#footnote-ref-3)
4. A term used by Elspeth Probyn to denote the “the constant way that one is always in between two languages, cultures, and histories ” [↑](#footnote-ref-4)