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

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Short title: **Moral dilemmas of research on infertility treatment seeking**

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***Abstract:*** *Infertility is a condition that has inherent cultural significance. Its presence in married couples fuels speculations and assigns certain demeaning identities. The availability of technically advanced treatments for infertility provides ‘hope’ to couples and women in particular to resolve these assigned identities due to the diagnosis of infertility. Care seeking for infertility is a vicious loop of success and failure and hence there is movement from one stage to another hoping for a resolution.*

*The paper focuses on the dilemmas of a medically trained public health researcher during the research with women who were unable to continue the suggested mainstream treatment but were continuing in the pathway by resorting to alternative but unlikely to succeed methods. The dilemma between the need to explain the unlikelihood of success as opposed to leaving them with ‘hope’ is discussed.*

Key words: moral dilemma, hope, inbetweeness, infertility

**Introduction**

A diagnosis of infertility fills those receiving it with a range of emotions and distress(1). A state of desperateness(2)confronts couples who face the inability to start a family. Assisted Reproductive Technology (ART) has the power to create ‘hope’(3)in the minds of those ‘desperate’ couples who are left with no other option to start a family. It is also assumed that those not attempting this so called miracle technology are at the receiving end of social ridicule for their lack of interest in starting a family(1). Since the treatment for infertility is both emotionally and physically exhausting and is filled with multiple failures at different points, couples are likely to want to abandon treatment at some point on the pathway to treatment. Even though individual couples who do not meet with success do give up treatment, overall, the number of couples taking recourse to the use of such technology is increasing. The presence of the technology is welcomed by women, and they are pleased that this gives them at least a chance to achieve their dream despite the risks(2). This high praise for the technology is demonstrated by Franklin (2) in her study, quoting that the women who were in the middle of the treatment cycle were all full of ‘hope’, meaning the women are not sure whether such a technology works for them or not. Here she adds that the desirable outcome need not only encompass the presence of a fruitful pregnancy but having given a try was more important than the very success of the treatment for these women. In this context, putting an end to the pursuit of having a child means the end of hope in their lives. The very hope that enabled them to persevere with treatment for infertility overcoming the multiple stressors including failure to achieve a child, also helps them to deny the potential childlessness(4).This means that trying the different treatment methods that are available out there was of utmost importance before completely abandoning the treatments.

There are ethical and moral dilemmas in every kind of research and it is a part of the everyday practice of research (5). But the dilemmas varied in different circumstances, it could be tangible and intangible. Moral dilemmas are challenging because there are often seem to pull in opposite directions(6).It becomes difficult to choose the morally right actions in personal interactions with other human beings when you are subjected to conflicting obligations.

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 suggested by the doctor, which at a medical level was the only possible method that could offer a potential solution to their problem. They were either not taking any kinds of treatments or were trying other systems of medicine or alternate forms of remedy.

It is important here to state my position so as to enable the 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 medically trained person in the modern medical tradition 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 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) that someone will be coming to talk to them about their treatment. 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.

**Ethical considerations**

The study was designed in multiple phases. The qualitative component constituted phase 1 and the quantitative survey component constituted phase 3 of the study. The phase 1 qualitative study and the phase 3 survey was cleared by the Institutional Ethics Committee of SCTIMST, the IEC clearance number for Phase 1: SCT/IEC/1112/NOVEMBER-2017 dated 23.11.2017 and for phase 3: SCT/IEC/1112/JULY-2018 dated 03.08.2018. Written informed consent was obtained from all the participants prior to the interview. The names of the respondents where ever they appear are changed to maintain anonymity.

**Methods**

In this article I would like to discuss the moral dilemmas encountered during the data collection. The identification of these dilemmas will be supported by the empirical evidence from the narratives from the qualitative component of the study and the survey data of women with the history of treatment sought for infertility. This study used both qualitative and quantitative methods to collect the data on the treatment seeking pathways of infertility. It was done in Thiruvananthapuram, Kollam, Kottayam and Malappuram districts. This gave the wide variation in the nature of participants with respect to their age at marriage, education, and religious denomination. This was important in infertility research specially when dealing with the treatments like In Vitro Fertilisation (IVF), artificial insemination etc.

The first phase was the qualitative phase, which was done in Thiruvananthapuram and Kollam districts of Kerala state, India. In this phase a total of 18 persons,16 women and two husbands (of the participants) were interviewed. Out of these only three were upper middle class, rest of the women belonged to lower and middles class socio-economic status. At the time of interview, eight had children born through treatment and via adoption (two women), others were either continuing treatment or has not yet initiated formal treatment for their fertility problem, while some had discontinued formal treatment. The infertility diagnosis of the couples included male factor, female factor and unexplained causes. The female factor included women with PCOD, tubal blockage and primary ovarian failure. Male factors included mainly azoospermia. The respondents were asked to elaborate on their care seeking pathway for infertility. The results of the exercise described why and how the couples seek care for infertility.

The community-based survey was done among 605 women who were either seeking care for infertility or had history of treatment seeking for infertility. It was done in three districts of Kerala viz., Thiruvananthapuram, Kottayam and Malappuram using a structured interview schedule.

The qualitative findings helped to ground the rationale for the deliberation of multiple centres by the couples for the treatment and during the quantitative phase of the study the actual treatment seeking pathway was elicited using interview schedule to understand the exact movement of the couples within the treatment seeking trajectory. While the whole process was morally challenging in multiple ways, this paper discusses the particular dilemma that I faced while interviewing women who were in the care seeking pathway, using a structured interview schedule.

The following sections situates the care seeking for infertility in Kerala by explaining how and why couples seek care for infertility. This will be followed by demonstrating the pathway of those who decide to deviate from the conventional modern medical treatment to other systems of medicine or alternate forms of finding a resolution to their problem and the reasons for it. I conclude by highlighting the specific moral dilemma that I faced undertaking this research.

**Stages of care-seeking**

There are mainly three to four stages of care seeking and depending on each couples’ characteristics the stage varies in length of time. First is a self-identification stage, where the couples think they may be having difficulty to get pregnant, which puts them into the next stage which is the initiation of treatment seeking, which is followed by the actual treatment stage, which is replete with multiple trajectories and finally the treatment discontinuation stage.

The treatment for infertility takes multiple trajectories with long or short breaks and the trajectory of care has couples resorting to alternative modes of care to find a solution to the problem. The care seeking for infertility lasts one month to many years depending on the reproductive impairment that the couple has along with other physical and structural factors in treatment seeking.

The couples usually start care-seeking with modern medicine. The treatment seeking starts with the initial investigations and diagnostic evaluations. The subsequent visits serve to decide on further action depending on the results of the preliminary investigations. This phase continues for a minimum of few days to less than 6 months at one centre, after which there is a tendency to seek care in another centre if the couple is unable to get a definitive diagnosis. If a diagnosis is made, then the next phase of the treatment is deliberated at the same centre, while another centre may be considered if the expected result is not achieved.

The treatment phase is usually the longest and can range from 6 months to many years with multiple breaks, different trajectories, and changes of site. This phase is where the couples are drained physically and emotionally due to different invasive procedures with both success and failure as outcomes. The treatment phase usually is characterised by multiple trajectories where the couples use different systems of medicines or different kinds of options being tried, sometimes even simultaneously. This phase can be shorter or longer for different couples. It is shorter for those who achieve the desired result earlier or those who abandon the treatment in between.

A total of 605 women were interviewed regarding their treatment seeking pathway, out of which 75.5% (457) of the women did not have a child at the time of interview and they were either continuing treatment(35.9%), stopped treatment completely (24.1%), were taking a break from treatment (36.8%), others mentioned that the doctor asked them to wait, or that partner was unwilling or they were trying religious methods (3.2%). Table 1 below shows the status of treatment of women who were not having child at the time of interview.

Table1: The status of treatment for women who did not have a child at the time of interview, (n=605)

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Status of women**  **at the time of interview** | | Continuing treatment | Stopped treatment completely | Taking break from treatment | Partner un-willing to continue | Currently no treatment suggested | Trying religious methods |
| No child | 457  (75.5%) | 164  (35.9%) | 110  (24.1%) | 168  (36.8%) | 1  (0.2%) | 12  (2.6%) | 2  (0.4%) |
| Had child/  Pregnant | 148 (24.5%) | - | - | - | - | - | - |

Women visited any number of centres, from to 1 to 12 centres at the time of interview, with some continuing to seek treatment, some dropping out of treatment temporarily and others stopping treatment permanently. Out of the total 605 women who were interviewed, at the time of interview- 494 (81.7%) women had visited at least two centres, 366(60.5%) visited at least three centres, 249(41.2%) visited at least four centres and approximately one-fourth (23.8%) of them visited at least five centres. While a little more than half of those who visited at least five centres took to a sixth centre (13.6%), similarly only 7.6% continued in the treatment trajectory by visiting a seventh centre. Only half of those who visited at least seven centres moved on to an eighth centre(3.6%), and only 9 (1.5%) visited at least 9 centres and only 5 (0.8%) proceeded to the tenth centre. Only one person (0.2%) persisted the pathway of care seeking by visiting 11 centres.

Among those who were still continuing the treatment at the time of the interview,20% visited at least 2 centres. While those who had stopped all treatment, maximum of 12 centres has been visited by the women with 20.9% of them having visited at least 3 centres. Those who were on break from treatment, 10 centres has been visited and among them 21.4% had visited at least 3 centres during the time up to the interview.

Examining the couples’ progress from centre (n) to centre (n+1), there are some who drop the first centre due to not wanting to continue the treatment that was suggested. Here, when the treatment suggested was IUI or IVF[[1]](#footnote-1), there is chance that they may drop the particular centre and proceed to the next or they may stop treatment altogether.

**Why do the couples seek care?**

This section aims to give the rationale to my arguments on the moral dilemmas as a researcher confronted with the women who were unable to proceed with the suggested treatment. This doesn’t mean they take themselves out completely from the care pathway, except for a few.

The discourse of infertility emphases on the social construction of infertility(7) 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. Thus, women become the primary reproductive agents among the couple and hence the inability to reproduce challenges their ability to 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(8–10). This in turn also makes the men embody this notion that reproductive impairment can happen only in the women’s bodies. This is drawn from the narratives of the women reinforcing the idea that reproductive responsibilities are embodied in women. Here they add that the men believe that they may not harbouring any problems which means that they also go with the popular notion that it will be the women’s body that may be having the problem.

*“Husband thought he did not have any problem I will be having problem but when the results came he became upset.”* (Alice,38 years, Husband having azoospermia)

*“…that time this operation* (for husband-Varicocelectomy)*and all he had and then they*(family members) *came to know but still they were not able to accept that they said we were saying this to cover up”*(Alice, 38 years, Husband having azoospermia)

*“What we read and hear, in everything what is being told is being a woman is getting pregnant and having a baby, after that only there are other things.”*(Elizabeth, 62 years, Unexplained infertility)

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(11,12). 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.

This also means when they are unable to undergo a specific test that they are advised due to the recalcitrance of their husbands to continue the treatment they may resort to other measures to prove themselves as functional viz., the alternate methods.

**Women who are left “hopeless”**

These are women who were not undergoing any modern medicine treatment at the time of interview, i.e., are those who had either abandoned all the treatment (24.1%)or those who were in the initial phase or treatment phase but were on a break from the treatment (36.8%).

There are some couples who decide to not further the treatment suggested by the treating doctor due to various reasons. Mostly the abrupt decision to abandon the treatment happens when the absolute male factor is the reason for the infertility in the couple. Here the treating doctor may suggest a particular method to achieve the desired outcome but the couple or either of the partners may be unwilling to undergo that treatment.

*“In xxx hospital they told about test tube[…] then they told about another sperm, that we were not interested so we said no”*(Shirley, Husband having azoospermia)

*“we went to xxx clinic because people were telling those who did not have children had after going there. So one of our friend who went there and asked us to go there. But we did not know this that they are injecting and that is how children are born. People outside doesn’t know. It is injecting other’s sperm in our uterus, like that. We have to stay there. So my husband told we don’t want. We did all the tests there. […] We gave all the tests results from all the places and the doctor did my tests. Then he told since I have AB negative blood it will be difficult to have child. So we will inject donor sperm, since AB negative and positive there will be problem. So I understood they are taking money and injecting others sperm and give children. So they asked us to come again, but we did not go. My husband was afraid.”* (Ancy, Husband having azoospermia)

During the survey the researcher encountered many 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 attempt IUI 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 is suggested. These women reported that they were not interested in undergoing ART treatments as they were not sure of the sperm that will be used to impregnate.

*“When we went to xxx hospital they told 3 lacs when I talked to people there, only 5 people will only get success out of 1000 and then if successful also getting a normal child is difficult and they may not use our semen, even if they tell they will be using our semen”* (Husband- Mini)

They are confused by the understanding that if their partner has sperms, then why do they have to undergo the ART procedure? In many cases they also cited 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 sperms. 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 those who were suggested IUI as the method of treatment were 32(5.3%), and IVF as the method was 128 (21.2%). Out of which 115 (19.0%) did not want to continue the treatment suggested by the doctor. Among those who were suggested IUI, 40.6% and those suggested IVF, 62.5% did not pursue it since they were not interested in continuing the suggested treatment.

In different centres the couples will be suggested different treatments and due to many reasons couples tend to stop treatment at a particular centre and may proceed to the next or stop treatment. When such movement happens 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 1 and 2, when couples move from centre 1 to centre 2 and from centre 2 to centre 3. Table 2 shows the transition of couples from one centre to another.

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=605 | Suggested treatment in this centre  (Centre 1) | | Discontinued since not want to continue the suggested treatment | | Ayurveda or Homeopathy or alternate methods as next point of care by those who were suggested | |
| IUI | IVF | IUI | IVF | IUI | IVF |
| Yes | 494  (81.7) | 5  (1.0) | 11  (2.2) | 2  (40.0) | 7  (63.6) | 4  (80.0) | 4  (36.4) |
| No | 111 (18.3) | 2  (1.8) | 3  (2.7) | - | 1  (33.3) | - | - |

It is also to be noted here that among the couples who were seeking treatment in the first centre, 39 (6.4%) had undergone IUI, and 1(0.7%)had undergone IVF. While this has increased to 42 (8.5%) who had undergone IUI and 8 (1.6%) had undergone IVF in the second centre.

Table 3:The transition of couples from centre 2 to centre 3, when IUI or IVF is suggested as the treatment

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | n=494 | Suggested treatment in this centre  (Centre 2) | | Discontinued since not want to continue the suggested treatment | | Ayurveda or Homeopathy or alternate methods as next point of care by those who were suggested | |
|  | Another centre visited | IUI | IVF | IUI | IVF | IUI | IVF |
| Yes | 367  (74.3) | 4  (1.1) | 28  (7.6) | 2  (50.0) | 19  (67.9) | 2  (50.0) | 8  (28.6) |
| No | 127  (25.7) | 4  (3.2) | 6  (4.7) | 1  (25.0) | 2  (33.3) | - | - |

This means that those who not wanting to undergo IUI or IVF mainly because they assume or they are told a donor sperm will be part of the treatment.

The decision to stop the treatment means that they are to exit the pathway of care seeking which would also mean that now the women is in a state of limbo regarding her body. 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- Mucuna pruriens) powder in milk, astrological remedies, eating other “divinised” things like banana, ghee to achieve pregnancy.

**Care-seeking pathway with multiple trajectories with alternate systems and methods**

Figure 1 shows the treatment pathway of a couple who had gone to multiple centres and has also tried alternate methods to treat their problem. The couple had postponed pregnancy for almost two years after marriage. They later started seeking treatment when the pregnancy did not occur when they tried. This along with the social pressure put them in the treatment seeking pathway. They started at centre 1 and got a diagnosis, here the male factor infertility was the cause for the inability to get pregnant. The husband had azoospermia, where there is absence of sperms in the ejaculate. They took treatment from two other centres to finally abandon the treatment altogether since the only treatment that the doctor suggested was to undergo IVF with a donor sperm. This put them into resorting to alternate methods like taking ayurvedic powders, folk remedies suggested by people to increase sperm count, taking some ghee and banana that were divinised by some faith healers[[2]](#footnote-2). These alternate methods were tried at multiple centres, and have even visited the astrologer who had reassured that they will get pregnant and hence continue to pursue the alternate methods.

Initiation of treatment seeking

Referred to Urologist

Diagnosis made

Care

Seeking

Pathway

Treatment phase

Exit care seeking pathway

Pregnancy

Surgery suggested

Stopped treatment

Ayurvedic powder

Faith healers

Astrological remedies

Folk remedies

Remedies for “dosham”- viz., Sarpadosham\*

Suggested IVF

Stopped treatment

Figure 1: Showing the care-seeking pathway of a couples with multiple trajectories

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

I faced dilemma in these situations as to whether to explain to them that this is false hope and they should seek treatment. This also stemmed from the strong biomedical perspective that shaped my nursing and public health training. Would it be right to dispel the hope that is makes them lead their life as it is? In certain cases, the use of donor sperm is the only available biomedical option and the researcher is sure that the participant is never going to undergo that treatment due to personal and cultural reasons. The dilemma was whether it was worth dispelling the hope with which people lived in need to provide accurate information about their situation.

The second dilemma concerned the option of informing the couples that the only method is to undergo IVF which is an expensive treatment and has less than 40%(13) chance of being successful( while the mean live birth from one cycle and its subsequent cryo-cycles was only 33%)(13).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. 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.

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 to be labelled as barren for the rest of their lives, even when the infertility is contributed by the reproductive impairment of the partner. Or it could be called that safe space of “inbetweeness”[[3]](#footnote-3) (14), where they find the solace of not being labelled as something stigmatising while still waiting to achieve the state of motherhood. Abandoning care seeking means an end to the hope and the many comforts that if offered to them. 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. 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.

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1. Here, when I refer to IUI or IVF it also includes those using donor sperms for fertilization in some cases [↑](#footnote-ref-1)
2. This includes those people who were called in Kerala context as “japikkunavar”(in Malayalam), “people who get possessed by spirits”. Here it is loosely translated as ‘faith healers’.

   \*The wrath of the serpent God [↑](#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)