

**FROM DIAGNOSIS TO PARENTHOOD: EVENT HISTORY ANALYSIS  
OF INFERTILITY TREATMENT TRAJECTORIES  
IN KERALA, INDIA**

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**SREE CHITRA TIRUNAL INSTITUTE  
FOR  
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Thiruvananthapuram**

**FROM DIAGNOSIS TO PARENTHOOD: EVENT HISTORY ANALYSIS  
OF INFERTILITY TREATMENT TRAJECTORIES  
IN KERALA, INDIA**

A THESIS PRESENTED BY

**SUNU C THOMAS**

TO

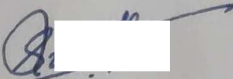
THE SREE CHITRA TIRUNAL INSTITUTE FOR  
MEDICAL SCIENCES AND TECHNOLOGY, TRIVANDRUM  
Thiruvananthapuram

IN PARTIAL FULFILMENT OF THE REQUIREMENTS  
FOR THE AWARD OF  
**DOCTOR OF PHILOSOPHY**

**2020**

### DECLARATION BY STUDENT

I, Sunu C Thomas hereby certify that I had personally carried out the work depicted in the thesis, entitled, "**From diagnosis to parenthood: Event history analysis of infertility treatment trajectories in Kerala, India**". No part of the thesis has been submitted for the award of any other degree or diploma prior to this date.

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Date: 3.12.2020



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This is to certify that **Ms. Sunu C Thomas**, in the department of **Achutha Menon Centre for Health Science Studies** of this institute has fulfilled the requirements prescribed for Ph.D. degree of the Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum.

The thesis entitled, "**From diagnosis to parenthood: Event history analysis of infertility treatment trajectories in Kerala, India**" was carried out under my direct supervision. No part of the thesis has been submitted for the award of any other degree or diploma prior to this date.

Clearance was obtained from the Institutional Ethics Committee for carrying out the study.

Signature:  

Date: 3/12/2020

## **APPROVAL OF THESIS**

The thesis entitled

**From diagnosis to parenthood: Event history analysis  
of infertility treatment trajectories  
in Kerala, India**

Submitted by

**SUNU C THOMAS**

for the degree of  
Doctor of Philosophy

of

**SREE CHITRA TIRUNAL INSTITUTE  
FOR  
MEDICAL SCIENCES AND TECHNOLOGY, TRIVANDRUM  
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Is evaluated and approved by



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**Dr Mala Ramanathan, Guide**



**Sivakami Muthusamy  
(Name of the thesis examiner)**

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## ABBREVIATIONS

AID	Artificial Insemination with Donor Sperm
ASFR	Age Specific Fertility Rate
ASHA	Accredited Social Health Activist
ASMFR	Age Specific Marital Fertility Rate
ASRM	American Society of Reproductive Medicine
ART	Assisted reproductive Technology
AYUSH	Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homeopathy
CDC	Centres for Disease Control and Prevention
CEB	Children Ever Born
CFR	Cumulative Fertility Rate
DHS	Department of Health Services
DLHS	District Level Household Survey
ESHRE	European Society of Human Reproduction and Embryology
GIFT	Gamete Intrafallopian Transfer
GP	Grama Panchayat
ICMART	International Committee for Monitoring Assisted Reproductive Technology
ICMR	Indian Council of Medical Research
ICPD	International Conference on Population and Development
ICSI	Intra Cytoplasmic Sperm Injection
IFFS	International Federation of Fertility Societies
IVF	In Vitro Fertilisation
IVF-ET	In Vitro Fertilisation-Embryo Transfer
IUI	Intra Uterine Insemination
MESA	Micro-Epididymal Sperm Aspiration
MoHFW	Ministry of Health and Family Welfare
NICE	National Institute for Health and Care Excellence

NFHS	National Family Health Survey
NHM	National Health Mission
NSSO	National Sample Survey Office
OBC	Other Backward Class
PCOD	Poly Cystic Ovarian Disease
PESA	Percutaneous Epididymal Sperm Aspiration
PID	Pelvic Inflammatory Disease
RCOG	Royal College of Obstetricians and Gynaecologists
SC	Scheduled Caste
SRH	Sexual and Reproductive Health
ST	Scheduled Tribe
TESA	Testicular Sperm Aspiration
TET	Tubal Embryo Transfer
TFR	Total Fertility Rate
WHO	World Health Organisation
ZIFT	Zygote Intrafallopian Transfer

## SYNOPSIS

Infertility is a major reproductive health problem affecting a significant proportion of couples. The experience of infertility is shaped by the social and cultural context of the individual and hence the inability to reproduce causes social, psychological and emotional consequences for the couples, particularly women. Individual desire to achieve parenthood and also the fear of the social consequences mainly initiates care seeking. Even though a majority of couples initiate treatment, a sizeable proportion discontinue treatment before achieving the desired results. This discontinuation is due to various factors viz., spontaneous conception, emotional distress, financial limitation and/or not wanting to continue the suggested treatment. It is reported that the premature cessation of treatment can affect the treatment success.

Fertility treatment has different stages in the treatment cycle from diagnostic workup to medical and surgical management to undergoing assisted conception. Although allopathy or treatment using modern medicine is the first choice for infertility care, multiple treatment methods are used by the couples for resolving infertility.

According to DLHS-3 (2007-08), among those who had primary infertility only 65 percent had used allopathic treatment. This means that 35 percent did not access any form of treatment or used other systems including traditional healers. So, when treatment seeking patterns for infertility is studied in a clinical setting, a comprehensive picture of the care pattern is lost. This is because not everyone will be seeking care for infertility and among those who seek care not all will be able to access and afford Assisted Reproductive Technology (ART) treatments. From a public health perspective, the population level understanding is needed for planning and evolving policy changes for infertility care in the country. Moreover, studying it using a medical perspective without a theoretical backing may narrow the focus. It also impedes getting a comprehensive understanding of the motivation behind the stated reasons for discontinuation.

In this context, it is important to identify the actual trajectories of mitigation that exist in practice and identify the stage of the infertility journey in which a couple choose a

particular method and when they choose to move from a particular stage of care seeking to another. This research is an exercise in explicating the practical choices exercised by the couples for infertility care in Kerala.

The fertility rates in Kerala, as measured by the Total Fertility Rate (TFR) is below replacement levels. This means other things remaining constant, given the low fertility levels, the population size would reduce in the long run. The relatively lower levels of fertility in Kerala and the postponement of pregnancy by women, means that women in Kerala may be in need for infertility care services. Given the fact that fecundity decreases with age, with rising age at first pregnancy the probability of getting pregnant declines. The DLHS-3 (2007-08) reported that in Kerala nearly 11 percent of ever married women in the ages 15-49 had infertility and out of which 86 percent had sought care for infertility. Barring this information, we do not know from where the care was sought and whether such care yielded a desired outcome. There has not been any systematic effort to understand care seeking for infertility at the population level. Considering the fact that infertility care is expensive and mostly concentrated in the private sector in Kerala, it is important to understand the extent and nature of care seeking for infertility in the state. Currently, treatment for infertility especially ARTs, is not a public health priority in the country. In the absence of any centrally sponsored or state mandated reimbursement schemes for infertility treatment, couples have to meet the costs involved through out of pocket expenditure. In these circumstances, it is important to understand whether couples who enter the care seeking pathway are able to sustain it or if they were negotiating alternatives to these medical means to achieve pregnancy. Therefore, the present study seeks to understand how couples with infertility seek care in Kerala.

The objectives of the study were:

1. to understand the trajectories of care seeking for resolution of infertility among couples and to identify reasons for these choices to resolve infertility,
2. to get the estimates of expected levels of infertility for Kerala and its districts and analysing the age pattern of infertility in these districts,
3. to describe the care seeking pathway for infertility among couples with infertility in Kerala,

4. to examine the inequalities in the care seeking for infertility by couples with infertility in Kerala and
5. to describe the infertility specific distress, in women undergoing treatment for infertility and to understand the possible consequences of infertility for women.

This study used a multiphase mixed methods design with three phases for which data collection was undertaken between November 2017 and May 2019. The first phase of the study used a qualitative design with in-depth interviews of women with infertility. This phase enabled an understanding of the trajectories of care seeking for resolving infertility by couples and to identify reasons for these choices. The results of this phase enabled the development of an interview schedule for phase III of the study. The second phase used data from the Census of India 2011 to estimate the expected levels of infertility and age patterns of infertility for Kerala and its districts. The districts were ranked by the expected levels of infertility to facilitate selection of study sites for the third phase of the study. The health care services in Kerala is discussed using available data and published materials on the health care institutions and utilisation. The third phase used both quantitative and qualitative methods concurrently to describe the care seeking pathway for infertility and examined the inequalities in care seeking. The qualitative component used in-depth interviews to describe the infertility specific distress in women undergoing treatment and to understand the possible consequences of infertility for women. In this study I refer to care seeking to include all the treatments used by the couples to treat infertility i.e., Allopathy, Ayurveda, Homeopathy and alternate methods like traditional or magico-religious remedies. Here I use Allopathy to refer to the conventional western medicine, it is also called biomedicine, mainstream medicine or western medicine.

All three phases of the study were cleared by the Institutional Ethics Committee of Sree Chitra Tirunal Institute for Medical Sciences and Technology. Phase I of the study was cleared by the IEC vide SCT/IEC/1112/NOVEMBER-2017 dated 23.11.2017 and phases II and III were cleared by the IEC vide SCT/IEC/1112/JULY-2018 dated 03.08.2018.

Using data from the Census of India 2011, infertility levels were estimated using both direct and indirect measures. The indirect measures were computed using the period based TFR which used all women irrespective of their marital status (Estimate 1) and the total marital fertility rate (TMFR) which used ever married women (instead of currently married women) (Estimate 2) using a method suggested by Pandey and Suchindran. The expected level of infertility in Kerala among all women was 168 per 1000 women, this measure cannot be a true reflection of the actual levels, while the expected level for Kerala was nearly six percent for ever married women. The direct measure used the '0' parity among ever married women in the age group 45-49 years (Estimate 3), and it was found to be 58 per 1000 ever married women in Kerala. The TMFR based estimate was higher than the state level for the southern districts compared to the northern districts, except Kozhikode. The direct measure (the number of women with '0' parity among ever married women aged 45-49) was higher than the state levels in the northern districts except Wayanad which had the lowest expected level of infertility at 45-49 years compared to the southern districts except Thiruvananthapuram. Given the lower age at marriage in the northern districts, the higher observed expected levels may be due to male out migration in these districts. The age pattern of infertility was estimated using the cohort based Children Ever Born (CEB) and period-based Cumulative Fertility Rate (CFR) measure. The difference between the CEB based measure and the CFR based measure indicate the potential improvement in fertility over time which gives rise to lower levels of infertility using the CFR as opposed to the CEB. The results indicate that up to age 30-34 years, the decline in levels of infertility was sharp. This is indicative of the natural decline owing to the fact that these are the prime reproductive ages for women. But from ages 30-34 to higher age groups, the decline in the expected levels of infertility slowed down. To understand the potential bridging of the infertility gap through medical intervention we computed the index of infertility using the extent of completed fertility up to the age 34. The index values were relatively higher in the northern districts of Kasaragod (0.40), Kannur (0.45), Kozhikode (0.35) and Malappuram (0.41). Nearly 40 percent reduction was observed in northern districts beyond age 34 compared to 20 to 25 percent in southern districts, which may be due to medical interventions.

The examination of the health care services and utilisation in Kerala indicated a stagnation in the growth of the public sector compared to the private sector. The better extent of use of formal medical care and utilisation of private sector for minor ailments was noted in Kerala compared to the rest of India. This is indicative of the privatisation and the medicalisation of health care in Kerala. The situation vis-à-vis reproductive health is also no different, the near universal institutional delivery is noted in the state and a major proportion of it is happening in the private sector.

The context and process of care seeking was explored by interviewing 16 women and two men who were husbands of the women. Due to the social construction of infertility, there was a social expectation that a married woman has to procreate within a certain period after marriage. The need to avert the blame of infertility and also the distress caused by this public scrutiny pushed them to initiate care seeking. Women reported that factors like knowledge about the condition and its treatment was one of the main facilitating factors for continuing treatment. While the presence of contacts within the system also eased the treatment processes, access and affordability determined the continuation of care seeking. It was reported that the recalcitrance of the husbands hindered continuous care seeking.

A total of 604 women were surveyed to elicit the care seeking pathway for infertility. At the time of interview, nearly one fourth of the couples had achieved pregnancy. Among those who did not have a child at the time of interview, an equal proportion were on break from treatment or were continuing treatment for infertility. Among those who had a child or were pregnant, half of them achieved it via spontaneous conception following ovulation induction or treatment of their partner.

*In this analysis using quantitative data, the unit of analysis is the couple and therefore the findings refer to the couple. However, with respect to the qualitative research, the person reporting was the woman and all findings relating to the treatment related distress, consequences experienced due to infertility and other similar reports relate to the women alone.*

Age at the start of the treatment, socio-economic status, type of infertility and the type of centres used by the couples were found to be significantly associated with the outcome i.e., achieving pregnancy. The proportion achieving pregnancy was high among couples who started the treatment before age 30 (woman's age). The duration of the marriage of the couples ranged from 13 months to 348 months (29 years), the proportion achieving pregnancy was high among those who initiated treatment within 10-15 years of marriage. Migrant status of the husbands in the earlier periods of marriage could be a possible explanation for this observation. In the sample, male infertility as the contributing factor for infertility was higher compared to female infertility. Although the proportion of male infertility was higher in the study, the proportion of men undergoing treatment was lesser compared to women in the study. One possible explanation is that most of the assisted reproductive treatments happen in the woman's body. Also, many women reported that the husbands do not present themselves for treatment. This could also be a reason for lower proportion of men undergoing treatment. The proportion of the couples who got pregnant was higher for female factor infertility compared to male factor infertility. It was least when both the couples had infertility.

In the study, the couples had used up to 11 centres, with 40 percent using at least four centres. The movement from one centre to another was higher earlier on in the care seeking pathway. Allopathy was the first point of care seeking for infertility for majority of the couples in the study. As the couples moved further along the care seeking continuum in terms of the number of centres visited, there was a shift from Allopathy to Ayurveda and Homeopathy. Alternate methods were also deliberated by the couples in the care seeking pathway alone or along with other systems of medicine.

The event history analysis using the life table approach showed that the medical management of women had the highest rate of achieving pregnancy across different categories of treatment stage in the time intervals 0-120 months. Treatments such as Intra Uterine Insemination (IUI) and In Vitro Fertilization (IVF) had higher rate of achieving pregnancy in the later duration in the pathway i.e., IUI after 5 years and IVF after 10 years. This means that such methods are being postponed by the couples in the earlier years of care seeking.

The rate of achieving pregnancy drops to almost one-third of what it is (from 0.0059 to 0.0020 for the period 0-60 months) when other methods was used alone or in combination with allopathy compared to when only allopathy was used. This finding does not represent the merit of one system of medicine over other. This means that when pregnancy is not achieved by the couples, they shift from one centre to another which may be Ayurveda or Homeopathy or alternate methods due to either financial limitation or the reluctance to undergo a suggested treatment. Among these, there may be couples who need assisted conception methods to achieve pregnancy. This may be the reason why they are not yielding the result when using other systems of medicine or alternate methods alone or in combination with allopathy.

The continuous cohabitation of the couples is an important factor that helps in early care seeking. 'Absentee' husband was a major impedance to care seeking. Men opted to stop care seeking while women persisted in the pathway of care since they were afraid of the consequences of the inability to reproduce. When a couple was advised IUI or IVF due to male infertility, men tended to either discontinue or decline treatment. Along with this, the women also had the responsibility to shield their husbands' reproductive impairment. Women also reported that the plurality of care seeking for infertility was fuelled by the 'hope' perpetuated by others in the community or by their own doctors. To avert the blame and burden of the consequences, women resort to treatment, and persist in seeking care due to the 'hope' that is being communicated to them. This 'hope' is attributed to treatment or other alternate methods which they feel can give them positive results.

'Hope' was one of the recurrent themes in the narratives of women as to why they continued in the care seeking pathway and do not think of alternate methods like adoption to achieve parenthood. Infertility care seeking as understood from the study did not happen in a vacuum, the social, economic and other factors were also catering to the 'hope'. Using the concepts *deterritorialization* and *reterritorialization* I have examined the 'political economy of hope' of infertility care and how this has permeated the socio-cultural discourse of infertility and has created inequality. The advancements in technology together with market forces have deterritorialized

reproductive medicine. The infertile couples are also deterritorialized by their feeling of not belonging to the fertile world. Reproductive medicine now has a heterogeneous group of stakeholders, in addition to the professionals from obstetrics and gynaecology and the couples with infertility. So, the demand created by the deterritorialized infertile couples and deterritorialized reproductive medicine form a new system, which causes inequality and creates multiple trajectories of care seeking.

It is established in the study that at least six percent of ever married women in the reproductive age groups may be in need of infertility services in the state. This means there is demand for infertility services in the Kerala. It is also established that this demand is being met by the private sector in the state. We found that majority of the participants in the study had used allopathic centres as the first point of care. This can be attributed to the 'desperateness' that the infertile couples hold to achieve pregnancy, which is used by the market forces to portray 'hope'. This 'hope' is the major pulling factor that makes the couples use these expensive technology-based solutions and not consider adoption.

The care seeking for infertility was characterised by multiple breaks, stopping treatment without desired outcome and utilisation of different forms of treatment. The care seeking was sustained for longer durations by the women compared to their spouses. While men withdraw from care seeking pathway citing the difficulties of treatment, the existing gender norms and roles prevented women from exercising such choices. It is demonstrated by their persistence in care seeking despite the physical and emotional difficulties of the condition and also the treatment. This is also reflected in the better probability of achieving pregnancy when only female factor was contributing to the infertility in the couples.

There was multiple care seeking trajectories where up to 11 centres were used by the couples. While the use of other systems of medicine like Ayurveda or Homeopathy was lower in the first centre, there is three to four times increase in use of it in the subsequent centres. The use of Ayurveda and Homeopathy was higher than the use of public sector allopathic care later on in the care continuum. Along with the reported

financial limitation for abandoning care this also means that public sector provisioning is limited.

While women wanted to persist with care seeking, the assisted conception was declined by them (by the husband or the couple) due to the fear of use of donor sperm. This means that there will be unnecessary extension of care seeking and also there are chances of using alternate and unauthorised methods to achieve pregnancy like use of magical remedies. It was also noted that there was a higher rate of achieving pregnancy with IUI and IVF towards the later duration of the treatment cycle. This could mean that those requiring such treatments are postponing it and trying other methods when these treatments are suggested. It could also be due to financial limitation to access such treatments, since such treatment centres are mainly concentrated in the private sector. This creates inequality for those who are unable to afford the infertility care. Spouses' decision was also an important factor in persisting care seeking by women.

These findings indicate that there is co-occurrence of socio-economic and gender inequality in care seeking for infertility. These factors cause premature cessation of treatment or utilisation of alternate methods, thereby prolonging the care seeking trajectory of the couples without the desired outcome. There are also misconceptions regarding various treatments which can seriously limit the achievement of positive outcomes for the couples.

Therefore, it is important to bring in a public discourse on infertility in the programmatic component of sexual and reproductive health programs with a focus on the potential for success and appropriate care for male and female infertility. Due to lack of adequate public provisioning of infertility care, there is inequality in access and affordability. There should be mechanisms to provide it at local levels, with referral services to higher centres offering comprehensive care. Possibility of some form of financial assistance can also reduce inequality in accessibility and affordability of the infertility care. The clinical practice can incorporate counselling as a routine part of their care and not limit it to a prerequisite in assisted conception. This will enable to uphold the morale of the couple who will be confused about the various treatments being suggested.

Further research is needed to understand the treatment delays and its consequences due to the out migration of husbands. It is also important to elicit the reasons for the drop out from care pathway by men. Research aimed at understanding this will provide evidence to incorporate comprehensive care for couples in the state and mitigate against the existing multiple axes of inequity including gender and economic factors in infertility care seeking.

## **Chapter 1**

### **Introduction**

#### **1.1 Introduction**

The International Conference on Population and Development (ICPD), 1994 has acknowledged reproductive health as a basic human right. Infertility care which was an under represented global health issue was also brought under the reproductive health care agenda. The ICPD 1994 mandate included appropriate measures for prevention and treatment of infertility. Globally there has been focus on controlling fertility, the inability to achieve desired fertility has not received due attention in the programs and policies of Sexual and Reproductive Health (SRH).

While infertility has been acknowledged as a public health issue by World Health organisation (WHO) and Centre for Disease Control (CDC), a public health approach to infertility has not been adopted by many governments (Lemoine & Ravitsky 2013). Infertility has always been overlooked in the area of public health, because measures to counter overpopulation has been a priority than catering to the needs of those who are unable to reproduce. But when reproduction is acknowledged as a basic human right, the inability to reproduce should also be the concern of the governments. Although the inability to reproduce does not jeopardize the physical health of an individual it poses grave consequences to those who suffer from it. This makes it an issue that calls for attention from state (Lemoine & Ravitsky 2013).

A public health approach is lacking due to the fact that it is seen as a problem concerning an individual and not as a problem of the collective. This makes its management also of low priority and it is reflected in the limited number of centres in the public sector to treat infertility (Benagiano & Farris 2003). The limited public provisioning thus gives way to the private sector to flourish, thereby exacerbating the inequalities and restricting the accessibility and affordability to infertility care.

The rights-based perspective on SRH cannot overlook the inability to achieve desired fertility, especially when it is involuntary. Individual choice to attain fertility has to be a focus in SRH care provisioning, and such provisioning has to factor in the problems of those who are not able to beget a child for reasons that could be corrected.

Infertility, defined as *the inability to achieve clinical pregnancy after 12 months or more of regular unprotected intercourse* (Zegers-Hochschild et al. 2009), affects nearly nine percent of the couples in the reproductive age group (Boivin et al. 2007). In 2010, 48.5 million couples were infertile, of which 19.2 million couples suffered from primary infertility (Mascarenhas et al. 2012a).

Given the magnitude of the problem of infertility, a public health understanding is much needed for programmatic planning and policy changes to address involuntary childlessness. The preventable causes of infertility, the inability to achieve the social expectation and hence consequences of it including stigma and the role of socio-economic inequalities in accessibility and affordability of the treatment make it an important public health issue that calls for attention (Benagiano & Farris 2003; Lemoine & Ravitsky 2013).

### **1.2 Focusing on infertility using a public health approach: Why is it important?**

Infertility has been receiving less attention in the public health realm largely due to the paradigm from which it is studied and explained. The dominant paradigm that discusses infertility is the biomedical paradigm. This has been fuelled by the bio(medicalisation) process that is being advanced in the area of reproduction. The (bio)medicalisation of infertility has widened its scope through the developments happening in the assisted reproduction. Infertility is a condition that has been documented to be using a wide variety of options as remedy by those suffering from it. The biomedical option is the dominant one that is the first option chosen by couples after due deliberation (van Balen et al. 1997). Various other methods are also considered by the couples to mitigate infertility. Within the biomedical paradigm, the medical management of infertility ranges from counselling regarding the timing and technique of the intercourse to sophisticated forms of treatment like the Assisted Reproductive Technology (ART).

The other options used by the couples to treat infertility can be categorised as traditional methods such as reflexology, acupuncture, traditional Chinese medicine, herbalism, hypnosis, spiritual healing (Coulson & Jenkins 2005), or consult

naturopaths, chiropractors, and/or acupuncturists (Stankiewicz et al. 2007). Hypnosis (Gravitz 1995; Levitas et al. 2006) and homeopathy (Gerhard & Wallis 2002) are also used by couples for treatment of infertility. In addition to these, there are religious practices being used by the couples to find solutions for their infertility through consulting traditional healers or religious healers and visiting mausoleums. They also use traditional drugs, tie amulets, and sacrifice animals as part of the religious practices to achieve pregnancy (Günay et al. 2005).

The reasons for choosing traditional methods were that the couples felt that unlike biomedical practitioners, the traditional healers were more attentive to their worries (Coulson & Jenkins 2005). The repeated failure with biomedical treatment modalities also leads couples to consider other options. Adoption is also a choice considered by some couples to resolve their state of childlessness. This choice is exercised with or without trying the biomedical methods of treating infertility.

A bio-medical approach to infertility will be more favourable to medicalisation. Medicalisation creates inequality, where preventive aspects receive less attention when compared to a public health approach. This means that equally vulnerable couples from specific strata may not receive the benefit they need. In addition, the process of medicalisation makes it an individual responsibility and shifts the blame to the individual (with respect to preventable causes) (Lemoine & Ravitsky 2013). Medicalisation of infertility has brought in technology-based solutions into the social and cultural discourse on infertility. This means couples who are unable to reproduce are provided with one additional option to consider. But this specific technology has its own drawbacks ranging from no guaranteed success to being expensive and extremely exhausting for the users due to the physical and emotional toll it takes (Franklin 1990). The presence of technological solution is a boon for infertile couples but when this technology is positively represented in the media, it automatically becomes popular in the socio-cultural narrative of infertility. There are consequences for couples, who are unable to afford or access it, because they can be now blamed for inaction by others. It also keeps the possible alternatives like adoption to achieve parenthood at bay (Bharadwaj 2003).

Accessibility and affordability are also at stake. According to Boivin et al., in 2007, among about 72.4 million women who were infertile, only 56 percent sought any medical care.

It is observed that the entry to medical treatment is not sustained by majority of the couples, they discontinue the treatment sooner or later depending on various factors. Financial limitations, psychological and physical burden were some of the reasons for treatment discontinuation (Van den Broeck et al. 2009).

While there are many countries which have reimbursement and coverage for Assisted Reproductive Technology (ART) treatments, this insurance coverage varies across countries. Though the reimbursement or coverage of treatment is carried out with restrictions from country to country, including the number of cycles that can be reimbursed, the age of the women, sexual orientation and usage of donor gametes, its use is on the increase as reported by the International Committee for Monitoring Assisted Reproductive Technologies (ICMART). ICMART reported a 6.4 percent increase in the number of oocyte aspirations and 27.6 percent increase in the Frozen Embryo Transfer (FET) between 2008 and 2010. While it is reported the ART utilisation has been constant between 2008 to 2010 globally (Dyer et al. 2016). Almost all European Union states except Greece have some form of state funding or reimbursement for ART. Countries from the Southeast Asian regions and South Asian regions viz., Bangladesh, India, Taiwan, the Philippines, Bangladesh, Sri Lanka, Thailand and some from Central and Latin American regions like Mexico, Columbia, Venezuela are not financially supporting any ART treatments (IFFS 2019). But even after the cycles are covered for there is a significant number of couples who discontinue treatment at different stages in their treatment cycle (Van den Broeck et al. 2009).

Even though financial limitation plays a major role, couples are drawn to trying everything before abandoning the treatment. This arises from the need to resolve the regret of not having tried enough for a child, hence ART which is the most advanced treatment is utilised by the couples in their treatment pathway (Van den Broeck et al. 2009). Other reasons like lack of success and psychological distress have been also

reported as the major reasons for treatment discontinuation (Rajkhowa et al. 2006). The longer the duration of the infertility, physical burden was reported as the major reason for discontinuation by the women. This is a practical possibility but such a reason may be a way of externalising the cause for discontinuation when the inability to achieve pregnancy becomes more evident for them (Van den Broeck et al. 2009). While some of the reasons for discontinuation of treatment by couples with infertility are known, there is limited understanding of the other causes for discontinuation of treatment and the interlinkages across them. When such studies get done they fail to provide a theoretical framework to explain it (Gameiro et al. 2012). It is known that not all the couples with infertility would be able to access and afford infertility care. So, when subjects are selected from clinics to understand care seeking for infertility a major proportion of infertile couples are not included and their experiences are excluded from the knowledge base.

### **1.3 Infertility levels and treatment patterns in India**

In India, according to DLHS 2007-08, 8.2 percent of ever married women in the age group 15-49 years reported having infertility, which includes both primary and secondary infertility. Within India, the highest level of infertility reported was in West Bengal with 14.1 percent, and the lowest was 2.3 percent in Meghalaya. Those who had infertility (both primary and secondary), 80 percent had sought treatment for infertility. Among those who had primary infertility, 82 percent reported having sought treatment, and among those who sought treatment, 65 percent had used allopathic treatments. There was an economic gradient to care seeking with 73 percent having taken treatment for primary infertility from the poorest wealth quintile, while 91 percent had done so in the highest wealth quintile. The use of allopathic treatment by those in the poorest quintile was nearly half of those who took it in the highest wealth quintile (IIPS 2010). This means that a significant proportion of those in need are either not accessing any form of treatment or are using other systems of medicines or traditional or religious methods to treat infertility in the country.

In India a majority of ART services are provided by private sector providers, and the facilities if at all available in the public sector are only offered in the tertiary centre

like the medical colleges (Widge & Cleland 2009). There were 1500 ART centres in the country in 2019, which is the highest among all the reporting countries (IFFS 2019). There was a 33 percent increase in the number of centres from 2016 in India. A majority of these are private physician clinics (350) and sole practitioner-based clinics (1000), while there were only 10 ART clinics in the public hospital (IFFS 2019). Due to the limited availability of infertility treatment in the public sector, significant sections of the society may not be able to undergo infertility treatments. The long waiting time and lack of infrastructure for diagnosis and treatment also forces people to give up on treatment at public sector institutions and those who are unable to afford treatments at the private sector may choose alternate pathways like consulting traditional healers and other unauthorised centres/people (Widge & Cleland 2009).

Although the exact number of the private providers is not known, the Indian Council of Medical Research (ICMR) is in the process of registering the ART clinics and banks in India. There are up to 532 centres registered under the National Registry of ART Clinics and Banks in India in October 2020, while the actual number of centres will be more than this (ICMR 2020). There are no centrally sponsored schemes offering financial assistance to the couples for infertility treatment. Some states have tailored programs to assist the infertile couples, the State Government of Assam has launched a scheme called 'Maturtva Yojana' to give financial assistance of up to five lakhs for couples who are not able to achieve pregnancy after three years of marriage in the tribal category. Similarly, in Goa couples in the tribal category who are married for more than three years without a child, will also get a financial assistance of up to five lakhs rupees for infertility treatment (Questions Lok Sabha 2017; Scheme India, n.d). The Ministry of Minority Affairs is also funding the 'Jiyo Parsi Scheme', for low and middle income Parsis to undergo IVF treatments (Parzor Foundation 2020).

#### **1.4 Rationale for the study**

Public health priority setting is largely utilitarian, focusing on maximising benefit or alleviation of suffering. While a majority of couples do not suffer from infertility related problems, it causes an inordinate amount of suffering to those who do. This is why a public health focus needs to be brought to the problem of infertility instead of

treating it as a problem of individuals. While public health uses surveillance and monitoring to collate information and identify changing priorities, there is hardly any representative data on infertility and this restricts the opportunities to call attention to it or bring this as an issue that deserves to be on the public health agenda of the country.

Currently much of the focus on infertility is understanding the experiences and consequences of infertility, and also the ethical concerns of assisted reproduction. A significant volume of this literature on infertility comes from the bio-medical paradigm where the treatment success and discontinuation among the clinic subjects are discussed. When we gauge infertility from the bio-medical paradigm, we tend to miss out on the socio-cultural contexts that shape the experience and the understanding of infertility. Because the socio-cultural context plays an important role in how infertility is experienced by the couples/ individuals and also shapes the way in which it is perceived. The measures adopted by couples to mitigate it are also influenced by the socio-cultural contexts of individual couples.

Even though studies on infertility in India have reported on the treatment pathways and predictors of treatment discontinuation at different stages, a majority of these studies have been based on infertility clinics or hospitals. Moreover, many of these exercises have limited infertility treatments to ART treatments. There have also been arguments that couples who are unable to afford the ART treatment may not enter into this treatment option at all (Van den Broeck et al. 2009). Infertility care encompass treatments from simple counselling to medications to the ART treatments. Even the diagnostic work up for infertility is exhaustive and expensive and couples can drop out without completing it and move on to alternate methods. As most of the studies that look into the treatment discontinuation are clinic-based studies, a comprehensive understanding of the care seeking trajectory with drop outs at multiple levels before reaching the clinic are absent.

Studies that cite the reason for discontinuation of treatment are based on retrospective surveys. While such studies often produce general responses from the couples viz., emotional or psychological or financial burden (Brandes et al. 2009), it is important to look beyond those responses. Since, treatment compliance is an important aspect of

success in such treatments it is important that couples who envisage treatment continue till completion of at least a certain type of treatment. The decision to continue or discontinue the treatment is solely the discretion of individual undergoing the treatment. But a clarity on where and what exactly the problems are in the treatment seeking pathway will be helpful in minimizing drop-outs.

Treatment discontinuation does not mean that the couples will stop treatment altogether, multiple pathways of care seeking have been demonstrated in infertility care (Gerrits 1997; Koster-Oyekan 1999; Dhont et al. 2010). It indicates that they may discontinue one treatment or clinic and pursue it from another. The various options available and being utilised by the couples with infertility depends upon individual choices, the ability to afford an option, and the cultural setting. Multiple trajectories are possible due to the diversity of treatment options and the constraints of these treatments. Such patterns of care-seeking are likely to be associated with different success rates but these trajectories and their consequences remain largely unexplored. In this context, it is important to identify the actual trajectories of mitigation that exist in practice and identify the stage of the infertility journey that couples choose a particular method and when they choose to move from a particular stage of care seeking to another. This research is an exercise in explicating the practical choices exercised.

With the declining fertility rates and the higher private sector participation in health, Kerala is a good site to study infertility care from a public health perspective. The fertility rate in Kerala, as measured by the Total Fertility Rate (TFR) is below replacement level. This means other things remaining constant, given the low fertility levels, the population size would reduce in the long run. The relatively lower levels of fertility in Kerala and the postponement of pregnancy by women, means that women in Kerala may be in need for infertility care services. As fecundity decreases with age, with rising age at first pregnancy the probability of getting pregnant declines. The DLHS-3 (2007-08) reported that in Kerala nearly 11 percent of ever married women in the ages 15-49 had infertility and out of this group, 86 percent had sought care for infertility (IIPS 2010). This means that according to Census 2011 data, there were

72,85,725 ever married women in the age group 15-49 years. If 11 percent of them were to be infertile, it means 8,01,429 ever married women were having infertility, out of which around 6,89,228 women would have sought care. Barring this information, we do not know from where the care was sought and whether such care yielded a desired outcome. There has not been any systematic effort to understand care seeking for infertility at the population level. Considering the fact that infertility care is expensive and mostly concentrated in the private sector in Kerala, it is important to understand the extent and nature of care seeking for infertility in the state. Currently, treatment for infertility especially ARTs, is not a public health priority in the country. In the absence of any centrally sponsored or state mandated reimbursement schemes for infertility treatment, couples have to meet the costs involved through out of pocket expenditure. By looking into the census figures of the ever-married women in the reproductive age group in 2011, we can have a rough approximation that about 0.7 million women may be accessing treatment for infertility. Even if half of them, that is about 0.35 million were to access modern medicine, the public health infrastructure currently available is not adequate to cater to their needs. That this group will seek care for infertility is inevitable because the sizable presence of private sector provisioning for reproductive health in general and infertility care in particular in Kerala will prompt them to do so. In these circumstances, it is important to understand whether couples who enter the care seeking pathway are able to sustain it or if they were negotiating alternatives to these medical means to achieve pregnancy. Therefore, the present study seeks to understand how couples with infertility seek care in Kerala.

The study attempted to answer the following research questions;

1. How do couples with infertility seek care for infertility in Kerala?
2. What are the inequalities in the care seeking for infertility in Kerala?
3. What are the consequences of infertility for women in Kerala?

The objectives of the study were;

1. to understand the trajectories of care seeking for resolution of infertility among couples and to identify reasons for these choices to resolve infertility,
2. to get the estimates of expected levels of infertility for Kerala and its districts and analysing the age pattern of infertility in these districts,
3. to describe the care seeking pathway for infertility among couples with infertility in Kerala,
4. to examine the inequalities in the care seeking for infertility by couples with infertility in Kerala and
5. to describe the infertility specific distress, in women undergoing treatment for infertility and to understand the possible consequences of infertility for women.

### **1.5 Organisation of the thesis**

Including this introductory chapter there are a total of ten chapters in this thesis. In the second chapter i.e., the review of literature, I will discuss literature that helped in conceptualising the study and helped frame the specific research question and objectives. The chapter is divided into four sections, the first section will discuss the definition of infertility, its global and national prevalence, and the types of infertility, its diagnosis and treatment. The second section will focus on the correlates of infertility and its treatment and the social construction of infertility. The third section will be on legislations and the insurance coverage or reimbursement for infertility. The last section, will discuss the conceptualisation of (bio)medicalisation and the ‘political economy of hope’.

The third chapter explains the methodology used for the three different phases of the study and the study design used specifically for phase III. It will also include the conceptual framework and the ethical considerations of the study. In this chapter I explain in detail the sampling strategies, sample selection processes, methods of data collection and analysis, for the three different phases of the study.

Chapters four to nine describe the results of the study. The fourth chapter addresses the objective of estimating the expected levels of infertility and its age patterns for Kerala and its districts. It includes a discussion on the available facilities in the state

for reproductive health care. The first section describes the demand for infertility services in the state by providing the estimates of the expected level of infertility and the second section discusses the health care context of Kerala and supply side for reproductive health care in the state. This chapter serves to establish the potential demand for infertility services and the infertility care availability in the state to meet this demand.

The fifth and sixth chapters describe the findings from the exploratory qualitative phase of the study. The fifth chapter addresses the research question on why couples seek care for infertility. The context and process of care seeking for infertility is the major focus of this chapter. It describes the reasons why care seeking for infertility happens and what are the factors that make couples pursue care. This chapter also explains the response to the diagnosis and treatment by the individual couples. Lastly this chapter elucidates the coping mechanisms if the desired outcome is not achieved.

The sixth chapter concentrates on the objective of understanding the trajectories of care seeking for resolution of infertility among couples. It explains how the couples seek care for infertility and what are the practical choices exercised by the couples. It provides an in-depth understanding of the choices used by the couples with infertility in Kerala. The different stages of care seeking in infertility and the multiple trajectories of the care are described. These understandings helped in framing the interview schedule for the community base survey in phase III of the study.

The seventh and eight chapters describe the findings of the community-based survey. The seventh chapter includes the socio-demographic profile of the couples with infertility in the three selected districts of Kerala and the various factors that are associated with achieving pregnancy. Here, the outcome of achievement of pregnancy by couples is described across their socio-demographic characteristics.

The eighth chapter addresses the objective to describe the treatment seeking pathway for infertility among couples with infertility in Kerala. It describes the care seeking pathway among those couples who actively seek/sought care across the three selected districts of Kerala. These two chapters describe the different choices actually exercised

by the couples to mitigate infertility. This includes the number and type of centres visited, and the reasons for discontinuation in each centre. It also describes the inequalities in care seeking for infertility.

The ninth chapter describes the infertility specific distress among women undergoing treatment for infertility and the possible consequences of infertility for women. The findings are based on qualitative in-depth interviews among selected women. This chapter helps in highlighting the gendered contexts with respect to the consequences of infertility for women thereby highlighting the inequality in the experience of the consequences.

In the tenth chapter which is the discussion and conclusions chapter, the findings of this thesis and their implications are discussed. Since the study used a multiphase design the findings of each phase fed into the other, to get a comprehensive picture of the care seeking for infertility in Kerala, it was important to synthesise the findings and its implication across the three phases of the study. This chapter aims to synthesise the findings by utilising the theoretical concepts to explain how care seeking for infertility happens in Kerala.

The findings are integrated into a cohesive explanatory framework, the 'hope framework' that was identified through this research process. I will also discuss the strengths and limitations of the study and the policy recommendations in this chapter.

## **Chapter 2**

### **Review of Literature**

In this chapter I will discuss the literature framing the conceptual framework, context and the rationale of the study. This chapter is divided into four sections; section I discusses the definition of infertility, its global and national prevalence, and the types of infertility, its diagnosis and treatment. Section II of this chapter includes the correlates of infertility and its treatment and the social construction of infertility. Section III describes the legislations to regulate ART services and the insurance coverage or reimbursement for infertility. The last section, i.e., section IV will discuss the conceptualisation of (bio)medicalisation and the ‘political economy of hope’.

#### **Section I: Definitions of infertility, its types and causes and its measurement**

This section will provide the different definitions used for estimation of infertility and the lack of consensus on the definition, which is a hindrance in getting global estimates for infertility. The biological aspects of infertility including the type of treatments are also discussed under this section. It will give an understanding of the various diagnosis and the biomedical treatments that are prescribed for the couples with infertility.

#### **2.1 Definition of infertility and its components**

Studies and surveys are done globally to elicit the burden of the condition but a global picture of infertility is lacking partly due the absence of a standard and consistent definition. The terms like childlessness, sterility, infecundity, and subfertility are used synonymously to define the condition in the literature. A systematic review of the literature reporting on the prevalence of infertility has highlighted the inconsistency in the definitions used in the studies (Gurunath et al. 2011).

The three main components in the definition of infertility are exposure time, exposure type (includes couple status, contraceptive use and desire for a child) and outcome, while the review points out the incomplete and inconsistent usage of these components in different studies (Mascarenhas et al. 2012b).

There are three major disciplines that define infertility viz., clinical, demographic and epidemiological. These three disciplines use varied definitions thus making comparison across studies difficult. To capture the problem of infertility at an individual level and to form a treatment regime a clinical definition helps. To understand the problem at a population level viz., its distribution in the population or to understand the extent of the problem a demographic or epidemiological definition will be helpful (Mascarenhas et al. 2012b).

According to the International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO), **clinically** infertility is defined as

*“a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse.”*  
(Zegers-Hochschild et al. 2009)

The **demographic definition** of infertility is

*“an inability to become pregnant with a live birth, within five years of exposure based upon a consistent union status, lack of contraceptive use, non-lactating and maintaining a desire for a child.”* (Mascarenhas et al. 2012b)

The **epidemiological definition** of infertility is

*“women of reproductive age (15–49 years) at risk of becoming pregnant (not pregnant, sexually active, not using contraception and not lactating) who report trying unsuccessfully for a pregnancy for two years or more.”* (World Health Organization 2006)

Examining the definitions from the three disciplines vis-à-vis the three components of the definitions we can draw the major differences in the definitions.

### **2.1.1 Exposure time**

Exposure time refers to ‘*the minimum time necessary to assess whether a union is infertile.*’ There is a tendency for misclassification based on the exposure time. A

longer exposure time is less likely to misclassify women as infertile when compared to a shorter exposure time (Mascarenhas et al. 2012b).

In the clinical definition one year is taken as the exposure time while the demographic definition mainly uses five to seven years and epidemiological definition usually uses 24 months exposure time to the risk of getting pregnant.

### **2.1.2 Exposure type**

Exposure time includes the couple status, contraceptive use and intent/desire to have a child (Mascarenhas et al. 2012b). Couple status is measured from the time of the first union (marriage or cohabitation). When there are multiple unions and only the first union is considered, there can be overestimation or underestimation of exposure time, therefore the prevalence of infertility respectively (Mascarenhas et al. 2012b).

Unprotected intercourse serves as a proxy for exposure but in household surveys, information regarding current use of contraceptives rather than continuous use is available (Mascarenhas et al. 2012b).

The desire to have children is also used as a proxy for unprotected intercourse and thus measure the exposure in women (Mascarenhas et al. 2012b).

### **2.1.3 Outcome**

Live birth is mostly used as the outcome indicator for infertility in household surveys since couples desire children, and not just pregnancies. Moreover, in household surveys, eliciting pregnancy is difficult due to underreporting of spontaneous and planned abortions (Mascarenhas et al. 2012b).

A review, done to understand the prevalence of infertility, used different definitions and hence the comparison between studies seemed difficult. In studies which used at least 12 months or more and less than 24 months exposure time, and regular intercourse or not using contraceptives and outcome as no conception, the prevalence of primary infertility ranged from 2.0 percent (Badr et al. 2006) to 38.4 percent (Gokler et al. 2014). A twelve-month exposure time was used in most of the studies reviewed and

thus there is a higher probability of misclassification of women as infertile and thus an overestimation of the prevalence.

## **2.2 Limitations in use of these definitions**

None of the studies reviewed have used all the three components of the definition completely; some used 12 months while some used 24 months to five years as the exposure time. The exposure status also differed between the studies. Exposure status is determined by unprotected sexual activity which involves both sexual activity and that such activity be without contraceptive use. Most studies determined exposure status by the couple status and contraceptive use or details of intercourse. An alternative to asking about contraceptive use is the desire to have a child, but this was less likely to be used in these studies. The outcome measure in majority of the studies was absence of pregnancy or conception. The demographic definition used the outcome as absence of child (Larsen 2003; Badr et al. 2006; Boivin et al. 2007; Safarinejad 2008; Wilkes et al. 2009; Kazem & Ali 2009; Bhattacharya et al. 2009; Ganguly & Unisa 2010; Adamson et al. 2011; Akhondi et al. 2012; Kumar 2012; Bushnik et al. 2012; Mascarenhas et al. 2012a; Thoma et al. 2013; Chandra & Stephen 2014; Gokler et al. 2014; Zhang et al. 2014; Kazemijaliseh et al. 2015)

Six different definitions were used to assess the prevalence of infertility. These definitions were self-reported infertility, unprotected intercourse for at least two years, tried to conceive for at least two years, subsequently infertile, subsequently infertile and wanting a child and childlessness. It was estimated that primary infertility was 2.5 percent from the definition ‘unprotected intercourse for at least two years’ and 1.8 percent from ‘tried to conceive for at least two years’, 3.5 percent were childless after at least five years of their first marriage or union compared with 1.9 percent after seven years. This could mean that women are delaying pregnancy even though they are not using contraception, thus this highlights the importance of eliciting the desire for child in surveys (Larsen 2005).

## **2.3 Global and national prevalence of infertility**

The desire to have a child and the inability to have it is a universal problem. In 2010, at a global level, infertility was estimated to be 48.5 million based on 277 survey data

sets, of which 19.2 million couples suffered from primary infertility and 29.3 million had secondary infertility. Among these 14.4 million were from South Asia and 10.0 million in Sub-Saharan Africa. Regional differences in the prevalence of primary infertility were reported by the authors with the lowest estimate of 1.5 per cent in the Latin America/Caribbean region to 2.6 percent in the North Africa/Middle East region. In 2010, middle income countries viz., Peru, Bolivia, Ecuador and El Salvador in Latin America, Poland, Kenya and the Republic of Korea had the lowest levels of primary infertility (Mascarenhas et al. 2012a). Based on the population in 2007, around 72.4 million people were infertile i.e., the global prevalence of infertility was estimated to be 9.0 percent (Boivin et al. 2007). The Demographic and Health Survey (DHS) report which had data from 47 demographic and health surveys from the developing countries estimated that in 2002, more than 186 million ever married women in the age group 15-49 years were infertile due to either primary or secondary infertility (Rutstein & Shah 2004).

In India, the prevalence of infertility was estimated to be 2.5 percent among women aged 25-49 years (Rutstein & Shah 2004). Estimates of childlessness using Census 2001 data vary widely among the Indian states from a low of three percent in Haryana to a high of 11 percent in Tamil Nadu. The levels were five percent in Maharashtra and Gujarat, while Kerala and Karnataka had 6 percent childlessness for ever married women in the ages 35-39 years (Ram 2010). Allowing for a five year marital duration, the estimates of infertility levels put it at 1.9 percent in NFHS-3 for the period 2005-06 (Ganguly & Unisa 2010). Using the same data (NFHS-3) in 2005-06, the estimate of infertility was highest in the southern region followed by the west. In south, Goa ranked highest with 4.5 percent, Andhra Pradesh with 3.6 percent and Kerala with 2.6 percent (Syamala 2012). The prevalence of infertility was 8.9 percent among 570 urban women in the age group 15-49 years in Central India (Katole & Saoji 2019). An epidemiological study done in Kashmir among 10,063 couples in the age group 15-44 years who were married for one year or more it was reported that 15.1 percent had primary infertility (Zargar et al. 1997). Another study in South India reported the prevalence of infertility as 12.6 percent among women aged 15-30 years (Adamson et al. 2011).

## **2.4 Infertility- types, diagnosis and treatment**

Infertility is mainly categorized as primary and secondary infertility;

primary infertility is “*when a woman is unable to ever bear a child, either due to the inability to become pregnant or the inability to carry a pregnancy to a live birth she would be classified as having primary infertility. Thus women whose pregnancy spontaneously miscarries, or whose pregnancy results in a still born child, without ever having had a live birth would present with primarily infertility.*” (Mascarenhas et al. 2012b), and

secondary infertility is “*when a woman is unable to bear a child, either due to the inability to become pregnant or the inability to carry a pregnancy to a live birth following either a previous pregnancy or a previous ability to carry a pregnancy to a live birth, she would be classified as having secondary infertility. Thus those who repeatedly spontaneously miscarry or whose pregnancy results in a stillbirth, or following a previous pregnancy or a previous ability to do so, are then not unable to carry a pregnancy to a live birth would present with secondarily infertility.*” (Mascarenhas et al. 2012b)

The current clinical approach to the investigations and the management of infertility is backed by the evidence-based guidelines issued by the Royal College of Obstetricians and Gynaecologists (RCOG), American Society of Reproductive Medicine (ASRM), and European Society of Human Reproduction and Embryology (ESHRE).

In the clinical setting, a couple is said to be infertile if there is no conception after one year of unprotected intercourse. Those who are not sterile but exhibit reproductive insufficiency are termed subfertile. In general, approximately 85-90 percent of young couples conceive within a year or some even within six months. Infertility is thus a condition that affects the rest 10-15 percent of the couples (Fritz & Speroff 2011).

The evaluation of infertility should focus on the couples and not on one partner alone. The infertility evaluation encompasses the identification and correction of the specific

causes of infertility where ever possible. Infertility in couples caused by male factor alone covers 20-30 percent of cases, female factor alone in 20-35 percent, both male and female factors contribute to infertility in 25-40 percent of cases and 10-20 percent are due to unexplained causes (Hamilton 2012; Hoffman et al. 2012; Vander Borgh & Wyns 2018).

#### **2.4.1 Female infertility**

***Ovulatory dysfunction:*** Problems in ovulatory function affect approximately 20 percent of couples with infertility (Fritz & Speroff 2011; Hamilton 2012). Anovulation, oligo ovulation can prevent or contribute to conception respectively. Ovulation can be assessed by eliciting the menstrual history, evaluating the basal body temperature, serum progesterone concentration, urine luteinizing hormone (LH) excretion. The evaluation of ovulation is the core component of infertility evaluation. In women with regular monthly menstruation, a properly timed serum progesterone concentration is the simplest and the most reliable method (Fritz & Speroff 2011).

***Cervical factors- abnormalities in sperm-mucus interaction:*** Cervical mucus helps in capturing the sperm from the ejaculate in the vagina, while excluding the seminal plasma and morphologically abnormal sperm. It helps in sperm survival thus extending the fertile interval between intercourse and ovulation. The post coital test is used for diagnosis of cervical factor infertility (Fritz & Speroff 2011).

***Uterine factor-anatomic and functional abnormalities:*** Uterine abnormalities are relatively uncommon cause of infertility, but should be ruled out in the evaluation of the couples with infertility. Anatomic and functional uterine abnormalities can impair fertility and also adversely affect pregnancy outcome. The anatomic uterine abnormalities that can adversely affect fertility include congenital malformations, leiomyomas and intrauterine adhesions, while the functional uterine anomaly is chronic endometritis. The evaluation of the uterine cavity is done by hysterosalpingography, transvaginal ultrasonography and hysteroscopy (Fritz & Speroff 2011).

***Tubal factor- tubal occlusion and adnexal adhesions:*** Tubal factor infertility is one of the most common causes of infertility and accounts for 30-35 percent of infertility cases. History of pelvic inflammatory disease, septic abortion, ruptured appendix, tubal surgery, or ectopic pregnancy are some of the causes for possible of tubal damage. Hysterosalpingography and laparoscopy are two methods for evaluation of tubal patency in infertile women (Fritz & Speroff 2011).

#### **2.4.2 Male infertility**

Advances in the understandings of the male reproductive function and the importance of male factor infertility has improved our recognition of male factor as a major cause of infertility. Male reproductive impairment accounts for the sole cause of infertility in 20-30 percent of the couples (Agarwal et al. 2015; Vander Borgh & Wyns 2018). Male infertility may be caused by various reasons, while some are treatable others may be idiopathic. The known causes of male infertility can be divided into four major categories viz., (1) Hypothalamic-pituitary disorder (1-2%), which may be congenital, acquired or can occur as a result of systemic illness, (2) Primary gonadal disorders (30-40%), both congenital and acquired, (3) disorders of sperm transport (10-20%), and (4) idiopathic(40-50%) (Iammarrone et al. 2003).

Male infertility can be diagnosed by the semen analysis (except in cases where sexual dysfunction is the cause). The initial assessment for male factor infertility should include one semen analysis with the sample collected after a period of at least three days of abstinence. It should be followed by another at least four weeks later if any abnormality exists in the previous analysis (Hamilton 2012). Semen analysis assesses the ejaculate volume and pH, sperm concentration and total sperm count, sperm motility, forward progression, total motile count and vitality, and sperm morphology (Iammarrone et al. 2003).

#### **2.4.3 Unexplained infertility**

After all the diagnostic evaluations fail to ascertain male or female factor cause for infertility, unexplained infertility is used as the diagnosis. The diagnosis of unexplained infertility implies evidence of normal semen parameters, ovulatory function, a normal uterine cavity, and bilateral tubal patency (Fritz & Speroff 2011).

#### **2.4.4 Diagnosis and treatment for infertility**

The diagnosis of the couples is made after investigation of both male and female. The male investigations are done to assess the semen parameters, and female investigations are done to assess whether there are any tubal and uterine abnormalities, and ovulatory problems. Once the diagnosis is made, treatment falls into three categories; (a) medical management which includes the use of drugs for ovulation induction, (b) surgical management including correction of varicocele in men, laparoscopy in women, (c) assisted reproduction techniques (National Collaborating Centre for Women's and Children's Health (NICE) 2012). The different types of infertility treatments are intrauterine insemination with donor sperm or partner's sperm, In vitro fertilization (IVF), Intra Cytoplasmic Sperm Injection (ICSI) which includes retrieving sperm via different procedure, viz., Microsurgical Epididymal Sperm Aspiration (MESA), Testicular Sperm Aspiration (TESA), Percutaneous Epididymal Sperm Aspiration (PESA), Gamete Intrafallopian Transfer (GIFT) and Zygote Intra Fallopian Transfer (ZIFT).

Intrauterine insemination with either partners' or donor semen involves the processing of semen in the laboratory so as to yield pure, activated sperm, devoid of seminal plasma, which are then directly placed into the uterus. Common indications for IUI are unreceptive uterine cervix that does not respond to medication, unexplained infertility, mild male factor, ejaculatory problems, mild endometriosis and donor sperm is used in cases where husband's sperm cannot be used (Hamilton 2012). Also, donor insemination can be used in cases where there is risk of transmitting genetic disorders to the offspring, or if there is rhesus incompatibility (National Collaborating Centre for Women's and Children's Health (NICE) 2012).

In vitro fertilization and embryo transfer (IVF-ET) involves the fertilization of the oocyte and the spermatozoa in the laboratory instead of in the woman's fallopian tube. IVF involves induction of ovulation in order to obtain multiple oocytes, thus making available more embryos with which higher pregnancy rates can be achieved. When the follicles are mature enough for fertilisation, they are aspirated to obtain the oocytes.

The oocytes are mixed with appropriately capacitated spermatozoa from the husband (or the donor, if the medical condition indicates the use of donor sperm) and kept in an incubator for fertilization which is observed microscopically after 16 to 18 hours. Embryos are transferred into the uterine cavity between days two and six after oocyte aspiration. Pregnancy is confirmed around 12 days after embryo transfer by determining the presence of hCG (Human Chorionic Gonadotropin) in blood or urine sample. The original indication for IVF was severe tubal disease, or tubal blockage. However, subnormal male factor is also an indication for IVF recently. Other indications include unexplained infertility, severe endometriosis, failed IUI and infertility of immunological origin (Hamilton 2012).

Gamete Intrafallopian Transfer (GIFT) or Tubal Embryo Transfer (TET) has been recommended for patients with undamaged fallopian tubes. Access to the tube is gained by laparoscopy or by retrograde catheterization through the uterine cervix. GIFT is associated with higher levels of pregnancy than IVF but with this procedure, the fertilizing capacity of the gametes cannot be assessed.

Intra Cytoplasmic Sperm Injection (ICSI) with ejaculated, epididymal or testicular spermatozoa is a procedure that have been developed when there are barriers (the zona pellucida and the ooplasmic membrane) that prevent the sperm from reaching the ooplasm. ICSI is the most widely accepted choice of treatment for male factor infertility, and in 2012 it accounted for nearly 76 percent of all ART procedures in USA (Boulet et al. 2015). ICSI can be carried out with fresh or frozen-thawed ejaculated or epididymal/testicular motile or live spermatozoa.

The indications of ICSI with ejaculated spermatozoa include severe male-factor infertility, obstructive azoospermia, hypogonadotropic hypogonadism, fertilization failure after standard IVF treatment, and number of spermatozoa in the ejaculate is too low for IVF (Iammarrone et al. 2003; National Collaborating Centre for Women's and Children's Health (NICE) 2012).

## **Section II: Correlates of infertility and its treatment seeking**

This section describes the determinants of infertility and its treatment seeking and the social construction of infertility and the experience of it. The various biological, social and environmental determinants of infertility will be described first. It will be followed by the narrative of the social construction of infertility and how this will shape the experience of infertility. The final part of this section will include the determinants of infertility treatment seeking.

### **2.5 Determinants of infertility**

***Socio-economic factors:*** Infertility is significantly higher among urban and better educated women (Syamala 2012) which could be due to postponement of pregnancy. While some studies reported that the lower education of the female partner was associated with infertility (Safarinejad 2008; Ganguly & Unisa 2010), most studies reported no association with education of the women or her spouse and infertility (Larsen 2003; Bushnik et al. 2012; Chandra & Stephen 2014). Remarried and divorced women had primary infertility more often than first-married women (Larsen 2003; Safarinejad 2008), this could be because infertility may be the reason for divorce among those women. Higher age at marriage was associated with higher prevalence of infertility (Syamala 2012). Occupation and income were also found to be associated with lower levels of infertility in women, where the more affluent and women with white-collar jobs had less fertility impairment compared to their counterparts who were unskilled labourers and with low income levels (Correia et al. 2014). This could be because women in the higher socio-economic position may be able to follow healthy lifestyles.

***Biological, environmental and lifestyle factors:*** Age of the female partner was significantly associated with infertility (Larsen 2003; Ganguly & Unisa 2010; Bushnik et al. 2012; Thoma et al. 2013). But male age was not found to be associated with fertility (Bushnik et al. 2012). Obesity and smoking in women were associated with infertility (Safarinejad 2008; Bhattacharya et al. 2009). Time to conception increases for women with a Body Mass Index (BMI) less than 19 and greater than 25 (Norman et al. 2004) and in men with BMI lesser than 20 and greater than 25 is associated with

reduced sperm quality, which in turn can affect the fertility (Jensen et al. 2004). Declining fertility can also be attributed to the prolonged exposure to psychological stress and environmental pollutants and also the use of alcohol, caffeine (Petraglia et al. 2013). High caffeine consumption and delayed chance of pregnancy has also been demonstrated in a multicentric study (Bolumar et al. 1997). There are also adverse effects of environmental toxins and radiation on reproduction, which means occupational exposure should be considered in couples having difficulty in getting pregnant (Petraglia et al. 2013). Another major cause for infertility is the use of gonadotoxic chemotherapy drugs and radiation. These when used especially in young children, can impair their future fertility (Petraglia et al. 2013)

***Medical/gynaecological conditions:*** Gynaecological factors like Pelvic Inflammatory Disease (PID), history of tubal surgery, other pelvic surgeries, endometriosis, chlamydial infection, tubo-ovarian surgery, salpingitis, ectopic pregnancy, varicocele, cryptorchidism were all found to be associated with infertility (Safarinejad 2008; Bhattacharya et al. 2009; Thoma et al. 2013). Sexually transmitted infections impair the fertility mostly in women through infection of the upper genital tract. The genito-urinary tract infection can lead to infertility and genital TB have a strong association with infertility (Namavar Jahromi et al. 2001).

## **2.6 Social construction and experience of infertility**

The social construction deals with the meanings of a phenomena that are developed through interaction in a social context (Conrad & Barker 2010). The crux of social construction is that it brings in the distinction between the disease and illness in its discussion of a phenomena (Eisenberg 1977; Conrad & Barker 2010).

Illnesses have both biomedical as well as cultural meanings. These cultural meanings are shaped by how society labels and interprets it. In a cultural context, these social and cultural meanings shape the experience of the condition and the consequences of it (example, stigmatization) (Skrzypek 2014).

The experience of infertility is shaped by varying social and cultural interpretations. In societies where motherhood is a norm, women without children are judged (Greil et al. 2011). One of the major differences in infertility and its social construction from other illnesses is that it is not defined by the presence of a pathological state. Infertility is basically a condition which is identified by the absence of a desired state (Greil et al. 2011). It is the discretion of the couples to define themselves as infertile to initiate the care seeking. Moreover, infertility is also characterised by the availability of alternatives like adoption, fostering or even changing the partners other than medical treatment (Greil et al. 2011). But, medicalization of infertility has deviated the construction of infertility since the availability of medical technology-based solutions for infertility has rendered the infertile couples with no alternatives to these medical interventions (Franklin 1997).

Social construction of infertility also gives an insight into the gendered experiences of infertility dictated by the power imbedded in the family, medicine and technology (Unnithan 2010). Within the patriarchal norms, heterosexual cohabitation was mainly meant to produce child and in many societies motherhood is viewed as a 'very powerful' status (Batoool & de Visser 2016). Women with infertility experienced it as a major bodily flaw and this undermined their general well-being. Women considered that they lacked something and they were in constant distress due to the visible normalcy of the outside body and inadequacy within their bodies, which challenged their self-worth (Batoool & de Visser 2016). In societies where having children is the social norm, being infertile was considered culturally deviant (Vanderlinden 2009). Infertility was thought to be caused by many cultural and medical factors by the community. It ranged from being promiscuous, use of contraception as the cause for infertility in women, masturbation, watery sperm to the inability to sustain an erection for men (Okonofua et al. 1997; Tabong & Adongo 2013). The construction of the illness experience centres around the woman and motherhood when a couple as a unit has to be considered for the illness experience of infertility. Thus, women experience a range of consequences due to the inability to reproduce which include bodily, psychological/emotional, cultural and social consequences. It includes the embodiment of bodily flaw, to problems in the sexual life, (Wirtberg et al. 2006;

Vanderlinden 2009), role failure, loss of identity and feeling depressed (Nahar & Richters 2011; Batool & de Visser 2016) to being subjects of gossip and social isolation (Okonofua et al. 1997; Hampshire et al. 2012; Batool & de Visser 2016).

Gendered construction of fertility makes the experience of infertility unpleasant. The value society places on 'motherhood' makes those women who are unable to achieve it feel that they have failed themselves in the role of woman (Vanderlinden 2009). The visibility of the absence of pregnancy on the female body and the invisibility of male reproductive impairment gets infertility attributed to woman as their problem. The social norms and roles that society and culture attribute to women stigmatises those women who are unable to fulfil the motherhood role. It has been established through various studies that women are invariably affected by infertility. They also face social, economic and emotional consequences due to infertility (Nahar & Richters 2011). The social consequences included marital disruption, stigmatisation of women, loss of privacy and the emotional consequences were feeling empty, sad and depressed, being blamed by the society, role failure and guilty feelings, isolation and loneliness, and feeling of loss of identity (Greil et al. 2010; Nahar & Richters 2011; Hampshire et al. 2012).

Women are physically and psychologically affected by infertility, from having to subject their bodies to various procedures to the negative self-image they construct due to the inability to procreate. Women also have fear of marital breakdown and divorce. This is especially of great concern for women who are economically dependent on their husbands (Nahar & Richters 2011). Women who do not have the desire to achieve motherhood are less likely to self-identify as infertile (Johnson & Fledderjohann 2012). There is a greater impact of a diagnosis of infertility on women than men (Becker & Nachtigall 1992). Women who are not diagnosed to have a personal infertility problem do not self-identify as infertile and therefore do not get affected by the consequences of the labelling and such women do not take responsibility for their partners impairment either (Miall 1986; Johnson & Fledderjohann 2012).

## **2.7 Determinants of treatment seeking for infertility**

According to the theories of help seeking, the identification of symptoms to actually seeking care for any health condition is a complex process (White et al. 2006a; Cornally & McCarthy 2011). It starts with the symptom, then the individual having the symptom should acknowledge that there is a problem, weigh the options of alternative responses and then there are behavioural responses (White et al. 2006a).

In case of infertility, recognizing that one has fertility problems is the important predictor for help-seeking (White et al. 2006a; White et al. 2006b). Once the couple as a unit perceive that there is a 'fertility' problem, then they will think of the need for treatment, or think of other options and weigh the benefit and barriers attached to each of the options. Accordingly, the couple may choose professional medical treatment, or they may choose self-care or religious methods or alternate medical solutions.

The wider social context in which the couple is living is a determinant of seeking care (White et al. 2006a). Within the social context of the couple, multiple contextual and individual factors may predispose one to seek treatment for infertility. Some of the determinants of help-seeking are the approval for infertility treatment in a society, the pressure for children from significant others or the society, perceived stigma of infertility, and support from others (White et al. 2006a). The countries where there is insurance coverage for infertility treatments there is an increased uptake of treatment (Bitler & Schmidt 2012; Farley Ordozensky Staniec & Webb 2007). The individual factors that would enable treatment seeking are the age, marital status, education, financial resources including insurance coverage and social support (White et al. 2006a).

### **Section III: Public provisioning for infertility care in India and the world**

This section will include the nature of public provisioning for infertility care across the globe. It will describe the legislation and guidelines to regulate ART practices and the type of coverage or reimbursement of ART services in health plans.

## **2.8 Legislations and guidelines to regulate ART practices**

The practice of Assisted Reproductive Technology (ART) is usually regulated by legislation of each country. These legislations and guidelines keep changing from time to time. This is done to safeguard the consumers of these services and also to curb unethical or unwanted practices.

### **2.8.1 The global context**

A survey by the International Federation of Fertility Societies (IFFS) found that out of the 89 countries that reported, 77 countries had legislations or guidelines or both to regulate ART services, 57 countries had legislations while 29 countries reported that there were no regulations in their country. Of the 57 countries that reported that there were legislations governing ART, 38 countries had Federal or National laws for regulation. These were countries like Australia, Brazil, Canada, Germany, Israel, New Zealand, Sweden, UK, USA among others. Nearly half of the reporting countries had either some agency overseeing the ARTs or licencing bodies or professional standards and guidelines.

ART centres were monitored in different countries and 56 countries reported that there was a monitoring system in place for their country. This is done through National Registries, on-site inspection and periodic reporting. There was also the requirement in place to licence the ART centres and 70 percent of the countries of the countries with licensing requirement in place had reported that they had multiple procedures. Some of the procedures involved in licensing mechanism were examination and certification of the centre, on-site inspections, and continuing education.

There is licensing of reproductive medicine physicians and endocrinologists with ART training. This is done through examination or certification and continuing education. The ART laboratories also had to be licensed in addition to the licensing of the whole centre.

### **2.8.2 The Indian context**

The legislation for regulation of assisted reproduction in India started with the National Guidelines published in 2005 for the Accreditation, Supervision and Regulation of

ART clinics in India by ICMR and the National Academy of Medical Sciences (NAMS), India. After deliberations for a participatory and consultative approach for a more comprehensive legislation, in 2008 the Ministry of Health and Family Welfare (MoHFW), and ICMR released the ART (Regulation) Bill and Rules 2008. There were many lacunae in the proposed Bill. Subsequently in 2010 ICMR brought out a revised version called the Draft ART (Regulation) Bill and Rules 2010. The draft Bill of 2010 brought in the issues of surrogacy but it was still not comprehensive enough and lacked the women and children's health right (Sarojini 2014; Banerjee & Kotiswaran 2020). The Surrogacy (Regulation) Bill, 2016 was introduced in Lok Sabha on 21 November 2016, after the government decided on separate legislations for regulation of ARTs and surrogacy.

The Assisted Reproductive Technology (Regulation) Bill 2020 was approved by the Union Cabinet of India in 2020. The Bill was introduced in Lok Sabha on 14 September 2020 and on 3 October 2020 it was referred to Standing committee and is awaiting the report of the committee (Lok Sabha 2020). The Bill is aimed at regulating ART services in the country. It seeks to establish a National Advisory Board, and also State Boards. The Bill also seeks to register and accredit the ART clinics in India and also form a National registry. These are expected to regulate and supervise ART clinics and banks in the country. ICMR has started enrolling ART centres across the country but has not yet provided any registration numbers for any centres, and 532 ART clinics are enrolled in it (ICMR, 2020).

## **2.9 Insurance coverage and/or reimbursement for ART treatments**

According to the IFFS report, in 2018 out of the 85 countries reporting to the International Federation of Fertility Societies, 40 countries had some form of insurance coverage or government funding for infertility treatment. Federal, National law or statutes that addresses reimbursement of ART procedures are in place in 36 countries, while 16 countries had State/Provincial/Regional laws/statutes/ordinances (IFFS 2019).

### **2.9.1 The global context**

Globally, when available, the coverage of reimbursement was provided under National Health Plan, State/Provincial/Regional Health Plan, private insurance or combination of government health plan and private insurance. Complete coverage or reimbursement or partial coverage or reimbursement of ART services were offered under these plans. Countries like Bulgaria, Chile, Czechia, France, Hungary, Israel, Latvia, Montenegro, Netherlands, Russia, Serbia, Slovenia, Spain, Sweden and UAE had complete coverage or reimbursement under National Health Plan.

Partial coverage or reimbursement under national health plans were available for Argentina, Australia, Austria, Belgium, Canada, Finland, Germany, Hong Kong, Iceland, Ireland, Japan, Kazakhstan, Kenya, Lithuania, New Zealand, Norway, Portugal, Singapore, The Republic of Korea, Tunisia, Turkey, UK and Uruguay.

State/Provincial/Regional Health plan offered complete coverage or reimbursement of ART services in Russia, Spain and UAE and partial coverage or reimbursement in Argentina, Bulgaria, Canada, Germany, Hong Kong, Italy, Japan, Poland, Sweden, Tunisia, UK, and USA.

Complete coverage or reimbursement was in place via private insurance in countries like Germany, Netherlands, Senegal, Serbia, UAE. Argentina, Australia, Bolivia, Canada, Ireland, Jordan, Kenya, Namibia, Panama, Spain, Sweden, Tunisia, USA, and Uruguay have partial coverage or reimbursement via private insurance.

A combination of government health plan and private insurance offered completed coverage or reimbursement in Germany and partial coverage or reimbursement in Australia, Canada, Israel, Jordan, Namibia, Romania, Spain, Tunisia, USA, Uruguay, Viet Nam.

Table 2.1 shows the type of ART services covered for or reimbursed under different health plans for the countries having coverage or reimbursement for ART services.

Table 2.1 ART services covered under health plan for different countries

Sl. No	Countries	National Health Plan	State/Provincial/Regional Health Plan	Private Insurance
1	Bulgaria	Fertility Medications, IVF, ICSI	IUI, IVF, ICSI	
2	Chile	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI		
3	Czechia	Diagnostic evaluation, Fertility Medications, IUI, IVF		
4	France	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI		
5	Hungary	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI		
6	Israel	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI		
7	Latvia	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI		
8	Montenegro	Diagnostic evaluation, Fertility Medications, IVF, ICSI		
9	Netherlands	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI		
10	Russia	Diagnostic evaluation, Fertility Medications, IVF, ICSI	IVF, ICSI	IVF, ICSI
11	Serbia	Diagnostic evaluation, Fertility Medications, IUI, IVF		
12	Slovenia	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI		
13	Spain	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI	IVF	

<b>Sl. No</b>	<b>Countries</b>	<b>National Health Plan</b>	<b>State/Provincial/Regional Health Plan</b>	<b>Private Insurance</b>
14	Sweden	Diagnostic evaluation, Fertility Medications, IUI, IVF		
15	UAE			Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI
16	Argentina	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI
17	Austria	Fertility Medications, IVF, ICSI		
18	Australia	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI		IVF, ICSI
19	Belgium	Diagnostic evaluation, Fertility Medications, IUI		
20	Canada	Diagnostic evaluation, IUI, IVF, ICSI		Fertility Medications
21	Finland	Diagnostic evaluation, Fertility Medications, IUI,		
22	Germany	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI		Diagnostic evaluation, Fertility Medications, IVF, ICSI
23	Hong Kong	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI	Diagnostic evaluation, Fertility Medications, IUI
24	Iceland	Fertility Medications, IVF, ICSI		
25	Ireland	Fertility Medications		Diagnostic evaluation, IUI, IVF, ICSI
26	Kazakhstan	Fertility Medications		
27	Kenya	Diagnostic evaluation, Fertility Medications, IVF, ICSI		Diagnostic evaluation, Fertility Medications, IVF, ICSI
28	Lithuania	Diagnostic evaluation, Fertility Medications, IVF, ICSI		

<b>Sl. No</b>	<b>Countries</b>	<b>National Health Plan</b>	<b>State/Provincial/Regional Health Plan</b>	<b>Private Insurance</b>
29	New Zealand	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI		
30	Norway	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI		
31	Portugal	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI		Diagnostic evaluation
32	Singapore	IUI, IVF, ICSI		
33	Republic of Korea	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI		
34	Tunisia	Diagnostic evaluation, Fertility Medications, IVF, ICSI		Diagnostic evaluation, Fertility Medications, IVF, ICSI
35	Turkey	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI		
36	UK		Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI	
37	Uruguay	Diagnostic evaluation, Fertility Medications, IUI, IVF, ICSI		
38	Russia		IVF, ICSI	
39	USA	Diagnostic evaluation,	Fertility Medications, IUI, IVF, ICSI	Fertility Medications, IUI, IVF
40	Italy	Fertility Medications	Diagnostic evaluation, IVF, ICSI	

Source: *IFFS, Surveillance, 2019, pp. 16-19*

### **2.9.2 The Indian context**

India does not have any regulations in place that addressed the reimbursement of ART procedures. India does not have any coverage or reimbursement of ART services under National Health Plans, State/Provincial/Regional Health Plan, or Private Insurance (IFFS 2019).

However, there are targeted schemes that offer financial assistance to the couples with infertility in selected states. The financial assistance scheme is called ‘Matrutva Yojana’ and the beneficiaries are couples belonging to Scheduled Tribe group. This scheme is in place in Assam and Goa, where financial assistance of up to Rs 5 lakh (0.5 million rupees) is given to couples married for three years and who do not have a child (Questions: Lok Sabha 2017). It covers all the medical expenses for fertility treatment, like medicines, doctor’s fees, diagnostic tests and procedures as advised. An advance amount of Rs. 25,000 will be given to meet the initial expenses if they produce ST certificate, marriage certificate and the certification by any doctor (MBBS or higher qualification) which states the couples need IVF or advanced fertility treatments (Scheme India, n.d). Another targeted financial assistance scheme called the ‘Jiyo Parsi’ Scheme under the Ministry of Minority Affairs was introduced in September 2013 to reduce the decline of Parsi Zoroastrian community in India. Under this scheme medical assistance for ART is provided, with a financial assistance of up to Rs. 8 lakhs (0.8 million rupees). It covers the diagnosis and treatment including medicines and assisted reproduction. Those with annual income of Rs.15 lakhs and below will get 100 percent assistance while 75 percent financial assistance is given to those couples with annual income of Rs. 15-25 lakhs. Those with annual income more than or equal to Rs.25 lakhs will receive only 50 percent financial assistance (Parzor Foundation, 2020)

### **Section IV: Conceptualisation of infertility**

This section includes the conceptualisation of (bio)medicalisation and ‘political economy of hope’. It will discuss how the individual aspiration that is part of infertility care seeking and the wider social, economic, political as well as cultural milieu interact

to form ‘hope’, which is one of the major driving force in sustaining infertility care by the couples. The first part of this section will discuss two important processes i.e., medicalisation and biomedicalisation that have permeated the infertility discourse. This will be followed by the conceptualisation of hope and ‘political economy of hope’ in various academic pursuits.

### **2.10 Medicalisation and Biomedicalisation**

Medicalisation was first used by Zola (1972) to describe how “*medicine has permeated the lives of human lives by the use of the labels ‘healthy’ and ‘ill’*”, which has its roots in the sick role proposed by Parsons (1951). ‘Medicalisation’ describes a process by which non-medical problems become defined and treated as medical problems, usually in terms of illness and disorders (Conrad 2007).

From 1970s, sociologists have worked on medicalisation vis-à-vis deviance and social control, which included studying hyperactivity in children, mental illness, child abuse and alcoholism (Conrad & Schneider 1980). Medicalisation is characterised by bringing in a previously non-medical problems under the medical jurisdiction (Conrad 1992). This also meant decontextualizing the problems as it is brought under medical control (Conrad 1992). Medicalisation focuses on the power and authority of the knowledge (of physicians) in the society as well in the day to day medical interactions (Bell & Figert 2015), while patients assume a passive role whereby whatever is ordered on them viz., diagnosis, treatment are to be complied with, without qualms (Lupton 1997). Medicalisation has permeated into all walks of life by expanding its jurisdiction into different moral, social and legal aspects and ‘control’ became a dominant concept in its scholarship (Bell & Figert 2015). Through this control, medicine overtook the dominance of church, families and the state to define the individuals who were previously considered deviant to be termed ‘sick’ (Conrad & Schneider 1980). The medicalisation literature is amply filled with this dominance of medicine (medical profession) and the role of population (patients) in bringing about medicalisation (Bell & Figert 2015).

Feminists scholars have studied the medicalisation theory mainly critiquing it for its patriarchal nature, and they argued that women’s bodies were mostly sites of

interventions especially in the medicalisation of reproduction (Conrad 2007). Some scholars have argued to ‘move beyond’ medicalisation (Rose 2007) and that newer concepts like *pharmaceuticalisation*, *biomedicalization*, and *geneticisation* should be brought in (Bell & Figert 2015).

By late 1990s, medical sociologists found medicalisation theory insufficient to explain the illness brought about by the advances in technoscientific biomedicine. A newer theorisation was sought which was termed biomedicalisation which exists along with medicalisation but is inclusive of the technoscientific transformation of dealing with illness.

*‘Biomedicalisation is a term for the increasingly complex, multi sited, multidirectional processes of medicalisation that today are being both extended and reconstituted through emergent social forms and practices of a highly and increasingly technoscientific biomedicine’* (Clarke et al. 2003).

According to Clarke and colleagues (2003), biomedicalisation *‘is co-constituted and manifest through five central (and overlapping) processes, viz., (1) major political and economic shifts; (2) A new focus on health and risk surveillance biomedicine; (3) The technoscientisation of biomedicine; (4) transformation of biomedical knowledge; (5) transformation of bodies and identities.’*

Privatised and corporatized services through the advances in technoscientific innovations that further biomedicine is the key process mentioned in the political and economic shift that manifest in biomedicalisation. The shift in focus from illness or disease to health and the emergence of risk surveillance which rely on prevention and early interventions is the second process mentioned. The newer technoscientific innovations in biomedicine like the use of medical technology and new designs and products are another key process that is involved in the biomedicalisation process. The fourth element is the production and distribution of health and medical knowledge through different media by making it a personal goal thereby furthering the impact of biomedicalisation.

This means there is shift from the controlling nature of medicine to transformation medicine, i.e., previously unrecognised identities are formed for example at the molecular level which can be individual identities or group identities like the ‘patient groups’ of certain conditions or diseases (Clarke et al. 2010). Clarke et al. (2010) reiterate that through these processes, medical autonomy and power have declined since biomedicalisation is characterised by more commercialisation of medicine, by shifting the power from the medicine to market. This commercialisation and commodification of healthcare, has shifted patients from passive consumers to active negotiators (Bell 2016).

Biomedicalisation helps in improving the lives of people by alleviating pain and suffering through its many technological advances nevertheless it also creates ‘choices’ (Clarke et al. 2010) and also ‘technoscientific identities’ (Clarke et al. 2003). It is also attributed in creating inequality due to the stratified biomedicalisation (Bell 2010).

### **2.10.1 (Bio)medicalisation and reproduction**

Women’s natural life processes are more medicalised than that of men’s and this means that gender also plays an important role in medicalisation (Riessman 1983). The gendered ideologies equate womanhood to motherhood, and this expectation is manifested in the abundance of various technologies that are available to allow women to have their fertility desires fulfilled (Baldwin 2019). The (bio)medicalisation in the area of reproduction was initially centred on pregnancy and childbirth which gave way to infertility with the advent of newer technologies to assist reproduction. The advancements in technology have put women in a more vulnerable position (Gabe et al. 2004; Conrad 2007), because of the focus of these technologies on women’s bodies rather than on the reproductive bodies of the couples (McNeil et al. 1990). Medicalization has made infertility care women’s responsibility as men’s role is limited to ‘*ejaculatory extensions*’ (Culley et al. 2013). In infertility care, the availability of Assisted Reproductive Technologies (ARTs) has become what Foucault has described as ‘governmentality’, since women with infertility feel obligated and compelled to reproduce via ARTs to achieve motherhood (Franklin 1997; Clarke et al.

2010). Medicalisation literature has both debated for and against it whereby it argues that medicalisation of reproduction has both empowered and disempowered women. Medicalisation is rooted in medicine which is an objective science, decontextualizes the infertility experience (Conrad 2007), and the medical gaze reorients the experience of the women to the realm of medicine. It thus creates inequality as these experiences are different for women of different social positions (Bell 2016). This means that women of low SES are prevented from accessing such care due to high cost, and other factors including the lack of understanding of what is communicated to them in the doctor patient interactions (Bell 2016). Medical hegemony in the medicalisation of infertility can dictate who should and should not be a mother. The treating physicians dictate who are deemed fit to reproduce and hence cause stratification in reproduction. This also alters the meaning of the experiences of infertility when placed within the medical discourse where women are defined based on their diagnosis and treatments.

Bell (2010) has demonstrated in her work that medicalisation of infertility has created stratified reproduction which has excluded certain groups of women. She has cited examples of how women of low socio-economic status are excluded from medicalised solutions of infertility. These exclusions in accessibility and affordability, she argues, creates alternate pathways to negotiate their childlessness.

### **2.11 Hope and ‘Political economy of hope’**

Couples become frustrated when confronted with diagnosis of infertility and realise their inability to move along the marital continuum from individual to couple to parenthood. Within the infertility discourse this is represented as ‘desperate’ (Franklin 1990). This desperateness to reproduce is then tied to hope by virtue of medical technology-based solutions for infertility. The development of Assisted Reproductive Technology (ART) for treatment of infertile couples was one of the major accomplishments in the field of reproductive medicine. The availability of medical options for assisting reproduction was not common until 1950s but during the late ‘70s to the ‘90s there has been a boom in biomedical development in infertility, and this has resulted in the availability of ART (Davis & Loughran 2017). During the 1950s artificial insemination with donated sperm and ovulation induction with hormones

were used to treat infertility but in the late 1970s there was use of technologies like the In Vitro Fertilisation (IVF) (Inhorn & van Balen 2002). More advanced technologies like the Intra Cytoplasmic Sperm injection (ICSI), and egg freezing became common in the 1990s (Wang & Sauer 2006). Hence a range of reproductive technologies are currently available in the market which could be used for resolving infertility. Thus, hope and hopelessness of the infertile couples started to depend on modern medicine, or the providers of this service.

Sarah Franklin (1990) has noted that with the introduction of these medical technologies the focus shifted from the stories of women to the medical experts, who will dictate the course of what happens in the woman's body. This objectivity is also noted in how patients are referred to in the everyday discourse of infertility, their identity is replaced by the anatomy viz., 'eggs', 'tubes' and 'ovaries'. Thus, the focus of infertility shifted from the person who desired a child to the experts who will give her a child. The stories of their success became important and were highlighted, promoting the idea that medical technology is the only source of hope for couples. These representations include the photographs of the happy couples to reinforce the victory of technology in turning the desperate couple to happy parents (Franklin 1990).

This techno-centric medicine has the power to raise hope in those who are the users of it (Helén 2004). Therefore, it is important here to bring in the conceptualisation of hope and how it is represented in literature and how has it been examined in the studies. This will be followed by the contextualization of hope in different discourses and how it is being created as a political and economic process.

Hope is conceptualised as something that is forward looking, which means that something that will happen in the future and uncertainty is the driving factor for hope (Miyazaki & Swedberg 2017). There is a three-step process as to how hope operates in an individual. First, and the most essential part of hope is the *wish*. Secondly, this wish has to be *for something*, which has a social dimension. Finally, the wish for something *to come true* and is the basic principle of hope. The one that an individual hopes for should be socially valid i.e., it needs acceptance and assistance from others for it to be fulfilled (Miyazaki & Swedberg 2017).

Hope has become part of the dominant discourse of science (Petersen & Seear 2011) and various studies have examined how technology and hope are operating together. The operationalising of 'hope' in scientific applications on humans through the use of technological solutions has been done by employing the concept of 'political economy of hope' a term first used by Good et al. (1990) in their study on oncology treatment where clinicians have to balance between disclosing the truth about the diagnosis while still maintaining hope about the prognosis. The paper explores the growing specialisations in the field of oncology and the increased research in the field of oncology and how the international culture of oncology poses new challenges to local practices. One of the issues raised in the paper is related to the norms of disclosure of cancer diagnosis and how this has implications for the production and utilisation of anti-cancer therapies. They put forth several hypotheses viz., each culture has its own way of operating and biomedicine also operates within this cultural milieu. Thus, international biomedicine operates with its local variants within each culture. It is also shaped by the availability of biomedical technology and therapeutics and also the society's disclosure pattern and physician-patient relationship. The local variants with respect to how biomedicine is operationalised also influences the choice of treatment and use of biomedical technology. The political economy of specialist-research oncology articulates within a society's cultural interpretation of 'hope'.

The authors have used the term 'political economy of hope' in this context to describe the link between research and treatment institutions. With the development of newer potential anti-cancer therapies, there is a need for patients on which to try them. These options offer the promise of hope to patients and their families who have reached the end of possible known interventions for the disease. In this context, health care providers who are also cancer researchers hold the promise of relief to patients who can enrol into studies testing these new therapies. Such a potential tends to affect the norms of disclosure about treatment options to patients, holding out the potential of hope rather than focusing on the need for hospice care which may offer some alleviation. Although this term has been used by the authors, it has not been described in detail in the paper and the paper focuses on the norms of disclosure of cancer

diagnosis and how they have to balance between disclosing the truth about the diagnosis while still maintaining hope about the prognosis.

The creation of a market for the unproven stem cell therapy, nascent stage umbilical cord blood therapy, newer treatments for cancer are all underpinned by 'hope'. Here, hope has three contrasting existences, hope of the patients that the treatments will improve their future, the providers' hope that the technologies can be legitimised for a thriving future industry, and lastly hope upheld by the critics of these technologies that they can protect the patients by bringing in regulatory frame for these technologies being sold to the public (Petersen et al. 2017).

This conceptualisation places hope well within the ambit of political economy. The concept of the 'political economy of hope' was originally used in the area of oncology ( Good et al. 1990), and subsequently in the context of patient activism in biomedical research (Novas 2006). "*The 'political economy of hope' is an anthropological concept which describes how personal and collective 'hope' is associated with political and economic structures that produce biomedicalization process*" (Mrig & Spencer 2018).

This concept has been used by authors in studying cancer treatment, embryonic stem cell therapy, umbilical cord blood banking, uses of stem cell therapy in degenerative diseases and patient group activism in biomedical research. The common thread in all these is the narrative of hope, that transcends the social and emotional realms of those who use this, and their investment in these technologies, emotionally and financially.

Different authors have employed the concept of 'political economy of hope' in their scientific pursuit to explain technologies that offer cures to the myriad health problems. Prasad (2014) in his study on overseas stem cell therapy explores how the political economy operates by focusing on the 'deterritorialization' of different 'regimes of truth' in the journey of the patients. The author here quotes Michel Foucault (1980) "*Each society, has its regime of truth, its 'general politics' of truth: that is, the types of discourse which it accepts and makes function as true*", to explain deterritorialization. Foucault explains that an individual's functioning is linked to the

society's 'regimes of truth', and this includes the '*class position, conditions of life and work and the general politics of truth of the society*' (Foucault 1980). This explains how individuals (here patients) select or use certain technologies, by bypassing different 'regimes of truth' and manage the risk and uncertainties of the therapy. This process then, enables the positioning of 'truth' from one realm or paradigm of knowledge to another, where by it gains better credibility or loses it, depending on what is desired by those who attempt it.

Underutilisation of hospice care among end-stage cancer patients also came to pass by employing the concept of 'political economy of hope'. The authors noted that there is an increase in the hospice care availability in the U.S on par with biomedicalization of end-stage cancer patients. But the possibility of a 'cure' for cancer instils hope in the end-stage patients inducing them to try new biomedical interventions. It becomes a tough decision to select hospice care or make one last attempt with a biomedical treatment option, of which many are available. The authors state that they used the term 'hope' to bring in the presence of the agency of the patients in fuelling the biomedical research. Patients, by being party to the decision for treatment may benefit from it or some others may benefit from the new interventions developed. Thus they render their bodies for novel treatments (Mrig & Spencer 2018). The emergence of regenerative medicine as a new field of 'hope' due to the promissory value of the cord blood has also used the concept to examine commercial blood banking and the dynamics of private and public sector banking (Martin et al. 2008).

Good (2003) explained the concepts of medical imaginary and political economy of hope, and how the public are drawn into using these technological advancements which may not offer success in all its endeavours. These are achieved through selling the success stories and circulating it through popular media.

## **Chapter 3**

### **Methodology**

This chapter describes the methodology used for undertaking the study, including the research design. The methodological and conceptual framework of the study and the ethical considerations in the conduct of the study are explained. The sampling strategies, sample selection processes, methods of data collection and analysis are explained separately for each of the three phases of the study. The chapter also gives a reflective account of the field work particularly focusing on the researcher's positionality.

#### **3.1 Study Design**

The study used a multiphase mixed methods design (Creswell & Clark 2011) with three phases completed between November 2017 to May 2019. It consisted of three distinct phases; a qualitative phase followed by a quantitative phase, this was followed by the third phase of the study which used a mixed methods approach. In phase I of the study which employed a qualitative methodology, data was collected and analysed which enabled the development of the instrument for the Phase III quantitative survey. The second phase used secondary data analysis and this exercise facilitated the selection of study setting for Phase III. The final phase used a concurrent embedded design, where both quantitative and qualitative methods were used.

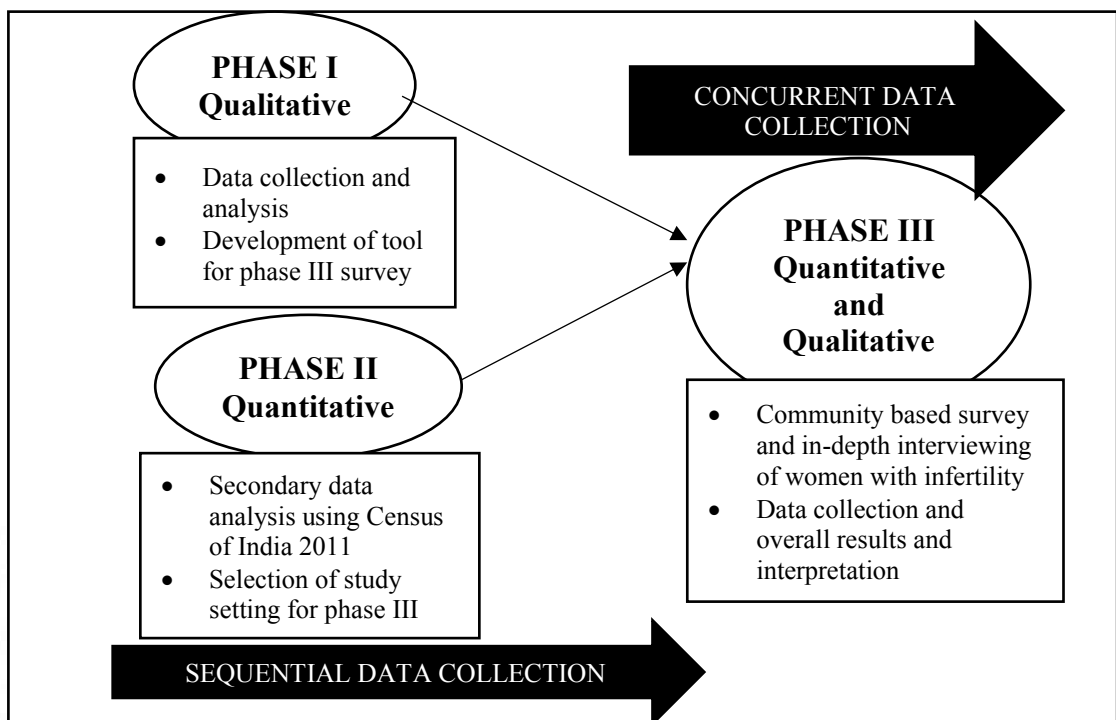


Fig 3.1: Flowchart showing different phases of the multiphase mixed methods design

### 3.1.1 Conceptual study plan

The study was done in three phases, phase I used a qualitative design with in-depth interviewing among the couples with infertility. This phase helped to understand the trajectories of care seeking for resolution of infertility among couples and to identify reasons for these choices made by couples. The results of this phase fed into the development of interview schedule for phase III of the study. The phase II of the study used Census of India 2011 data to get the estimates of expected levels of infertility for Kerala and its districts and the age pattern of infertility in these districts. Ranking of the districts based on the expected level of infertility was done to select the study sites for phase III data collection.

Phase III used both quantitative and qualitative methods to describe the care seeking pathway for infertility in Kerala and to examine the inequalities in the care seeking for infertility in Kerala. This phase also used in-depth interviewing to describe the infertility specific distress, in women undergoing treatment for infertility and to understand the possible consequences of infertility for women. The study plan describing these sequences is shown in figure 3.2.

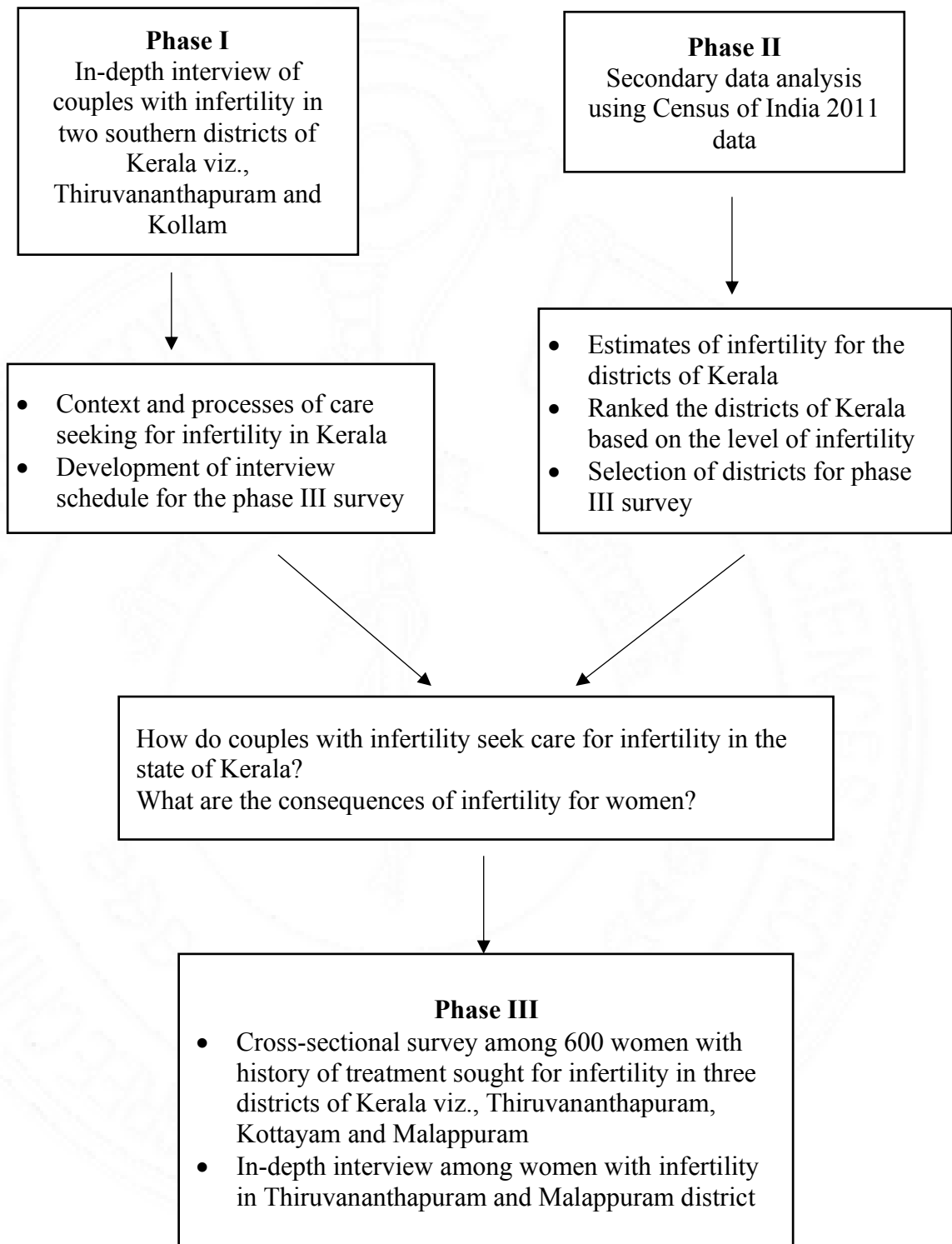


Fig 3.2: The study plan designed in three phases

### **3.2 Conceptual framework of the study**

The conceptual framework of the study is shown in figure 3.3, which was developed after literature review to understand the care seeking trajectory of couples with infertility. Studies have shown that there is a social burden to infertility which is highly gendered. With the presence of the Assisted Reproductive Technologies (ART), this burden has increased. It is because most of the treatment procedures happen on woman's body, and this adds to the existing burden of women. Most ART based treatments are concentrated in the private for-profit sector and hence couples will have accessibility and affordability issues relating to these treatments. Hence, the conceptualisation of the study is based on the following assumptions;

1. There is a social burden of infertility which is highly gendered, it means within a given social context women are burdened more by the presence of infertility, even when the inability to reproduce is caused by male factor. To reduce this burden women/couples resort to treatment.
2. There are advancements in the technology-based solutions to treat infertility which is mainly concentrated in the private sector. Therefore, such technologies when they create opportunities for solutions, also create burdens in terms of physical difficulties of the treatment per se. This burden is mostly borne by women. The concentration of such technology-based solutions in the private sector further make them less accessible by certain sections of the society creating inequality.
3. Infertility care seeking is at the multiple axes of intersecting factors, availability, affordability based on the social context and the desperation caused by both the gendered social burden and its consequences.

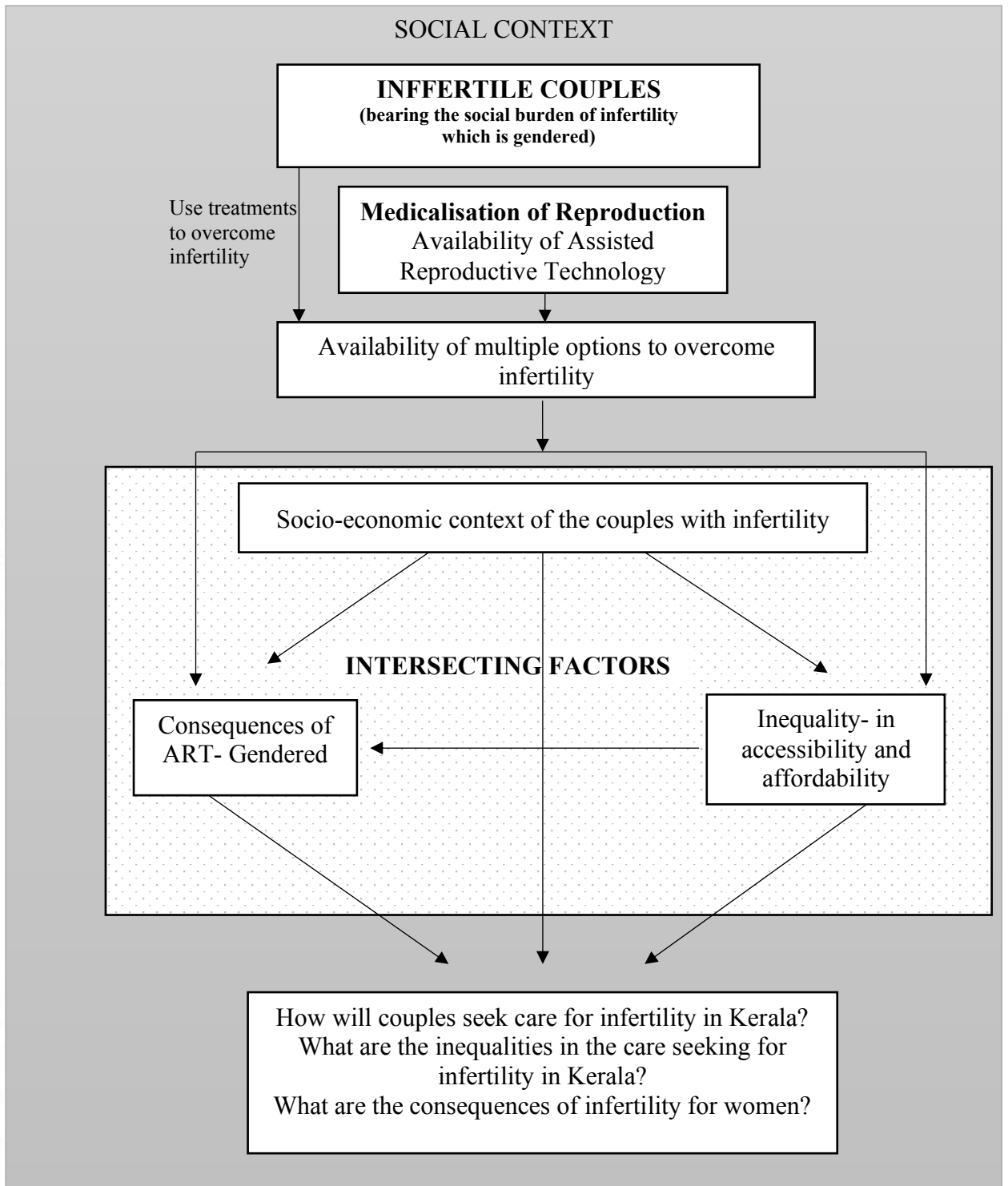


Fig 3.3: Conceptual framework for the study

### 3.3 Operational definitions

The operational definitions of terminologies used in the study are shown in table 3.1.

Table 3.1: Operational definitions of terminologies used in the study

<b>Terminology</b>	<b>Definition</b>
Infertility	In this study infertility is defined as the inability to achieve pregnancy after 12 months of marriage.
Couple with infertility	In this study ‘couple with infertility’ is defined as heterosexual man and woman who are married for at least a year, and do not have a child or those who are married for at least an year and have a child or are currently pregnant but have history of treatment sought for infertility.
Other systems of medicine	In this study other systems of medicine include Ayurveda and Homeopathy.
Alternate methods	Alternate methods in this study include traditional and faith-based remedies as well as magical remedies.
Care seeking	Care seeking is defined in this study as all the mainstream treatment methods and alternates that are used by the couples for treating infertility.
Allopathy	In this study, conventional western medicine or biomedicine or mainstream or western medicine is referred to as Allopathy – the term commonly used to refer to it in the Indian context.

### 3.4 Ethical considerations

The three phases of the study were cleared by the Institutional Ethics Committee of SCTIMST. Phase I of the study was cleared by IEC vide SCT/IEC/1112/NOVEMBER-2017 dated 23.11.2017 and the phase II and III were cleared by IEC vide SCT/IEC/1112/JULY-2018 dated 03.08.2018. The IEC clearance certificates are attached in appendix A1 and appendix A2.

#### 3.4.1 Informed consent

In phase I of the study, the participants were approached via friends or Accredited Social Health Activists (ASHA workers), to get their permission. I approached the participants if they were willing to be interviewed. At the time of interview, written

informed consent was obtained from all the participants including the consent to audio record the interviews. The information sheet and the consent form used for phase I is given in appendix A3 (English) and appendix A4 (Malayalam).

Phase III consisted of a quantitative survey and a qualitative component using in-depth interviews (IDIs). This phase was done after getting permission from the National Health Mission (NHM), Kerala to avail the help of ASHA workers for recruiting the participants. The permission letter from State Mission Director, NHM and the DMOs (Kottayam and Malappuram is attached) as Appendix A5. The ASHA workers identified appropriate participants in their area of work, informed the potential participants about the study and sought their willingness. Those who indicated willingness were approached for the survey and IDI components. After approaching them, the information sheet was given or was read to them and only after obtaining their written informed consent was the interview done. Anyone who was not willing to take part in the study after reading the informed consent was allowed to drop out. The information sheet and consent form used for phase III survey are given in appendix A6 (English) and appendix A7 (Malayalam) and for the IDI is given in appendix A8 (English) and appendix A9 (Malayalam).

The information sheet given to the participants outlined the nature of the study and the nature of their participation, and what was expected of them. It was also stated in the information sheet that the participation in the study was purely voluntary and the participants were free to withdraw from the interview any time. The information sheet also sought permission to audio record the interview in case IDI was used to collect data. The contact details of the IEC contact were also given in the information sheet for clarifications, if any of the participants had doubts or complaints regarding the conduct of the study.

### **3.4.2 Confidentiality and Anonymity**

The confidentiality needs of the participants was considered during data collection and analysis by removing potentially identifying information. All the information collected were kept under safe custody of the PI and the names of the respondents and other identifying information where ever they appear were changed to maintain anonymity.

Materials that could potentially identify the participants like the consent forms are kept separately under the safe custody of the PI and will continue to be for the duration mandated by regulations. Electronic data are stored in password protected folders and only the researcher has access to it.

### **3.5 Study setting**

#### **3.5.1 Phase I**

Phase I of the study was done in two southern districts of Kerala viz., Thiruvananthapuram and Kollam. This was the exploratory phase of the study and hence the districts were conveniently selected.

#### **3.5.2 Phase II**

This section does not include the details of study setting as it is not relevant for this phase.

#### **3.5.3 Phase III**

The study setting for phase III were the districts Thiruvananthapuram, Kottayam and Malappuram. These districts were selected based on the ranking of districts by the expected level of infertility based on Cumulative Fertility Rate (CFR) based measure in the age group 45-49 years from Census of India 2011 data. The reason for preferring CFR based ranking as opposed to Children Ever Born (CEB) based ranking is because CEB represents the cumulative experience of past cohorts. CFR is a synthetic cohort depicting the cumulative fertility experience at the current point of time. The total children ever born in the last year divided by the total ever married women gave the (modified) age specific (marital) fertility rate (ASMFR). Using the ASMFR, cumulative (marital) fertility rate was computed. This was used to calculate the expected infertility level in each age group using the formula suggested by Pandey and Suchindran (1987). The formula used is explained in detail in this chapter under section 3.9.2.1.

The district with the highest expected level of infertility was given rank 1 and the lowest was given rank 14. After ranking the districts, they were divided into three groups each representing a category of infertility levels; category 1 with high levels of

expected infertility included districts with rank 1 to rank 4 which were Pathanamthitta, Alappuzha, Thiruvananthapuram and Kollam respectively, category 2 with moderate levels of expected infertility included districts with rank 5 to rank 9 which were Ernakulam, Thrissur, Kozhikode, Kottayam and Palakkad, and category 3 with relatively low levels of expected infertility included districts with rank 10 to rank 14 which included Idukki, Wayanad, Kannur, Malappuram and Kasaragod respectively. From each category, the last but one district was selected for the study, to avoid the extreme outliers. Hence, from category 1 Thiruvananthapuram, from category 2 Kottayam and from category 3 Malappuram were selected for the study.

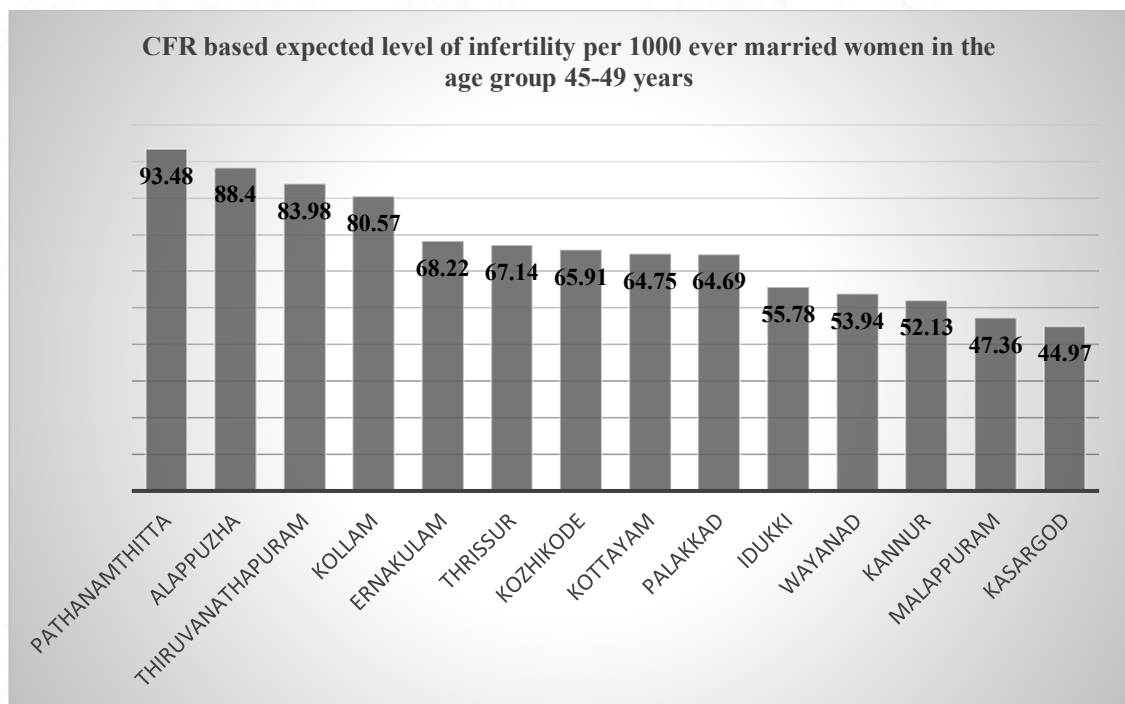


Fig 3.4: Distribution of the districts based on the expected level of infertility

### 3.6 Sampling and Recruitment

In this section the sampling and recruitment of the subjects is explained for each of the three phases of the study.

#### 3.6.1 Phase I

The participants were selected by snowball sampling with the help of friends, and also by contacting ASHA workers. A total of 18 participants were interviewed in this phase, which included 16 women and two men who were husbands of these women. Women

who were married for at least an year, both those who had started care seeking and those waiting to seek treatment were included in the study. Those who had child after treatment were also included. The primary respondents were women and husbands were interviewed only if the women gave permission to do so.

### **3.6.2 Phase II**

This section does not include the details of sampling and recruitment as it is not relevant for this phase.

### **3.6.3 Phase III**

This phase used a mixed-methods design, it used both quantitative and qualitative methods concurrently.

The proportion of the population of couples who would seek any kind of treatment for infertility is approximately 80.0 percent (Boivin et al. 2007). Taking this to be the expected proportion of persons who would seek treatment for infertility within the population, 95 percent confidence interval and a precision of 5 and design effect 2, the sample size was calculated as 492 using Open Epi version 3.01. For the purpose of dividing the sample across three districts equally, the sample size was rounded off to 600.

The eligibility criteria were women in the age group 20-44 years, who were married for at least 12 months and who did not have a child, with history of care sought for infertility. Women in the age group 20-44 years who were married for at least 12 months and who had a child/children born but had a history of care sought for infertility were also included. Only women in the households who were current residents (de jure) at the time of the study of Thiruvananthapuram, Kottayam and Malappuram districts, and those who were able to speak or understand Malayalam/English were considered. Women who had sought treatment for more than 15 years (to prevent recall bias and also treatment processes were very different in earlier times) were excluded from the study.

From each district 200 subjects were selected. A systematic random sampling strategy was used to select the sample. From urban and rural areas of each district, 100 subjects each were selected. The selection of subjects from the urban and rural area are given in figures 3.5 and 3.6 respectively.

For the urban areas, the names of the municipality or corporation in a district were numbered in alphabetical order and from this five municipalities or corporation were randomly selected by lottery method. Under each municipality or corporation there were different number of wards, therefore the total number of wards in each selected municipality or corporation was divided by five, and if this number be 'x' (rounded off to the next whole number if it was a decimal number) and then from one to x, a number was randomly selected and this was the number of the first ward. The next ward was selected by adding 'x' to the first ward and so on till five wards from each selected municipality or corporation were selected. If due to any reason the selected ward was not feasible, then the immediate next ward was selected. From each selected ward, four subjects were selected with the help of the ASHA worker.

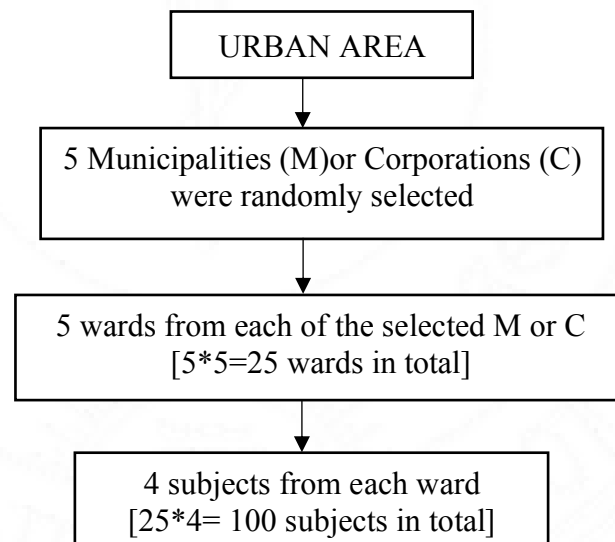


Fig 3.5: Selection of subjects from urban areas in each of the selected districts in Kerala

For the rural areas, the total number of blocks in Thiruvananthapuram and Kottayam districts were 11 each and in Malappuram district it was 15. The name of the blocks were numbered in alphabetical order for each district. From this list, 10 blocks were randomly selected. The next step was the selection of grama panchayat (GP), the number of GPs under each block were different. Therefore, first the GPs were numbered in the alphabetical order for each district and the total number in each block was divided by two, allowing for this quotient to be 'x'. The first GP in each block was selected by selecting a random number between one to x, and the next GP by adding x to the previous number. From the two selected GPs, one ward each has to be selected which was selected randomly. If due to any reason the selected ward was not feasible, then the immediate next ward was selected. From each selected ward, five subjects were identified with the help of ASHA worker.

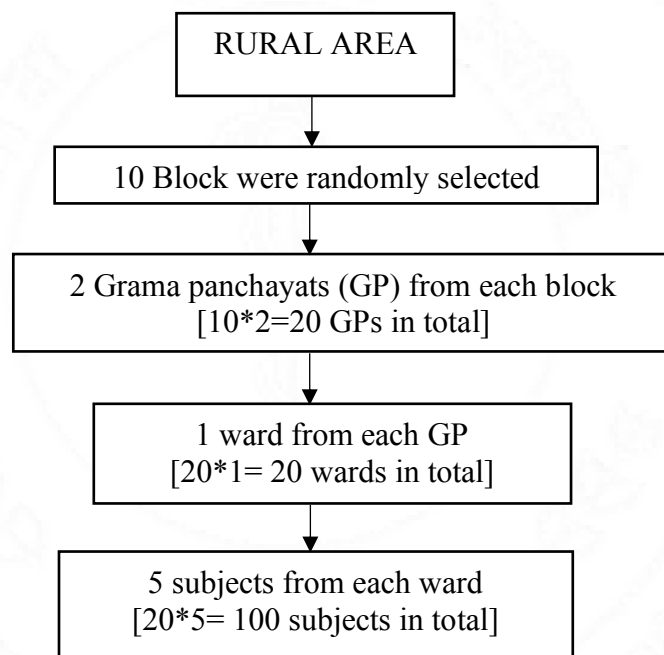


Fig 3.6: Selection of subjects from rural areas in each of the selected districts in Kerala

Ten women were selected for in-depth interviews from the selected wards in Malappuram and Thiruvananthapuram district. Some of them were identified during the survey while other were randomly selected. These were women with specific characteristics that lead to better descriptions of the experiences of the consequences of living with infertility.

### **3.7 Data collection**

The data collection tools and methods are explained in this section, using the three phases of the study.

#### **3.7.1 Phase I**

The data collection for this phase was done between November 2017 to March 2018. In-depth interviews were used in phase I to obtain the data. An in-depth interview guide was used to collect data. Women were selected as the primary respondents and if they gave permission their husbands were also interviewed. The participants were asked when they identified having difficulty in getting pregnant and what were the choices exercised by them in resolving it. They were also asked what helped them in this process and also who were the key decision makers in the process. The IDI guides used for phase I data collection are given in appendices A10 (English) and A11 (Malayalam).

#### **3.7.2 Phase II**

This section does not include the details of sampling and recruitment as it is not relevant for this phase.

#### **3.7.3 Phase III**

The third phase had two distinct methods of data collection one was a community-based survey and another was in-depth interviews of selected women. The data collection for this phase was done from August 2018 to May 2019. Both the survey and the in-depth interviews were done concurrently.

The survey data was collected using Open Data Kit (ODK) collect. The interview schedule form was created in the ODK platform and a tablet was used for data collection.

An interview schedule was used to collect data which was used to capture the actual care seeking trajectory of couples with infertility in Kerala. The interview schedule was divided into different sections and an initial screening section enabled identification of eligible participants. This was done by the ASHA workers in most cases who identified

the potential participants based on the eligibility criteria. But before starting the interview, I confirmed it again with the participants. The remaining sections included socio-demographic profile, socio-economic status, marital, reproductive and family history, consequences of infertility, current status vis-à-vis the treatment, identification of the problem and initiation of treatment seeking and finally the treatment history for infertility. The interview schedule is given in appendices A12 (English) and A13 (Malayalam). Each interview lasted 15 minutes to about 30 minutes based on the actual care seeking pathway of the couples.

The sample size fixed for the survey was 600 but in anticipation that some of the respondents may have more than 15 years of treatment history a few extra interviews were done in certain wards as deemed necessary. This was because the total duration of treatment was calculated based on the starting of the treatment and the last date of treatment. Some of them were just on the border while collecting data and hence extra interviews were done to compensate if those cases exceeded 15 years while computing the duration of treatment. Hence, there were 604 interviews in total at the end of the data cleaning process that fulfilled the inclusion criteria.

The data collection for the qualitative phase was done among 10 women some of whom were identified during the survey while others were randomly selected. IDI guide was used for data collection. The participants were asked about the treatments they have undergone in trying to conceive and the specific meaning it has to your life. Each interview lasted about 40 minutes to one hour. The IDI guides used for phase III data collection are given in appendices A14 (English) and A15 (Malayalam).

### **3.8 Reflections on fieldwork-reflexivity and positionality**

It is important here to state my position so as to enable the understanding of the findings in totality. I am an unmarried woman in early thirties, trained nurse and a public health graduate. Although my status as an unmarried woman barred me from going through the experience of infertility, the medical understanding of it helped me acknowledge the difficulties of the condition. So, as a woman researching this particular problem, I was not able to detach my reproductive body from the women I was interviewing. Most of the issues that the women discussed resonated with the

woman in me first and subsequently the researcher. Since I come from a biomedical school, I understand the treatments and the merits of Allopathy. In this study I do not discredit the merits of other systems of medicine in infertility care. But I do not have the scholarship to understand the working of other systems of medicine.

Sharing the same cultural identity as that of my participants, and being a woman helped me enter the personal space of the participants. I did face negative experiences especially from male participants who were not at all comfortable of my presence even though the primary respondents were women in the study. Nonetheless, there were also men who were open and happy to share their experiences with me.

### **3.9 Data Analysis**

In this section the plan for data analysis for different phases of the study are detailed.

#### **3.9.1 Phase I**

Grounded Theory approach was used to identify the most relevant concepts in the care seeking trajectories of the interviewees. The first three interviews were completed and transcribed and translated verbatim by the PI. One interview was analysed using RQDA software starting with open coding by reading the interview line by line and coding each sentence. After finishing the first interview, the second and third interviews were coded using constant comparison to the codes already created. Memos were created and then the subsequent interviews were undertaken to capture the emerging categories and notions that were not captured in the previous interviews. After about five to six interviews there was saturation in the codes. A major gap identified was that the pure female factor infertility story was not complete with the interviews conducted. Subsequent interviews were done by interviewing women who had female factor problems as the cause for their infertility in order to achieve a form of theoretical saturation (Morse 2007).

Codes were merged to form categories and finally the categories which were similar in meanings were merged to form the themes.

### **3.9.2 Phase II**

Secondary data analysis using the Census of India, 2011 was done to estimate the levels of infertility for Kerala and its districts and analyse the age patterns of infertility in the districts of Kerala. To estimate the levels and examine the age patterns of infertility, data on children ever born among ever married women (Fertility Table- F3) and births during the past one year among currently married women by birth order (Fertility tables-F9) from the Census of India, 2011 Fertility Series were used (Census of India: F-Series: Fertility Tables 2011).

Due to dearth of comprehensive data on the number of infertility centres in the state, the private sector involvement in infertility care in the state is demonstrated based on other data sources. For this I have used data from published articles and reports to understand the health care services and utilization in Kerala. Data from the reports of the National Sample Survey Organisation (NSSO), Central Bureau of Health Intelligence, Census of India, National Family Health Surveys, Ministry of Health and Family Welfare, Survey and Design Division of Department of Economics and Statistics and Department of Health Services, Kerala were utilized.

The NSSO health survey data was used to understand the medicalisation and the growth of the private sector. The Department of Health Services, Kerala data was used to establish the predominance of private sector in health care delivery in the state and also to demonstrate the growth of the private sector in the state compared to the public sector using the medical institutions and personnel under the Kerala Department of Health Services. The privatisation of the reproductive health care in Kerala is established using the level of institutional deliveries in public and private sector hospitals Kerala.

#### **3.9.2.1 Measuring infertility**

The conventional measure of period fertility is age specific fertility. The Total Fertility Rate (TFR), as period measure, provides average number of children a woman is expected to bear if she survives to the end of child bearing according to the prevailing 'fertility condition' of the year. As such, the total fertility rate is the cumulative age-specific fertility rate at the end of reproductive life.

Infertility has been estimated using the formulation suggested by Pandey and Suchindran (1987) for estimation of reproductive events where infertility is described as a Poisson process for a given fertility schedule indicated by the TFR ‘ $\lambda$ ’ and birth orders indicated by ‘ $k$ ’. This essentially gives the expected number of women with birth order ‘0’ per 1000 women in a particular age group given the age schedule of fertility represented by the current TFR.

If we let  $X$  = the number of events in a given interval, and if the mean number of events per interval is ‘ $\lambda$ ’. The probability of observing  $k$  events in a given interval is given by;

$$P(X=k) = \frac{e^{-\lambda} \cdot \lambda^k}{k!}$$

where  $k= 0,1,2,3,4,\dots$  and  $\lambda=\text{TFR}$ ,

In estimating the levels of infertility  $k=0$ , and therefore the probability of observing the events in a given interval is given by the formula

$$P(X=k) = e^{-\lambda}, \text{ where } \lambda=\text{TFR} \text{-----(1)}$$

Infertility estimation was done using Census data (2011) using three different measures for the 14 districts of Kerala. Estimate 1, which is based on age specific fertility rate and estimate 2, based on age specific marital fertility rates are indirect measures and estimate 3, calculated using ‘0’ parity women in the age group 45-49 years is direct measure of infertility.

***Indirect estimate of infertility based on age specific fertility rate (ASFR) and age specific marital fertility rate (ASMFR):*** Estimate 1, it uses the period based TFR measure for all women irrespective of their marital status. The number of total women and total number of births for last one year was used to compute the Age Specific Fertility Rates (ASFRs) and from this TFR was computed. This was then used to estimate the expected level of infertility using formula (1).

In estimate 2, for computation of expected levels of infertility, total ever married women and total births for past one year was used. Here we have taken ever married women and not currently married women to make it comparable with estimate three

which has the same denominator. For this age specific (marital) fertility was computed and the levels of infertility were estimated using the formula (1).

***Direct measure of infertility using '0' parity of women in the age group 45-49 years:***

The expected level of infertility was estimated by dividing the total number of women with '0' parity in the age group 45-49 years by total number of ever married women in the age group 45-49 years.

***Examining age patterns of infertility:*** The age patterns of infertility was examined using the cohort-based measure of Children Ever Born (CEB) by age of ever married women and the period-based measure of Cumulative Fertility Rates (CFR) by age for ever married women. Here, ever married women was used as the denominator to compute the CFR based estimate and not currently married women. This was done so as to enable the comparison across CEB and CFR measures. The CFR measure which uses birth in the past one year based on currently married women gave very small estimates of expected levels of infertility and thus comparison was difficult.

CEB based estimate was used to describe the variations across the different age cohorts. The CEB measure would accommodate multiple regimes of fertility and mortality within itself. We have included mortality of children as a factor affecting CEB, on the assumption that sometimes CEB levels can exclude those children born but died subsequently and this then, affected the reported fertility of women. The total children ever born in an age group divide by total ever married women in that age group was computed to give the average children ever born for that age group and this was used to get the expected infertility estimate using the formula  $e^{-\lambda}$ . This gave the age pattern of infertility using the cohort based CEB measure.

The CFR is a synthetic cohort constructed using births during the past one year. Therefore, it represents the period experience of fertility. The CFR based estimate helps to describe the current age pattern and the likely changes in it. Using the F-9 table of census 2011 on number of women and ever married women by present age, number of births last year by sex and birth order, CFR based estimate was computed.

The Age specific marital fertility rate (ASMFR) was computed by dividing total births for last one year by the total ever married women instead of currently married women as is the convention to render comparisons with the CEB based measure. From this, the cumulative marital fertility rate was computed and this was multiplied by five in age group to get the cumulative fertility rate.

$$CFR(x) = \int_a^x m(a) da$$

where  $m(a)$  is the age specific fertility rate at age 'a'

The probability of not having birth before age  $x$  is given by  $e^{-\int_a^x m(a) da}$ .

Thus, the infertility level for each age group is given by the formula  $e^{-CFR}$ .

### 3.9.2.2 Indexing infertility rates

By examining the ASFR, it was found that close to 90 percent (87%) of the TFR is achieved by 30-34 years. There is very limited scope for extension of TFR after this age. Therefore, this age group (30-34) was used to index the infertility levels. By indexing using the ASMFRs (2<sup>nd</sup> estimate), the potential for change in infertility status by age and age cohorts is explained. For the purposes of indexing the CFR based measure was preferred as it is a synthetic cohort depicting the cumulative fertility experience at the current point of time.

The index of infertility is given by the formula;

$$\text{Index} = \frac{[\text{Inf}(30-34 \text{ years}) - \text{Inf}(45-49 \text{ years})]}{\text{Inf}(45-49 \text{ years})}$$

where 'Inf' is the expected level of infertility for the age group within the parenthesis.

As we are looking for intervention aided reductions, if we assume that there is very limited scope for natural fertility-based extension after 34 years (and 90% of TFR is achieved by this age); one can assume that decrements in infertility are a consequence of interventions. As this is an attempt to capture the potential need for these interventions; this form of indexing (against infertility at or up to age 45-49 years) was preferred. What the index represents is the potential for reduction (or increase) in infertility below (or above) what is expected at age 45-49 years; that occurred between ages 35-49 years.

### **3.9.3 Phase III**

The data analysis will be discussed in two sections; the first section will discuss the analysis of quantitative survey data and the second section will discuss the qualitative interview data.

#### **3.9.3.1 Quantitative Survey Data**

The dependant variable used in the analysis was achieving pregnancy and the independent variables used were duration of marriage, employment status of the couple, religion, socio-economic status of the couple, age at start of treatment, family history of infertility, type of infertility experience by the couple, type of centre used by the couple.

The data analysis was done using RStudio version 1.2.1335 and STATA version 16. Data was analysed to explain the different factors related to infertility and its treatment viz., physiological factors and health systems factors respectively. The descriptive statistics included proportions. Bivariate analysis was done to understand the probability of achieving pregnancy with different independent variables. Chi-square test was done to check for associations between the selected independent variables and the probability of getting pregnant.

A descriptive analysis of the care seeking pathway of the couples across 11 centres was done. The event history analysis using a life table approach was done to compute the rate of achieving pregnancy by the couples across different categories.

The life table approach was found to be suitable for analysis in the study since;

1. We were using interval and not individual time for estimating the survival functions.
2. Less than 50 percent of the observations had only had the event i.e., pregnancy during the study period and therefore censoring had to be managed.
3. There were more number of participants who had stopped or lost to follow-up from the care seeking pathway before having the event.

Life table analysis was done to estimate the survival and hazard rate of couples persisting in the pathway across time was calculated. The conditional rate of getting pregnant adjusted for duration (failure rate) with different stages of treatment, type of infertility, and type of the centre used by the couples were also calculated.

***Assumptions for event history analysis:***

- i. The time interval in the study was between 1-180 months, the mean duration of treatment was 59.9 months and hence ~60 months interval was taken to calculate the time interval i.e., 1-60 months, 60-120 months, 120-180 months and 180 and above (these are participants who were still continuing in the pathway at 180 months when the interview was done).
- ii. For the survival analysis, there are participants who had a child/were pregnant at the time of interview and those who did not have a child at the time of interview. Those with the child/were pregnant are the ones who had the event (pregnancy) and others are those without the event. Those without the event at the time of interview were either continuing the care, or were taking a break from the treatment or had stopped the treatment. Those who were taking a break at the time of interview or those who had stopped the treatment were labelled as the censored events in the study, because their exact survival times is not known.
- iii. Here, the event which is pregnancy is considered single decrement (non-competing) i.e., transitioning from non-pregnant to pregnant state. So, those who had conceived in between but could not complete the pregnancy to term will be assumed to have not had the event, this is also true for those who had a child at the time of interview and those who were pregnant at the time of interview. It should also be noted that at the time of interview, if a woman reported to be pregnant, she is considered to have had the event since we do not know the outcome of that pregnancy but at least at the time of interview she was found to have had the event.
- iv. For the survival analysis, the different stages of treatment were ascertained based on the highest achieved treatment at any centre by the participant. So, we have labelled the stages as preliminary investigations, advanced

investigations for women, medical management of women, medical management of men, medical management of both, Intra Uterine Insemination (IUI), and In Vitro Fertilisation (IVF). The stage preliminary investigations is the lowest and IVF is highest stage in this sequence. Those who had used only Ayurveda or Homeopathy only is a separate category. But if they have combined Ayurveda or Homeopathy with Allopathy, then the highest achieved treatment in Allopathy will be taken as the stage achieved by the participant. Hence, across centres couples would have undergone different treatments some repeating the same treatments. So at any centre  $C_i$ , if stage  $j$  is achieved then the highest  $j$  achieved is taken for the staging, even if they have proceeded to  $C_{i+n}$ , but has a  $(j-n)$  stage.

#### **3.9.3.2 Qualitative in-depth interviews**

The interviews were recorded, and transcribed and translated verbatim by the researcher. the analysis of the interviews was done using a grounded theory approach. The interviews were analysed using RQDA software starting with open coding by reading the interview line by line and coding each sentence. After creating preliminary codes for one transcript, the rest of the coding was done by a method of constant comparison to the already created codes and additional codes were created. Constant comparison was employed to establish the analytic distinctions of the concepts and themes during the analysis (Charmaz 2006).

The initial codes which were similar in meanings were merged to form the axial codes and the second level merging of axial codes enabled the identification of the themes.

#### **3.9.4 Reporting of the findings**

In the result chapters (Chapter4-9), for the analysis using quantitative data, the unit of analysis is the couple and therefore the findings refer to the couple. However, with respect to the qualitative research, the person reporting was the woman and all findings relating to the treatment related distress, consequences experienced due to infertility and other similar reports relate to the women alone.

### **3.10 Synthesising evidence across methods**

Each analytical phase was distinct and each phase flowed from the previous phase. There was, therefore a certain chronological parallel to the evidence building across phases. This enabled the synthesising of evidence across all three phases including both the qualitative and quantitative components.



## **Chapter 4**

### **Estimates of infertility and health care services in Kerala, India**

This chapter gives an overview of the health care context in Kerala and the demand for infertility services in the state. It addresses the objective of estimating the expected levels of infertility and its age pattern for Kerala and its districts and discusses the available facilities in the state for reproductive health care. It is divided into three sections, section I discusses the results on the expected levels of infertility based on the analysis of the Census 2011 data. Section II discusses the health care context of Kerala using available data and published materials on the health care institutions and utilisation. In addition, it provides supply side statistics of reproductive health care in the state. Section III discusses the major findings of this chapter.

The estimates of the expected levels of infertility in the districts of Kerala would be a proxy measure for the potential demand for infertility care in the state. This is compared with the provisioning for health care delivery for infertility in the state. It sets the stage for the potential need for infertility services and the extent to which it can be fulfilled. Thus, this chapter provides a prelude to why the actual care-seeking happens in a certain way in the state of Kerala, all of which will be addressed in the subsequent chapters.

Kerala fares the best in the reproductive health care in the country and reproductive health care services are highly medicalised in Kerala unlike other states. The National Family Health Survey-4 (NFHS-4) reported that the institutional deliveries in Kerala was 99.9 percent with 38.4 in the public sector and 61.4 percent in the private sector in 2015-16 (IIPS and ICF 2018). This points to the fact that reproductive health care service delivery happens in a highly medicalised context in the state and many of these services, specifically reproductive health care is most often sought in the private sector rather than the public sector.

## **Section I: Estimates of levels of infertility in Kerala, India 2010-11**

This section will discuss the expected level of infertility for the Kerala and its districts. First, I will present the findings of the direct and indirect estimates of infertility which will be followed by the indexing of infertility based on Cumulative Fertility Rate (CFR) and the ranking of the districts based on the CFR.

The fertility measures from the Census of India, 2011 data are based on two questions viz., the children surviving (CS) (number of children surviving at present-also include daughters and sons presently not staying with the mother) and children ever born(CEB) (total number of children ever born alive-also include both living and dead daughters and sons) for currently married, widowed, divorced, or separated women and the number of children born alive during the past one year (i.e., 1 March 2010 to 28 February 2011) for currently married women.

The infertility measures were computed using the fertility regime across specific age groups. Both direct and indirect methods of estimation were used to compute the expected level of infertility. The indirect method of estimation used period based Total Fertility Rate (TFR) and Total Marital Fertility Rates (TMFR). The TFR based measure used all women irrespective of their marital status to get the Age Specific Fertility Rate (ASFR). For computing TMFRs, the number of ever married women were used instead of the usual currently married women to get the Age Specific Marital Fertility Rate (ASMFRs). For specific age groups, these computations used the ASFR and ASMFR. The third estimate which is the direct estimate used the total number of women with '0' parity in the age group 45-49 years and total number of ever married women in the age group 45-49 years to get the expected level of infertility in that age group. The various estimation processes and the results are described in this section.

### **4.1 Indirect estimates of infertility based on Age Specific Fertility Rates (ASFR) and modified Age Specific Marital Fertility Rates (ASMFR)**

The first estimate used the TFR based measure to obtain the expected level of infertility among all women in Kerala. The exact formula for this computational process has been detailed in chapter 3. The expected level of infertility for Kerala per 1000 women in the reproductive ages was 168 for the period 2010-11 (as this

computation used the Census of India 2011 data). The expected level of infertility ranged from a high of 228 per 1000 women in Pathanamthitta district to a low of 112 per 1000 women in Malappuram. Most of the northern districts viz., Kasaragod, Kannur, Wayanad, Kozhikode, and Malappuram have expected levels of infertility less than the overall expected level for Kerala of 168 per 1000 women. The southern districts have higher expected levels of infertility, i.e., more than 190 per 1000 women in the reproductive ages. Followed by Pathanamthitta, the ASFR based infertility levels was highest in Thiruvananthapuram district with expected level of 214 per 1000 women. This estimate uses all women in the reproductive ages, and therefore does not reflect the actual expected levels since these women have the potential of becoming pregnant only if they enter the marital union and child bearing outside of marriage is not the norm. Table 4.1 has all three estimates of infertility by district.

The alternative estimate used the age specific marital fertility rate, as it permits separating the effect of overall fertility changes in nuptiality (age at marriage, propensity to marry and the marriage stability) from that of changes in the level of fertility within marriage. Age specific rates may be converted to approximate rates based on marital status by restricting the base population to currently married or ever married because of the norm regarding births within marriage that operates across the state. Here this measure used ever married women and hence is an approximate measure of expected infertility levels. Its limitation is that the period of exposure to fertility though relevant is not considered for those women who might not have been married for the complete duration of the past one year which is the reference period for the births.

The ASMFR based estimate of expected level of infertility for the state of Kerala was 61 per 1000 ever married women in the reproductive ages. Across districts, this ranged from a low of 45 per 1000 in Kasaragod to a high of 93 per 1000 in Pathanamthitta. The next highest to Pathanamthitta is Alappuzha with an expected level of infertility at 88 per 1000 ever married women.

#### **4.2 Direct measure of infertility using women with '0' parity at ages 45-49 years**

The expected level of infertility using the proportion of those with '0' parity among women aged 45-49 in Kerala was estimated to be 58 per 1000 ever married women. This estimate was highest in Malappuram with 67 per 1000 ever married women in the age group 45-49 years indicating that 67 out of every 1000 ever married women will remain childless at the end of their reproductive span. It was followed by Kasaragod which had an expected level of infertility of 64 per 1000 ever married women and Thiruvananthapuram with an expected level of 62 per 1000 ever married women. This estimate was the lowest in Wayanad district with an expected level of 44 per 1000, followed by Idukki with 47 per 1000 and Kollam with 49 per 1000 ever married women. Table 4.1 gives the three estimates for all the districts. Except Thiruvananthapuram and Ernakulam, all the other southern districts had expected levels of infertility below that of the state's expected level of infertility for the age group 45-49 years which is 58 per 1000 women. The northern districts like Kasaragod, Malappuram, Palakkad and Thrissur had expected infertility levels above the state's expected level of infertility while Kannur, and Kozhikode had the same levels as expected for the state of Kerala.

Table 4.1: Estimates of expected level of infertility for Kerala state and its districts, 2011

Districts	Expected level of Infertility (per 1000)		
	Based on ASFR	Based on ASMFR	Based on '0' parity at 45-49 years
Kerala	167.73	61.48	57.92
Kasaragod	131.35	44.97	63.80
Kannur	138.26	52.13	58.01
Wayanad	154.13	53.94	43.51
Kozhikode	158.05	65.91	58.42
Malappuram	111.97	47.36	67.48
Palakkad	171.91	64.69	63.64
Thrissur	184.14	67.14	59.56
Ernakulam	190.31	68.22	58.94
Idukki	175.24	55.78	47.09
Kottayam	191.42	64.75	50.77
Alappuzha	202.85	88.40	57.76
Pathanamthitta	228.09	93.48	49.99
Kollam	199.44	80.57	48.95
Thiruvananthapuram	214.22	83.98	61.54

### 4.3 Age patterns of infertility

The age pattern of infertility was estimated using the cohort based CEB and period-based CFR measure. These measures will provide an understanding of the fertility regime for the state since the direct and indirect estimates showed varying levels of infertility. If the fertility regime has been a constant then the CEB and CFR based measure of infertility will be more or less equal.

The total children ever born in the last year to ever married women in specific age groups provides estimates of CEB by age. The age pattern of infertility was estimated using CFR, to describe the current age pattern and the likely changes in it. The CFR

by age, should the fertility regime be a constant, match the CEB at that age. We used the levels of CEB and CFR across age groups to calculate the expected infertility level in each age group using the Poisson process. This gave an estimate of the expected levels of infertility for different age groups across the districts of Kerala. The variation in the pattern across age groups provides a reflection of the change in the age patterns of infertility.

Table 4.2 shows the cohort and period measure of expected levels of infertility. The expected levels of infertility declined as the age increased. This is as expected owing to fact of marriage and subsequent childbearing. The table facilitated an examination of the differences between CEB and CFR for districts and the changes in infertility levels across age groups within a district using both the cohort and period measures. The difference between the CEB based measure and the CFR based measure indicate the potential improvement in fertility over time, which gives rise to lower levels of infertility using the CFR as opposed to the CEB. The measure of infertility using the CEB is indicative of fertility levels in an earlier regime as opposed to the current one. The potential levels of infertility in the recent fertility regimes have reduced when compared to those that prevailed earlier, as indicated by the gap between the CEB measure and the CFR measure with the difference always favouring the cohort based CEB. There is an exception to this pattern however in Malappuram district where at ages 40-44 and 45-49, the CFR based measure was higher than the CEB based measure. Clearly, Malappuram has higher levels of infertility in the current period as indicated by the CFR based measure and also the ASMFR based measure.

The expected levels of infertility in table 4.2, indicate that up to age 30-34 years, the decline in levels of infertility was sharp. This is indicative of the natural decline owing to the fact that these are the prime reproductive ages for women. But as we move from 30-34 to higher age groups, the decline in the expected levels of infertility slowed down. As the women move from age 30-34 to 35-39, the highest decline was seen in Kottayam and Pathanamthitta.

Table 4.2: Age pattern of expected levels of infertility for Kerala state and its districts, 2011

Districts	CEB/ CFR	Expected level of infertility						
		15-19	20-24	25-29	30-34	35-39	40-44	45-49
Kerala	CEB	710.43	440.51	242.26	152.41	126.23	114.04	99.75
	CFR	554.99	222.23	109.34	77.99	69.93	66.50	61.48
Kasaragod	CEB	709.92	442.18	218.28	123.10	87.59	70.49	57.21
	CFR	555.50	210.75	95.95	63.10	53.46	49.70	44.97
Kannur	CEB	715.78	467.33	255.47	154.25	120.7	102.64	83.18
	CFR	581.93	235.17	112.56	75.52	64.24	58.28	52.13
Wayanad	CEB	697.89	394.18	195.78	120.49	101.49	94.01	79.41
	CFR	525.98	195.52	93.71	68.96	62.52	59.06	53.94
Kozhikode	CEB	707.16	430.92	225.21	139.08	116.89	104.35	88.82
	CFR	565.05	236.84	122.05	88.93	80.02	74.78	65.91
Malappuram	CEB	688.23	373.59	165.18	88.73	64.22	51.29	40.17
	CFR	482.90	194.57	97.40	66.80	58.05	53.75	47.36
Palakkad	CEB	673.99	384.32	204.60	134.83	112.89	100.83	81.14
	CFR	505.22	197.94	105.50	81.31	74.72	71.05	64.69
Thrissur	CEB	742.99	474.69	254.09	165.28	143.59	132.77	118.14
	CFR	592.41	222.55	107.52	79.05	72.24	70.17	67.14

(contd.)

Table 4.2: Age pattern of expected levels of infertility for Kerala state and its districts, 2011 (contd.)

Districts	CEB/CFR	Expected level of infertility						
		15-19	20-24	25-29	30-34	35-39	40-44	45-49
Ernakulam	CEB	755.29	514.4	306.64	191.17	160.97	149.76	136.16
	CFR	674.31	258.48	117.46	81.11	72.93	70.97	68.22
Idukki	CEB	727.64	449.06	256.86	157.82	128.37	116.94	103.57
	CFR	621.64	226.14	99.29	68.00	61.35	59.15	55.78
Kottayam	CEB	779.11	531.63	322.73	188.8	147.75	135.10	126.87
	CFR	740.11	305.58	128.76	80.42	69.79	67.48	64.75
Alappuzha	CEB	777.08	526.52	313.52	199.70	167.25	150.57	135.76
	CFR	729.75	311.84	151.39	107.91	97.41	93.85	88.40
Pathanamthitta	CEB	793.28	545.10	334.35	205.17	166.21	151.03	137.95
	CFR	756.97	333.48	159.12	111.78	100.92	97.94	93.48
Kollam	CEB	729.71	474.48	271.67	182.28	158.32	145.88	129.58
	CFR	616.23	246.93	127.31	96.90	89.79	86.46	80.57
Thiruvananthapuram	CEB	724.71	476.73	277.66	185.21	158.97	145.05	131.22
	CFR	599.47	251.85	134.11	103.30	95.64	91.06	83.98

#### 4.4 Index of infertility

The index of infertility was computed to compare the level of infertility that is bridged between the ages 30-34 and 45-49 as 90 percent of TFR is achieved by age 30-34 years which could be biologically feasible. Then, subsequent reductions in expected levels of infertility at 45-49 years that is observed may be due to intervention aided decline.

To capture this, we have computed the Index of infertility as given below:

$$\text{Index of Infertility, } I_{inf} = \frac{\text{Infertility}(30-34) - \text{Infertility}(45-49)}{\text{Infertility}(45-49)}$$

This computation was done using only the CFR as it represents the rate of change in fertility levels in the current period. Higher values of the index indicated that there was a possibility of interventions that may be happening at ages 35 and beyond.

The indexed value ranged between a high of 0.45 in Kannur to a low of 0.18 in Thrissur. This represents the extent to which the infertility levels may potentially be bridged between ages 35-49. About 40-45 percent of it may be bridged in Kannur, Kasaragod and Malappuram. Alternatively, in the southern districts of Ernakulam Idukki, Kottayam, Alappuzha, Pathanamthitta, Kollam and Thiruvananthapuram it ranged between 0.19-0.24. It means, in these districts, a very limited proportion of the infertility gets bridged in the ages 35 and above.

Table 4.3: Index of infertility using CFR based expected level of infertility for Kerala state and its districts, 2011

Districts	Age group				CFR based Indexed value
	30-34	35-39	40-44	45-49	
Kerala	77.99	69.93	66.50	61.48	0.27
Kasaragod	63.10	53.46	49.70	44.97	0.40
Kannur	75.52	64.24	58.28	52.13	0.45
Wayanad	68.96	62.52	59.06	53.94	0.28
Kozhikode	88.93	80.02	74.78	65.91	0.35
Malappuram	66.80	58.05	53.75	47.36	0.41
Palakkad	81.31	74.72	71.05	64.69	0.26
Thrissur	79.05	72.24	70.17	67.14	0.18
Ernakulam	81.11	72.93	70.97	68.22	0.19
Idukki	68.00	61.35	59.15	55.78	0.22
Kottayam	80.42	69.79	67.48	64.75	0.24
Alappuzha	107.91	97.41	93.85	88.40	0.22
Pathanamthitta	111.78	100.92	97.94	93.48	0.20
Kollam	96.90	89.79	86.46	80.57	0.20
Thiruvananthapuram	103.30	95.64	91.06	83.98	0.23

#### 4.5 Ranking of the districts based on expected level of infertility

The expected level of infertility in the age group 45-49 years from Census of India 2011 was used to rank the districts. Age pattern of infertility was estimated using CFR, to describe the current age pattern and the likely changes in it. The reason for preferring CFR based ranking as opposed to CEB based ranking is because CEB represents the cumulative experience of past cohorts. CFR is a synthetic cohort depicting the cumulative fertility experience at the current point of time.

The district with the highest expected level of infertility in the age group 45-49 years was given rank 1 and the lowest was given rank 14. Table 4.4 gives the ranking of the districts based on the expected level of infertility.

Table 4.4: Ranking of the districts of Kerala based on the expected level of infertility at ages 45-49 years, 2011

<b>Districts</b>	<b>Expected level of infertility in the age group 45-49 years (CFR based)</b>	<b>Rank</b>
Kerala	61.48	-
Kasaragod	44.97	14
Kannur	52.13	12
Wayanad	53.94	11
Kozhikode	65.91	7
Malappuram	47.36	13
Palakkad	64.69	9
Thrissur	67.14	6
Ernakulam	68.22	5
Idukki	55.78	10
Kottayam	64.75	8
Alappuzha	88.40	2
Pathanamthitta	93.48	1
Kollam	80.57	4
Thiruvananthapuram	83.98	3

After ranking the districts, they were grouped into three categories as high (Category 1: Rank 1-4), medium (Category 2: Rank 5-9) and low expected level (Category 3: Rank 10-14) of infertility. The category 1 included districts with rank 1 to rank 4 which were Pathanamthitta, Alappuzha, Thiruvananthapuram and Kollam respectively, category 2 included districts with rank 5 to rank 9 which were Ernakulam, Thrissur, Kozhikode, Kottayam and Palakkad, and category 3 included districts with rank 10 to rank 14 which included Idukki, Wayanad, Kannur, Malappuram and Kasaragod respectively. From each category the district with the last but one rank was selected for the study to avoid extremities and yet maintain representativeness. So, from category 1 Thiruvananthapuram, from category 2 Kottayam and from category 3 Malappuram was selected for the study.

## **Section II: Kerala context - Health care availability for reproductive health**

The reproductive health care which is part of the health care services in Kerala operates in a highly medicalised context. The state has also witnessed privatisation of health care sector. The term privatisation refers to “*the growth of the ‘for profit’ sector and its inter-relationship with the public sector*” (Baru 2006). The private sector has grown over the years and shares a major part of health care delivery in the country. There are wide differences in the absolute number of beds in private and public sectors. During the early 1980s, Kerala moved into privatised health care delivery (Kutty 2000). The growth of the private sector was inevitable due to various favourable factors in the state. The fiscal crisis in the state health system meant that there were limited or no financial resources to boost the existing health care system to meet the needs of the population. The ease with which private sector could set up hospitals, the rising amount of disposable income among the people in the state and the public sector’s inability to cater to the increasing demand for health care contributed to the growth of the private sector in the state (Kutty 2000; Dilip 2010).

Due to lack of consistent data on the health facilities available in the public and private sectors over the years, drawing direct conclusions about its extent and scope was difficult. The data represented here are from different reports and articles which were based on data sources from National Sample Survey Organisation (NSSO), Central Bureau of Health Intelligence, Census of India, National Family Health Surveys, Ministry of Health and Family Welfare, Survey and Design Division of Department of Economics and Statistics and Department of Health Services, Kerala.

I will discuss the Kerala health care context under three different sections; first the medicalisation and the growth of the private sector will be discussed based on the NSSO health survey data. It will be followed by the health care delivery in Kerala where the predominance of private sector in health care delivery and the stagnation in growth of the public sector will be demonstrated using information on the number of medical institutions and personnel under the Kerala Department of Health Services. The last section will discuss the privatisation of the reproductive health care in Kerala using the extent of institutional deliveries in public and private sector hospitals Kerala.

#### 4.6 Medicalisation and growth of private sector in Kerala

Medicalisation of the health care in Kerala is demonstrated by the utilisation of health care based on the NSSO Surveys' 71<sup>st</sup> round in 2014 and 75<sup>th</sup> round in 2017-18. This medicalisation may have also led to the growth of the private sector (as we are unable to demonstrate the actual association), as evidenced by the difference in growth of beds in the private and public sector between 1993-1999 in Kerala.

During 1993-1999, the number of beds in public institutions grew from 28030 to 30323, while the private sector beds increased from 49169 to 67517. This means that there was only eight percent increase in the public sector beds while there was a 37 percent increase in the private sector beds during the six-year period. When indexed against the year 1983, in 1993 we see that there was about 12.7 percent increase in the beds in the public sector whereas the growth was about 170 percent in the private sector. By 1999, against the 1983 figures, the private sector registered a 270 percent growth.

Table 4.5: Growth of beds in public and private health sector in Kerala

Year	Public Sector	Growth as a percentage of the situation in 1973	Private Sector	Growth as a percentage of the situation in 1973*
1973	19623	-	0	-
1983	24875	26.8*	18203	100.0*
1993	28030	12.7 <sup>#</sup>	49169 <sup>#</sup>	170.1
1999	30323	21.9 <sup>#</sup>	67517 <sup>#</sup>	270.9

Source: Baru, 2006, p.14

\*-indexed against 1973, #-indexed against 1983

The special health rounds of the NSSO provide information on ailments experienced by individuals and the nature of health care sought. These data enable an understanding of the extent of privatisation in health care utilisation for both ambulatory care and hospitalisation in the state, when compared to the country as a whole. From the NSS 71<sup>st</sup> round we see that in India nearly 70 percent of the medical advice for spells of ailments (ambulatory care) were sought from private sector in the rural areas and nearly 80 percent in the urban areas. But in Kerala, this was nearly 64 percent in the

rural areas and nearly 70 percent in urban areas. Majority of those seeking care in private sector in India was contributed by the private doctor or clinic but private hospitals predominantly catered to such care in Kerala. While comparing the type of medical advice used by Kerala to that of national average, there was a higher use of public hospitals and private hospitals in Kerala, and lower use of private doctor/clinic than the national average.

Table 4.6: Distribution of spells of ailment treated on medical advice (per 1000 cases) over levels of care in rural and urban areas, Kerala and India, 2014 (NSSO 71<sup>st</sup> round)

Site	India/ State	Level of care				All
		HSC or PHC etc	Public Hospital	Private doctor/clinic	Private hospital	
Rural	India	115	168	507	210	1000
	Kerala	153	210	338	300	1000
Urban	India	39	173	500	288	1000
	Kerala	55	256	375	314	1000

Source: NSSO 71<sup>st</sup> round, Table 31b, p A-150 & A-156.

In the 75<sup>th</sup> round also we see that the spells of ailments in India were treated by private doctor or clinic for a majority. This was followed by majority using public hospitals in rural areas in India, while there was a slightly higher use of private hospitals in urban areas compared to public hospitals. In Kerala, public sector was used predominantly in both urban and rural areas, followed by private hospitals. While we compare medical care, Kerala had a higher use of both public and private hospitals compared to the national average, and there was less use of private doctor/clinic and informal health care provider when compared to the national average.

These findings show that there is higher use of formal medical care in Kerala for minor ailments, which points to the medicalisation of health care in Kerala. I have examined this process further by looking at hospitalization, as reported in the two rounds of the NSSO, 71<sup>st</sup> (2014) and 75<sup>th</sup> (2017-18).

Table 4.7: Percentage distribution of spells of ailment treated on medical advice (per 100 cases) over levels of care in rural and urban areas, Kerala and India, 2017-18 (NSSO 75<sup>th</sup> round)

Site	India/ State	Level of care					All
		Govt/ public hospital	Private hospital	Charita ble/ trust/ NGO hospital	Private Doctor/ clinic	Informa l Health Care provider	
Rural	India	32.5	20.8	0.9	41.4	4.3	100.0
	Kerala	51.8	31.0	1.5	15.7	0.0	100.0
Urban	India	26.2	27.3	1.3	44.3	0.9	100.0
	Kerala	41.7	31.8	1.3	24.7	0.4	100.0

Source: NSSO 75<sup>th</sup> round, Table A45, p A952 & A955.

The hospitalization by type of ward used given in table 4.8 and table 4.9, indicates that there was a dominant use of the special paying wards in private sector particularly in both the rural and urban areas in 2014 as indicated by the NSSO's 71<sup>st</sup> round.

Table 4.8: Distribution of hospitalization cases (excluding childbirth) during 365 days over levels of care and type of ward in rural and urban areas (per 1000 cases) in rural and urban areas, Kerala and India, 2014 (NSSO 71<sup>st</sup> round)

Site	India/ State	Public/Govt Hospital			Private Hospital			Total
		Free	Paying general	Paying special	Free	Paying general	Paying special	
Rural	India	318	59	5	29	454	135	1000
	Kerala	270	31	8	37	287	367	1000
Urban	India	216	49	8	31	463	233	1000
	Kerala	211	51	22	18	291	407	1000

Source: NSSO 71<sup>st</sup> round, Tables T12c-R & T12c-U, pp. A63-A64.

By 2017-18 (NSSO, 75<sup>th</sup> round), the gap in use of private sector special paying facilities between Kerala and India was three times more for rural Kerala and two time more for urban Kerala. This indicates that growth in the private sector in Kerala state could have been a consequence of the supply keeping up with the demand for private services as evinced by the higher utilization rates in 2014 and in 2017-18.

Table 4.9: Percentage distribution of hospitalization cases (excluding childbirth) during 365 days over levels of care in public and private hospitals and type of ward (per 100 cases) in rural and urban areas, Kerala and India, 2017-18 (NSSO 75<sup>th</sup> round)

Site	India/ State	Public/Govt Hospital			Private Hospital				
		Free	Paying		Total	Free	Paying		Total
			Gen	Spl			Gen	Spl	
Rural	India	92.3	7.0	0.7	100.0	3.3	79.8	16.9	100.0
	Kerala	88.5	8.5	3.0	100.0	3.5	42.6	53.9	100.0
Urban	India	91.2	7.6	1.2	100.0	2.9	72.7	24.4	100.0
	Kerala	85.4	9.2	5.4	100.0	2.6	45.3	52.1	100.0

*Gen-general, Spl- special, Source: NSSO 75<sup>th</sup> round, Table Statement9, pp. S14-S15.*

#### 4.7 Health care delivery in Kerala: Stagnant public sector

Available data on the number of government hospitals in Kerala for the years 2000-01 up to the year 2003-04 is presented in table 4.10. The total number of beds in the public sector reduced over time from 2001 to 2003-04. The total number of institutions under the public sector reported in 2000-01 was 1281 with a bed strength of 43895, this reduced to 1270 institutions in 2002-03 with a 20 percent reduction in the number of beds. In 2003-04 there was an eight percent increase in the number of beds in the public sector. Whatever be the reason for the reduction in the number of public sector beds, clearly the benefit of this accrued to the private sector as indicated by the utilisation in tables 4.8 and 4.9.

Table 4.10: Total number of government institutions (public sector) and number of beds in Kerala, 2000-01 to 2003-04

Type of institution	2000-01		2001-02		2002-03		2003-04	
	No of units	No of Beds	No of units	No of Beds	No of units	No of Beds	No of units	No of Beds
Hospitals	143	31883	143	31883	130	22636	132	22645
PHC and MCH centres	943	5215	943	5215	933	5060	931	7716
Dispensaries	54	176	54	176	55	176	59	190
TB clinics	21	290	21	290	22	266	18	216
Leprosy centres	15	1916	15	1916	15	1916	18	1916
Community Health centres	105	4415	105	4415	115	4726	115	4840
<b>Total</b>	<b>1281</b>	<b>43895</b>	<b>1281</b>	<b>43895</b>	<b>1270</b>	<b>34780</b>	<b>1273</b>	<b>37523</b>

Source: *Statistics for Planning, 2005, p.353-357, Department of Economics and Statistic, Government of Kerala*

The change in the number of institutions and their relative bed strength in the public sector from 2013-14 to 2019 in Kerala is given in table 4.11 and this data is based on the various reports from the Department of Economics and Statistics, Government of Kerala. While public sector facilities are accounted for, the documenting of the private sector facilities in Kerala is rather sketchy. The number of private sector health care facilities are available only for the period 2016. With this limited information, the attempt here is to provide a picture of the health infrastructure in the state.

There is stagnation in the public health infrastructure in the state with almost no changes from 2013-14 to 2019, across all districts. The average number of beds per unit in the public sector has also stagnated, indicating no form of augmentation at least in the number of beds happened over this period. On the contrary, the overall number of beds declined by a count of 382 while the number of units increased by a count of eight.

The number of private sector units listed for the year 2016 is almost 10 times the number of facilities available in the public sector in the period 2019. The extent of

private sector is weaker in districts like Wayanad, Palakkad and Pathanamthitta where the ratio of private to public sector institutions (in 2016 and 2019 respectively) was between five to seven. Compared to this, districts like Kozhikode, Malappuram, Ernakulam and Kottayam had close to 11-16 times the number of private sector units to public sector units.

Table 4.11: Medical institutions in Kerala in the public (under the Department of Health Services) and in the private sector, 2013 to 2019

Districts	Medical institutions in Kerala-Public Sector*	Medical institutions in Kerala-Public Sector**	Medical institutions in Kerala-Public Sector***	Number of private hospital in Kerala****
	2013-2014	2018	2019	2016
Kerala	1278(38400)	1283(37843)	1286(38018)	12363(105373)
Kasaragod	57 (1093)	57 (1087)	57 (1087)	487 (1806)
Kannur	108 (3070)	111 (2966)	111 (2966)	959 (7184)
Wayanad	41 (1408)	42 (1357)	45 (1367)	301 (2284)
Kozhikode	92 (2820)	93 (2820)	93 (2820)	1206 (8764)
Malappuram	124 (2627)	125 (2411)	125 (2546)	1353 (8767)
Palakkad	114 (2764)	114 (2769)	114 (2769)	653 (6561)
Thrissur	118 (3519)	118 (3435)	118 (3435)	979 (11267)
Ernakulam	115 (4502)	115 (4517)	115 (4525)	1810 (17806)
Idukki	64 (1085)	63 (1096)	63 (1096)	487 (4984)
Kottayam	84 (2925)	84 (2817)	84 (2817)	980 (7622)
Alappuzha	90 (3404)	89 (3406)	89 (3406)	881 (4112)
Pathanamthitta	64 (1942)	66 (1938)	66 (1960)	451 (5873)
Kollam	89 (2388)	88 (2310)	88 (2310)	850 (7995)
Thiruvananthapuram	118(4853)	118 (4914)	118 (4914)	966 (10348)

# No of beds is given in the parenthesis

Source: \* Directorate of Health Services, 2014,p.7. \*\*Directorate of Health Services, 2017-18,p.7

\*\*\* Economic Review, 2019,p.217, Kerala State Planning Board, Government of Kerala.

\*\*\*\*Statistical Handbook Kerala, 2017,p.129, Department of Economics and Statistics, Government of Kerala.

A profile of the distribution of medical officers and beds in the public sector across the districts of Kerala is given in table 4.12. It gives the ratio of number of government

beds per government doctor (doctor bed ratio) and the population per government hospital bed (bed population ratio) in Kerala and its districts for 2013-14.

In 2013-14, there were variations in the beds per doctor ratio across the districts. Ernakulam, Alappuzha and Thiruvananthapuram had 10 or more beds per doctor in the public sector, which is way beyond the state level of eight beds per doctor. Districts like Wayanad, Kozhikode, Palakkad, Idukki and Kottayam had better ratios of four to six beds per doctor in the public sector. But this belies the dominant presence of the private sector in Kozhikode and Kottayam. The other indicator that shows how public sector health services are stretched is the population per government bed ratio. For 2013-14, Kasaragod, Kozhikode, Malappuram, Palakkad, Idukki and Kollam have ratios greater than 1000 population per bed, while districts like Kottayam, Alappuzha, Pathanamthitta and Thiruvananthapuram have a population between 600-700 per bed.

To describe the weak presence of the public sector, comparisons of the size of the government sector against that of the private sector in terms of number of units could be fallacious because the government sector has an additional public health role that includes prevention of diseases and a host of services engaged in prevention through the various staff such as Auxiliary Nurse Midwives, Public Health Nurses and others.

For this reason, it becomes important to examine if the government sector is in a better position with respect to its coverage in terms of the Medical officers and other paramedical staff. In the absence of alternatives, I have used the district wise population figures from the 2011 census for the state to describe this coverage across districts.

The distribution of medical officers and all medical and paramedical staff per 2011 population was better off in Idukki and Pathanamthitta districts while it was poorer in Alappuzha, Malappuram and Kozhikode. This means that Alappuzha, Palakkad, Malappuram, Kozhikode and Kollam have a relatively poorer distribution of public sector medical officers when compared to Idukki, Wayanad, Kottayam, and Kasaragod. The distribution of medical and paramedical staff is also rather thin in Alappuzha, Malappuram, Kozhikode, Palakkad Kollam and Trissur. Essentially there

is a poor distribution of public health services in the northern districts when compared to the southern districts.



Table 4.12: Distribution of medical officers and beds in the public sector across the districts in Kerala

Districts	<sup>1</sup> Doctor/ bed ratio*	Bed population ratio*	MOs under DHS**	Medical and Paramedical Personnel under DHS**	MO per 2011 Census population**	Medical and Paramedical Personnel per 2011 census population**
	2013-14	2013-14	2019	2019		
Kerala	8	873	5510	26899	605947	124122
Kasaragod	6	1192	238	1120	547311	116304
Kannur	8	823	467	2219	540822	113819
Wayanad	6	716	206	948	396387	86135
Kozhikode	7	1096	379	2023	815183	152721
Malappuram	6	1565	523	2469	786034	166503
Palakkad	4	1017	409	2157	687260	130315
Thrissur	8	884	458	2278	679111	136538
Ernakulam	14	715	521	2526	629532	129844
Idukki	6	1021	410	1920	270110	57680
Kottayam	6	671	392	1809	504945	109419
Alappuzha	11	623	240	1268	884143	167346
Pathanamthitta	8	616	315	1383	379536	86445
Kollam	8	1101	364	1907	722446	137897
Thiruvananthapuram	10	681	588	2837	562463	116577

<sup>1</sup>The doctor/bed ratio indicates the number of beds available in the public sector for each modern medicine doctor in service

Source: \* Directorate of Health Services, 2014, p.10-11. \*\* Economic Review 2019, p.219, Kerala State Planning Board, Government of Kerala.

#### 4.8 Declining birth rates and increasing privatization of reproductive health care services in Kerala

The percentage of deliveries conducted in Kerala between the year 2010 to 2017 in the public and private sector is given in table 4.13. We see that there was only a 5 percent increase in the deliveries conducted from 2010-2017 in the public sector. Private sector conducted more twice the amount of deliveries (12%) compared to the public sector in the same period.

Table 4.13: Distribution of birth by type of medical institution at the time of delivery in Kerala, 2010-2017

Year	Public Sector	Private Sector
2010	21.13	57.97
2011	20.30	56.77
2012	21.07	58.34
2013	26.67	64.44
2014	28.84	67.35
2015	27.42	67.96
2016	25.45	70.02
2017 (Provisional)	26.51	70.33

Source: *Statistical Abstract, 2019, p.28, Department of Economics and Statistics, Government of Kerala.*

Table 4.14 gives the birth rates for three time periods and the total fertility rates (TFRs) for the districts of Kerala. In general, fertility in Kerala is rather low with the TFR at 1.8 for the state in 2011. There are variations in the TFRs across districts with Pathanamthitta and Thiruvananthapuram having a low of 1.5 and Malappuram recording a relatively higher TFR of 2.2. Since then, the birth rates have further declined across all districts. The birth rates are not comparable across time because the age distribution of the population would not be a constant, temporal comparisons within this short period would be valid for the same districts. In Kerala between 2010-2016, there was a 1.3 percent decline in the birth rate. The highest decline was observed in Kollam district and the lowest in Pathanamthitta (0.4) followed by Malappuram (0.5). Only Wayanad reported a 0.9 percent increase in the birth rate in this time period.

Table 4.14: Declining birth rates and total fertility rates for Kerala state and its districts, 2010-2016

Districts	Birth rate in Kerala*			TFR Census 2011**
	2010	2013	2016	2011
Kerala	15.75	15.88	14.48	1.8
Kasaragod	16.69	16.42	15.14	2.0
Kannur	18.67	18.81	16.88	2.0
Wayanad	16.66	17.87	17.51	1.9
Kozhikode	18.06	18.61	17.48	1.8
Malappuram	21.29	21.66	20.8	2.2
Palakkad	13.88	14.50	12.83	1.8
Thrissur	17.15	16.23	14.53	1.7
Ernakulam	14.07	13.46	12.92	1.7
Idukki	12.63	12.71	10.96	1.7
Kottayam	13.70	14.34	11.88	1.7
Alappuzha	9.89	10.03	8.14	1.6
Pathanamthitta	13.90	13.80	13.53	1.5
Kollam	13.71	12.43	10.57	1.6
Thiruvananthapuram	14.52	15.42	13.43	1.5

Source: \* *Statistical Handbook Kerala, 2017, p. 124, Department of Economics and Statistics, Government of Kerala.* \*\*2011 Census of India Data, Fertility Table:F-9, Number of women and currently married women by present age, number of births last year by sex and birth order.

Given the reduction in the number of births across the districts in Kerala, I also provide evidence to show that the private sector dominates in delivery care. Table 4.15, provides data on the proportion of deliveries that occurred in public institutions at two time points, across all districts.

There is near universal institutional delivery in the state but we see that a majority of these occurred in the private sector. Across the districts of Kerala, only 30-40 percent of deliveries were conducted in the public sector in 2013-14 and 2015-16. Ernakulam district reported the lowest percentage of public sector deliveries followed by Malappuram and Thrissur. Given the dominance of the private sector in Ernakulam and Malappuram, this is not surprising. Two southern districts Alappuzha and

Thiruvananthapuram had more deliveries in public sector than private sector possibly because of the improved presence of the public sector in these districts.

4.15: Institutional births in public sector facility for Kerala state and its districts, 2013-14 and 2015-16

Districts	Percentage of deliveries in public sector*	Percentage of deliveries in public sector**
	2013-14	2015-16
Kerala	30.4	38.4
Kasaragod	19.3	28.5
Kannur	26.4	40.2
Wayanad	43.1	47.3
Kozhikode	44.3	45.5
Malappuram	18.7	32.7
Palakkad	23.0	33.0
Thrissur	19.1	34.7
Ernakulam	17.3	19.7
Idukki	30.6	43.9
Kottayam	38.3	49.4
Alappuzha	52.5	44.5
Pathanamthitta	28.4	46.2
Kollam	33.2	41.6
Thiruvananthapuram	56.5	50.6

\* Directorate of Health Services, 2014, p.14. \*\*International Institute for Population Sciences (IIPS) and ICF, 2018, p.83.

### Section III: Discussion

#### 4.9 Strengths and limitations in this exercise

The estimates of infertility are based on indirect estimates, especially estimates 1 and 2. These have the limitation of the inbuilt assumptions such as unchanging fertility regimes across time. The third estimate describes the fertility regime of women who have completed their fertility and may vary from the experiences of women entering their reproductive period in more recent times. The conclusions regarding the public sector provisioning for reproductive health care in Kerala has used data from different sources, this could have led to some limitations. While comparability across these

different data sets may have led to over/underestimation of the actual situation, but data within each source are strong and hence it adds to the strength of the findings. In addition, I have also used community surveys which is self-reported and therefore, could be biased. The data on private sector facilities and utilisation was not available across all the time periods, and hence conclusions arrived at may not be comprehensive.

#### **4.10 Rising demand for infertility services in Kerala**

The indirect estimates for infertility (using the Total Fertility Rate) for Kerala indicates an expected level of infertility of 168 women for every 1000 women in the reproductive ages. The expected infertility rates for the northern districts of Kasaragod, Kannur, Wayanad, Kozhikode and Malappuram were lower than the expected level for the state. The southern districts of Kottayam, Alappuzha, Pathanamthitta, Kollam and Thiruvananthapuram had higher expected rates of infertility when compared to the northern districts. Since the infertility estimate uses the existing period estimate of fertility, those regions with relatively higher age at marriage and lower fertility seem to have higher expected levels of infertility. This potential anomaly is adjusted in the second indirect measure of infertility that uses the TMFR for estimation. This estimate takes away the risk of including women who are not at risk of child bearing from the ambit of measuring potential infertility. This alternative provides an estimate of infertility as 61 per 1000 ever married women in the reproductive ages. Barring Kozhikode, all the other northern districts such as Kasaragod, Kannur, Wayanad, Malappuram have expected levels of infertility lower than the state average of 61 per 1000 ever married women. The same southern districts have levels higher than that of the state with Pathanamthitta having the highest levels. This is because the infertility estimate is a function of both the number of fertility events per ever married woman (quantum) and the age at childbearing (tempo of fertility). Across districts of Kerala, these two are not the same, with the northern districts having higher number of fertility events per woman and on an average at earlier ages when compared to women in the southern districts.

The best way to represent the actual infertility levels is to use the cohort experiences, the third estimate actually uses the completed fertility experiences to estimate the potential levels of infertility. This estimate actually provides a varying picture of the levels of infertility among ever married women in the reproductive years. Using this direct estimate of infertility (which is based on the cohort estimate), one notices that the northern districts have relatively higher rates of ever married women who remain childless at the end of the reproductive period than the southern districts. Malappuram with approximately 67.5 women per 1000 ever married women represents the highest level of childless women followed by Kasaragod and Palakkad which have 63.8 and 63.6 per 1000 ever married women respectively. Given that these districts do not have relatively higher levels of age at marriage wherein postponement of child bearing could result in childlessness, it is possible that the male out migration from these districts resulted in these relatively higher proportions of women remaining childless (see appendix table A16 and A17 on proportion of emigrants to district population for Kerala using various rounds of Kerala Migration Surveys). But this is speculative and a more careful evaluation may provide the actual reasons. Southern districts (barring Thiruvananthapuram) have relatively lower rates of childless women at ages 45-49 with Kollam at 48.9, Pathanamthitta at 49.9 and Kottayam at 50.8 per 1000 ever married women.

The infertility levels are almost uniformly higher across all ages using the cohort based CEB to estimate infertility when compared to the period CFR based estimate. The only district where the CFR based estimate is higher than the CEB based measure is in Malappuram where by age 40-44, the CFR based measure overshoots that based on CEB. The age pattern of infertility across districts using both the CEB and the CFR to estimate infertility levels indicates a rapid decline across ages up to 30-34 and then a gradual reduction in the rate of decline. Declines after the age 35-39 are marginal on the basis of the CFR based infertility measure. These declines could be indicative of intervention driven reductions in infertility levels. It is possible that older women who did not have the option of intervention driven reduction in infertility levels remain childless in Malappuram whereas younger women have the benefit of intervention-based reduction in infertility levels at younger ages.

To understand the potential bridging of the infertility gap through medical intervention we had computed the index of infertility. The index values are relatively higher in the northern districts of Kasaragod (0.40), Kannur (0.45), Kozhikode (0.35) and Malappuram (0.41). What this essentially means is that there is reason to believe that some of the reduction in infertility that is happening beyond ages 34 in these districts could be due to medical interventions. The reduction is not substantial and manages merely a maximum of 40 percent reduction in infertility after age 34 when one examines it against what it is at 45-49 years. It is still a better reduction when compared to the potential for reduction in the southern districts where the index value ranges between 0.20 to 0.24. Possibly due to the potential intervention driven reduction in infertility in the northern districts, these four districts, namely Kasaragod, Malappuram, Kannur and Wayanad are the districts with the lowest levels of infertility using period-based CFRs. The age specific decline in infertility levels in the northern districts are indicative of intervention driven reductions at higher ages of 35 and above. The southern districts systematically have the highest levels of infertility with Pathanamthitta at 93.5, Alappuzha at 88.4, Thiruvananthapuram at 83.9 and Kollam at 80.6 for every 1000 ever married women. What this evidence collectively indicates is that there is a potential demand for services to reduce infertility levels across the state. This demand is being possibly partly addressed, though at relatively higher ages in the northern districts through medical interventions but is less likely to be addressed in the southern districts or possibly identified and addressed at younger ages.

#### **4.11 Limited public provisioning for infertility services in Kerala**

The limited exploration of the supply side indicates the dual processes of medicalization as well as privatisation of reproductive health care in the state. The growth in the private sector for health care in general during the two decades following the initial introduction has been phenomenal. While the public sector grew at fairly low rates during the 1973-99 period, the private sector growth was 270 percent of what it started out as. That this growth actually could have been in response to the demand for services which the public sector could not cope with is also clear. We see the relatively higher level of use of private hospitals in the state for ambulatory care when

compared to the rest of India. This pattern repeats itself for hospitalised care but much more strongly as Kerala seems to prefer private hospitals and that too for special services within it.

Across the state, growth in the public sector health care has stagnated during the period from 2001 to 2004, where the number of units barely increased and the bed strength in these units increased marginally. With limited information on the private sector— its extent and scope, what is clear is that across all districts it is omnipresent and some districts like Ernakulam, Kozhikode, Malappuram and Kottayam had a strong presence when compared to districts like Wayanad, Palakkad and Pathanamthitta. The distribution of medical officers in the public sector and also the collective medical and paramedical staff, districts like Kozhikode, Malappuram, Palakkad, Thrissur, Ernakulam, Alappuzha and Kollam have a population to medical officers or population to medical personnel rates higher than the state average. Thus, it is not merely the stagnating growth in the public sector, but also the relatively weak coverage across these districts that is an issue. There are serious gaps in public health facilities in the northern districts when compared to the southern districts, even though some southern districts like Alappuzha and Kollam are relatively less endowed with public health facilities.

Kerala's fertility levels are low, and continue to decline as indicated by the relatively low TFR and birth rates across all districts. There is near universal institutional delivery across the state, barring a few districts where it may not be 100 percent (IIPS and ICF 2018). These births are more likely to happen in private sector institutions than public sector institutions, given the propensity to prefer private and specialised care for hospitalisation in the state.

As infertility care is highly specialised, it would be secondary and tertiary care units that cater to this need. The increasing need for infertility care and the limited availability of such facilities would mean that those in need would have to take recourse to private health care facilities across the state. The availability of health care services in the public sector is not uniform across all districts, the private sector would actively seek to fulfil the gap in public sector provisioning for infertility care.

## **Chapter 5**

### **The context and process of care seeking for infertility in Kerala**

This chapter is aimed at addressing the research question on why couples seek care for infertility and explains their multiple reasons. The manner in which couples enter the process of care seeking and continue on the pathway forms the core of this chapter. The major theme that anchors this chapter is how couples reach a diagnosis of infertility and the factors that push them on to the care seeking pathway and into the hope continuum. To build this narrative I have taken recourse to in-depth interviews among 16 women and two men, who were husbands of the women seeking infertility treatment in the two southern districts of Kerala, Thiruvananthapuram and Kollam. The interviews enabled an understanding of the process of treatment seeking for infertility. I aim to describe the context in which couples seek care for infertility, what makes them persist or drop out. Such treatment seeking has always been fraught with personal struggles of coping with infertility and also the stress associated with treatment process.

#### **5.1 Participants' profile**

Out of the 16 participants, only three were upper middle class, rest of the women belonged to lower and middle class socio-economic status. At the time of interview, six had children born through treatment and two via adoption (two of them), others were either continuing treatment or has not yet initiated formal treatment for their fertility problem. The infertility diagnosis of the couples included male factor, female factor and unexplained causes. The female factor included women with polycystic ovarian disease (PCOD), tubal blockage and primary ovarian failure. Male factors included mainly azoospermia. Table 5.1 presents the participants' characteristics.

Table 5.1: Characteristics of the participants interviewed

Sl no	Name of the participant*	Age	Years since marriage	Whether having a child at the time of the interview	Broad diagnosis
1	Mubina	34	12 years	yes, now having secondary infertility	PCOD
2	Susie	44	23 years	Yes	Unexplained
3	Alice	38	12 years	No	Azoospermia
4	Shirley	35	9 years	No	Azoospermia
5	Elizabeth	62	39 years	Yes, adopted	Unexplained
6	Rani	42	18 years	Yes	Unexplained
7	Leela	45	20 years	Yes	Fibroid uterus
8	Ancy	40	20 years	No	Azoospermia
9	Mini	48	14 years	No	Fibroid uterus
10	Asha	25	3 years	No	Not yet started treatment
11	Rekha	26	2 years	No	PCOD
12	Radhika	26	3 years	No	Not yet started treatment
13	Vani	38	14 years	Yes	B/L tubal block
14	Aswathy	40	20 years	Yes	Primary ovarian failure
15	Bindhu	40	11 years	Yes, Adopted	PCOD
16	Remya	32	5 years	No	Unexplained

\*Names changed to provide anonymity

A grounded theory approach was used to analyse why and how people seek care for infertility. The interviews were either recorded or the notes expanded and transcribed and translated verbatim by the PI. One interview was analysed by using RQDA software starting with open coding by reading the interview line by line and coding each sentence. After finishing the first interview, the subsequent transcripts were coded using constant comparison to the codes already created. The initial codes which

were similar in meanings were merged to form the axial codes and the second level merging of axial codes enabled the identification of the themes.

The themes developed after coding of the interviews explain why the couples sought treatment and what made them persist in the pathway of care or drop out. I have used the word care seeking carefully and eschewed treatment seeking as treatment seems more indicative of medical care from the available options but here care seeking included professional, folk and popular systems of care (Kleinman 1980). The interviews were from the women and it reflects the specific issues of women when the couple was having difficulty in conceiving. The treatment seeking happened in a social context and this shaped the individual's action and the collective responses to it. The treatment pathway varied for each couple depending on their knowledge of the condition and its treatment. Since infertility is a condition that is visibly exhibited in the woman's body through the absence of pregnancy, the onus of undertaking corrective measures also lies within these bodies. Hence, the struggle to continue the treatment also becomes the responsibility of the women. But sometimes due to certain factors the desired outcome is not achieved by the couples due to multiple factors viz., biological, treatment related, or financial to name a few. Then it becomes imperative for them to externalise the delay so as not to be seen as having faulty bodies which is a source of public ridicule in the community.

There were 13 themes identified in all and these themes are presented here under the following categories viz., the contextual factors, the individual factors, treatment facilitating factors, individual's responses to diagnosis and various treatment, factors interfering with treatment process, consequences of infertility and resolution and coping. The context and process in the pathway to care seeking is shown in figure 5.1.

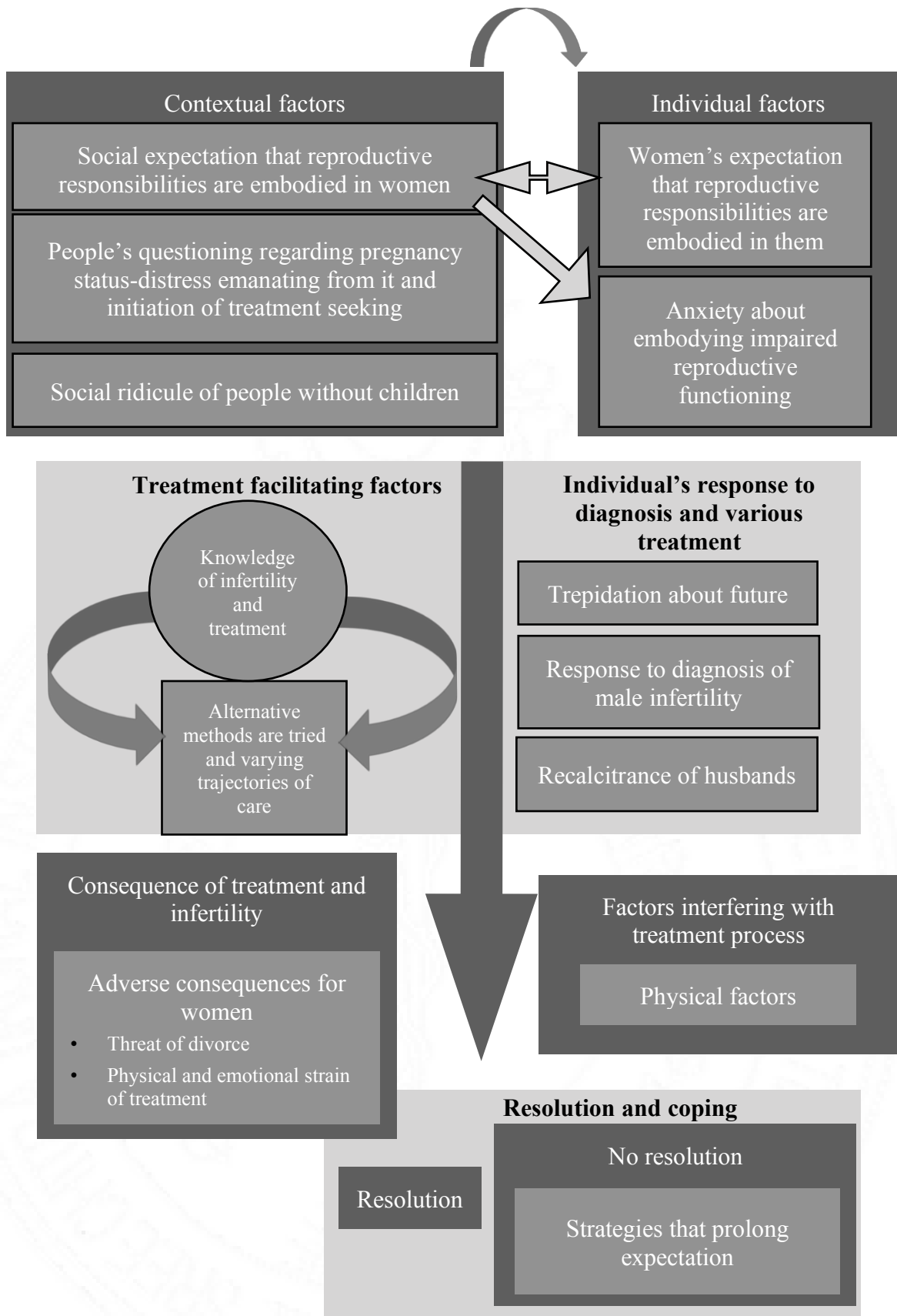


Fig 5.1: Couples' care seeking for infertility: means and reasons

## **5.2 Contextual factors**

Infertility and the treatment seeking cannot be discussed without the socio-cultural context in which it operates. Gender norms and roles that operate embody the fact that women are reproductive bodies, therefore the impairment of or the inability to reproduce is centred in their bodies. This general notion of women's bodies being the reason for the inability to reproduce puts pressure on women who are married. This means that they have to prove their reproductive bodies are not impaired and satisfy the socially prescribed norm. Even when the male body has the problem, the social construction of infertility centres on female body and thus only the female body is under scrutiny and has to pass the test. This social construction causes society to question the absence of pregnancy of its married female members. This causes distress among women followed by an attempt at initiating the process of treatment to find the solution for the problem.

### **5.2.1 Social expectation that reproductive responsibilities are embodied in women**

There is a general notion that of the couple, women's bodies harbour fertility impairing conditions. One woman said that her husband felt that she will be having the problem that prevented the pregnancy. This notion of women having the problem directs community members to question women when couples do not get pregnant after a period of time following marriage. These questions are inevitably directed to the woman even when the man is 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)

In some families the diagnosis of male infertility is not accepted by the men's family due this notion. Women have said that the husband's family did not accept the fact that their son was having the fertility impairing condition.

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

### **5.2.2 People's curiosity regarding pregnancy status-Distress emanating from it and the initiation of treatment seeking**

Women reported that they go through distress due to the persistent questioning regarding the pregnancy status by their friends, relatives and other acquaintances who presumably have their welfare at heart. They said it was extremely painful to be asked about the status of pregnancy. Married couples, particularly those without children, in the early phases of the marriage are often asked by well-meaning others who have their interests at heart 'is there any good news?'

*"After marriage after some months they start asking 'vishesham ille' (colloquial way of asking whether pregnant or not) and you get fed up hearing that. Because of this we have issues facing the public like when we go for some function. I had difficulty going for functions so that was the problem."* (Mubina, 34 years, PCOD)

This is understood to indicate information regarding pregnancy status. This is routine and is part of an expression of civility while meeting newlyweds. When couples are unable to conceive for whatever reasons, these expressions of civility trigger anxiety and distress. It is then that these expressions of civility impose a burden on those having to respond and they see it as persistent questioning regarding pregnancy status. This persistent questioning, as reported by the respondents, triggered initiation of seeking treatment. Some women said this also forced them to restart the treatment they have stopped in between due to other constraints. Most of these constraints are of a financial nature, but the cost of treatment is not a matter of concern for those questioning the women regarding their pregnancy status.

*"then everyone started asking and we also felt (the need), we went for treatment."* (Rekha, 26 years, PCOD)

*"When people are telling this and that and making fun so it was painful so we thought we will go there (to a centre) and see."* (Alice, 38 years, Husband having azoospermia)

*“...now my husband is saying that we will sell this land or mortgage the land and go (for treatment) but I am afraid. When people are making fun of us, my husband said, we will go for treatment.”* (Alice, 38 years, Husband having azoospermia)

*“Relatives and other people will be asking, why are you waiting again? Go somewhere, what is the use in staying like this? Go. So when they compel us, initially we won't think about it because money and all it is anyway this much, let it happen somehow on its own like that we will stay with that thought. But when people repeatedly ask, we get sad.”* (Rani, 42 years, Unexplained infertility)

*“...so when it was like 3-4 years after marriage, people will be like there is no child yet or something like that, 'nothing yet' kind of questions and because of that— nothing yet, nothing yet, questions we went and saw a doctor.”* (Elizabeth, 62 years, Unexplained infertility)

*“I have heard people saying you have not yet had (a child), and that makes me sad....”* (Rekha, 26 years, PCOD)

### **5.2.3 Social ridicule of people without children**

Couples without children were always reminded by those around them that they were not worthy of doing anything that others would normally do, like earning more money or building a house. Such activities were meant for those who have someone who would inherit these assets. They said they were constantly questioned on why and for whom they were doing these things for. The childless women were often ridiculed for expressing their happiness stating how could they exhibit happiness when they have not been able to reproduce. Women reported they were always under public scrutiny about how they behaved and presented themselves in the public. According to the women, the society wanted them to be sad and mourning over their fate and should always be expressing grief. Women who behaved otherwise were looked askance at for their behaviour.

*“Yeah that time and all have had a lot of pain. They will say no children are there right, they will say things that insult us, no children are there then why are you building house and all that. What you have is enough right, since you don’t have children. Now why you have to earn so much ... like this so many things. We can only listen to this right?”* (Rani, 42 years, Unexplained infertility)

People also have the notion that the childless women do not have sex and this cause them to be childless. And that women without children were unhappy and sexually not satisfied, but that they were pretending to be happy in the public. Though this is not explicitly stated to the women, it is implied, enforcing the need to pretend to be sadden by the childlessness.

*“When I smile and all, how I can smile be like this and laugh like this. People consider that I am unhappy because I am not... that (sex) is not there, you are understanding what I am telling isn’t. I am not using that word. I am starved in that that why I am not having child so I am actually unhappy and I am just pretending.”* (Elizabeth, 62 years, Unexplained infertility)

### **5.3 Individual factors**

The individual level factors are those operated at the level of the women who did not have a child. The women themselves embodied the idea that it was their responsibility to reproduce. This created a sense of anxiety about impaired reproductive functioning in them. They started to worry whether they were having faulty bodies which made them unable to reproduce. This idea was reinforced by the contextual factors which created the expectation that women were the ones who carried the reproductive responsibility.

### **5.3.1 Women's belief that reproductive responsibilities are embodied in them**

Women often felt that it was the fault in their body that caused the inability to get pregnant. They often embodied the idea that it was the responsibility of the women to get pregnant and have a child and all other things were secondary to it in a woman's life.

*"I knew I had this deficiency, as a woman this is a deficiency, right?"* (Elizabeth, 62 years, Unexplained infertility)

*"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)

*"Interviewer: Do you ever feel that it is because of the fault in your body?"*

*Respondent: Yeah that thought come in between why is it like this for me?"* (Rekha, 26 years, PCOD)

Once they got pregnant or had a child, they felt they were one among the other 'fertile woman', and until then they felt like outsiders to the group.

*"But when I got my daughter, I felt I got inside the circle"* (Elizabeth 62 years, Unexplained infertility)

### **5.3.2 Anxiety about embodying impaired reproductive functioning**

Women were worried about embodying the impairment in reproductive function and this made them sad when there were delays in getting pregnant. They reported that they got sad when they saw women of the peer group having children.

*"Yeah we will get sad, for first few months and all it was really very sad I used to cry all day."* (Rekha, 26 years, PCOD)

*"There are 2-3 people who have got married after me, they all have children now so when I see that I am sad."* (Asha, 25 years, Not yet diagnosed)

In the husband's family, when the sisters-in-laws were having children it was an extremely sad situation for the woman who was not getting pregnant. She felt inadequate in her capacity as a woman to reproduce.

*“In my husband's house when I went there after marriage, husband's elder brother only had a child- 3-month-old small baby. After that, between 2.5-3 years another brother got married, sister got married and they started having babies and everyone together has 4-5 children now. When babies were born, umm... for me naturally I have affection for babies both of us have affection for babies that is our nature. We wanted children, it was always there in our mind but somehow it did not happen.”* (Elizabeth, 62 years, Unexplained infertility)

#### **5.4 Treatment facilitating factors**

This section elaborates on the treatment facilitating factors i.e., the factors that facilitated the care seeking among the couples or that which extended the care seeking among them. This was characterised by the contacts within the system and the overall knowledge about infertility and its treatment which acted as facilitators or barriers in care seeking among the couples.

##### **5.4.1 Knowledge of infertility and treatment options facilitating care seeking or extending care seeking**

One of the main facilitating factors was the knowledge about the condition and its treatment. Those who knew about the condition or those who had contacts within the system found it easier to navigate the system. For some, biological issues alone caused the delay while for others delay was due to limitations with regard to access and affordability of infertility care. People who had relatives who were doctors, said it was easier for them and they had not faced much difficulty in accessing care. One of the participants also added that it would have been difficult if there was no contact within the system especially in the public sector where she sought care.

*“Basically because I had someone there, ... may be because of that I did not face any problems [...]. Nothing, because I haven't gone to the clinic as such. My mother-in-law's sister is a doctor so through phone or when we go home we contact and get the prescriptions so I haven't gone to the clinic as such. I haven't faced difficulty since people are there just go get the scan done and come so there wasn't much difficulty.”* (Mubina, 34 years, PCOD)

Those who had no understanding of infertility and its treatment, had a long trajectory of care seeking by way of prolonging it and trying out different alternatives. Some said they had tried all means and had even used unauthorised alternatives that claimed to improve sperm count. These people kept on shuttling between one provider to another in keeping with the suggestions received from friends and family.

*“First someone here had taken us to Dr x, we took admission and took medicines. For about 1-2 years we took treatment but since we were not getting pregnant, we stopped going there. Then Dr y, someone who had child after going there asked me to go there, so for some time we went there, after going there also we didn't have child. [...] Recently, like xxx (referring to a neighbour) had a child after going to one hospital, so we were asked to go to that hospital. We went there only once, that time itself it cost Rupees 25,000. After that he (meaning husband) won't come there saying it is just to loot the money.”* (Susie, 42 years, Unexplained infertility)

*“We went for homeopathy treatment, xxx (referring to a friend) said homeopathy is good, they got child after taking homeopathic medicine, so we went there but he (husband) doesn't like going and coming and all. So 5-6 times we went and then he was not interested to come and told me not to go. Homeopathy we took for 1-1.5 years and then I used to go and get medicines.”* (Susie, 42 years, Unexplained infertility)

*“Everyone recommended Ayurveda- there is some massage treatment, after the body is made okay and one will have child here in xxx (referring to the place)- they have called us but it will cost so much. There are people who have had got pregnant after going there and so they suggested that we go there, but we did not go.”* (Susie, 42 years, Unexplained infertility)

*“After that we went to xxx government hospital and the doctor there is from yyy place or something one person told. They took us there we met them at the church so we went and met the doctor at his home and then went to xxx hospital. We did IUI there but pregnancy did not happen, we did 3-4 times so we stopped going there.”* (Susie, 42 years, Unexplained infertility)

*“I went there after being told about it by my sister, one of my uncle’s daughter, had gone there had taken medicines and had a baby so they told me to go there so went there. [...] Someone without children near my house, so nearby a girl did not had children for 6-7 years they got after going to madam. So they told us about it and we went there.”* (Alice, 38 years, Husband having azoospermia)

*“How do you decide where to go? People come and tell that doctor is good and all so we go.”* (Shirley, 35 years, Husband having azoospermia)

*“Someone who has gone there said that there are two three places that are good. [...] That is because success is achieved quickly there.*

*Interviewer: Do you know anyone who has successfully used these facilities?*

*Respondent: Yes, we know that is why we went there. We were told that this Dr x is very good. Then in one hospital Dr y, she is good like that people told. Nothing was happening. Another hospital also was said to be good. So we went there too but at last we went to xxx hospital (referring to a private hospital). Then last we went to yyy clinic (private infertility clinic). [...] Someone who had gone there had told my husband. He is good so go and see. When people say that you will get a child quickly, we tend to jump to that place. That will be better, so long term treatment is not needed, we will get results easily in that thought we will opt that.”* (Rani, 42 years, Unexplained infertility)

This lack of knowledge was reported to cause a lot of emotional stress and strain to the participants. The uncertainty regarding infertility and its treatment triggered emotional responses in women. Adding to this, the expectations of the family regarding pregnancy also triggered psychological consequences. Women also reported

that they feared that the presence of other medical or surgical conditions in them was interfering with the current state of infertility.

Some of them stated that they were even misinformed that services like ART were available only in private hospitals and this prevented them from accessing the public sector.

*“See, we do not have any knowledge about it. In my family nobody had undergone such treatments, nobody knows anything about this and do not know how this will go forward. First of all we don’t know, then we don’t what will happen, that fear is there. So there was mental strain.” [...] Altogether an ‘uncertainty’ that is the right word.”* (Vani, 38 years, B/L tubal block)

## **5.5 Individual’s response to diagnosis and various treatments**

The individual’s response to the diagnosis and treatment includes the various ways men and women react to the different diagnosis and the prolonged treatment for their condition. This basically should be read within the context in which he/she is operating. Since the responses of the individual to their diagnosis and treatment are shaped by the context in which they live.

### **5.5.1 Trepidation about the future**

There was a sense of apprehension about the future among women when they were confronted with the problem of infertility. This was evident from the narratives of the women who expressed apprehension about the future when they went for the diagnosis. The impending results caused a sense of worry about the future, they feared that if they were to be diagnosed with fertility impairment what future holds for them.

One of the women whose husband was diagnosed with the problem causing infertility expressed the fear that if she was diagnosed with the problem, then her future would have been sabotaged by the in-laws. She also expressed a sense of relief on learning that she was not having the fertility impairing condition of the two of them.

*“When we went for getting the results, that day my heart was beating fast. What it will be...? Whether there is any problem? How will life be? I was thinking all these and praying. If the problem was for me, they are males we cannot tell, their mind may change and their people will all together destroy my life. [...] It was a relief when it was not me, the problem was not for me, that was a relief.”* (Alice, 38 years, Husband having azoospermia)

### **5.5.2 Responses to diagnosis of male infertility**

The major departure was seen when the diagnosis of infertility was made in the male partner. In these cases, the husband either owned his reproductive impairment or else the wife took the blame so as to protect the husband from shame.

Husbands who owned up to their reproductive impairment did so because they were afraid that their wives would leave them. When the wife was having normal reproductive function, this was one of the major driving factors which made the man acknowledge to others that he was having the problem. There was also the issue of shame associated with male infertility and this may be also a reason why men wanted to hide their reproductive impairment. In such cases, the burden was shifted to the woman since she had to take the blame of infertility when the husband was the one contributing to their infertility status. One of the women stated that she herself took the blame of infertility so as not to make the husband sad.

One of them said when the husband was diagnosed as having fertility impairing condition, he asked the wife not to leave him and go. In some cases when male infertility was the reported cause of infertility in the couple, the husband took ownership of their problem and told others that he was having the problem to those ridiculing the wife.

*“In my home everyone knows that husband is having the problem, and I have told them not to tell this to anyone in the neighbourhood. In my place (maternal home) I have told everyone it is my problem. To everyone there also (husband’s house) I have told it is my problem.”* (Alice, 38 years, Husband having azoospermia)

*“My husband also doesn’t tell anything, he is nice. He tells no to leave him and go since there is no child. So we both don’t have any problem and we don’t fight regarding this.”* (Ancy, 40 years, Husband having azoospermia)

*“He told that lady who asked me that she don’t have any problem I am having the problem.”* (Alice 38 years, Husband having azoospermia)

*“But I don’t tell about these things and make him sad or anything, I just keep it to mind and live. Haven’t told anything about it. If my face becomes a little bit dark also, he tells I know why you are like this, you can marry somebody else if you want. So I don’t show anything if I get angry also, he will get sad.”* (Alice, 38 years, Husband having azoospermia)

### **5.5.3 Recalcitrance of husbands affecting treatment**

Women reported that husbands were unwilling to pursue the treatment, regardless of whether or not they were having an infertility related problem. One of them said her husband was lazy to go for treatment and was afraid of the treatment procedures and hence he does not turn up for treatment. Some women said that the husbands also exhibited reluctance to even initiate the treatment seeking process and kept postponing it giving various explanations. Financial constraint was also cited by women as one of the major reasons why the husbands did not want to pursue the treatment. Some of them were daily wage labourers, who said going for treatment meant loss of a day’s work and thus their wage. Therefore, the prolonged treatment was burdensome for many as they could not find resources to continue the treatment.

*“Both of us go together to see the doctor and on that day, he cannot go for work. We pawn gold jewellery and go for treatment. We go, our time, money everything is lost and there is no result also.”* (Alice, 38 years, Husband having azoospermia)

*“He will take medicines only if I give and he is very lazy to go to the hospitals and is also afraid of surgery.”* (Shirley, 35 years, Husband having azoospermia)

*“In xxx hospital, we have to go early morning and take token and wait. In another hospital we went, they gave medicine and then since nothing was happening then my husband was not willing to go anywhere since it was taking so much money. So I did not go anywhere after that.”* (Ancy, 40 years, Husband having azoospermia)

## **5.6 Factors interfering with treatment process**

This theme describes the physical factors that interfered with the treatment. Treatment was initiated with a lot of negotiations between husband and wife, especially when one or both were working. This along with other factors affected the treatment process considerably.

### **5.6.1 Physical factors that interfere with treatment**

Women reported that the initiation of treatment itself was delayed due to the job-related factors and the fear of break in treatment made them delay trying for the child. This also continued when they initiated treatment, since the treatment demanded the husband and wife to stay together and try for pregnancy. The wife stated that first she had to wait for the husband to get a transfer so as to go for a regular treatment. Once this was done the working arrangement was such that they were unable to have properly timed sexual contact. One of them was having night shift and this interfered with the treatment process.

*“I came to know about PCOD six months after marriage and we did not have a proper married life because husband comes here for three days and in those three days may be once or twice we will have sex. That time it will not be ovulation period, so problems because of that. And then I have night duty so there are problems like that so we did not take any treatments for first one year. And if we take treatment also I am here and husband is there so no use of taking medicines so we waited for the transfer to be together.”* (Rekha, 26 years, PCOD)

## **5.7 Consequence of infertility and treatment**

The consequences of experiencing infertility and seeking treatment are mainly experienced by the women. Infertility itself puts the woman at a disadvantaged position and she is faced with the threat of being thrown out of the family owing to her

inability to reproduce. In addition to this distress, she also has to bear the burden of the treatment even when her spouse has the problem. The treatment stress and the physical pain and emotional strain of the treatment are all centred in the women's body.

#### **5.7.1 Adverse consequences of reproductive impairment for only women**

It was reported by the women that they were always blamed for the inability to reproduce. This blame translates for some into threats of divorce and other consequences. One woman reported that even when her husband was diagnosed as the one having the fertility impairing condition, his family members were unwilling to believe it. They tried to arrange a second marriage for her husband because they believed that only women will be having the problem. This is a major adverse consequence of infertility that the women have to go through.

*“Oh when we were not having children they plan to get him married to another person.”* (Alice, 38 years, Husband having azoospermia)

#### **5.7.2 Negative externalities of treatment seeking process**

Both physical and emotional difficulties were reported by women as part of the treatment process. The prolonged treatment process was tiring for the couples especially, when combined with the absence of desired outcome. Women reported that they went through a lot of emotional strain due to the treatment process and had also endured physical pain when undergoing procedures like IUI. The multiple cycles of induction and IUI created a lot of physical and mental trauma for the women. But they persisted with the treatment in the hope for a child.

Women also said that financial issues were a major problem as most of the assisted reproductive techniques needed a lot of money. The lack of financial back up made it difficult for them to pursue treatment. The everyday difficulties of going for the treatment was also highlighted by many women, the centres where they sought treatment was very far away and getting there was not easy. This required that they catch an early bus to reach the place and one of them said that the place would already

be crowded when they reached there. This meant they had to wait for a long time to see the doctor.

*“Since because of this treatment, in between I was so much emotionally down. Treatment means in between they checked whether I am having block in the tube and all, so it was so painful so I could not bear it. And I became emotional/ mentally weak.”*  
(Vani, 38 years, B/L tubal block)

*“IUI is very painful and I am afraid of that. I have endured so much pain.”* (Rani, 42 years, Unexplained infertility)

*“After that we once went to xxx hospital, we went there recently just before one year. There it was told if we have house and property then we can try injecting sperm.”*  
(Alice, 38 years, Husband having azoospermia)

## **5.8 Resolution and coping**

The final step of the treatment pathway is achieving pregnancy, but this state is not achieved by everyone. Those who have not achieved this may stop or continue with the treatment. This phase is characterised by women externalising the delay in getting pregnant, particularly when the pathway to resolution is extended without a desired outcome.

### **5.8.1 Strategies that prolong the expectation of resolution (hope)**

The women who were unable to find a resolution to their problem started externalising their problem. Women attached their difficulty in getting pregnant to outside factors like astrological problems, will of God, and blamed it on the inappropriateness of astrological planetary alignments in their horoscope. They also identified unfavourable family situations as a reason for the delay in getting pregnant. This facilitated their propensity to hang on to ‘hope’ which then extended their stay in the state of limbo otherwise called ‘inbetweenness’ by Probyn (1996)

One of them reported that her inability to get pregnant and the decision to adopt and thus start a family was put on hold for a very long time by the parent’s fear of societal stigma.

*“Then I thought, why I am crying? God has planned a time for us and so it will happen that time.”* (Rekha, 26 years, PCOD)

*“There is ‘sarpadosham’ (curse of the serpent God) it is not very big we can go and solve it so we go to ‘nagakshethram’ (temple for snakes) and all and the house we are living is also having some problem like the position of the bathroom and all and I feel there is some problem.”* (Rekha, 26 years, PCOD)

*“When I tell my mother I am going to adopt a child my mother will tell no need, what neighbour and relatives will tell. She asked ‘Why don’t you try for some more time and then go to some doctor?’, so when we went to the doctor there was no problem.”* (Elizabeth, 62 years, Unexplained infertility)

## **5.9 Discussion**

The findings from this component of the analysis provide insights into what shapes the couples’ decision for treatment and highlights how women bear the burden of the inability to reproduce by the couples. The first observation is that the women who are unable to conceive due to problems of either or both partners, start getting anxious about it. There is a social expectation that a married woman has to procreate within a certain period after marriage. This puts the blame on women when they are unable to get pregnant. Due to this popular notion, women who are unable to reproduce also start embodying the idea that the reproductive impairment is in their body. Women also internalise the inability to get pregnant as their fault, they consider themselves as incapable, abnormal and defective (Sandelowski et al. 1990). This in turn also makes the men believe that reproductive impairment can happen only in women’s bodies. There is a general perception that infertility is seen as a problem of the woman (Greil et al. 1988).

Women also get pressurised by the public enquiries regarding their pregnancy status. The need to avert the blame and also the distress caused by public enquiry makes them start care seeking. There is also the relentless public scrutiny of the married woman who hasn’t reproduced and these manifest as inquiries by concerned others regarding

the potential pregnancy status. Such inquiries are not seen as an invasion of privacy within the cultural context (Basu 2012; Manzar & Chaturvedi 2017), they are seen as an expression of interest in the welfare of the couple by concerned others. Women felt pressurised by this scrutiny and well-meaning inquiries regarding their pregnancy status (Batoool & de Visser 2016). It causes distress and propels the urgency to initiate care seeking.

Treatment seeking is a long process so the decision to start treatment puts them on the care seeking pathway but the ability to continue seeking care was depended upon other factors as well. Women reported that factor like knowledge about the condition and its treatment was one of the main facilitating factors for treatment. Presence of contacts within the system also eased the treatment seeking processes. Access and affordability were also cited as the reasons for treatment seeking.

They also felt that there was a huge difference when the diagnosis was made, women felt relieved on learning that the reproductive impairment was not theirs as it took off the anxiety of marital breakdown. They were threatened by the possibility of divorce. While men took the diagnosis of male infertility with surprise, some owned their problem, in other cases women took the blame to avert the shame on their husbands. In such cases the husband's family were not ready to accept it was their son's problem. Women also reported that their husbands were recalcitrant in seeking treatment which affected the treatment. Griel et al. (1988) reported that men tend to stop the treatment earlier than their wives. There is also stigma associated with infertility and there is evidence that the stigma attached to male infertility is high (Becker 2002) and this also could be a reason for the women taking blame for their spouse's reproductive impairment. Once the treatment seeking was initiated after lot of negotiations between husband and wife, working arrangements interfered with the demands of the treatment. While they pull through all this, there were other factors that were demanding on the women. Physical pain and emotional distress was part of the treatment cycle and this was mostly endured only by women.

When the treatment did not end in a favourable outcome, women externalized the delay to get pregnant. This could be a way of coping by women and this also helps

them to remove the self from victimisation and also the ridicule of the society. Given the existing social and gender norms in society, women are more likely to be affected by infertility than men (Greil et al. 1988).

These observations point to the fact that infertility cannot be studied without taking into account these external factors like the social and cultural norms that shape it. This also tells us that the fear of the consequences is one of the main factors that makes women initiate and endure in the pathway. These are constructed and shaped by the gender norms prevalent in the society.

## **Chapter 6**

### **Care seeking trajectory of couples with infertility in Kerala**

This chapter fulfils the objective of understanding the trajectories of care seeking for resolution of infertility among couples. It explains how the couples actually ‘move around’ in the care seeking pathway. I use the phrase ‘move around’ to indicate the lack of a sure forward or upward direction to this movement.

This exercise aimed at understanding what the couples did to mitigate the infertility that was afflicting them. It does not describe why they did so, however. It describes the practical means employed by couples while going about seeking a solution for their fertility problem. The findings from this section were used to design the interview schedule for phase III of the study. To explain this process of ‘moving around’ by couples, I have used in-depth interviews from 16 women and two men, who were husbands of the women seeking infertility treatment in the two southern districts of Kerala, Thiruvananthapuram and Kollam.

#### **6.1 Participants and analysis**

The details of the participants are in chapter 5. The process of care seeking was arrived at using in-depth interviews with women and findings are discussed below. The interviews were analysed using RQDA software starting with open coding by reading the interview line by line and coding each sentence specifically looking to describe the care seeking process. The initial codes which were similar in meanings were merged to form the axial codes and the second level merging of axial codes enabled the identification of the themes. The themes developed after coding are discussed here, under nine major themes.

#### **6.2 The process of treatment seeking for infertility**

The process of treatment seeking for infertility by couples is a complex interactive process between the self, the family and the social and cultural norms that prevail. The steps in treatment seeking presented here does not mean that it is a linear process as depicted but is an on and off pathway that meanders, longer or shorter, depending on many factors viz., the extent of the reproductive impairment, the socio-economic

situation, the opportunities and constraints and also the social norms. The treatment seeking process is explained in nine different themes viz., postponement of pregnancy, recognition of difficulty in getting pregnant, pressure to have a child, decision making for treatment, initiation of treatment seeking, initiation of treatment, treatment phase, pressure to continue treatment and discontinuation or stopping treatment.

### **6.2.1 Postponement of pregnancy**

While women planned on starting a family immediately after marriage, some women did report that they had postponed pregnancy for up to two years after marriage. Work related commitments and personal reasons were cited as reasons for postponing pregnancy. Women reported that coitus interruptus and condoms were used as methods of contraception to delay pregnancy.

*“Interviewer: You said for two years you didn’t not want kids, that time did you use anything to prevent it?”*

*Respondent: No, nothing like that. When we have intercourse at the time of ejaculation, he withdraws it. We did not use condom and all” (Alice, 38 years, Husband having azoospermia)*

*“We started going to hospitals after 2 years, first year we were not planning to have kids.” (Shirley, 35 years, Husband having azoospermia)*

*“Immediately after marriage did not feel like having a child and I think that was the idiotic thing. He used condom and used to tell no need now like that. That time I was working in a private school, so I thought no need now because of this work.” (Leela, 45 years, Fibroid uterus)*

### **6.2.2 Recognising difficulty in getting pregnant**

The women reported that they recognised that they may be having difficulty in getting pregnant after trying to get pregnant for more than 2 years. This along with other factors like desire for a child and pressure from near and dear ones pushed them to initiate treatment seeking. The need to go for treatment also stemmed from having to endure prying questions about the absence of pregnancy.

*“We did not know that there is a problem like this, for two years we were not planning for kids after that when we tried also it was not happening, periods was coming, so we decided to go. So when we asked my uncle’s daughter, she suggested that we go to this place,.... Like that we went.”* (Alice, 38 years, Husband having azoospermia)

### **6.2.3 Pressure to have a child**

The need to have a child is both due the individual’s desire to have a child, and also through pressure from the family/significant others and prying questions about the pregnancy from all and sundry. The women said that they were subjected to pressure by family, friends and others to get pregnant. This pressure, in tandem with the desire to have a child, led them to start thinking about seeking care. Almost everyone said they were asked about the absence of pregnancy after 1 year of marriage and this in turn put pressure on them to view their inability to get pregnant as a problem and initiate seeking care.

*“...and then everyone started asking (about pregnancy) and we also felt so we went for treatment”* (Rekha, 26 years, PCOD)

*“After marriage, in 2 months people starts asking (about pregnancy), then I told my husband and then he said that all his friends had child after 2 to 3 or 4 years.”* (Asha, 25 years, not yet diagnosed)

*“I don’t remember exactly when we sought the first treatment. So when it was like 3-4 years people will be asking like there is no child yet like that, ‘nothing yet’ kind of questions because of that ‘nothing yet’, ‘nothing yet’ questioning, we went and saw a doctor.”* (Elizabeth, 62 years, Unexplained infertility)

*“After marriage for 2 years we did not plan to have kids, then in family people were scolding us asking us not to postpone. So when we wanted it, it was not happening so we thought of showing to someone.”* (Alice, 38 years, Husband having azoospermia)

#### **6.2.4 Decision making for treatment seeking**

Most of the women who were interviewed reported the decision to initiate and continue treatment was made jointly by both partners. But the regularity of this treatment seeking faded as years elapsed. As the treatment proceeded, the onus of continuation seemed to fully rest on the female partner. This was particularly evident when the male partner was having an impairment in their reproductive function.

*“...both of us go together to see the doctor [...] we both only made decisions regarding going to the doctor.”* (Alice, 38 years, Husband having azoospermia)

*“we both took the decision together to go for the treatment.”* (Mubina, 34 years, PCOD)

*“In xxx hospital we went, they gave medicine and then and since nothing was happening then my husband was not willing to go anywhere since it was taking so much money. So I did not go anywhere after that.”* (Ancy, 40 years, Husband having azoospermia)

*“When it was 8 years I used to go on my own and did something without my husband’s knowledge. I used to go to Mother Theresa ’s convent in the evening when I was sure it will one day come to my home you feel like a I was in a different mental state, pain ...not happening that sadness is there”* (Elizabeth, 62 years, Unexplained infertility)

*“Between 2010- 2012 we did not go anywhere [...] only this talk is there he will not go anywhere, he is lazy I will try everything that people tell”* (Shirley, 35 years, Husband having azoospermia)

#### **6.2.5 Initiation of treatment seeking**

Once the couple arrived at the decision to seek treatment, they start to think about the facility or the doctor to consult. The decision to go to a particular place was arrived at after multiple deliberations. There was a tendency to consult others to decide on the place of treatment. The factors such as success rate at a particular place, location of the place, the financial status of the couples, sex of the treating doctor were considered before the couple decided to proceed to a particular centre for treatment of infertility.

**Decision based on consultation with others:** A particular facility was selected almost always after consultation with another person. This could be the network of people who have successfully used a particular facility/a treatment or someone in the neighbourhood who would suggest a place. This network may be directly linked to the couple who see themselves as needing infertility treatment or may be through a friend or family. Sometimes doctors who were friends are also consulted to initiate the treatment.

*“This Dr.V is very good like that someone said to us. Then Dr T, she is also good like that people told us, so we went there also”* (Rani, 42 years, Unexplained infertility)

*“First we saw in xxx Dr.R, before that my sister’s sister-in-law is a gynaecologist, I saw her and she only asked me to see Dr.R and we went and saw this Dr.R and he was in xxx medical college.”* (Elizabeth, 62 years, Unexplained infertility)

**Choice of site:** The site for treatment was selected based on suggestions by others who had successfully used it. This was because the couples wanted to get quick results, and therefore selected a place that had already proven to be successful for someone known to them. Others mentioned that the facility for treatment was chosen based on accessibility.

*“Interviewer: Who asked you to go there?”*

*Respondent: There... one of my husband’s colleague, he had some infection and after taking treatment for one month they had and that chechi [referring to husband’s colleague’s wife] had some cyst or fibroid and it was cured after showing to xxx hospital... that is how we went there.”* (Rekha, 26 years, PCOD)

*“Interviewer: Why did you chose the particular place?”*

*Respondent: That is because it will be successful fast that is why. When people tell we will get soon so we tend to jump to that place. That will be better, so long term treatment is not needed, we will get results easily in that thought we will opt that.”* (Rani, 42 years, Unexplained infertility)

Choice was also made between private and government facility to seek care. Lack of faith in a particular system like government facility was a driving factor for choosing private facility. Women felt that there was accountability for the money spend in a private facility unlike government. The only reason for choosing a government facility was lesser treatment costs compared to private facility.

*“Interviewer: Why did you not try government hospital?”*

*Respondent: There will be lot of people so maybe we won't get correct treatment”*  
(Rekha, 26 years, PCOD)

*“Interviewer: Why don't you go to government hospital?”*

*Respondent: There and all we need recommendation. We have to go and give money at home, this operation also happened after we went and gave money at their home. Otherwise we have to stay like dogs, no one will bother. No faith in government hospital. They are sitting for money, we have to go and give money in their home.”*  
(Ancy, 42 years, Husband having azoospermia)

*“Money will be less there [referring to government hospital] people who have gone there has told me so only we planned to go.”* (Asha, 25 years, not yet diagnosed)

**Preference regarding treating doctor and facility:** Women preferred female to male doctors as they felt comfortable with the former. Some preferred to seek care in sites where they knew someone, as this made the process easy but some preferred to seek care where they did not know anyone due to fear of stigma.

*“...so in my hospital also doctor is there, he is a male doctor so I am not very comfortable and again I have to face him and I have been working there for 5 years so people's questions like 'what happened?' so you know how women will be so they will tell like oh Rekha is having a problem like that, or her husband is having like this, so it will spread like that so that was a difficulty for me so we decided to go outside.”*  
(Rekha, 26 years, PCOD)

### **6.2.6 Initiation of treatment at the site**

This phase involved the actual act of seeking treatment at a facility or at the clinic of a doctor. It started with a visit to the centre/doctor and initiation of investigations for the infertility problem that the couples have identified. This specific phase of initiation of treatment was usually short, not more than six months in a centre, during this phase couples changed the centre based on the desired outcome. Those who felt that their desired outcome was not being achieved changed the place of treatment. The pattern of care seeking at the new site took a recurring format as in the previous step i.e., initiation of treatment seeking, the couples consulted with others on a place that could offer them their desired outcome, examined the success rate at the site and so on.

***Initial investigations and a tentative/definitive diagnosis:*** The treatment seeking started with the initial investigations and diagnostic evaluations and procedures. Initiation of diagnosis as reported, was done through blood and semen tests for female and male partner respectively. Although some women reported there was hierarchy in testing and that the husband's investigations started only later.

*“Interviewer: Did they do tests for you?”*

*Respondent: Only for me all the tests were done for the first time. My husband was not checked, in both xxx [name of hospital] and yyy [name of hospital]. So when I was found to have no complaint they started checking husband. First they did not check husband's blood group and count they checked only me.” ( Ancy, 42 years, Husband having azoospermia)*

The reports of the investigation were produced during the subsequent visits and further action depended on the test results. Some of the couples had to go through a battery of different tests and monitoring to determine whether or not their condition was improving.

*“...last we went to Dr K, doctor also told I will conceive for sure, finding out both my tubes are patent sending my husband to another doctor looking the count” (Elizabeth, 62 years, Unexplained infertility)*

*“...since count was low so maybe a small operation will be needed”* (Shirley, 35 years, Husband having azoospermia)

*“So when they checked husband’s semen doctor told it is slowly getting motile”* (Alice, 38 years, Husband having azoospermia)

This was a continuous and distressing process, both physically and emotionally. The couples usually started care-seeking with allopathy medicine. This phase continued for a minimum of few days to less than six months at one centre. There was a tendency to seek care in another centre if the couple was unable to get a definitive diagnosis. If a diagnosis was made, then they proceeded to the next phase of the treatment cycle in the same centre and opted to go to another if the expected result was not achieved.

*“... yes, to hospital only, here in xxx [name of the place], Dr. N”* (Shirley, 35 years, Husband having azoospermia)

*“After 1-2 years, we went to hospital, First here someone here had taken to Dr.M, we took admission took medicines 1-2 years we took treatment but since we were not getting pregnant we stopped going there.”* (Susie, 42 years, Unexplained)

*“...first time we went that time itself tests were done”* (Alice, 38 years, Husband having azoospermia)

The diagnosis included fibroid uterus, fallopian tube block, polycystic ovarian disease, primary ovarian failure, abnormalities in semen viz., low motility, azoospermia, erectile dysfunction and unexplained infertility among the respondents.

*“when they looked husband’s count there was nothing not even one sperm was also there, all the sperms were dead”* (Alice, 38 years, Husband having azoospermia)

*“...after tests, when we showed the doctor the results, she told us that there is no count”* (Shirley, 35 years, Husband having azoospermia)

*“I was having a fibroid, after 2 years of marriage I came to know that. When I went for treatment in xxx[name of the place], there they found out that there is fibroid. So did operation and removed it.”* (Leela, 45 years, Fibroid uterus)

*“then scan was done for me and PCOD was there and it was excess”* (Rekha, 26 years, PCOD)

**Consultation with others to change site:** If the desired outcome was not achieved, most couples deliberated with others to identify a place that would offer success. This phase was also characterised by people giving their opinions on the places that might provide success, when they encountered couples with infertility who have not yet achieved success.

**Break in treatment:** There were breaks in treatment even during the initial phase of treatment. This usually happened for those who have not achieved the desired outcome within a short time period. Break in the initial phase also happened when the man in the infertile couple backed out from the treatment cycle.

*“We stopped there after 1 year and then went to xxx hospital. We stopped because we were not getting results only money was getting wasted. After going there also it was not getting done soon.”* (Rani, 42 years, Unexplained infertility)

*“First we went to Dr.D in 2007, I went there after being suggested by my sister [...] We went there like 6-7 times [...] so each time we go to test husband, we get medicines and take that... like that. She will give medicines for 2 weeks and we take that and have to go again, it was like that all the time count will be checked... so each time we go they test husband, they check... check... but nothing is happening... no count is there. After that we did not take any medicines... After 2007 for almost 2 years we did not do anything.”* ( Alice, 38 years, Husband having azoospermia)

### **6.2.7 Treatment phase**

The treatment phase was usually the longest and ranged from six months to many years with multiple breaks, different trajectories and change of sites. This is the phase where the couple proceeded for treatment including medications or injections to other

invasive ART procedures to achieve pregnancy. It was the most demanding phase for the couple, physically, emotionally and psychologically. This phase also demanded significant financial resources and some couples exhausted their resources. During this phase couples took break in care seeking to replenish their financial resources or completely abandoned the treatment. An alternative pathway for the couples was to try other systems of medicine such as Homeopathy, Ayurveda or Unani and also try alternative medicines from the folk tradition which advertised magical cures to achieve pregnancy.

***Multiple trajectories:*** The treatment phase consisted of multiple trajectories with different systems of medicines and different kinds of options being tried one after the other or simultaneously. The treatment phase included treatments for the various conditions that were diagnosed for the couple, and it ranged from medications, invasive surgeries to use of different assisted reproductive techniques. This phase lasted for very long for some couples while it was shorter for others. It was shorter for those who achieved the desired result earlier or those who abandoned the treatment in between. I describe one such trajectory of care seeking across multiple sites offering allopathic treatment in figure 6.1.

Figure 6.1 shows the treatment pathway of a couple who negotiated multiple sites for treatment. This couple had only tried Allopathy and no alternative methods were tried for getting pregnant. This was the treatment trajectory of a 38-year-old, educated and employed woman. The initial postponement of pregnancy was because the woman got a job at a location that was different from that of her husband and the resultant discontinuity in co-residence. Once they started staying together, they noticed the inability to get pregnant, and this along with the pressure to start a family put them in the treatment seeking pathway. Treatment centres one and two were visited in order to get a definitive diagnosis. Once the diagnosis was achieved in the second centre, they sought treatment at one of the major IVF centres in the state as the woman was diagnosed as having bilateral tubal block that made normal conception impossible. This meant, she had to undergo IVF treatment to get pregnant, and two cycles of IVF were done in the third centre with no success. The emotional and physical stress of the

IVF treatment made them take a break for two years during which they suspended all kinds of treatment. After two years, again through a friend who had successfully used a centre referred them to another centre. This centre was also a specialised infertility clinic. Here, the women underwent one cycle of IVF and had a positive result.



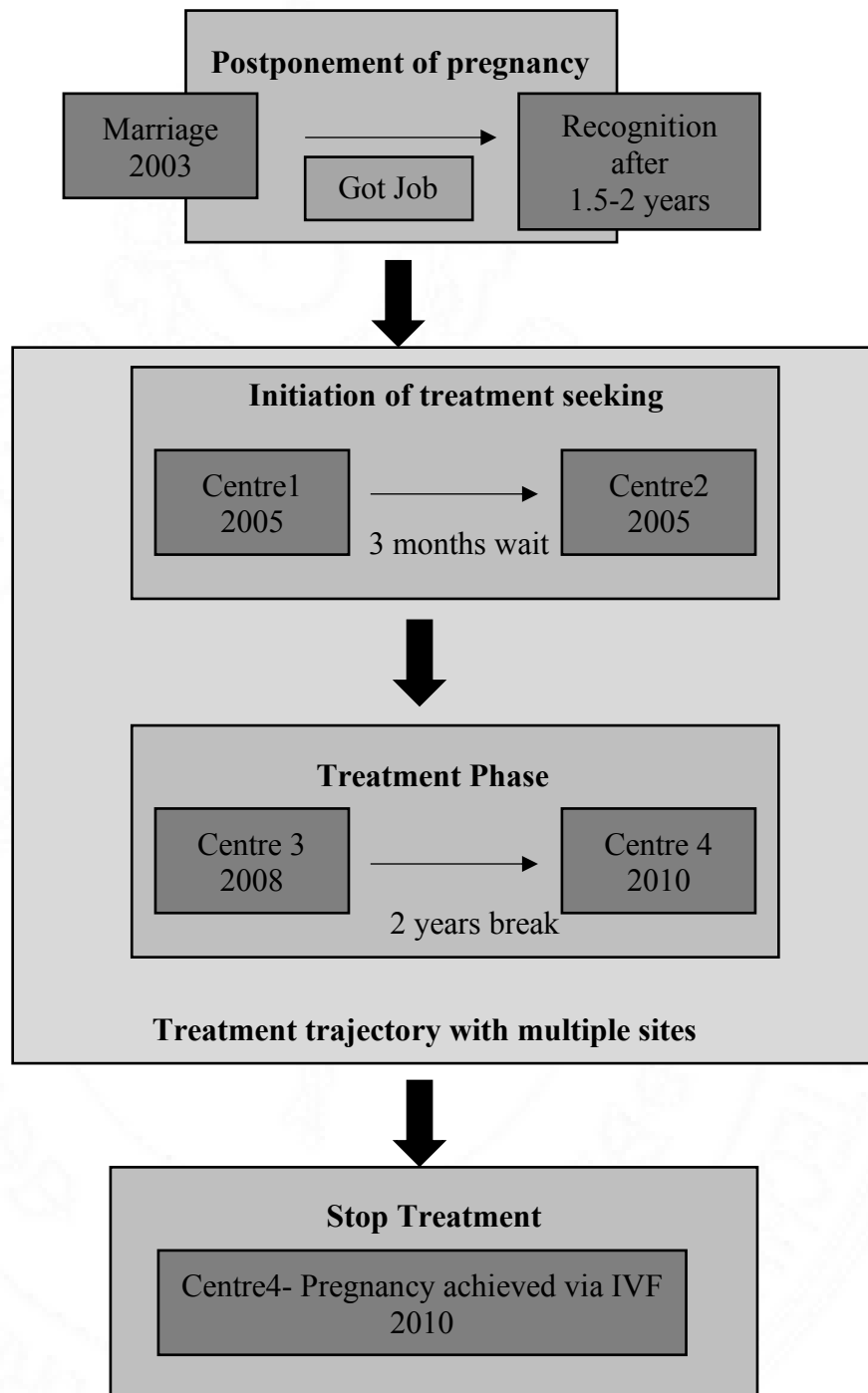


Fig 6.1: Treatment pathway of a couple with multiple sites

**Alternative methods:** In the treatment phase, there was a tendency among the couples with infertility to try alternate methods and also combine different treatments. Faith based methods, astrologers, or folk remedies were tried and medicines that were advertised through the media for correcting certain conditions that caused infertility were also used. Some reported combining allopathy and homeopathic medicines during the treatment phase.

There was also reported self-treatment for male infertility. The male partner when diagnosed with problems in semen parameters had resorted to self-medication. This practise of self-medication is usually follows a diagnosis of infertility due to the male partner. They do not immediately resort to self-medication, this was either started after unsuccessful treatment outcomes using allopathic medicines or other system of medicines. The practice of self-medication was also combined with the mainstream system of medication that they were undergoing. This practise was initiated usually when they did not find any positive outcome with the treatment they were undergoing. Seeking of such alternative options by the male partner was facilitated by the opinions given by friends or family who had used such products. These self-medications mainly consisted of powders, holy water provided by the religious entities and folk medicines which were mainly powders or certain food items, parts of medicinal plants and so on. The participants also reported using ready-made powder mixes claiming to be Ayurvedic medicines, which were introduced to them either by friends or family or those that they have familiarised themselves via advertisement in the television channels or newspapers.

*“Yes, I have gone to one place like that. God will come in someone’s body like that one place. There also when I said I am not having any problem, they told then take husband and do the tests. Someone who had child after going there had told me, so I went here. It’s all belief.”* (Asha, 25 years, Not yet diagnosed)

*“I said right, we took homeo medicine in between, for 3 weeks we did not tell this to the doctor in xxx hospital but we were taking homeo. After that we went to do laparoscopy that time I was pregnant but we do not know for sure in which treatment it happened, homeo or in the other?”* (Rani, 42 years, unexplained)

*“It has been 5 years since we have gone to hospital, after that only we started doing this to increase sperm count– gave ‘naykurniparippu’ (Velvet bean/Mucuna pruriens) powder in egg and milk, boiled it and husband took for 41 days [...] to increase the count, then ‘neyokke japichu kazhichitundu’ (consumed ritually divinised ghee)” ( Shirley, 35 years, Husband having azoospermia)*

*“Then we saw an advertisement in the television for increasing (sperm) count regarding one tablet it is somewhere in Trivandrum. We called them and told the medicine’s name and they said they will deliver it here.... Took the medicine for one month but we did not do any tests, my husband was so sad so we did not go for any test after that.” ( Alice, 38 years, Husband having azoospermia)*

**Physical and emotional burden:** There was a lot of physical stress in the body reported by women due to various treatment procedures. There was also the emotional burden due to the non-manifestation of success of the treatment. Most of the women said they endured all this in the hope that they will get success in the end.

*“So since because of this treatment in between I was so much emotionally feeling sad. Treatment means in between they checked whether I am having block in the tube and all, it was so painful and I could not bear it. And I was emotional/ mentally weak.” (Vani, 38 years, B/L tubal block)*

*“When taking these different medicines there used to be weakness in the body.” ( Susie, 42 years, Unexplained)*

*“...now I am fed up with the treatment also because of these injections and medicines.[...] I am fed up because every month you have to do follicular study the scanning has to be done 3-4 times, transvaginal examination is there and male doctors will be there.” (Mubina, 34 years, PCOD)*

**Break in treatment:** Break in treatment happened due to multiple reasons viz., physical distress due to exposing the body to different kinds of tests and treatments

most of which were invasive and painful, financial difficulties, due to logistical reasons, and also physician related or treatment centre related problems.

*“In between we stopped because of financial difficulty [...]. Then for 2-3 years there was no treatment.”* (Leela, 45 years, Fibroid uterus)

*“The hospitals we go are all private and it costs so much for all the tests and all. Some time we have to mortgage gold and all. When it is too much... we will stop for some time.”* (Rani, 42 years, Unexplained infertility)

*“Almost 2 years we took break, because we thought let the effect of the medicines go. Because we have taken lot of medicines, this hormone is injected, 8 or 9 injections to increase the size and the number of the ova. We were afraid of that, Doctors will tell not to be afraid but husband will tell these injections so as not to affect our health in any ways, if we go take treatment soon again medicine will go in like that. Then finance also.”* ( Vani, 38 years, B/L tubal block)

I have narrated the trajectory across allopathic to alternative medicine treatment options in figure 6.2. This represents the treatment pathway for many others who meander across multiple treatment options in the allopathic tradition and also take recourse to alternative treatment options including those that are faith and folk based.

Figure 6.2 shows the treatment pathway of a couple who had gone to multiple centres and has also tried alternate methods for their problem. The couple had postponed pregnancy for almost two years after marriage. They later started seeking treatment when they did not get pregnant in spite of trying. The desire to have a child, and the absence of pregnancy along with the social pressure made them initiate treatment. They started at the first centre and got a diagnosis, where it was diagnosed as male factor infertility (husband had azoospermia- absence of sperm in the ejaculate) as the cause for the inability to get pregnant. Once the diagnosis was made, the doctor completely disowned them telling there is nothing that can be done with their condition. Hence, they took a complete break from treatment. Later, they saw some advertisements in television regarding some medicines which could improve sperm

count. They bought these medicines and it was consumed by the husband, but no semen testing was done in the interim period to check the status. Later that same year, they were told by someone to seek care in a facility and they consulted the doctor who gave them reassurance. The reassurance by the doctor made them continue care in the same centre. But later this particular doctor was transferred and the couples stopped seeking care in the centre because they felt that they had to undergo all the tests again with a new doctor. After this they took a break for five years and again restarted treatment at a new centre, where they were told about the ART treatment to achieve pregnancy. A lot of money was needed for this treatment and being a daily wage labourer, the husband was not able to afford the treatment so they completely discontinued the treatment.

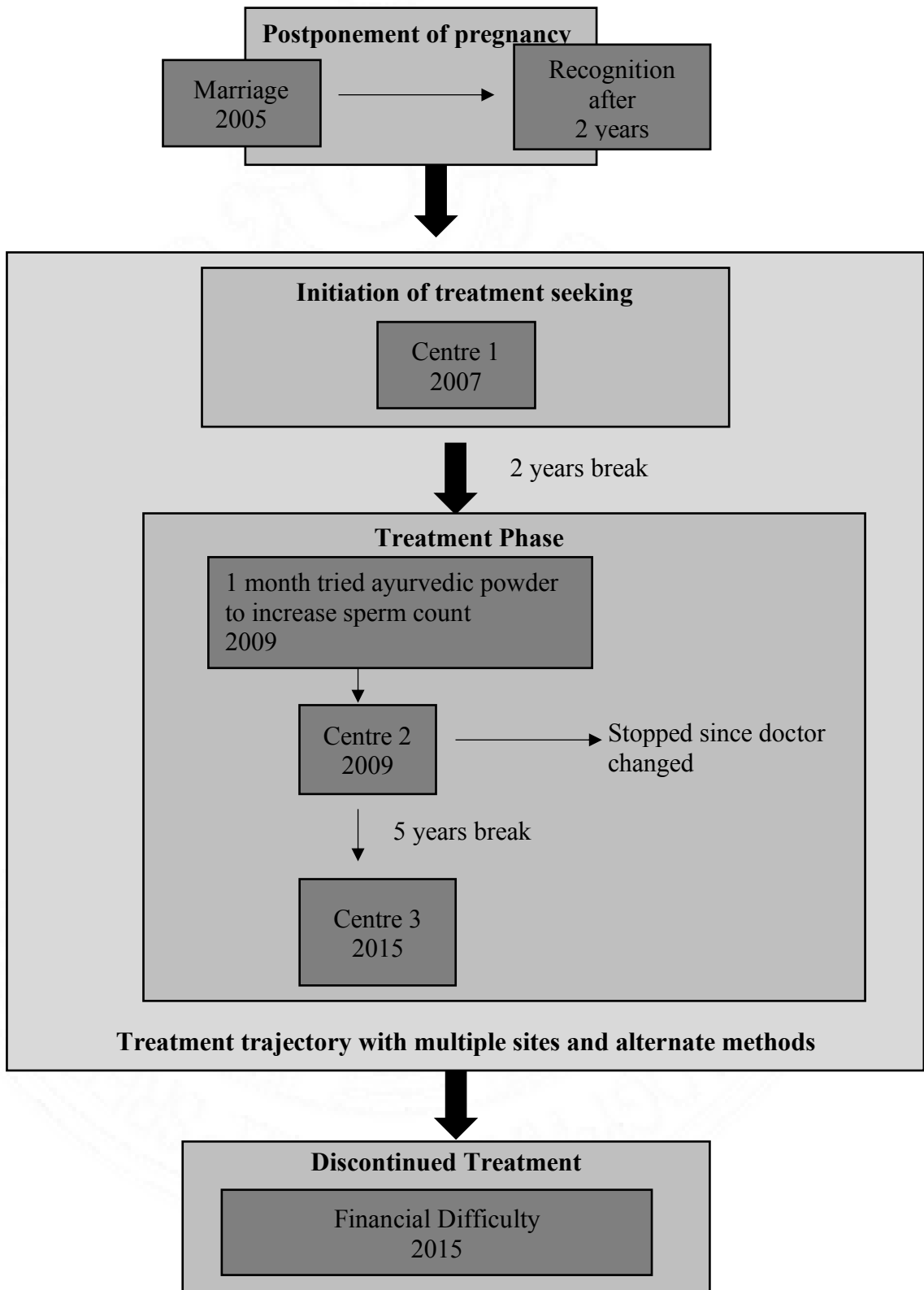


Fig 6.2: Treatment pathway of a couple with multiple sites and use of alternate methods

### **6.2.8 Pressure to continue treatment**

The couples stopped the treatment in between or discontinued treatment from a specific centre for a short while due to various reasons. During this phase there was again pressure to continue treatment.

*“We went there (hospital) for almost one year and when it was not getting okay then we stopped. Relatives and other people will be asking why are you waiting again go somewhere, what is the use in staying like this go so when they compel, we will go for treatment again.”* (Rani, 42 years, Unexplained infertility)

### **6.2.9 Discontinuing/Stopping the treatment**

There were external and internal factors that resulted in the discontinuation of the treatment. The external factors included lack of trust in the treating doctor, and treating facility, unacceptability of specific procedures, and financial constraints.

*“In xxx hospital Dr.S, the doctor is good but we were not able to cope with their ways, doctor is consulting but all the information is shared by the nurses to the patient. But doctor should be telling everything to us right? May be because they don't have time that's why. It was different from all the places we have gone to. All other facilities are there but we couldn't cope with it. Tests were all done.”* (Rani, 42 years, Unexplained infertility)

*“Interviewer: Why did you discontinue treatment in Ernakulam?”*

*Respondent: I already said this isn't, to go and come it was difficult since it will cost more. There are 3 doctors for each it is 500 rupees, so if we see one doctor we have to pay Rs500 and then to go to another room we have to go down and pay again Rs500 so one day if we have to see 3 doctors 1500 rupees will get over like that. Then medicines and all[...]*” (Rekha, 26 years, PCOD)

The treatment was also discontinued when the treating doctor was unsure of further management and reiterated this to the patients. In certain cases the doctor asked the patient to stop treatment as there were no further treatments available for them.

*“If at least one sperm was there we could have done something, the doctor said to us, but all the sperms are ‘dead’.”* ( Alice, 38 years, Husband having azoospermia)

*“Then when we went again doctor told it is not possible, we do not have egg (ovum).”*  
(Mini, 48 years, Fibroid uterus)

*“That doctor when she saw the report and all, she told that this was enough and she was not ready to do anything more, this is only enough even if we do this is only what you get. She said that only tablets is enough. The doctor was not ready to do again anything with us. Asked us to take tablets.”* ( Rani, 42 years, Unexplained infertility)

There was also lack of trust in the procedure being carried out in certain facilities and this resulted in the discontinuation of treatment in that facility.

*“So in between time like before the next visit or so in office like one lady had twins, it happened after treatment from Dr.V, like they stayed there for 10 months there and then they had baby (laughing)... I became depressed that time. My mother was also working in Secretariat and a lady working with her was telling... see the stories, don't go and give yourself to some doctor (valla doctor aduthonnum poyi thalavechukodukkallum). She is telling me, see that girl's husband had some problem so they told him that we will tell her that your wife is having the problem and we will make her understand and something like in vitro nobody will ever know and you only will know, so they became sad. So this lady is telling me like they are holding the baby and they went and stayed there for 10 months, I became very depressed in that so from there like for some time we were like no need to go for all these things.”* (Elizabeth, 62 years, Unexplained infertility)

The change of treating doctor also caused the discontinuation of the treatment. This was due to the fear that they have to go through all the overwhelming investigations once again if another doctor was to be consulted.

*“...that madam got transferred to some other place she was a very old madam then another doctor came so my husband was not interested in showing to that new doctor so he will not come so we left it and was not taking any medicines also [...]. Madam was not well, so she stopped coming then another madam came. And then we were not interested to go since we had to do all the tests again from beginning so he said no need and so we did not go.”* (Alice, 38 years, Husband having azoospermia)

Unacceptability of certain treatment procedures like use of donor sperm also resulted in the discontinuation of treatment when these were suggested as the treatment option.

*“It is injecting other’s sperm in our uterus, like that. We have to stay there. So my husband said we don’t want. We did all the tests there.”* (Ancy, 42 years, Husband having azoospermia)

Some discontinued the treatment once all the investigations were exhausted. Financial constraint was also a major driving factor for discontinuation of treatment.

*“It used to take so much money we used to do daily wage and all the money was spend for this in hospitals and we felt fed up [she was repeatedly saying this] so much money we lost, all the money we were earning was spend. So husband told I don’t know how long I will be healthy so no need if god gives let him give if not let it be”* ( Alice, 38 years, husband having azoospermia)

The internal factors were the lack of hope, the discontinuation was triggered by the fact that there was no positive result by way of pregnancy even after rigorously following everything the doctor suggested.

*“When we went to xxx infertility clinic they told 3 lakhs when I talked to people there 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 sperm, even if they tell they will be using our sperm.”* (Husband of Mini, 52 years, fibroid uterus )

### **6.3 Discussion**

The findings here is in agreement with studies on infertility treatment seeking where multiple trajectories of care seeking was identified. The initiation of treatment seeking is driven by the recognition by the couples that there is a difficulty in getting pregnant, there is pressure from significant others and the desire to have a child. In case of infertility, recognising that one has fertility problems is the single most predictor for help-seeking (White et al. 2006a; White et al. 2006b). Once the individual or couple as a unit perceives that there is a 'fertility' problem, they identify the need for treatment, or think of other options, weighing the benefits and barriers attached to each of the options. Accordingly, the couple chose professional medical treatment, or may choose self-care or religious methods or alternate medical solutions. The type of facility is selected after deliberation with others. Women reported that they prefer to have female doctors over males as they feel more comfortable with them. The decision to initiate treatment is made jointly by the couples but the care seeking was not sustained by the couples as the number of years in treatment increased. This as reported by women was due to the husbands' unwillingness to continue the treatment.

There are different stages of treatment seeking which starts with the diagnostic work up and in this phase itself if the couples seem to be not satisfied with the process, they tend to change the place. They also reported that the diagnostic phase was distressing due to continuous testing, which affected them both physically and emotionally. They also tend to take break from treatment due to various reasons, the women also reported that such breaks were taken when their spouses backed out from treatment, or when they did not get the desired outcome.

Multiple trajectories are adopted by couples in getting the desired outcome. These trajectories of care seeking are interrupted and continued at different stages depending on a number of factors. The treatment seeking takes multiple breaks and pauses, and these offer relief to the couples and enables them to replenish their resources, the emotional and physical stress of the treatment. In some cases, the couples abandon the treatment half way through without achieving desired results. They may do this due to financial constraints, lack of adequate information, unclear results or diagnosis and/or

the unsatisfactory way they are dealt with by the health professionals (Sundby 1997). In this study it was identified that the reasons for discontinuation were both internal factors and external factors. The internal factors were lack of hope in a positive result. The external factors included lack of trust in the treating facility, financial constraints, unacceptability in certain treatment procedures and doctor's decision to stop treatment.

Alternative methods like faith-based healing, folk medicines and other systems of medicine are also tried by the couples in the process as shown in figure 6.2. This has been demonstrated in studies done elsewhere, and it was reported that the infertile couples try many or few options that are available viz., medical help, alternative medicine, adoption, and fostering to exit their state of infertility (van Balen et al. 1997). These choices are either made by the couple at different times depending on the stage they are in or they may try different options simultaneously (van Balen et al. 1997). Trying multiple options for treatment or combining treatments by the couples or women of the infertile couple is also documented (Dhont et al. 2010).

## **Chapter 7**

### **Socio-demographic profile of the couples and the factors related to infertility and its treatment**

This chapter aims to examine the inequalities in the care seeking pathways by examining the various independent factors associated with the outcome variable, described as 'pregnant/having child' status. The results of this chapter are based on the findings from the community-based survey done among 604 women in the three selected districts of Kerala viz., Thiruvananthapuram, Kottayam and Malappuram. The respondents for the community based survey were the women, who were interviewed to capture the care seeking pathway of the couples. The spouses being referred to are the husbands of these women who were interviewed.

The chapter is divided into five sections, section one presents the general profile of the respondents and their spouses across the three selected districts, section two and three explain the different factors related to infertility and its treatment viz., physiological factors and health systems factors respectively. Section four explains the outcome variable viz., pregnant or with child status. Section five examines the outcome i.e., probability of achieving pregnancy against different correlates.

#### **Section I: Profile of the respondents and their spouses across the three selected districts of Kerala**

This section includes the basic profile of the respondents and their spouses who were interviewed in the three districts. The sequence in which this findings are organised are as follows; the district wise distribution of the couples, followed by the socio-demographic characteristics of the respondents and their spouses across the three selected district viz., age of the respondents and their spouses, duration of marriage up to the time of interview, education, occupation, religion, caste, socio-economic status and the marital status of the respondents and their spouses. In this and the subsequent sections, Thiruvananthapuram will be abbreviated as TVM, Kottayam as KTYM and Malappuram as MLP.

A total of 604 women were surveyed to elicit the treatment seeking pathways. Of these, 196 (32.4%) women were interviewed in Thiruvananthapuram district, 201 (33.3%) women in Kottayam district and 207 (34.3%) in Malappuram district.

Table 7.1: Distribution of couples who had sought treatment for infertility in the selected districts of Kerala

<b>District</b>	<b>Couples %</b>
Thiruvananthapuram (TVM)	32.4
Kottayam (KTYM)	33.3
Malappuram (MLP)	34.3
Total	100.0 (604)

Of the total women interviewed, 304 (50.3%) were from rural areas and 300 (49.7%) were from urban areas. Of those from urban areas, 18 (3.0%) were from larger conglomerations called corporations, and 282 (46.7%) were from smaller urban settings that are called municipalities.

## **7.1 Socio-demographic profile of the couples**

In general, this analysis includes 604 women from three districts of Kerala. However, one of the respondents was divorced at the time of interview and therefore, details of her ex-husband have not been included in the analysis for spouses. Hence, the sample size for spouses is only 603.

### **7.1.1 Age of respondents and their spouses**

The mean age of respondents at the time of interview was 32.4 years (20-44 years) and the mean age of the spouses was 38.5 years (23-62 years).

### **7.1.2 Duration of marriage**

The duration of the marriage of couples ranged from 13 months to 348 months (29 years). It is important to note here that women with less than 12 months duration were excluded from the sample due to the inclusion criteria of married for at least 12 months.

Majority of the couples had a marriage duration more than five years and up to 10 years. In Thiruvananthapuram district 31 percent of the couples had a marriage

duration between 5-10 years, while in Kottayam it was 39 percent and 34 percent in Malappuram district. Nearly 14 percent of the couples in Malappuram were married for more than or equal to 20 years. In Thiruvananthapuram those having a marriage duration  $\geq 20$  years was seven percent and in Kottayam district it was only 3.5 percent.

Table 7.2: Percentage distribution of couples by duration of marriage in the selected districts of Kerala

Duration of marriage	Couples %			
	TVM	KTYM	MLP	Total
1-5 years	24.5	23.9	15.0	21.0
5-10 years	31.1	38.8	34.3	34.8
10-15 years	23.0	22.9	22.7	22.9
15-20 years	14.3	10.9	14.5	13.2
$\geq 20$ years	7.1	3.5	13.5	8.1
Total	100.0 (196)	100.0 (201)	100.0 (207)	100.0 (604)

### 7.1.3 Waiting time to treatment

The waiting time to treatment was calculated as the duration from marriage to the starting of treatment. It was computed by subtracting the date of marriage from the date of start of treatment. The duration ranged from one month to 182 months.

Mean waiting time for starting treatment from the date of marriage was 24.9 months and the Standard Deviation (SD) was 19.1 months. The median waiting time for starting treatment was 19 months.

A small proportion (7.0%) of the couples had initiated treatment in less than six months after the marriage, while a majority of the couples had initiated treatment at 12 months or more, while 37 percent initiated the treatment at 24 months and more. In Malappuram and Thiruvananthapuram, majority of the couples (~ 40.0%) had started treatment at  $\geq 24$  months, and this could be due to the greater number of overseas workers in these two districts (Table 7.6).

Table 7.3: Distribution of the waiting time to starting treatment among the couples with infertility in the selected districts of Kerala

Duration from date of marriage to starting treatment	Couples %			
	TVM	KTYM	MLP	Total
<6 months	5.6	7.0	6.8	6.5
6-12 months	20.4	17.4	11.6	16.4
12-24 months	28.6	44.8	33.3	35.6
24-60months	39.3	29.8	41.5	36.9
>=60 months	6.1	1.0	6.8	4.6
Total	100.0 (196)	100.0 (201)	100.0 (207)	100.0 (604)

#### 7.1.4 Education of couples

Among the respondents, nearly 40 percent had high school education, and a little more than one fourth had higher secondary education. Thirty percent of the respondents had been educated beyond diploma level. A miniscule proportion of the sample, only 3.6 percent had education up to seventh standard and two were illiterate (0.3%).

Majority of the spouses were educated up to high school (54.6%), and 16.1 percent were educated up to higher secondary level. A little less than one fifth of the spouses had education up to diploma and above. While seven were illiterate (1.2%), 10.1 percent were educated up to seventh standard. While examining the variation in educational levels across districts, Kottayam had distinctly higher levels of education, followed by Thiruvananthapuram. Malappuram had the least levels of education for both the respondents and their partners.

Table 7.4: Percentage distribution of respondents and their spouses by educational levels across selected districts of Kerala.

Education	Respondents %				Spouses %			
	TVM	KTYM	MLP	Total	TVM	KTYM	MLP	Total
Illiterate	0.0	0.5	0.5	0.3	0	0.5	2.9	1.2
Up to 7 <sup>th</sup> standard	3.6	1.5	5.8	3.6	7.7	5.5	16.9	10.1
Highschool 8 <sup>th</sup> -10 <sup>th</sup>	34.2	33.8	49.7	39.4	49.2	49.2	64.7	54.6
Higher secondary (11 <sup>th</sup> -12 <sup>th</sup> )	27.0	21.9	29.5	26.2	20.5	17.9	10.1	16.1
Diploma	5.6	10.9	3.4	6.6	6.7	9.0	1.5	5.6
Graduate	22.5	22.4	9.7	18.1	13.3	12.4	3.4	9.6
PG and above	7.1	9.0	1.4	5.8	2.6	5.5	0.5	2.8
Total	100.0 (196)	100.0 (201)	100.0 (207)	100.0 (604)	100.0 (195)	100.0 (201)	100.0 (207)	100.0 (603)

The educational levels of the couple as a unit is given in table 7.5, if the respondent and her spouse had the same level of education, then it is categorised as equal level of education. If the respondent had more education than her spouse, then it is categorised separately and if the respondent had less education than her spouse then it is grouped as a third category. This form of categorisation hopefully would indicate the joint function of education of the partners. More than 45 percent of the respondents had more education than their spouse. A little more than two-fifth of the respondents and their spouses had same education, while only 10.8 percent had lesser education than their spouse. This pattern is similar across Thiruvananthapuram and Kottayam where about 45 percent of the respondents had educational levels greater than that of their spouses while in Malappuram, this was almost 50 percent.

Table 7.5: Percentage distribution of couples by the joint educational levels across selected districts of Kerala

Education	Couples %			Total
	TVM	KTYM	MLP	
Education of respondent = Education of spouse	41.3	42.8	43.5	42.5
Education of respondent > Education of spouse	44.9	45.3	49.7	46.7
Education of respondent < Education of spouse	13.8	11.9	6.8	10.8
Total	100.0 (196)	100.0 (201)	100.0 (207)	100.0 (604)

#### 7.1.5 Occupation of respondents and their spouses

Majority of the respondents were unemployed, and if at all employed, they were either salaried/self-employed (11.6%) or unskilled daily wage labourers (2.0%). While a little more than 50 percent of the spouses were unskilled daily wage earners (54.6%), less than one fourth of the spouses were either salaried employees or self-employed. Overseas workers contributed to 12.8 percent of the total among the spouses, which is about one in eight of the spouses.

Table 7.6: Percentage distribution of respondents and their spouses by occupation in selected districts of Kerala

Occupation	Respondents %				Spouses %			
	TVM	KTYM	MLP	Total	TVM	KTYM	MLP	Total
No job/ Unemployed	83.7	77.6	89.9	83.8	1.5	1.5	3.9	2.3
Unskilled- daily wage	2.0	2.0	1.9	2.0	46.2	56.7	60.4	54.6
Skilled- Daily wage	1.0	1.5	0.5	0.9	5.6	2.0	0.9	2.8
Salaried or self- employed	11.3	16.4	7.2	11.6	19.0	33.3	15.5	22.5
Government	2.1	2.5	0.5	1.7	7.7	5.5	1.9	5.0
Overseas	-	-	-	-	20.0	1.0	17.4	12.8
Total	100.0 (196)	100.0 (201)	100.0 (207)	100.0 (604)	100.0 (195)	100.0 (201)	100.0 (207)	100.0 (603)

Viewing the joint employment status of the couple is relevant to determining their financial ability and time availability for care seeking. Employment status of the couple was categorised into four groups, both employed, both not employed, respondent employed but spouse not employed, respondent not employed but spouse employed. More than 80 of the respondents were not employed while their spouses were. This proportion was highest in Malappuram (86.4%), followed by Thiruvananthapuram (83.2%) and Kottayam (76.6%). Both the respondent and spouse were employed for 15.4 percent of those in the sample. Kottayam district has the highest proportion (~22.0%) of both employed, while in Thiruvananthapuram around 14.8 percent of the couples were employed and Malappuram has the least (9.7%) among the three districts. Only a very small proportion had both not employed (1.7%) or with respondent employed while the spouse was not employed (0.8%).

Table 7.7: Percentage distribution of couples by the joint occupational status across selected districts of Kerala

Employment status of the couple	Couples %			
	TVM	KTYM	MLP	Total
Both not employed	0.5	1.0	3.4	1.7
Respondent not employed but spouse employed	83.2	76.6	86.4	82.1
Respondent employed but spouse not employed	1.5	0.5	0.5	0.8
Both employed	14.8	21.9	9.7	15.4
Total	100.0 (196)	100.0 (201)	100.0 (207)	100.0 (604)

#### 7.1.6 Religion of respondents and their spouses

Approximately 50 percent of the respondents were Hindus (49.3%), while 33.6 percent were Muslims and less than one fifth were Christians (17.1%). The highest percentage of Hindus were from Thiruvananthapuram district, Muslims constituted the highest percentage in Malappuram and Christians dominated in Kottayam district.

Table 7.8: Percentage distribution of respondents and their spouses by religion in selected districts of Kerala

Religion	Respondents %				Spouses %			
	TVM	KTYM	MLP	Total	TVM	KTYM	MLP	Total
Hindu	59.2	55.2	34.3	49.3	58.5	55.7	34.3	49.2
Muslim	24.0	11.0	64.7	33.6	24.4	10.8	64.7	33.7
Christian	16.8	33.8	1.0	17.1	17.1	33.5	1.0	17.1
Total	100.0 (196)	100.0 (201)	100.0 (207)	100.0 (604)	100.0 (195)	100.0 (201)	100.0 (207)	100.0 (603)

#### 7.1.7 Caste of respondents and their spouses

Majority of the respondents and their spouses belonged to other backward caste category. The percentage of respondents belonging to Scheduled Caste (SC) category and general category were more or less the same. Nearly one percent of the respondents and their spouses belonged to scheduled tribes. The percentage of

scheduled tribe respondents/spouses was higher in Kottayam district when compared to Thiruvananthapuram or Malappuram districts.

Table 7.9: Percentage distribution of respondents and their spouses by caste in selected districts of Kerala

Caste	Respondents %				Spouses %			
	TVM	KTYM	MLP	Total	TVM	KTYM	MLP	Total
General	15.3	30.4	1.9	15.7	14.9	29.9	1.9	15.4
OBC	69.9	53.7	83.6	69.2	69.7	53.2	83.6	69.0
SC	14.8	12.9	14.5	14.1	15.4	13.4	14.5	14.4
ST	0.0	3.0	0.0	1.0	0.0	3.5	0.0	1.2
Total	100.0 (196)	100.0 (201)	100.0 (207)	100.0 (604)	100.0 (195)	100.0 (201)	100.0 (207)	100.0 (603)

#### 7.1.8 Socio-economic status of couples

The socio-economic status was captured using a set of eight variables viz., house ownership, house having air conditioner (AC), car ownership, flooring of the house, roofing of the house, cooking fuel, compound wall and gate. The house ownership had four categories (rented=0, owned by husband and others=1, joint ownership=2, self-ownership=3), flooring of the house (mud/clay/sand or cement=0, tiles=1, marble/granite/wood=2) and roofing of the house (thatched/plastic=0, tiles=1, concrete=2) had three categories. House having AC, car ownership, compound wall and gate had two categories each (no=0, yes=1). Cooking fuel also had two categories (wood=0, electricity/LPG, biogas=1). These categories are hierarchically arranged so that the higher value indicates a better status.

The socio-economic score was calculated by adding the score for all the eight items for each individual. The theoretical score ranged from 0-12. The observed score ranged from 0-10. The score was categorised as low SES [0-3), middle SES [3-6), upper middle SES [6-9), high SES [9,10].

Majority of the couples were in the middle SES across all the three districts. The percentage of couples in the low SES category was highest in Kottayam, while all the three districts had almost equal proportions (~6.0%) belonging to high SES. The

percentage belonging to middle SES and upper middle SES was highest in Malappuram, and Thiruvananthapuram respectively.

In Thiruvananthapuram district, a little more than fifty percent belonged to middle SES category, while in Malappuram it was almost 62 percent and in Kottayam only 46.3 percent were in middle SES category. In Thiruvananthapuram while 31 percent were in upper middle SES, a little more than half of that percent belonged to upper middle SES in Kottayam and Malappuram (~16-17%). In Kottayam district the low SES category was 30.8 percent while in Malappuram it was 15.9 percent and 12.3 percent belonged to low SES in Thiruvananthapuram.

Table 7.10: Percentage distribution of couples by socio-economic status in the selected districts of Kerala

SES	Couples %			
	TVM	KTYM	MLP	Total
Low	12.3	30.8	15.9	19.7
Middle	51.5	46.3	61.9	53.3
Upper middle	30.6	16.9	16.4	21.2
High	5.6	6.0	5.8	5.8
Total	100.0 (196)	100.0 (201)	100.0 (207)	100.0 (604)

### 7.1.9 Marital status of respondents and their spouses

More than 95 percent of the respondents had been married only once (96.9%) at the time of interview. However, a slightly lesser percentage of the spouses had been married only once (93.4%). Slightly more than twice the percentage of spouses had been married more than once when compared to the respondents (6.6% vs 3.1%). Out of 40 spouses who had been married two or more times at the time of interview, 39 of them had second marriage and one had third marriage at the time of interview.

Table 7.11: Percentage distribution of respondents and their spouses by marital status at the time of interview in the selected districts of Kerala

Marital status at the time of interview	Respondents %				Spouses %			
	TVM	KTYM	MLP	Total	TVM	KTYM	MLP	Total
First marriage	98.0	97.5	95.2	96.9	95.4	98.0	87.0	93.4
Second marriage/more	2.0	2.5	4.8	3.1	4.6	2.0	13.0	6.6
Total	100.0 (196)	100.0 (201)	100.0 (207)	100.0 (604)	100.0 (196)	100.0 (201)	100.0 (207)	100.0 (604)

Malappuram district had a higher proportion of spouses having been married two or more times when compared to the respondents. Here, when compared to the respondents, twice the percentage of spouses had been married more than once (13.0% vs 4.8%). This pattern is repeated in Thiruvananthapuram district with 9 (4.6%) of the spouses being married more than once when compared to the respondents (2.0%). It was Kottayam that a higher percentage of respondents (2.5%) who had been married more than once when compared to the spouses (2.0%).

## Section II: Physiological factors related to infertility and its treatment

In this section, the physiological factors related to infertility and its treatment are examined. This includes the age of the respondent at the start of treatment and at pregnancy, family history of infertility, type of infertility diagnosed in the couples, and the history of reproductive impairment in the women prior to marriage.

### 7.2 Age at start of the treatment

The age of the respondents at the time of starting treatment was calculated using the current age, date of interview and the start date of treatment. The exact method of computation of the age is described in the appendix A18. The ages of the respondents at the time of starting treatment ranged from 14 years to 41 years. Mean age of the respondents at the time of starting treatment was 24.6 years, with a SD of 4.6 years. The median age of the respondents at the start of the treatment was 24 years.

Table 7.12: Percentage distribution of the age of respondents at the time of starting the treatment in the selected districts of Kerala

<b>Age of the respondent at the time of starting treatment</b>	<b>Respondents %</b>
<20 years	10.6
20-25 years	43.7
25-30 years	30.3
30-35 years	12.3
>=35 years	3.1
Total	100.0 (604)

### **7.3 Age of respondent at pregnancy**

Age at the time of pregnancy was computed based on the available information on age of the respondent at the time of interview, date of interview, date of starting the treatment for each respondent and the total duration of treatment for infertility till pregnancy. The exact method of computation of the age is described in the appendix A19.

The age of the respondents at the time of pregnancy ranged from 17 years to 42 years, with the mean age at pregnancy of 27.7 years. The median age at pregnancy was 27 years.

### **7.4 Family history of infertility**

The family history of infertility was elicited using details of siblings of the respondent or the spouse who were childless at the time of interview after at least one year of marriage and/or if they had history of treatment sought for infertility. Among the respondents 257 reported siblings without child or with history of infertility treatment or both and among the spouses of the respondents, 314 had siblings without child or with history of infertility treatment or both. Slightly more than one out of ten of the women (11.9%) reported that they had siblings with infertility problems and 102 (16.9%) reported that their siblings had a history of seeking treatment for infertility. The extent of childlessness after one year of marriage amongst spouses' siblings was 13.7 percent (83 persons) and about one fifth of the spouses' siblings (20.5%) had a history of seeking treatment for infertility. The respondents who had a sibling with

either childlessness or history of treatment was 13.7 percent, and that of the spouse was 17.7 percent.

Table 7.13: Percentage distribution of respondents and their spouses' family history of infertility, Kerala

<b>Family history of infertility</b>	<b>Respondents # %</b>	<b>Spouses# %</b>
Siblings without child after at least one year of marriage	11.9	13.7
Siblings with history of infertility treatment	16.9	20.5
Siblings without child or history of treatment	13.7	17.7
Total	100.0 (604)	100.0 (604)

<sup>#</sup> This computation includes those who could not report on the status of siblings and therefore the column percentages will not add to 100.

Of those respondents who reported that their siblings were childless, a little more than half of the siblings were sisters (52.8%) and one fourth were brothers (23.6%). Two of them reported that both brother and sister did not have a child, and the rest reported that their siblings were not having children, their spouses were reported to have fertility impairing conditions. Those who reported that their spouses' siblings did not have a child, more than half reported that the spouse's brother was the one not having a child (56.7%), while 30.1% reported it was the sister of the spouse who did not have a child. Seven out of them reported that both the brother and sister of the spouse did not have children. Four reported that their spouse's siblings did not have children but the condition impairing infertility was that of their spouses'.

Table 7.14: Percentage distribution of the nature of sibling relationship indicative of family history of infertility for respondents and their spouses, Kerala

<b>Relation of the sibling</b>	<b>Respondents %</b>	<b>Spouses %</b>
Sister	52.8	30.1
Brother	23.6	56.7
Both sister and brother	2.8	8.4
Sister has no child, but reproductive impairment for brother in law	8.3	1.2
Brother has no child, but reproductive impairment for sister in law	8.3	3.6
Both the siblings do not have child but their spouses have reproductive impairment	4.2	0.0
Total	100.0 (72)	100.0 (83)

A person is said to have a family history of infertility if either the respondent or their partner has a sibling with infertility or history of treatment taken for infertility. Majority of the respondents and their spouses did not have a family history of infertility, while 17.7 percent of the spouses had a history of infertility, 13.5 percent of the respondents themselves had family history of infertility.

Table 7.15: Percentage distribution of couples by the potential source of family history of infertility, Kerala

<b>Family history of infertility for</b>	<b>Couples %</b>
Respondent	13.7
Spouse	17.7
Both	5.8
None	62.8
Total	100.0 (604)

### 7.5 Diagnosis of infertility

The type of infertility causing difficulty in pregnancy was identified by asking the respondent to report on the reason for infertility. Most of this was through self-reports and in some cases confirmed with the medical reports. Male factor infertility alone contributed to 35.4 percent of the cases. One fourth of them was due to female factor only (26.7%). Both male and female factor contributed to 13.2 percent of the infertility

among the couples. One fifth of them reported unexplained infertility and 4.5 percent reported they were not yet diagnosed at the time of interview.

Table 7.16: Percentage distribution of couples by type of infertility, Kerala

Type of infertility	Couples %
Male factor	35.4
Female factor	26.7
Both male and female factor	13.2
Unexplained	20.2
Others, not diagnosed	4.5
Total	100.0 (604)

Among those with male infertility, oligospermia was the major complaint that was reported by the participants, followed by azoospermia (not shown in table). With respect to female factor infertility, PCOD was reported to be the major contributor followed by endocrine problems and tubal factors.

### **7.6 Women's history of reproduction impairing conditions prior to marriage**

Approximately one fourth (23.3%) of the women reported that they had some form of reproductive problem prior to marriage, while 76.7 percent reported they did not have any reproductive problems prior to marriage. Among those who reported problems, 3 (2.1%) each reported had dysmenorrhea (painful menstrual bleeding) or menorrhagia (heavy menstrual bleeding). Thyroid related problems were reported by 9 (6.4%) respondents while thyroid with irregular menstrual cycle was reported by 2 (1.4%). Irregular menstrual cycle alone was reported by 120 out of 141 women (85.2%) who reported having reproduction impairing conditions prior to marriage. One of them reported late menarche and the menstrual cycle for her was induced by medicines, one reported having uterine fibroids or cyst and two reported having PCOD.

Table 7.17: Percentage distribution of respondents who reported reproductive problems before marriage by type of problem, Kerala

<b>Reproductive problem affecting fertility prior to marriage</b>	<b>Respondents %</b>
Dysmenorrhea	2.1
Menorrhagia	2.1
Thyroid	6.4
Irregular menstrual cycle	85.2
Thyroid and Irregular cycle	1.4
Late menarche-induced with medicines	0.7
Uterine fibroids or cysts	0.7
PCOD	1.4
Total	100.0 (141)

### **Section III: Health system factors related to infertility and its treatment**

In this section the health system factors are examined vis-à-vis infertility and its treatment. It includes the number and the types of centres visited by the couples during their entire treatment duration, the current status of the treatment of those who reported not having a child/pregnant at the time of interview and the type of treatment used by those who reported having a child/pregnant at the time of interview to achieve this status. This gives a summary of the care seeking of couples and the various type of methods employed by them to resolve infertility. It helps in further identifying the health system factors responsible for seeking care, and achieving the outcomes and also explains what were the factors hindering the achievement of the outcome.

#### **7.7 Number of centres visited during the entire treatment duration**

The total number of centres visited by the respondents is given in table 7.18. Nearly 80 percent of them had visited at least two centres, and 60 percent visited at least three centres. At least four centres were visited by two fifth of the respondents and less than one fourth visited at least five centres. Just about 81 out of the 604 (13.4%) visited at least 6 centres or more for infertility care.

Table 7.18: Percentage distribution of couples by the least number of centres visited during the treatment duration, Kerala

<b>Number of centres visited</b>	<b>Couples %</b>
At least 1	604 (100.0)
At least 2	493 (81.6)
At least 3	366 (60.6)
At least 4	249 (41.2)
At least 5	143 (23.7)
At least 6	81 (13.4)
At least 7	45 (7.5)
At least 8	22 (3.6)
At least 9	8 (1.3)
At least 10	5 (0.8)
At least 11	1 (0.2)

### **7.8 Type of centres visited during the treatment period**

The respondents reported the various types of centres they had visited for seeking care for infertility. Allopathy, Ayurveda, Homeopathy, alternative methods like folk medicines, faith-based approaches for resolving infertility had been used by way of treatment. Majority of the respondents had used only allopathy (53.0%). An equal proportion (13.7%) of them had combined Ayurveda or Homeopathy with the Allopathy treatment. Four of them used only Ayurveda and one used only Homeopathy, while one respondent used both Homeopathy and Ayurveda for treatment. All three of these were used by 7.5 percent of the respondents during their treatment for infertility.

For purposes of this analysis, ‘alternate methods’ included Unani (here not the other system of medicine but unqualified healers practicing under that label), ‘ayurvedic’ powders supplied by different not appropriately qualified persons, traditional or folk medicines, temple rituals and faith-based approaches for resolving infertility. Most of these were used in combination with more formal forms of medicine to treat infertility.

‘Alternate methods’ were used along with Allopathy by 7.5 percent of the participants. Allopathy, Homeopathy and alternate methods was used by 2.5 percent of the participants, while Allopathy, Ayurveda and alternate methods was tried by four couples. Two of the couples had used all of these viz., Allopathy, Ayurveda, Homeopathy and alternate methods.

Table 7.19: Percentage distribution of couples by the type and combination of centres used for resolving infertility, Kerala

Type of centre used for treatment	Couples %
Allopathy only	53.0
Ayurveda only	0.7
Homeopathy only	0.2
Allopathy and Ayurveda	13.7
Allopathy and Homeopathy	13.7
Allopathy, Ayurveda and Homeopathy	7.5
Homeopathy and Ayurveda	0.2
Allopathy, Homeopathy and Alternate methods	2.5
Allopathy and Alternate methods	7.5
Allopathy, Ayurveda and Alternate methods	0.7
Allopathy, Ayurveda, Homeopathy and Alternate methods	0.3
Total	100.0 (604)

### 7.9 Treatment status at the time of interview

Those respondents who reported not having a child or being pregnant at the time of interview were asked about their current status of treatment. There were 457 couples who did not have a child at the time of interview and were in different stages of the treatment trajectory. Out of these 457 respondents, 35.9 percent were continuing treatment and 36.8 percent were taking a break from treatment. Nearly one-fourth of them (24.1%) reported they had stopped all the treatment, while 2.6 percent said they were not taking treatment since their treating doctor had asked them to wait. One of them reported that their spouse was unwilling to continue the treatment and two reported they were trying religious approaches and hence were not on modern medicine treatment at the time of interview.

Table 7.20: Percentage distribution of couples who had no children and were not pregnant at the time of interview by treatment status, Kerala

<b>Treatment status</b>	<b>Couples %</b>
Break from treatment	36.8
Continuing treatment	35.9
Stopped treatment	24.1
Currently no treatment since doctor asked to wait	2.6
Partner unwilling to continue treatment	0.2
Faith based approaches to resolving infertility	0.4
Total	100.0 (457)

### 7.10 Treatment through which pregnancy was achieved

In all, 147 out of the 604 couples achieved pregnancy through the various treatments or other means. Nearly fifty percent of couples conceived normally after ovulation induction for the women or treatment for the spouse. One fourth of the pregnancies happened when the respondent or spouse had stopped taking medicines either by way of completely abandoning the treatment or while taking a break between treatment episodes. Assisted reproduction helped 15.6 percent of the respondents to achieve pregnancy either via IUI, Artificial Insemination with Donor Sperm (AID), or IVF/ICSI. A small proportion (8.8%) also reported they got pregnant via other forms of treatment.

Table 7.21: Percentage distribution of the couples who achieved pregnancy status by means through which it was achieved, Kerala

<b>Treatment through which the child was born</b>	<b>Couples %</b>
After stopping all treatment, including during the break	25.9
Normally conceived after OI, partner undergoing treatment	49.7
ART- IUI, AID, IVF/ICSI	15.6*
while on other treatment including Ayurveda, Homeopathy or alternate methods	8.8
Total	100.0 (147)

\*15(65.2%) couples achieved pregnancy via IUI and 8(34.8%) achieved pregnancy via IVF

#### **Section IV: Outcome variable - achieving pregnancy**

The outcome variable for the study was defined as the achievement of pregnancy by the respondents. At the time of interview, 147 (24.3%) were either pregnant or were having a child and 457 (75.7%) were not pregnant or not having a child.

The district wise pregnancy status/with child status at the time of interview is given in table 7.22. In Malappuram district more than 80 percent did not have child or were not pregnant at the time of interview, while in Kottayam and Thiruvananthapuram districts the proportion who did not have a child or were pregnant was approximately 71 percent. Kottayam district and Thiruvananthapuram district had nearly 29 percent of the couples who had achieved pregnancy or were with child at the time of interview. The percentage of couples who achieved pregnancy or with child status in Malappuram was about half of that of couples in the other two districts.

Table 7.22: Percentage distribution of couples who achieved pregnancy or with child status by districts, Kerala

<b>Achieved pregnancy or with child status</b>	<b>Couples %</b>			<b>Total</b>
	<b>TVM</b>	<b>KTYM</b>	<b>MLP</b>	
Yes	28.1	29.4	15.9	24.3
No	71.9	70.6	84.1	75.7
Total	100.0 (196)	100.0 (201)	100.0 (207)	100.0 (604)

#### **Section V: Pregnancy status and characteristics of couples**

The proportion of women who got pregnant by their characteristics will be explained under three different categories, viz., with the socio-demographic factors, physiological factors, and the health system factors.

##### **7.11 Association of pregnancy status and socio-demographic characteristics**

The proportion who got pregnant with the duration of the marriage, education of the couple, employment status of the couple, religion of the couple and the SES of the couple is explained in this section. Chi-square tests were done for examining associations, if any between the selected socio-demographic variables and the outcome i.e., achieving pregnancy.

### 7.11.1 Duration of marriage

The proportion who got pregnant was high among those who had a marriage duration of 10 to 15 years. When the duration of marriage was less than five years, the proportion getting pregnant was 16 percent while this proportion increased to 27 percent as the duration of marriage increased to 5 -10 years. The maximum proportion who got pregnant was observed in the marriage duration between 10 to 15 years (31.0%). As the duration increases to more than 15 years, there is a decline in the proportion who get pregnant. This proportion declines further when the duration of marriage is more than 20 years.

Table 7.23: Proportion of couples who got pregnant /with child status by duration of marriage, Kerala

Duration of marriage (in years)	Total Couples		Couples having child/ pregnant		Proportion of couples who got pregnant	p value
	Frequency	%	Frequency	%		
1-5 years	143	23.7	24	16.3	0.16	0.06
5- 10 years	207	34.3	56	38.1	0.27	
10- 15 years	136	22.5	42	28.6	0.31	
15-20 years	78	12.9	17	11.6	0.22	
20+ years	40	6.6)	8	5.4	0.20	
Total	604	100.0	147	100.0	0.24	

### 7.11.2 Education of couples

The proportion who got pregnant was slightly higher when the education of the respondent was higher than the education of the spouse. The proportion who got pregnant was almost same when both the respondent and spouse had same level of education or when the education of the spouse was more than the respondent. No significant association was found between the education of the couple and the achievement of pregnancy.

Table 7.24: Proportion of couples who got pregnant /with child status by the joint education status of couples, Kerala

Education of the couple	Total Couples		Couples having child/ pregnant		Proportion of couples who got pregnant	p value
	Frequency	%	Frequency	%		
Education of respondent= Education of spouse	257	42.5	58	39.5	0.23	0.47
Education of respondent> Education of spouse	282	46.7	75	51.0	0.27	
Education of respondent< Education of spouse	65	10.8	14	9.5	0.22	
Total	604	100.0	147	100.0	0.24	

### 7.11.3 Employment status of couples

The proportion of couples who got pregnant was observed to be higher when the respondent was not employed but spouse was employed. This proportion was lower when both were employed compared to when both were not employed. But the number of couples in the both not employed category is very less and hence the high proportion may not be truly reflective of the actual association.

Table 7.25: Proportion of couples who got pregnant /with child status by joint occupational status of couples, Kerala

Employment status of the couple	Total Couples		Couples having child/pregnant		Proportion of couples who got pregnant	p value <sup>#</sup>
	Frequency	%	Frequency	%		
Both not employed	10	1.7	3	2.0	0.3	0.01
Respondent not employed but spouse employed	496	82.1	126	85.7	0.25	
Respondent employed but spouse not employed	5	0.8	0	0.0	0	
Both employed	93	15.4	18	12.0	0.19	
Total	604	100.0	147	100.0	0.24	

<sup>#</sup>chi square test was done for three groups by merging two and three to form either of them employed

#### 7.11.4 Religion of couples

Couples who belonged to the Muslim religious persuasion had a relatively lower proportion who got pregnant compared to those belonging to other religious persuasions viz., Hinduism and Christianity. There was no association with religion and achieving pregnancy among the couples who had used infertility treatments.

Table 7.26: Proportion of couples who got pregnant /with child status by religion of couples, Kerala

Religion of the couple	Total Couples		Couples having child/pregnant		Proportion of couples who got pregnant	p value
	Frequency	%	Frequency	%		
Hindu	298	49.3	76	51.7	0.26	0.12
Muslim	203	33.6	40	27.2	0.20	
Christian	103	17.1	31	21.1	0.30	
Total	604	100.0	147	100.0	0.24	

### 7.11.5 Socioeconomic status of couples

The proportion of couples who got pregnant or with child status was higher among the upper middle SES group compared to other groups and the lowest among the middle SES group. Socio-economic status was found to be significantly associated with achieving pregnancy.

Table 7.27: Proportion of couples who got pregnant /with child status by socio-economic status of the couples, Kerala

SES status (SES score)	Total Couples		Couples having child/pregnant		Proportion of couples who got pregnant	p value
	Frequency	%	Frequency	%		
Low (0-3)	119	19.7	28	19.1	0.24	0.01
Middle (3-6)	322	53.3	66	44.9	0.20	
Upper middle (6-9)	128	21.2	45	30.6	0.35	
High ( $\geq 9$ )	35	5.8	8	5.4	0.23	
Total	604	100.0	147	100.0	0.24	

### 7.12 Association of pregnancy status and selected physiological characteristics

Among all the physiological characteristics, family history of infertility, and type of infertility experienced by the couple were examined for associations with achieving pregnancy status.

#### 7.12.1 Age at start of treatment

The proportion of women who achieved pregnancy was high among those who started treatment before 30 years of age. This proportion decreased as the age of initiating treatment increased above 30 years. The age of initiating treatment was found to be significantly associated with achieving pregnancy.

Table 7.28: Proportion of couples who got pregnant /with child status by age at start of treatment of the respondents, Kerala

Age of the respondent at the time of starting treatment	Total respondents		Couples having child/pregnant		Proportion of couples who got pregnant	p value <sup>#</sup>
	Frequency	%	Frequency	%		
<20 years	64	10.6	21	14.3	0.33	0.04
20-25 years	264	43.7	57	38.8	0.26	
25-30 years	183	30.3	53	36.1	0.29	
30-35 years	74	12.3	13	8.8	0.18	
>=35 years	19	3.1	3	2.0	0.16	
Total	604	100.0	147	100.0	0.24	

<sup>#</sup> chi-square test done for four categories of age of the respondents at the start of the treatment by combining 30-35 years and >=35 as >=30 years

### 7.12.2 Family history of infertility

The proportion of couples who got pregnant or with child status was low if both the respondent and their spouse had a family history of infertility. The proportion achieving pregnancy was almost the same if the spouse alone had a family history or no one had any family history of infertility. The proportion who achieved pregnancy or with child status was relatively higher when the respondent alone had any family history of infertility.

Table 7.29: Proportion of couples who got pregnant /with child status by family history of infertility of the couples, Kerala

Family history of infertility for:	Total Couples		Couples having child/pregnant		Proportion of couples who got pregnant	p value <sup>#</sup>
	Frequency	%	Frequency	%		
Woman	83	13.7	25	17.0	0.30	0.80
Spouse	107	17.7	25	17.0	0.23	
Both	35	5.8	3	2.0	0.09	
None	379	62.8	94	64.0	0.25	
Total	604	100.0	147	100.0	0.24	

<sup>#</sup> chi-square test done for two categories, family history of infertility and no family history for infertility

### 7.12.3 Type of infertility experienced by couples

The proportion who got pregnant was high when the infertility was reported to be due to female factor and it was lowest when the contributing factor for infertility was reported as both male and female factor infertility. Male factor alone also had a lower probability of achieving pregnancy when compared to others. The type of infertility experienced by the couple was significantly associated with achieving pregnant status.

Table 7.30: Proportion of couples who got pregnant /with child status by the type of infertility experienced by the couples, Kerala

Diagnosis	Total Couples		Couples having child/pregnant		Proportion of couples who got pregnant	p value
	Frequency	%	Frequency	%		
Male factor	214	35.4	45	30.6	0.21	0.03
Female factor	161	26.7	53	36.1	0.33	
Both	80	13.2	15	10.2	0.19	
Unexplained	149	24.7	34	23.1	0.23	
Total	604	100.0	147	100.0	0.24	

### 7.13 Association of pregnancy status with health system factors

The health system factors viz., type of centre used by the couples was examined for associations if any, with achieving pregnancy.

#### 7.13.1 Type of centres

The type of centre was divided into only Allopathy and Allopathy along with other treatments or other treatments alone. The proportion of couples who got pregnant or with child status was higher if they used allopathy compared to those who have used other methods alone or in combination with allopathy. There was significant association between the type of centre used by the couple and the outcome.

Table 7.31: Proportion of couples who got pregnant /with child status by type of centres used by the couple, Kerala

Type of centres	Total Couples		Couples having child/pregnant		Proportion of couples who got pregnant	p value
	Frequency	%	Frequency	%		
Allopathy Only	321	53.1	93	63.3	0.29	0.01
Others only or with Allopathy	283	46.9	54	36.7	0.19	
Total	604	100.0	147	100.0	0.24	

#### 7.14 Discussion

The mean age of the respondents was 32 years in the sample and that of their spouses was 39 years. Majority of the women in the sample had marriage duration between 5-10 years. The longer marriage duration ( $\geq 20$  years) was highest among couples in Malappuram district, which could be due to the early marriage in this community while shorter marriage duration (1-5 years) was highest in Kottayam district. The time taken to start care seeking between 1-2 years of marriage was highest in Kottayam district which could be due to the late age at marriage in this district and hence the urgency to seek care. But care seeking initiated between 2-5 years and after 5 years of marriage was high in Malappuram when compared to other districts, and this could be due to the migrant status of men in this district. Majority of the respondents were either equally educated or more educated than their spouses in the sample. The level of literacy is comparable with the literacy levels of the three districts in 2011 where in the female literacy rates were 90.89 percent, 95.67 percent and 91.55 percent for Thiruvananthapuram, Kottayam and Malappuram respectively (Census of India 2011a).

In the sample, majority of the respondents were not employed while their spouses were. This proportion was lowest in Kottayam district while Thiruvananthapuram and Malappuram had almost equal proportion of respondents not employed while their spouses were. Kottayam district also had higher proportion of both respondents and their spouses employed. The patterns are similar to the proportion of female workers

among those aged 15-59 (including main and marginal workers). In Thiruvananthapuram, Kottayam and Malappuram the proportion of female workers among those aged 15-59 were 28.1 percent, 29.7 percent and 11.3 percent respectively according to the Census 2011 (Census of India 2011b). The fact that more women were not employed means that they were in a better position (with respect to time) to seek treatment as wage loss would not be an issue for them, but it would be for the spouses who were more likely to be employed.

Most of the respondents in the sample belonged to Hindu religion. While comparing the religious distribution of the respondents with that of the district using the Census of 2011, we find that the percentage of Hindus is lesser in the sample (58.8%) when compared to 66.5 percent for Thiruvananthapuram district. Proportionately, the proportion of Muslims is higher in the sample, when compared to the distribution of Muslims in the district (24.2% vs 23.7%). A similar higher representation of Muslims in the sample from Kottayam is also noticed (10.8% in the sample vs.6.4% in the district). The Malappuram sample, on the other hand indicates a higher proportion of Hindus than found in the population in the district (34.3% vs 27.6%) (Census of India 2011c).

When compared to the Census figures for the districts, the sample had a higher percentage of representation of the ST group for Kottayam where the ST group represents merely 1.1 percent of the population. In Thiruvananthapuram and Malappuram, the sample did not identify any persons from the ST category. In these two districts Kottayam and Thiruvananthapuram, the percentage of ST population was 0.6 percent and 0.8 percent respectively (Census of India 2011d).

In the sample, there was a higher proportion of couples who reported having male infertility compared to female infertility. The proportion of male infertility was slightly higher than the range of estimated distribution of it in the overall cause of infertility (35.4% vs 20.0-30.0%) (Hamilton 2012; Hoffman et al. 2012; Vander Borgh & Wyns 2018). This could be due to the overestimation of male infertility, possibly due to testing done in private labs. The proportion of infertility due to female factor causes was within the range of estimated distribution of it in the overall cause of infertility

(26.7% vs 20.0-35.0%) (Hamilton 2012; Hoffman et al. 2012). Infertility due to problems in both partners was less than the range of estimated distribution of it in the overall cause of infertility (13.2% vs 25-40.0%) (ESHRE 2020). Infertility due to unexplained causes was almost similar to the estimated distribution of it in the overall cause of infertility (20.2% vs 10.0-20.0%) (ESHRE 2020; Hoffman et al. 2012).

Multiple centres were negotiated by couples for infertility care in the study, and this use of multiple centres for infertility treatment has been demonstrated in a study done in Kerala. The same study also reported using multiple systems of medicine and alternate methods for infertility treatment. Allopathy was used as the first point of care in the study and this was also reported in the same study (Ravi 2017).

At the time of interview, nearly one fourth of the couples had achieved the desired outcome. Among those who did not have a child at the time of interview, almost equal proportion were on break from treatment or were continuing treatment for infertility. Among those who had a child, half of them achieved it via normal conception following ovulation induction or treatment of their partner.

The proportion who achieved pregnancy was high among those couples who initiated treatment within 10-15 years of marriage. The possible explanation could be the migrant status of the husbands in the earlier periods of marriage. In the study, nearly 30 percent of the spouses were working/ had worked overseas. Out of this, 12 percent of the spouses were working overseas at the time of the study and 20 percent reported that their spouse had history of working overseas during the earlier period of marriage. Education, employment status and religion of the couples were not significantly associated with the outcome i.e., achieving pregnancy, while socio-economic status was found to be significantly associated with achieving pregnancy. Given that the private sector care is more frequently sought, this association is not surprising.

Among physiological factors, age at start of treatment and type of infertility were significantly associated with achieving outcome. This age at start of treatment could also be a outcome of the migrant status of the husbands, where those who started treatment at 25-30 years had higher proportion who got pregnant.

Type of centre used by the couples was also found to be significantly associated with achieving the outcome. Those who combined the different systems of medicines had a lower proportion achieving pregnancy compared to those who used allopathy alone. This could mean that those requiring assisted conception may be using other systems of medicine which may be causing the delay in achieving pregnancy. It was seen in the study that that 32 (5.3%) couples were suggested IUI and 128 (21.2%) were suggested IVF. Two fifths of those suggested IUI (40.6%) and more than three fifths of those suggested IVF (62.5%) did not pursue it as they did not want to take up those treatment options. The unwillingness or inability of the couples to take up the optimal option for resolving infertility could be due to the stigma associated with use of donor sperms or due to lack of resources as mentioned in chapters 9, or other un-identified reasons.

## **Chapter 8**

### **Care seeking pathways for infertility in the three selected districts of Kerala**

This chapter address the objective to describe the care seeking pathway for infertility of couples with infertility in Kerala. It describes the care seeking pathway for infertility among couples who actively seek/sought care in the three selected districts of Kerala. These findings are based on the community based survey done among 604 women who have history of care seeking for infertility. The care seeking pathway for couples includes multiple centres for infertility care. For convenience we propose to refer to the centre and its level using the abbreviation C followed by the Arabic numeral to indicate the level, thus referring to the sixth centre as C6. In all, the maximum number of centres visited was 11.

This chapter consists of two sections. The first section provides a descriptive analysis of the care seeking pathway across the maximum of 11 centres during the duration of up to 15 years for some who persisted. The second section provides the event history analysis using a life table approach to compute the conditional rate (hazard or failure rate) of achieving pregnancy for the couples.

#### **Section I: Care seeking pathways for infertility among couples**

This section includes the description of the care seeking pathway among couples for infertility. It includes a summary of the total number of couples entering and exiting each infertility centre, types of centres visited, treatments taken in each centre, duration of time spent in each centre, status of the couple who did not move from one centre to another and lastly the reasons for discontinuation from each centre.

#### **8.1 Entry and exit of couples at each centre**

The number of couples who enter and exit each centre is summarised in Table 8.1. Those who remain in the same centre were those who continue treatment there or meet with success through achievement of pregnancy in that centre or those who stopped treatment entirely after seeking it at that centre or were taking a break from treatment (Table 8.5 gives the details). From table 8.1 we see that the number of couples moving to the next centre for care are higher than those remaining at the same centre up to the

level of the sixth centre (C6). From C7, the pattern reverses with higher proportions choosing to remain in that centre. The exception to this were those in C9 in the care seeking trajectory, wherein 62.5 percent move to next centre.

Table 8.1: Distribution of couples entering and exiting the care seeking pathway in each centre during care seeking for infertility

Centre No	Couples entering and exiting the centres			Couples not shifting to another centre		
	Couples moving to the next centre	Couples not shifting to the next centre	Total	Continuing in the same centre	Exiting the centre	Total
C1	81.6	18.4	100.0 (604)	18.9	81.1	100.0 (111)
C 2	74.2	25.8	100.0 (493)	27.6	72.4	100.0 (127)
C 3	68.0	32.0	100.0 (366)	31.6	68.4	100.0 (117)
C 4	57.4	42.6	100.0 (249)	22.6	77.4	100.0 (106)
C 5	56.6	43.4	100.0 (143)	29.0	71.0	100.0 (62)
C 6	55.6	44.4	100.0 (81)	36.1	63.9	100.0 (36)
C 7	48.9	51.1	100.0 (45)	34.8	65.2	100.0 (23)
C 8	36.4	63.6	100.0 (22)	28.6	71.4	100.0 (14)
C 9	62.5	37.5	100.0 (8)	66.7	33.3	100.0 (3)
C 10	20.0	80.0	100.0 (5)	75.0	25.0	100.0 (4)
C 11	0.0	100.0	100.0 (1)	0.0	100.0	100.0 (1)

## 8.2 Types of centres visited by couples during care seeking for infertility

The distribution of centres the couples visited by the type of medical practice is given in table 8.2. The most preferred type of medical practice was Allopathy. Such Allopathic centres offering infertility care were mostly concentrated in the private sector. Ayurveda, Homeopathy and alternate methods were also used by couples for resolving their infertility. The alternative methods mentioned here includes ‘unani’- not AYUSH (Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homeopathy), folk medicines and faith-based methods. A majority of the couples used Allopathic centres as the first point of care while a sharp rise in the number of people who had used Ayurveda, Homeopathy and alternate methods was noted from C2 onwards and the number of couples using this remained more or less same up to C4. Another

important feature of this pattern of care seeking is the proportion using Allopathic centres in the public sector and the proportion using it in private centres. Couples initiate use of AYUSH (Ayurveda and Homeopathy) and alternate methods combined from the entry into the second Allopathic centre and this proportion tends to gradually increase in comparison to the Allopathic centres in the public sector. The reason of more couples shifting to other systems could be because of the issue of unaffordability of care in private sector and the limited number of facilities in the public sector for infertility treatment.

Table 8.2: Percentage distribution of couples visiting different types of centres during care seeking for infertility

Centre No	Type of centre %					Total
	Allopathy-Public	Allopathy-Private	Ayurveda	Homeopathy	Alternate Methods	
C1	11.4	86.0	1.3	1.3	-	100.0 (604)
C2	12.2	73.6	5.9	8.1	0.2	100.0 (493)
C3	10.9	70.5	10.7	7.4	0.5	100.0 (366)
C4	13.7	61.4	11.2	12.1	1.6	100.0 (249)
C5	11.2	59.4	14.7	14.0	0.7	100.0 (143)
C6	14.8	63.0	8.6	12.4	1.2	100.0 (81)
C7	15.6	48.8	20.0	15.6	-	100.0 (45)
C8	13.7	50.0	4.5	27.3	4.5	100.0 (22)
C9	-	75.0	-	25.0	-	100.0 (8)
C10	20.0	20.0	-	60.0	-	100.0 (5)
C11	-	100.0	-	-	-	100.0 (1)

In addition, the tendency to shift from one centre to another happens when hope is instilled by someone who had used it successfully or someone else whose acquaintance had. These factors may be driving the couples who shift to other systems of medicine or alternate methods as they move along this care seeking pathway.

### **8.3 Treatments taken across various centres by couples during care seeking for infertility**

There are different levels of treatment that were sought and obtained at each centre. Hence, if in any centre the couples had only undergone preliminary investigations, which included history taking, blood and semen analysis, with some vitamin tablets for some it is reported as preliminary investigations only (PI), if they had undergone preliminary investigations (PI) and other advanced investigations like hysteroscopy, hysterosalpingography (HSG), laparoscopy, then it is reported as advanced investigations for women (AI women). If along with PI and AI women, some medical management like follicular study, medical management for regulating menstruation and ovulation induction were done it is labelled as medical management of women (MM women). If PI along with treatment for men or only treatment for men was provided, then it is labelled medical management of men (MM men). And if medical management had been done for both men and women, then it is labelled as medical management both (MM both). If along with these IUI was done, then IUI was taken as the treatment and if IVF was undergone by any couple, IVF was taken as the treatment undergone by the couple. Others category include- waiting for IUI or IVF or other treatments but had not yet started it at the time of interview, or if the couples had gone to Ayurveda or Homeopathy centres, they were labelled as taking medicines under the 'others' category.

Across centres the proportion of women getting medical management for infertility was more compared to other treatments. This could be because to undergo IUI and IVF, the women would be induced for ovulation. Intra Uterine Insemination (IUI) and Invitro Fertilisation (IVF) were utilised by 8-10 percent in the first two centres and it increased to almost 15 percent by the time the couples went to C3, while the use of IUI and IVF decreased to 10 percent at C4. But after that in all the subsequent centres, the proportion of couples undergoing IUI and IVF is more than 10 percent. This means that those who were persisting in the pathway started using IUI and IVF once other treatment modalities had been exhausted without the desired results. In Chapter 7 (Table 7.16) we had discussed the type of infertility that was causing difficulty in

achieving pregnancy for couples, we had noted that for this study population male factor alone contributed to a higher percentage of infertility. But table 8.3 indicates that the proportion of men alone undergoing treatment is less compared to women alone or both men and women undergoing treatment.

Table 8.3: Percentage distribution of treatments taken across various centres by the couples during their care seeking for infertility

Centre No	Type of treatment								Total
	PI only	AI women	MM women	MM Men	MM both	IUI	IVF	Others	
C1	19.5	2.0	30.8	13.2	24.5	6.5	0.2	3.3	100.0 (604)
C2	12.0	2.0	28.2	12.4	22.5	8.5	1.6	12.8	100.0 (493)
C3	12.6	1.4	25.4	9.3	19.1	12.8	2.5	16.9	100.0 (366)
C4	12.5	2.8	26.9	8.8	18.1	8.8	1.6	20.5	100.0 (249)
C5	18.9	1.4	21.0	8.4	11.2	10.5	5.6	23.0	100.0 (143)
C6	14.8	3.7	21.0	9.9	11.1	14.8	6.2	18.5	100.0 (81)
C7	15.6	2.2	20.0	6.7	13.3	6.7	4.4	31.1	100.0 (45)
C8	22.7	-	36.5	-	13.6	4.5	9.1	13.6	100.0 (22)
C9	-	-	50.0	-	37.5	-	12.5	-	100.0 (8)
C10	20.0	-	60.0	-	-	-	-	20.0	100.0 (5)
C11	-	-	-	-	100.0	-	-	-	100.0 (1)

If in any of the centres, Ayurveda or Homeopathy was used by the couple, then they were given medicines i.e., either for the respondent alone, or for the spouse only or for both. In majority of the cases, medicines were given to both the respondents and their spouses. In some situations, at levels C1 and C2, some couples were only asked to do a semen analysis and were referred to an Allopathic centre.

#### 8.4 Duration of time spent for treatment by couples in each centre during care seeking for infertility

The entire treatment duration for the 604 couples across all the centres, was between one month and 180 months, with a mean duration of 60 (59.9) months. This is inclusive of the time they had taken off from treatment. The upper limit of 180 months is an artefact of the exclusion criteria, namely those who had sought treatment for more than 15 years due to potential recall bias.

The duration of time (in months) spent by those couples who moved from one centre to another is shown in table 8.4. This includes the time spent on treatment and duration when there was a break from treatment. An average duration of six to eight months was spent in treatment by the couples in the treatment phase. The average duration of treatment was highest in the first three centres. The average break duration ranged between 8-19 months, and was the highest in the third centre.

Table 8.4: Distribution of the duration of time spent for treatment and break from treatment by couples in each centre during care seeking for infertility

Centre No	Duration (in months)-Treatment			Duration (in months)-Break		
	Minimum	Maximum	Mean	Minimum	Maximum	Mean
C1	1	84	8.0	1	167	16.6
C 2	1	66	8.1	1	137	16.8
C 3	1	72	8.2	1	117	18.9
C 4	1	96	7.0	1	86	12.9
C 5	1	36	6.5	1	75	13.5
C 6	1	25	7.0	1	96	14.6
C 7	1	25	6.3	1	33	10.6
C 8	1	24	6.2	1	45	13.5
C 9	1	12	6.0	1	23	8.3
C 10	-	1	1.0	-	6	6.0
C 11	-	7	7.0	-	-	-

#### 8.5 Status of couples who did not move from once centre to another

The number of couples who reported that they did not move to another centre were counted across centres. The reasons for not moving to another centre is shown in table

8.5. The couples either stopped the treatment, took a break from treatment, were currently not on treatment (because the medical professional had asked them to wait before starting treatment or because the spouse was unwilling to follow through on treatment), got pregnant or were continuing in the same centre.

From the first centre 111 couples reported that they did not go to another centre. One fourth of them reported that they were taking a break from the current treatment, while 32 percent did not go to a second centre as they got pregnant. Almost an equal proportion of couples reported that they either stopped treatment completely or were continuing in the same centre.

In C2, 127 reported not moving to another centre, of which the majority (29.1%) said they got pregnant and hence did not have to move to another centre. While nearly 28 percent were continuing treatment in C2, approximately 27 percent reported that they took break from treatment and almost 13 percent had stopped all treatment after C2.

In C3, there were 117 couples who did not move to another centre. A majority (31.6%) of them reported that they were still continuing in the same centre, and 27.3 percent were taking a break from treatment. In the third centre, 21.4 percent reported they got pregnant and almost 19 percent reported they stopped all treatments and hence did not go to another centre.

In C4, 106 respondents did not go to another centre. Here there was no transition to another centre because majority of the respondents said they were taking break from treatment (34.0%), and almost 23 percent said they either got pregnant or were continuing in the same centre, while one-fifth of them had stopped treatment after C4.

In C5, 62 reported not going to another centre, 16 percent reported they got pregnant and 29 percent reported they were continuing in C5. In C6, of the 36 who reported not going to another centre, majority (36.1%) were continuing in the C6 itself and nearly 28 percent got pregnant. Others were either taking a break or had stopped treatment.

From C7 to C10, among those who did not go to the next centre, a majority were either continuing in the same centre or were taking break from the treatment.

We can see here that in the first two centres (C1 & C2) couples exited the treatment pathway with a higher proportion getting pregnant followed by a majority taking break from treatment. By the time couples reached the third or higher order of centres, the proportion of those taking a break from treatment increases. The proportion of couples who stop treatment or are on no treatment tends to also increase by C5. Most persons got pregnant by C4, and after that, they more or less seemed to have stopped treatment or were taking a break from treatment. Essentially, what this means is that on an average, couples persist in seeking care for infertility up to at least four centres but after that, tend to stop permanently or take a break from care seeking.

Table 8.5: Percentage distribution of the reason for not transitioning from one centre to another by couples during care seeking for infertility

Centre No	Status of treatment at the time of interview					Total
	Stopped treatment	Taking a break from treatment	Currently no treatment	Got pregnant	Continuing treatment	
C1	17.1	25.2	6.3	32.4	19.0	100.0 (111)
C 2	12.6	26.8	3.9	29.1	27.6	100.0 (127)
C 3	18.8	27.3	0.9	21.4	31.6	100.0 (117)
C 4	20.8	34.0	-	22.6	22.6	100.0 (106)
C 5	25.8	27.4	1.6	16.1	29.1	100.0 (62)
C 6	16.7	19.4	-	27.8	36.1	100.0 (36)
C 7	17.4	34.8	4.3	8.7	34.8	100.0 (23)
C 8	21.4	28.6	-	21.4	28.6	100.0 (14)
C 9	-	33.3	-	-	66.7	100.0 (3)
C 10	25.0	-	-	-	75.0	100.0 (4)
C 11	100.0	-	-	-	-	100.0 (1)

## **8.6 Reasons for discontinuation in each centre by couples during care seeking for infertility**

The reasons for discontinuation included, psychological distress of treatment, physical burden of treatment, clinic related issues, no faith in treatment success, poor prognosis, logistic/practical reasons, personal reasons, trying on one's own, postponement of treatment/taking a break from treatment, doctor censoring<sup>1</sup>(Gameiro et al, 2012), financial issues, treatment related logistical problems, other health problems, not wanting to pursue a specific treatment, pursuing alternative methods/treatments, no longer wish to have a child, continue the treatment, pregnant/conceived and other reasons. Different reasons were mentioned by the respondents for discontinuing treatment from a particular centre. Since the respondents gave multiple responses for discontinuation in each centre, similar reasons were later grouped together to form single group, in all, determining six distinct groups of reasons for discontinuation.

The respondents reported a reason or a combination of these five reasons, and these reasons are tabulated in table 8.6.

No faith in the success of the treatment was cited as the reason for discontinuation by majority of the respondents across the centres. Following this, financial issues and other logistical and personal issues were stated as reasons for discontinuation.

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<sup>1</sup>Doctor censoring here means when the treating doctor decided to stop continuing treatment as he/she finds the condition of the patient not amenable to treatment or when all the treatment modalities have exhausted without an outcome or improvement in the condition of the patient.

Table 8.6: Percentage distribution of reasons for discontinuation by couples in each centre during their care seeking for infertility

<b>Reasons for discontinuation</b>	<b>C1</b>	<b>C2</b>	<b>C3</b>	<b>C4</b>	<b>C5</b>	<b>C6</b>	<b>C7</b>	<b>C8</b>	<b>C9</b>	<b>C10</b>	<b>C11</b>
Health/ bodily related (HB) <sup>1</sup>	3.6	4.8	5.1	2.2	2.4	2.9	-	5.0	-	-	-
Clinic / treatment related (CT) <sup>2</sup>	5.0	7.8	9.3	8.4	16.0	7.3	11.3	5.0	16.7	-	-
No faith in treatment success (NF) <sup>3</sup>	22.4	26.1	23.3	29.8	29.6	26.4	34.2	30.0	50.0	-	100.0
Financial/ logistical/ personal issue (FLP) <sup>4</sup>	12.1	16.3	19.5	17.6	14.4	19.1	5.7	10.0	-	-	-

<sup>1</sup>HB included psychological distress of treatment, physical burden of treatment, and other health problems, <sup>2</sup>CT included clinic related issues, and do not want to pursue specific treatment, <sup>3</sup>NF included no faith in treatment success and poor prognosis, <sup>4</sup>FLP included logistic/practical reasons, personal reasons, financial issues, and treatment related logistical problems, <sup>5</sup>OTNT included trying on own, postponement of treatment/taking a break from treatment, doctor censoring, pursuing alternative methods/treatment, no longer wish to have a child, <sup>6</sup>P included only those who got pregnant, reasons 7-18, included a combination of the above reason 1-5 as represented.

Table 8.6: Percentage distribution of reasons for discontinuation by couples in each centre during their care seeking for infertility (Contd.)

<b>Reasons for discontinuation</b>	<b>C1</b>	<b>C2</b>	<b>C3</b>	<b>C4</b>	<b>C5</b>	<b>C6</b>	<b>C7</b>	<b>C8</b>	<b>C9</b>	<b>C10</b>	<b>C11</b>
Pursuing other treatments/ not taking treatment (OTNT) <sup>5</sup>	9.1	5.4	4.8	7.9	4.0	5.9	5.7	10.0	-	-	-
Got pregnant (P) <sup>6</sup>	4.6	6.3	4.5	6.1	4.8	13.2	5.7	15.0	-	-	-
HB-CT <sup>7</sup>	0.2	0.4	0.3	0.4	1.6	-	-	-	-	-	-
HB-FLP <sup>8</sup>	0.7	0.9	0.6	-	-	-	2.9	-	-	-	-
HB-NF <sup>9</sup>	0.7	-	0.3	0.4	-	-	2.9	-	-	-	-
HB-NF-FLP <sup>10</sup>	0.2	0.2	-	-	0.8	-	-	-	-	-	-
HB-OTNT <sup>11</sup>	-	0.2	-	-	-	-	-	-	-	-	-

<sup>1</sup>HB included psychological distress of treatment, physical burden of treatment, and other health problems, <sup>2</sup>CT included clinic related issues, and do not want to pursue specific treatment, <sup>3</sup>NF included no faith in treatment success and poor prognosis, <sup>4</sup>FLP included logistic/practical reasons, personal reasons, financial issues, and treatment related logistical problems, <sup>5</sup>OTNT included trying on own, postponement of treatment/taking a break from treatment, doctor censoring, pursuing alternative methods/treatment, no longer wish to have a child, <sup>6</sup>P included only those who got pregnant, reasons 7-18, included a combination of the above reason 1-5 as represented.

Table 8.6: Percentage distribution of reasons for discontinuation by couples in each centre during their care seeking for infertility (Contd.)

<b>Reasons for discontinuation</b>	<b>C1</b>	<b>C2</b>	<b>C3</b>	<b>C4</b>	<b>C5</b>	<b>C6</b>	<b>C7</b>	<b>C8</b>	<b>C9</b>	<b>C10</b>	<b>C11</b>
CT-FLP <sup>12</sup>	0.3	1.5	2.4	2.2	1.6	-	2.9	-	-	-	-
CT-NF <sup>13</sup>	0.5	0.9	-	0.4	-	1.5	-	-	-	-	-
CT-OTNT <sup>14</sup>	-	0.4	0.3	0.9	-	1.5	2.9	-	-	-	-
CT-NF-FLD <sup>15</sup>	-	-	-	-	-	1.5	-	-	-	-	-
NF-FLP <sup>16</sup>	2.2	3.3	3.6	2.7	3.2	1.5	2.9	-	16.7	-	-
NF-OTNT <sup>17</sup>	-	0.7	0.6	0.4	0.8	1.5	-	-	-	-	-
FLP-OTNT <sup>18</sup>	0.3	0.2	0.6	0.9	1.6	1.5	2.9	-	-	-	-
Others	38.1	24.6	24.8	19.7	19.2	16.2	20.0	25.0	16.7	100.0	-
Total	100.0 (585)	100.0 (460)	100.0 (334)	100.0 (228)	100.0 (125)	100.0 (68)	100.0 (35)	100.0 (20)	100.0 (6)	100.0 (2)	100.0 (1)

<sup>1</sup>HB included psychological distress of treatment, physical burden of treatment, and other health problems, <sup>2</sup>CT included clinic related issues, and do not want to pursue specific treatment, <sup>3</sup>NF included no faith in treatment success and poor prognosis, <sup>4</sup>FLP included logistic/practical reasons, personal reasons, financial issues, and treatment related logistical problems, <sup>5</sup>OTNT included trying on own, postponement of treatment/taking a break from treatment, doctor censoring, pursuing alternative methods/treatment, no longer wish to have a child, <sup>6</sup>P included only those who got pregnant, reasons 7-18, included a combination of the above reason 1-5 as represented.

## **Section II: Event history analysis: Rate of achieving pregnancy in couples with infertility using a life table approach**

Event history analysis or survival analysis involves the modelling of the time to event data. The treatment duration, which is the time to event variable in this context ranged from 1 to 180 months. Couples who had more than 15 years (180 months) of treatment duration were excluded from the survey, but there were a few couples who were still in the care seeking pathway at 180 months during the survey. The data was collected retrospectively for each participant from the time of entering the care pathway for infertility up to when the event occurred (here pregnancy) or up to when they discontinued treatment (i.e., those who took break from treatment or had stopped treatment). Others who did not belong to either of these categories and were still continuing in the pathway at the time of interview, did not have the event till the last day of observation i.e., the date of interview. These are censored data in this study i.e., those who stopped treatment, those who took break from treatment and those who did not have the event till the last day of observation. Due to the presence of censored data i.e., when the time to event is not observed, survival analysis offers the best means to manage censored data.

### **8.7 Life table approach depicting survival probabilities and failure rate in couples with infertility**

The tables 8.7 and 8.8 summarise the major statistical estimations from the life table analysis. The survival function is the probability that an individual survives longer than a specific time 't' i.e., any specific value of the variable time to event or survival time 'T'. Here the survival function means that the probability of continuing in the care seeking pathway without the achieving pregnancy.

The hazard function  $h(t)$  of survival time 'T' give the instantaneous rate of occurrence of the event. It is defined as the rate of failure during a very small time interval, assuming that the individual has survived to the beginning of the interval. Since our event of interest is pregnancy, here the hazard function denotes the rate of getting pregnant during a given time interval  $(t, t+\Delta t)$ , provided the individual had continued

in the care seeking pathway. Pregnancy rate is used here to refer to the hazard/failure rate, which is the conditional probability for pregnancy adjusted for time.

In this study, for the survival time variable, the 25<sup>th</sup> percentile is 69 months and the 50<sup>th</sup> percentile is 177 months. It means that 25 percent of the participants have survival times less than 69 months and 50 percent of the participants have survival time less than 177 months. There are missing values for the 75<sup>th</sup> percentile, which is the result of high prevalence of censoring in this study.

The survival probabilities of the couples with infertility i.e., the probability of continuing in the care seeking pathway at least up to time ‘t’ after entering the care seeking for infertility is given in table 8.7. Here the total exposure time of 180 months is grouped into 4 intervals of 60 months each. The probability of continuing in the care seeking pathway at least to 60 months without the outcome was 0.79 and this dropped to nearly half at the end of the observation period i.e., 180 months. It also indicates that only 79 out of 100 persist in treatment for more than 60 months and as duration of exposure goes up, the probability of persisting in care amongst those who did not get pregnant tends to decline. The probability of couples continuing in the care seeking pathway for more than 120 months is 64 percent and it declined to 54 percent at 180 months and more.

Table 8.7: Life table survival probabilities of continuing in the state of infertility across time with standard errors and confidence intervals

<b>Treatment duration in months</b>	<b>Total number at the beginning of the interval</b>	<b>Pregnancy</b>	<b>Censored</b>	<b>Probability of continuing in the care seeking pathway (Survival)</b>	<b>Std. Error</b>	<b>95% CI</b>
0 - 60	604	100	243	0.7927	0.0185	0.7538-0.8263
60 -120	261	38	137	0.6363	0.0271	0.5804-0.6867
120 -180	86	8	69	0.5374	0.0395	0.4571-0.6111
180 -	9	1	8	0.4299	0.1012	0.2327-0.6134

The hazard function  $h(t)$  is the conditional probability of having the event (getting pregnant here) at any given time  $(t, t+\Delta t)$ , having survived (continued in the pathway without the outcome) up to that time. The rate of pregnancy in the interval 0-60 months was 0.0039 which decreased to 0.0037 in the interval 60-120 and to 0.0028 in the interval 120-180 months. It means that if 1000 couples, start treatment, about 4 will get pregnant at any given time between 0-5 years, if they persist treatment up to the end of that period. Of those who continue in their care seeking pathway for infertility, again, only 4 out of 1000 couples will get pregnant at any given time between the interval between 5-10 years if they have persisted in the treatment up to the end of the period. This reduces to 3 per 1000 in 10-15 years. It should be noted that the CI for the hazard rate widens as we move from the duration 0-60 to 180 and above months. Here hazard is a conditional failure rate which means that the attainment of event i.e., pregnancy here is conditional up on the continuation in care seeking pathway. While the decline in the rate of pregnancy is not stark, it should be read against the wide CI for this rate.

Table 8.8: Life table hazard rate of couples persisting in the pathway across time with standard errors and confidence intervals

Treatment duration in months	Total number at the beginning of the interval	Cumulative pregnancy rate (Cum. Failure)	Std. Error	Conditional rate of achieving pregnancy (Hazard)	Std. Error	95% CI
0- 60	604	0.2073	0.0185	0.0039	0.0004	0.0031-0.0046
60 -120	261	0.3637	0.0271	0.0037	0.0006	0.0025-0.0048
120 -180	86	0.4626	0.0395	0.0028	0.001	0.0009-0.0047
180 -	9	0.5701	0.1012	-	-	-

### 8.8 Conditional rate of getting pregnant with different treatments

The couples at the time of interview were in different stages of treatments, stage one included preliminary investigation only, followed by stage two which was advanced

investigations for women. The third stage of treatment was medical management of women, the next or fourth stage was management for men. If both men and women had undergone management for their problems this constituted another category called the medical management both, which was stage five. If the couples had undergone IUI they fall into the sixth and if they undergone IVF they will fall into the final or seventh stage of treatment.

The categorisation of couples in the specific stage was based on the highest stage attained. It should be remembered that couples progress through stages unidirectionally. This means, one cannot return to diagnosis stage if they have progressed along to a higher stage. This categorisation of the different stages means if a couple has undergone preliminary investigations only, they fall into the 'preliminary investigations' category. But if they had done preliminary investigations and/or medical management of women and medical management of men, then they belong to 'medical management of both' category. There were some participants who reported they had only taken Homeopathic or Ayurvedic treatment, and they form a separate category. The summary of the stage of treatment attained and the pregnancy rate in that stage is given in table 8.9.

From table 8.9 it is clear that the cumulative pregnancy rate is higher in the group where there is medical management of women compared to medical management of men or both. The cumulative pregnancy rate is higher in the IVF category compared to the IUI category.

From the hazard rates given in table 8.8 we note that the only 4 per 1000 couples get pregnant at any given time in the interval 0-60 months, if they persisted treatment up to that time. The pregnancy rate, if they persisted in the care seeking with different stages of treatment, it was about 6 per 1000 couples if it was medical management of women only, and 4 per 1000 couples if the treatment was done only for men. It further dropped to 3 per 1000 if it was medical management of both or if the couple had to move to IUI. It was as low as 2 per 1000 couples at any given time in the interval 0-60 months, if they persisted treatment up to that time and undergone IVF.

If the couples continued in the care seeking pathway for 10 years with the medical management of women only, it yields the same failure rate, of 6 per 1000 couples getting pregnant at any given time in the interval 60-120 months, if they persisted treatment up to that time, while it is 3 per 1000 couples for medical management of men alone in the same time interval. It is important to note the failure rate here means getting pregnant. The failure rate drops to almost 1 per 1000 couples at any given time in the interval 60-120 months, if they persisted treatment up to that time and the treatment is done for both the couples. The IUI and IVF shows an increase in their failure rate if the couples persist for 10 years which is 6 per 1000 couples and 3 per 1000 couples at any given time in the interval 60-120 months, if they persisted treatment up to that time for IUI and IVF respectively.

If they persist in the care seeking pathway for 15 years, the failure rate i.e., the conditional rate for pregnancy is 0 per 1000 couple at any given time in the interval 120-180 months, if they persisted treatment up to that time for those undergoing treatment only for women, which means that the male partner in these couples may be having the problem and they are not willing to take treatment and it is the women who are taking treatment. The failure rate is 3 per 1000 couples for those taking management for men alone, for both and for IUI. Here the IUI shows a decline in rate of achieving pregnancy. The IVF shows a failure rate of 4 per 1000 couples at any given time in the interval 120-180 months, if they persisted treatment up to that time, which is lesser than the 10 years outcome but it yields the highest outcome in the 15-year duration among all the different treatment stages.

This could mean that those couples who need IVF as the definite treatment are not attempting it earlier and they are going in for it when all other treatment methods are exhausted. Hence it results in a higher pregnancy rate for IVF in the later stages of treatment seeking.

Regarding the management of men only, those who seek care earlier and stick with the treatment regime may be likely to get the outcome. It declines as the time period increases to 10 or 15 years and the outcome is a constant which means these may be men who require assisted reproductive techniques but are still doing medical

management or are continuing in the pathway by using alternate systems of medicine for their problem.



Table 8.9: Conditional rate of getting pregnant with different stages of treatment

<b>Treatment duration in months</b>	<b>Total number at the beginning of the interval</b>	<b>Cumulative pregnancy rate (Cum. Failure)</b>	<b>Std. Error</b>	<b>Conditional rate of failure (achieving pregnancy) (Hazard)</b>	<b>Std. Error</b>	<b>95% CI</b>
<b>Other methods only used</b>						
0-60	6	0.5000	0.2500	0.0111	0.0074	0.0000- 0.0256
<b>Preliminary investigations only</b>						
0-60	41	0.2857	0.0913	0.0056	0.0021	0.0015-0.0096
60-120	1	1.0000	-	0.0333	-	-
<b>Advanced investigations for women</b>						
0-60	11	0.0000	0.0000	0.0000	-	-
60-120	4	0.0000	0.0000	0.0000	-	-
120-180	3	0.0000	0.0000	0.0000	-	-
<b>Medical management of women only</b>						
0-60	121	0.3204	0.0491	0.0064	0.0012	0.0041-0.0086
60-120	31	0.5367	0.0753	0.0063	0.0023	0.0017-0.0109
120-180	6	0.5367	0.0753	0.0000	-	-
180-	1	0.5367	0.0753	-	-	-
<b>Medical management of men only</b>						
0-60	65	0.2136	0.0571	0.0040	0.0012	0.0016-0.0063
60-120	27	0.3287	0.0784	0.0026	0.0015	0.0000-0.0056
120-180	11	0.4320	0.1159	0.0028	0.0028	0.0000-0.0082
180-	1	0.4320	0.1159	-	-	-

Table 8.9: Conditional rate of getting pregnant with different stages of treatment (contd.)

<b>Treatment duration in months</b>	<b>Total number at the beginning of the interval</b>	<b>Cumulative pregnancy rate (Cum. Failure)</b>	<b>Std. Error</b>	<b>Conditional rate of failure (achieving pregnancy) (Hazard)</b>	<b>Std. Error</b>	<b>95% CI</b>
<b>Medical management of both men and women</b>						
0-60	190	0.1873	0.0319	0.0034	0.0006	0.0022-0.0047
60-120	81	0.2464	0.0411	0.0013	0.0006	0.0000-0.0025
120-180	25	0.3541	0.0788	0.0026	0.0018	0.0000-0.0061
180-	1	0.3541	0.0788	-	-	-
<b>Intra uterine Insemination</b>						
0-60	138	0.1526	0.0322	0.0028	0.0006	0.0015-0.0040
60-120	92	0.3947	0.0512	0.0056	0.0012	0.0032-0.0080
120-180	28	0.5082	0.0723	0.0034	0.0020	0.0000-0.0073
180-	1	0.5082	0.0723	-	-	-
<b>Invitro Fertilization</b>						
0-60	32	0.1311	0.0611	0.0023	0.0012	0.0001-0.0046
60-120	25	0.2583	0.0856	0.0026	0.0015	0.0000-0.0056
120-180	13	0.4066	0.1161	0.0037	0.0026	0.0000-0.0088
180-	5	0.6044	0.1791	-	-	-

### **8.9 Conditional rate of getting pregnant with the type of infertility of couples**

The couples had different type of infertility diagnosis and were divided into male factor, female factor, both male and female factor and unexplained reasons. The rate of pregnancy with respect to the diagnosis is summarised in table 8.10. The rate of getting pregnant with male infertility was lower compared to other types of infertility. The conditional rate of achieving pregnancy in all the categories showed a lower probability in the 0-60 months interval compared to the 60-120 months interval except for male infertility. This tends to drop again in the 120-180 months period. In male infertility the conditional rate of achieving pregnancy was higher in the 0-60 months treatment duration compared to 60-120 months duration, the pregnancy rate showed a rise in the 120-180 months duration.

This table reinforces what was seen in the conditional failure with different treatments. Here, those with male infertility has higher rate of pregnancy at 5 years treatment period, while this tends to drop at 10 year period and it tends to again raise in the 15 year period. This pattern could be because some couples went for IVF only in the 10-15 year period after exhausting all other options. Female infertility has the highest failure rate i.e., achieving pregnancy in all the time intervals 5-15 years period, with the highest at 5-10 years, the possible explanation for it could be the migrant status of the husbands. Since during the earlier years of marriage the husbands may be still working abroad and due to shorter period of vacation, the pregnancy rate is reduced because the exposure period and fertile period may not always coincide. When both partners in a couple are having some conditions that impair reproduction, the pregnancy rate is 3 per 1000 couples at any given time in the interval 60-120 months, if they persisted treatment up to that time and is 0 per 1000 couples at any given time in the interval 120-180 months, if they persisted treatment up to that time. This can also point to the need to use assisted reproduction when these couples were still pursuing lower levels of treatment with medicines Allopathic or other systems of medicine. In unexplained infertility also there is higher pregnancy rate at 10 year period i.e., 5 per 1000 couples compared to 5 year period which is 4 per 1000 and at

15 years it is 3 per 1000 couples. This could also be indicative of the use of alternate systems by those couples who may need ART.

Table 8.10: Conditional rate of getting pregnant with diagnosis of infertility

Treatment duration in months	Total number at the beginning of the interval	Cumulative pregnancy rate (Cum. Failure)	Std. Error	Conditional failure rate(of achieving pregnancy) (Hazard)	Std. Error	95% CI
<b>Male infertility</b>						
0-60	214	0.1897	0.0297	0.0035	0.0006	0.0023-0.0047
60-120	101	0.2816	0.0404	0.0020	0.0007	0.0006-0.0034
120-180	32	0.4290	0.0731	0.0030	0.0019	0.0001-0.0075
180-	3	0.4290	0.0731	-	-	-
<b>Female infertility</b>						
0-60	161	0.2605	0.0384	0.0050	0.0008	0.0033-0.0067
60-120	66	0.4817	0.0536	0.0059	0.0014	0.0030-0.0087
120-180	25	0.5820	0.0676	0.0036	0.0021	0.0000-0.0076
180-	3	0.5820	0.0676	-	-	-
<b>Both male and female infertility</b>						
0-60	80	0.1395	0.0431	0.0025	0.0008	0.0009-0.0041
60-120	40	0.2783	0.0674	0.0029	0.0013	0.0004-0.0055
120-180	17	0.2783	0.0674	0.0000	-	-
180-	2	0.7594	0.2787	-	-	-
<b>Unexplained infertility</b>						
0-60	149	0.2115	0.0383	0.0039	0.0008	0.0024-0.0055
60-120	54	0.4007	0.0622	0.0045	0.0015	0.0016-0.0075
120-180	12	0.4863	0.0955	0.0026	0.0026	0.0000-0.0076
180-	1	0.4863	0.0955	-	-	-

### **8.10 Conditional rate of getting pregnant with the type of centres used by couples**

The couples had used Allopathy alone across centres or other systems of medicine or alternate methods alone or in combination with Allopathy across the centres. The failure rate i.e., the conditional rate of achieving pregnancy with the type of centre used by couple is shown in table 8.11.

The cumulative failure rate is higher for those using allopathy alone compared to those using other methods alone or with Allopathy. Here we can see that the pregnancy rate is 6 per 1000 couples at any given time in the interval 0-60 months, if they persisted treatment up to that time among those who used Allopathy alone, this rate reduces to 5 per 1000 couples and 4 per 1000 couples at any given time in the interval 60-120 months and 120-180 months, if they persisted treatment up to that time respectively.

While among those couples who had used other methods like Homeopathy, Ayurveda or alternate methods alone or along with Allopathy across different centres, the pregnancy rate was 2 per 1000 couples at any given time in the interval 0-60 months, if they persisted treatment up to that time, which increased to 3 per 1000 couples at any given time in the interval 60-120 months and 120-180 months, if they persisted treatment up to that time. From the table 8.2 (on type of centre visited by the couples), it is clear that although couples tend to use other systems of medicine or alternate methods more frequently as they move to the next centre, the number of couples who use the Allopathy centre in private sector remains higher. This possibly explains the results here, i.e., those who are persisting in the pathway for 10 or 15 years may be using more Allopathic centres in combination with other centres compared to those in the care seeking pathway for 5 years and hence the higher rate of pregnancy among those couples.

Table 8.11: Conditional rate of getting pregnant with type of centres used by couples

Treatment duration in months	Total number at the beginning of the interval	Cumulative pregnancy rate (Cum. Failure)	Std. Error	Conditional failure rate (of achieving pregnancy) (Hazard)	Std. Error	95% CI
<b>Allopathy only</b>						
0-60	321	0.3006	0.0296	0.0059	0.0007	0.0046-0.0072
60-120	86	0.4958	0.0445	0.0054	0.0013	0.0029-0.0079
120-180	25	0.5966	0.0631	0.0037	0.0021	0.0000-0.0079
180-	2	0.5966	0.0631	-	-	-
<b>Other methods alone or in combination with Allopathy</b>						
0-60	283	0.1152	0.0205	0.0020	0.0004	0.0013-0.0028
60-120	175	0.2535	0.0332	0.0028	0.0006	0.0016-0.0041
120-180	61	0.3557	0.0513	0.0025	0.0011	0.0003-0.0046
180-	7	0.5168	0.1447	-	-	-

### 8.11 Discussion

In the present study, the couples have used up to 11 centres for infertility care. There is transition from one centre to another at a different pace in different centres. The volume of movement from one centre to another is higher in the earlier stages of the care seeking pathway. The tendency to jump from centre to centre declines as the number of centres visited increases. The possible reason for this could be the desire to achieve pregnancy as fast as possible. The inability to achieve it at any centre may be propelling their movement to the next centre.

Allopathy was used by most of the couples, and it was the first point of care seeking for infertility for majority of the couples in the study. As the couples moved to the next centre along the care seeking continuum there was a shift from Allopathy to Ayurveda and Homeopathy. These alternate methods were negotiated by the couples in the care seeking pathway alone or along with other systems of medicine. The long waiting time in the Allopathy system for many procedures especially in the government sector, the low faith in the success of the treatment and high cost of care for Allopathic treatment

which tend to be concentrated more in the private sector are some of the factors for this shift from centre to centre. All of these factors, combined with the positive feedback and anecdotal narratives of success of certain providers also lure the couples into trying it for themselves.

Even though the proportion of male infertility is higher in the study, we see a mismatch in the proportion of men and women undergoing treatment. Proportion of women undergoing treatment was higher compared to men undergoing treatment. One possible explanation is that most of the assisted reproductive treatments are centred on the woman's body. Women reported that the husbands do not present themselves for treatment. This could also be a reason for lower proportion of men undergoing treatment.

The duration of treatment spent by the couples was highest in C4, after which the time spent by the couples in subsequent centres declined drastically. This decline may be because the number of couples who stopped treatment was higher after C4. The findings suggest that majority of the couples had got pregnant by C4. It could also be the couples who are continuing in the care seeking pathway beyond C4 are those with male factor infertility or those who needed ART procedure but were delaying it. Hence a lesser number is seen beyond C4 and also the lesser duration spent in each centre beyond C4, due to the unacceptability of undergoing ART treatments by couples for various reasons.

The life table analysis shows that the medical management of women yields the highest failure rate (failure rate here means probability of getting pregnant per unit of time) across different treatment stages in different time intervals across the period 0-120 months. This can be read against the failure rate in different categories of infertility, where couples with only female factor infertility present a higher failure rate. This could be because females continue to persist the treatment while men are reluctant to undergo treatment, especially when male factor infertility is the cause and they are suggested ART treatment. The reluctance to undergo assisted conception reported by the respondents in the qualitative component of the study is validated by the findings here. We can see that assisted reproductive technology including IUI using

donor sperm and IVF are producing higher failure rate in the later duration in the pathway i.e., IUI after 5 years and IVF after 10 years. This means that such methods are being postponed by the couples in the earlier years of their care seeking due to various reasons.

The failure rate drops to almost one-third when using other methods alone or in combination with Allopathy compared to when using Allopathy alone. This result cannot be naively interpreted as Allopathy offers better results compared to other methods or AYUSH. The tendency to move to other centres which may be AYUSH or alternate methods happen when the couples do not achieve desired results. These may be resultant when couples who need assisted conception methods to achieve pregnancy. Due to inability to afford such treatments and/or reluctance to undergo such treatments, they may forgo Allopathic treatment. This may be the reason why they are not yielding the result when using other systems of medicine or alternated methods alone or in combination with Allopathy.

The care seeking pathway for infertility can be long or short for different couples depending on their diagnosis, the ability to afford treatment at any centre, and also the persistence in the care seeking pathway. Multiple trajectories are adopted by couples so as to achieve the desired result which puts them in a pathway where unauthorised measures are adopted to achieve pregnancy. The reluctance to undergo certain treatment methods due to personal, religious or cultural reasons are some factors which are responsible for prolonging the care seeking pathway of couples.

## **Chapter 9**

### **Gendered consequences of the care seeking process**

This chapter presents the results of the final phase of the research process which aimed to describe the infertility specific distress in women undergoing treatment for infertility and to understand the possible consequences of infertility for women. The narratives were elicited using in-depth interviews among 10 women who had sought care for infertility in the two districts of Kerala, Thiruvananthapuram and Malappuram. The interviews enabled an understanding of the gendered consequences of infertility vis-à-vis the process of care seeking for infertility. I aim to describe the process of care seeking and the differences in it when male or female factor reproductive impairment in the couple is the cause for infertility. This process of care seeking has gendered implications as women are adversely affected due to the absence of a child emotionally and socially. They have to bear the physical burden of the various treatment procedures as well.

#### **9.1 Participants' profile**

Among the 10 participants interviewed, seven of them had infertility due to male factor two had female factor infertility and one had both male and female factor infertility. Two of the husbands were in gulf after marriage for a significant time, and eight of them had their husbands staying with them. One of them at the time of interview was a widow.

Table 9.1: Profile of the participants interviewed

Sl no	Name of the participant*	Age	Type of infertility	Husband (was/is) in gulf
1	Shyla	36	Female factor	Yes
2	Radha	53	Male factor	Yes
3	Nihar	30	Both male and female factor	No
4	Jasmine	30	Male factor	No
5	Sulfath	27	Male factor	No
6	Raji	34	Male factor	No
7	Maya	46	Female factor	No
8	Naiha	32	Male factor	No
9	Malathy	38	Male factor	No
10	Shahina	37	Male factor	No

\*Names changed to provide anonymity

The themes developed after merging of the codes are explained below in four sub-headings viz., the process of care seeking describing the differences in male and female factor infertility, gendered nature of infertility, sustaining care by virtue of ‘hope’ and lastly, the process of coping by women.

### **9.2 Process of care seeking: Differences in male and female factor infertility**

The care seeking for infertility starts with the recognition of the problem when there is delay in getting pregnant after trying to get pregnant. This recognition ignites care seeking for infertility which culminates only with achieving a successful pregnancy. While for others who have not achieved the pregnancy status, the care seeking continues in varied forms even as they wait for a positive outcome to happen. This process continues intermittently for some when finances are an issue while others voluntarily withdraw when their reproductive processes have halted. But regardless of the cause of infertility the process of care seeking begins and continues only if the male partner takes a proactive role in the process. Care seeking for infertility diverge depending on the diagnosis with mostly couples having

female factor infertility staying in the pathway longer than those with male infertility alone.

### **9.2.1 Absent male partners: Impedance to early recognition and care seeking for infertility**

The recognition of infertility by the couples is the foremost factor in initiating care seeking but such an event also depends on other factors like cohabitation of the couples for a fairly reasonable amount of time so as to enable a recognition that something is wrong. The women reported that due to the absence of their husbands at home there was delay in initiating the treatment. They also added that there was intermittence in treatment seeking due to work related responsibilities of their husbands. They were employed overseas and this was a barrier to continuity in care seeking.

*“After marriage, husband stayed here for three months and then went back. Then when he came again he stayed for two years and we tried. We went to the doctor when nothing was happening.”* (Shyla, 36 years, wife having reproductive impairment)

*“I got married at 14 years, I had menarche after coming here only. After marriage husband went to gulf and he came back after 6 or 7 years. That time he stayed here for 5-6 months, and we showed the doctor but we did not do any major treatment then. He went back to gulf again. Then every year he used to come, then only we started treatment.”* (Radha, 53 years with male factor infertility)

Couples with male factor infertility reported that the doctors advised the husbands to stay back at home so as to improve their sperm count, if they were working overseas. This was reported by the women as not feasible because of financial responsibilities at home.

*“Then only doctor checked and told the climate is not okay. When you adjust to the climate here, again you go back to Gulf. Either you stay here or take the wife with you, and that both should stay together. Count will not improve if you go - like that doctor told.”* (Radha, 53 years with male factor infertility)

In contrast to this, early recognition and care seeking was reported by women whose husbands were at home. In such cases treatment was initiated within a span of two years of marriage.

*“It has been 14 years since marriage, after six months we started treatment. From then to now there is treatment, now it's been a while since we have stopped treatment.”* (Jasmine, 30 years with male factor infertility)

### **9.2.2 Divergences in care seeking pattern for male factor infertility and female factor infertility**

There appears a divergence in the care seeking pattern for couples with male and female factor infertility. The presence of male factor alone as the cause of infertility resulted in a truncation of the mainstream (allopathic) treatment due a range of reasons, which are discussed subsequently in this chapter. Initial treatment seeking was done by most men and this trajectory of care seeking stopped at different points. Some decided not to pursue treatment once the diagnosis of male infertility was made while others went on to seek medical or surgical corrections as advised by the treating physicians. But when advanced treatment options like IUI or IVF were suggested as treatment, majority of the men declined such treatment and hesitated to continue allopathic treatments. Due to the side effects of the medicines many men reported that they discontinued the treatment since it was impairing their daily activities and work. As men were having to work, they were unable to attend the consultations with the doctor. While women continue to seek care for their problem even with all the difficulties of the treatment, men seem to stop at some point.

#### ***Disappearing men: Discontinuation of care seeking for male factor infertility***

Women reported that their husbands were not interested in continuing with specific treatment suggested by the doctor and thus either dropped from the treatment pathway

or sought other methods of care. This was particularly reported by women whose husbands were having low sperm count and needed IUI or other ART treatments. Such treatments were not acceptable to the husbands and they felt that these were not needed. There was a prevailing notion that insemination treatments used donor sperm and this was unacceptable. One woman reported that they had done IUI but with husband's sperm.

*"I was not having any issues to do IUI/IVF but husband was not interested".* (Radha, 53 years with male factor infertility)

*"Doctor told sperm count is low, try taking the medicines. If it is not improving with medicines we will do this like that he told. He told about injecting sperm, but when doctor told about the injecting treatment husband said no need."* (Jasmine, 30 years with male factor infertility)

*"They told like this, after doing tube test (HSG) if there is no positive results, then have to inject sperm, after hearing that my husband was not agreeing."* (Sulfath, 27 years with male factor infertility)

*"Why we are not interested in it is because people say different opinions, we have not enquired about it more, they say it is done by taking another sperm (someone else's sperm) and injecting. Pregnancy happening that way is not right that's why."* (Sulfath, 27 years with male factor infertility)

One of the women also complained that her husband's reluctance to listen to the suggestions has created the current situation in her life, which left her alone after her husband's death.

*"Then he always told me what if there is no child, we will live like this. Now I think if he had listened about adoption there would have been a child."* (Radha, 53 years with male factor infertility)

***Persistent women: Women continue seeking care amidst difficulties***

Women experienced physical and cultural difficulties during the treatment process. The physical discomforts stem from the various treatment procedures and the need to comply with the instructions of the doctor. This included the need to have intercourse on the day when injection was given for ovulation induction. They stated that the injection was painful and it was hard for them to even sit but were driven by the need to have a child which made them forget the physical pain. Some even added that on such days the inclination to have sexual activity diminished but they had done it just for having the child. There were also cultural difficulties for them when the examination was done by male doctors.

*“When given injection, it will be very painful, we can’t even sit properly by pressing the back. The day when injection is given that day it will be very painful, then they ask to have sexual contact on that day itself. Then it is for us, right? so we overcome it.”* (Sulfath, 27 years with male factor infertility)

*“I am having the problem, so how much ever pain is there I will have to endure it because I should have a child somehow.”* (Shyla, 36 years with female factor infertility)

*“Yeah, pain is there while doing scan. Where ever we go all the doctors will be male, so when they do scan and all it is difficult for us. If it is Dr X or Dr Y they are all men and they only will be doing the scan, so it is difficult for us. Then the tiredness due to taking the medicines, medicines have a lot of side effects.”* (Shahina, 37 years with male factor infertility)

But all these difficulties were endured by the women thinking that they will get a child at the end of it. Women said they were not unhappy in bearing the difficulties but were stressed when they had to do the pregnancy test after all these hardships.

*“No problems like that. During that time we will not feel fed up, we are doing it with a hope so there won’t be that feeling of fed up. Then when we get to know it has not happened then there is despair.”* (Maya, 46 years with female factor infertility)

*“No, there is no tension when doctors advise to have intercourse on specific dates, but tension is when we do the pregnancy test. Then both of us will get up in the morning do the test, if it is negative then that day is over will be crying and all. That time is the tension. Otherwise no tension, it is for having child right. Some days they say not to have sex, for good sperm to form.”*(Malathy, 38 years with male factor infertility)

### **9.2.3 Misinformation/Misconceptions about ART treatment leading to its non-adoption**

The reluctance to do IUI/IVF stems from hearsay knowledge about the use of donor sperm in such treatments. There is a popular notion that treatments like ART are not needed if the man’s semen shows evidence of the presence of sperms. Therefore, when such treatments are suggested, they think donor sperm will be used nefariously and it is not necessary because the man’s semen has sperms. Women have reported that they were unaware of the details of the treatment due to poor communication by providers or lack of understanding of information communicated to them.

*“There is no one who has done such (ART) treatment here, I don’t know anyone. But people say it will be someone else’s sperm and it won’t be ours. It will be someone else’s we cannot believe what it is right.”* (Jasmine, 30 years with male factor infertility)

*“It may be because of our lack of knowledge. We have been told by the doctor that both of you get admitted and then we get you sperm and do it and all.”* (Sulfath, 27 years with male factor infertility)

### **9.2.4 Acceptance of ART treatments: Female factor infertility as the cause**

IVF was adopted by couples when female factor is the cause for infertility and male partner was completely normal. This meant that the idea of having own sperm was very much needed to adopt ART treatments. There was inhibition to undergo treatments like ART which was needed, owing to its conceptions held by the couples.

*“When we were planning to do IVF. But doctor told it is not needed for us, there is a lot of eggs, and it is done for those who do not have eggs. But husband was adamant about doing it, we need a lot of money to do it, in gulf we spent 30,000 dirhams, he was very adamant about doing it. So like that we did it.”* (Shyla, 36 years with female factor infertility)

*“Husband did not have any issues in undergoing IVF treatment, everyone was like somehow a pregnancy should happen. Since I delivered once [had Intra Uterine Death], somehow one will happen like that hope was there. That is why we borrowed money and did IVF.”* (Maya, 46 years with female factor infertility)

### **9.3 Consequences of infertility for women**

Infertility invariably places the women in a more disadvantaged position due to the gender norms and roles prevalent in the society. For instance, when men were able to discontinue treatment at their whim, women continue to persist in the care pathway because of the consequences they have to face in the family and the society.

#### **9.3.1 Women were forced to persist in the care seeking pathway due to social norms**

The social norms regarding the need for a child and the role challenges of not fulfilling parenthood both place women at cross-roads demanding that she be seen choosing some sort of care.

Society questions women at every juncture regarding the absence of pregnancy and this makes her persist in the pathway of care. There is always interference by the community members regarding the status of pregnancy and the course of treatment.

*“I pray that no women in this earth should have this situation. Whichever child, but everyone should have one child for themselves. Those without a child will be totally separated or are made to feel alone/separated from the rest. When we go for some functions and all, we will be alone.”* (Maya, 46 years with female factor infertility)

Women believe there is no meaning to life without a child, this is reinforced by the notions of the society which stipulates that a married woman should have at least one child.

*“Yes they ask, till now nothing has happened or no child yet - like that. I tell no. I am fed up hearing that.”* (Naiha, 32 years with male factor infertility)

### **9.3.2 Inevitability of blame for infertility for women**

The inevitability of the blame and burden of infertility falling on women is demonstrated by the narratives of the women. They said that even when the reproductive impairment was their husband's, the family blamed the women. They also compared the difference in reaction to male and female infertility, when men were having problem they acquiesce and sympathise while women had to live in fear about the questionings of the society and the threat of divorce.

*“That we will be separated from the society. Then there will be a threat for divorce, there are such things happening in the society.”* (Raji, 34 years with male factor infertility)

*“In house we do things whatever we can. When we take medicines, we will be tired, then they say you are just lying down without doing anything.”* (Raji, 34 years with male factor infertility)

*“Husband is driver, so he said that the high dose medicines and the job I am getting tired, so he was not interested to take that medicines.”* (Raji, 34 years with male factor infertility)

*“If I was having the problem I would have been in my house (meaning natal home).”* (Jasmine, 30 years with male factor infertility)

Women will be labelled as infertile for not being able to get pregnant and have to face reprobation from the family and the community. Even when they were not having any impairment, they had to take the blame to deflect exposure of husband as the person

with infertility. Men rarely acknowledged that it was their problem which stemmed from the reluctance to discuss male infertility publicly.

*“Yes, there is a little bit of problem in the family. It will not be like our own mothers, out of 100 people 90 people will be like this kind of people. So whatever it is it will not be like our own mother. We are going in harmony in a way we can.”* (Raji, 34 years with male factor infertility)

### **9.3.3 Distress caused by infertility-borne mainly by women**

Women are invariably affected by infertility even if the reproductive impairment is that of their spouse. The absence of a child creates a lot of emotional consequences for women including feeling of distress when seeing others with children or while when others tend to parental roles. This distress stems from the inability to perform such duties themselves and also these instances remind them of their own body, it makes them question whether the body of the self is defective or faulty.

*“When others pamper their child we also will wish one for us. We will not be like this forever right, we will get old, so when we fall there should be someone to hold us right?”* (Naiha, 32 years with male factor infertility)

Women reported that such distress affected them more since they stayed at home most of the time and did not had a mechanism to vent their feelings, while men tend to cope with it by resorting to alcohol or engaging in other activities.

*“When I stay at home it will be more, when I stay at home, after all work I will have a lot of thoughts, ...”* (Raji, 34 years with male factor infertility)

### **9.4 ‘Hope’: A way to sustaining the care**

Continuation of treatment does not only impinge up on the women’s endurance but also on the communicated or miscommunicated ‘hope’ through the providers’ good offices. This results in the sustenance of care seeking for infertility among couples. They tend to be driven by the ‘hope’ that one or the other treatment will bring in a solution to their problem.

#### **9.4.1 Plurality in care seeking for infertility due to ‘acceptance’ of misinformation and ‘hope’**

The presence of ‘hope’ which was passed on by people who were successful in their pursuit drove the couples with infertility to seeking care. They shuttled between care providers to achieve a positive outcome. Women said that they shifted from provide to provider suggested by others hoping that they will get pregnant somehow.

*“We have taken English medicines (allopathy), have taken ‘nadanmarunnu’ (traditional treatments) and all medicines. English medicines alone we have shown to 5-6 places. Each people tell one place, we will go and show there.” (Jasmine, 30 years with male factor infertility)*

They also reiterated that the plurality in care seeking did not happen in the vacuum but was fuelled by the responses from the providers. They said they were never told by the treating doctor that they harboured a condition that made it impossible for them to get pregnant. They also added that the information provided by the providers was very crucial in taking up treatments or abandoning them. This created ‘hope’ in them and hence abandoning care was not a sensible option and made them continue in the pathway of care. This also meant that when medical options were exhausted, they relied on alternate methods to achieve pregnancy.

*“I was not having any problem to do IUI but husband was not interested. Husband was not interested because there was hope that pregnancy will happen by taking medicines and all. He was taking medicines, so count was improving, it will happen like that hope was there.”(Radha, 53 years with male factor infertility)*

*“Doctors told that we will have child. There are no reasons for not to have. Will have there is no difficulties like that. We had visited about 10-12 doctors till now, when people tell we go to different places. Each person will tell one place so we go there. We will go to one place then when there is no result we go to another place with the hope that it will happen. Then we will take treatment for 6 months there, and when*

*there is no result we will change from there.” (Nihar, 30 years with male and female factor infertility)*

The possibilities fostered by this ‘hope’ causes them to forgo discussions on the option of adoption. The ‘hope’ of having an own child someday prepts the couple to venture into adoption.

*“I have not thought about adoption until now. We will have a child like that we have been told. So there is no need for us to think about adoption. So how much ever time it will take we hope one should happen.”(Raji, 34 years with male factor infertility)*

*“No, we haven't thought about adoption because ours has not slipped out of our hand, when our hope is over then only will we think about another thing right.”(Sulfath, 27 years with male factor infertility)*

#### **9.4.2 Sustenance of treatment also fuelled by financial resources**

Although ‘hope’ plays a role in treatment seeking, other factors including the presence of financial resources were important to sustain the care seeking. Women reported that treatment was sought intermittently (shifting from allopathic to alternative too) due to financial limitations. This continued till a solution was achieved or when both physical and fiscal resources exhausted.

*“When there is no money we will not show the doctor, we have to get it from here from the sea [husband is fisherman], when there is no money we stop. Then when we get money then only we will treat. One time it cost around 1000-2000 rupees. If there is that much money we will go if not there then we will not show doctor. We have sold the gold and have taken treatment.” (Jasmine, 30 years with male factor infertility)*

#### **9.5 Coping by women**

When women are confronted with blame and experience distress associated with it, they find ways of reducing it.

### **9.5.1 Ways of eliminating/reducing such distress experienced by women**

The distress reducing measures as shared by women were learning to live with infertility. This is done by ignoring those who were casting blame on them or confronting them. They find solace by learning to live without casting blame on each other for instance when the husband is having the problem the wife accepts it and lives with it and vice-versa. Some women said that they do not admit their husband's problems and thereby shield them from the blame.

Some women also said there was a supportive environment within the family and it was less stressful in such situations when the partner or the in-laws do not blame.

*“One lady told “she is a ‘machi’” ( ‘machi’ is a derogatory word which means one without a child), then they will be telling these without us hearing. One lady has told which I overheard. And I got very sad. My sister in law was also there, she also did not have a child then. That day I told that lady, this is because you have not faced it you do not know the pain of it. When I told like this she understood the intensity of what she said. She said sorry. They may be telling it because of their lack of knowledge.”*  
(Sulfath, 27 years with male factor infertility)

*“We share our sadness, we do not blame each other and all. This all is what god gives, there is no use blaming another person for it. It is me who tells the sadness.”*  
(Sulfath, 27 years with male factor infertility)

*“We both do not blame each other. We tell there is no problem, God will correct it like that we tell. We only have to know our problems.”* (Malathy, 38 years with male factor infertility)

*“People used to tell “that lady without the child is coming” and I just ignore it.”*(Radha, 53 years with male factor infertility)

*“There is no blaming in the family. They will ask whose problem is it, so if I tell it is husband's problem, then there is no issues since it is because of his problem.”*  
(Jasmine, 30 years with male factor infertility)

### 9.5.2 Apathy

Women reported that even after being medically proven that they were not having the reproductive impairment the in-laws blame them. Some of them added that because their own son would never be blamed, the blame will fall on the women. They tend to develop an apathetic acceptance after years of shielding the partners.

*“Since we are coming from our house to another house, we will only be criticised. Parents will not blame their own children. Always will blame those who have come. Any mother in law or anyone will, their own children will not have any shortcoming [...] Long back husband’s family asked him to re-marry, that time he has asked if there is no child in that also what will I do? But then also he has not told anyone that he is having the problem he has only told what if that is also like this? Will you give food for that person like that he has asked to his sisters. He never let it outside, it is his problem like that he has never told. When someone asks he just gives counter answers, sisters or other when they ask he will not tell, to sisters he tells what if that also do not have what will you do, will you give like that he asks. So I thought I don’t have to tell it. [...] What to tell, I had forgotten all the things. What we have done, what we have not done everything I forgot.”* (Radha, 53 years with male factor infertility)

### 9.6 Discussion

The findings from the analysis of this data shows that the continuous cohabitation of the couples is an important factor that helps in early care seeking. The intermittency in treatment seeking caused by the non-availability of the husband is a major cause for treatment not succeeding. When care seeking is initiated, depending on the diagnosis viz., male factor or female factor, the treatment trajectories diverge. If there is male involvement, either the side effects of the treatment or time constraints due to job or both brings the care seeking to halt. But if female factor is the cause for infertility, there is systematic effort at treatment seeking by women even if the process is painful, or emotionally disturbing. Such difficulties are withstood by women because of the social and cultural environment which causes them to look at the trade off in terms of the cultural significance of having a child. This has been discussed in studies where it was reported that while women take a proactive role in care seeking, men take a passive

role (Batool & de Visser 2016). Men tend to escape the physical and mental trauma mostly owing to the fact that male infertility is never discussed in the public domain as one of the main causes of infertility among couples.

Women continue to persist in the pathway of care because they are afraid of being abandoned by the husband and fear divorce. This has been reported in studies done elsewhere and they also discussed that those women who were economically dependent on their husbands fear this abandonment more and tried to cover up the male infertility issues (Nahar & Richters 2011).

Women persist in the pathway of care due the emotional distress caused by labelling and the agony of watching other people catering to their own children. The continuous inquisition of the public regarding the status of the pregnancy also makes them persist in the pathway (Batool & de Visser 2016). Regardless of the causes for infertility, male factor, female factor or both, the care seeking is impeded by lack of knowledge or understanding of the various treatment procedures. The wrong beliefs about the use of donor sperm or the general disinterest among men to undergo treatment results in intermittent care seeking. Continuation of treatment does not only impinge upon the women's endurance but also communicated or miscommunicated 'hope' from doctors. This 'hope' combined with the notion of an own child prevent adoption as a means to ward off discriminatory labelling. Along with these, care seeking is sustained by the availability of money. This intermittent treatment utilises other systems of medicine, or alternate methods or magical remedies depending on which ever of these is said to produce results. The seeking of allopathic treatment when it physically possible or financially feasible and use of alternative options when it is not continues till they reach a stage when either their physical or financial resources are exhausted.

This process is extremely tiring and physically exhausting for women who have to take the blame and also subject their bodies to various treatments. The emotional distress that the couples go through can be significantly reduced if there is acceptance among both husband and wife or if male infertility is carefully hidden by women accepting it and the partner shielding the women from adverse consequences like divorce. On the other hand, minor bodily problems which are treatable leave them highly anxious as to

their situation vis-a-vis the marriage. They were afraid that any stated problem in the female body will disrupt the marital arrangement for them.

From having to take the blame for infertility to bearing the physical and emotional difficulties of treatment and finally to be ridiculed and challenged by the society and experiencing mental distress, women are invariably more affected by the absence of a child. This arises partly because of socially construction of infertility and partly because of the gender norms and roles prevalent in the society.

## **Chapter 10**

### **Discussion and Conclusions**

In this chapter I will discuss the empirical findings of this thesis and their implications. This discussion is based on the ‘hope framework’ identified through this research process. I will also discuss the limitations of the study and the policy recommendations in this chapter.

The empirical findings presented in the thesis were based on the following research questions;

1. What is the expected level of infertility for Kerala and its districts?
2. How do couples seek care for infertility in Kerala and what are the reasons for the care seeking for infertility?
3. Is there any inequality in the care seeking for infertility in Kerala?
4. What are the consequences of infertility for women in Kerala?

#### **10.1 Care seeking for infertility: ‘Political economy of hope’, deterritorialization and reterritorialization**

In this study, I use Gille Deleuze and Felix Guattari’s concepts of deterritorialization and reterritorialization (Deleuze & Guattari 1987) to understand the ‘political economy of hope’ in infertility care. These concepts will be used to draw together the findings of the study, and to explain how the deterritorialization of reproductive health care and the deterritorialized infertile couples together sustain the ‘political economy of hope’.

‘Hope’ was a recurrent narrative in the stories of women who sought infertility care. But, ‘hope’ tends to be more at an individual level and although the study focused on individual care seeking, it encompassed more than just individual problems. Infertility care seeking does not happen in a vacuum and there are other contextual factors at play like the social, economic and political factors. Thus, the concept of ‘political economy of hope’ a term first used by Good et al. (1990), is used here to recognize and link the multiple processes that operate in the care seeking pathway for infertility. The conceptualisation of ‘political economy of hope’ serves as a vantage point to examine

the care seeking for infertility because infertility care involves multiple stakeholders with varied interests.

The 'political economy of hope' in this context refers to the power or the authority of biomedicine or the power of knowledge along with the political and economic forces that control this power, which creates hope among those with infertility. The clear heterogeneity of interest of this knowledge lends itself to be scrutinised under the scope of 'political economy of hope'. Here, hope takes a submissive role to the knowledge and it (hope) operates at multiple levels to transcend the boundaries of physical, emotional and financial barriers of the couples with infertility. By layering the construction of 'hope of parenthood', the multiple risks involved and the probability of failure of the procedure(s) involved in infertility care are papered over from the realm of reproductive medicine to the realm of political economy of hope. This serves to synthesise the multiple players' (including those of the significant others, providers and regulators) desired option of converting individual desire for a child to a thriving enterprise that feeds off on this hope to builds a market for itself. Such a building up of hope does not happen in a demographic or socio-economic vacuum. The value of a child emerges out of declining fertility rates. Child birth itself does not provide scope for profits when birth rates are shrinking and therefore market driven reproductive care industry needs to look at other segments that offer the promise of better returns for investors. In addition, professionalisation of obstetrics and gynaecology as a process calls for the application of 'improved' technology into the reproductive process, building up its social status within peer groups of medical professionals. All three forces contribute to the building up of the political economy of hope, building up the expectations of overcoming biological limitation.

'Political economy of hope' is sustained by different stakeholders, in infertility care it includes scientists, clinicians, patients, bio-technology industry, and market forces. But different stakeholders have different interests in this and to explain how each of these operate in conjunction to sustain this 'hope', I have used the concept of deterritorialization. Deterritorialization means *destabilising the spatial boundaries or increase internal heterogeneity* whereas reterritorialization means *establishing a new*

*relationship, a new process, a new interaction, a new interlinking* (Deleuze & Guattari 1987). My analysis here focuses on the care seeking pathway for infertility and how couples navigated different trajectories to achieve their desired outcome. In the subsequent sections, the infertility care seeking's 'political economy of hope' will be explained using the findings of the study and how couples territorialized on infertility care.

Reproductive medicine is a specialised field concerning the male and female reproductive systems and this field specialises in the diagnosis and treatment of infertility. This specific field of medicine is deterritorialized in the context of the reproductive care, and the specialised knowledge of doctors is used by the market to form a for profit sector. This means that the infertility care delivery is deterritorialized. It is not only the infertility care that is deterritorialized but the infertile couples are also deterritorialized. This will be explained in subsequent section based on the empirical findings.

### **10.2 Demand for infertility services and (bio)medicalization of infertility**

According to the Census 2011, the expected level of infertility for Kerala was estimated to be 16.8 percent among all women in the age group 15-49 years. The expected level of infertility was 6.1 percent for ever married women in this age group. It was 5.8 percent for women in the age group 45-49 years. Based on the Census of India data analysis the childlessness level was four percent in 1981 and six percent in 2001 for ever married women aged 35-39 years (Ram 2010). The infertility level for India was 11.8 percent based on the criteria 'sex but no pregnancy' and it was 16.8 percent based on the criteria 'sex but no birth' in 1998-99 (Rutstein & Shah 2004). The NFHS-2 and NFHS-3 data estimated the infertility levels to be 2.0 percent and 1.9 percent respectively for women married for 5 years (Ganguly & Unisa 2010).

The expected level of infertility at 45-49 years was high in Malappuram (6.7%) and low in Wayanad (4.4%). The expected level of infertility was high in Pathanamthitta (9.3%) and low in Kasaragod (4.5%) among the ever-married women in the age group 15-49 years. The infertility levels based on the 45-49 years may be reflective of a true level since beyond this age group, even the intervention assisted reproduction is

restricted due to the limitations of biological functioning. But these measures which are based on the end of childbearing years in a woman, may not be reflective of the recent trends of infertility (Rutstein & Shah 2004).

The age pattern of infertility measured using the period measure, gave an idea of expected levels of infertility by age. The rate of decline in infertility in this group is possibly indicative of intervention aided decline. For all districts in Kerala except Malappuram, the current expected levels of infertility was lower than the CEB based measure. This could possibly be indicative of the absence of intervention in this district either due to absence of infertility services or due to non-utilization of available services.

#### **10.2.1 Demand for infertility services in the state**

The analysis of data from the Census of 2011 demonstrates that there is a definite demand for infertility services by the couples beyond age 35 years. As noted, 90 percent of the TFR is achieved by age 30-34 years and beyond this age there is a decline in the natural fertility due to the biological limitation of the reproductive functions in women. It is thus clear that beyond this age, some couples who are infertile and have not achieved pregnancy, will be in need of medical interventions to achieve pregnancy. It was estimated that around 6-7 percent of couples in the age group 35-49 years may be in need of infertility services in Kerala.

In Kerala, there is higher level of private sector participation in health care and this is noted in reproductive health care services also. This engagement of the private sector is higher in the northern districts compared to the southern districts. We have noted that the northern districts viz., Kasaragod, Malappuram and Palakkad have very high expected levels of infertility at 45-49 years. We also observed that in these districts the proportion of institutional deliveries in the public sector is between 20-30 percent. This means a large share of reproductive health care in these districts is through the private sector pointing to the privatisation of reproductive health care particularly in the northern districts of Kerala. Although the exact number of private providers offering infertility services in the state is not known, majority of infertility services are concentrated in the private sector. This can be discerned from the data on the number

of centres in the country, according to the International Federation of Fertility Societies (IFFS) surveillance report (2016), there are around 1000 ART centres in India of which 99.5 percent of the centres are private physician clinics and only 0.5 percent are public hospital-based clinics (IFFS 2016). This can be attributed to the (bio)medicalization of infertility and also the market operating on reproductive services. The public sector infertility services are mainly concentrated in the government medical college hospitals in Kerala, and not every district of Kerala has a government medical college and where ever available, a fully functional infertility clinic is not part of all medical colleges. Thus, this shortage in public sector facilities creates an opportunity for the private sector (Sadanandan 2001) to expand infertility services in the state. Such a state of affairs means that financially less endowed couples may not be able to afford infertility services, which has significant out of pocket expenditure.

Using the CEB based and CFR based expected level of infertility, a higher CFR based measure compared to CEB based measure means that the level of infertility expected in the present is higher than that of what it actually should be. In Malappuram, there is a higher burden of infertility in the present than what is expected based on CEB based infertility level. One of the reasons could be that there is less intervention happening in this district, or conditions requiring interventions are being not used by the couples due to personal reasons or difficulty in accessibility and affordability of such treatments, which was reported in the survey.

Based on the indexed values we see that only a small proportion of infertility has gotten bridged between 35-49 years with northern districts having more proportion getting pregnant at later ages compared to southern districts. In Malappuram, we see that from the census data, nearly 40 percent of the infertility is bridged between 35-49 years while in Kottayam and Thiruvananthapuram, this proportion is as low as 23-24 percent. This could mean that in districts like Malappuram, postponement of pregnancy is happening due to the migrant status of the husbands, and treatment is initiated fully when the spouses return from overseas and this explains the 40 percent of bridging that happens in the later ages. While in Kottayam and Thiruvananthapuram, interventions may be happening in earlier ages and the very few

cases who are less responsive to the treatments may be continuing the treatment till later ages. From the survey data, we noted that in Thiruvananthapuram and Kottayam approximately 29 percent had achieved pregnancy while in Malappuram only 16 percent had achieved pregnancy.

Despite the high cost of care in the private sector and less number of facilities in the public sector, in the analysis of the survey data to understand the care seeking pathway of infertility, we see only a small proportion utilised the public sector (11.0%) compared to the private sector which was used by 86.0 percent of the couples, when they initiated the care seeking. Most of them stayed in the care pathway for many years and visited multiple centres.

We have noted that there is medicalisation of health care in Kerala where majority used formal medical care for minor ailments and this care for the ailments is predominantly sought from both the public and private hospitals in the state. The presence of private sector in the health care sector is also demonstrated by the proportion of facilities in both public and private sector. We also see a huge presence of private sector in Kerala where majority of the institutional deliveries are happening in the private sector. So, when we look at infertility care, which is a highly specialised care, the limited facilities in the public sector would drive the couples to seek care in the private sector hospitals which is clearly evident in the study where more than 80 percent are seeking care in a private facility.

Thus, the demand for infertility services which is not met by the public sector, is taken over by the private sector. This together with the biomedical advances in the infertility care, which is catalysed by the market forces offers new opportunities for the private for-profit sector. Reproductive health care mainly consisted of treating gynaecological morbidity and childbirth (Becker & Nachtigall 1992) has shifted its focus to infertility care also when the gynaecologists started specialising in reproductive endocrinology. The (bio)medicalization which has brought about advancements in reproductive technology to treat infertility have enabled the couples to manage their condition which would have been impossible in earlier times. The (bio)medicalization process which is driven by the technoscientific advancements and the market forces (McCabe

2019), has blurred the boundary between the disciplinary power of medicine and market forces.

This deterritorialises reproductive medicine, where market forces use the disciplinary knowledge of the doctors creating specialised knowledge and also creates ‘hope’ for the infertile couples to use the technologies to achieve their parenthood dream through popular media representations of the success of these technologies.

### **10.3 Care seeking for infertility: From ‘desperateness’ to ‘hope’**

The infertile couples are referred to as ‘desperate’ in popular representations of infertility (Franklin 1990), and this desperateness stems from the natural desire for a child independent of the social context, along with other socio-cultural factors. Therefore, the desperateness as noted by Franklin (1990) arises because of the social pressure to conform and the biological pressure to reproduce. This pressure to conform to the norm and to have own child was observed in this study.

From recognising the difficulty to get pregnant to care seeking to achieving the outcome or stopping the treatment at each stage the couples were confronted with multiple problems. The care seeking was initiated by the context and the individual factors of the couples and the treatment related factors decided whether they continued in this pathway or not. In the study it was noted that the decision to start treatment stemmed from the desire to have a child and also the pressure due to public inquisitions regarding achievement of pregnancy status. The role of social contexts in shaping care seeking for infertility was reiterated in this study by the women who reported that they were constantly under the public scrutiny and were also objects of social ridicule in the absence of a pregnancy. This made them emotionally vulnerable and this pressure forced them to seek care not only in the beginning but also during the times when they took a break from the treatment. Riessman (2000) reported similar accounts of women who said that they sought care because of the public scrutiny and labelling. This public scrutiny of women stems from the notions of womanhood and motherhood which is prevalent in the society (Widge 2005).

The expectation from society made the women embody the idea that it is their bodies that were harbouring the problem. Women were anxious about embodying reproductive impairment when they failed to get pregnant. This was mainly due to the fear of marital disruption and other social repercussions. The women in the infertile couple live in fear of marital disruption and abandonment and their lives were subjected to stigma and gossips (Nahar & Richters 2011). This happened even in the absence of absolute female infertility, because male infertility diagnosis also brought in uncertainties in women's life. They were blamed for it by the in-laws, and to add insult to injury they had to take the blame voluntarily to avert shame for their husbands. Male infertility is seen as something not absolute, since it is believed that as long as they can ejaculate they are fertile (Inhorn 2003). Women shoulder the blame for their husband's infertility problem to avert stigma, psychological trauma and possible marital disruptions that can occur if male infertility is disclosed (Inhorn 2003).

The gender norms attribute the motherhood role to women and those who fail to attain this role are subjected to isolation, stigma and social ostracization (Hampshire et al. 2012). So, women fear this state and strive to achieve motherhood by any means. What this essentially entails is that they have to continue seeking care till they achieved the desired outcome.

We see here that the couples have visited multiple doctors or hospitals, even alternate methods like faith-based healing, folk medicines and magical remedies were also used by couples to achieve the desired outcome. The respondents in the study had used up to 11 centres at the time of survey, with up to four centres used by 40 percent of the respondents. While majority of them had used only allopathy for treatment, some of them had combined it with Ayurveda, Homeopathy and even with alternate methods. It has been reported in studies that the most frequently deliberated option was medical help by the couples (van Balen et al. 1997). A preference for Allopathic system of medicine was observed in a study done in Kerala (Ravi 2017), which also showed that the infertile couples used different systems of medicine to achieve the outcome (ibid). This indicates that the couples are trying everything within their means to achieve pregnancy, which points to their 'desperateness' to conform to the norm/reproduce.

Because even when they reported that the treatment cycles were physical and emotionally demanding they chose to stay in the pathway.

Majority of them got pregnant at the first two centres, while among the couples who proceeded to the third or higher order centres, the proportion of those taking a break from treatment increased. The reasons reported for taking break or stopping treatment at a specific centre were, no faith in the treatment being successful at that centre, or they had exhausted their financial resources and the break time helped them to replenish the resources. Also, some stopped treatment due to the unacceptability of the proposed treatment (viz., IUI or IVF) by the doctor. The in-depth interviews with women found that this unacceptability stemmed from the fear that donor sperm will be used. This unacceptability of donor sperm has been reported in a study done in Kerala (Ravi 2017), while another study from India reported that the use of donor sperm was acceptable to the couples compared to adoption, but there was always secrecy in the use of it due to social and cultural boundaries (Bharadwaj 2003).

Couples who needed assisted reproductive methods to achieve pregnancy declined it due to the fear of use of donor sperm. This also meant that they try alternate methods to achieve pregnancy thereby prolonging their care seeking. The taboo attached to donor sperm is evident in the narratives of women who reported that assisted reproduction was done in cases where the husband had no reproductive impairment and only the wife had a problem.

Another reason for break in the treatment or stopping treatment as reported by the women was that the treatment cycles were demanding and this affected them both physically and emotionally. While this was cited as a reason for stopping treatment, women simultaneously averred their efforts to seeking care as long as they could because they wanted a child and they were also afraid of the adverse consequences it had if they did not. They also said that even though they were ready to continue treatment, husbands who were subjected to any kind of treatment, discontinued the care trajectory citing physical weakness and the inability to continue the treatment. They were breadwinners of the family and hence their physical agility was important

compared to women who were likely to be verbally abused by in-laws if they took some rest after taking medicines.

Even when desired outcome was not achieved after a considerable period of treatment, the couples continued to use different methods because they were sustained by 'hope'. This was a common theme that emerged in the in-depth interviews, that they had the 'hope' that they will get pregnant. The reassurance by the treating doctors and success stories of others who had utilised infertility services were some of the factors that sustained the 'hope' in the couples to continue to seek care. Hope has been attributed to both positively and negatively in previous studies, where the positive aspects have stated that it helps sometimes in making the treatment effective while the same hope can hinder the acceptance of non-success (Volgsten et al. 2010; Boden 2013) thereby prolonging their quest to parenthood through various treatments.

This desperateness of the couples is used by the infertility clinics which transform the desperation to 'hope'. This aspect of 'hope' is portrayed in popular media representations of successful and happy couples who could achieve their desired outcome through the technological interventions. This medical hope which is portrayed via the advertisement do make unrealistic claims viz., guaranteeing pregnancy, and this makes couples to choose the clinics (Davis & Loughran 2017).

The notion of an outsider i.e., a feeling of not belonging to the fertile world was expressed by the women in their narratives. This isolation and loss of identity means that they consider themselves different from the women who reproduce. The inability to reproduce resulted in a sense of exclusion from the fertile group and also a loss of identity (Franklin, 1997). This alienation from the fertile world renders the infertile couples deterritorialized. Thus, the couples with infertility are deterritorialized by their sense of exclusion from the fertile group.

### **10.3.1 Consequences of infertility for women**

From diagnosis to parenthood, women are affected by infertility more strongly when compared to men, and this can be attributed to the social construction of reproductive bodies and the gendered ideologies of equating womanhood to motherhood. Women felt that they are always under scrutiny for the inability to achieve pregnancy and

because of this they are forced to stay in the care seeking pathway when their spouses are usually not questioned for their inconsistent care seeking. Women's bodies emerge in the infertility discourse as the site of fault even when the diagnosis is that of male impairment. The gendered construction of women's bodies as the site of fault eventually gives rise to embodied uncertainties in women who think that it is their bodies which may be having the impairment. This makes them go through battery of tests and invasive procedures to evict blame and other negative repercussions of being infertile. In this study women reported that they were afraid of being abandoned by the husband or the in-laws if they were to be diagnosed with the problem. Women reported that they had to endure a lot of physical and emotional distress but continued in the care seeking pathway thinking it is for a child. But they also added that their husbands discontinued care seeking citing physical discomforts of treatment. Women are often willing to do whatever is needed to remove their infertility status as observed by Griel et al., (1988).

Even though women want to continue treatment, it is always dependent on their partner. The husbands are sometimes absent from the care seeking pathway due to various reasons or if they are present, certain treatments are declined by the husbands. So, even if the women want to, the decision to continue or discontinue the treatment is almost entirely that of their spouses. This is reported in the study that assisted reproduction was mainly chosen as a treatment in many instances when male infertility was ruled out as the diagnosis. Men tend to have more decision making power in heterosexual marriages, and their co-operation is needed for women to undergo IVF using either the husband's sperm or donor sperm (Lorber & Bandlamudi 1993). This can sometimes lead to overtreatment (through multiple methods being tried) or cessation of treatment without achieving the desired results (Greil et al. 1988).

Thus, we can see here that the persistence in care seeking by women or not seeking care is gendered. The absence of discussion of male infertility within the infertility discourse due to the stigma associated with it and also the association of male infertility with masculinity or manhood, the consequences of infertility inevitably falls on women. Women in most instances shoulder the blame for their partner's

reproductive impairment and this is also highly gendered in its construction. This is referred to as 'courtesy stigma' by Miall (1986). They are grateful for their husbands not abandoning them while they silently take on their husband's inability to reproduce.

Women suffer from role failure i.e., inability to have a child and be a mother when having to deal with infertility (Griel et al., 1988). The only solution they see to this is treatment, and when treatments do not bring desired results or when they have to stop treatment, they hold on to 'hope'. This 'hope' can take many forms, the myriad other treatments which they feel can give them positive results. So, when a woman's *raison d'etre* for existence is gauged by her ability to become a mother, they refuse to let go the 'hope' that these myriad treatments could offer. Franklin (1990) gave accounts of women who are drawn by the slender hope that their treating physicians give and who refused to give up treatment because of this. This will prevent couples from deliberating other child-rearing option like adoption.

This hope of the infertile couples is framed by popular medical representations to portray medical technologies as the obvious solution for the problem (Franklin, 1990). Although 'hope' played an important role in treatment seeking in the study, other factors including the availability of financial resources were found to be needed to sustain care seeking. Women reported that treatment was sought intermittently (shifting from Allopathic to alternative too) due to financial limitations. This means that when technology offers the solution and raises the 'hope' of couples, they are constrained by the limitations of affordability. When such technological solutions are available, it moves from choice to responsibility of the couples to undergo the treatment. Hence, such technological advancements put those who are unable to afford it in a disadvantaged position. These opportunities may be used by unauthorised and unregulated providers and similar persons with entrepreneurial skills to make couples use their services which may not yield positive results by design.

#### **10.4 Care seeking for infertility- ‘political economy of hope’: Reterritorialization and the new norm**

In infertility care we see that ‘hope’ plays an important role but we also know that this hope is created by the newer technologies. In the absence of such technologies couples who were infertile could move on from blaming their inability to try to achieve parenthood through other methods like adoption. But now, the availability of reproductive technologies have created ‘hope’ for the couples which is clear from the narratives of the women and also from their actions in negotiating multiple centres. This ‘hope’ is created by the treating doctors, others who have successfully used these technologies and the media portrayals of the success of the reproductive technology.

The findings from the study show that there is a clear demand for infertility care from the couples. We also know that the medicalisation of infertility has produced advancements in reproductive technologies. There is high level of private sector participation in infertility care in the state, which can be due to the demand of infertility care in the state. However, this demand is not adequately catered to through public sector provisioning. The infertility care service has been deterritorialized by virtue of the presence of market forces through the biomedicalisation of infertility, which creates ‘hope’ for the couples. The deterritorialized infertility care and the couples with infertility who are also deterritorialized due to the medicalisation and the social construction of infertility forms a new system. They now form a unit and this unit reterritorializes and the use of technological advancements in reproductive medicine becomes the new norm. This reterritorialized system creates inequality among those who cannot afford the care and also exacerbates existing gender inequalities. This is because the new norm of the reterritorialized system puts pressure on the women who are already burdened by the social construction of reproduction. So, in the reterritorialized context which is created by the market forces and propelled by the consumers (here the infertile couples), the exclusion of a majority is inevitable if the public health care system fails to intervene to cater to the needs of the couples who are unable to afford the infertility care.

#### **10.4.1 Inequality in care seeking for infertility in Kerala**

Multiple centres were used by the couples to seek care for infertility. We see that nearly 82 percent of the couples who started the care seeking had moved to another centre during their care seeking period. This means majority of them had not achieved their desired outcome at the first centre. From the second centre onwards, more than 50 percent of those entering each centre moved to the next centre up to the sixth centre, when totally up to 11 centres were used by some of the couples in the study. Majority (97 %) of the couples in the sample who reported pregnancy got so by the sixth centre.

Nearly one-fourth of the respondents had started treatment within one year of marriage, which means they would have entered into marriage at a late age. When we look into the age of starting treatment, 15 percent of the respondents were 30 or above when they started the treatment. And those who started treatment at ages 30 and above had lesser proportion getting pregnant compared to those started treatment earlier. This means that those who entered late in to marriage and had started seeking care at later ages were having difficulty in getting pregnant. Biological limitation could be one of the reasons for this observation. It could also mean that those who were older when they started treatment would have needed assisted reproduction and it was not affordable for the couples. In the sample majority of them belonged to the middle SES category and therefore the privatised infertility care would be expensive by their standards.

The couples were found using different methods to treat infertility, viz., Allopathy , Ayurveda, Homeopathy and alternate methods. Majority of them used Allopathy as the first line of treatment and it was continued by a majority across centres, but we see a shift to other systems of medicine subsequently. While only one percent used Ayurveda and Homeopathy when they started treatment, we see that in the second centre, three to four times more couples had used Ayurveda and five times more couples had used Homeopathy. This use of alternate systems of medicine continued to be higher than the use of allopathic centres in the public sector. This is because of the concentration of Allopathic treatment centres in private sector and hence the affordability becomes a problem and couples may opt to choose alternate systems of

medicine. Also, the couples reported long waiting times and also lack of knowledge of infertility treatment facilities in the public sector. Lack of trust in public hospitals, and long waiting times among others were reasons cited for opting for private practitioners by patients (Pinto & Udwadia 2010).

Across all centres, the proportion of women alone undergoing management was the highest compared to men or both undergoing management. Possible reasons for this could be that the treatment for infertility mainly is centred on women's bodies and women have stated that their husbands did not continue in the care seeking pathway.

The life table analysis showed that the rate of failure (getting pregnant) is higher for female factor infertility compared to male factor infertility across all the time intervals. This also is reflective of women staying in the care seeking pathway longer than men, and/or trying to achieve the desired outcome by persisting in the pathway. Similarly, management of only women had a higher rate of failure (getting pregnant), across all treatment durations except for 120-180 months, which was the highest for IVF. This means that couples requiring assisted conception are delaying it and the migrant status of the husbands could also contribute to the delay in treatment in this state. Regarding the management of men only, those who seek care earlier and stick to the treatment regime may get the desired outcome. But this probability declines as time period increases to 10 or 15 years and the outcome is a constant which means these may be men who require assisted reproduction who were still doing medical management or were taking alternate system of medicine for their problem. Medical management of both had a lower probability of getting pregnant compared to men alone in all age intervals.

In the sample, a majority of the respondents were not employed and only their spouses were employed. The inflexibility of the job, most of them being daily wage labourers, meant loss of a day's wages if they had to go for treatment. This is one of the main reasons for the reduced participation by men observed in care seeking.

IUI had a lower rate of failure at 0-60 months than medical management of men while it had a higher rate of failure at 60-180 months. This means that those requiring IUI

would have started using it after 60 months. Similarly, IVF also showed a lower rate of failure at 0-120 months and thereafter a higher probability of failure. This also is indicative of the later use of assisted conception by couples. This resonates with the narratives of the women who stated that they were reluctant to use such technology assisted conception due to fear of the use of donor sperm and also the constraints of financial resources. This means they are prolonging the pathway of care unnecessarily by using alternate methods when they clearly need ART for conception.

These findings are indicative of the socio-economic inequality in accessing the treatment for infertility. This is also reinforced by the narratives of the women in the in-depth interviews, who said that they had to pawn gold or had to borrow money to undergo the treatment. Many of them reported they had to take breaks to replenish the financial resources so as to restart treatment. Disparities in fertility treatment has been established in studies where women in the low SES had utilised the assisted reproductive technologies less frequently when compared to their better off counterparts (Bell 2010; Harris et al. 2016). Gender inequality also exists in the care seeking for infertility, since the burden of care seeking falls on women as they are faced with more adverse consequences due to the inability to reproduce by either of the couples.

Infertility care seeking's 'political economy of hope' is demonstrated in figure 10.1 which explains how from diagnosis to parenthood, such hope is maintained through the different structural, contextual and individual processes.

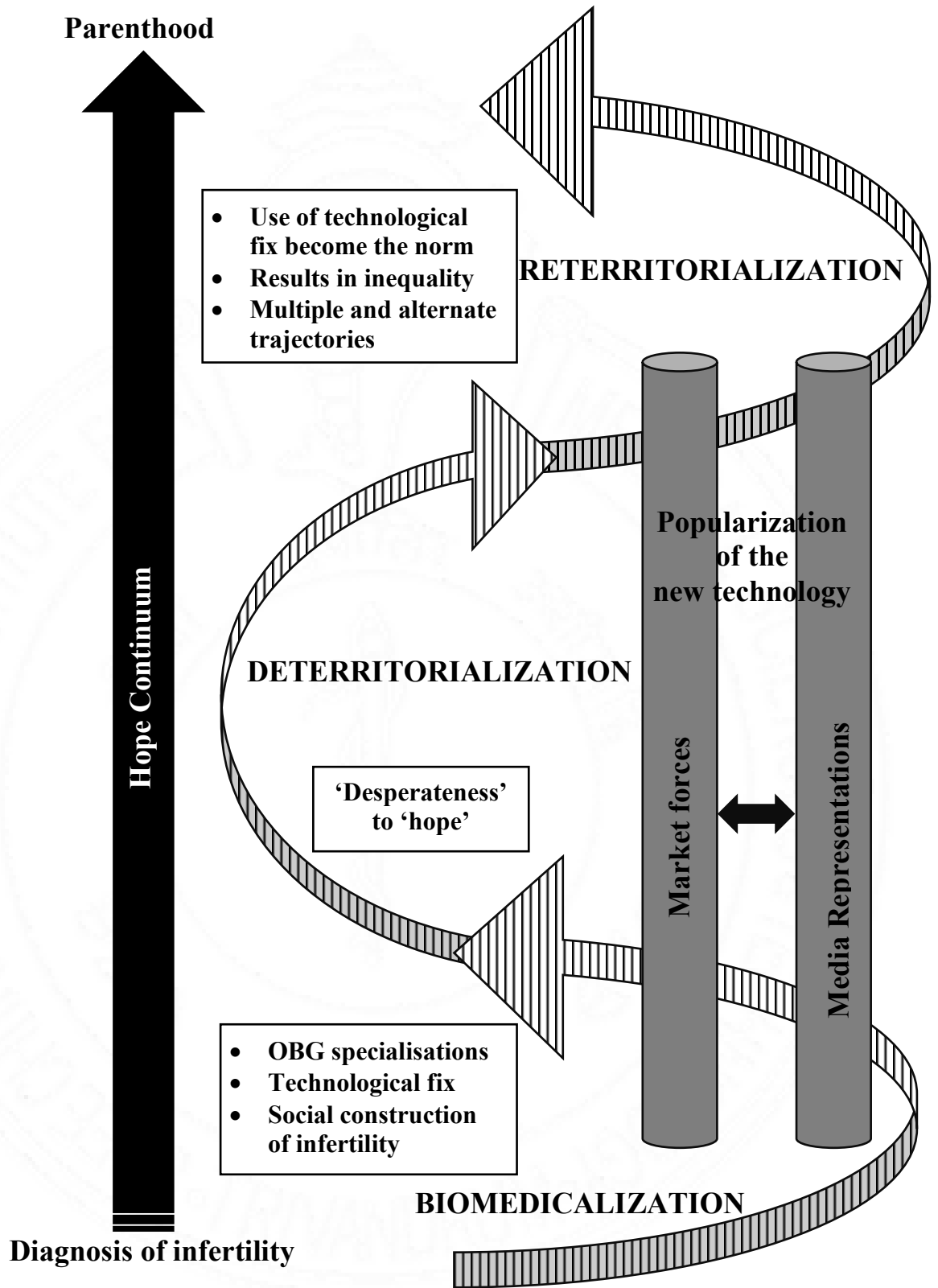


Fig 10.1: Care seeking for infertility-‘political economy of hope’

## **10.5 Conclusions**

The major objective of this study was to understand the care seeking pathway of couples with infertility in Kerala. The care seeking for infertility is a long process, with multiple centres and multiple options deliberated by the couples to achieve the desired outcome. This process of care seeking is prolonged by 'hope'. Those with female factor infertility have higher probability of getting pregnant even though the proportion of male factor infertility was higher in the sample. This is because women tend to persist in the pathway due to the possible consequences of infertility for them.

Socio-economic inequality emerged as a significant determinant in the care seeking for infertility in the study. The infertility care, which comes under the umbrella of reproductive health care, concentrated in the private sector is not affordable for all sections of the couples who need such services. The affordability of infertility care by the couples is also a contributing factor in the prolonging of care seeking for infertility. The affordability of infertility services has also pushed some couples to seek care from alternate systems or other methods. The study established that the probability of achieving pregnancy is significantly higher when the couples use allopathy alone compared to using other systems of medicine. Gender inequality is also evident in the care seeking for infertility in the study, where women have to stay in the pathway despite the physical and emotional difficulties of the treatment. Men tend to drop out from the care seeking pathway more haphazardly and this has consequences for the woman in the couple. There seemed a general reluctance among the couples to undergo assisted reproduction. This was attributed to poor knowledge regarding the treatment and also fear of using donor sperm, along with financial limitations to undergo such treatments. This also has prolonged the care seeking trajectory of the couples in the study, wherein those who needed assisted reproduction abandoned that and pursued alternate methods.

### **10.6 Strengths and Limitations of the study**

The findings from the study is comparable with the findings from other studies that has looked at the infertility discourse. Most of the studies on infertility are based in the infertility clinic and hence a large proportion of those who cannot afford such facilities are not included in the study. The major strength of this study is that it is a community-based study and is representative of the population of Kerala.

There is a lack of data on the infertility care services in the state, and hence the privatisation of reproductive health care in Kerala is discussed based on the available data from different sources on public sector provisioning for reproductive health care in Kerala, this may not give a complete picture of the privatisation of the infertility care in Kerala. The selection of districts is based on the expected level of infertility at 45-49 years of the 2011 Census data and it describes the fertility regime of women who have completed their fertility. The experiences of the women entering the reproductive period in the recent times may be different from what was observed based on the 2011 Census.

The treatment history was self-reported and hence there may be possibility of recall bias when the treatment period is longer and therefore result in misinformation on the diagnosis and treatment. I have tried to reduce this by corroborating it with the treatment records of those women who were willing to share it with me. Since the study was community based and the subjects were selected randomly, there is more censoring in the study than those with the event (pregnancy), which may also have brought in a bias in the findings. Male partners were not interviewed in the study and their experiences are missing and the interpretations drawn in the study are based on the women's responses regarding their spouses.

### **10.7 Recommendations**

The study has carefully described the care seeking pathway of the couples with all its myriad variations and I would like to put forth the following recommendations based on the finding at the policy level, for clinical practise and recommendations for further research. There is information asymmetry in infertility care, where the couples have misinformation regarding the nature of treatments and this prevents them from

accessing the optimal treatment choices that are needed. Therefore, it is important to bring in a public discourse on infertility in the programmatic component of sexual and reproductive health programs with a focus on the potential for success and appropriate care for male and female infertility. A major lacuna is the absence of a comprehensive data on infertility at the population level. This will help in designing the health programs with focus on infertility.

There is inequality in access and affordability of infertility care, this is due to the lack of adequate public sector participation in infertility care. The right to family is a basic right of everyone and hence there should be more public provisioning for infertility care. This care should be provided at local levels, with comprehensive referral care at least at district levels given the requirements of economies of scale for such provisioning. This can cater to the needs of many couples who cannot afford treatment at the private centres, which result in premature cessation of treatment or using unnecessary treatments that do not yield results. There is a need to look into this aspect and the possibility of some form of financial assistance by looking into innovative ways for offering treatment, viz., lesser number of cycles or induction protocols for appropriate people, who do not have the resources to afford treatment. This will also bring in needed regulation of the sector which seems to be driven mostly by market forces, with its accompanying information asymmetry.

In the clinical practise, there need to be provisioning of counselling for all the couples irrespective of the treatment stage they are in. Currently, counselling services are being provided only to those couples undergoing ART treatments. There is significant apprehension and confusion for many couples at every stage of their treatment, hence counselling will help them alleviate their worries to some extent and help to uplift their morale.

There is also treatment delay happening due to the migrant status of the husbands and due to the work-related restrictions. Further research is need to determine the extent of delay in initiating treatment in couples with infertility due to the migrant husbands.

The care seeking pathway for infertility is dependent on the husbands' willingness to continue the treatment and on the diagnosis of infertility. It is important to elicit the reasons for the drop out from care pathway by husbands. Research aimed at understanding this will give more evidence to incorporate comprehensive care for couples in the state.

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### Annexure A: List of publications

Sl No	Author(s)	Title	Journal	Year	Volume (Issue)
1	Thomas SC	Dispelling hope and leaving the couples in a state of 'inbetweenness': Moral dilemmas of infertility research	Indian Journal of Medical Ethics	2021	6(3)
2	Thomas SC	Maintaining confidentiality while gaining access to the community	Indian Journal of Medical Ethics	2020	5 (1)
3	Thomas SC	Exploring literature for conceptualisations of male infertility: A phenomenological analysis	The Qualitative Report	2018	23 (4)

## 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

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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 i.e., 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 IVF (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

<sup>1</sup>Here, when I refer to IUI or IVF it also includes some cases where donor sperms were used for fertilisation.

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

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## Maintaining confidentiality while gaining access to the community

SUNU C THOMAS

**Keywords:** Gatekeepers, privacy, research access, ASHA, confidentiality, sensitive information

### Introduction

Qualitative research is used to enhance the understanding of many issues but this method poses certain unique difficulties and ethical dilemmas for the researcher. These tend to be magnified when researching sensitive topics (1). The use of gatekeepers adds another layer of ethical issues or dilemmas. The term "gatekeeper" describes individuals, groups, and organisations that act as intermediaries between researchers and participants (2). A gatekeeper occupies an important position in the research process by helping the researcher access the participants. This serves to save the researcher's time and resources during the research process, and also to guarantee the researcher's legitimacy to the participants (2, 3).

### The case

The qualitative component of a community-based study used in-depth interviews to understand treatment-seeking pathways among couples with infertility<sup>1</sup>. Given the challenges of locating couples with infertility within the community, the researcher recruited participants through various gatekeepers including a specialist at an infertility clinic, friends, and health workers (Accredited Social Health Activist or ASHA<sup>2</sup> who is from the same community). Community members in general and women in particular are wary of outsiders collecting information about the intimate details of families. The ASHA can help recruit study participants as she is familiar with the families in the community, and also reassures them about the researcher's credentials.

The researcher would contact the ASHA explaining the purpose of the research, and ask for help locating study participants. The ASHA would identify potential study participants and obtain interview appointments with them; she also usually accompanied the researcher to the appointment. Though the researcher would inform the ASHA of the research topic as well as its sensitiveness, the ASHA

usually stayed with the researcher during the data collection process, to reassure herself that the researcher was not discussing anything other than what she had been informed about. However, when possible, the researcher revisited the participants without the ASHA worker being present, in order to probe sensitive issues that needed exploration. All interviews were conducted after obtaining the participants' informed consent.

In one case, the researcher interviewed a woman who had undergone in vitro fertilisation (IVF). The ASHA accompanied the researcher to the participant's house. She did not actively listen to the conversation between the researcher and the participant; there was an anganwadi<sup>3</sup> attached to the participant's house, and the ASHA chatted with the mothers who came to drop their children there. The participant narrated details of the treatment that she had undergone. She said that she was found to have defective ova production because of which she had been unable to conceive after repeated IVF treatments. She eventually underwent IVF with donor ova and subsequently delivered a child.

At the end of the interview, the woman told the researcher that her use of donor ova was confidential and only close family members knew about it; not even the husband's family was aware of it. The researcher reassured the participant that this information would not be shared with anyone.

As the researcher was about to leave the house, she was summoned back by the participant's mother who expressed her discontentment in her daughter being asked personal questions. She was also worried that the ASHA worker may have overheard the interview on this sensitive topic. The mother scolded her daughter for sharing the information with the researcher. Although the researcher reassured the mother that the data would not be shared with anyone, the mother was worried.

### Questions

1. What are the key ethical issues at stake in this situation?
2. Should community-based workers be used to identify subjects for participation in research on sensitive or stigmatising health conditions? Why, or why not?
3. Can steps be taken to ensure confidentiality when a third party is present during the data collection process?
4. How can we ensure that the process of recruitment for such research is not coercive?

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### Notes

- <sup>1</sup> In this study, a "couple with infertility" has been defined as a couple who have been married for a minimum of one year, and are seeking treatment, or have a history of treatment, for achieving pregnancy.
- <sup>2</sup> ASHAs are trained female community health activists. Selected from the community itself and accountable to it, the ASHA is trained to be an interface between the community and the public health system.

- <sup>3</sup> The Anganwadi or "courtyard shelter" is the focal point for delivery of the government's Integrated Child Development Services, through which children under the age of 6 are given supplementary nutrition, immunisation and pre-school education, and mothers are given supplementary nutrition.

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## Community gatekeepers and the conundrum of confidentiality and coercion

VIJAYAPRASAD GOPICHANDRAN

**Keywords:** Gatekeepers, public health research, access, coercion, confidentiality,

Sunu Thomas has described (1) a research study in which she gained access through a community health worker to members of the community seeking treatment for infertility. One of the research participants who had undergone such a sensitive treatment and her family were concerned that the community health worker's presence during the interview would breach the confidentiality of their health information. In this commentary, I will discuss the issues of balancing accessibility versus confidentiality, and of coercion in the process of approaching community members through gatekeepers of the community.

Frontline community health workers are often the gatekeepers through whom public health researchers access community members to conduct their research. The health workers are usually themselves members of the community and so have first-hand information about the potential research participants. In a typical rural context in India, public hospital records and health system information may not be reliable, making access to patients difficult. Moreover, even if a researcher got the address details of a potential research participant through hospital records, the complex layout of streets, lanes and houses in rural India makes locating people arduous. Therefore, public health researchers largely depend on community health workers to identify potential research

participants.

The issue described by the researcher in this case is very common in public health research, especially when it is based in the community. Two years ago, I was involved in a community-based qualitative research project to understand the experiences of women who suffered stillbirths in the public health facilities of Tamil Nadu. Our team approached, through the village health nurses (VHN), the families of women who had suffered a stillbirth. The VHN is the frontline community health worker in Tamil Nadu who takes care of a population of about 5000 individuals and plays the vital role of a bridge between the community and the primary healthcare system. Many of the mothers whom we approached had lost their babies during delivery in the public health system and so had a sense of anger and resentment against the health system. Some of them were even angry with the VHN, as she is the face of the public health system in the community. As described by the author, we too had been worried that the presence of the VHN during the interviews could breach the interviewees' confidentiality.

Multiple ethical concerns have been raised in this case study. I would like to discuss two main confidentiality concerns. The first is whether it is appropriate for researchers to gain access to communities through frontline health workers. Frontline health workers are the vital link between communities and the health system. The community members sometimes reveal very sensitive information about their health to community health workers, in order to secure their help to access health system facilities. Often, the community health worker is part of the community herself. So, being an insider, she is already privy to some personal information about the members and the community. Therefore, like the fiduciary doctor-patient relationship and its inherent covenant of confidentiality, the community health worker's- relationship with the community

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## Annexure B: Curriculum Vitae

### Personal Information

- Name and address : Sunu C Thomas, Punnathala Friends Nagar-1,  
Zion-4, Thottakad, Thangasseri, Kollam-691007  
+91 8281548652
- Date of Birth : 12 December 1988
- Email : [sunusarathomas@gmail.com](mailto:sunusarathomas@gmail.com)

### Education

- **Doctor of Philosophy (PhD)-Public Health| January 2016-December 2020|** Achutha Menon Centre for Health Science Studies (AMCHSS), Sree Chitra Tirunal Institute for Medical Sciences and Technology, Thiruvananthapuram
- **Master of Public Health(MPH)| January 2013-December 2014 |** Achutha Menon Centre for Health Science Studies (AMCHSS), Sree Chitra Tirunal Institute for Medical Sciences and Technology, Thiruvananthapuram
- **Bachelor of Science (Nursing)| August 2007-June 2011|** Jawaharlal Institute of Postgraduate Medical Education and Research (JIPMER), Puducherry

### Work experience

- 1 May 2019-30 June 2019 | Research consultant for a project “To understand the efficiency, effectiveness, impact and sustainability of Mahtari Jatan Yojana (MJY) and try to understand the nutrition status of pregnant women in Chhattisgarh.”
- 1 July 2015 - 31 December 2015 | Research Associate at AMCHSS, Sree Chitra Tirunal Institute for Medical Sciences and Technology for a Qualitative research project “MTP/EC services for women in a population in reproductive health transition: Providers’ and institutions attitudes and women’s access to these services in Kerala.”
- 1 May 2015-30 June 2015 | Research Assistant for ICRIER’s *Health Policy Initiative* on a qualitative study “Building a framework for addressing chronic diseases in India” which included interviewing stakeholders in Kerala and Chennai and submission of a report on these

### Publications

- Thomas S.C. Dispelling hope and leaving the couples in a state of ‘inbetweenness’: Moral dilemmas of 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, 2021

- Thomas S C. Maintaining confidentiality while gaining access to the community. *Indian J Med Ethics*. 2020 Jan-Mar; 5(1) NS: 10-11. DOI: 10.20529/IJME.2020.008.
- Thomas S. C. (2018). Exploring literature for conceptualisations of male infertility: A phenomenological analysis. *The Qualitative Report*, 23(4), 978-1000. Retrieved from <https://nsuworks.nova.edu/tqr/vol23/iss4/18>

### **Presentations (Oral/ Poster)**

- 5-7 December 2018 | **Presented a poster titled “Medicalization of infertility: Women’s agency to negotiate treatment or discontinue it”** at the 14<sup>th</sup> World Congress of Bioethics and & 7<sup>th</sup> National Bioethics conference at St. John's National Academy of Health Sciences
- 5-7 December 2018 | **Speaker at the symposium on “Public Health Ethics and Qualitative Research; Experiences from the field”** at the 14<sup>th</sup> World Congress of Bioethics and & 7<sup>th</sup> National Bioethics conference at St. John's National Academy of Health Sciences
- 20-22 March 2017 | **Presented paper titled “Exploring literature for conceptualisations of male infertility: A phenomenological analysis”** at AROGYAM peri-doctoral workshop at Achutha Menon Centre for Health Science Studies (AMCHSS) ; Which was subsequently published
- 12-15 January 2017 | **Presented poster titled “Identifying ethical challenges in resolving male infertility: an examination of ‘One Part woman’”** at sixth National Bioethics conference at YASHADA, Pune
- December 2015 | **Presented paper on “Gender and Schizophrenia”** at AMCCON held at Achutha Menon Centre for Health Science Studies (AMCHSS)

### **Achievements and scholarship**

- PhD fellowship for full-time research in Public Health under the project titled: “Closing the gaps: Health Equity Research Initiative in India” supported by International Development Research Centre (IDRC), Canada
- Qualified University Grants Commission-National Eligibility Test (UGC-NET) in 2018



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**Institutional Ethics Committee**  
(IEC Regn No. ECR/189/Inst/KL/2013)

SCT/IEC/1112/NOVEMBER-2017

23.11.2017

**Ms. Sunu C Thomas**  
PhD Student  
AMCHSS, SCTIMST

Dear Ms. Sunu C Thomas,

The Institutional Ethics Committee reviewed your application to conduct the study entitled "TREATMENT CHOICES AMONG COUPLES WITH INFERTILITY: A QUALITATIVE ENQUIRY AMONG COUPLES WITH INFERTILITY IN THE SOUTHERN DISTRICTS OF KERALA (IEC/1112)" on 23<sup>rd</sup> November, 2017.

**The following documents were reviewed:**

1. Covering Letter addressed to the Chairman, IEC, SCTIMST, dated 24.10.2017 with checklist
2. Copy of the letter addressed to the Principal with the remarks
3. List of amendments made in the proposal and IEC Application form
4. Copy of IEC Approval Letter dated 7.10.2017
5. Revised IEC Application Form and Project Proposal
6. Revised Participant details form in English and Malayalam
7. Revised In-depth interview guide (for female partner and for male partner/significant others) in English and Malayalam
8. Revised Participant Information Sheet and Consent Form (for female partner and for male partner/significant others) in English and Malayalam
9. CV of Principal Investigator

**The IEC Review Criteria**

The study fulfils the expedited criteria from ethics review criteria vide section 9.1 of the Standard Operating Procedures (April 2017) of the SCTIMST-IEC.

**IEC Decision**

The IEC approved the conduct of the study in the present form. The IEC reiterates the need for maintenance of confidentiality of research documents in view of the sensitivity of the topic being researched.

**Remarks:**

The Institutional Ethics Committee expects to be informed about the progress of the study, any SAE occurring in the course of the study, any changes in the protocol and patient information/informed consent and asks to be provided a copy of the final report.

There was no member of the study team who participated in voting / decision making process. The ethics committee is organized and operated according to the requirements of Good Clinical Practice and the requirements of the Indian Council of Medical Research (ICMR).

Sincerely,

**Mala Ramanathan**  
Member Secretary, IEC



श्री चित्रा तिरुनाल आयुर्विज्ञान और प्रौद्योगिकी संस्थान, त्रिवेन्द्रम  
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**Institutional Ethics Committee**  
(IEC Regn No. ECR/189/Inst/KL/2013/RR-16)

SCT/IEC/1112/JULY-2018

03.08.2018

**Ms. Sunu C Thomas**  
PhD Student  
AMCHSS, SCTIMST

Dear Ms. Sunu C Thomas,

The Institutional Ethics Committee reviewed your application to conduct the study entitled "TREATMENT SEEKING FOR INFERTILITY AMONG MARRIED WOMEN IN KERALA: IDENTIFYING THE PATHWAYS AND INEQUALITIES IN THE PATHWAYS TO THE RESOLUTION OF INFERTILITY (IEC/1112)" on 3<sup>rd</sup> August , 2018.

**The following documents were reviewed:**

Original submission

1. Covering Letter addressed to the Chairman, IEC, SCTIMST, dated 12.07.2018 with checklist
2. IEC Application Form
3. Full Proposal
4. TAC Approval Letter dated 04.07.2018)
5. Interview Schedule for survey in English and Malayalam
6. In-depth Interview Guide in English and Malayalam
7. Informed Consent Form for Survey in English and Malayalam
8. Informed Consent Form for In-depth interview in English and Malayalam
9. CV of Principal Investigator

Revised submission

1. Covering Letter addressed to the Chairman, IEC, SCTIMST, dated 31.07.2018 with checklist
2. IEC Application Form
3. Full Proposal
4. TAC Approval Letter dated 04.07.2018)
5. Interview Schedule for survey in English and Malayalam
6. In-depth Interview Guide in English and Malayalam
7. Informed Consent Form for Survey in English and Malayalam
8. Informed Consent Form for In-depth interview in English and Malayalam
9. CV of Principal Investigator

**The IEC Review Criteria**

The study fulfils the expedited criteria from ethics review criteria vide section 9.1 of the Standard Operating Procedures (April 2017) of the SCTIMST-IEC.

**IEC Decision**

The IEC approved the conduct of the study in the present form.

**Remarks:**

The Institutional Ethics Committee expects to be informed about the progress of the study, any SAE occurring in the course of the study, any changes in the protocol and patient information/informed consent and asks to be provided a copy of the final report.

There was no member of the study team who participated in voting / decision making process. The ethics committee is organized and operated according to the requirements of Good Clinical Practice and the requirements of the Indian Council of Medical Research (ICMR).

Sincerely,

**Mala Ramanathan**  
Member Secretary, IEC

### **A3: Informed consent for phase I in-depth interview (English)**

#### **Informed consent**

##### **Participant information sheet- for female partner**

I am Sunu C Thomas and I am doing PhD at Achutha Menon Centre for Health Sciences Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Thiruvananthapuram. I am conducting this study “Treatment choices among couples with infertility: A qualitative enquiry among couples with infertility in the southern districts of Kerala”. The purpose of the study is to find out the various things (or treatments) couples, who do not have a child but want to have a child, do to get pregnant and have a child. Participation involves a conversation including some questions regarding the treatment choices you have made to resolve your problem in getting pregnant and why these choices were made by you. Some of these may cause painful recollections and should you now wish to dwell on them, you can refuse to answer any specific questions. Thus, you may choose to answer all or some of the questions that I put to you. There will be no direct benefits to you for participating in this interview. The interview will take about 40 minutes to an hour. If you are willing I would like to audio- record the interview. I would like to assure you that all the information shared with me will be kept confidential and will only be used for research and publication purpose. Your individual identity will never be used in any research output nor shared with anyone else in process of communication of data.

This study has been cleared by the Institutional Ethics Committee of the SCTIMST, Thiruvananthapuram.

I therefore would be grateful if you agree to participate in this study. The participation in the study is purely voluntary. You have the right to withdraw your participation at any time during the interview without any explanation. You are free to refuse to answer any of the questions at any time. In case you need any additional information and clarification you may contact me, or my guide. For further queries regarding the study you can address them to the Member Secretary of the Institute Ethics Committee at Sree Chitra Tirunal Institute, for Medical Sciences and Technology Dr.Mala Ramanathan ( phone no:- 0471-2524234). The details of contacts are given below.

Now I request to give your consent to participate in this study by signing below. Thank you.

Name of the Interviewer & Signature:

Date & Place:

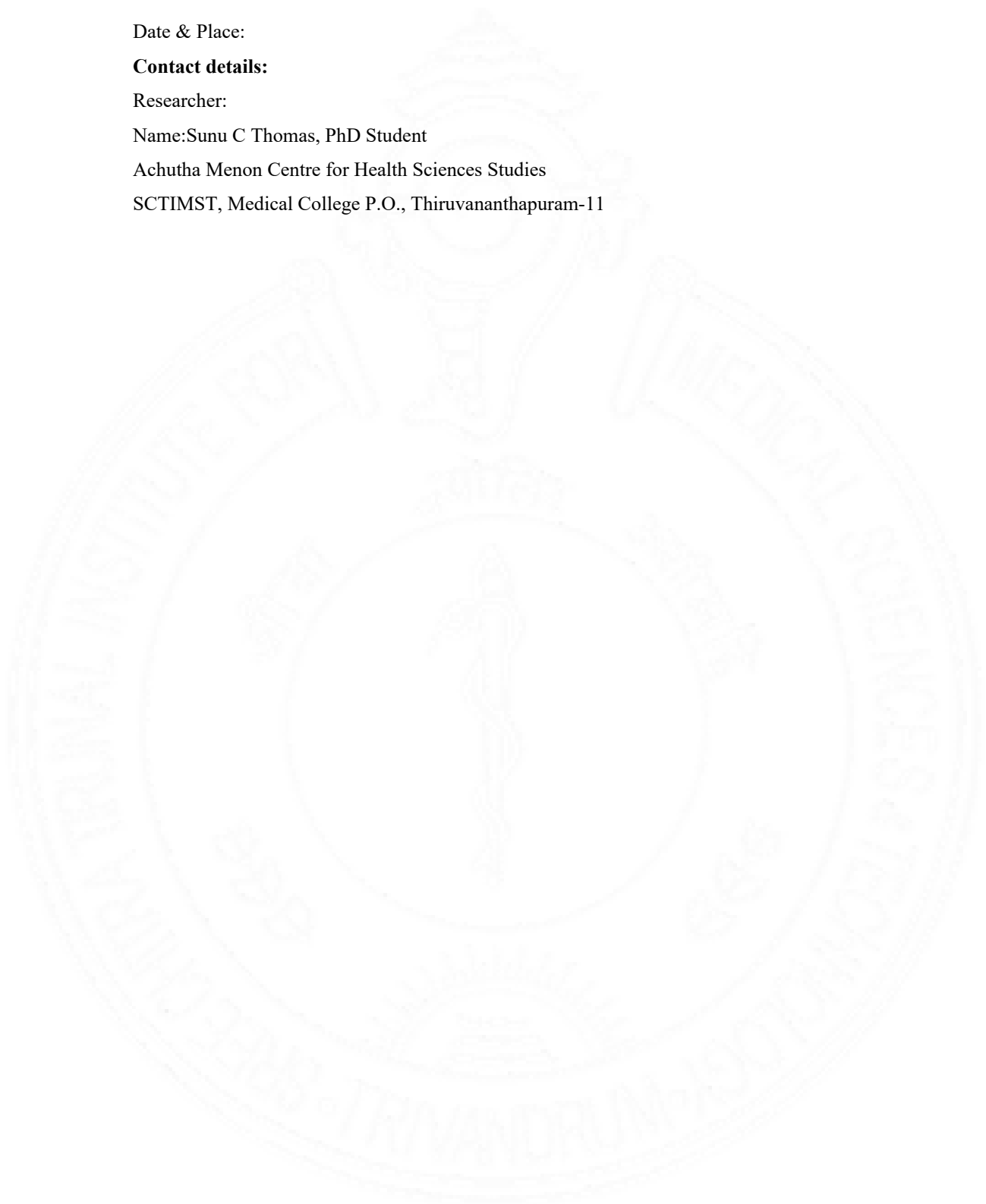
**Contact details:**

Researcher:

Name: Sunu C Thomas, PhD Student

Achutha Menon Centre for Health Sciences Studies

SCTIMST, Medical College P.O., Thiruvananthapuram-11



### **Consent form**

I have read/ been read out the details in the information sheet. The purpose of the study and my involvement has been explained and all my questions have been answered. By signing/providing thumb impression on this consent form, I indicate that I understand what will be expected from me and that I am willing to participate in this study. I know that I can withdraw at any time. I have been informed who should be contacted if the need arises.

I, ..... agree to participate in the study.

Name of the Participant & Signature:

Date & Place:

If the respondent is illiterate,

Name of the witness:

Signature of the witness:

## **Informed consent**

### **Participant information sheet- for male partner/ significant others**

I am Sunu C Thomas and I am doing PhD at Achutha Menon Centre for Health Sciences Studies, SreeChitraTirunal Institute for Medical Sciences and Technology, Thiruvananthapuram. I am conducting this study “Treatment choices among couples with infertility: A qualitative enquiry among couples with infertility in the southern districts of Kerala”. The purpose of the study is to find out the various things (or treatments) couples, who do not have a child but want to have a child, do to get pregnant and have a child.

Participation involves a conversation including some questions regarding the treatment choices you have made to resolve your problem in getting pregnant and why these choices were made by you. Some of these may cause painful recollections and should you now wish to dwell on them, you can refuse to answer any specific questions. Thus, you may choose to answer all or some of the questions that I put to you. There will be no direct benefits to you for participating in this interview. The interview will take about 40 minutes to an hour. If you are willing I would like to audio- record the interview. I would like to assure you that all the information shared with me will be kept confidential and will only be used for research and publication purpose. Your individual identity will never be used in any research output nor shared with anyone else in process of communication of data.

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Now I request to give your consent to participate in this study by signing below. Thank you.

Name of the Interviewer & Signature:

Date & Place:

**Contact details:**

Researcher:

Name: Sunu C Thomas, PhD Student

Achutha Menon Centre for Health Sciences Studies

SCTIMST, Medical College P.O., Thiruvananthapuram-11

### **Consent form**

I have read/ been read out the details in the information sheet. The purpose of the study and my involvement has been explained and all my questions have been answered. By signing/providing thumb impression on this consent form, I indicate that I understand what will be expected from me and that I am willing to participate in this study. I know that I can withdraw at any time. I have been informed who should be contacted if the need arises.

I, ..... agree to participate in the study.

Name of the Participant & Signature:

Date & Place:

If the respondent is illiterate,

Name of the witness:

Signature of the witness:

**A4: Informed consent for phase I in-depth interview (Malayalam)**

**പഠനത്തിൽ പങ്കെടുക്കുന്നവർക്കുള്ള വിവരണപത്രിക- ഭാഗ്യ**

എന്റെ പേര് സുനു സി തോമസ്, ഞാൻ ശ്രീ ചിത്ര തിരുനാൾ ഇൻസ്റ്റിറ്റ്യൂട്ടിലെ അച്യുത മേനോൻ സെന്ററിൽ പൊതുജനാരോഗ്യത്തിൽ പി എച് ഡി ചെയ്യുന്നു. എന്റെ പി എച് ഡിയുടെ ഭാഗമായി ഞാൻ ഒരു പഠനം നടത്തുന്നു. "വന്ധ്യതയുള്ള ദമ്പതികളുടെ ചികിത്സ തരങ്ങൾ: കേരളത്തിലെ തെക്കൻ ജില്ലകളിൽ വന്ധ്യതയുള്ള ദമ്പതികളുടെ ഇടയിൽ ഗുണപരമായ അന്വേഷണം". ഈ പഠനം കൊണ്ട് ഉദ്ദേശിക്കുന്നത് കുട്ടികൾ ഉണ്ടാകാൻ ബുദ്ധിമുട്ടുള്ളതും എന്നാൽ കുട്ടികൾ വേണം എന്ന് ആഗ്രഹിക്കുന്ന ദമ്പതികൾ ഇതിനായി എന്തെല്ലാം മാർഗ്ഗങ്ങൾ/ ചികിത്സകൾ ചെയ്യും എന്നറിയുന്നതിനാണ്.

അതുകൊണ്ട് ഈ പഠനത്തിൽ പങ്കാളിയാകാൻ ഞാൻ താങ്കളോട് അഭ്യർത്ഥിക്കുന്നു. ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ സമ്മതമാണെങ്കിൽ ഞാൻ തങ്ങളെ അഭിമുഖം ചെയ്യാൻ താത്പര്യപ്പെടുന്നു. താങ്കൾ ഗർഭം ധരിക്കുന്നതിനായി എന്തെല്ലാം മാർഗ്ഗങ്ങൾ അല്ലെങ്കിൽ ചികിത്സകൾ ആണ് തിരഞ്ഞെടുത്തതെന്നും ആ ചികിത്സ/ മാർഗ്ഗം എന്തുകൊണ്ട് തിരഞ്ഞെടുത്തു എന്നതിനെ കുറിച്ചും ചില കാര്യങ്ങൾ ഞാൻ ചോദിക്കാൻ ഉദ്ദേശിക്കുന്നത്. ചില ചോദ്യങ്ങൾ താങ്കൾക്ക് അസ്വസ്ഥത ഉണ്ടാക്കിയേക്കാം. അത്തരത്തിൽ താങ്കളെ അസ്വസ്ഥമാക്കുന്ന ചോദ്യങ്ങൾക്ക് ഉത്തരം നൽകാതിരിക്കാൻ താങ്കൾക്ക് പൂർണ്ണ സ്വാതന്ത്ര്യം ഉണ്ട്. ഈ പഠനത്തിൽ പങ്കാളി ആകുന്നത് കൊണ്ട് താങ്കൾക്ക് നേരിട്ട് ഒരു പ്രയോജനവും ലഭിക്കുന്നതല്ല. ഈ അഭിമുഖം ഏകദേശം 40 മിനിറ്റ് മുതൽ ഒരു മണിക്കൂർ വരെ ദൈർഘ്യം ഉണ്ടാകാം. താങ്കൾക്ക് സമ്മതമാണെങ്കിൽ ഈ അഭിമുഖം ഞാൻ റെക്കോർഡ് ചെയ്യാൻ താത്പര്യപ്പെടുന്നു. താങ്കൾ തരുന്ന വിവരങ്ങൾ തീർത്തും പഠനാവശ്യത്തിനുമാത്രമേ ഉപയോഗിക്കുകയുള്ളൂ.

താങ്കളുടെ പേരോ താങ്കളെ തിരിച്ചറിയാൻ കഴിയുന്ന മറ്റ് വിവരങ്ങളോ ഞാൻ എവിടെയും (വിശകലനം ചെയ്യുമ്പോഴോ പ്രബന്ധത്തിലോ) സൂചിപ്പിക്കുന്നതല്ല, മറ്റാരുമായും പങ്കിടുന്നതുമല്ല. ഈ പഠനത്തിൽ താങ്കളുടെ പങ്കാളിത്തം തികച്ചും സ്വമനസ്സാലെ ഉള്ളതാണ്. ഈ പഠനത്തിൽനിന്നും താങ്കൾക്ക് എപ്പോൾ വേണമെങ്കിലും പിന്മാറാവുന്നതാണ്.

ഈ പഠനം ശ്രീ ചിത്ര തിരുനാൾ ഇൻസ്റ്റിറ്റ്യൂട്ടിലെ ഇൻസ്റ്റിറ്റ്യൂഷനൽ എത്തിക്സ് കമ്മിറ്റി അംഗീകരിച്ചതാണ്. എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ ചോദിക്കാവുന്നതാണ്. ഭാവിയിൽ ഈ പഠനത്തെ കുറിച്ച് എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ എന്നോട് അല്ലെങ്കിൽ എന്റെ പി എച് ഡി ഗൈഡിനോടോ ചോദിക്കാവുന്നതാണ്. എന്റെ പഠനത്തെക്കുറിച്ചു താങ്കൾക്ക് എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ ശ്രീ ചിത്ര തിരുനാൾ ഇൻസ്റ്റിറ്റ്യൂട്ടിലെ ഇൻസ്റ്റിറ്റ്യൂഷനൽ എത്തിക്സ് കമ്മിറ്റിയുടെ മെമ്പർ സെക്രട്ടറിയായ ഡോക്ടർ മാല രാമനാഥൻ നോട് ചോദിക്കാവുന്നതാണ് ( 0471-2524234). Email id: [mala@sctimst.ac.in](mailto:mala@sctimst.ac.in).

ചുവടെ ചേർത്തിട്ടുള്ള സമ്മതപത്രത്തിൽ ഒപ്പു വച്ചുകൊണ്ടു ഈ പഠനത്തിൽ പങ്കെടുക്കാനുള്ള താങ്കളുടെ സമ്മതം രേഖപ്പെടുത്തണം എന്ന് അഭ്യർത്ഥിക്കുന്നു . നന്ദി അഭിമുഖം ചെയ്യുന്ന വ്യക്തിയുടെ പേര് & ഒപ്പ്:

തീയതി & സ്ഥലം:  
ബന്ധപ്പെടാനുള്ള വിവരങ്ങൾ:  
ഗവേഷക: സുനു സി തോമസ് , പി എച് പി സൂടെന്റ്  
അച്യുത മേനോൻ സെന്റർ ഫോർ ഹെൽത്ത് സയൻസ് സ്റ്റുഡീസ്  
സ് സി ടി ഐ എം സ് ടി, മെഡിക്കൽ കോളേജ് പി .ഓ ., തിരുവനന്തപുരം -11

**സമ്മതപത്രം**

പഠനവിവരണം മുഴുവൻ ഞാൻ വായിച്ചു / എന്നെ വായിച്ചു കേൾപ്പിച്ചു. ഈ പഠനത്തിന്റെ ഉദ്ദേശവും ഈ പഠനത്തിൽ എനിക്കുള്ള പങ്കാളിത്തവും എന്നോട് വിവരിച്ചിട്ടുണ്ട്. ഈ സമ്മതപത്രത്തിൽ ഒപ്പു / വിരലടയാളം വയ്ക്കുന്നത് ഈ പഠനത്തിൽ പങ്കാളിയാകാനുള്ള എന്റെ പൂർണ്ണസമ്മതത്തെ അറിയിക്കുന്നു. ഈ പഠനത്തിൽ നിന്നും എപ്പോൾ വേണമെങ്കിലും പിന്മാറാം എന്നും എനിക്കറിയാം. എന്തെങ്കിലും വിശദീകരണം ആവശ്യമുണ്ടെങ്കിൽ ആരെ ബന്ധപ്പെടണം എന്നും എനിക്കറിയാം.

ഞാൻ..... ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ തയാറാണ് .

പേര്  
ഒപ്പ്/ വിരലടയാളം

തീയതി & സ്ഥലം

പ്രതിവദിക്കുന്നയാൾ നിരക്ഷര ആണെങ്കിൽ,  
സാക്ഷിയുടെ പേര്  
സാക്ഷിയുടെ ഒപ്പ്

**പഠനത്തിൽ പങ്കെടുക്കുന്നവർക്കുള്ള വിവരണപത്രിക- ഭർത്താവ് / മറ്റ് പ്രധാന വ്യക്തികൾ**

എന്റെ പേര് സുനു സി തോമസ്, ഞാൻ ശ്രീ ചിത്ര തിരുനാൾ ഇസ്റ്റിട്യൂട്ടിലെ അച്യുത മേനോൻ സെന്ററിൽ പൊതുജനാരോഗ്യത്തിൽ പി എച്ച് ഡി ചെയ്യുന്നു. എന്റെ പി എച്ച് ഡിയുടെ ഭാഗമായി ഞാൻ ഒരു പഠനം നടത്തുന്നു. "വന്ധ്യതയുള്ള ദമ്പതികളുടെ ചികിത്സ തരങ്ങൾ: കേരളത്തിലെ തെക്കൻ ജില്ലകളിൽ വന്ധ്യതയുള്ള ദമ്പതികളുടെ ഇടയിൽ ഗുണപരമായ അന്വേഷണം". ഈ പഠനം കൊണ്ട് ഉദ്ദേശിക്കുന്നത് കുട്ടികൾ ഉണ്ടാകാൻ ബുദ്ധിമുട്ടുള്ളതും എന്നാൽ കുട്ടികൾ വേണം എന്ന് ആഗ്രഹിക്കുന്ന ദമ്പതികൾ ഇതിനായി എന്തെല്ലാം മാർഗ്ഗങ്ങൾ/ ചികിത്സകൾ ചെയ്യും എന്നറിയുന്നതിനാണ്.

അതുകൊണ്ട് ഈ പഠനത്തിൽ പങ്കാളിയാകാൻ ഞാൻ താങ്കളോട് അഭ്യർത്ഥിക്കുന്നു. ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ സമ്മതമാണെങ്കിൽ ഞാൻ തങ്ങളെ അഭിമുഖം ചെയ്യാൻ താത്പര്യപ്പെടുന്നു. താങ്കൾ ഗർഭം ധരിക്കുന്നതിനായി എന്തെല്ലാം മാർഗ്ഗങ്ങൾ അല്ലെങ്കിൽ ചികിത്സകൾ ആണ് തിരഞ്ഞെടുത്തതെന്നും ആ ചികിത്സ/ മാർഗ്ഗം എന്തുകൊണ്ട് തിരഞ്ഞെടുത്തു എന്നതിനെ കുറിച്ചും ചില കാര്യങ്ങൾ ഞാൻ ചോദിച്ച് കാൻ ഉദ്ദേശിക്കുന്നത്. ചില ചോദ്യങ്ങൾ താങ്കൾക്ക് അസ്വസ്ഥത ഉണ്ടാക്കിയേക്കാം. അത്തരത്തിൽ താങ്കളെ അസ്വസ്ഥനാക്കുന്ന ചോദ്യങ്ങൾക്ക് ഉത്തരം നൽകാതിരിക്കാൻ താങ്കൾക്ക് പൂർണ്ണ സ്വാതന്ത്ര്യം ഉണ്ട്. ഈ പഠനത്തിൽ പങ്കാളി ആകുന്നത് കൊണ്ട് താങ്കൾക്ക് നേരിട്ട് ഒരു പ്രയോജനവും ലഭിക്കുന്നതല്ല. ഈ അഭിമുഖം ഏകദേശം 40 മിനിറ്റ് മുതൽ ഒരു മണിക്കൂർ വരെ ദൈർഘ്യം ഉണ്ടാകാം. താങ്കൾക്ക് സമ്മതമാണെങ്കിൽ ഈ അഭിമുഖം ഞാൻ റെക്കോർഡ് ചെയ്യാൻ താത്പര്യപ്പെടുന്നു. താങ്കൾ തരുന്ന വിവരങ്ങൾ തീർത്തും പഠനാവശ്യത്തിനുമാത്രമേ ഉപയോഗിക്കുകയുള്ളൂ.

താങ്കളുടെ പേരോ താങ്കളെ തിരിച്ചറിയാൻ കഴിയുന്ന മറ്റ് വിവരങ്ങളോ ഞാൻ എവിടെയും (വിശകലനം ചെയ്യുമ്പോഴോ പ്രബന്ധത്തിലോ) സൂചിപ്പിക്കുന്നതല്ല, മറ്റൊരുമായും പങ്കിടുന്നതുമല്ല. ഈ പഠനത്തിൽ താങ്കളുടെ പങ്കാളിത്തം തികച്ചും സ്വമനസ്സാലെ ഉള്ളതാണ്. ഈ പഠനത്തിൽനിന്നും താങ്കൾക്ക് എപ്പോൾ വേണമെങ്കിലും പിന്മാറാവുന്നതാണ്.

ഈ പഠനം ശ്രീ ചിത്ര തിരുനാൾ ഇസ്റ്റിട്യൂട്ടിലെ ഇസ്റ്റിട്യൂഷനൽ എത്തിക്സ് കമ്മിറ്റി അംഗീകരിച്ചതാണ്. എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ ചോദിക്കാവുന്നതാണ്. ഭാവിയിൽ ഈ പഠനത്തിന് കുറിച്ച് എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ എന്നോട് അല്ലെങ്കിൽ എന്റെ പി എച്ച് ഡി ഗൈഡിനോടൊ ചോദിക്കാവുന്നതാണ്. എന്റെ പഠനത്തെക്കുറിച്ച് താങ്കൾക്ക് എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ ശ്രീ ചിത്ര തിരുനാൾ ഇസ്റ്റിട്യൂട്ടിലെ ഇസ്റ്റിട്യൂഷനൽ എത്തിക്സ് കമ്മിറ്റിയുടെ മെമ്പർ സെക്രട്ടറിയായ ഡോക്ടർ മാല രാമനാഥൻ നോട് ചോദിക്കാവുന്നതാണ് ( 0471-2524234). Email id: [mala@sctimst.ac.in](mailto:mala@sctimst.ac.in).

ചുവടെ ചേർത്തിട്ടുള്ള സമ്മതപത്രത്തിൽ ഒപ്പു വച്ചുകൊണ്ടു ഈ പഠനത്തിൽ പങ്കെടുക്കാനുള്ള താങ്കളുടെ സമ്മതം രേഖപ്പെടുത്തണം എന്ന് അഭ്യർത്ഥിക്കുന്നു . നന്ദി അഭിമുഖം ചെയ്യുന്ന വ്യക്തിയുടെ പേര് & ഒപ്പ്:

തീയതി & സ്ഥലം:  
ബന്ധപ്പെടാനുള്ള വിവരങ്ങൾ:  
ഗവേഷക: സുനു സി തോമസ് , പി എച്ഐ സൂടെന്റർ  
അച്യുത മേനോൻ സെന്റർ ഫോർ ഹെൽത്ത് സയൻസ് സ്റ്റഡീസ്  
സ് സി ടി ഐ എം സ് ടി, മെഡിക്കൽ കോളേജ് പി .ഓ ., തിരുവനന്തപുരം -11

**സമ്മതപത്രം**

പഠനവിവരണം മുഴുവൻ ഞാൻ വായിച്ചു / എന്നെ വായിച്ചു കേൾപ്പിച്ചു. ഈ പഠനത്തിന്റെ ഉദ്ദേശവും ഈ പഠനത്തിൽ എനിക്കുള്ള പങ്കാളിത്തവും എന്നോട് വിവരിച്ചിട്ടുണ്ട്. ഈ സമ്മതപത്രത്തിൽ ഒപ്പു / വിരലടയാളം വയ്ക്കുന്നത് ഈ പഠനത്തിൽ പങ്കാളിയാകാനുള്ള എന്റെ പൂർണ്ണസമ്മതത്തെ അറിയിക്കുന്നു. ഈ പഠനത്തിൽ നിന്നും എപ്പോൾ വേണമെങ്കിലും പിന്മാറാം എന്നും എനിക്കറിയാം. എന്തെങ്കിലും വിശദീകരണം ആവശ്യമുണ്ടെങ്കിൽ ആരെ ബന്ധപ്പെടണം എന്നും എനിക്കറിയാം.

ഞാൻ..... ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ തയാറാണ്.

പേര്  
ഒപ്പ്/ വിരലടയാളം

തീയതി & സ്ഥലം

പ്രതിവദിക്കുന്നയാൾ നിരക്ഷരൻ ആണെങ്കിൽ,  
സാക്ഷിയുടെ പേര്  
സാക്ഷിയുടെ ഒപ്പ്



NATIONAL HEALTH MISSION  
General Hospital Junction, Thiruvananthapuram 695035  
Tel fax: 91-471 2301181, 2302784  
email: smdnrhm@gmail.com  
Website: www.arogyakeralam.gov.in

No. NHM/4220/CSD/2018/SPMSU

Dated: 22.09.2018

Draft #1 of File NHM/4220/CSD/2018/SPMSU Approved by State Mission Director on 22-Sep-2018 06:51 PM - Page 1

From

State Mission Director

To

The District Programme Managers  
Trivandrum, Kottayam & Malappuram Districts

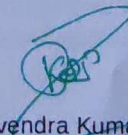
Sir / Madam

Sub:- NHM - Permission for availing ASHA 's for meeting women who are undergoing treatment for infertility in Trivandrum, Kottayam & Malappuram Districts - reg

Ref:- Letter from Ms. Sunu C Thomas ,PhD Scholar in Achuthamenon Centre for Health Science Studies , Trivandrum dated 06/08/2018

In the reference cited above, permission was given to Ms. Sunu C Thomas doing her PhD in Achuthamenon Centre for Health Science Studies , Trivandrum regarding the treatment pathways of infertile couple. For identifying such women who are undergoing treatment for infertility, the assistance of ASHA workers can be utilised and will remunerate Rs. 200 per ASHA in urban areas and Rs. 250 for rural areas that is for 4 couples in urban areas and 5 couples in rural areas. The list of panchayaths is annexed where the study will be conducted and and you are directed to assign ASHAs for the same in the respective areas. The draft study report may be submitted to state Mission Director at the completion of the study.

Yours faithfully

  
Keshvendra Kumar IAS  
State Mission Director

Copy to

Ms. Sunu C. Thomas ,Achuthamenon Centre for Health Science Studies , Trivandrum

**PROCEEDINGS OF THE DISTRICT MEDICAL OFFICER OF HEALTH KOTTAYAM**

**Sub:** HSD – Permission for availing assistance of ASHA workers for conducting survey among women who have undergone treatment for infertility in Kottayam District – sanctioned - orders issued.

**Read:** 1) Letter No.NHM/4220/CSD/2018/SPMSU dated 22/09/2018 State Mission Director,NHM,Thiruvananthapuram.

2.Letter from Ms.Sunu C Thomas,Ph D Scholar in Achuthamenon Centre for Health Science Studies Thiruvananthapuram dated 06/08/2018

**ORDER No. C4/3103/2019/DMO(H)K Dated 01/03/2019**

Vide letter 2<sup>nd</sup> cited above, Ms.Sunu C Thomas,PhD Scholar in Achuthamenon Centre for Health Science Studies,Thiruvananthapuram has sought permission for conducting Survey among Women who have undergone or is undergoing treatment for infertility in Kottayam District with the helpm of the ASHA Workers.

Considering her request and letter from the State Mission Director,National Health Mission,Thiruvananthapuram,Ms Sunu C Thomas is permitted to conduct survey with the help of ASHA workers in the selected ward of Kottayam district (list attached) with the following conditions .

- 1.Remuneration will be given to ASHA workers as directed in the letter of State Mission Director.
- 2.The Survey will not affect the normal duties of ASHA workers and the health sytem of Kottayam district
- 3.The draft study report may be submitted to State Mission Director and the District Medical Officer Health Kottayam at the completion of study

All Medical Officers of concerned area where survey is to be conducted are directed to provide maximum support to Ms Sunu C Thomas to conduct the survey

Sd/-

**Dr. JACOB VARGHESE**  
District Medical Officer (H), Kottayam.

To : Ms. Sunu CThomas

Copy To :

- 1.The Concerned Medical Officers
- 2.File.

//Forwarded/By Order//

*Geetha Kalyan*  
Junior Superintendent



SP  
01/3/19

PROCEEDINGS OF THE DISTRICT MEDICAL OFFICER OF HEALTH MALAPPURAM

Sub:- DMO(H) Malappuram – Permission for availing assistance of ASHA workers for conducting survey among women who have undergone treatment for infertility in Malappuram District – granted orders issued.

- Read:- 1) Lr. No. NHM/4220/CSD/2018/SPMSU dated 22-09-2008 State Mission Director, NHM, Thiruvananthapuram.  
2) Letter from Ms. Sunu. C Thomas, PhD Scholar in Achuthamenon Centre for Health Science Studies TVM dated 06.08.2018.

Order No: C5/35193/2018/DMO(H)MPM dated 18/12/2018.

As per letter referred as 2<sup>nd</sup>, Ms. Sunu. C Thomas, PhD Scholar in Achuthamenon Centre for Health Science Studies, Thiruvananthapuram has sought permission for conducting Survey among Women who have undergone or is undergoing treatment for infertility in Malappuram District with the help of the ASHA Workers.

Considering her request and letter from State Mission Director, National Health Mission, Thiruvananthapuram, Ms. Sunu. C Thomas is permitted to conduct Survey with the help of ASHA Workers in the selected ward of Malappuram District (list attached) with following conditions:

- 1) Remuneration will be given to ASHA workers as directed in the letter of State Mission Director.
- 2) The Survey will not affect the normal duties of ASHA workers and health system of Malappuram District.
- 3) The draft study report may be submitted to State Mission Director and District Medical Officer (Health) Malappuram at the completion of the study.

All Medical Officers of concerned areas where survey is to be conducted are directed to provide maximum support to Ms. Sunu. C Thomas to conduct the Survey.

Sd/-  
Dr. Sakeena. K  
District Medical Officer (H) Malappuram

To:

Ms. Sunu. C Thomas

Copy to-

- 1) The Concerned Medical Officers.
- 2) S.F/File.



//Forwarded by order//

*[Signature]*  
Superintendent.

S.N. 18/12/2018

**A6: Informed consent for phase III community-based survey (English)**

**Informed consent form**

**Participant information sheet**

I am Sunu C Thomas and I am doing PhD at Achutha Menon Centre for Health Sciences Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Thiruvananthapuram. I am conducting this study “Treatment seeking for infertility among married women in Kerala: Identifying the pathways and inequalities in the pathways to the resolution of infertility” as part of my PhD. The purpose of the study is to find out the various treatments that women who have or had difficulty in getting pregnant, do to get pregnant and have a child and the time taken for the treatments. Participation involves answering a set of questions regarding the treatments you have undergone and the time period of each treatment, to resolve your problem in getting pregnant. Some of these may cause painful recollections and should you now wish to dwell on them, you can refuse to answer any specific questions. Thus, you may choose to answer all or some of the questions that I put to you. There will be no direct benefits to you for participating in this interview. The interview will take about 1 hour of your time. I would like to assure you that all the information shared with me will be kept confidential and will only be used for research and publication purpose. Your individual identity will never be used in any research output nor shared with anyone else in process of communication of data.

This study has been cleared by the Institutional Ethics Committee of the SCTIMST, Thiruvananthapuram.

I therefore would be grateful if you agree to participate in this study. The participation in the study is purely voluntary. You have the right to withdraw your participation at any time during the interview without any explanation. You are free to refuse to answer any of the questions at any time. In case you need any additional information and clarification you may contact me,

or my guide. For further queries regarding the study you can address them to the Member Secretary of the Institute Ethics Committee at Sree Chitra Tirunal Institute, for Medical Sciences and Technology Dr.Mala Ramanathan ( phone no:- 0471-2524234). The details of contacts are given below.

Now I request to give your consent to participate in this study by signing below. Thank you.

Name of the Interviewer & Signature:

Date & Place:

**Contact details:**

Researcher:

Name: Sunu C Thomas, PhD Student

Achutha Menon Centre for Health Sciences Studies

SCTIMST, Medical College P.O., Thiruvananthapuram-11

### Consent form

I have read/ been read out the details in the information sheet. The purpose of the study and my involvement has been explained and all my questions have been answered. By signing/providing thumb impression on this consent form, I indicate that I understand what will be expected from me and that I am willing to participate in this study. I know that I can withdraw at any time. I have been informed who should be contacted if the need arises.

I, ..... agree to participate in the study.

Name of the Participant

Signature/thumb impression:

Date & Place:

If the respondent is illiterate,

Name of the witness:

Signature of the witness

Date & Place:

**A7: Informed consent for phase III community-based survey (Malayalam)**

**പഠനത്തിൽ പങ്കെടുക്കുന്നവർക്കുള്ള വിവരണപത്രിക**

എന്റെ പേര് സുനു സി തോമസ്, ഞാൻ ശ്രീ ചിത്ര തിരുനാൾ ഇന്റർട്രിപ്പ്യൂട്ടിലെ അച്യുത മേനോൻ സെന്ററിൽ പൊതുജനാരോഗ്യത്തിൽ പി എച് ഡി ചെയ്യുന്നു. എന്റെ പി എച് ഡിയുടെ ഭാഗമായി ഞാൻ ഒരു പഠനം നടത്തുന്നു. "കേരളത്തിലെ വിവാഹിതരായ സ്ത്രീകളിലെ വന്ധ്യതയ്ക്കുള്ള ചികിത്സ തേടൽ: വന്ധ്യതയുടെ പരിഹാരത്തിലേക്കുള്ള പാതകളും അസമത്വങ്ങളും" . ഈ പഠനം കൊണ്ടുദ്ദേശിക്കുന്നത് ഗർഭം ധരിക്കാൻ ബുദ്ധിമുട്ടുള്ള അല്ലെങ്കിൽ ബുദ്ധിമുട്ടുണ്ടായിരുന്നതായ സ്ത്രീകൾ എന്തെല്ലാം തരത്തിലുള്ള ചികിത്സകളാണ് എടുത്തതെന്നും അതിനു എത്ര സമയം എടുത്തു എന്നും അറിയുന്നതിനാണ് അതുകൊണ്ട് ഈ പഠനത്തിൽ പങ്കാളിയാകാൻ ഞാൻ താങ്കളോട് അഭ്യർത്ഥിക്കുന്നു. ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ സമ്മതമാണെങ്കിൽ ഞാൻ തങ്ങളെ അഭിമുഖം ചെയ്യാൻ താത്പര്യപ്പെടുന്നു. താങ്കൾ ഗർഭം ധരിക്കുന്നതിനു വേണ്ടി ചെയ്ത/ ശ്രമിച്ച വിവിധ തരത്തിലുള്ള ചികിത്സകളും ഓരോ ചികിത്സാ കാലഘട്ടവും എന്താണ് എന്നറിയുന്നതിനെ കുറിച്ച് ചില ചോദ്യങ്ങൾക്കുള്ള ഉത്തരം നൽകുക മാത്രമാണ് ഈ അഭിമുഖത്തിൽ പങ്കാളിയാകുന്നതുകൊണ്ടു താങ്കൾ ചെയ്യേണ്ടത്.

ചില ചോദ്യങ്ങൾ താങ്കൾക്ക് അസ്വസ്ഥത ഉണ്ടാക്കിയേക്കാം. അത്തരത്തിൽ താങ്കളെ അസ്വസ്ഥമാക്കുന്ന ചോദ്യങ്ങൾക്ക് ഉത്തരം നൽകാതിരിക്കാൻ താങ്കൾക്ക് പൂർണ്ണ സ്വാതന്ത്ര്യം ഉണ്ട്. ഈ പഠനത്തിൽ പങ്കാളി ആകുന്നത് കൊണ്ട് താങ്കൾക്ക് നേരിട്ട് ഒരു പ്രയോജനവും ലഭിക്കുന്നതല്ല. ഈ അഭിമുഖം ഏകദേശം 1 മണിക്കൂർ വരെ ദൈർഘ്യം ഉണ്ടാകാം. താങ്കൾ തരുന്ന വിവരങ്ങൾ തീർത്തും പഠനാവശ്യത്തിനുമാത്രമേ ഉപയോഗിക്കുകയുള്ളൂ.

താങ്കളുടെ പേരോ താങ്കളെ തിരിച്ചറിയാൻ കഴിയുന്ന മറ്റ് വിവരങ്ങളോ ഞാൻ എവിടെയും (വിശകലനം ചെയ്യുമ്പോഴോ പ്രബന്ധത്തിലോ) സൂചിപ്പിക്കുന്നതല്ല, മറ്റാരുമായും പങ്കിടുന്നതുമല്ല. ഈ പഠനത്തിൽ താങ്കളുടെ പങ്കാളിത്തം തികച്ചും സ്വമനസ്സാലെ ഉള്ളതാണ്. ഈ പഠനത്തിൽനിന്നും താങ്കൾക്ക് എപ്പോൾ വേണമെങ്കിലും പിന്മാറ്റാവുന്നതാണ്.

ഈ പഠനം ശ്രീ ചിത്ര തിരുനാൾ ഇന്റർട്രിപ്പ്യൂട്ടിലെ ഇന്റർട്രിപ്പ്യൂഷനൽ എത്തിക്സ് കമ്മിറ്റി അംഗീകരിച്ചതാണ്. എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ ചോദിക്കാവുന്നതാണ്. ഭാവിയിൽ ഈ പഠനത്തെ കുറിച്ച് എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ എന്നോട് അല്ലെങ്കിൽ എന്റെ പി എച് ഡി ഗൈഡിനോടോ ചോദിക്കാവുന്നതാണ്. എന്റെ പഠനത്തെക്കുറിച്ചു താങ്കൾക്ക് എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ ശ്രീ ചിത്ര തിരുനാൾ ഇന്റർട്രിപ്പ്യൂട്ടിലെ ഇന്റർട്രിപ്പ്യൂഷനൽ എത്തിക്സ് കമ്മിറ്റിയുടെ മെമ്പർ സെക്രട്ടറിയായ ഡോക്ടർ മാല രാമനാഥൻ നോട് ചോദിക്കാവുന്നതാണ് ( 0471-2524234). Email id: [mala@sctimst.ac.in](mailto:mala@sctimst.ac.in).

ചുവടെ ചേർത്തിട്ടുള്ള സമ്മതപത്രത്തിൽ ഒപ്പു വച്ചുകൊണ്ടു ഈ പഠനത്തിൽ പങ്കെടുക്കാനുള്ള താങ്കളുടെ സമ്മതം രേഖപ്പെടുത്തണം എന്ന് അഭ്യർത്ഥിക്കുന്നു . നന്ദി അഭിമുഖം ചെയ്യുന്ന വ്യക്തിയുടെ പേര് & ഒപ്പ്:  
തീയതി & സ്ഥലം:  
ബന്ധപ്പെടാനുള്ള വിവരങ്ങൾ:  
ഗവേഷക: സുനു സി തോമസ് , പി എപ്പി സൂടെന്റ്  
അച്യുത മേനോൻ സെന്റർ ഫോർ ഹെൽത്ത് സയൻസ് സ്റ്റുഡീസ്  
സ് സി ടി ഐ എം സി ടി, മെഡിക്കൽ കോളേജ് പി .ഓ ., തിരുവനന്തപുരം -11

**സമ്മതപത്രം**

പഠനവിവരണം മുഴുവൻ ഞാൻ വായിച്ചു / എന്നെ വായിച്ചു കേൾപ്പിച്ചു. ഈ പഠനത്തിന്റെ ഉദ്ദേശവും ഈ പഠനത്തിൽ എനിക്കുള്ള പങ്കാളിത്തവും എന്നോട് വിവരിച്ചിട്ടുണ്ട്. ഈ സമ്മതപത്രത്തിൽ ഒപ്പു / വിരലടയാളം വയ്ക്കുന്നത് ഈ പഠനത്തിൽ പങ്കാളിയാകാനുള്ള എന്റെ പൂർണ്ണസമ്മതത്തെ അറിയിക്കുന്നു. ഈ പഠനത്തിൽ നിന്നും എപ്പോൾ വേണമെങ്കിലും പിന്മാറാം എന്നും എനിക്കറിയാം. എന്തെങ്കിലും വിശദീകരണം ആവശ്യമുണ്ടെങ്കിൽ ആരെ ബന്ധപ്പെടണം എന്നും എനിക്കറിയാം.

ഞാൻ..... ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ തയ്യാറാണ് .

പേര് :  
ഒപ്പ്/ വിരലടയാളം:

തീയതി & സ്ഥലം:

പ്രതിവദിക്കുന്നയാൾ നിരക്ഷര ആണെങ്കിൽ,

സാക്ഷിയുടെ പേര്:

സാക്ഷിയുടെ ഒപ്പ് :

തീയതി & സ്ഥലം:

**Informed consent form**

**Participant information sheet- In depth Interview**

I am Sunu C Thomas and I am doing PhD at Achutha Menon Centre for Health Sciences Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Thiruvananthapuram. I am conducting this study “Treatment seeking for infertility among married women in Kerala: Identifying the pathways and inequalities in the pathways to the resolution of infertility” as part of my PhD. As part of the study I would like to understand more about the treatments you have undergone and your experience of undergoing the treatments. Participation involves a conversation including some questions regarding the kind of treatment you have undergone in trying to conceive and the specific meaning it has to your life. Some of these may cause painful recollections and should you now wish to dwell on them, you can refuse to answer any specific questions. Thus, you may choose to answer all or some of the questions that I put to you. There will be no direct benefits to you for participating in this interview. The interview will take about 30-40minutes. If you are willing I would like to audio- record the interview. I would like to assure you that all the information shared with me will be kept confidential and will only be used for research and publication purpose. Your individual identity will never be used in any research output nor shared with anyone else in process of communication of data.

This study has been cleared by the Institutional Ethics Committee of the SCTIMST, Thiruvananthapuram.

I therefore would be grateful if you agree to participate in this study. The participation in the study is purely voluntary. You have the right to withdraw your participation at any time during the interview without any explanation. You are free to refuse to answer any of the questions at any time. In case you need any additional information and clarification you may contact me,

or my guide. For further queries regarding the study you can address them to the Member Secretary of the Institute Ethics Committee at Sree Chitra Tirunal Institute, for Medical Sciences and Technology Dr.Mala Ramanathan ( phone no:- 0471-2524234). The details of contacts are given below.

Now I request to give your consent to participate in this study by signing below. Thank you.

Name of the Interviewer & Signature:

Date & Place:

**Contact details:**

Researcher:

Name: Sunu C Thomas, PhD Student

Achutha Menon Centre for Health Sciences Studies

SCTIMST, Medical College P.O., Thiruvananthapuram-11

### **Consent form**

I have read/ been read out the details in the information sheet. The purpose of the study and my involvement has been explained and all my questions have been answered. By signing/providing thumb impression on this consent form, I indicate that I understand what will be expected from me and that I am willing to participate in this study. I know that I can withdraw at any time. I have been informed who should be contacted if the need arises.

I, ..... agree to participate in the study.

Name of the Participant

Signature/thumb impression:

Date & Place:

If the respondent is illiterate,

Name of the witness:

Signature of the witness

Date & Place:

**A9: Informed consent for phase III in-depth interview (Malayalam)**

**പഠനത്തിൽ പങ്കെടുക്കുന്നവർക്കുള്ള വിവരണപത്രിക- ഗഹനമായ അഭിമുഖം നടത്തുന്നതിന്**

എന്റെ പേര് സുനു സി തോമസ്, ഞാൻ ശ്രീ ചിത്ര തിരുനാൾ ഇന്റർവ്യൂയിലെ അച്യുത മേനോൻ സെന്ററിൽ പൊതുജനാരോഗ്യത്തിൽ പി എച്ച് ഡി ചെയ്യുന്നു. എന്റെ പി എച്ച് ഡിയുടെ ഭാഗമായി ഞാൻ ഒരു പഠനം നടത്തുന്നു. "കേരളത്തിലെ വിവാഹിതരായ സ്ത്രീകളിലെ വന്ധ്യതയ്ക്കുള്ള ചികിത്സ തേടൽ: വന്ധ്യതയുടെ പരിഹാരത്തിലേക്കുള്ള പാതകളും അസമത്വങ്ങളും". ഈ പഠനത്തിന്റെ ഭാഗമായി താങ്കൾ സീക്രട്ടി ചികിത്സാ രീതികളെക്കുറിച്ചും ചികിത്സാ അനുഭവങ്ങളെക്കുറിച്ചും കൂടുതൽ അറിയാൻ ആഗ്രഹിക്കുന്നു.

അതുകൊണ്ട് ഈ പഠനത്തിൽ പങ്കാളിയാകാൻ ഞാൻ താങ്കളോട് അഭ്യർത്ഥിക്കുന്നു. ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ സമ്മതമാണെങ്കിൽ ഞാൻ തങ്ങളെ അഭിമുഖം ചെയ്യാൻ താത്പര്യപ്പെടുന്നു. താങ്കൾ ഗർഭം ധരിക്കുന്നതിനു വേണ്ടി ചെയ്ത/ ശ്രമിച്ച വിവിധ തരത്തിലുള്ള ചികിത്സകളും അതിനു നിങ്ങളുടെ ജീവിതത്തിലെ അർത്ഥം എന്താണ് എന്നറിയാനായി കുറിച്ച് ചില ചോദ്യങ്ങൾക്കുള്ള ഉത്തരം നൽകുക മാത്രമാണ് ഈ അഭിമുഖത്തിൽ പങ്കാളിയാകുന്നതുകൊണ്ടു താങ്കൾ ചെയ്യേണ്ടത്.

ചില ചോദ്യങ്ങൾ താങ്കൾക്ക് അസാധ്യമായ ഉണ്ടാക്കിയേക്കാം. അത്തരത്തിൽ താങ്കളെ അസന്മാദമാക്കുന്ന ചോദ്യങ്ങൾക്ക് ഉത്തരം നൽകാതിരിക്കാൻ താങ്കൾക്ക് പൂർണ്ണ സ്വാതന്ത്ര്യം ഉണ്ട്. ഈ പഠനത്തിൽ പങ്കാളി ആകുന്നതുകൊണ്ട് താങ്കൾക്ക് നേരിട്ട് ഒരു പ്രയോജനവും ലഭിക്കുന്നതല്ല. ഈ അഭിമുഖം ഏകദേശം 30-40 മിനിറ്റ് വരെ ദൈർഘ്യം ഉണ്ടാകാം. താങ്കൾക്ക് സമ്മതമാണെങ്കിൽ ഈ അഭിമുഖം ഞാൻ റെക്കോർഡ് ചെയ്യാൻ താത്പര്യപ്പെടുന്നു. താങ്കൾ തരുന്ന വിവരങ്ങൾ തീർത്തും പഠനാവശ്യത്തിനുമത്രമേ ഉപയോഗിക്കുകയുള്ളൂ.

താങ്കളുടെ പേരോ താങ്കളെ തിരിച്ചറിയാൻ കഴിയുന്ന മറ്റ് വിവരങ്ങളോ ഞാൻ എവിടെയും (വിശകലനം ചെയ്യുമ്പോഴോ പ്രബന്ധത്തിലോ) സൂചിപ്പിക്കുന്നതല്ല, മറ്റാരുമായും പങ്കിടുന്നതുമല്ല. ഈ പഠനത്തിൽ താങ്കളുടെ പങ്കാളിത്തം തികച്ചും സ്വമനസ്സാലെ ഉള്ളതാണ്. ഈ പഠനത്തിൽനിന്നും താങ്കൾക്ക് എപ്പോൾ വേണമെങ്കിലും പിന്മാറ്റാവുന്നതാണ്.

ഈ പഠനം ശ്രീ ചിത്ര തിരുനാൾ ഇന്റർവ്യൂയിലെ ഇന്റർവ്യൂഷനൽ എത്തിക്സ് കമ്മിറ്റി അംഗീകരിച്ചതാണ്. എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ ചോദിക്കാവുന്നതാണ്. ഭാവിയിൽ ഈ പഠനത്തെ കുറിച്ച് എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ എന്നോട് അല്ലെങ്കിൽ എന്റെ പി എച്ച് ഡി ഗൈഡിനോടോ ചോദിക്കാവുന്നതാണ്. എന്റെ പഠനത്തെക്കുറിച്ചു താങ്കൾക്ക് എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ ശ്രീ ചിത്ര തിരുനാൾ ഇന്റർവ്യൂയിലെ ഇന്റർവ്യൂഷനൽ എത്തിക്സ് കമ്മിറ്റിയുടെ മെമ്പർ സെക്രട്ടറിയായ ഡോക്ടർ മാല രാമനാഥൻ നോട് ചോദിക്കാവുന്നതാണ് ( 0471-2524234). Email id: [mala@sctimst.ac.in](mailto:mala@sctimst.ac.in).

ചുവടെ ചേർത്തിട്ടുള്ള സമ്മതപത്രത്തിൽ ഒപ്പു വച്ചുകൊണ്ടു ഈ പഠനത്തിൽ പങ്കെടുക്കാനുള്ള താങ്കളുടെ സമ്മതം രേഖപ്പെടുത്തണം എന്ന് അഭ്യർത്ഥിക്കുന്നു . നന്ദി അഭിമുഖം ചെയ്യുന്ന വ്യക്തിയുടെ പേര് & ഒപ്പ്:  
 തീയതി & സ്ഥലം:  
 ബന്ധപ്പെടാനുള്ള വിവരങ്ങൾ:  
 ഗവേഷക: സുനു സി തോമസ് , പി എച്ഐ സൂടെന്റർ  
 അച്യുത മേനോൻ സെന്റർ ഫോർ ഹെൽത്ത് സയൻസ് സ്റ്റുഡീസ്  
 സി സി ടി ഐ എം സി ടി, മെഡിക്കൽ കോളേജ് പി .ഓ ., തിരുവനന്തപുരം -11

**സമ്മതപത്രം**

പഠനവിവരണം മുഴുവൻ ഞാൻ വായിച്ചു / എന്നെ വായിച്ചു കേൾപ്പിച്ചു. ഈ പഠനത്തിന്റെ ഉദ്ദേശവും ഈ പഠനത്തിൽ എനിക്കുള്ള പങ്കാളിത്തവും എന്നോട് വിവരിച്ചിട്ടുണ്ട്. ഈ സമ്മതപത്രത്തിൽ ഒപ്പു / വിരലടയാളം വയ്ക്കുന്നത് ഈ പഠനത്തിൽ പങ്കാളിയാകാനുള്ള എന്റെ പൂർണ്ണസമ്മതത്തെ അറിയിക്കുന്നു. ഈ പഠനത്തിൽ നിന്നും എപ്പോൾ വേണമെങ്കിലും പിന്മാറാം എന്നും എനിക്കറിയാം. എന്തെങ്കിലും വിശദീകരണം ആവശ്യമുണ്ടെങ്കിൽ ആരെ ബന്ധപ്പെടണം എന്നും എനിക്കറിയാം.

ഞാൻ..... ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ തയ്യാറാണ് .

പേര്  
ഒപ്പ്/ വിരലടയാളം

തീയതി & സ്ഥലം

പ്രതിവദിക്കുന്നയാൾ നിരക്ഷര ആണെങ്കിൽ,  
സാക്ഷിയുടെ പേര്  
സാക്ഷിയുടെ ഒപ്പ്  
തീയതി & സ്ഥലം

**A10: In-depth interview guide for phase I in-depth interview (English)**

**Treatment choices among couples with infertility: A qualitative enquiry among couples with infertility in the southern districts of Kerala**

Achutha Menon Centre for Health Science studies  
Sree Chitra Tirunal Institute for Medical Science and Technology  
Trivandrum-11

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**Participant Details**

**Identification No:**

1	Name of the respondent- female partner	
2	Age of the respondent	
3	Name of the husband	
4	Age of the husband	
5	How long have you been married?	
6	Have you been trying to get pregnant? (at the time of interview)	Yes/No
7	If yes for Q6, how long have you been trying to get pregnant?	
8	If no for Q6, have you ever tried, after marriage to get pregnant?	Yes/No if yes continue, if no discontinue the interview

## **In-depth interview guide for the female partner**

### **INTRODUCTION:**

Thank you very much for agreeing to be interviewed. I understand that you have been married for... years and is having some difficulty in getting pregnant. I would like to understand more about this and the steps taken by you/your partner in getting pregnant. My questions to you will relate more to the kind of treatment choices you have made in trying to conceive and the reasons for choosing a particular choice over another. There are no right or wrong answers to my questions, and I am more interested in your opinions regarding the choices you made and why you made that choice.

How did you decide that you need to get help/treatment to get pregnant? How long after the marriage was this?

**PROBE FOR WHO INITIATED THE TALK/REALIZED THE PROBLEM:** like themselves/partner/family/friends/medical professional/others

After thinking that one or both of you may have difficulties associated with having children, what was the next step? What did you think needs to be done and what did you actually do? Why?

What were the various options that you considered? How did you identify these?

Who initiated the process for the first step? **PROBE:** like themselves/partner/family/friends/medical professional/others

What were the other options considered? And why? Why did you/your partner choose this option?

What other treatments by way of alternative modalities such as unani/ayurved/etc did you consider? How did that help?

What were the things that helped during the process of infertility treatment and what were the things that made things difficult? What did you and your partner do to resolve these problems?

What are the other things that you are likely to do now to resolve the problem?

Who are all the persons whom you would consider as key persons in your decision making regarding your treatment seeking and how are they important?

Seek permission to approach the partner (if mentioned above) and also any other significant persons. With your permission, I would like to talk to your partner about the same things. Would you object to my talking to him separately regarding these matters?

YES/NO

If yes, Name/contact details to fix appointment

Are there any other persons who you consider important to your treatment seeking who might be willing to talk to me? If so, could you tell me who they are?

Names and relationship and contact details.

I would also like to contact you for clarifications during analysis or to clarify any other information. Do you have any objection to this? YES/NO

LEAVE TAKING: Thank you very much for patiently answering all my questions. I am very grateful to you for giving me the time and explaining the treatment choices that you made and why you made them regarding your fertility problem. I would like to assure you that I will not mention either your name or any identifying information in my analysis or dissertation.

## **In-depth interview guide for the male partner/any other significant persons**

### **INTRODUCTION:**

Thank you very much for agreeing to be interviewed. I understand that ...(mention the female partners name) and you (if husband) have been married for... years and is having some difficulty in getting pregnant. I would like to understand more about this and the steps taken by you/your partner in getting pregnant. My questions to you will relate more to the kind of treatment choices you have made in trying to conceive and the reasons for choosing a particular choice over another. There are no right or wrong answers to my questions, and I am more interested in your opinions regarding the choices made and why those choices were made.

In what way were you involved in the decision to seek the treatment?

What were the other options considered? And why?

Why did you/your partner choose this option?

What other treatments by way of alternative modalities such as unani/ayurved/etc did you consider? How did that help?

What were the things that helped during the process of infertility treatment and what were the things that made things difficult?

What are the other things that you are likely to do now to resolve the problem?

I would also like to contact you for clarifications during analysis or to clarify any other information. Do you have any objection to this? YES/NO

**LEAVE TAKING:** Thank you very much for patiently answering all my questions. I am very grateful to you for giving me the time and explaining the treatment choices that you made and why you made them regarding your fertility problem. I would like to assure you that I will not mention either your name or any identifying information in my analysis or dissertation.

Annexure-II

"വന്ധ്യതയുള്ള ദമ്പതികളുടെ ചികിത്സാ തരങ്ങൾ: കേരളത്തിലെ തെക്കൻ ജില്ലകളിൽ വന്ധ്യതയുള്ള ദമ്പതികളുടെ ഇടയിൽ ഗുണപരമായ അന്വേഷണം"

അച്യുത മേനോൻ സെന്റർ ഫോർ ഹെൽത്ത് സയൻസ് സ്റ്റുഡിസ് ,  
ശ്രീ ചിത്ര തിരുനാൾ ഇൻസ്റ്റിറ്റ്യൂട്ട് ഫോർ മെഡിക്കൽ സയൻസസ് ആൻഡ് ടെക്നോളജി ,  
മെഡിക്കൽ കോളേജ് പി .ഓ ., തിരുവനന്തപുരം -11

ID NO:

1	പ്രതിവദിക്കുന്ന വ്യക്തിയുടെ പേര് -ഭാര്യ	
2	പ്രതിവദിക്കുന്ന വ്യക്തിയുടെ വയസ്സ്	
3	ഭർത്താവിന്റെ പേര്	
4	ഭർത്താവിന്റെ വയസ്സ്	
5	താങ്കൾ വിവാഹിതയായിട്ട് എത്ര നാളായി ?	
6	ഗർഭിണിയാകുന്നതിനുവേണ്ടി ഇപ്പോൾ നിങ്ങൾ ശ്രമിക്കുന്നുണ്ടോ? (അഭിമുഖം ചെയ്യുന്ന സമയത്തു)	ഉണ്ട് / ഇല്ല
7	ഉണ്ടെങ്കിൽ, എത്ര നാളായി ഗർഭം ധരിക്കാൻ ശ്രമിക്കുന്നു ?	
8	ഇല്ലെങ്കിൽ, വിവാഹത്തിന് ശേഷം എപ്പോഴെങ്കിലും ഗർഭം ധരിക്കാൻ ശ്രമിച്ചിട്ടുണ്ടോ ?	ഉണ്ട് / ഇല്ല ഉണ്ടെങ്കിൽ അഭിമുഖം തുടരുക ഇല്ലെങ്കിൽ അഭിമുഖം അവസാനിപ്പിക്കുക

**ഗഹനമായ അഭിമുഖം നടത്തുന്നതിനുള്ള മാർഗനിർദ്ദേശം (ഭാര്യയോട് ചോദിക്കുന്നതിന്) ആമുഖം:**

താങ്കളെ അഭിമുഖം ചെയ്യാൻ സമ്മതം തന്നതിനു നന്ദി. താങ്കൾ വിവാഹിതയായിട്ടു ... നാളായി എന്നും താങ്കൾക്ക് ഗർഭംധരിക്കുന്നതിനു ചില ബുദ്ധിമുട്ടുകൾ ഉണ്ടെന്നും ഞാൻ മനസ്സിലാക്കുന്നു. ഇത് സംബന്ധിച്ചു കൂടുതൽ വിവരങ്ങൾ അറിയാൻ ഞാൻ താൽപ്പര്യപ്പെടുന്നു, താങ്കളും താങ്കളുടെ പങ്കാളിയും ഗർഭംധരിക്കുന്നതിനു വേണ്ടി എന്തെല്ലാം നടപടികളാണ് സ്വീകരിച്ചതെന്നും അറിയാൻ താൽപ്പര്യപ്പെടുന്നു. എന്റെ ചോദ്യങ്ങൾ താങ്കൾ ഗർഭം ധരിക്കുന്നതിനു വേണ്ടി ചെയ്ത/ ശ്രമിച്ച വിവിധ തരത്തിലുള്ള ചികിത്സകളും അവ തിരഞ്ഞെടുത്തതിനുള്ള കാരണങ്ങൾ സംബന്ധിച്ചുമാണ്. എന്റെ ചോദ്യങ്ങൾക്ക് ശരിയോ തെറ്റോ ഉത്തരം ഇല്ല മറിച്ച് താങ്കൾ ഒരു പ്രത്യേക ചികിത്സ തിരഞ്ഞെടുത്തതിലുള്ള അഭിപ്രായവും അത് തിരഞ്ഞെടുക്കാനുള്ള കരണത്തിനെപ്പറ്റിയും അറിയുന്നതിനാണ്.

എങ്ങനെയാണ് താങ്കൾക്ക് കുട്ടികൾ ഉണ്ടാകുന്നതിന് സഹായം/ ചികിത്സ ആവശ്യമാണെന്ന് തീരുമാനിച്ചത്? വിവാഹത്തിനുശേഷം എത്രനാൾ കഴിഞ്ഞാണ് ഇത് സംബന്ധിച്ചുള്ള തീരുമാനത്തിൽ എത്തിയത്?

പ്രോബ്: ഇതിനെ പറ്റിയുള്ള ചർച്ചകൾ ആരംഭിച്ചത് ആരാണ് / കുട്ടികൾ ഉണ്ടാകുന്നതിന് ബുദ്ധിമുട്ടുണ്ടെന്ന് ആരാണ് മനസ്സിലാക്കിയത് : സ്വയം/ പങ്കാളി / ബന്ധുക്കൾ / സുഹൃത്തുക്കൾ / വൈദ്യസംബന്ധമായ വ്യക്തികൾ / മറ്റാരെങ്കിലും കുട്ടികൾ ഉണ്ടാകുന്നത് സംബന്ധിച്ചു / ഗർഭംധരിക്കുന്നത് സംബന്ധിച്ചു താങ്കൾക്കോ പങ്കാളിക്കോ ബുദ്ധിമുട്ട് ഉണ്ടെന്ന് മനസ്സിലാക്കിയതിനുശേഷം അടുത്തനടപടി എന്തായിരുന്നു?

എന്തു ചെയ്യാനും എന്നാണ് കരുതിയത്? തങ്ങൾ എന്താണ് ചെയ്തത്? എന്തുകൊണ്ടാണ് അങ്ങനെ ചെയ്തത്?

എന്തെല്ലാം തരത്തിലുള്ള മാർഗ്ഗങ്ങൾ പരിഗണിച്ചിരുന്നു? ഇതൊക്കെ എങ്ങനെയാണ് താങ്കൾ അറിഞ്ഞത് / മനസ്സിലാക്കിയത്?

ആദ്യമായി എന്ത് ചെയ്യാനാണ് തീരുമാനിച്ചത്? ഈ തീരുമാനം ആദ്യം എടുത്തത്/ തുടങ്ങിവെച്ചത് ആരാണ്? പ്രോബ്: സ്വയം/ പങ്കാളി / ബന്ധുക്കൾ / സുഹൃത്തുക്കൾ / വൈദ്യസംബന്ധമായ വ്യക്തികൾ / മറ്റാരെങ്കിലും

മറ്റൊന്നെല്ലാം മാർഗ്ഗങ്ങൾ ആണ് പരിഗണിച്ചത്? എന്തുകൊണ്ട്? ഈ മാർഗ്ഗം താങ്കളോ പങ്കാളിയോ എന്തുകൊണ്ടാണ് തിരഞ്ഞെടുത്തത്?

മറ്റ് ചികിത്സകൾ ഉദാഹരണത്തിന് യൂനാനി/ ആയുർവേദം എന്തെങ്കിലും പരിഗണിച്ചിരുന്നോ? പരിഗണിച്ചെങ്കിൽ ഇത് ഏതെങ്കിലും തരത്തിൽ സഹായിച്ചോ?

വന്ധ്യതാചികിത്സയുടെ ഓരോ ഘട്ടത്തിലും എന്തെല്ലാം കാര്യങ്ങൾ താങ്കൾക്ക് സഹായമായി തോന്നിയിട്ടുണ്ട്? എന്തെല്ലാം കാര്യങ്ങൾ ഓരോ ഘട്ടത്തിലും ബുദ്ധിമുട്ടുണ്ടാക്കിയിട്ടുണ്ട്? ഈ ബുദ്ധിമുട്ടുകൾ പരിഹരിക്കാൻ താങ്കളും പങ്കാളിയും എന്തെല്ലാം ചെയ്തിട്ടുണ്ട്?

താങ്കൾ ഈ പ്രശ്നം പരിഹരിക്കാൻ ഇനി ഇപ്പോൾ ചെയ്യാൻ സാധ്യത ഉള്ള കാര്യങ്ങൾ എന്തൊക്കെയാണ്?

താങ്കളുടെ ചികിത്സ സംബന്ധിച്ചു തീരുമാനങ്ങൾ എടുക്കുന്നതിൽ സുപ്രധാനമായ പങ്കുവഹിച്ച മറ്റു വ്യക്തികൾ ആരാക്കെയാണ്? അവർ ഏതു തരത്തിലാണ് പ്രാധാന്യം അർഹിക്കുന്നത്?

താങ്കളുടെ അനുവാദത്തോടുകൂടി താങ്കളുടെ പങ്കാളിയുമായി ഇതേ കാര്യങ്ങൾ ചോദിച്ചറിയാൻ താത്പര്യപ്പെടുന്നു. ചികിത്സ സംബന്ധിച്ച വിവരങ്ങൾ താങ്കളുടെ പങ്കാളിയുമായി ഒറ്റയ്ക്ക് സംസാരിക്കുന്നതിൽ എന്തെങ്കിലും എതിർപ്പുണ്ടോ? ഉണ്ട്/ഇല്ല

എതിർപ്പില്ലെങ്കിൽ , പങ്കാളിയെ അഭിമുഖം ചെയ്യാൻ സമയം ഉറപ്പിക്കുക  
പേരും മറ്റ് വിവരങ്ങളും ചോദിക്കുക

താങ്കളുടെ ചികിത്സ സംബന്ധിച്ചു തീരുമാനങ്ങൾ എടുക്കുന്നതിൽ സുപ്രധാനമായ പങ്കുവഹിച്ച മറ്റുവ്യക്തികൾ ആരെങ്കിലും എന്നോട് സംസാരിക്കാൻ താല്പര്യപ്പെടുമോ? ഉണ്ടെങ്കിൽ ആരെയാക്കെയാണ് എന്ന് പറയാമോ? അവരോടു ഞാൻ സംസാരിക്കുന്നതിൽ തങ്ങൾക്കു എതിർപ്പുണ്ടോ? ഉണ്ട്/ഇല്ല

ഇല്ലെങ്കിൽ , പേരും മറ്റ് വിവരങ്ങളും ചോദിക്കുക  
അഭിമുഖം ചെയ്യാൻ സമയം ഉറപ്പിക്കുക

ഇത് വിശകലനം ചെയ്യുമ്പോൾ എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ അല്ലെങ്കിൽ മറ്റെന്തെങ്കിലും കാര്യങ്ങൾ വ്യക്തമാക്കണമെങ്കിൽ ഞാൻ താങ്കളെ വീണ്ടും ബന്ധപ്പെടുന്നതിൽ വിരോധം ഉണ്ടോ? ഉണ്ട്/ഇല്ല

സംഭാഷണം അവസാനിപ്പിക്കുക :

താങ്കളുടെ വിലപ്പെട്ട സമയം ചിലവാക്കി എന്റെ ചോദ്യങ്ങൾക്ക് ക്ഷമാപൂർവ്വം ഉത്തരം തന്നതിനും താങ്കൾ പരിഗണിച്ച ചികിത്സകളെ കുറിച്ചും അത് എന്തുകൊണ്ട് താങ്കളുടെ വന്ധ്യതാ പ്രശ്നത്തിന് തിരഞ്ഞെടുത്തെന്നും വളരെ വ്യക്തമായി വിശദീകരിച്ചതിനും നന്ദി. താങ്കളുടെ പേരോ താങ്കളെ തിരിച്ചറിയാൻ കഴിയുന്ന മറ്റ് വിവരങ്ങളോ ഞാൻ എവിടെയും (വിശകലനം ചെയ്യുമ്പോഴോ പ്രബന്ധത്തിലോ) സൂചിപ്പിക്കുന്നതല്ല.

**ഗഹനമായ അഭിമുഖം നടത്തുന്നതിനുള്ള മാർഗനിർദ്ദേശം  
(ഭർത്താവിനോട് / മറ്റ് പ്രധാനവ്യക്തികളോട് ചോദിക്കുന്നതിന്)**

ആമുഖം:

താങ്കളെ അഭിമുഖം ചെയ്യാൻ സമ്മതം തന്നതിനു നന്ദി. താങ്കളും (ഭർത്താവായെങ്കിൽ) താങ്കളുടെ ഭാര്യയായ..... യും (പേര്) വിവാഹിതയായിട്ടു ... നാളായി എന്നും താങ്കൾക്ക് ഗർഭം ധരിക്കുന്നതിനു ചില ബുദ്ധിമുട്ടുകൾ ഉണ്ടെന്നും ഞാൻ മനസ്സിലാക്കുന്നു. ഇത് സംബന്ധിച്ചു കൂടുതൽ വിവരങ്ങൾ അറിയാൻ ഞാൻ താത്പര്യപ്പെടുന്നു, താങ്കളും താങ്കളുടെ പങ്കാളിയും ഗർഭം ധരിക്കുന്നതിനു വേണ്ടി എന്തെല്ലാം നടപടികളാണ് സ്വീകരിച്ചതെന്നും അറിയാൻ താത്പര്യപ്പെടുന്നു. താങ്കളും താങ്കളുടെ പങ്കാളിയും / .... (പേര്- മറ്റു വ്യക്തികളെയാണ് അഭിമുഖം ചെയ്യുന്നതെങ്കിൽ)

എടുത്തുകൊണ്ടിരിക്കുന്ന ചികിത്സയെപ്പറ്റി കൂടുതൽ മനസ്സിലാക്കാൻ ഞാൻ താല്പര്യപ്പെടുന്നു. എന്റെ ചോദ്യങ്ങൾ താങ്കൾ/താങ്കളുടെ പങ്കാളി / .... (പേര്- മറ്റു വ്യക്തികളെയാണ് അഭിമുഖം ചെയ്യുന്നതെങ്കിൽ) ഗർഭം ധരിക്കുന്നതിനു വേണ്ടി ചെയ്ത/ ശ്രമിച്ച വിവിധ തരത്തിലുള്ള ചികിത്സകളും അവ തിരഞ്ഞെടുത്തതിനുള്ള കാരണങ്ങൾ സംബന്ധിച്ചുമാണ്. എന്റെ ചോദ്യങ്ങൾക്ക് ശരിയോ തെറ്റോ ഉത്തരം ഇല്ല മറിച്ച് താങ്കൾ ഒരു പ്രത്യേക ചികിത്സ തിരഞ്ഞെടുത്തതിലുള്ള അഭിപ്രായവും അത് തിരഞ്ഞെടുക്കാനുള്ള കാരണത്തിനെപ്പറ്റിയും അറിയുന്നതിനാണ്.

ചികിത്സ തേടുന്നതിനുള്ള തീരുമാനങ്ങളിൽ താങ്കൾ ഏതു തരത്തിലാണ് ഉൾപ്പെട്ടിട്ടുള്ളത്?

എന്തെല്ലാം മാർഗ്ഗങ്ങൾ പരിഗണിച്ചിരുന്നു ? എന്തുകൊണ്ട് ?

ഈ മാർഗം താങ്കളോ പങ്കാളിയോ എന്തുകൊണ്ടാണ് തിരഞ്ഞെടുത്തത് ?

മറ്റ് ചികിത്സകൾ ഉദാഹരണത്തിന് യൂനാനി/ ആയുർവേദം എന്തെങ്കിലും പരിഗണിച്ചിരുന്നോ? പരിഗണിച്ചെങ്കിൽ ഇത് ഏതെങ്കിലും തരത്തിൽ സഹായിച്ചോ ?

വന്ധ്യതാചികിത്സയുടെ ഓരോ ഘട്ടത്തിലും എന്തെല്ലാം കാര്യങ്ങൾ താങ്കൾക്ക് സഹായമായി തോന്നിയിട്ടുണ്ട് ? എന്തെല്ലാം കാര്യങ്ങൾ ഓരോ ഘട്ടത്തിലും ബുദ്ധിമുട്ടുണ്ടാക്കിയിട്ടുണ്ട് ? ഈ ബുദ്ധിമുട്ടുകൾ പരിഹരിക്കാൻ താങ്കളും പങ്കാളിയും എന്തെല്ലാം ചെയ്തിട്ടുണ്ട്? താങ്കൾ ഈ പ്രശ്നം പരിഹരിക്കാൻ ഇനി ഇപ്പോൾ ചെയ്യാൻ സാധ്യത ഉള്ള കാര്യങ്ങൾ എന്തൊക്കെയാണ് ?

സംഭാഷണം അവസാനിപ്പിക്കുക :

താങ്കളുടെ വിലപ്പെട്ട സമയം ചിലവാക്കി എന്റെ ചോദ്യങ്ങൾക്ക് ക്ഷമാപൂർവ്വം ഉത്തരം തന്നതിനും താങ്കൾ പരിഗണിച്ച ചികിത്സകളെ കുറിച്ചും അത് എന്തുകൊണ്ട് താങ്കൾ/താങ്കളുടെ പങ്കാളി / .... (പേര്- മറ്റു വ്യക്തികളെയാണ് അഭിമുഖം ചെയ്യുന്നതെങ്കിൽ) വന്ധ്യതാ പ്രശ്നത്തിന് തിരഞ്ഞെടുത്തെന്നും വളരെ വ്യക്തമായി വിശദീകരിച്ചതിനും നന്ദി. താങ്കളുടെ പേരോ താങ്കളെ തിരിച്ചറിയാൻ കഴിയുന്ന മറ്റ് വിവരങ്ങളോ ഞാൻ എവിടെയും (വിശകലനം ചെയ്യുമ്പോഴോ പ്രബന്ധത്തിലോ) സൂചിപ്പിക്കുന്നതല്ല.

**പഠനത്തിൽ പങ്കെടുക്കുന്നവർക്കുള്ള വിവരണപത്രിക- ഭാര്യ**

എന്റെ പേര് സുനു സി തോമസ്, ഞാൻ ശ്രീ ചിത്ര തിരുനാൾ ഇസ്റ്റിട്യൂട്ടിലെ അച്യുത മേനോൻ സെന്ററിൽ പൊതുജനാരോഗ്യത്തിൽ പി എച് ഡി ചെയ്യുന്നു. എന്റെ പി എച് ഡിയുടെ ഭാഗമായി ഞാൻ ഒരു പഠനം നടത്തുന്നു. "വന്ധ്യതയുള്ള ദമ്പതികളുടെ ചികിത്സ തരങ്ങൾ: കേരളത്തിലെ തെക്കൻ ജില്ലകളിൽ വന്ധ്യതയുള്ള ദമ്പതികളുടെ ഇടയിൽ ഗുണപരമായ അന്വേഷണം". ഈ പഠനം കൊണ്ട് ഉദ്ദേശിക്കുന്നത് കുട്ടികൾ ഉണ്ടാകാൻ ബുദ്ധിമുട്ടുള്ളതും എന്നാൽ കുട്ടികൾ വേണം എന്ന് ആഗ്രഹിക്കുന്ന ദമ്പതികൾ ഇതിനായി എന്തെല്ലാം മാർഗ്ഗങ്ങൾ/ ചികിത്സകൾ ചെയ്യും എന്നറിയുന്നതിനാണ്.

അതുകൊണ്ട് ഈ പഠനത്തിൽ പങ്കാളിയാകാൻ ഞാൻ താങ്കളോട് അഭ്യർത്ഥിക്കുന്നു. ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ സമ്മതമാണെങ്കിൽ ഞാൻ തങ്ങളെ അഭിമുഖം ചെയ്യാൻ താത്പര്യപ്പെടുന്നു. താങ്കൾ ഗർഭം ധരിക്കുന്നതിനായി എന്തെല്ലാം മാർഗ്ഗങ്ങൾ അല്ലെങ്കിൽ ചികിത്സകൾ ആണ് തിരഞ്ഞെടുത്തതെന്നും ആ ചികിത്സ/ മാർഗ്ഗം എന്തുകൊണ്ട് തിരഞ്ഞെടുത്തു എന്നതിനെ കുറിച്ചും ചില കാര്യങ്ങൾ ഞാൻ ചോദിച്ച് കാൻ ഉദ്ദേശിക്കുന്നത്. ചില ചോദ്യങ്ങൾ താങ്കൾക്ക് അസ്വസ്ഥത ഉണ്ടാക്കിയേക്കാം. അത്തരത്തിൽ താങ്കളെ അസ്വസ്ഥമാക്കുന്ന ചോദ്യങ്ങൾക്ക് ഉത്തരം നൽകാതിരിക്കാൻ താങ്കൾക്ക് പൂർണ്ണ സ്വാതന്ത്ര്യം ഉണ്ട്. ഈ പഠനത്തിൽ പങ്കാളി ആകുന്നത് കൊണ്ട് താങ്കൾക്ക് നേരിട്ട് ഒരു പ്രയോജനവും ലഭിക്കുന്നതല്ല. ഈ അഭിമുഖം ഏകദേശം 40 മിനിറ്റ് മുതൽ ഒരു മണിക്കൂർ വരെ ദൈർഘ്യം ഉണ്ടാകാം. താങ്കൾക്ക് സമ്മതമാണെങ്കിൽ ഈ അഭിമുഖം ഞാൻ റെക്കോർഡ് ചെയ്യാൻ താത്പര്യപ്പെടുന്നു. താങ്കൾ തരുന്ന വിവരങ്ങൾ തീർത്തും പഠനാവശ്യത്തിനുമാത്രമേ ഉപയോഗിക്കുകയുള്ളൂ.

താങ്കളുടെ പേരോ താങ്കളെ തിരിച്ചറിയാൻ കഴിയുന്ന മറ്റ് വിവരങ്ങളോ ഞാൻ എവിടെയും (വിശകലനം ചെയ്യുമ്പോഴോ പ്രബന്ധത്തിലോ) സൂചിപ്പിക്കുന്നതല്ല, മറ്റാരുമായും പങ്കിടുന്നതുമല്ല. ഈ പഠനത്തിൽ താങ്കളുടെ പങ്കാളിത്തം തികച്ചും സ്വമനസ്സാലെ ഉള്ളതാണ്. ഈ പഠനത്തിൽനിന്നും താങ്കൾക്ക് എപ്പോൾ വേണമെങ്കിലും പിന്മാറാവുന്നതാണ്.

ഈ പഠനം ശ്രീ ചിത്ര തിരുനാൾ ഇസ്റ്റിട്യൂട്ടിലെ ഇസ്റ്റിട്യൂഷനൽ എത്തിക്സ് കമ്മിറ്റി അംഗീകരിച്ചതാണ്. എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ ചോദിക്കാവുന്നതാണ്. ഭാവിയിൽ ഈ പഠനത്തെ കുറിച്ച് എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ എന്നോട് അല്ലെങ്കിൽ എന്റെ പി എച് ഡി ഗൈഡിനോടോ ചോദിക്കാവുന്നതാണ്. എന്റെ പഠനത്തെക്കുറിച്ചു താങ്കൾക്ക് എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ ശ്രീ ചിത്ര തിരുനാൾ ഇസ്റ്റിട്യൂട്ടിലെ ഇസ്റ്റിട്യൂഷനൽ എത്തിക്സ് കമ്മിറ്റിയുടെ മെമ്പർ സെക്രട്ടറിയായ ഡോക്ടർ മാല രാമനാഥൻ നോട് ചോദിക്കാവുന്നതാണ് ( 0471-2524234). Email id: [mala@sctimst.ac.in](mailto:mala@sctimst.ac.in).

ചുവടെ ചേർത്തിട്ടുള്ള സമ്മതപത്രത്തിൽ ഒപ്പു വച്ചുകൊണ്ടു ഈ പഠനത്തിൽ പങ്കെടുക്കാനുള്ള താങ്കളുടെ സമ്മതം രേഖപ്പെടുത്തണം എന്ന് അഭ്യർത്ഥിക്കുന്നു . നന്ദി അഭിമുഖം ചെയ്യുന്ന വ്യക്തിയുടെ പേര് & ഒപ്പ്:  
തീയതി & സ്ഥലം:

ബന്ധപ്പെടാനുള്ള വിവരങ്ങൾ:  
ഗവേഷക: സുനു സി തോമസ് , പി എച് പി സൂടെന്റ്  
അച്യുത മേനോൻ സെന്റർ ഫോർ ഹെൽത്ത് സയൻസ് സ്റ്റഡീസ്  
സ് സി ടി ഐ എം സ് ടി, മെഡിക്കൽ കോളേജ് പി .ഓ ., തിരുവനന്തപുരം -11

**സമ്മതപത്രം**

പഠനവിവരണം മുഴുവൻ ഞാൻ വായിച്ചു / എന്നെ വായിച്ചു കേൾപ്പിച്ചു. ഈ പഠനത്തിന്റെ ഉദ്ദേശവും ഈ പഠനത്തിൽ എനിക്കുള്ള പങ്കാളിത്തവും എന്നോട് വിവരിച്ചിട്ടുണ്ട്. ഈ സമ്മതപത്രത്തിൽ ഒപ്പു / വിരലടയാളം വയ്ക്കുന്നത് ഈ പഠനത്തിൽ പങ്കാളിയാകാനുള്ള എന്റെ പൂർണ്ണസമ്മതത്തെ അറിയിക്കുന്നു. ഈ പഠനത്തിൽ നിന്നും എപ്പോൾ വേണമെങ്കിലും പിന്മാറാം എന്നും എനിക്കറിയാം. എന്തെങ്കിലും വിശദീകരണം ആവശ്യമുണ്ടെങ്കിൽ ആരെ ബന്ധപ്പെടണം എന്നും എനിക്കറിയാം.

ഞാൻ..... ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ തയാറാണ് .

പേര്  
ഒപ്പ്/ വിരലടയാളം

തീയതി & സ്ഥലം

പ്രതിവദിക്കുന്നയാൾ നിരക്ഷര ആണെങ്കിൽ,  
സാക്ഷിയുടെ പേര്  
സാക്ഷിയുടെ ഒപ്പ്

**പഠനത്തിൽ പങ്കെടുക്കുന്നവർക്കുള്ള വിവരണപത്രിക- ഭർത്താവ് / മറ്റ് പ്രധാന വ്യക്തികൾ**

എന്റെ പേര് സുനു സി തോമസ്, ഞാൻ ശ്രീ ചിത്ര തിരുനാൾ ഇസ്റ്റിട്യൂട്ടിലെ അച്യുത മേനോൻ സെന്ററിൽ പൊതുജനാരോഗ്യത്തിൽ പി എച്ച് ഡി ചെയ്യുന്നു. എന്റെ പി എച്ച് ഡിയുടെ ഭാഗമായി ഞാൻ ഒരു പഠനം നടത്തുന്നു. "വന്ധ്യതയുള്ള ദമ്പതികളുടെ ചികിത്സ തരങ്ങൾ: കേരളത്തിലെ തെക്കൻ ജില്ലകളിൽ വന്ധ്യതയുള്ള ദമ്പതികളുടെ ഇടയിൽ ഗുണപരമായ അന്വേഷണം". ഈ പഠനം കൊണ്ട് ഉദ്ദേശിക്കുന്നത് കുട്ടികൾ ഉണ്ടാകാൻ ബുദ്ധിമുട്ടുള്ളതും എന്നാൽ കുട്ടികൾ വേണം എന്ന് ആഗ്രഹിക്കുന്ന ദമ്പതികൾ ഇതിനായി എന്തെല്ലാം മാർഗ്ഗങ്ങൾ/ ചികിത്സകൾ ചെയ്യും എന്നറിയുന്നതിനാണ്.

അതുകൊണ്ട് ഈ പഠനത്തിൽ പങ്കാളിയാകാൻ ഞാൻ താങ്കളോട് അഭ്യർത്ഥിക്കുന്നു. ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ സമ്മതമാണെങ്കിൽ ഞാൻ തങ്ങളെ അഭിമുഖം ചെയ്യാൻ താത്പര്യപ്പെടുന്നു. താങ്കൾ ഗർഭം ധരിക്കുന്നതിനായി എന്തെല്ലാം മാർഗ്ഗങ്ങൾ അല്ലെങ്കിൽ ചികിത്സകൾ ആണ് തിരഞ്ഞെടുത്തതെന്നും ആ ചികിത്സ/ മാർഗ്ഗം എന്തുകൊണ്ട് തിരഞ്ഞെടുത്തു എന്നതിനെ കുറിച്ചും ചില കാര്യങ്ങൾ ഞാൻ ചോദിച്ച് കാൻ ഉദ്ദേശിക്കുന്നത്. ചില ചോദ്യങ്ങൾ താങ്കൾക്ക് അസ്വസ്ഥത ഉണ്ടാക്കിയേക്കാം. അത്തരത്തിൽ താങ്കളെ അസ്വസ്ഥനാക്കുന്ന ചോദ്യങ്ങൾക്ക് ഉത്തരം നൽകാതിരിക്കാൻ താങ്കൾക്ക് പൂർണ്ണ സ്വാതന്ത്ര്യം ഉണ്ട്. ഈ പഠനത്തിൽ പങ്കാളി ആകുന്നത് കൊണ്ട് താങ്കൾക്ക് നേരിട്ട് ഒരു പ്രയോജനവും ലഭിക്കുന്നതല്ല. ഈ അഭിമുഖം ഏകദേശം 40 മിനിറ്റ് മുതൽ ഒരു മണിക്കൂർ വരെ ദൈർഘ്യം ഉണ്ടാകാം. താങ്കൾക്ക് സമ്മതമാണെങ്കിൽ ഈ അഭിമുഖം ഞാൻ റെക്കോർഡ് ചെയ്യാൻ താത്പര്യപ്പെടുന്നു. താങ്കൾ തരുന്ന വിവരങ്ങൾ തീർത്തും പഠനാവശ്യത്തിനുമാത്രമേ ഉപയോഗിക്കുകയുള്ളൂ.

താങ്കളുടെ പേരോ താങ്കളെ തിരിച്ചറിയാൻ കഴിയുന്ന മറ്റ് വിവരങ്ങളോ ഞാൻ എവിടെയും (വിശകലനം ചെയ്യുമ്പോഴോ പ്രബന്ധത്തിലോ) സൂചിപ്പിക്കുന്നതല്ല, മറ്റാരുമായും പങ്കിടുന്നതുമല്ല. ഈ പഠനത്തിൽ താങ്കളുടെ പങ്കാളിത്തം തികച്ചും സ്വമനസ്സാലെ ഉള്ളതാണ്. ഈ പഠനത്തിൽനിന്നും താങ്കൾക്ക് എപ്പോൾ വേണമെങ്കിലും പിന്മാറാവുന്നതാണ്.

ഈ പഠനം ശ്രീ ചിത്ര തിരുനാൾ ഇസ്റ്റിട്യൂട്ടിലെ ഇസ്റ്റിട്യൂഷനൽ എത്തിക്സ് കമ്മിറ്റി അംഗീകരിച്ചതാണ്. എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ ചോദിക്കാവുന്നതാണ്. ഭാവിയിൽ ഈ പഠനത്തിന് കുറിച്ച് എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ എന്നോട് അല്ലെങ്കിൽ എന്റെ പി എച്ച് ഡി ഗൈഡിനോടൊ ചോദിക്കാവുന്നതാണ്. എന്റെ പഠനത്തെക്കുറിച്ച് താങ്കൾക്ക് എന്തെങ്കിലും സംശയങ്ങൾ ഉണ്ടെങ്കിൽ ശ്രീ ചിത്ര തിരുനാൾ ഇസ്റ്റിട്യൂട്ടിലെ ഇസ്റ്റിട്യൂഷനൽ എത്തിക്സ് കമ്മിറ്റിയുടെ മെമ്പർ സെക്രട്ടറിയായ ഡോക്ടർ മാല രാമനാഥൻ നോട് ചോദിക്കാവുന്നതാണ് ( 0471-2524234). Email id: [mala@sctimst.ac.in](mailto:mala@sctimst.ac.in).

ചുവടെ ചേർത്തിട്ടുള്ള സമ്മതപത്രത്തിൽ ഒപ്പു വച്ചുകൊണ്ടു ഈ പഠനത്തിൽ പങ്കെടുക്കാനുള്ള താങ്കളുടെ സമ്മതം രേഖപ്പെടുത്തണം എന്ന് അഭ്യർത്ഥിക്കുന്നു . നന്ദി അഭിമുഖം ചെയ്യുന്ന വ്യക്തിയുടെ പേര് & ഒപ്പ്:  
തീയതി & സ്ഥലം:  
ബന്ധപ്പെടാനുള്ള വിവരങ്ങൾ:  
ഗവേഷക: സുനു സി തോമസ് , പി എച്ഐ സൂടെന്റർ  
അച്യുത മേനോൻ സെന്റർ ഫോർ ഹെൽത്ത് സയൻസ് സ്റ്റഡീസ്  
സ് സി ടി ഐ എം സ് ടി, മെഡിക്കൽ കോളേജ് പി .ഓ ., തിരുവനന്തപുരം -11

**സമ്മതപത്രം**

പഠനവിവരണം മുഴുവൻ ഞാൻ വായിച്ചു / എന്നെ വായിച്ചു കേൾപ്പിച്ചു. ഈ പഠനത്തിന്റെ ഉദ്ദേശവും ഈ പഠനത്തിൽ എനിക്കുള്ള പങ്കാളിത്തവും എന്നോട് വിവരിച്ചിട്ടുണ്ട്. ഈ സമ്മതപത്രത്തിൽ ഒപ്പു / വിരലടയാളം വയ്ക്കുന്നത് ഈ പഠനത്തിൽ പങ്കാളിയാകാനുള്ള എന്റെ പൂർണ്ണസമ്മതത്തെ അറിയിക്കുന്നു. ഈ പഠനത്തിൽ നിന്നും എപ്പോൾ വേണമെങ്കിലും പിന്മാറാം എന്നും എനിക്കറിയാം. എന്തെങ്കിലും വിശദീകരണം ആവശ്യമുണ്ടെങ്കിൽ ആരെ ബന്ധപ്പെടണം എന്നും എനിക്കറിയാം.

ഞാൻ..... ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ തയാറാണ്.

പേര്  
ഒപ്പ്/ വിരലടയാളം

തീയതി & സ്ഥലം

പ്രതിവദിക്കുന്നയാൾ നിരക്ഷരൻ ആണെങ്കിൽ,  
സാക്ഷിയുടെ പേര്  
സാക്ഷിയുടെ ഒപ്പ്

**A12: Interview schedule for phase III community-based survey (English)**

**Treatment seeking for infertility among married women in Kerala: Identifying the pathways and inequalities in the pathways to the resolution of infertility**

**SECTION-I**

**Identification details**

(This section can be answered by any adult member of the household)

ID Number:

Date of interview:

Name and signature of the interviewer:

Sl no	Particulars	Response
1	HH number	
2	District	
3	Urban/Rural	1. Urban 2. Rural
4	Municipality/Corporation/Panchayat	1. Municipality..... 2. Corporation..... 3. Panchayat a. Block..... b. Grama Panchayat.....
5	Ward Name or Number	
6	Address/ Phone number for communication	

**SECTION II**

**Screening Questions**

(For the identified woman in reproductive age)

Sl no	Particulars	Response	To be entered by the interviewer later- convert the time periods in months since marriage and enter
7	How long have you been married? <b>OR</b> When did you get married?	<input type="checkbox"/> <input type="checkbox"/> years / <input type="checkbox"/> <input type="checkbox"/> months <input type="checkbox"/> <input type="checkbox"/> month/ <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> year [enter the exact date]  [If less than 12 months stop the interview] <b>SKIP TO Q 12</b> <i>If having a child through treatment</i>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> months [Take this as starting]
8	Are you and your husband trying to get pregnant?	1. Yes 2. No, [stop the interview]	
9	How long have you been trying?	<input type="checkbox"/> <input type="checkbox"/> Months/ <input type="checkbox"/> <input type="checkbox"/> years [If less than 12 months stop the interview]	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> months
10	Have you (or your husband) ever sought any medical help to get pregnant?	1. Yes 2. No, specify reason.....[Stop the interview]	
11	How long have you been taking treatment? (Mention duration in number of years or months)	<input type="checkbox"/> <input type="checkbox"/> year(s)/ <input type="checkbox"/> <input type="checkbox"/> month(s) [If more than 15 years stop the interview]	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> months
12	After how many years of treatment did you get the child?(Mention total years or months since the first treatment)	<input type="checkbox"/> <input type="checkbox"/> year(s)/ <input type="checkbox"/> <input type="checkbox"/> month(s) [If more than 15 years stop the interview]	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> months

**SECTION III**

**Socio-demographic details**

(Respondent will be woman who had child through treatment or who is childless)

Sl No	Respondent*	Spouse
13	A. What is your name?	B. What is your husband's name?
14	A. In which month and year were you born? <input type="checkbox"/> <input type="checkbox"/> Month <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Year [Mention exact date]	B. In which month and year were your husband born? <input type="checkbox"/> <input type="checkbox"/> Month <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Year [Mention exact date]

15	A. What was your age on your last birthday? □□years	C. What was your husband's age on his last birthday? □□ years
16	A. Up to what level have have studied? 1. Illiterate 2. No formal education, but can read and write in at least one language 3. Primary School education (till 7) 4. High school education (8-10) 5. Higher secondary education (11-12) 6. Diploma 7. Graduate 8. Post graduate and above 9. Others, specify.....	B. Up to what level have have your husband studied? 1. Illiterate 2. No formal education, but can read and write in at least one language 3. Primary School education (till 7) 4. High school education (8-10) 5. Higher secondary education (11-12) 6. Diploma 7. Graduate 8. Post graduate and above 9. Others, specify.....
17	A. What is your religion? 1. Hindu 2. Muslim 3. Christian 4. Others, specify.....	D. What is your husband's religion? 1. Hindu 2. Muslim 3. Christian 4. Others, specify.....
18	A. What is your caste? 1. SC 2. ST 3. OBC 4. Others, specify.....	B. What is your husband' caste? 1. SC 2. ST 3. OBC 4. Others, specify.....
19	A. What is your occupation? 1. Unemployed 2. Labourer 3. Daily wages 4. Monthly salaried employment 5. Self employment 6. Government Job 7. Student 8. Others, specify.....	E. What is your husband's occupation? 1. Unemployed 2. Labourer 3. Daily wages 4. Monthly salaried employment 5. Self employment 6. Government Job 7. Student 8. Others,specify.....

**To capture the Socio-economic status**

Sl no	Questions	Response
20	Is this house you are currently living in, own house or rented house?	1. Own house 2. Rented house, , <i>go to Q23</i>
21	Who owns this house?	1. Self 2. husband 3. Both 4. Other family members 5. Don't know 6. Others, Specify...
22	What is the total land area where this house is located?	□□cents [If flat, don't ask this question]
23	Does your house have air conditioner?	1. Yes, ..... rooms 2. No
24	Does your household own a car?	1. Yes 2. No
25	What is the main fuel used for cooking in this household?	1. Electricity 2. LPG 3. Kerosene 4. Wood 5. Others, Specify.....
26	If LPG is the main fuel, how long does one cylinder last in your household?	□□month(s)
27	What is the approximate electricity bill for two months?	.....rupees/ 2 months
28	What is the main material used for flooring?	1. Mud/Clay/Dung 2. Cement 3. Ceramic Tiles 4. Marble/granite 5. Polished wood 6. Others, Specify.....

29	What is the main material used for roofing?	1. No roof 2. Thatched 3. Asbestos sheet 4. Bricks 5. Concrete 6. Others, specify.....
30	Is there a compound wall surrounding the house?	1. Yes 2. No
31	Is there a gate for this house?	1. Yes 2. No
32	When the members of your household gets sick, where do they generally go for treatment?	1. Government hospital 2. Private hospital 3. Others, Specify.....
33	Is any usual member of this household covered by any health scheme or health insurance?	1. Yes, Specify..... 2. No

**SECTION IV**  
**Marital, Reproductive and Family details**

SI No	Particulars	Response
34	Is this your first marriage?	1. Yes, <i>go to Q36</i> 2. No, Specify.....
35	Was the inability to have a child the reason for the previous divorce?	1. Yes 2. No
36	Is this your husband's first marriage?	1. Yes, <i>go to Q38</i> 2. No, Specify.....
37	Was the inability to have a child a reason for the previous divorce?	1. Yes 2. No
38	Have you ever been diagnosed as having any of these conditions that may affect your ability to have children before marriage? <i>Multiple entries possible</i>	1. PCOD 2. Any problems related to menstruation like endometriosis 3. Fibroid uterus 4. Thyroid problem 5. Others, Specify..... 6. No
39	Is there anyone in your immediate family (meaning brothers, sisters), who are married and do not have children?	1. Yes, specify..... 2. No
40	Is there anyone in your immediate family (meaning brothers, sisters), who has undergone treatment for infertility in your family?	1. Yes, specify..... 2. No
41	Is there anyone in your husband's immediate family (meaning brothers, sisters), who are married and do not have children?	1. Yes, specify..... 2. No
42	Is there anyone in the immediate family (meaning brothers, sisters) who has undergone treatment for infertility in your husband's family?	1. Yes, specify..... 2. No

**SECTION V**  
**Consequences of infertility**

SI no	Questions	Response
43	Do people close to you put pressure (or had put pressure) on you to get pregnant?	1. Yes 2. No, <i>go to Q45</i>
44	Who is/was the person putting pressure on you to have a child? <i>Multiple entries possible</i>	1. Husband 2. Mother in law 3. Father in law 4. Own parents 5. Friends 6. Society in general 7. Self 8. Others, specify.....
45	Have you ever experienced any problem in your marriage due to difficulty in getting pregnant? [Ask for current marriage only]	1. Yes 2. No

46	Does your husband mentioned or indicated any form of distress due to the difficulties in conceiving?	1. Yes 2. No
47	Have you ever mentioned or indicated any form of distress due to the difficulties in conceiving?	1. Yes 2. No
48	Has the difficulty in getting pregnant affected your sexual life in any way?	1. Yes 2. No
49	Have you faced any form violence from your partner due to difficulty in getting pregnant?	1. Yes, specify..... 2. No
50	Have you faced any form violence from your partner's family due to difficulty in getting pregnant?	1. Yes, specify..... 2. No
51	Have you ever faced any threat for divorce due to difficulty in getting pregnant?	1. Yes 2. No
		<b>SKIP to Q56</b> <b>If having a child through treatment</b>
52	Because you do not have a child, have you faced problems meeting or mixing with people in your community/neighbourhood?	1. Yes 2. No
53	Because you do not have a child, have you wanted to be on your own, away from others in your community/neighbourhood?	1. Yes 2. No
54	Because you do not have children, have you experienced any emotional distress?	1. Yes 2. No
55	<b>Ask those who are currently childless:</b> What are the difficulties you are facing in undergoing treatment? <i>Open ended</i>	
56	<b>Ask those who have had a child after infertility treatment:</b> What were the difficulties you faced while undergoing treatment for infertility? <i>Open ended</i>	

**SECTION VI**  
**Current status**

If the respondent is not having a child, ask Q57

If the respondent is having a child/pregnant at the time of interview through treatment, ask Q58

SL no	Questions	Response
57	How would you describe your care seeking for having a child now?	1. Continuing treatment 2. Stopped treatment completely 3. Taking a break from treatment/ stopped treatment for sometime 4. Others, Specify.....
58	What was the treatment through which the child was born?	1. Natural conception after OI <sup>1</sup> 2. IUI <sup>2</sup> with husband's sperm 3. AI <sup>3</sup> with donor sperm 4. IVF <sup>4</sup> with husband's sperm and wife's ovum 5. IVF with husband's sperm and donor ovum 6. IVF with donor sperm and wife's ovum 7. IVF with donor sperm and donor ovum 8. Surrogacy, specify... 9. While on other treatment, Specify..... 10. Not through treatment, adopted 11. Others, specify.....

<sup>1</sup> Ovulation Induction  
<sup>2</sup> Intra Uterine Insemination  
<sup>3</sup> Artificial Insemination  
<sup>4</sup> InVitro Fertilization

**SECTION VII**

**Identification of the problem and initiation of treatment seeking**

<b>Sl no</b>	<b>Questions</b>	<b>Response</b>	<b>To be entered by the interviewer later-convert the time periods in months since marriage and enter</b>
59	After marriage when did you identify that there is difficulty getting pregnant?	1. Within 6 months to 1 year 2. Between 1- 2 years 3. After 2 years within 5 years 4. Five or more years	<input type="text"/> <input type="text"/> <input type="text"/> months
60	What did you do after finding you have difficulty getting pregnant?	1. Immediately consulted doctor, <b>go to Q62</b> 2. Thought of going for treatment but delayed 3. Tried religious/faith based Methods 4. Others, Specify...	
61	How long did you take to start treatment after identifying you have difficulty getting pregnant?( <i>current marriage</i> )	<input type="text"/> <input type="text"/> (in months)	<input type="text"/> <input type="text"/> <input type="text"/> months
62	Who initiated the treatment seeking process? <i>Multiple entries possible</i>	1. Self 2. Husband 3. Both 4. Own family 5. Husband's family 6. Friends 7. Others, specify...	
63	Which year did you start treatment? ( <i>mention the month also if you remember</i> )	<input type="checkbox"/> <input type="checkbox"/> Exact Month <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Exact Year	<input type="text"/> <input type="text"/> <input type="text"/> months
64	How many years/months did you continue the treatment? (include the break periods also if any) If the respondent is still continuing treatment, mention the total duration till date	<input type="text"/> <input type="text"/> months/ <input type="text"/> <input type="text"/> years   + <input type="text"/> <input type="text"/> months/ <input type="text"/> <input type="text"/> years <b>[Break period]</b>	<input type="text"/> <input type="text"/> <input type="text"/> months
65	When did you stop the treatment? ( <i>if result achieved or otherwise who completely stopped seeking care</i> )	<input type="checkbox"/> <input type="checkbox"/> Exact Month <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Exact Year	<input type="text"/> <input type="text"/> <input type="text"/> months
66	How many centers or hospitals or doctors, have you been to till date for infertility treatment? ( <i>Mention only the allopathic treatment</i> )	<input type="text"/> <input type="text"/> + <input type="text"/> <input type="text"/> (others)	
67	Who was diagnosed as having the problem?	1. Husband had problem 2. I had problem 3. Both had problem 4. Unexplained 5. Others, Specify.....	

**SECTION VIII**  
**Treatment history for Infertility**  
(Attach more pages if more treatment sought)

ID number:		Serial no□		
SI no	Question	T□ (Enter the response and the time period for each)	T□ (Enter the response and the time period for each)	T□ (Enter the Response and the time period for each)
68	When did you start the treatment?	□□□□ [Mention the exact year] <b>OR</b> □□months/□□years [Mention the duration after marriage]	□□□□ [Mention the exact year] <b>OR</b> □□months/□□years [Mention the duration after marriage]	□□□□ [Mention the exact year] <b>OR</b> □□months/□□years [Mention the duration after marriage]
69	Which was the centre or doctor you consulted?			
70	What were the different treatment related activities done at this centre?	1. Preliminary investigations only 2. Check tube patency- Laparoscopy, hysterosalpingography 3. Monitoring of menstrual cycles, trying on own 4. Regularizing cycles by means of medication 5. Surgical/medical treatments to correct semen problems 6. Ovulation Induction 7. IUI 8. IVF 9. IVF with donor ova or sperm 10. Others, Specify.....	1. Preliminary investigations only 2. Check tube patency- Laparoscopy, hysterosalpingography 3. Monitoring of menstrual cycles, trying on own 4. Regularizing cycles by means of medication 5. Surgical/medical treatments to correct semen problems 6. Ovulation Induction 7. IUI 8. Artificial Insemination 9. IVF 10. IVF with donor gametes 11. Others, Specify.....	1. Preliminary investigations only 2. Check tube patency- Laparoscopy, hysterosalpingography 3. Monitoring of menstrual cycles, trying on own 4. Regularizing cycles by means of medication 5. Surgical/medical treatments to correct semen problems 6. Ovulation Induction 7. IUI 8. Artificial Insemination 9. IVF 10. IVF with donor gametes 11. Others, Specify.....
71	How long did you continue at this centre?  <i>(If the respondent can recall, mention the exact number of number of months)</i>	1. 1- 6 months 2. Up to 1 year 3. 1- 2 years 4. 2-5 years 5. Five or more years □□ months [Mention the number of months] □□□months [The interviewer to enter the duration in months since marriage ]	1. 1- 6 months 2. Up to 1 year 3. 1- 2 years 4. 2-5 years 5. Five or more years □□ months [Mention the number of months] □□□months [The interviewer to enter the duration in months since marriage ]	1. 1-6 months 2. Up to 1 year 3. 2 years 4. 2-5 years 5. Five or more years □□ months [Mention the number of months] □□□months [The interviewer to enter the duration in months since marriage ]
72	Did you seek treatment at another facility after that? <b>If yes, fill the next Column also ie., T2/3/...</b>	1. Yes 2. No	1. Yes 2. No	1. Yes 2. No
73	What was the break period between the first and the next treatment? <i>(If the respondent can recall,</i>	1. 1- 6 months 2. Up to 1 year 3. 1- 2 years 4. > 2 years, specify..... □□ months [Mention the number of months]	1. 1- 6 months 2. Up to 1 year 3. 1- 2 years 4. > 2 years, specify..... □□ months [Mention the number of months]	1. 1- 6 months 2. Up to 1 year 3. 1-2 years 4. > 2 years, specify..... □□ months [Mention the number of months]

	<i>mention the exact number of number of months</i>	□□□months [The interviewer to enter the duration in months since marriage ]	□□□months [The interviewer to enter the duration in months since marriage ]	□□□months [The interviewer to enter the duration in months since marriage ]
74	<p>Why did you discontinue the treatment at this particular facility?</p> <p><i>(Multiple options possible)</i></p>	<ol style="list-style-type: none"> <li>1. Psychological distress of treatment</li> <li>2. Physical burden of treatment</li> <li>3. Clinic related issues</li> <li>4. No faith in treatment success</li> <li>5. Poor prognosis</li> <li>6. Logistic/practical reasons</li> <li>7. Personal reasons</li> <li>8. Trying on own</li> <li>9. Postponement of treatment/taking a break from treatment</li> <li>10. Doctor censoring</li> <li>11. Financial issues</li> <li>12. Treatment related logistical problems</li> <li>13. Other health problems</li> <li>14. Do not want to pursue specific treatment</li> <li>15. Pursuing alternative methods/treatment</li> <li>16. No longer wish to have a child</li> <li>17. Others(specify)</li> </ol>	<ol style="list-style-type: none"> <li>1. Psychological burden of treatment</li> <li>2. Physical burden of treatment</li> <li>3. Clinic related issues</li> <li>4. No faith in treatment success</li> <li>5. Poor prognosis</li> <li>6. Logistic/practical reasons</li> <li>7. Personal reasons</li> <li>8. Trying on own</li> <li>9. Postponement of treatment/taking a break from treatment</li> <li>10. Doctor censoring</li> <li>11. Financial issues</li> <li>12. Treatment related logistical problems</li> <li>13. Other health problems</li> <li>14. Do not want to pursue specific treatment</li> <li>15. Pursuing alternative methods/treatment</li> <li>16. No longer wish to have a child</li> <li>17. Others(specify)</li> </ol>	<ol style="list-style-type: none"> <li>1. Psychological burden of treatment</li> <li>2. Physical burden of treatment</li> <li>3. Clinic related issues</li> <li>4. No faith in treatment success</li> <li>5. Poor prognosis</li> <li>6. Logistic/practical reasons</li> <li>7. Personal reasons</li> <li>8. Trying on own</li> <li>9. Postponement of treatment/taking a break from treatment</li> <li>10. Doctor censoring</li> <li>11. Financial issues</li> <li>12. Treatment related logistical problems</li> <li>13. Other health problems</li> <li>14. Do not want to pursue specific treatment</li> <li>15. Pursuing alternative methods/treatment</li> <li>16. No longer wish to have a child</li> <li>17. Others(specify)</li> </ol>

**A13: Interview schedule for phase III community-based survey (Malayalam)**

കേരളത്തിലെ വിവാഹിതരായ സ്ത്രീകളിലെ വന്ധ്യതയ്ക്കുള്ള ചികിത്സ തേടൽ: വന്ധ്യതയുടെ പരിഹാരത്തിലേക്കുള്ള പാതകളും അസമത്വങ്ങളും തിരിച്ചറിയൽ

Section- I

തിരിച്ചറിയൽ വിശദാംശങ്ങൾ  
(ഈ സെക്ഷനിലെ ചോദ്യങ്ങൾക്ക് വീട്ടിലെ പ്രായപൂർത്തിയായ ഏതൊരു അംഗത്തിനും ഉത്തരം നൽകാവുന്നതാണ്)

ഐ ഡി നമ്പർ :  
തീയതി :  
അഭിമുഖം നടത്തുന്നയാളുടെ പേരും ഒപ്പും:

SI No	വിവരങ്ങൾ/ ചോദ്യങ്ങൾ	ഉത്തരം
1	വീട്ട് നമ്പർ	
2	ജില്ല	
3	അർബൻ/ റൂറൽ	1. അർബൻ 2. റൂറൽ
4	മുനിസിപ്പാലിറ്റി/ കോർപ്പറേഷൻ/ പഞ്ചായത്ത്	1. മുനിസിപ്പാലിറ്റി ..... 2. കോർപ്പറേഷൻ ..... 3. പഞ്ചായത്ത് A. ബ്ലോക്ക് പഞ്ചായത്ത് ..... B. ഗ്രാമപഞ്ചായത്ത്.....
5	വാർഡിന്റെ പേര് / നമ്പർ	
6	ആശയവിനിമയത്തിനായുള്ള വിലാസം/ ഫോൺ നമ്പർ	

Section-II

പഠനത്തിൽ ഉൾപ്പെടുത്തണോ വേണ്ടയോ എന്നു തീരുമാനിക്കാനുള്ള ചോദ്യങ്ങൾ  
(കുട്ടി ഇല്ലാത്തതോ അല്ലെങ്കിൽ ചികിത്സയിലൂടെ കുട്ടി ഉണ്ടായതോ ആയ സ്ത്രീകളോട് മാത്രം ചോദിക്കുക)

SI No	വിവരങ്ങൾ/ ചോദ്യങ്ങൾ	ഉത്തരം/ പ്രതികരണം	അഭിമുഖ സംഭാഷകൻ പിന്നീട് രേഖപ്പെടുത്തുക -വിവാഹം മുതൽ ഇത് വരെയുള്ള മാസമായി സമയപരിധി മാറ്റുക
7	താങ്കളുടെ വിവാഹം കഴിഞ്ഞിട്ട് എത്രനാളായി? അല്ലെങ്കിൽ താങ്കൾ വിവാഹിതയായത് എന്നാണ്?	<input type="checkbox"/> വർഷം / <input type="checkbox"/> മാസം അല്ലെങ്കിൽ <input type="checkbox"/> മാസം / <input type="checkbox"/> വർഷം [ക്യൂത്യമായ തീയതി രേഖപ്പെടുത്തുക] <b>[12 മാസത്തിൽ കുറവാണെങ്കിൽ അഭിമുഖം അവസാനിപ്പിക്കുക]</b> <b>ചികിത്സയിലൂടെ കുട്ടി ഉണ്ടായ സ്ത്രീയാണെങ്കിൽ Q12ലേക്ക് പോകുക</b>	<input type="checkbox"/> മാസം <b>[ഇത് തുടക്കമായി എടുക്കുക]</b>
8	ഗർഭം ധരിക്കുന്നതിനായി താങ്കളും താങ്കളുടെ ഭർത്താവും ശ്രമിക്കുന്നുണ്ടോ?	1. ഉണ്ട് 2. ഇല്ല, <b>[അഭിമുഖം അവസാനിപ്പിക്കുക]</b>	
9	എത്ര നാളായി ശ്രമിക്കുന്നു?	<input type="checkbox"/> മാസം/ <input type="checkbox"/> വർഷം <b>[12 മാസത്തിൽ കുറവാണെങ്കിൽ അഭിമുഖം അവസാനിപ്പിക്കുക]</b>	<input type="checkbox"/> മാസം

10	താങ്കളോ താങ്കളുടെ ഭർത്താവോ ഗർഭം ധരിക്കുന്നതിനായി എന്തെങ്കിലും തരത്തിലുള്ള വൈദ്യസഹായം തേടിയിട്ടുണ്ടോ?	1. ഉണ്ട് 2. ഇല്ല, കാരണം വ്യക്തമാക്കുക ..... <b>[അഭിമുഖം അവസാനിപ്പിക്കുക]</b>	
11	എത്ര നാളായി താങ്കൾ ചികിത്സ എടുക്കുന്നുണ്ട് ?	<input type="checkbox"/> മാസം/ <input type="checkbox"/> വർഷം <b>[15 വർഷത്തിൽ കൂടുതൽ ആണെങ്കിൽ അഭിമുഖം അവസാനിപ്പിക്കുക]</b>	<input type="checkbox"/> മാസം
12	എത്ര നാളത്തെ ചികിത്സയിലൂടെ ആണ് കുട്ടി ഉണ്ടായത്?	<input type="checkbox"/> മാസം/ <input type="checkbox"/> വർഷം <b>[15 വർഷത്തിൽ കൂടുതൽ ആണെങ്കിൽ അഭിമുഖം അവസാനിപ്പിക്കുക]</b>	<input type="checkbox"/> മാസം

Section-III

സാമൂഹ്യ-ജനസംഖ്യാപരമായ വിവരങ്ങൾ

(പ്രതിവതിക്കുന്ന വ്യക്തി കുട്ടി ഇല്ലാത്തതോ അല്ലെങ്കിൽ ചികിത്സയിലൂടെ കുട്ടി ഉണ്ടായതോ ആയ സ്ത്രീകൾ മാത്രം)

SI No	പ്രതിവതിക്കുന്ന വ്യക്തി	പ്രതിവതിക്കുന്ന വ്യക്തിയുടെ ഭർത്താവ്
13	A. താങ്കളുടെ പേരെന്താണ്?	B. താങ്കളുടെ ഭർത്താവിന്റെ പേരെന്താണ്?
14	A.താങ്കൾ ഏത് മാസവും വർഷവും ആണ് ജനിച്ചത്? <input type="checkbox"/> മാസം / <input type="checkbox"/> വർഷം [കൃത്യമായ തീയതി രേഖപ്പെടുത്തുക]	B.താങ്കളുടെ ഭർത്താവ് ഏത് മാസവും വർഷവും ആണ് ജനിച്ചത്? <input type="checkbox"/> മാസം / <input type="checkbox"/> വർഷം [കൃത്യമായ തീയതി രേഖപ്പെടുത്തുക]
15	A.അവസാനം കഴിഞ്ഞ ജന്മദിനത്തിൽ താങ്കൾക്ക് എത്ര വയസായിരുന്നു? <input type="checkbox"/> വയസ്സ്	B. അവസാനം കഴിഞ്ഞ ജന്മദിനത്തിൽ താങ്കളുടെ ഭർത്താവിന് എത്ര വയസായിരുന്നു? <input type="checkbox"/> വയസ്സ്
16	A.താങ്കൾ ഏതുവരെ പഠിച്ചിട്ടുണ്ട്? 1. നിരക്ഷര 2. ഔപചാരിക വിദ്യാഭ്യാസമില്ല, പക്ഷെ ഏതെങ്കിലും ഒരു ഭാഷയിൽ വായിക്കാനും എഴുതാനും അറിയാം 3. പ്രാഥമിക സ്കൂൾ തലം (7 വരെ) 4. ഹൈസ്കൂൾ തലം(8-10) 5. ഹയർ സെക്കൻഡറി തലം (11-12) 6. ഡിപ്ലോമ 7. ബിരുദം 8. ബിരുദാനന്തര ബിരുദമോ അതിൽ മുകളിലോ 9. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....	B. താങ്കളുടെ ഭർത്താവ് ഏതുവരെ പഠിച്ചിട്ടുണ്ട്? 1. നിരക്ഷരൻ 2. ഔപചാരിക വിദ്യാഭ്യാസമില്ല, പക്ഷെ ഏതെങ്കിലും ഒരു ഭാഷയിൽ വായിക്കാനും എഴുതാനും അറിയാം 3. പ്രാഥമിക സ്കൂൾ തലം(7 വരെ) 4. ഹൈസ്കൂൾ തലം (8-10) 5. ഹയർ സെക്കൻഡറി തലം(11-12) 6. ഡിപ്ലോമ 7. ബിരുദം 8. ബിരുദാനന്തര ബിരുദമോ അതിൽ മുകളിലോ 9. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....
17	A. താങ്കളുടെ മതം ഏതാണ്? 1. ഹിന്ദു 2. മുസ്ലിം 3. ക്രിസ്ത്യൻ 4. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....	B. താങ്കളുടെ ഭർത്താവിന്റെ മതം ഏതാണ്? 1. ഹിന്ദു 2. മുസ്ലിം 3. ക്രിസ്ത്യൻ 4. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....
18	A. താങ്കളുടെ ജാതി ഏതാണ്? 1. ഷെഡ്യൂൾഡ് കാസ്റ്റ് 2. ഷെഡ്യൂൾഡ് ക്ലാസ്സ് 3. ഓ ബി സി 4. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....	B. താങ്കളുടെ ഭർത്താവിന്റെ ജാതി ഏതാണ്? 1. ഷെഡ്യൂൾഡ് കാസ്റ്റ് 2. ഷെഡ്യൂൾഡ് ക്ലാസ്സ് 3. ഓ ബി സി 4. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....

19	A. താങ്കളുടെ ജോലി എന്താണ്? 1. ജോലിയില്ല 2. കുലിപ്പണി 3. ദിവസക്കൂലി 4. മാസശമ്പളം ഉള്ള ജോലി 5. സ്വയംതൊഴിൽ 6. ഗവണ്മെന്റ് ജോലി 7. വിദ്യാർത്ഥി 8. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....	B. താങ്കളുടെ ഭർത്താവിന്റെ ജോലി എന്താണ്? 1. ജോലിയില്ല 2. കുലിപ്പണി 3. ദിവസക്കൂലി 4. മാസശമ്പളം ഉള്ള ജോലി 5. സ്വയംതൊഴിൽ 6. ഗവണ്മെന്റ് ജോലി 7. വിദ്യാർത്ഥി 8. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....
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സാമൂഹിക-സാമ്പത്തിക നില അറിയുന്നതിനുള്ള ചോദ്യങ്ങൾ

SI No	വിവരങ്ങൾ/ ചോദ്യങ്ങൾ	ഉത്തരം/ പ്രതികരണം
20	താങ്കൾ ഇപ്പോൾ താമസിക്കുന്ന ഈ വീട് സ്വന്തം വീടാണോ വാടക വീടാണോ?	1. സ്വന്തം വീട് 2. വാടക വീട് , <b>Q23 ലേക്ക് പോകുക</b>
21	ഈ വീട് ആരുടെ ഉടമസ്ഥതയിലാണ് ?	1. സ്വന്തം 2. ഭർത്താവിന്റെ 3. രണ്ടുപേരുടെയും 4. മറ്റ് കുടുംബാംഗങ്ങളുടെ 5. അറിയില്ല 6. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....
22	ഈ വീട് നിൽക്കുന്ന ഭൂമിയുടെ പൂർണ്ണ വിസ്തീർണം എത്രയാണ്?	.....സെന്റ് [ഏറ്റവും അടുത്തുള്ള ഈ ചോദ്യം വേണ്ട ]
23	താങ്കളുടെ വീട്ടിൽ എയർ കണ്ടീഷണർ (എ സി) ഉണ്ടോ?	1. ഉണ്ട്, എത്ര മുറിയിൽ ..... 2. ഇല്ല
24	താങ്കളുടെ വീട്ടിൽ ആർക്കെങ്കിലും കാർ ഉണ്ടോ?	1. ഉണ്ട് 2. ഇല്ല
25	താങ്കളുടെ വീട്ടിൽ പാചകത്തിനായി ഉപയോഗിക്കുന്ന പ്രധാന ഇന്ധനം എന്താണ്?	1. വൈദ്യുതി 2. എൽ പി ജി 3. മണ്ണെണ്ണ 4. വിറക് 5. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....
26	എൽ പി ജിയാണ് പ്രധാന ഇന്ധനമെങ്കിൽ ഒരു സിലിണ്ടർ എത്രനാൾ നിൽക്കും?	.....മാസം
27	താങ്കളുടെ വീട്ടിലെ രണ്ടുമാസത്തെ ഏകദേശം വൈദ്യുതി ബില്ലിന് എത്രയാണ്?	.....രൂപ/ 2 മാസം
28	തറ നിർമ്മിച്ചിരിക്കുന്ന മുഖ്യവസ്തു എന്താണ്?	1. ചെളി/കളിമണ്ണ്/ചാണകം 2. സിമന്റ് 3. സെറാമിക് ടൈൽസ് 4. മാർബിൾ/ഗ്രാനൈറ്റ് 5. മിനുക്കിയ തടി 6. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....
29	മേൽക്കൂര നിർമ്മിച്ചിരിക്കുന്ന മുഖ്യവസ്തു എന്താണ്?	1. മേൽക്കൂര ഇല്ല 2. മേഞ്ഞത് 3. ആസ്ബസ്റ്റോസ് ഷീറ്റ് 4. ഓട് 5. കോൺക്രീറ്റ് 6. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....
30	വീടിന് ചുറ്റുമതിൽ ഉണ്ടോ?	1. ഉണ്ട് 2. ഇല്ല
31	ഈ വീടിന് ഗേറ്റ് ഉണ്ടോ?	1. ഉണ്ട് 2. ഇല്ല

32	താങ്കളുടെ വീട്ടിൽ ആർക്കെങ്കിലും അസുഖം പിടിപെട്ടാൽ , എവിടെയാണ് സാധാരണയായി ചികിത്സക്ക് പോകാറുള്ളത്?	1. ഗവണ്മെന്റ് ആശുപത്രി 2. പ്രൈവറ്റ് ആശുപത്രി 3. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....
33	ഈ വീട്ടിലെ ഏതെങ്കിലും അംഗങ്ങൾക്ക് എന്തെങ്കിലും തരത്തിലുള്ള ആരോഗ്യ പദ്ധതിയോ ആരോഗ്യ ഇൻഷുറൻസോ ഉണ്ടോ?	1. ഉണ്ട്, വ്യക്തമാക്കുക..... 2. ഇല്ല

**Section-IV**

വിവാഹസംബന്ധവും, പ്രത്യുല്പാദനസംബന്ധവും, കുടുംബസംബന്ധവുമായ വിവരങ്ങൾ

SI No	വിവരങ്ങൾ/ ചോദ്യങ്ങൾ	ഉത്തരം/ പ്രതികരണം
34	ഇത് താങ്കളുടെ ആദ്യ വിവാഹമാണോ?	1. അതെ, <b>Q36 ലേക്ക് പോകുക</b> 2. അല്ല, വ്യക്തമാക്കുക .....
35	കുട്ടികൾ ഉണ്ടാകാൻ ബുദ്ധിമുട്ടുള്ളതാണോ മുൻപത്തെ വിവാഹബന്ധം വേർപിരിയാൻ കാരണം?	1. അതെ 2. അല്ല
36	ഇത് താങ്കളുടെ ഭർത്താവിന്റെ ആദ്യ വിവാഹമാണോ?	1. അതെ, <b>Q38 ലേക്ക് പോകുക</b> 2. അല്ല, വ്യക്തമാക്കുക .....
37	കുട്ടികൾ ഉണ്ടാകാൻ ബുദ്ധിമുട്ടുള്ളതാണോ മുൻപത്തെ വിവാഹബന്ധം വേർപിരിയാൻ കാരണം?	1. അതെ 2. അല്ല
38	വിവാഹത്തിന് മുൻപേ താങ്കൾക്ക് പ്രത്യുല്പാദനത്തെ ബാധിക്കുന്ന എന്തെങ്കിലും തരത്തിലുള്ള അവസ്ഥകൾ ഉണ്ടായിരുന്നതായി കണ്ടുപിടിച്ചിട്ടുണ്ടോ? [ഒന്നിൽ കൂടുതൽ ഉത്തരമാകാം]	1. പി സി ഓ ഡി 2. എൻഡോമെട്രിയോസിസ് പോലെയുള്ള ആർത്തവസംബന്ധമായ പ്രശ്നങ്ങൾ 3. ഗർഭാശയ മുഴുകൾ 4. തൈറോയ്ഡ് 5. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക .....
39	താങ്കളുടെ തൊട്ടടുത്ത ബന്ധത്തിലുള്ള (സഹോദരനോ, സഹോദരിക്കോ) വിവാഹിതരായ ആർക്കെങ്കിലും കുട്ടികൾ ഇല്ലാത്തതായി ഉണ്ടോ?	1. ഉണ്ട്, വ്യക്തമാക്കുക .....
40	താങ്കളുടെ തൊട്ടടുത്ത ബന്ധത്തിലുള്ള (സഹോദരനോ, സഹോദരിക്കോ) ആരെങ്കിലും വന്ധ്യതാ ചികിത്സ നടത്തിയിട്ടുണ്ടോ ?	1. ഉണ്ട്, വ്യക്തമാക്കുക .....
41	താങ്കളുടെ ഭർത്താവിന്റെ തൊട്ടടുത്ത ബന്ധത്തിലുള്ള (സഹോദരനോ, സഹോദരിക്കോ) വിവാഹിതരായ ആർക്കെങ്കിലും കുട്ടികൾ ഇല്ലാത്തതായി ഉണ്ടോ?	1. ഉണ്ട്, വ്യക്തമാക്കുക .....
42	താങ്കളുടെ ഭർത്താവിന്റെ തൊട്ടടുത്ത ബന്ധത്തിലുള്ള (സഹോദരനോ, സഹോദരിക്കോ) ആരെങ്കിലും വന്ധ്യതാ ചികിത്സ നടത്തിയിട്ടുണ്ടോ ?	1. ഉണ്ട്, വ്യക്തമാക്കുക .....

**Section-V**

വന്ധ്യതയുടെ പ്രത്യാഘാതങ്ങൾ

SI No	വിവരങ്ങൾ/ ചോദ്യങ്ങൾ	ഉത്തരം/ പ്രതികരണം
43	താങ്കളുമായി അടുപ്പമുള്ള ആളുകൾ ഗർഭംധരിക്കുന്നതിനായി സമ്മർദ്ദം ചെലുത്താറുണ്ടോ/ചെലുത്തിയിട്ടുണ്ടോ?	1. ഉണ്ട് 2. ഇല്ല, <b>Q45 ലേക്ക് പോകുക</b>

44	ഇത്തരത്തിൽ സമ്മർദ്ദം ചെലുത്തുന്ന/ചെലുത്തിയ വ്യക്തി/ വ്യക്തികൾ ആരൊക്കെയാണ്? [ഒന്നിൽ കൂടുതൽ ഉത്തരമാകാം]	1. ഭർത്താവ് 2. അമ്മായിയമ്മ 3. അമ്മായിയച്ഛൻ 4. സ്വന്തം മാതാപിതാക്കൾ 5. കൂട്ടുകാർ 6. പൊതു സമൂഹം 7. സ്വന്തമായി 8. മറ്റാരെങ്കിലും, വ്യക്തമാക്കുക.....
45	ഗർഭം ധരിക്കാൻ ബുദ്ധിമുട്ടുള്ളതുകൊണ്ടു എപ്പോഴെങ്കിലും താങ്കളുടെ വിവാഹബന്ധത്തിൽ എന്തെങ്കിലും പ്രശ്നങ്ങൾ ഉണ്ടായിട്ടുണ്ടോ? (നിലവിലുള്ള ബന്ധത്തിൽ)	1. ഉണ്ട് 2. ഇല്ല
46	ഗർഭം ധരിക്കാൻ ബുദ്ധിമുട്ടുള്ളതുകൊണ്ടു എപ്പോഴെങ്കിലും താങ്കളുടെ ഭർത്താവ് എന്തെങ്കിലും തരത്തിലുള്ള വൈഷമ്യം പ്രകടിപ്പിച്ചിട്ടുണ്ടോ?	1. ഉണ്ട് 2. ഇല്ല
47	ഗർഭം ധരിക്കാൻ ബുദ്ധിമുട്ടുള്ളതുകൊണ്ടു എപ്പോഴെങ്കിലും താങ്കൾ എന്തെങ്കിലും തരത്തിലുള്ള വൈഷമ്യം പ്രകടിപ്പിച്ചിട്ടുണ്ടോ?	1. ഉണ്ട് 2. ഇല്ല
48	ഗർഭം ധരിക്കാൻ ബുദ്ധിമുട്ടുള്ളതുകൊണ്ടു താങ്കളുടെ ലൈംഗികബന്ധത്തിൽ എന്തെങ്കിലും പ്രശ്നങ്ങൾ ഉണ്ടായിട്ടുണ്ടോ?	1. ഉണ്ട് 2. ഇല്ല
49	ഗർഭം ധരിക്കാൻ ബുദ്ധിമുട്ടുള്ളതുകൊണ്ട് ഭർത്താവിൽ നിന്നും എന്തെങ്കിലും തരത്തിലുള്ള പീഡനം നേരിട്ടിട്ടുണ്ടോ ?	1. ഉണ്ട്, വ്യക്തമാക്കുക..... 2. ഇല്ല
50	ഗർഭം ധരിക്കാൻ ബുദ്ധിമുട്ടുള്ളതുകൊണ്ട് ഭർത്താവിന്റെ കൂടുബന്ധത്തിൽ നിന്നും എന്തെങ്കിലും തരത്തിലുള്ള പീഡനം നേരിട്ടിട്ടുണ്ടോ ?	1. ഉണ്ട്, വ്യക്തമാക്കുക..... 2. ഇല്ല
51	ഗർഭം ധരിക്കാൻ ബുദ്ധിമുട്ടുള്ളതുകൊണ്ട് എപ്പോഴെങ്കിലും വിവാഹമോചന ഭീഷണി ഉണ്ടായിട്ടുണ്ടോ?	1. ഉണ്ട് 2. ഇല്ല <b>ചികിത്സയിലൂടെ കൂട്ടി ഉണ്ടായ സ്ത്രീയാണെങ്കിൽ Q56 ലേക്ക് പോകുക</b>
52	കുട്ടിയില്ലാത്തതുകൊണ്ട്, താങ്കൾക്ക് സമൂഹത്തിലെയോ അയല്പക്കത്തെയോ ആളുകളുമായി ഇടപഴകുന്നതിനു എന്തെങ്കിലും പ്രശ്നങ്ങൾ നേരിട്ടിട്ടുണ്ടോ?	1. ഉണ്ട് 2. ഇല്ല
53	കുട്ടിയില്ലാത്തതുകൊണ്ട്, താങ്കൾക്ക് സമൂഹത്തിലെയോ അയല്പക്കത്തെയോ ആളുകളുമായി അകന്നു ഒറ്റക്കിരിക്കാൻ താല്പര്യപ്പെടുന്നുണ്ടോ?	1. ഉണ്ട് 2. ഇല്ല
54	കുട്ടിയില്ലാത്തതുകൊണ്ട് എന്തെങ്കിലും തരത്തിലുള്ള മാനസിക സമ്മർദ്ദം താങ്കൾ എപ്പോഴെങ്കിലും അനുഭവിച്ചിട്ടുണ്ടോ?	1. ഉണ്ട് 2. ഇല്ല
55	<b>ഇപ്പോൾ കുട്ടികൾ ഇല്ലാത്ത സ്ത്രീകളോട് ചോദിക്കുക:</b> എന്തെല്ലാം ബുദ്ധിമുട്ടുകൾ ആണ് ചികിത്സ നടത്തുമ്പോൾ താങ്കൾ നേരിട്ടുകൊണ്ടിരിക്കുന്നത്? (Open ended)	
56	<b>വന്ധ്യതാ ചികിത്സയിലൂടെ കൂട്ടിയുണ്ടായ സ്ത്രീകളോട് ചോദിക്കുക:</b> എന്തെല്ലാം ബുദ്ധിമുട്ടുകൾ ആണ് ചികിത്സ നടത്തുമ്പോൾ താങ്കൾ നേരിട്ടത്? (Open ended)	

Section VI  
ഇപ്പോഴത്തെ സ്ഥിതി അറിയുന്നതിന്

പ്രതിവദിക്കുന്ന സ്ത്രീയ്ക്ക് കൂട്ടി ഇല്ലെങ്കിൽ, **Q57** ചോദിക്കുക  
പ്രതിവദിക്കുന്ന സ്ത്രീയ്ക്ക് വന്ധ്യതാ ചികിത്സയിലൂടെ കൂട്ടി ഉണ്ടെങ്കിൽ, **Q58** ചോദിക്കുക

SI No	വിവരങ്ങൾ/ ചോദ്യങ്ങൾ	ഉത്തരം/ പ്രതികരണം
57	ഇപ്പോൾ താങ്കൾക്ക് കൂട്ടികൾ ഉണ്ടാകുന്നതിനായുള്ള ചികിത്സയെ താങ്കൾ എങ്ങനെ വിശദീകരിക്കും?	<ol style="list-style-type: none"> <li>1. ചികിത്സ തുടരുന്നു</li> <li>2. ചികിത്സ പൂർണ്ണമായും അവസാനിപ്പിച്ചു</li> <li>3. ചികിത്സയിൽ നിന്നും ഒരു അവധിയെടുത്തിരിക്കുന്നു / കുറച്ചുനാളത്തേക്കു ചികിത്സ നിർത്തിവെച്ചിരുന്നു</li> <li>4. മറ്റെന്തെങ്കിലും, വ്യക്തമാക്കുക.....</li> </ol>
58	എന്ത് ചികിത്സയിലൂടെയാണ് താങ്കളുടെ കൂട്ടി ജനിച്ചത്?	<ol style="list-style-type: none"> <li>1. അണ്ഡോൽപാദനം<sup>1</sup> നടത്തിയശേഷം സ്വാഭാവികമായി ഗർഭധരിച്ചു</li> <li>2. ഐ യു ഐ? (ഭർത്താവിന്റെ ബീജം ഉപയോഗിച്ച്)</li> <li>3. ഐ യു ഐ (ദാതാവിൽ നിന്നും ലഭിച്ച ബീജം ഉപയോഗിച്ച്)</li> <li>4. ഐ വി എഫ് (ഭർത്താവിന്റെ ബീജവും,ദാര്യുടെ അണ്ഡവും ഉപയോഗിച്ച്)</li> <li>5. ഐ വി എഫ് (ഭർത്താവിന്റെ ബീജവും,ദാതാവിന്റെ അണ്ഡവും ഉപയോഗിച്ച്)</li> <li>6. ഐ വി എഫ് (ദാതാവിന്റെ ബീജവും,ദാര്യുടെ അണ്ഡവും ഉപയോഗിച്ച്)</li> <li>7. ഐ വി എഫ് (ദാതാവിന്റെ ബീജവും,ദാതാവിന്റെ അണ്ഡവും ഉപയോഗിച്ച്)</li> <li>8. വാടക ഗർഭധാരണം.....</li> <li>9. മറ്റെന്തെങ്കിലും ചികിത്സയിൽ ആയിരിക്കുമ്പോൾ, വ്യക്തമാക്കുക.....</li> <li>10. ചികിത്സയിലൂടെയല്ല, ദത്തെടുത്തത്</li> <li>11. മറ്റെന്തെങ്കിലും, വ്യക്തമാക്കുക.....</li> </ol>

<sup>1</sup> ഓവുലേഷൻ ഇൻഡക്ഷൻ  
<sup>2</sup> ഗർഭപാത്രത്തിനുള്ളിൽ ഉള്ള ബീജസങ്കലനം  
<sup>3</sup> കൃത്രിമ ഗർഭധാരണം

Section- VII  
പ്രശ്നം കണ്ടെത്തുകയും ചികിത്സ ആരംഭിക്കുകയും ചെയ്യുന്നതിനെ കുറിച്ച്

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59	വിവാഹത്തിനു ശേഷം എപ്പോഴാണ് ഗർഭധരിക്കാൻ ബുദ്ധിമുട്ടുണ്ടെന്ന് താങ്കൾ തിരിച്ചറിഞ്ഞത്?	<ol style="list-style-type: none"> <li>1. 6 മാസത്തിനും 1 വർഷത്തിനും ഇടയിൽ</li> <li>2. 1-2 വർഷത്തിന് ഇടയിൽ</li> <li>3. 2 വർഷത്തിന് ശേഷവും 5 വർഷത്തിനുള്ളിൽ</li> <li>4. 5 വർഷമോ അതിൽ കൂടുതലോ</li> </ol>	<input type="checkbox"/> മാസം
60	ഗർഭധരിക്കാൻ ബുദ്ധിമുട്ടുണ്ടെന്ന് മനസ്സിലാക്കിയശേഷം താങ്കൾ എന്താണ് ഉടനെ ചെയ്തത് ?	<ol style="list-style-type: none"> <li>1. ഉടനെത്തന്നെ ഡോക്ടറെ കണ്ടു, <b>Q62</b>ലേക്ക് പോകുക</li> <li>2. ചികിത്സക്ക് പോകണം എന്ന് വിചാരിച്ചു പക്ഷെ വൈകിപ്പിച്ചു</li> <li>3. മതപരമായ/ വിശ്വാസപരമായ മാർഗ്ഗങ്ങൾ പരീക്ഷിച്ചു</li> <li>4. മറ്റെന്തെങ്കിലും, വ്യക്തമാക്കുക.....</li> </ol>	
61	ഗർഭധരിക്കാൻ ബുദ്ധിമുട്ടുണ്ടെന്ന് മനസ്സിലാക്കിയശേഷം താങ്കൾ ചികിത്സ തുടങ്ങാൻ കൃത്യമായി എത്ര നാൾ എടുത്തു ?	<input type="checkbox"/> മാസം	<input type="checkbox"/> മാസം

62	ആരാണ് ചികിത്സ തുടങ്ങാൻ പ്രേരിപ്പിച്ചത്? [ഒന്നിൽ കൂടുതൽ ഉത്തരമാകാം]	1. സ്വന്തമായി 2. ഭർത്താവ് 3. രണ്ടുപേരും 4. സ്വന്തം വീട്ടുകാർ 5. ഭർത്താവിന്റെ വീട്ടുകാർ 6. കൂട്ടുകാർ 7. മറ്റാരെങ്കിലും, വ്യക്തമാക്കുക.....	
63	എപ്പോഴാണ് താങ്കൾ ചികിത്സ ആരംഭിച്ചത് ? (കൃത്യമായ മാസം ഓർമ്മയുണ്ടെങ്കിൽ അതും പറയുക)	<input type="checkbox"/> കൃത്യ മാസം/ <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> കൃത്യ വർഷം	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> മാസം
64	എത്ര നാൾ (മാസം/വർഷം) താങ്കൾ ചികിത്സ തുടർന്നു? (ചികിത്സയുടെ ഇടയിൽ എടുത്ത ഇടവേളകളും ഉൾപ്പെടുത്തി ) [ഇപ്-പോഴും ചികിത്സ തുടരുന്നവരാണെങ്കിൽ അഭിമുഖം നടത്തുന്ന ദിവസം വരെയുള്ള കാലയളവ് രേഖപ്പെടുത്തുക]	<input type="checkbox"/> <input type="checkbox"/> മാസം/ <input type="checkbox"/> <input type="checkbox"/> വർഷം	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> മാസം
65	എപ്പോഴാണ് താങ്കൾ ചികിത്സ നിർത്തിയത് ? (ചികിത്സാ ഫലം ലഭിച്ചവരും അല്ലെങ്കിൽ പൂർണ്ണമായും ചികിത്സ അവസാനിപ്പിച്ചവരും മാത്രം)	<input type="checkbox"/> കൃത്യ മാസം/ <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> കൃത്യ വർഷം	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> മാസം
66	ഈ കാലയളവിനുള്ളിൽ വന്ധ്യത ചികിത്സയ്ക്കായി താങ്കൾ എത്ര ആശുപത്രി അല്ലെങ്കിൽ വന്ധ്യതചികിത്സാ കേന്ദ്രം അല്ലെങ്കിൽ ഡോക്ടർമാരുടെ അടുത്ത് പോയിട്ടുണ്ട്?	<input type="checkbox"/> <input type="checkbox"/> (അലോപ്പതി) + <input type="checkbox"/> <input type="checkbox"/> (മറ്റുള്ളവ)	
67	ആർക്കാണ് പ്രശ്നം എന്നാണ് കണ്ടുപിടിച്ചത് ?	1. ഭർത്താവിനായിരുന്നു പ്രശ്നം 2. എനിക്കായിരുന്നു പ്രശ്നം 3. രണ്ടുപേരുടെയും പ്രശ്നം 4. വിശദീകരിക്കാൻ ആകാത്തത് അതായതു രണ്ടുപേർക്കും പ്രശ്നങ്ങൾ ഇല്ല 5. മറ്റൊരാളിലും, വ്യക്തമാക്കുക .....	

Section VIII

വന്ധ്യതാ ചികിത്സാ വിവരങ്ങൾ

(കൂടുതൽ ചികിത്സതേടിയിട്ടുണ്ടെങ്കിൽ കൂടുതൽ പേജുകൾ ചേർക്കുക)

ഐ ഡി നമ്പർ:

സെക്ഷൻ സീരിയൽ നമ്പർ

SI No	വിവരങ്ങൾ/ ചോദ്യങ്ങൾ	T0	T0	T0
68	എപ്പോഴാണ് താങ്കൾ ചികിത്സ ആരംഭിച്ചത് ?	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> [കൃത്യമായ വർഷം രേഖപ്പെടുത്തുക] <b>അഭിമുഖ സംഭാഷകൻ പിന്നീട് രേഖപ്പെടുത്തുക</b> ↓ <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> മാസം [വിവാഹത്തിന് ശേഷമുള്ള ദൈർഘ്യം രേഖപ്പെടുത്തുക ]	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> [കൃത്യമായ വർഷം രേഖപ്പെടുത്തുക] <b>അഭിമുഖ സംഭാഷകൻ പിന്നീട് രേഖപ്പെടുത്തുക</b> ↓ <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> മാസം [വിവാഹത്തിന് ശേഷമുള്ള ദൈർഘ്യം രേഖപ്പെടുത്തുക ]	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> [കൃത്യമായ വർഷം രേഖപ്പെടുത്തുക] <b>അഭിമുഖ സംഭാഷകൻ പിന്നീട് രേഖപ്പെടുത്തുക</b> ↓ <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> മാസം [വിവാഹത്തിന് ശേഷമുള്ള ദൈർഘ്യം രേഖപ്പെടുത്തുക ]
69	ഏതു ഡോക്ടർ അല്ലെങ്കിൽ കേന്ദ്രത്തിൽ ആണ് നിങ്ങൾ ചികിത്സതേടിയത് ?			

<p>70</p> <p>ഈ കേന്ദ്രത്തിൽ താങ്കൾ നടത്തിയ വിവിധ ചികിത്സകൾ എന്തൊക്കെയാണ്? <b>[ഒന്നിൽ കൂടുതൽ ഉത്തരം ആകാം ]</b></p>	<ol style="list-style-type: none"> <li>1. പ്രാഥമിക പരിശോധനകൾ മാത്രം</li> <li>2. ഫെല്ലോപിയൻ ട്യൂബിൽ എന്തെങ്കിലും തടസ്സങ്ങൾ ഉണ്ടോ എന്ന് പരിശോധിക്കുക [ട്യൂബ് ടെസ്റ്റ്] - ലാപ്രോസ്കോപ്പി, ഹൈസ്റ്ററോസൽപിഞ്ചോഗ്രാഫി</li> <li>3. മാസമുറ/ആർത്തവ ചക്രം നിരീക്ഷിക്കുക, സ്വന്തമായി ഗർഭം ധരിക്കാൻ ശ്രമിക്കുക</li> <li>4. മരുന്ന്കൾ വഴി മാസമുറ/ആർത്തവ ചക്രം ക്രമീകരിക്കുക</li> <li>5. പുരുഷന്മാരുടെ ബീജത്തിലെ പ്രശ്നങ്ങൾ പരിഹരിക്കാനുള്ള ശസ്ത്രക്രിയ, ബീജത്തിലെ പ്രശ്നങ്ങൾ പരിഹരിക്കാനുള്ള മരുന്ന്കൾ,</li> <li>6. അണ്ഡോല്പാദനം നടത്താനുള്ള മരുന്ന്കൾ (ഓവുലേഷൻ ഇൻഡക്ഷൻ)</li> <li>7. ഐ യു ഐ</li> <li>8. ഐ വി ഫ്</li> <li>9. ഐ വി എഫ് (ദാതാവിന്റെ അണ്ഡം/ ബീജം ഉപയോഗിച്ച്)</li> <li>10. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....</li> </ol>	<ol style="list-style-type: none"> <li>1. പ്രാഥമിക പരിശോധനകൾ മാത്രം</li> <li>2. ഫെല്ലോപിയൻ ട്യൂബിൽ എന്തെങ്കിലും തടസ്സങ്ങൾ ഉണ്ടോ എന്ന് പരിശോധിക്കുക [ട്യൂബ് ടെസ്റ്റ്] - ലാപ്രോസ്കോപ്പി, ഹൈസ്റ്ററോസൽപിഞ്ചോഗ്രാഫി</li> <li>3. മാസമുറ/ആർത്തവ ചക്രം നിരീക്ഷിക്കുക, സ്വന്തമായി ഗർഭം ധരിക്കാൻ ശ്രമിക്കുക</li> <li>4. മരുന്ന്കൾ വഴി മാസമുറ/ആർത്തവ ചക്രം ക്രമീകരിക്കുക</li> <li>5. പുരുഷന്മാരുടെ ബീജത്തിലെ പ്രശ്നങ്ങൾ പരിഹരിക്കാനുള്ള ശസ്ത്രക്രിയ, ബീജത്തിലെ പ്രശ്നങ്ങൾ പരിഹരിക്കാനുള്ള മരുന്ന്കൾ,</li> <li>6. അണ്ഡോല്പാദനം നടത്താനുള്ള മരുന്ന്കൾ (ഓവുലേഷൻ ഇൻഡക്ഷൻ)</li> <li>7. ഐ യു ഐ</li> <li>8. ഐ വി ഫ്</li> <li>9. ഐ വി എഫ് (ദാതാവിന്റെ അണ്ഡം/ ബീജം ഉപയോഗിച്ച്)</li> <li>10. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....</li> </ol>	<ol style="list-style-type: none"> <li>1. പ്രാഥമിക പരിശോധനകൾ മാത്രം</li> <li>2. ഫെല്ലോപിയൻ ട്യൂബിൽ എന്തെങ്കിലും തടസ്സങ്ങൾ ഉണ്ടോ എന്ന് പരിശോധിക്കുക [ട്യൂബ് ടെസ്റ്റ്] - ലാപ്രോസ്കോപ്പി, ഹൈസ്റ്ററോസൽപിഞ്ചോഗ്രാഫി</li> <li>3. മാസമുറ/ആർത്തവ ചക്രം നിരീക്ഷിക്കുക, സ്വന്തമായി ഗർഭം ധരിക്കാൻ ശ്രമിക്കുക</li> <li>4. മരുന്ന്കൾ വഴി മാസമുറ/ആർത്തവ ചക്രം ക്രമീകരിക്കുക</li> <li>5. പുരുഷന്മാരുടെ ബീജത്തിലെ പ്രശ്നങ്ങൾ പരിഹരിക്കാനുള്ള ശസ്ത്രക്രിയ, ബീജത്തിലെ പ്രശ്നങ്ങൾ പരിഹരിക്കാനുള്ള മരുന്ന്കൾ,</li> <li>6. അണ്ഡോല്പാദനം നടത്താനുള്ള മരുന്ന്കൾ (ഓവുലേഷൻ ഇൻഡക്ഷൻ)</li> <li>7. ഐ യു ഐ</li> <li>8. ഐ വി ഫ്</li> <li>9. ഐ വി എഫ് (ദാതാവിന്റെ അണ്ഡം/ ബീജം ഉപയോഗിച്ച്)</li> <li>10. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....</li> </ol>
<p>71</p> <p>താങ്കൾ ഈ കേന്ദ്രത്തിൽ എത്രനാൾ തുടർന്നു? <b>[പ്രതിവതിക്കുന്ന വ്യക്തിക്ക് ഓർമ്മയുണ്ടെങ്കിൽ കൃത്യമായ ദൈർഘ്യം രേഖപ്പെടുത്തുക]</b></p>	<ol style="list-style-type: none"> <li>1. 1-6 മാസം വരെ</li> <li>2. 1 വർഷം വരെ</li> <li>3. 1-2 വർഷം വരെ</li> <li>4. 2-5 വർഷം വരെ</li> <li>5. 5 ഓ അതിൽ കൂടുതലോ വർഷം വരെ</li> </ol> <p><input type="checkbox"/>മാസം</p> <p><b>അഭിമുഖ സംഭാഷകൻ പിന്നീട് രേഖപ്പെടുത്തുക</b></p> <p>↓</p> <p><input type="checkbox"/><input type="checkbox"/>മാസം</p> <p>[വിവാഹത്തിന് ശേഷമുള്ള ദൈർഘ്യം രേഖപ്പെടുത്തുക ]</p>	<ol style="list-style-type: none"> <li>1. 1-6 മാസം വരെ</li> <li>2. 1 വർഷം വരെ</li> <li>3. 1-2 വർഷം വരെ</li> <li>4. 2-5 വർഷം വരെ</li> <li>5. 5 ഓ അതിൽ കൂടുതലോ വർഷം വരെ</li> </ol> <p><input type="checkbox"/>മാസം</p> <p><b>അഭിമുഖ സംഭാഷകൻ പിന്നീട് രേഖപ്പെടുത്തുക</b></p> <p>↓</p> <p><input type="checkbox"/><input type="checkbox"/>മാസം</p> <p>[വിവാഹത്തിന് ശേഷമുള്ള ദൈർഘ്യം രേഖപ്പെടുത്തുക ]</p>	<ol style="list-style-type: none"> <li>1. 1-6 മാസം വരെ</li> <li>2. 1 വർഷം വരെ</li> <li>3. 1-2 വർഷം വരെ</li> <li>4. 2-5 വർഷം വരെ</li> <li>5. 5 ഓ അതിൽ കൂടുതലോ വർഷം വരെ</li> </ol> <p><input type="checkbox"/>മാസം</p> <p><b>അഭിമുഖ സംഭാഷകൻ പിന്നീട് രേഖപ്പെടുത്തുക</b></p> <p>↓</p> <p><input type="checkbox"/><input type="checkbox"/>മാസം</p> <p>[വിവാഹത്തിന് ശേഷമുള്ള ദൈർഘ്യം രേഖപ്പെടുത്തുക ]</p>
<p>72</p> <p>അതിനു ശേഷം താങ്കൾ മറ്റേതെങ്കിലും കേന്ദ്രത്തിൽ ചികിത്സ തേടിയിട്ടുണ്ടോ? <b>[ഉണ്ടെങ്കിൽ അടുത്ത കോളവും T2/3/... പുരിപ്പിക്കുക]</b></p>	<ol style="list-style-type: none"> <li>1. ഉണ്ട്</li> <li>2. ഇല്ല</li> </ol>	<ol style="list-style-type: none"> <li>1. ഉണ്ട്</li> <li>2. ഇല്ല</li> </ol>	<ol style="list-style-type: none"> <li>1. ഉണ്ട്</li> <li>2. ഇല്ല</li> </ol>

<p>73</p> <p>അടുത്ത ചികിത്സ ആരംഭിച്ചതിനും ഈ ചികിത്സ നിർത്തിയതിനും ഇടയ്ക്കു എത്രനാൾ ഇടവേള ഉണ്ടായിരുന്നു? [പ്രതിവതിക്കുന്ന വ്യക്തിക്ക് ഓർമ്മയുണ്ടെങ്കിൽ കൃത്യമായ ദൈർഘ്യം രേഖപ്പെടുത്തുക]</p>	<ol style="list-style-type: none"> <li>1-6 മാസം വരെ</li> <li>1 വർഷം വരെ</li> <li>1-2 വർഷം വരെ</li> <li>2 വർഷത്തിൽ കൂടുതൽ, വ്യക്തമാക്കുക</li> </ol> <p>.....</p> <p style="text-align: center;"><input type="checkbox"/>മാസം <b>അഭിമുഖ സംഭാഷകൻ പിന്നീട് രേഖപ്പെടുത്തുക</b></p> <p style="text-align: center;">↓</p> <p style="text-align: center;"><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/>മാസം [വിവാഹത്തിന് ശേഷമുള്ള ദൈർഘ്യം രേഖപ്പെടുത്തുക ]</p>	<ol style="list-style-type: none"> <li>1-6 മാസം വരെ</li> <li>1 വർഷം വരെ</li> <li>1-2 വർഷം വരെ</li> <li>2 വർഷത്തിൽ കൂടുതൽ, വ്യക്തമാക്കുക</li> </ol> <p>.....</p> <p style="text-align: center;"><input type="checkbox"/>മാസം <b>അഭിമുഖ സംഭാഷകൻ പിന്നീട് രേഖപ്പെടുത്തുക</b></p> <p style="text-align: center;">↓</p> <p style="text-align: center;"><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/>മാസം [വിവാഹത്തിന് ശേഷമുള്ള ദൈർഘ്യം രേഖപ്പെടുത്തുക ]</p>	<ol style="list-style-type: none"> <li>1-6 മാസം വരെ</li> <li>1 വർഷം വരെ</li> <li>1-2 വർഷം വരെ</li> <li>2 വർഷത്തിൽ കൂടുതൽ, വ്യക്തമാക്കുക</li> </ol> <p>.....</p> <p style="text-align: center;"><input type="checkbox"/>മാസം <b>അഭിമുഖ സംഭാഷകൻ പിന്നീട് രേഖപ്പെടുത്തുക</b></p> <p style="text-align: center;">↓</p> <p style="text-align: center;"><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/>മാസം [വിവാഹത്തിന് ശേഷമുള്ള ദൈർഘ്യം രേഖപ്പെടുത്തുക ]</p>
<p>74</p> <p>ഈ കേന്ദ്രത്തിലെ ചികിത്സ താങ്കൾ എന്തുകൊണ്ടാണ് നിർത്തിയത് അല്ലെങ്കിൽ ഇടക്കുവെച്ചു ഉപേക്ഷിച്ചത് ? ഒന്നിൽ കൂടുതൽ ഉത്തരം ആകാം</p>	<ol style="list-style-type: none"> <li>1. ചികിത്സാസംബന്ധമായി ഉള്ള മാനസിക സമ്മർദ്ദം</li> <li>2. ചികിത്സാസംബന്ധമായി ഉള്ള ശാരീരിക സമ്മർദ്ദം</li> <li>3. ചികിത്സാകേന്ദ്രം സംബന്ധിച്ചുള്ള പ്രശ്നം</li> <li>4. ചികിത്സ ഫലപ്രാപ്തിയെക്കുറിച്ചു വിശ്വാസമില്ല</li> <li>5. മോശമായ രോഗപുരോഗതി</li> <li>6. പ്രായോഗികമായ ബുദ്ധിമുട്ടുകൾ</li> <li>7. വ്യക്തിഗതമായ പ്രശ്നങ്ങൾ</li> <li>8. സ്വന്തമായി ഗർഭം ധരിക്കാൻ ശ്രമിക്കുന്നു</li> <li>9. ചികിത്സ കുറച്ചുനാളത്തേക്കു മാറ്റിവയ്ക്കുന്നു/ ചികിത്സയിൽ നിന്ന് ഒരു ഇടവേള എടുക്കുന്നു</li> <li>10. ഡോക്ടർ നീക്കം ചെയ്തു</li> <li>11. സാമ്പത്തിക ബുദ്ധിമുട്ടുകൾ</li> <li>12. ചികിത്സയുമായി ബന്ധപ്പെട്ടുള്ള സേവനങ്ങളുടെ പ്രശ്നം</li> <li>13. മറ്റേതെങ്കിലും ആരോഗ്യ പ്രശ്നം</li> <li>14. ഈ നിശ്ചിതമായ ചികിത്സ തുടരാൻ താല്പര്യമില്ല</li> <li>15. ഇതര മാർഗ്ഗങ്ങൾ/ ചികിത്സകൾ ചെയ്യുന്നു</li> <li>16. ഒരു കുട്ടിയെ ആഗ്രഹിക്കുന്നില്ല</li> <li>17. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....</li> </ol> <p>.....</p>	<ol style="list-style-type: none"> <li>1. ചികിത്സാസംബന്ധമായി ഉള്ള മാനസിക സമ്മർദ്ദം</li> <li>2. ചികിത്സാസംബന്ധമായി ഉള്ള ശാരീരിക സമ്മർദ്ദം</li> <li>3. ചികിത്സാകേന്ദ്രം സംബന്ധിച്ചുള്ള പ്രശ്നം</li> <li>4. ചികിത്സ ഫലപ്രാപ്തിയെക്കുറിച്ചു വിശ്വാസമില്ല</li> <li>5. മോശമായ രോഗപുരോഗതി</li> <li>6. പ്രായോഗികമായ ബുദ്ധിമുട്ടുകൾ</li> <li>7. വ്യക്തിഗതമായ പ്രശ്നങ്ങൾ</li> <li>8. സ്വന്തമായി ഗർഭം ധരിക്കാൻ ശ്രമിക്കുന്നു</li> <li>9. ചികിത്സ കുറച്ചുനാളത്തേക്കു മാറ്റിവയ്ക്കുന്നു/ ചികിത്സയിൽ നിന്ന് ഒരു ഇടവേള എടുക്കുന്നു</li> <li>10. ഡോക്ടർ നീക്കം ചെയ്തു</li> <li>11. സാമ്പത്തിക ബുദ്ധിമുട്ടുകൾ</li> <li>12. ചികിത്സയുമായി ബന്ധപ്പെട്ടുള്ള സേവനങ്ങളുടെ പ്രശ്നം</li> <li>13. മറ്റേതെങ്കിലും ആരോഗ്യ പ്രശ്നം</li> <li>14. ഈ നിശ്ചിതമായ ചികിത്സ തുടരാൻ താല്പര്യമില്ല</li> <li>15. ഇതര മാർഗ്ഗങ്ങൾ/ ചികിത്സകൾ ചെയ്യുന്നു</li> <li>16. ഒരു കുട്ടിയെ ആഗ്രഹിക്കുന്നില്ല</li> <li>17. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....</li> </ol> <p>.....</p>	<ol style="list-style-type: none"> <li>1. ചികിത്സാസംബന്ധമായി ഉള്ള മാനസിക സമ്മർദ്ദം</li> <li>2. ചികിത്സാസംബന്ധമായി ഉള്ള ശാരീരിക സമ്മർദ്ദം</li> <li>3. ചികിത്സാകേന്ദ്രം സംബന്ധിച്ചുള്ള പ്രശ്നം</li> <li>4. ചികിത്സ ഫലപ്രാപ്തിയെക്കുറിച്ചു വിശ്വാസമില്ല</li> <li>5. മോശമായ രോഗപുരോഗതി</li> <li>6. പ്രായോഗികമായ ബുദ്ധിമുട്ടുകൾ</li> <li>7. വ്യക്തിഗതമായ പ്രശ്നങ്ങൾ</li> <li>8. സ്വന്തമായി ഗർഭം ധരിക്കാൻ ശ്രമിക്കുന്നു</li> <li>9. ചികിത്സ കുറച്ചുനാളത്തേക്കു മാറ്റിവയ്ക്കുന്നു/ ചികിത്സയിൽ നിന്ന് ഒരു ഇടവേള എടുക്കുന്നു</li> <li>10. ഡോക്ടർ നീക്കം ചെയ്തു</li> <li>11. സാമ്പത്തിക ബുദ്ധിമുട്ടുകൾ</li> <li>12. ചികിത്സയുമായി ബന്ധപ്പെട്ടുള്ള സേവനങ്ങളുടെ പ്രശ്നം</li> <li>13. മറ്റേതെങ്കിലും ആരോഗ്യ പ്രശ്നം</li> <li>14. ഈ നിശ്ചിതമായ ചികിത്സ തുടരാൻ താല്പര്യമില്ല</li> <li>15. ഇതര മാർഗ്ഗങ്ങൾ/ ചികിത്സകൾ ചെയ്യുന്നു</li> <li>16. ഒരു കുട്ടിയെ ആഗ്രഹിക്കുന്നില്ല</li> <li>17. മറ്റേതെങ്കിലും, വ്യക്തമാക്കുക.....</li> </ol> <p>.....</p>

**A14: In-depth interview guide for phase III in-depth interview (English)**  
**In-depth interview guide**

**INTRODUCTION:**

Thank you very much for agreeing to be interviewed. I understand that you have been married for... years and had some difficulty in getting pregnant. I also understand that you have taken different treatments for resolving this. I would like to understand more about this and your experience of undergoing the treatment. My questions to you will relate more to the kind of treatment you have undergone in trying to conceive and the specific meaning it has to your life. There are no right or wrong answers to my questions, and I am more interested in your opinions regarding your experiences of living with the infertility.

Can you describe your experiences with undergoing treatment for getting pregnant? What parts of this treatment were difficult? Why was it difficult? What did you and your partner do to solve the problems about this treatment process? How did the doctor and the other people at the hospital/treatment site help?

What was the diagnosis regarding the infertility? How did you feel about the diagnosis? What was the reaction of others in your family, including your partner to it? How did you deal with these reactions? Can you explain what happened following the diagnosis – in terms of how people behaved towards you and how you reacted to it?

How did the treatment effect you? PROBE: when the diagnosis was your problem vs your husband's problem

What context or situations have typically influenced or affected this experience of having difficulty to get pregnant?

LEAVE TAKING: Thank you very much for patiently answering all my questions. I am very grateful to you for giving me the time and explaining your experiences regarding your fertility problem. I would like to assure you that I will not mention either your name or any identifying information in my analysis or dissertation.

**A15: In-depth interview guide for phase III in-depth interview (Malayalam)**

**ഗവനമായ അഭിമുഖം നടത്തുന്നതിനുള്ള മാർഗനിർദ്ദേശം**

ആമുഖം: താങ്കളെ അഭിമുഖം ചെയ്യാൻ സമ്മതം തന്നതിനു നന്ദി. താങ്കൾ വിവാഹിതയായിട്ടു ... നാളായി എന്നും താങ്കൾക്ക് ഗർഭം ധരിക്കുന്നതിനു ചില ബുദ്ധിമുട്ടുകൾ ഉണ്ടെന്നും ഞാൻ മനസ്സിലാക്കുന്നു. ഇത് പരിഹരിക്കാനായി താങ്കൾ വ്യത്യസ്ത ചികിത്സകൾ സ്വീകരിച്ചിട്ടുണ്ടെന്ന് ഞാൻ മനസ്സിലാക്കുന്നു. ഇത് സംബന്ധിച്ചു കൂടുതൽ വിവരങ്ങൾ അറിയാൻ ഞാൻ താത്പര്യപ്പെടുന്നു, ചികിത്സ നടത്തുമ്പോൾ ഉണ്ടായ അനുഭവങ്ങളെ കുറിച്ചും അറിയാൻ താത്പര്യപ്പെടുന്നു.

എന്റെ ചോദ്യങ്ങൾ താങ്കൾ ഗർഭം ധരിക്കുന്നതിനു വേണ്ടി ചെയ്ത/ ശ്രമിച്ച വിവിധ തരത്തിലുള്ള ചികിത്സകളും അതിനു നിങ്ങളുടെ ജീവിതത്തിലെ അർത്ഥം എന്താണ് എന്നറിയുന്നതിനും വേണ്ടിയാണു . എന്റെ ചോദ്യങ്ങൾക്ക് ശരിയോ തെറ്റോ ഉത്തരം ഇല്ല മറിച്ചു വന്ധ്യതകൊണ്ടുള്ള ജീവിതാനുഭവങ്ങളെ സംബന്ധിച്ചുള്ള താങ്കളുടെ അഭിപ്രായങ്ങൾ അറിയാനാണ് എനിക്ക് കൂടുതൽ താല്പര്യം.

ഗർഭിണിയാകാൻ ചികിത്സിക്കുന്നതിലൂടെ താങ്കൾക്കുണ്ടായ അനുഭവങ്ങൾ വിവരിക്കാനാകുമോ? ഈ ചികിത്സയുടെ ഏതെല്ലാം ഭാഗങ്ങൾ ആയിരുന്നു വിഷമകരമായിരുന്നത്? എന്തുകൊണ്ടാണ് അത് ബുദ്ധിമുട്ടായിരുന്നത്?

താങ്കളും താങ്കളുടെ പങ്കാളിയും ഈ ചികിത്സാരീതിയെക്കുറിച്ചുള്ള പ്രശ്നങ്ങൾ പരിഹരിക്കാൻ എന്താണ് ചെയ്തത്? ആശുപത്രി / ചികിത്സ സ്ഥലത്ത് ഡോക്ടറും മറ്റു ആളുകളും എങ്ങനെയാണ് സഹായിച്ചത്? വന്ധ്യത സംബന്ധിച്ച രോഗനിർണയം എന്തായിരുന്നു? രോഗനിർണയത്തെക്കുറിച്ച് താങ്കൾക്ക് എന്തു തോന്നുന്നു? താങ്കളുടെ പങ്കാളിയുടെയും കുടുംബത്തിലെ മറ്റുള്ളവരുടെ പ്രതികരണം എന്തായിരുന്നു? ഈ പ്രതികരണങ്ങൾ താങ്കൾ എങ്ങനെയാണ് കൈകാര്യം ചെയ്തത്?

രോഗനിർണയത്തിനുശേഷം എന്താണ് സംഭവിച്ചതെന്ന് വിശദീകരിക്കാമോ - ആളുകൾ താങ്കളോട് പെരുമാറിയതും അതിനോടു താങ്കൾ പ്രതികരിച്ചതും എങ്ങനെയായിരുന്നു?

ചികിത്സകൾ താങ്കളെ എങ്ങനെ ബാധിച്ചു? പ്രോബ് : രോഗനിർണയം താങ്കളുമായി ബന്ധപ്പെട്ടിരിക്കുമ്പോൾ, രോഗനിർണയം താങ്കളുടെ ഭർത്താവുമായി ബന്ധപ്പെട്ടിരുന്നപ്പോൾ

ഗർഭിണിയാകാൻ ബുദ്ധിമുട്ടുള്ള ഈ അനുഭവത്തെ ഏതു സന്ദർഭം അല്ലെങ്കിൽ സാഹചര്യങ്ങൾ സാധാരണഗതിയിൽ സാധിനിച്ചു അല്ലെങ്കിൽ ബാധിച്ചു?

സംഭാഷണം അവസാനിപ്പിക്കുക :

താങ്കളുടെ വിലപ്പെട്ട സമയം ചിലവാക്കി എന്റെ ചോദ്യങ്ങൾക്ക് ക്ഷമാപൂർവ്വം ഉത്തരം തന്നതിനും താങ്കൾ പരിഗണിച്ച ചികിത്സകളെ കുറിച്ചും അത് എന്തുകൊണ്ട് താങ്കളുടെ വന്ധ്യതാ പ്രശ്നത്തിന് തിരഞ്ഞെടുത്തെന്നും വളരെ വ്യക്തമായി വിശദീകരിച്ചതിനും നന്ദി. താങ്കളുടെ പേരോ താങ്കളെ തിരിച്ചറിയാൻ കഴിയുന്ന മറ്റ് വിവരങ്ങളോ ഞാൻ എവിടെയും (വിശകലനം ചെയ്യുമ്പോഴോ പ്രബന്ധത്തിലോ) സൂചിപ്പിക്കുന്നതല്ല.

**A16: Status of emigration in Kerala and its districts, 1998-2018**

Table 1: Proportion of emigrants by districts of Kerala, 1998-2018

District	Emigrants								
	1998*	2001	Percentage	2008*	2011	Percentage	2018*	2011	Percentage
	KMS A	Census B	of Total population C=A/B	KMS D	Census E	of Total population F=D/E	KMS G	Census H	of Total population I=G/H
Emigrants	Population	Percentage	EMI	Population	Percentage	EMI	Population	Percentage	
Thiruvananthapuram	130705	3234356	4.04	308481	3301427	9.34	137007	3301427	4.15
Kollam	102977	2585208	3.98	207516	2635375	7.87	240527	2635375	9.13
Pathanamthitta	97505	1234016	7.90	120990	1197412	10.10	109836	1197412	9.17
Alappuzha	62870	2109160	2.98	131719	2127789	6.19	136857	2127789	6.43
Kottayam	35494	1953646	1.82	89351	1974551	4.53	166625	1974551	8.44
Idukki	7390	1129221	0.65	5792	1108974	0.52	32893	1108974	2.97
Ernakulam	103750	3105798	3.34	120979	3282388	3.69	53418	3282388	1.63
Thrissur	161102	2974232	5.42	284068	3121200	9.10	241150	3121200	7.73

Source: \*Rajan and Zachariah, 2019, p 25 and Census of India, 2001 and 2011

(contd.)

Table 1: Proportion of emigrants by districts of Kerala, 1998-2018 (contd.)

District	Emigrants								
	1998*	2001	Percentage	2008*	2011	Percentage	2018*	2011	Percentage
	KMS A	Census B	of Total population C=A/B	KMS D	Census E	of Total population F=D/E	KMS G	Census H	of Total population I=G/H
Emigrants	Population	Percentage	EMI	Population	Percentage	EMI	Population	Percentage	
Palakkad	116026	2617482	4.43	189815	2809934	6.76	89065	2809934	3.17
Malappuram	296710	3625471	8.18	334572	4112920	8.13	406054	4112920	9.87
Kozhikode	116026	2879131	4.03	199163	3086293	6.45	160691	3086293	5.21
Wayanad	4552	780619	0.58	13996	817420	1.71	30650	817420	3.75
Kannur	88065	2408956	3.66	119119	2523003	4.72	249834	2523003	9.90
Kasaragod	38747	1204078	3.22	67851	1307375	5.19	67281	1307375	5.15
Total	1361919	31841374	4.28	2193412	33406061	6.57	2121887	33406061	6.35

Source: \*Rajan and Zachariah, 2019, p 25 and Census of India, 2001 and 2011

**A17: Emigrants by marital status and sex, 1998-2018**

Table 2: Emigrants by marital status and sex, 1998-2018

Marital Status	Male						Female					
	1998*	2003*	2008*	2011**	2013***	2018***	1998*	2003*	2007*	2011**	2013***	2018***
Never married/unmarried	49.8	60.9	56.1	63.8	44.8	24.8	17.4	25.1	13.2	45.9	32.3	33.0
Married	49.8	39.0	43.4	36.1	53.0	74.5	79.2	74.3	85.7	52.8	55.3	65.5
Others(W/S/D*)	0.4	0.1	0.5	0.1	2.2	0.7	3.4	0.6	1.1	1.3	12.4	1.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

\* W- Widow/widower, S-Separated, D-Divorced

Source: \*Rajan and Zachariah, 2007, p 31. \*\*Rajan and Zachariah, 2012, p 50. \*\*\*Rajan and Zachariah, 2019, p 32

**A18: Calculation of age of the respondent at the time of starting treatment**

The age of the respondent at the time of starting the treatment was calculated using the current age and the date of starting the treatment and the date of interview. The difference between the date of interview and the date of starting the treatment gave the number of years since starting the treatment, i.e., x years

No of year since start of treatment= (date of interview)- (date of starting the treatment)= x years \_\_\_\_\_ (1)

From this, the age of the respondent at the time of starting the treatment was computed, i.e., by subtracting x years from the age of the respondent at the time of the interview.

Age at the time of starting treatment = (age at the time of interview)-(x years)\_\_\_\_\_ (2)

### **A19: Calculation of age of the respondent at pregnancy**

The age at pregnancy was calculated using the available information on age of the respondent at the time of interview, date of interview, date of starting the treatment for each respondent and the total duration of treatment for infertility till pregnancy. The total duration of the treatment for each individual is the calculated from the individual duration spend in each centre till they got pregnant or till they stopped treatment or till the time of interview if they were continuing the treatment.

The difference between the date of interview and the date of starting the treatment gave the number of years since starting the treatment, i.e., x years

No of year since start of treatment and first treatment= (date of interview)- (date of starting the treatment)= x years \_\_\_\_\_ (1)

From this, the age of the respondent at the time of starting the treatment was computed, i.e., by subtracting x years from the age of the respondent at the time of the interview.













Age at the time of starting treatment = (age at the time of interview)-(x years)\_\_\_\_\_ (2)

And, the age of the respondent at pregnancy was computed using the equation (3)  
Age of the respondent at pregnancy= Age at the time of starting treatment + Duration of treatment till pregnancy \_\_\_\_\_ (3)



## Document Information

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