Pathways Taken By Childless Women in Pursuit for a Baby

A Qualitative Study Among Childless Women in Kerala, India

Nayana Geetha Ravi



Supervisor: Dr Heidi Fjeld

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Abstract

In this world, millions of people experience childlessness. According to the report of Demographic and Family Health Survey (2002), 186 million ever-married women of reproductive age group in developing countries were infertile and infertility leads to childlessness. However, it is still not considered as a public health priority as the major focus is on overpopulation. It is just contemplated as an ancillary issue to overpopulation. Globally, Childlessness is seen as a women's problem even though male factor contributes to half of the cases of childlessness. This is because motherhood is considered as a milestone for women in many societies, and failure to accomplish this role marginalizes the position of the women in the family and society.

To escape from the stigmatized life, these women constantly try out different treatment forms by risking their life. There is lack of data regarding the treatment pathways and treatment experiences of childless women from the South Indian state of Kerala. The aim of the study was to explore the treatment pathway and perceptions of childless women regarding their treatments and their life. Moreover the available treatment services were also mapped. A qualitative research design was used to explore these issues. Under this qualitative paradigm, a phenomenological approach was employed to get into the childless women's real life experiences.

The findings from this study project the different treatment pathways and the most prioritised systems of medicines in a chronological order. The childless women were desperate to find a solution for their inability and this took them from one treatment provider to the other, building up a treatment pathway. Along these quest pathways, these women lost their wealth and health to different treatment providers. In spite of many hardships, the undying hope and desire led them forward. The women experienced a lot of pressure from the family members and society but had a strong bond with their spouses. These perceived pressures and plight for treatments were the result of the social and cultural construction around motherhood. This highlights the need for regulation and monitoring of private hospitals, implementation of a treatment protocol and for incorporation of infertility treatment services into the public sector hospitals in India to protect the childless women from the claws of commercialised private health sector.

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Abbreviations

AIDS Acquired Immune Deficiency Syndrome

ASHA Accredited Social Health Activist

ART Assisted Reproductive Technology

AYUSH Ayurveda, Yoga and Naturaopathy, Unani, Siddha and Homoeopathy

DLHS District Level Household and Facility Survey

HDI Human Development Index

IUI Intrauterine Insemination

ICSI Intracytoplasmic Sperm Injection

IVF Invitro Fertilisation

NFHS National Family Health Survey

NSD Norwegian Social Science Data Service

PCOS Polycystic Ovarian Syndrome

PHC Primary Health Centre

REK Regional Committee for Medicine and Health science Ethics

TB Tuberculosis

WHO World Health Organisation

Table of Contents

1	Introd	luction	1
	1.1 Ba	ckground	3
	1.1.1	Country profile	3
	1.1.2	Glimpse of Kerala	4
	1.1.3	Life of malayali women	7
	1.1.4	Health sector in Kerala	10
2	Litora	ture Review	1.1.
_		nificance of motherhood	
		ciocultural impact of childlessness	
		alth seeking behaviour	
		ailable treatment services	
		ping with childlessness	
		oject rationale	
		jectives of the study	
_		·	
3		dology	
		search design	
		idy site and population	
		mple size and recruitment	
		ta collection techniques	
	3.4.1 3.4.2	Observations and informal conversations Participant interviews	
	3.4.2	Key informant interviews	
		ta handling	
	3.5.1	Anonymizing and data storage	
	3.5.2	Transcription	
		ta analysis	
	3.6.1	Reflexivity	
	3.6.2	Theoretical perspective	
	3.6.3	Steps of analysis	
		ustworthiness of the study	
		nitations of the study	
		nical considerations	
4		lgs	
		eatment pathways	
	4.1.1	General pathways	
	4.1.2	Less common pathways	
	4.1.3	Explanations for the shift	
	4.1.4	Key informants viewpoints on childless couples and their treatments	
	4.1.5 4.1.6	Source of information in treatment seeking	
	4.1.6	Challenges hindering the treatment pathways	
		Parallel religious pathwaying childless	
	4.2 Be	Feelings of childless women	
	4.2.1	Pressurization faced	
	4.2.3	Women's explanation on childlessness	
	4.2.3	Consequences faced due to childlessness	
		ping up with childlessness	
		Leading a husy life	

4.3.2	Being with children	77
4.3.3	Self care	79
Discus	ssion	83
5.1 De	terminants influencing the treatment pathways	83
5.2 Pe	rceptions of the childless women	87
5.2.1	Self protection strategies	90
Conclu	usions and Recommendations	92
Epilog	zue	94
Litteraturliste		95
Appen	ndix	100
	4.4 Su Discus 5.1 De 5.2 Pe 5.2.1 Conclu Epilog Littera	4.3.2 Being with children

1 Introduction

Parenthood embraces a significant role in the lives of many individuals and they plan their lives accordingly. But then few of them fail to achieve spontaneous conception and are left to deal with the hard truth of childlessness or in Inhorn's words, "reproduction gone awry", shattering their dreams (1). It may be caused by infertility, pregnancy loss and stillbirth or due to death of an infant. In some cultures, the perceptions of causes are dominated by beliefs in magic, mystics and miracles (2,3). Childlessness is seen as a women's problem even though male factor contributes to half of the cases of infertility (1). A woman is referred to as childless, when she has been married for at least five years, and has no living children (4). Infertility is defined as the inability of sexually active, non-contracepting couple to achieve pregnancy in one year (5).

According to WHO, Infertility is a disease of the reproductive system that results in a disability (5). This disability affects couples around the globe. According to the Demographic and Health Surveys (4), WHO estimates that more than 186 million married women of reproductive age group in developing countries live with a wish to conceive. In simple terms, one in every four couples in developing countries is affected by infertility (6). According to Mascarenhas et al., in 2010 around 48.5 million couples were infertile worldwide (7). His findings were based on analysis of household survey data from 277 demographic and reproductive health surveys. But Boivin et al. in 2006 estimated that 72.4 million people are currently infertile and among them approximately 40.5 million are seeking infertility medical care. His study was based on population surveys published since 1990 (8). All these discrepancies in numbers point towards the involvement of both male and female factors, inconsistencies in use of definitions and lack of a common diagnostic tool worldwide (9). In addition to that, the estimates mostly address the woman or the outcome of a pregnancy or live birth (6). But many cases from these countries go unreported due to the stigma bound to childlessness and varied cultural understanding of motherhood (10,11).

The predominant feature of childlessness is its transformation from a private misery into a public stigma with devastating consequences (10). The consequences fall within the domains of community effects, in-law effects and marital effects. It is mostly the women who take the brunt of these consequences because of the widely assumed notion that it is the women's fault and male infertility is rarely recognised in the society (1,12). In many societies, a women gain status through motherhood and when she fails to do so, it results in gendered

suffering (1,10). A childless women experiences low identity, self-esteem, physical health, depression, anxiety, stress, stigma and shame when compared to their male counterparts (13). Women are targets for fertility treatment in many cultures and societies and they are the ones supposed to take treatment (11,14). Despite the role of men and women in childlessness, it is mostly the women who endure painful investigations and treatment procedures resulting in physical and emotional discomfort (13). These treatments can range from simple hormonal therapies to highly invasive interventions and their success rates vary (15). According to Sundby, these interventions are economically and emotionally costly (2). In spite of that, women go on a never-ending treatment journey, which Inhorn refers to as the 'quest for conception' (16). This shift occurs out of desperation (11).

This treatment-seeking pathway may include multiple care providers and is dependent on their social and economic background. These providers include practitioners of biomedicine, alternative medicines and spiritual healers (3,11,16). The perceived pressure from partners, in-laws, parents, community, stigma, experiences and support from friends can also influence this pathway (17). Studies from around the world have shown that infertile women and increasingly men particularly use bio medical services. But the advanced bio medical services for childlessness like ART lies under private domain and to them these patients are just 'money makers' (1,16).

There is little evidence on prevalence of Infertility in South Asia and most of it comes from surveys and census (18). It is estimated that infertility in India is at 8%, Pakistan 10%, 11 % in Srilanka, 12% in Nepal and 15% in Bangladesh and this data was taken at the end of reproductive age of females. Research on socio cultural and behavioural aspect of infertility in South Asia is also sparse. The diverse social, cultural and ethnic groups and public policies further complicate the scenario in this region (9). The identified underlying cause for infertility among women in Asia are hormonal or endocrine disturbances, tubal abnormalities, uterine and cervical disturbances while male infertility is attributed to oligozoospermia (poor or low sperm count) (18). According to Van Balen and Gerrits, the prevalence of infertility is highest in areas with highest fertility, resulting in so-called 'barrenness among plenty' (19). In such places, childlessness is considered as an ancillary issue to overpopulation and the major focus still lie on population control (20). This must be reason why it is neglected by policy makers and researchers in a country like India, where 8.8 per cent of women faces lifetime primary or secondary infertility. Three fourth of these women suffer from primary infertility. This data was obtained fro DLHS 3, in which questions on infertility were included for the first time and it is a valid data as it is was a representative sample for whole

population of India (21). The prevalence is similar to that estimated for developed countries (8). A study based on NFHS 2 showed that southern and western regions of India have higher childlessness (22). No other comprehensive measure on prevalence of infertility has yet been carried out (21). As in other developing countries, infertility services are not provided under any government programmes, as the focus is still on population control. Even though this issue have not received much attention from the policy makers in India, the media and medical practitioners focusing on infertility treatment project it as significant and growing problem and this was the inspiration for this study (23).

The South Indian State of Kerala was chosen as the study site because the state has seen an increase in number of infertility clinics over the past few years, and the practitioners in the field of infertility from this state has shown their concern over the increase in rate of infertility through mass media. Based on the district level household and facility survey (2007-2008), the prevalence of childlessness in Kerala was found to be at 10.5% (24). A study conducted in Thiruvananthapuram district of Kerala and Kanyakumari and Thirunelveli districts of Tamil Nadu pointed out that primary infertility was higher than secondary infertility (25). According to her, PCOS increased the risk of childlessness in these districts in South India. This study aims to get a better understanding of the childlessness scenario in the state.

1.1 Background

1.1.1 Country profile

India is home to one of the oldest civilizations in the world and is noted for its vibrant cultural heritage. It shares borders with Pakistan in the northwest, China, Nepal and Bhutan to the north and Myanmar and Bangladesh on the east, thereby occupying a major portion of the South Asian Subcontinent. India covers an area of 32,87,263 sq. km stretching from the mighty Himalayas to the tropical rain forests of the south making it the seventh largest country in the world, and the most populous democracy with 1,210,193,422 residents



Figure 1 Political Map of India

as of 1st march 2011. Hindus constituted the majority with 80.5%, Muslims came second at 13.4%, followed by Christians, Sikhs, Buddhists and Jains. The sex ratio as per the 2011 census is 940 females per 1000 males. Literacy rate in the Country stands at 74.04 per cent with 82.14% for males and 65.46% for females. The life expectancy of males is 65.8 years and for females, it is 68.1 years during the period of 2006-2011 (26).

India is a federal republic, governed under parliamentary system and it consists of 29 states and 7 union territories. 22 different languages have been recognised by the constitution of India with Hindi as the official language. English is also used for official purposes by law. Each state and union territory has one or more official languages. All states and union territories of Pondicherry and the National Capital, Delhi have elected legislatures and governments. The remaining union territories are governed directly by the central government through administrators (26).

According to International Monetary Fund, it is the sixth largest economy based on market exchange rates and third largest by purchasing power parity. In spite of its economic growth, there still exist the socio economic challenges and inequalities resulting in poverty, public health issues and corruption.

This study focused on the life of childless women in South Indian state of Kerala. As every Indian state is unique, a brief description is required to understand the life and socio cultural scenario in Kerala. So the demography, socio cultural background, health system and status of women in Kerala will be described in the upcoming sections.

1.1.2 Glimpse of Kerala

Kerala lies on the extreme southwest of the Indian subcontinent and bounded by the Arabian Sea on the west and the Western Ghats to the east. It has a long coastline lined by coconut trees and paddy fields. The backwaters, rivers and the interconnected canals add up the beauty, thereby making it the 'Venice of the



Figure 2 Political Map of Kerala

East'. The state is divided into 14 districts, 63 *taluks*, 520 towns and 1018 villages for administrative purposes with Thiruvananthapuram as its capital. It has an active political society. Kerala has been alternatively ruled by two political coalitions; one led by the Indian

national Congress and the other by the Communist Party Of India (Marxist) (27). Malayalam is the official language and the people of Kerala are referred to as 'malayalis' (28).

History

The legend says that Kerala was formed when the warrior sage 'Parasurama' threw his axe into the sea and it is believed that the land arose from the water. Parasurama is considered to be the sixth avatar of Lord Vishnu in Hinduism. Hence Kerala is referred to as the 'God's Own Country' (28). The land was known for its spice trade with the Romans and Arabs as early as Third century BC. Through the trade routes came in Jews, Syrian Christians and Muslims and they settled in port towns in harmony. Agriculture and trade flourished under the Chera Dynasty. As the time passed the caste system brought in by the Aryan Brahmin settlers to Kerala became increasingly rigid on embracing unapproachability and untouchability. The Hindus of lower cast suffered a lot during that era. Later the Portuguese, Dutch and English reached the coast of Kerala and they utilized the unrest and quarrels among the smaller princely states to gain control over the land. The English East India Company overthrew the Portuguese and Dutch and eventually turned the whole of India into a British colony (28).

Advent of Reforms

The rigid caste system and associated taboos existed even during the British Rule. This gave way to the socio religious reform movements, which led on to become a freedom struggle and establishment of a government in the 20th century. Until then the low castes and non-Hindus were not eligible to hold government offices. The temple entry proclamation by the Maharaja of Travancore was the first such move by a 'maharaja' of the conservative Hindu state, allowing temple entry for Hindus of all castes. The Prime Minister of Madras referred to it as the 'greatest religious reform movement' in the country after Asoka. In 1920s and 1930s the farmers and labourers joined the freedom movement in Kerala, which gave a boost to the national freedom movement and led to the establishment of a left wing in Kerala politics. In the beginning, they remained organised under the congress socialist party but later they grew apart and led to the formation of the communist Party in 1939 in *Pinarayi*, Kerala. After India's independence from the British rule, the states were reorganized on linguistic basis. All Malayalam speaking regions were united to form the state of Kerala on November 1st 1956. The matrilineal system or the 'marumakkathayam' followed by some of the Hindu castes and *Mopillas* among Muslims came to an end after independence (28).

Demography

The state is inhabited by 33, 387, 677 people as per the 2011 census, making it the thirteenth largest state in India by population. The census showed a decline in rural population by - 25.96% and the urban population has grown by 92.72%, as compared to the 2001 census. The government attributed the growth to the increase in number of towns from 159 in 2001 to 520 in 2011. The sex ratio is 1084 females per 1000 males. Total fertility rate is 1.70. The state has the highest literacy rate in the country with 93.91%. The female literacy rate in the state is at 91.98%, one of the highest in Asia. The interest in education shown by the people has led on to the economical and social progressions in the state. Kerala is considered as a religiously tolerant state with 54.73% Hindus, 26.56% Muslims, 18.38% Christians and 0.32% belonging to other religions or not following any religion. Hence the national festival *Onam* is celebrated by *malayalis* of all faith (28).

Kerala Model of Development

High levels of social development in spite of low economic advancement are referred to as the Kerala model of development. This model had drawn attention of social development scientists around the world. Kerala has achieved remarkable social developments over the past few decades. This was achieved through state interventions, public actions and popular movements. The role of left government in the achievements was pointed out in many studies (29). People with lower level of income could also benefit from this developmental model as state interventions focused on welfare policies and social reforms such as land reforms, education, and public health services and subsidised food distribution. Education gave way to gender equality and women's accessibility to education, which in turn resulted in better health of children and reduced fertility rate. This education also resulted in a mismatch between the labour force and labour market and the people's expectation also grew with education, which couldn't be met by deserving job opportunities. Unemployment was a grave problem to Kerala and some of them emigrated to gulf countries. So, the economic situation in the state stagnated in spite of high human development. The other reasons behind it were overemphasis on welfare programs, discriminatory policies of centre towards state in budget allocation, power shortage, labour militancy, party politicization at local level and use of gulf remittance in consumption rather than in investments. This in turn affected the welfare schemes. From 1990, a new model has come up with democratic decentralization accompanied with community based strategies and policy making to incorporate sustainable

development. This new model laid on a greater focus on participation of citizens, municipalities and *panchayats* (30). Non-resident *malayalis* play a significant role in development at family, community and state level. Private expenditure in health and education has helped the state to keep up the HDI in spite of the struggling economic growth (28). HDI of Kerala is the highest in India at 0.712. Life expectancy at birth for males is 70.9 and for females is 75.9 in 1993-1997 (27). It is calculated based on life expectancy, education and per capita income.

1.1.3 Life of malayali women

Socio economic status

Kerala women are praised for their high literacy rate. Education was always prioritised in the society even from pre independence era. It is essential for a woman from middle class and upper class to acquire a bachelor's degree in order to get a qualified and professional husband. The women also realised that they have a better chance in acquiring a job with education and this encouraged them to stay in schools and postpone marriage. Higher education levels determine delayed marriage and first birth resulting in less number of children. Mean age of marriage for women is 22.7 years and for males it is 28.7 years. Earlier they lived in joint family and shared resources; but now there is a shift to nuclear families for social and economic convenience (31).

Though Kerala has achieved gender equality in health and education, they have not managed to do so in social and economic roles (27). Critics point out that suicide rate is three times the national average and highest in India. It is higher among unemployed and less educated women (32). Gender inequalities exist in labour force resulting in higher unemployment among women. In spite of being said that women enjoy a higher status, the decision making power is vested in the hands of men and they enjoy a greater power than women in society and family.

Marriage

Marriage is an unavoidable institution in life of a malayali woman. Exploring this tradition gives an idea of gender relations and inequalities in Kerala society. Most of the marriages are arranged marriages and the partners are picked by the parents and relatives based on religion, caste, education, age and socio economic status. Every religious groups and castes practice

their own marriage customs and traditions. Even the laws related to marriage, divorce and inheritances varies from religion to religion (31).

Inheritance and Dowry system

Dowry system and gender based violence is mentioned in detail as it has a strong influence on women's health. *Mappilas* in Muslim community and *Nairs* and *Ezhavas* from Hindu community followed a matrilineal system before. Under this system, women enjoyed a higher position in the society. Since 1925, there was a transition from matrilineal joint family, following an inheritance through the maternal line to an individual inheritance. This led to a decline in women's right to properties. Christian succession laws of early twentieth century were biased against the women. If a father died, the unmarried daughter could claim only one third or a quarter of a son's share of paternal property. The practice of a bride price or *mehr*, among Muslims was supplemented with a wealth transfer from the bride's household as dowry (31).

Traditionally a woman's right to her family wealth was given as a dowry or *sthreedanam* during the time of marriage and was a system among the higher class but now it has spread to all religions and castes. Even though the dowry prohibition act states that giving or taking a dowry is a crime and punishable by act, it has a little impact on the practice. In turn it has become extensive in every section of society. In reality, the women are not benefitted from the dowry money. The groom and his family use it up for paying off debt, starting a business or to pay dowry for unmarried women in their families. Nowadays, it is demanded by the groom's family and goes on a rise depending on the groom's education, profession and family status. Even the unemployed men demand a dowry. This in turn pressurizes the girl's family to save up for paying off dowry. With income disparities, some of them struggle to meet the dowry expectations. The parents struggle and dowry related quarrels in the husband's house causes anxiety and stress in women leading to suicides in some cases. Dowry related suicide rates have tripled between 1994 and 2000 (31).

Gender based violence

Extensive violence against women in society and at home undermines the social development, education and gender equality. Unequal power relationship among men and women give way to violence. They experience abuse, domestic and sexual violence commonly. Studies point out that women facing domestic violence quadrupled between 1994 and 1997 (33). 69% of women who participated in a community based study from

Trivandrum in Kerala reported being subjected to some form of violence. Domestic violence starts closely related to financial transactions related to marriage. Some even end up in murders. A survey conducted by social welfare department reported increase in female abortions(33). All these point towards decline in value of girls and women in the society.

Health of the women in Kerala

Most of the women in Kerala take up the recommended three antenatal visits. Two third managed to get the recommended antenatal visits but postnatal check up was not done in 13%. But in some cases, the antenatal visits goes higher than required, resulting in excessive medicalization, surgeries, interventions and use of medical technologies (29). This happens even when the pregnancy is not at any risks. *Malayalis* have a higher sensitivity to medical issues thereby increasing medicalization. Excessive medicalization of pregnancy related issues raises cost during pregnancy care and delivery and the expenditure is much higher in Kerala compared to the National level, both in public and private sector.

It is of grave concern that one third of deliveries in Kerala are caesarean section, three times higher than the national rate and much higher than the recommended 15% by WHO (29). Kerala has a high rate of institutional deliveries and a greater dependence on private hospitals. The increase in the rate of caesarean section could be profit driven, though further research is needed to assess this situation. In some cases, the woman's family members request the caesarean section, in order to give birth at an auspicious time. The maternal mortality rate in Kerala between 2004 and 2006 is at 95 and it is relatively low. The family planning usage in the country is also high. Most of the women have accessibility to sanitary facilities.

Occupational health hazard is one of the major health problem faced by the women, which is neglected. Most of the women labourers work in tea plantations, coir factories, cashew factories, and fish handling units, where their working conditions deteriorate their health. They work in unhealthy and unhygienic situation without protective gears and unfavourable working postures. The women have a poor mental health out of anxiety and stress, arising mostly from marital disputes. This need to be dealt in a gender sensitive approach as family and society views women's mental illness differently, which may hamper health-seeking behaviour. Obesity is found to be higher in Kerala women and cancer is also on arise, but the exact prevalence rate is not recorded. According to the cancer registry of Regional cancer Centre in Thiruvananthapuram, breast, cervix and thyroid are the mostly affected cancer sites in women in Kerala (29).

1.1.4 Health sector in Kerala

Public health sector

The government health sector aims at providing affordable and satisfactory health care to all and the focus is laid on prevention, control and management of communicable and noncommunicable diseases. To impart quality health services to all, the government has started a new program, 'Aardram' that aims at improving the basic infrastructure of government hospitals and to promote patient friendly hospital initiatives. People in Kerala take treatment from mainly three systems of medicines, i.e. Allopathic, Ayurveda and Homeopathy. Here, the modern medicine is referred to as allopathic medicine. Due to the higher cost of allopathic treatments, there is a greater dependency on alternative medicines, namely Ayurveda and Homeopathy. Their services are regulated and provided by AYUSH. It refers to Ayurveda, Yoga and Naturaopathy, Unani, Siddha and Homoeopathy. Earlier, AYUSH was part of family and welfare department but in order to focus and promote their research, education and services, government separated it and made it into an independent department (28). Under AYUSH, there is a Department for Indian system of medicines focusing on Ayurveda, Yoga and Naturopathy, Unani and Siddha and a Department of Homeopathy. These systems of medicines help in better outreach of health services. District medical officers of concerned system manage at the district level and a director for each system monitors the state level functioning. This multiple health services provide people an opportunity to make choices but there is a strong power variation among the different systems (34).

Achievement in ART

Two government hospitals in Kerala have achieved glory by delivering IVF babies. SAT hospital in Thiruvananthapuram, the oldest tertiary level maternal and childcare hospital in the state became the first government hospital in South India to deliver an IVF baby in 2013 (35). A second IVF baby under public sector hospital was delivered in Kottayam medical college in 2016 (36).

Private health sector

The private health sector has improved the accessibility to health care. The government eased up and promoted this sector to provide better health care. The Kerala state industrial

development cooperation supports and promotes the multispecialty hospitals, which has infrastructures on par with hospitals in developed countries. This sector has grown fast and steadily over the past decade, employing more doctors and staffs compared to the government hospitals. They have better infrastructures and in patient capacities compared to government hospitals and provide advanced care in medical field. Private sector also imparts care in alternative medicines like Ayurveda and Homoeopathy (37).

The infertility treatment in the state is also mainly provided by the private sector. 89.6% villages in Kerala have private clinics (24). According to a newspaper report, the infertility clinics have doubled over the past years. Their growth and functioning is not monitored or regulated, and their quality and ethics are questionable. There is no available research data on the number and the functioning of private hospitals here.

Systems of medicine

Allopathic medicine

Allopathic medicine is also known as modern medicine, biomedicine or western medicine. Under this system, diagnosis is based on signs and symptoms, and treatment is done using drugs, surgeries and other interventions. This treatment under public sector is provided through 5094 sub centres, 59 dispensaries, 18 tuberculosis and leprosy control clinics, 929 primary health centres, 114 community health centres, and 136 hospitals. Hospitals include general, district and taluk hospitals. They have in-patient facilities with 23 871 beds in hospitals, 7675 in primary health centres and 4730 in community health centres. Also, 8402 beds are available in government medical colleges, and the state also has 73 cooperative hospitals. Allopathic treatment is also provided by private hospitals but their exact number is not recorded. Based on a survey conducted in 2004, there are 12 467 private hospitals and 1942 of them have in patient facilities with a bed strength of 64 491. 37% of hospitals under private sector provided allopathic treatment and these hospitals provided most of the inpatient care in private sector (29). Family welfare programs and control and eradication programs run by the directorate of health services are as follows: National programme for control of blindness, National TB control programme, National filarial control programme, National malaria eradication program, National leprosy eradication program, Sexually transmitted diseases control programme, National AIDS control programme, State mental health programme, Physical medicine and rehabilitation, Family welfare programme, Maternal and child health programme, universal immunisation programme, Child survival and safe motherhood programme (38).

Ayurveda

Ayurveda means 'science of life' and is mentioned in Vedas, which makes it a relatively old system of medicine. It takes into consideration physical, mental, social and spiritual characteristic of a human being. It has a strong lineage in Kerala, making it more popular and on par with allopathic medicine. Under the public sector, there are 117 Ayurveda hospitals with 2764 beds, 747 dispensaries and three Ayurveda medical colleges. About 39% of private medical institutions provide Ayurveda treatment (29). It is practiced on the basis of five primordial elements. These elements are Vata (Ether + Air), Pitta (Fire) and Kapha (Water + Earth) known as 'Tri Doshas' (three doshas), and these elements are present in a human being. The physical, mental and spiritual attributes are 'Satva', 'Raja' and 'Tamas'. According to Ayurveda, good health is defined when all these entities are in equilibrium and an imbalance of these entities due to any factors result in disease. The treatment is provided through drugs, procedures, diet restrictions, exercises and improving general life style.

Earlier the physician made the medicines in his house or surrounding area from natural ingredients, but now it has become more commercialised because of their increasing demand. The mechanised medicines are more palatable, with an improved shelf life and the contents are also mentioned. As the medicine productions have become mechanised, there is a concern about change in products, its traditional authenticity and clinical value (39).

Homoeopathy

Hahnemann is the father of homoeopathy and the scientific principles stated and proved by him forms the backbone of homoeopathic treatment till date. Kerala has achieved great heights in practice, education, research and popularity of Homoeopathy. Its popularity lies within the safety and gentleness of its medicines (40). There are 31 homoeo hospitals with 970 beds, 611 dispensaries and two homoeo medical colleges in the state under public sector. They also run special programs for epidemic control, prevention and control of lifestyle diseases, school health programmes and a gender based programme to promote women health care. In homoeopathy, physician takes a holistic approach in treatment by promoting mental, emotional, physical and spiritual level. The doses are tailored for a patient based on the overall health status.

The gender-based programme named 'Seethalayam' under the homoeopathy needs a special mention. This programme aims at women empowerment by improving their physical, mental and social health. Lady physicians assess the problems of the women and provide treatment

accordingly. The psychologist present at the centre provides counselling. Considering the increasing infertility cases in the state, infertility treatment is also incorporated into it. This is a significant step taken by the department.

Siddha

Siddha is an old and traditional system of medicine developed in Tamil Nadu; South India This system highlights relation between universe and human body referred to as 'Andapinda Thathuvam'. Maintenance of health is considered as cooperation between the physical component 'Udal Thathu' and physiological units 'Uyir Thathu'. In this system emphasis is given that one can keep diseases away by taking proper diet at proper time in proper quantity. 80% of drugs are based on herbal products and great care is taken in raw drug purification. In life threatening and chronic diseases metals and minerals are used along with herbal preparations. These drugs are given in a minimal dose with adjuvants and diet restriction (41).

Privacy issues in health care institutions

Privacy and confidentiality is important in women's health especially regarding sexual and mental health. When these rights are not available in a health care institution, it may affect their health seeking behaviour. A study pointed out that the hospitals and PHCs do not have separate or individual consultation rooms. More than one doctor uses a consultation room at the same time and there would not be any partitions. The doors will be kept open and other patients will also be standing in the consultation rooms when the doctors examines the patients. This may prevent a woman from seeking treatment, when she has sensitive information to share about her health condition (29).

2 Literature Review

A literature review was done during the planning phase and to write the proposal. It was done in order to understand the existing knowledge of childlessness from India. The main search engines for the literature search were PubMed, Google scholar and WHO websites. Further literature search was done during the fieldwork in order to keep updates. The keywords used for the searches were treatment pathway, health seeking behaviour, infertility, childlessness, South Asia, India, Kerala, socio cultural, consequences, coping mechanism, treatment services ART, IVF and these keywords were used in different combinations to find the relevant literatures.

2.1 Significance of motherhood

In India, every marriage is expected to bring about a child. It is the next inevitable step to marriage (42). Riessman stated that sexual reproduction is a means to social reproduction (43). The patriarchal system, patrilocal residence, property, inheritance, lineage and caste mark the significance of fertility (44). It is fertility that determines womanhood, so motherhood is considered as a milestone in the life of women. This motherhood is accepted only when it is born out of wedlock (9,43). The religious laws of Hindus, Christians, Muslims and Sikhs preach it as a women's duty (43). In fact, fertility and femininity lies closely interwoven. It is also the main source of power and identity for women in the patriarchal system (45). She gets this power by bearing and rearing children and it is considered to be her primary function in a hierarchical society (42). A child is a necessity for women's existence as she becomes complete only when she is a mother. It strengthens her marital relationship, which maybe weak in some cases as most of the marriages in India are arranged by parents or kin. Some women believe that they get a meaning in their life after giving birth (42). To others, it helps in transition to adulthood or in fulfilling the duties of an adult (9,45).

Even when a woman is not interested in childbearing, she try to conceive just to please husband and in laws. Some are subjected to external pressures from society (9). It is important for men to have children in order to prove masculinity and produce heir in order to continue the family line and perform religious rituals for the redemption of departed souls (46). For performing such rituals, a male progeny is desired still. So there is a pressure not just in producing a baby, but a male one (9).

Children are considered as a security for old age as there is no social welfare system to protect the old. Not only that, it is the age-old practice that children take care of their old parents (43). To urban middle class women, her child is the topic of everyday discussion with her friends. Poor women see children as extra earning hands, bringing in economic security. Others believe that children bring joy and happiness and give them emotional and biological satisfaction to see a part of themselves. So, child bearing is the ultimate goal of a marriage and child is the source of labour, income, happiness and security (9,42).

The role of motherhood is adorned into young girls by encouraging them to take maternal roles and care for their siblings. Onset of her puberty is celebrated by inviting the near and dear ones, announcing her fit for future motherhood. It has become evident from these studies that life of an Indian women revolves around a child. A child determines everything starting from her identity to security in old age. In a context with gender, power, and resource inequalities, childbearing is substantial for survival (42).

2.2 Sociocultural impact of childlessness

The ideology of motherhood explains the importance of child bearing in Indian society. Being childless has more negative social, emotional and cultural consequences than any other non-life threatening condition (20). As it is the woman who get pregnant and deliver a baby, the failure to do so points that to be her mistake. It is the cultural norm and it compromises the women's status (9,47). In a society where motherhood is highly priced, this results in stigma and social exclusion and isolation. This in turn impairs the women's physical and psychological health. The helpless women is pressurised by her family and community to conceive. This takes away her power to make her own reproductive decision (47).

Fertility needs to be viewed in a cultural context because of the close ties between kinship and offspring. Men who participated in Mehta and Kapadia's study reported that they let their women to be blamed, as it is difficult for the family and society to accept that the fault lies in the men (42). These women not only suffer in the society, but they take blame and rude comments from their family members at home, compelling them to move out of the house. They are made to suffer more if there is an already existing dowry issue (43). The inlaws mocked the women, not their sons regarding childlessness (9). The topic of their inability became part of the daily family communications in a joint family. The women are made to do additional household works and treated badly. Childless women had less autonomy than women with children in making decision on what to cook and when to seek

health care (22). The couples felt difficult to discuss their sexual problems with their family members but they told them about their treatments (48). Women felt uncomfortable on being questioned about their fertility status and inability to conceive during family gatherings and public places. Strangers even showed their concern and this made the childless couples angry and frustrated (43). These emotional disturbances sometimes affected their marital life. In some cases, the elders lectured about the importance of having a child. In fact, their sexual lives were also discussed. Findings from Nene et al.'s study from Pune pointed out that childless people felt emotionally harassed during auspicious gatherings(48). These auspicious occasions may include children's birth, naming ceremony, birthdays and celebration of first pregnancies (20,48). Unisa in her study from Andhra Pradesh pointed out that childless women are not allowed to bless newly weds during their marriage as they fear that it will make the newly weds also childless (20). The women are avoided from important ceremonies, as they are considered as bad luck or inauspicious (49). The anticipated fear of questions and comments encouraged the childless women to embrace social isolation (20).

Mehta and Kapadia pointed out that some treatment providers are also under the gender ideology constructed by the society and started treating the women, even without checking the husband (42). Childless women are considered to be different. They are stigmatised and called names referring to them as infertile (42,43,45,48). Dhar concluded that the couples are stigmatised based on the perceptions of the society on childlessness (45)

Childless women are also excluded from social circle of women with young children as they discuss about women without children (43). Findings from Riessman's study in Kerala showed that it is difficult to escape from the judgements of the neighbours, as fertility of childbearing women is visible to all living around her (43). They are considered worthless (42)and cursed when they have been childless for a long time. Because of this, negative comments are made about them during fights (49). Most of the time, the women suffered in silence (48). They received very little social support (20). The need for conception is not just a biological need, but a social one also. Women have limited autonomy regarding decision making in social, cultural and political context (49). These social and economic disadvantages made them more vulnerable. The women fear infertility as they lose their power and status, leading to low self-esteem (20). According to Widge, women from lower socioeconomic class suffered more socially (9). Riessman found from her study in Kerala that education and occupation can helps childless women to defend both social and self-stigma (43).

Personal consequences

Childlessness has negative impact on physical and psychological health of women. This in turn reflected on their marital life (9). Sometimes the husband and his family blame the women and it is seen that the extended family utilize the situation of childlessness (9,45). At least few of them feared of breakage in their marital bonds and felt threatened of remarriage (50). The social and familial pressure pushes them to lead a life full of guilt, regret, embarrassment and frustration (48). They reported a 'feeling of loss' in a study conducted by Mehta and Kapadia in Vadodara (42). Out of the fear of being confronted with questions in the society, they imposed isolation over themselves from attending social gatherings (20,42). The social and cultural obligation build around motherhood pushes the childless women into a tragic life, and they are made to believe that it was due to their personal failure. When the expectations go in vain, they limit themselves from friends and relatives, feel insecured, angry, guilty, depressed, lonely and some even engage in smoking and alcohol (9,51).

2.3 Health seeking behaviour

The childlessness is perceived to be a women's problem, so it is the women who initiate and continue the treatment (42). But in some circumstances, the men also cooperate with the treatments. In the study done in Andhra Pradesh and Uttar Pradesh, they found a preference for allopathic treatment from private hospitals (20,52). According to DLHS 3, 82% of childless women in India took treatment and in that 65% preferred allopathic treatment (24). Even though the first preference for many is Allopathic; Ayurveda, Homoeopathy, traditional and religious treatments are also popular (20,53). Findings from a study in a tribal group showed higher dependence on traditional healers, as they were unaware of medical treatments and technologies (54). According to the study conducted by Unisa in Andhra Pradesh, the childless women and couples took treatment from different providers for a long time (20). The treatments costs were high and required repeated visits, which made them leave the treatments even when they wanted to continue. The treatment costs included consultation, medicine, investigation and intervention costs. Some of them could not afford to pay these costs and take treatments from private care providers (20,55). This exposed them to inappropriate and ineffective treatments, which gave them wrong hopes. Some of them didn't know where to seek treatment, as there are no infertility treatment providers in rural setting. In some cases the elders were against taking treatments (20).

Childless women started taking treatments when they grew impatient over their inability or due to social pressure (9,20). Few of them had the 'wait and watch' attitude due to their reluctance to take treatments and fear of being diagnosed infertile. Treatment seeking varied from few months to 25 years. The strong desire to have their own biological child made them take treatment for so long. They never lost hope in spite of treatment failures.

The treatment seeking was higher in urban areas among people with higher income while it was lower in rural areas and among tribals (21,54,56). The reason behind this was that treatment facilities are higher in urban areas (55). Educational status of the couples and socio economic status also influenced their health seeking behaviour (21,52). Couples from higher socio economic status took IVF treatments with great hopes to have a biological child (9). These treatments can result in emotional and bodily distress, financial insecurity, social and geographical relocation and disruption of daily activities. In spite of these adversities, they try repeatedly in order to negotiate a position in family and society (9). It is the women who goes through the pain, but the decision to leave the treatments were taken by the husbands and in-laws (23,42).

Many women sought help from religious places and persons out of strong beliefs and low costs (20,42). They wore charms, participated in religious rites and rituals, visited temples and astrologers (49). Some of them took religious practices and allopathic treatments simultaneously or consequently (51). A strong desire and hope for conception is seen behind this ardent health seeking behaviour.

2.4 Available treatment services

Infertility treatment is not part of any public health program in India. Only limited infertility services are provided through public sector hospitals and that too at tertiary levels like medical colleges. It is difficult for people living in villages and rural areas to access these available services. The diagnostic works and facilities delivered are not sufficient and standardized (52). The primary health centres and community health centres do not have the infrastructure to provide even the basic infertility services. Most of the doctors who participated in a study by Widge and Cleland informed that 20-30% of infertility can be prevented but the there is no focus on preventive measures (55). The government hospitals are unhygienic, overcrowded, under staffed, lacks confidentiality, medicines, tests and have unfriendly staffs. Untrained staffs with little resources and limited decision-making power manage them. Moreover, the public doctors practice privately to increase their income and

sometimes they send off their patients to private clinic. So the consultation hours available in the government hospitals will be less.

The available treatment is not effective as there is a lack of coordination between gynaecologists, infertility specialists, surgeons and lab technicians (47). There does not exist fixed days for infertility treatments and the care providers are not specifically trained in providing it. Not only that, there is no proper referral system, and information is not passed on to patients properly. The public sector doctors complain that there is no protocol, enough salary and medical education curriculum does not provide necessary knowledge and skills in infertility management and counselling. The gynaecology departments in public sector hospitals are not sufficient to deal with the number of infertility cases and it is a low priority to the government, making it difficult to get the budgets. According to the private doctors, the corruption in the public system, lack of comprehensive approach by the doctors, scarcity of other staffs and lack of coordination among them makes it difficult in imparting appropriate treatment

The Indian government promoted the private sector in health to reduce the burden on state but now the private sector dominates the health market with no standards and regulations over price and quality (57,58). The people are compelled to seek treatment from private care providers, as they only provide the necessary infertility treatment. Exploitation is high in this sector as there is no price regulation and even the quality of care is not assuring. People from lower socio economic class struggle, as it is not affordable for them (21,55).

ART in India

Last twenty years have seen sprouting of infertility clinics providing ART through out the country. The growth is denoted by the increase in members of Indian Society For Assisted Reproduction. Due to the absence of a national registry, the exact number of infertility clinics or ART babies is not known (23). The services offered by the clinics are of varying quality and are provided at varying prices, making it affordable only for the upper middle class and high class (55). ART is not provided under the public sector or there are no clinics providing advanced treatments at a subsidised price. All ART services are run under private sector and it is market driven making it accessible only to the people from higher socio economic status. The clinics advertise themselves as to help infertile couples, but actually they are benefitted out of it. ART is being suggested for all forms of infertility. The childless couples consider it as a blessing and take treatment with hope to have a biological child. There is an increase in number of such couples approaching ART clinics and they consider it as a great scientific

accomplishment. Some of them are conservative and they are reluctant to use donor sperms and eggs, as lineage is strongly desired while others use unknown donor sperm. To some women it is unacceptable to use a donor sperm while others fear that there husband may not agree (50).

All the infertility clinics are located in the cities, making it difficult for the people from rural areas and the cost of transportation to reach these clinics increases the overall expenditure further (52). Most of the clinics don't take an informed consent and even if they do, it is for namesake. They have no regulation for use of donor eggs and sperms. Lack of regulation, standardization and protocol gives way to exploitation. The cost of the procedures and drugs given vary from clinic to clinic across the country. The couples are not aware about the procedures, the cost, the duration of the treatments and they are not informed about it. Women understand the suffering only when they go through it (42). They are not even aware of the possible side effects like ovarian hyper stimulation syndrome and ectopic pregnancies and do not receive counselling in most of the cases. Multiple births through IVF can put the mother at high risk but it is projected as an achievement (23). Doctors advertise themselves with twins in hand. All these physical and psychological suffering, side effects and complications of the treatment make it worse for the childless women. Even then some of them desperately repeat IVF and the clinicians never discourage them, as there only concern is profit.

The ethical and moral issues arising out of ART remain unexplained and this can lead on to misuse of this treatment. It is feared that IVF may intensify sex selective abortions as some doctors give the couples choice of selection (9). There is also concern about efficiency and safety of the treatments provided. The ART Bill was drafted By Indian council of Medical research to regulate the ART industry but it is still not passed by the government, keeping the infertility treatment services in darkness.

Marketing of hopes

IVF clinics draw in childless couples using marketing strategies by exaggerating their success rates through advertisements on channels, Internet, through websites, hoardings, conducting camps and by offering packages and concessions. They create the demand by exaggerating the infertility numbers and highlighting the desperation and suffering of childless couples. Sarojini et al. in her study concludes that IVF is a commercialized and professionalised reproduction where women's reproductive elements are tested, stimulated, transferred, frozen, bought and sold (23).

2.5 Coping with childlessness

The childless women found refuge in religious practices like praying and visiting temples (9). In a study by Dhar, the participants took fasts and performed rituals in temples to pardon them of their sins and bless them with a child. In Hinduism, it is believed that a person become childless due to the sins committed in previous births. So they prayed to pardon them of their sins (45).

Some of them built their family by fostering relative's children while others got involved with social organisations. Few others tried to think positively about their childlessness. Out of their concern about lineage childless couples tried to adopt a child within the family and it is mostly their brother's or sister's. These adoptions are informal with no legal bindings (9,20). Adoption of an unknown child is the last choice because of the preference for a biological child (18,20,50). The majority of participants in Mulgaonkar's study said that they were not interested in adoption (51). Women who are against adoption either wants to prove their fertility or thinks that an adopted child will not love and care for them like their biological child (20). A study from Vadodara showed that women are willing to adopt from outside the family but men only wanted to adopt someone within their family and they spend time with children from their family (42). In a joint family, it is difficult to take a decision about adoption (9). A study done by Riessman in Kerala found that married women who cannot bear children construct gender identities around other principles. These women wanted to be known positively, not as victims of infertility. They adorn these identities in the present to transcended stigma and victimization. The resistance strategies the women adopted are speaking up for themselves, averting the blame from them through positive thinking, purposive avoidance and rejecting motherhood (43).

2.6 Project rationale

Majority of the available studies on life experiences and health seeking behaviour of childless women are from North India. Other than Unisa et al.'s study from Andhra Pradesh and Riessman's study from Kerala (1994-1995), there are no other qualitative studies from South India. Riesman mainly focussed on the resistance practices of childless women in Kerala against stigma (43). There is lack of studies regarding the reliable measures of childlessness and health care demands of childless women from Kerala.

The only data available regarding the prevalence of infertility is from DLHS 3 (2007-2008). According to DLHS 3, 11% of women in Kerala have infertility and in that 8.7% of them suffer from primary infertility. In simple terms, one in every ten, ever-married women suffered from infertility problems in almost all the districts in Kerala. 83% of them have difficulty in conceiving for the first time. The survey showed that women from poor families and with low literacy have difficult in conceiving. 86.7% of these women have taken treatment (24). There is lack of knowledge about the treatment pathway, which these women have taken. This study seeks to explore their treatment pathways and experiences on this pathway. Research is also sparse on available treatment options for childlessness and this study aims to understand the available treatment options. Kerala is praised for its high literacy rate and status of women. It is interesting to understand how these women perceive this condition and the study seeks to understand their perceptions regarding childlessness.

Benefits of the study

This knowledge can help to notify concerned authorities on:

- The intensity of sufferings undergone by childless women.
- Need for a treatment protocol.
- Need for incorporating infertility treatment and counselling into public health system from PHC level.
- To monitor and implement regulations on private hospitals and infertility clinics.
- Conducting researches to evaluate the efficiency of alternative medical systems in the treatment of infertility.
- Need for allotting more funds to women welfare projects under 'Seethalayam'.

2.7 Objectives of the study

Research objective

The study aims to explore the treatment pathways sought by the childless women and their perceptions on the treatments and childless life in Kerala.

Specific objectives

- To explore the treatment pathways sought by the childless women
- To identify the treatment options available for infertility
- To understand women's experiences with the treatments
- To understand the childless women's perceptions regarding their life

3 Methodology

In this chapter, the research method used for implementing this study, study site, data collection techniques, theoretical framework, analysis, quality and ethical considerations will be discussed.

3.1 Research design

Qualitative methodology is employed in this study, considering its exploratory design. They provide a rich description of a multifaceted phenomenon. Looking at the life of childless women through a qualitative lens helps to bring out the real lived experiences of these women and their perceptions. Through this method, one can find out how childless women define their condition, when they make decision to seek treatment and what happens along their treatment pathway and how they perceive their life in the sociocultural context (59). Under the umbrella of qualitative method, a phenomenological approach was taken to get a broad picture of their real life. This gives people an opportunity to speak their mind rather than confining it to pre decided categories. Use of a flexible and open-ended approach helps to adapt to the setting and bring out a rich and explanatory data.

In-depth interviews, key informants interview, opportunistic observations and informal talks have been used to gather data. Opportunistic observations and informal talks helped to get a background understanding of the treatment services and people's general perceptions towards the health care providers. There is no much information about infertility treatments in Kerala other than newspapers articles and advertisements by the hospitals. Key informant interviews were helpful in understanding the treatments that are available specifically for infertility in Allopathic, Ayurveda and Homoeopathy. In-depth interviews with the childless women gave a detailed insight into their life in a natural setting. Because of the following reasons, qualitative methodology was found to be appropriate for this study.

3.2 Study site and population

The study was done in Pathanamthitta district, Kerala from September 2016-November 2016. The land has a hilly terrain and reserve forests. This made data collection a bit challenging at times. According to 2011 population census, total fertility rate in Pathanamthitta was 1.2, lowest in India itself. It has a high literacy rate among women at 96.55% and average age of marriage for girls is 23.2, which is also higher compared to other districts (60). This study

site was ideal considering the objectives of the study. No only that there is a variation in the population as people of different social and religious classes live together in harmony here.

The original plan was to recruit the women from a private infertility clinic, private medical college,



Figure 3 Political Map of Pathanamthitta

Homoeopathy dispensaries and Ayurveda dispensaries and from the community. The infertility hospital did not want to get involved with the study. The private medical college didn't receive much infertility cases on a regular basis. In spite of waiting for a week, the researcher could not get a single case that fitted the requirement criteria. The gynaecologist in the Ayurveda dispensary did not have any contact information of the patients and she also did not get patients regularly. The Homoeopathy dispensary under the government sector ran infertility clinic twice a week and the district medical officer was welcoming. This gave me an opportunity to observe the functioning in a clinic run by the government and be around childless women seeking treatment. Five participants were recruited from there. As there was a limited time frame for the fieldwork, the rest of the participants were recruited from the villages with the help of a local guide who was known to people in that area. With his help, it was much easier as he had very good contacts in the villages. This actually benefitted the explorative nature of the study as the participants belonged to different classes, religions and casts. They were from small towns and rural villages in Pathanamthitta. These women had a diverse background making the data varied.

3.3 Sample size and recruitment

Childless women of age group 25-49 years who were seeking treatment or those who had sought treatment before were included in the study. Recruiting the women from the community helped in finding the women who were not taking the treatment now. That was important in finding the reasons why the women stopped the treatment. These women were recruited through snow balling technique. Purposive sampling technique was used to identify participants of desired characteristics like different educational background, social class, religion and occupation. The focus was to get an in-depth understanding of a phenomenon

and was not concerned about representativeness of the sample. In this way, it helped in getting a productive sample. Totally twenty-four participants were included in the study. The number was fixed based on the supervisor's advice. Five women were recruited from the Homoeopathy dispensary and nineteen women were recruited from the community. The local guide visited the women and gave them a brief description of the study. Those who were willing to participate were included in the study. In the homoeopathy dispensary, the participants were recruited with the help of doctors working there.

Table 1 List of Participants

		Wife	Wife			Husband		
Pseudo Name	Religion	Age	Educational Qualification	Occupation	Age	Educational Qualification	Occupation	
Razia	Muslim	28	BA	Housewife	32	Religious Studies	Own Business	
Fathima	Muslim	31	MSc, BEd	Own Business	34	MSc, BEd	Teacher	
Rekha	Hindu	38	12 th grade / Higher Secondary	Housewife	42	10 th grade / Secondary	Driver	
Molly	Pentecost	38	10 th grade / Secondary	Housewife	40	8 th grade	Own Business	
Lekshmi	Hindu	49	12 th grade / Higher Secondary	Own Business	53	10 th grade / Secondary	Own Business	
Shobana	Hindu	48	12 th grade / Higher Secondary	Housewife	52	10 th grade / Secondary	Peon	
Nandini	Hindu	27	BSc Nursing	Housewife	30	10 th grade / Secondary	Labourer, Driver	
Pushpa	Hindu (Tribe)	39	10 th grade / Secondary	Cook	48	8 th grade	Rubber tapping	
Nirmala	Hindu	30	MSc Maths	Home Tuition	35	12 th grade / Higher Secondary	Auto Driver	
Jalaja	Hindu	42	12 th grade / Higher Secondary	Public Health Nurse	47	10 th grade / Secondary	Police Constable	
Ritha	Christian	43	PDC	Housewife	51	PDC	Own Business	

Surojam	Hindu	46	Degree (Not	ASHA	41	Degree (Not	Driver
			Completed)	worker		Completed)	
Revathy	Hindu	38	Degree	Housewife	44	Degree	Astrologer
Elsa	Christian	43		Housewife	48	12 th grade /	Navy
						Higher	(voluntary
						Secondary	retirement)
Parvathy	Hindu	40	BCom	Own	44	12 th grade /	Own
				Business		Higher	Business
						Secondary	
Subaida	Muslim	32	BEd	Clerk	42	Biomed	Own
						Engineer	Business
Kamala	Hindu	35	10 th grade /	Housewife	42	7th	Own
			Secondary				Business
Mary	Hindu	36	Degree	Medical	46	10 th grade /	Auto Driver
				Transcription		Secondary	
				ist			
Sreedevi	Hindu	38	12 th grade /	Housewife	48	10 th grade /	Auto Driver
			Higher			Secondary	
			Secondary				
Saranya	Christian	39	PDC	Nurse	40	PDC	Electrician
Tresa	Christian	30	10 th grade /	Housewife	40	9 th grade	Driver
			Secondary				
Mariama	Pentecost	40	PDC	Preschool	42	10 th grade /	Driver
				Teacher		Secondary	
Annie	Christian	32	BSc	Receptionist	37	10 th grade /	Driver
						Secondary	
Neena	Christian	30	General	Private	37	12 th grade /	Own
			Nursing	Tuition		Higher	Business
						Secondary	

The Key informants were an Allopathic doctor, Ayurveda doctor, Homoeopathy doctor and a psychologist who was counselling childless women at the homoeopathy dispensary and also had a prior experience in working at a private infertility clinic. The Allopathic and Ayurveda doctors were specialist in gynaecology and the homoeopathy doctor was dealing gynaecological cases for the past three years. All the key informants were also women. They were chosen, as the participants in the study mentioned their names and were satisfied with their treatments. These doctors and psychologist were contacted with the help of local supervisor and local contacts

Table 2 List of Key Informants

1	Female Allopathic Gynaecologist	Private Medical College		
2	Female Ayurveda Gynaecologist	Government Ayurveda Dispensary		
3	Female Homeopathy Doctor (dealing with infertility)	Homeopathy Dispensary (Seethalayam)		
4	Female Clinical Psychologist	Homeopathy Dispensary (Seethalayam)		

3.4 Data collection techniques

The data was collected through observations and informal conversations, semi-structured interviews with the participants and unstructured interviews with the key informants. All the conversations were in Malayalam, the local language shared by the participants and me. Triangulation of methods was done to enhance the credibility and confidence in the findings. Triangulation means use of different methods, different sources, different researchers or analysts and different theories to study and understand the same research topic. This helps to find evidences to strengthen the final conclusion (61). It provides different perspectives of the same issue, enable comparison of the differences and similarities, helps in finding out the missing pieces, discover unique information and brings about completeness to the data. Focus group discussions were not employed as advised by the local supervisor. Childlessness is a sensitive issue and the women might not be interested to have an open discussion.

3.4.1 Observations and informal conversations

First three weeks were devoted in making observations and having informal talks. I visited the community medicine experts in in a medical college and had a talk with them. They gave suggestions on how to approach the participants and were sceptical about the participant's cooperation. According to them, it was an arduous task to convince the people to sign the informed consent form and was also advised not to record the conversations. Other than the regular government surveys, the people in this part were new to being a part of a qualitative study and they saw studies with a suspicion. This gave an idea on what to expect on the field and to be prepared.

Some of these experts had their own experiences of being childless while others spoke generally about the topic. The gynaecology out patient department in the medical college and Homoeopathy dispensary were also visited prior to data collection. The observations there

gave a better understanding of a general scenario in the out patient departments, people's expressions, the confidentiality issues, how the treatment process worked and the relations between the care provider and patients. The observations made were noted down as descriptive notes in a field notebook. These hospital and clinic visits facilitated to come in contact with other health workers and to have informal conversations about the existing politics between different medical systems, the plight of childless women that was seen in their eyes and exploitation stories. They all gave oral consent to use their information in developing the background for the study. It gave a good introduction to the society in general with a focus on the issues of being childless in that society. The observations were also made in the participant's house to understand their interpersonal relationships. Sometimes their husbands and mother in-laws or mothers came up and told their stories.

3.4.2 Participant interviews

In-depth interviews were conducted with the participants, as it is the best technique to understand the views or opinions of the participants and to gain knowledge about the study topic. These interviews were semi structured, which made them flexible and gave the researcher opportunities for probing. First two interviews were a bit challenging but it got better with time. The interviews with fifteen participants were carried out in their home. This made them more comfortable. The interview started with greetings, and I introduced myself to the participant and her family members if they were at home. They asked questions about my whereabouts and I answered to all their queries. They also introduced themselves after that. Then I explained about the project and took the consent. These informal conversations in the beginning took away the anxiety and uneasiness in majority of the cases. Few of them felt at ease after a while. Majority of the participants opened up about their problems and some of them said that they spoke so openly about it for the first time. It made them happy that at least someone was concerned about their sufferings and some even showed their medical reports even without being asked. The interviews were carried out in a private room, which gave the women more confidence to speak up. In few cases, the husbands and the mother in laws dropped in once in a while to check. Malayalis have a great sense of hospitality and tea was offered in many cases and as a polite gesture, I drank the tea. Each interview lasted between thirty minutes to an hour. The remaining five participants who were recruited from the community were interviewed in their workplace as I did not want to interfere with their daily activities and the women also preferred the same. The five participants from the Homoeopathy dispensary were interviewed in a private room near the

consultation room. The interviews took place when they were waiting to see the doctor or when they were done with their consultation. These interviews gave a detailed insight into the perceptions, experiences and treatment choices made by these women. This helped in building up an in-depth knowledge on the topic under study. It was also the best option to study a sensitive topic like childlessness as it gave women the privacy to speak about their personal experiences and problems. All these interviews were conducted in *Malayalam*. The fieldwork was stopped when the data reached its saturation and also due to time limit.

3.4.3 Key informant interviews

They were all busy with their works and the psychologist took place in their consultation rooms. They were all busy with their works and the interview was conducted in between during their break time. The interviews were unstructured as nothing much was known about the available treatment options and the further questions were based on the responses picked up during the interview. It was more of like a conversation. It lasted between twenty to thirty minutes. The interview with the Allopathic doctor took place in her house during the lunchtime. These interviews helped to understand the existing treatment options, their professional opinions, health seeking behaviour and psychological status of the childless women. Even though a bit challenging, all these interviews were recorded as hand written notes and my prior experience with case taking in clinical practice helped with it. Towards the end of the fieldwork, I got a good understanding and answers to the research questions from these interviews and observations.

3.5 Data handling

3.5.1 Anonymizing and data storage

The names and personal information that can relate to the participants were replaced with a pseudonym. Pseudonyms give a more human touch to the descriptions. All the collected data and materials used for data collection were kept safely locked up in a safe along with the password-protected laptop used for the fieldwork. Only I could access all these data

3.5.2 Transcription

Descriptive notes were taken during direct observations and interviews in the clinics and in participant's homes. After each day's fieldwork, these notes were read to fill in any missing parts. All these were stored in a password-protected laptop. Transcription of the interviews was a priority, as the interviews were not recorded. It was done as a two-step process. First, the interviews were written word by word in Malayalam using pen and paper in a detailed manner. This was done either the same night or on the next day to prevent loss of any information. These transcribed interviews were organized in a chronological order based on the dates and kept away safely. The second step of transcription took place after returning back to Norway on completion of fieldwork. The detailed interviews were re-transcribed into English. The transcription was done meticulously in order to prevent loss of any valuable data and the emotions of the participants were also reflected.

3.6 Data analysis

3.6.1 Reflexivity

A researcher's background and position influences the topic chosen, course of investigations, interpretation of data, the findings that are elicited first and the way the conclusions are drawn out. Along with that there will be pre-conceptions from prior experiences and literatures read. So, it is practical to acknowledge the researchers influence rather than claiming neutrality. The best way to do that is to recognise the influence of the researcher at every single steps involved in the research process (62).

I had a few preconceptions about the childless women's understanding of their condition and marital status from the literature review done during the initial phase. So there was always a concern whether this would interfere with the subjectivity and the interpretation was done keeping this in mind. The study site was my hometown but I lived abroad throughout my life. The only contact with the town was the home visits during my vacations. I had a general idea about the people but not to a level that it can influence the research. The study sites were mostly the rural villages and I have never been to those areas before. In the eyes of the local people, I was a wealthy non-resident Indian. But they appreciated my simple dressing and ability to speak Malayalam, the local language fluently.

My deep interest in the topic, the common language and being a woman narrowed down the gap. Most of the women had a feeling that no one cared about childless women. They

complained that there were many childless women in their area but no one had ever come for a survey regarding this particular issue. This has a positive and a negative side. The positive facet was that they were happy that finally there was someone to hear their problems. The negativity is that they might have exaggerated their problems to draw in attention, which in turn might have affected the data. My medical background and my position as a doctor gave more confidence to the women. It is mainly because doctors are generally respected in the society. Moreover, the participants saw this as a great opportunity to clear their doubts and to show their medical reports and I tried to clarify their doubts and gave explanations in the best possible way. This might have served as an advantage, thereby encouraging the women to speak out without any inhibitions. At the same time, I clarified that this study was part of a master thesis program and that it was not part of any medical camp conducted by the local hospitals. But I doubt whether my position might have influenced at least a few of them to participate with the hope of getting any treatment benefits or other assistances in the future. This doubt was established when a participant contacted me later for job recommendation. That again raises the doubt whether these women participated for the sake of benefits, which might have had an influence on the data. Most of the participants claimed that they had a good marriage. It should be considered that I look like a happily married woman from the same society and that might have encouraged them to hide their marital issues.

Great care was taken in all the phases to see that my appearances, prior experiences in clinical practice and knowledge did not influence the research process to an extent that it adulterates the new knowledge generated.

3.6.2 Theoretical perspective

Phenomenological approach was used to give a theoretical perspective for this study. This study was carried out with a sole purpose of understanding the lived experiences, perceptions and treatment choices made by the childless women and phenomenological approach is best suited for this purpose. This method was developed by Husserl who believed that one can understand the material world only through consciousness and a knowledge can only be gained through experiences (63). According to Desjarlais, this approach is useful to reconstruct meaning to be a human, have pain and sufferings and then to recover and live among others. He defines it as the study of a phenomenon in a way it appeals to the consciousness of a person or a group of person (64). Even though different researchers associate it with different explanations, the prime focus is on understanding how people make

sense of an experience and what meaning they give to it. It is widely used in research in fields of sociology, psychology, education and health sciences (65).

Phenomenologists look into how the people put up a phenomenon they experience in a way that it makes sense of the world and thereby develop a worldview. According to them there exists a commonality in human experience and they focus on finding a meaning to it and that everyone understands it. This phenomenon mentioned may be an emotion, culture or relationships. Bracketing holds the prime position in phenomenology. It means that one has to set aside all his preconceptions and previous experiences with a phenomenon before entering into the field and one should do that with an open mind (66).

In this study, I wanted to understand the experiences, perceptions and treatment choices of childless women in the sociocultural background of Kerala and phenomenology was the best tool for understanding such a sensitive issue. So if one needs to understand this phenomenon, then the women who are living their life with it should be asked and it is only through their answers and life that this could be understood. From the phenomenological viewpoint, the women's body serves as the origin and various engagements related to the social, emotional and physical aspects are carried out from her body (64). Drawing out a result from a phenomenological perspective can be complex as it considers a phenomenon as a whole, therefore the results can be multiple and intense. On analysing the phenomenon of childlessness in this study, it has emerged as complex multi faceted phenomenon.

3.6.3 Steps of analysis

Transcription: Phenomenological analysis of the data begins with the transcription of the data. All-important findings on fields are also added while transcribing. Margin is left on the right side of the page to add the meanings that come up on repeated reading of the texts.

Bracketing- I tried to hold back my institutions as much as possible and looked at the interview of the woman without any conceptions. In simple words, to look at what the person had to say and not what I wanted to hear. Complete bracketing may not be possible and it has been discussed in the above paragraph. But efforts were taken to see the phenomenon through the women's words and life (67).

Repeated Reading-The transcribed texts were read again and again. The additional notes written along with it regarding the participant was also read. Thereby the emotions and the real life situations were not lost. This was very important in this study due to the absence of recordings. It helped in understanding the true meanings of the woman's expressions (67).

Coding-great effort was taken to read through the lines of every sentence and paragraph of the interview and identify the general codes. The texts were read repetitively to ensure that all the significant codes were identified. Once that was done, the research questions were read to find the relevant codes from the large number of general codes. All the interviews were analysed similarly and then the repetitive codes were picked up (67).

Categorising-The finalised codes were examined again and again to see whether it pointed to a common core and the ones with a common essence were clustered into a category(67).

Development of Theme -The identified categories were compared and clustered to identify main themes. At the end of analysis, three main themes evolved out of this study (67).

3.7 Trustworthiness of the study

Dependability

The concept of dependability states that the field experience of the researcher will be different from the prior expectations and secondly the findings should be traceable back to the expressions and meanings given by the participant. The objective of the study was to explore the treatment pathway and perceptions of childless women about their condition. First of all, an attempt was taken to describe every process involved in this study in a detailed manner, to ensure that similar results would emerge if the study were to be repeated in the same context. Ideally qualitative methodology was used with a phenomenological paradigm, which is suitable for the exploratory nature of the study. Purposive sampling was done for participant recruitment, ensuring a varied and productive sample. The in-depth interviews along with key informant interviews and observations assure the dependability of the study (68).

Confirmability

The main focus of confirmability is to ensure that the phenomenon is understood from the research participants' perspective and that it reflects the meanings given by the participants regarding their experiences. Its aim is to see that the goal of the research is met through the participant's perceptions and the study is carried out based on its purpose. It ensures that the interpretations of the researcher on the participant's perceptions are rooted in the meanings given by the participant. As mentioned before the usage of qualitative methodology and phenomenological approach justifies that the participant's meanings are brought out through the researcher's interpretation. Triangulation of the data through observation, key informant

interviews and in-depth interviews with the participants helped in reducing investigator bias. The existing weaknesses are failure to conduct focus group discussions and to audio record the interviews.(69).

Transferability

Transferability denotes applicability of the study in similar setting or context. There is a lack of thick descriptions on the background of the study site due to time limit but thick descriptions are provided about the life of the women. Participants with a diverse background were included from the community to enhance the richness of the data. The usage of the research design and approaches justified the purpose of the study thereby assuring transferability of this study in a similar context (70).

Credibility

It refers to the accuracy in the research regarding the data collection, analysis and interpretation. A connection should exist between the participant's expressions and the evolved codes and themes. The researcher's interpretations should be a reflection of the participant's expression. The appropriate sample and methodology were employed for the study. Probing was done throughout the interviews, whenever necessary. But the truthfulness of the participants cannot be assured fully. I did triangulation to cross check the information shared by the participants. The methods employed were in-depth participant interviews, observations and key informant interviews. The entire process of data collection and analysis was done methodically, keeping in mind the reflexivity. At different stages of analysis, the findings were discussed with the supervisor to refine the process. (71).

3.8 Limitations of the study

- The limited time frame restricted the chances to explore extensively about the available services within the public and private health systems.
- The interviews could not be recorded. This might have resulted in data loss and also the emotions of the participants might have been missed in the written data.

- The focus group discussions could not be conducted considering the sensitive nature
 of the subject and lack of interest among participants to meet at a common arena.
 Much vital and interesting information could have been collected through them.
- Most of the participants referred to their partners also during the interviews. It would haven been a richer data if the husbands were also included in the study.

3.9 Ethical considerations

Ethical approval

The research protocol was submitted to Regional Committee for Medicine and Health science Ethics (REK) in may 2016 for getting ethical clearance but they responded that the project did not fall under their consideration. Then it was send to Norwegian Social Science Data Service (NSD). NSD recommended adding the end date of the project in the informed consent form. The institutional review board of Pushpagiri Medical College Hospital approved the study to be carried out in Kerala. The protocol and ethical clearance documents were submitted to the district medical officer of Homoeopathy to recruit patients from the Homoeopathy dispensary in Pathanamthitta.

Informed consent, confidentiality and anonymity

A written informed consent was taken from all the participants after explaining about the details of the study and their doubts regarding the study was cleared before initiating the interview. All the participants were literate and they could read and give the consent. The pattern adopted for informed consent was based on the WHO informed consent format. The participants were informed that they could withdraw from the study, if they feel uncomfortable.

Childlessness is a sensitive issue and the participants found it comfortable to speak from their homes while others were comfortable to speak in the privacy of a room in their shop or in the clinic. So the interviews were conducted in settings convenient to the participants. The participants' identities are kept anonymous. They were assured anonymity during the study. Soon after the interview, their names were coded and they were assigned a pseudonym and the list containing the codes were kept in a safe by the researcher. Any other characteristic information that could trace back to them was deleted. All the data related to the study are stored in a password-protected laptop and the researcher only accesses this laptop. The field

notebook with the scratch notes and detailed texts is kept in the safe, and it is also password protected. All this data will be destructed after completion of the thesis.

4 Findings

The findings of this study are conversed in this chapter under three main headings. These are the main themes that evolved during analysis of the data. The first theme shows the treatments sought by childless women, the second theme helps to get a better understanding of the life of childless women and the third theme shows the coping mechanisms adopted by these women over the years to overcome their long struggle.

4.1 Treatment pathways

The participants in this study moved from one treatment provider to the other to find a cure for their childlessness. They mainly depended on Allopathic, ayurveda and homoeopathy doctors for their treatment. The factors influencing this shift are discussed later in detail. The pathways followed by the majority of the women are referred to as the 'general pathway' while the pathways taken by just one woman is referred to as the 'less common pathway'. These pathways can be understood better by taking a closer look at the narratives of the women who took these pathways.

4.1.1 General pathways

Pathways taken by more than two women were referred to as general pathways and four different general pathways were identified in this study. Majority of the women have taken one of these pathways. Some of the pathways are very long while others are comparatively shorter. While following these pathways they moved between Allopathic, ayurveda and homoeopathy systems of medicine. A preference for Allopathic system of medicine is seen among the participants while homoeopathy appears to be the last choice. The pathways are named as the Allopathic-Ayurveda-Allopathic-Ayurveda-homoeopathy pathway, Allopathic-Ayurveda-Allopathic-Ayurveda pathway and Allopathic Homoeopathy pathway.

Allopathic-Ayurveda-Allopathic-Ayurveda-Homoeopathy

This is the longest pathway and three women have taken this pathway. These women went to different Allopathic hospitals. When it didn't give them any results, they went to Ayurveda hospital. They took treatment there between six months to a year; then again went back to hospitals providing Allopathic treatment. As it was not working again, they went back to another Ayurveda hospital. Finally, they decided to try Homeopathy clinics. This pathway

can be better understand by taking a look at 38 year old Revathy's life. I met her at the Homoeopathy dispensary after her consultation. She looked very tired and stressed up.

She is married to an astrologer (*Jyotishan*) for past 12 years. Revathy was under pressure from her in-laws to get pregnant soon after her marriage because her brother-in law does not have a child. They tried for a year but she couldn't conceive. Because of the compulsions at home, they decided to see a doctor. An uncle of hers' who was working at the capital city told them about a good gynaecologist there. So, they decided to consult that doctor. The doctor did a few scans and other investigations for both of them. She told them that both of them are not having any problem and just gave her tablets to take for ten days and assured that both of them are not having any problem. They were happy to hear that and waited for a few years without treatment as the doctor told that they did not need any treatment. As years went by, everyone started suggesting doctors. One of their friends suggested a hospital with infertility treatment and told that the treatment there was very good. So even though it was far for them, they went there. The doctor did a scan and found some growth in her uterus. Then they did D&C and send it for biopsy. They told that it was okay but her prolactin was high and gave her medicines. They were not happy with the treatment and it was also very expensive there. Not only that it was too far for them. So they stopped going there after a couple of times. Money was also a problem. She was not working and her husband also does not earn much. They had to take care of his parents as well. They were all staying together in a rented house. Hoping that she would conceive naturally, they waited for a year. But then nothing happened, and they decided to try an ayurveda doctor in government ayurveda hospital in another town. They heard about that doctor from someone, who told them that he was a good doctor and was not expensive also. He gave her some ghee and powders to take but did not say anything in particular. She could only take treatment there for a month because they doctor was going to Gulf. She thought it was her bad luck because the doctor was so good to them and the price was also reasonable.

They were a bit disappointed then. At that time, there neighbour told them about a doctor from another district. They decided to see him. It was very far for them and the transportation it self costs a lot of money. Not only that, they could only see that doctor at night, around eight which made matters really difficult. His consultation was in his house. They had to wait for really long time, as there were a lot of patients to see him. Some times when it got really late, they had to rent a room and stay. His consultation was also expensive, so they had to spend quite a lot of money for each visit. In spite of all these hardships, the doctor never told

them anything, but gave her some tonics for six months. They did not find any point in continuing with his treatment, so stopped after that.

Then their friends suggested about a doctor in the nearby hospital. They told that many people conceived after taking his treatment. So they went there immediately as it was nearby. First he took a scan and gave her medicines for fifteen days. Then he told that he needed to do a tube test to see if there was any problem there and the result was normal. He then advised for a laparoscopy but the cost was too high for them. They asked the doctor, if they would get a definite result with that test and the doctor told them that he was neither sure about it. So they stopped going there after a few months treatment. She became emotional by saying all this. She started crying. They had spent all her husband's saving in paying for treatments, but no result and she did not even know her problem. People enquire about her problem and when she says that both of them are not having any problem, they make fun of her.

From someone they heard about an ayurveda centre, a little far from their home. They had to see that doctor every week because he gave them medicines only for five days. After that they ha to go and see him and repeat the medicines. The doctor prepares all his medicines freshly and those medicines are not available to buy from outside. He gave us powders, lehyams and tablets. It was very expensive. Each week they had to pay 3000 rupees for medicines and consultation. It was not just the medicines; she also had strict dietary restrictions. She could not take non-veg, spices and salt. They did that for six months. It landed them in a huge financial crisis. They did not have that much income. Finally her father took a loan and gave them for taking treatment. After six moths, they asked the doctor if there was any point in continuing. The doctor patted her on her shoulder and told her, " do not worry daughter. You will get pregnant with this medicines but you will have to give it some time." They continued the treatment for a year but no results. They had already paid one and a half lakh rupees by then, which was quite a huge amount for them. She and her husband cried a lot together then. They felt so helpless. They did not have any money in there hand. Every single penny they earned was spent on treatments with a hope. She could not take any treatment for seven months because of their financial problems. During then, they heard about 'Seethalayam' in Homoeopathy dispensary. They heard that treatment was free and many couples have conceived after taking that treatment. So they decided to go there as they have not tried homoeopathy yet and it was also very close to their home. She started the treatment there a week ago. All the tests were run and a detailed history was also taken. She still has a hope and prays sincerely to find a result with this one at least.

Allopathic-Ayurveda-Allopathic pathway

Women who followed this pathway first took treatment from hospitals providing Allopathic treatment in their town. When it failed, they moved on to Ayurveda. They try for that for six months to one year. After that they return back to try different Allopathic hospitals. Six participants in the study followed this pathway. This pathway can be explained by Razia's story.

Twenty eight year old Razia is a housewife. She has been married for the past six years to a businessman. She belongs to a wealthy family and lives with her husband and in-laws. I interviewed her in in their family home, so her curious mother in-law lingered around us for a while with some comments and questions. But then she got bored and left. That gave more voice for Razia to speak out her story. Till then it was just restricted to a yes or no or a smaller reply. She tried to get pregnant, six months after her marriage. She waited for one and a half years to see if she could become pregnant. Then he mother started compelling her to take treatment because her sister is also childless and is taking treatment for the past ten years. So she asked her husband to go to a nearby hospital with an infertility clinic. She heard from her neighbours and friends that a lot of childless couples take treatment from there and get children. They visited the doctor and he did some investigations and scan and told that there is nothing wrong with them. He gave her folic acid tablets and told her that she will get pregnant naturally. The clinic was very crowded that they had to stand for the whole day. Even though the hospital was near to their house, it took them almost a day to see the doctor and come back. They went there only twice because she felt that it was a waste of tome as the doctor was just prescribing folic acid tablets.

After that they went to a hospital in another district, suggested by their family friend. That hospital also had an infertility clinic. There also the doctor repeated all the scans and investigations and gave her on pills to regulate ovulation. This continued for six moths. After that they injected dye into her uterus and told her that she is having a block in one of her tube and that she needs to try IVF to get pregnant. It was a painful and very costly procedure. They took a lot of injections, that I felt there was no place left in my body to get a prick. The procedures were very painful but she went through it with a hope of getting a child. They waited eagerly but she did not get pregnant. She was very upset that in spite of going through all these pain and taking quite a lot of medicines, she could not get pregnant. She stopped that treatment after a year with the failure of IVF. Her friend was also facing a similar problem but she conceived after taking ayurveda treatment from a hospital in another city. So Razia

also went to that hospital with her husband. The doctor gave her kashyams, which was bitter and she had to follow a lot of food restrictions. She got tired of it and stopped after six months as she felt it was not helpful. The treatment was not expensive, but a long way to travel. It is a terrible experience to take medicines continuously for years. She was fed up of it, so her husband took her for a pilgrimage to a mosque of a saint in Tamil Nadu. After carrying out some prayers and rituals there, they came back and started treatment in a specialised infertility clinic near her sister's house. Her sister is also taking treatment from there. It is really far but they stay at their sister's house when they have an appointment. While waiting to see the doctor, all the patients sit together and talk about all the treatments and hardships they have undergone. There were patients from different parts of Kerala and it was always very crowded. Once they got appointment at night, around two o'clock. The doctor dozed off half way through the consultation. She is still on pills to regulate her ovulation and she is not very happy with it. But they are continuing treatment there. She feels she is fortunate than other patients there because patients come and wait for days together to see the doctor. Some of them will be lying on the floor. At least she can go and stay at her sister's place and she is happy about it. During her last visit, the doctor suggested IVF. They decided to give it a try once more because the doctor told them that some people can conceive only after repeated IVF trials. She is very scared about going through all that pain again, but she is not ready to give up hope. They have planned an IVF for her the coming month and she was very anxious about it, especially because her menses has become irregular over the past few months. I tried to answer all her queries and bid her goodbye after that.

Allopathic-Ayurveda pathway

Seven women who participated in the study took medical treatment from different hospitals and when they did not get any results, they moved to take Ayurveda treatment. This can be understood by looking into thirty eight year old Rekha's story. She met me in her parent's house in the village. She was a bit reserved to talk in the beginning, but became comfortable after a while and opened up about her problems and opinions. She got married at the age of twenty-four and it was a love marriage. Before her marriage she did a short term nursing course and worked as a nurse in Delhi but her family was not happy with her working away from home and after marriage her husband did not want her to work. Her husband is a bus driver and she is a housewife now. Her periods started becoming irregular when she was twenty but she never cared about it, as she didn't know that she had to see a doctor and no one told her. Four months after her marriage she missed her periods and her mother in law

asked her to go and check. She went and took the urine test from a nearby hospital but it was negative. She didn't get periods after that. She waited for few months and then went to a hospital in the nearby town with her husband. She was the one who took the initiative to start the treatment. Doctor told her that she has some cysts in her ovary and that she is having PCOD. She was given tablets to take but she felt tired after taking it. She took those medicines only for a year because her periods were not getting correct and she was gaining weight also. Besides she had to do all the household works but the tablets made her tired and she was unable to do her chores. So finally she stopped taking the tablets. After that she heard from her neighbours that there is a good gynaecologist in the private medical college in the district and she went there with her mother. She liked the doctor as she patiently listened to all her problems and gave her medicines to correct her cycles. She felt tired after taking that tablet also. During that time, her sister in law got pregnant. She felt really sad because both of them got married at the same time. Her husband and mother in law started caring for sister in law and she felt neglected. She had to do all the household work by herself and the pills made it difficult to work. So she stopped the pills as she felt that no one cared for her and no one bothered to take her to the hospital. She couldn't go there alone as it was too far for her to go alone. She took treatment from there only for six months. Her husband also did not show any interest in going to the hospitals as he felt it was not important to have a child. Moreover he was worried that the doctor may ask him to skip alcohol and smoking and to take treatments.

Then they went to the big infertility hospital in the town as everyone spoke about it. The hospital was always crowded and they had to wait for long hours to see the doctor. The doctors did a lot of tests to find her problem. She had to undergo D& C but they could not find anything wrong, so after a few months the doctor asked her to do a laparoscopy but that also turned out to be useless. Another doctor in the same hospital told her that there was no use of doing D & C. After a few months, the doctor suggested IUI, but her husband didn't agree for that, as he doubts that they might be using someone's sperm. Her husband could not take her as he was a daily wageworker in a bus and he was also not interested to sit and wait for long hours in the hospital. So her mother accompanied her over the following visits. The treatment was very expensive. Every time when she went there for an appointment, she was asked to take injections costing around 1300 rupees. They could not afford this. Once they told the main doctor, who is also the owner of the hospital that they could not afford to take those injections any longer and the doctor's reply shocked both of them. He said that "if u want to catch a fish, then u have to put in the bait many times and this is just like that. They

were deeply hurt by his heartless and cold statement. They never went back after that. She took treatment from there for almost six months.

After that she did not take treatment for many years. She did not have the money and her husband did not want to spend his earnings on it. Few years back she moved to the town with her husband and nephew for his education. Her new neighbors in the town told her about a doctor in a hospital in the town treating infertility cases. She went there alone, as her husband was not interested. The doctor asked her to reduce weight and told her that her hormonal levels were imbalanced. She found it difficult to take the medicines which he gave as it caused stomach burns. She already had discomfort in her stomach by taking the medicines before but she continued that treatment for five months. She was not happy with the hospital setting and did not want to go back after that. Two years back, her husband's friend told them about a 'vaidyan' or Ayurveda practitioner from another village, treating childless couples. Her husband took her there and she was given 'kashayams' and 'lehyams'. Her stomach problems made it difficult to take the medicines but she took them for a year and her cycles became regular. The treatment was reasonable for them but she could not continue with that treatment for long, as her husband could not get leave to take her. She is happy with her life now but somewhere deep in her heart she still wishes to have her own child and is hoping for a miracle.

Allopathic-Homoeopathy pathway

Three women who followed this pathway consulted medical doctors in different hospitals to find a solution for their childlessness and when nothing worked, they went to take homeopathy treatment. Thirty six year old Saranya's story can provide insight into this pathway. I met her in the homeopathy dispensary during one of her routine clinical visits. Saranya has been married for the last fifteen years and worked as a medical transcriptionist before, but later due to family problems had to leave her job. She waited for one year after her marriage to get pregnant but she could not. There was a lot of compulsion from her mother in law. Because of the pressure, she went to a hospital in the town with her husband. They did tests for her and her husband and told her that she has immature follicles and that her husband has reduced count. Both of them were given medicines and she was given injections as well. She was advised IUI and she tried it three times. There was no result but they continued with medicines and injections for two years with hope of getting pregnant. After two years they had to stop all treatments because of their financial constraints and problems with her mother in law. They moved out of her in-law's house and rented out

another house. Few years passed by without any treatment and when they had some money in hand, they went to a hospital with infertility treatment in the town. The doctor did a tube test for her and told that she has a block in her left tube. He advised her to do IUI and she did it again, but with no success. She was put on medicines to stimulate follicular maturation and her husband was treated for low sperm count. They continued going there for six months but stopped after that because they were not getting any results. Both of them had to buy medicines and had to pay for repeated consultations. It was too expensive for them to handle. After that her relatives and friends told her about a laparoscopic surgeon whom they have seen on TV and told that he is good at treating infertility cases. So they went to see him, even though it was too far for them. The treatment was very expensive and the transportation cost made it even way too expensive. The doctor did a laparoscopy for her and advised to reduce weight. She was given medicines and her cycles became correct. After that he suggested IUI but that did not work again. With whatever money they had left in their hand, they continued with the treatment. But after five months they had to stop treatment, as they did not get any result and they ran out of money also. Because of that, they had to stop all treatments for a while. After few months she saw an advertisement in a newspaper about a medical camp conducted by an IVF clinic. She went there with her husband to see what was happening there. Their detailed history was taken and was given counselling. They were campaigning for IVF treatment provided at their hospital. The hospital was offering IVF packages to childless couples attending the camp at a lower price than other hospitals. The woman and her husband thought that this was a good opportunity for them, as they couldn't afford IVF otherwise. They immediately collected whatever they had in hand and started treatment at that hospital. Her husband was given medicines to improve his sperm count and she was put on hormone therapy. Once they started treatment here, she started reading materials related to IVF from Google to get better understanding of the procedures. She told that they created an artificial menstrual cycle for her and did an embryo transfer. Her eyes were in tears when she spoke about the procedures. It was too painful that she could not express it in words. She had many hormone injections and scans every alternate day. Ovum pick and embryo transfer was done under anaesthesia. She was admitted there for five days and was given injections. But the HCG test came negative and the couples sat and cried helplessly. It broke their heart and also their wallet. The doctor came and consoled them and said that he could do another trial for them at a much lower price. They still wanted to take one more chance but had no money in hand. So she sold all her gold and whatever they had left in their hand to pay for the next trial. But that trial also ended in vain and during that trial, she developed pain and itching at the injection site. The doctor had to discontinue all medicines and she was admitted in the hospital for a few days. She broke into tears when she told this. They felt lost and disappointed. She went through all these sufferings to get a baby but everything ended up in vain. She did not take treatment for a couple of months after this. That is when she saw an article about Seethalayam clinics run under the state homeopathic department. It was written that the treatments were free and that many couples got babies after taking treatment from there. So she decided to try that and moreover it was free. She started treatment there a month back. Her husband tries to accompany her whenever possible. He is a driver and if he does not go for work, then he won't get money for that day. Already they do not have any money and they cannot afford to do so. She is still continuing her new treatment with a ray of hope.



Figure 4 General pathways

4.1.2 Less common pathways

Some women took treatment pathways, which were different from the general pathways that evolved out from the study. They were categorised as less common pathway as each of the below mentioned pathways were taken only by a woman.

Allopathic-Siddha-Homoeopathy pathway

In this pathway, the woman took medical treatment from an Allopathic hospital and when that did not give any result, she went to a Siddha doctor. She was not happy with that treatment, so she moved on to take treatment from a homoeopathy hospital. Her name is Jalaja and she is a forty two year old housewife, who has been married for the past eleven years.

I visited her in her house, where she lived with her in-laws and husband. She worked as a junior public health nurse before, so she was excited to be a part of the study. She wanted to know the purpose of the study and to discuss on the medical issues underlying infertility. She is not working now, but trying to get a job nearby. She wanted to have a baby immediately after her marriage. But she had to live separately from her husband for few years as they worked in different towns. At that time she got severe pains during her periods. So she consulted a gynaecologist and took a scan. That is when they found that she had multiple fibroids in her uterus and cysts in her ovary. Doctor advised her to undergo surgery immediately. The surgery got complicated as she lost a lot of blood during the surgery. They couldn't control bleeding and her blood group was AB negative and it was difficult for them to find a donor. They scrapped out the fibroids and removed one ovary during the surgery. She was advised rest for six months and was also asked not to engage in sex during that time. After that she left the job and started living with her husband. She tried for a year to get pregnant but nothing happened. Then she started working in a hospital in a small town and the doctor was nice to her. The doctor did a scan for her and found a small fibroid but assured her that it was not at all a problem. She was also asked to bring her husband. Her husband came and took the tests. The doctor told that he had reduced sperm motility and he was given medicines for that. He was also advised to repeat the test after few months. He took the treatment only for six months as the doctor asked him to stop drinking alcohol. After that he didn't want to continue treatment there. She felt that it was more important for her husband to drink than to have a child. After a few years, she took the initiative again to go for treatments. One of her family friends told her to go and see a Siddha doctor in a village. She went there with her husband. Both of them were given 'kashayams' and tablets. They felt that the treatment was not effective for them, so stopped going for the treatment after six months. Again she did not take treatment for a few years as her husband was not showing much interest but she continued looking for advertisements in newspapers and magazines and found an advertisement about a doctor in another district. She contacted them to get further details and when she told her husband about this, he didn't show any interest in going. He felt ashamed to take treatment for his problem. Even though she wanted to go, it was difficult for her to travel alone that far. Then she saw a TV program done by an infertility specialist, who runs an infertility clinic in the nearby district. She found that TV show interesting as he spoke

about issues related to infertility, about his hospital and treatment provided there. She contacted the hospital but then she understood that it was not affordable for her and left it.

After a few years, her friend working in a homeopathic hospital asked her to come and see the doctor there. Her husband agreed and they both went there together. Both of them had to take medicines and there were also food restrictions. They took it for a while but after that had to stop because the hospital was far and her husband could not get leave to take her there. She felt that there was no point in going alone, as her husband also needed treatment. For past four years she has not gone for any treatments as neither of them is taking the initiative. The women still has the desire but she doesn't know how her husband feels. She is still living with the hope that she might get a child

Allopathic-Herbal Medicine pathway

In this pathway, the woman took treatment from different Allopathic hospitals and eventually she got tired of all the treatments and stopped taking it. During that time two men pretending to be herbal medicine practitioners were sent to her by the priest in her church. She trusted them as the priest had sent them and took their medicines for two months. Later she heard from the people in her church that those men were frauds and the villagers had driven them off.

Forty three year old Elsa had to go through this pathway. She has been married for eighteen years. She is a housewife and helps her husband in his rubber plantation. When I visited her, she was working in the plantation. She greeted me happily and introduced me to her in laws and husband. Then we moved to a room where she could talk privately. She was happy to share her experience with me. After their marriage, they had to live apart for a year as she was working as a clerk in Mumbai and he was working in Navy. They wanted to have a child only after two years. Later they shifted to Kerala and she waited for five years to get pregnant. Everyone started asking and they also realised that something was wrong. So they went to see an infertility specialist in a hospital in the town. He did some investigations and gave her medicines to take. She took that for six months, but stopped going there after that as she felt it was not effective.

At that time, they saw an advertisement about an infertility hospital that provide advanced infertility care in the neighbouring district. Her husband took her there even though it was far. If they go early in the morning, they could reach back only at night. Doctor did laparoscopy and other investigations and told that everything was normal. She was given metformin tablets to take. They had to go there twice or thrice in a month. After one visit, the doctor told

them that her husband has reduced sperm count and he was given medicines for that. Then the doctor advised them to do IUI and she underwent three IUIs every month. They became fed with the long travels, hours and hours of waiting and ineffective treatments. Not only that, it was very expensive. They had to sell her gold and had spent all their savings. They ran out of money after that and were frustrated as there was no result in spite of spending everything. Few months went without any treatment. Later her sister in law asked her to go and see the famous infertility specialist in the town. She went there with her husband. The doctor did some investigations and told her that there were irregularities in her ovulation and hormone levels and she had thyroid problem as well. She was given three expensive injections and a lot of medicines. They had spent rest of their money there. After a couple of visits, they both became emotionally hurt as they didn't have any money with them and there was no result from the treatment. Both of them decided together not to take any more treatments. Few years later, two men approached the priest in their church and told him that they prepare herbal medicines to cure infertility and that many couples had benefitted from their medicines. He trusted them and knowing her problem, introduced them to her and her husband. They still had the yearning for a baby, so they took the medicines and ghee and gave them the money they asked for. They never doubted anything and continued taking the medicines. After a few months, people in her church told that those men were frauds and villagers drove them away. She was deeply hurt and decided not to try anything else. The priest also felt sorry, as he was the one who introduced them. Even though she had not taken treatments for a while, somewhere deep in her heart she misses giving birth to her own child and she ended up the interview in tears and became very emotional.

Prayers

Thirty eight year old Molly has taken this pathway, as she is a Pentecost believer. According to her prayer was the best means to get a baby. She said that she has never taken any treatments and she doesn't like to take any medicines. Another participant introduced me to her. She has been married for eleven years and wanted to conceive immediately. They have been waiting since then but nothing happened. She prayed regularly and did fasting to get a baby. She was also under a lot of pressure from her in laws and her parents. Everyone started asking questions. But she continued with her prayers and fasting as she had a strong belief. Three years ago, her husband had a problem with his varicose veins and he went to see a doctor. The doctor told him that he had some hormonal imbalance as well. Out of compulsion from other family members, she also went to see a doctor. Doctor told that she is also having

hormonal problems and asked her to reduce weight. She did not take any medicines he gave but continued praying and fasting. Recently she found herself a remedy for losing weight. Now instead of drinking water, she started to drink green tea. She claimed that she has lost wait after doing it. Just a month back, her husband underwent a surgery for his varicose problem. She is sad that they don't have a baby yet but is still continuing with her prayers and fasting as she hope to get an answer one day.

Allopathic-Allopathic hospital in neighbouring state pathway

Thirty-year-old Neena was the only participant who went to another state in India to get treatment for infertility. Before that, she tried two Allopathic doctors in Kerala. I met her in her house and the house was crowded with small children who came to her for tuitions and she looked very happy around them. She was a bit reserved in giving answers and her husband was also around most of the time.

She got married six years ago. One month after their marriage, her husband went back to Gulf as he was working there and she returned back to her work place in another Indian state. She was working as a nurse there. Her cycles started becoming irregular after her marriage but she didn't take it seriously. After a year, they both came back to Kerala and started living together. They wanted a baby immediately and waited for a few months but she was unable to get pregnant. There were questions from neighbors also. During then, one of their neighbors got a baby after taking treatment from the famous infertility clinic in the district and they suggested them to go and see that doctor. So they went there after waiting for a few months. The doctor did a scan and ran some tests on her and told her that she was having PCOD and that she has to reduce weight. He started medicines for her. Her husband also took some tests and he also had a reduced sperm count and was given medicines to increase his count. After a few months, the doctor gave her a white powder to reduce her weight. She developed allergic reactions to that powder and had to take many medicines to get better. She developed acidity in her stomach after taking too many medicines, that she could no longer take any more medicines. Then they did IUI as suggested by the doctor, but no results. She grew really tired, that it became very difficult for her to work and it was also time for her husband to return back to Gulf. They did not take any treatment for almost four years. In between, two years ago, the priest in their church told them about an allopathic doctor in a neighbouring village and they went to see him. He checked all their test reports and gave her just two bottles of syrup. They were not convinced by his treatment and she did not take that medicine. They waited again. Her husband left his job in Gulf and started a small business in

their town. Her husband's friend told them to take treatment from the big hospital in the neighbouring state as many couples have got children after taking treatment from there. They started treatment there few months back and had almost eight consultations till now. A lot of tests and scans were done and the doctor said that only her husband has a reduced count and he was given medicines for it. They are very happy with the treatment and the doctor, as many couples have got children after taking treatment from her. Last time when they went for consultation, they stayed there for two months as it was too far for them to come and go. It was very expensive, as they had to rent a house and buy essential stuffs there. Along with that, the tests, medicines and consultations all cost a lot of money but they want a baby and they are spending for it. During their last consultation, the doctor advised them to do IVF and they are preparing to take IVF in the following month. She seemed to be very confident about her treatment and was eagerly looking forward for her IVF trial.

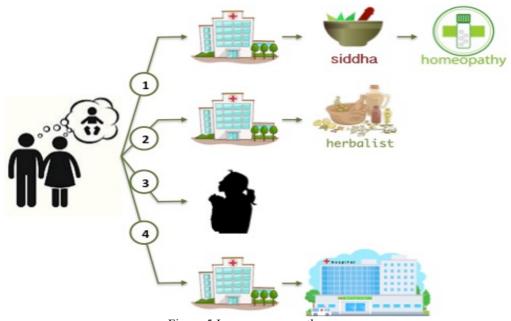


Figure 5 Less common pathways

4.1.3 Explanations for the shift

All these above mentioned pathways were the result of yearning of twenty-four childless women to be a mother. Over the past years, these women went from one hospital to other, shifted between different systems of medicines and paid all their life saving to realise their unquenchable desire. They started this journey when they realised that they had a problem or when the family members and neighbours questioned them. The durations of each treatment in this pathway varied from two months to three years. Most of the women enjoyed the

support and company of their husbands initially but as time passed by, the husbands lost interest and eventually the women had to stop her treatments. Affordability, accessibility, overcrowding, working hours, lack of trust in the care providers and the bodily repercussions caused by the treatments posed as a barrier to the treatment pathways. Along with that, the women or couple gets sad, frustrated and disappointed when they do not get any results from the treatment in spite of taking many medicines and going through painful procedures. Some of them decided to take a break when the doctor said that they do not have any problem and then they wait for some time to conceive naturally.

The above-mentioned barriers and emotional suffering either led the women from one provider to the other, made them take a break in between or else they had to completely stop their treatments. Each of these barriers will be discussed briefly in the following sections:

Every woman had her own reasons to move from one care provider to the other. Most of the women in this study haven't given up yet. They still have a hope and are in search for a new doctor or new system of medicine hoping that the new treatment could work some miracle on them. Only thing that they need is an assurance that the treatment will give them a baby.

4.1.4 Key informants viewpoints on childless couples and their treatments

All the key informants said that their patients were desperate when they came to them. They all wanted to get a result soon because they might have already gone through a lot before coming to them. So they were less receptive to what the doctors said. Some patients even showed their frustration towards the doctors when they asked them about their detailed history or when they were asked to repeats some tests. They would not continue a treatment for long. When they hear about a new treatment at some other place, they leave the treatment and go. The doctors reasoned that the desperation and frustration of childless couples with care providers led them from one hospital to other or from one system of medicine to other. The ayurveda doctor feels that even some of the educated couples did not know the right time to involve in sexual act. So some problems are very basic like this. According to the doctors, majority of the women presented with PCOS, pelvic inflammatory diseases, tubal defects and fibroids. Male infertility was also a common problem. The allopathic gynaecologist said that she only treated infertility cases with medications and IUI but other assisted reproductive services were made available in many of the infertility hospitals in Kerala. These services include IUI, ICSI and IVF. The homoeopathy doctor felt that the emotional distress also

caused childlessness. She added that most the patients came to them at a late stage. They might have taken all sorts of treatments and their body was very weak when they came to them. It was a big challenge to treat such cases but they had a good success rate with many cases. They only used medicines to treat and their treatment was based on the patient's detailed medical, personal and emotional history.

Conflicts between the allopathic system and the other systems of medicine.

The ayurveda doctor and the homoeopathy doctor mentioned about the conflicts between the practitioners of different systems of medicine. The Ayurveda doctor said that the Indian Medical Association and the allopathic doctors do not accept doctors of other systems of medicines as equal. She is an ayurveda gynaecologist and she was trained to conduct deliveries and even they she could not attend the deliveries of her cases. She was disappointed about it. The doctor claimed that she had successfully treated seventy-five infertility cases and added that her treatment techniques are not invasive like allopathic treatment.

The homoeopathy doctor also had a similar opinion. She said the doctors from the allopathic system of medicine hesitated to take scans for homoeopathy patients. Some of them were even ridiculed for taking homeopathy. She had to refer her successful cases to allopathic gynaecologist after three months. After that she has no control over her cases. There exists a lack of acceptance and respect towards doctors practicing alternative system from allopathic doctors. According to her, The Indian Medical Association dominates the health care sector and they do not accept other systems of medicine. During my observations, I found that some allopathic medical doctors whispered among themselves that childless patients were simply wasting money with ayurveda and homoeopathy systems of medicine.

4.1.5 Source of information in treatment seeking

There are no awareness programs or information centres at the primary health centre where they could get information on what to do regarding their inability. The health workers at these centres are not capable to advice and guide the women to make the right treatment choices regarding treatments. So the women choses their treatment providers based on the public opinion, by listening to advices of friends and relatives and through mass media advertisements. The zealous women wanting to conceive her own baby goes and tries every treatment that she hears is good or when someone known to her got a baby after taking treatment from that particular place.

Interpersonal relations

Relatives, friends, neighbours and people in their community provided the treatment information for the childless women. It was seen that the public opinion about a hospital, doctor or treatment form had a greater influence on these women. The popularity of the clinic attracted them. When they heard that the hospital has a good doctor, who provided infertility treatment, they tried to visit that hospital. The bigger the hospital with many patients coming in, then the name of the hospital gets praised in the community. It is this word that reaches the ears of these women or their friends and leads the childless women there. The word 'good' doctor, 'good' hospital or a 'good' treatment means a lot to these women. Then they think that they may also have a chance in these 'good' hands.

Few women received advices regarding treatments from their siblings and relatives. Two women got advise from the priest in their church regarding treatment providers. When the women saw a neighbour or a friend getting a child after taking treatment from a doctor, they also tried to get help from the same doctor. They felt more convinced in visiting those doctors. Four women went to treatment providers by looking at other patients' experiences. Thirty one year old Fathima is one among them.

She adds: My neighbour took treatment for a long time from a hospital in the town and then she got a baby. She advised me to take the treatment from there, as they didn't have any kind of problems with the treatments. So I also took treatment from there for a while.

Few women complained that there were no reliable people to help them and guide them in seeking treatment. So they followed the available information.

Role of mass media

Everyone tries to sell hope to desperate childless couples through advertisements in television, magazines and newspapers, health programs in television channels, infertility medical camp and flex boards along highways. I had observed many of these advertisements during my fieldwork. The advertisements highlight the significance of motherhood or depict that the life is miserable without a child. Popular celebrities endorse some of these advertisements. They tell the public that they can also have this luck or opportunity by visiting a particular hospital. There are many flex boards of different infertility hospitals on sides of the highways in Kerala. Everyone claimed to provide International standard treatment and displays percentages of their pregnancy achievements in childless couples. These commercials draw in childless women to there hospitals. Many of them followed these

advertisements on televisions, newspapers and magazines to find different treatment providers. One woman used the Internet to find out about a care provider while another one used Internet to understand about her treatment procedures. Doctors also conducted talk shows on televisions about infertility and gave viewers an opportunity to ring them up and discuss their problems. They also talked about the advanced treatments in this field and that these treatments were provided through their hospitals. Few participants were viewers of such programs and they had gone to see the doctors after seeing them on television.

Forty eight year old Sarojam first started her treatment after seeing a doctor's talk show on television.

Sarojam adds: I saw Dr...talk show on TV. He gave an interesting talk about the problems causing infertility and about the treatments to be taken for it. His hospital was also shown and it was a big hospital with a lot of facilities. He provided latest treatments for infertility at his hospital. So we decided to go there.

4.1.6 Challenges hindering the treatment pathways

All the study participants were forced to leave the treatments because of one or the other obstacles that came up on their treatment pathway. These hurdles were in the form of distance, treatment costs, their husband's working hours or lack of interest, treatment side effects and lack of confidence in care providers.

Accessibility

When they found a new hospital or a doctor for treatment, they did not care about the distance initially. They went to hospitals in far off places in Kerala. But it became difficult when they had to repeatedly go for treatments, probably once in every month or in some cases even more than that. They also had a higher chance to leave the treatment when they had to travel for a longer duration. Forty three year old Ritha took her treatment from an infertility specialist doctor in the neighbouring district. She adds:

He asked us to come frequently. It was very far for us, so it was getting difficult to visit the doctor frequently, so we stopped going there.

Many women complained that they became physically weak after taking the medications and undergoing procedures, which made travelling for long distances difficult. When the husband's could not accompany them due to their lack of interest or due to working hours, it became difficult for the women to travel alone to a distant hospital. Rekha was taking

treatment from an ayurveda practitioner from a village but the distance was a big problem for her. She adds:

It is difficult for us to travel to the vaidyan's clinic each time. My husband is a daily wageworker, so has to go for work. I cannot go alone till there; it is very far from here. So I stopped going as there was no one to take me.

Another issue is that when a care provider or treatment centre is far away, they may have to rent rooms to stay plus pay for food and transportation, which all adds up the cost. So as the distance increases, their overall expenditure for a day's treatment went high.

Thirty eight year old Sreedevi wanted to go and see an ayurveda doctor as her relative conceived after taking treatment from there. Somehow she managed to convince her husband to take her there but it was very far from their home. This is what she had to say about it:

It was very far from here. We had to go there every month. We had to see the doctor in his house and sometimes we had to wait till night. The doctor only gave the medicines. It was so expensive with the travel, food, accommodation and medicines. We couldn't continue long with that treatment

Affordability

Earlier, it was seen that the extra expenses incurred due to the distance was a big burden for the women and her husband. But it is not just the extra expenses; the cost of the treatment is also a hurdle for most of them. Majority of them complained that all the treatments were expensive and they did not get any benefit out of these treatments. Many of them had spent all their life savings on it. Once their money got over, they started selling of their possessions to pay for treatments. Three women sold their gold jewellery to pay for their treatment when they did not have cash in their hand. One of my participant told that an infertility hospital even had a small bank where they could pawn their jewellery. Thirty five year old Kamala and her husband were financially broke after taking treatment from two allopathic infertility hospitals and they had to sell their house. She adds:

We took treatment from there for more than a year. There was no result at all. We even sold our house to pay off the debts that we have incurred by going for these treatments.

Every single visit to the hospital was expensive. They had to pay the consultation fee, registration fee or renewal fee, lab investigations fee, Fee for scans or other investigation modalities, interventions and finally for medicines. The women said that they were subjected repeatedly for all the investigations and scans and it was same in every hospital. In many cases, both the husband and wife had to take the medicines. All these added up into a huge

amount, which turned out to be monetary burden for the childless women and her husband. Sarojam was taking treatment from an infertility hospital for three years and this is what she had to say: For each visit, we had to pay 3000, 5000 or 10000 rupees. Every visit they took ultrasound and a lot of investigations. Sometimes I had to take injections, which were also very expensive. These treatments are expensive, we do not have so much money but we need a baby. So we are giving them every thing that we have.

Two women said that they could not even think of going for treatments in the beginning as their husbands had the burden of their families on their shoulder. Thirty nine year old Pushpa is one among them and she adds:

We couldn't go for the appointments. We had lots of problem in our family. We didn't have enough money for all these. My husband's sister had a heart problem. She was only seventeen years. Doctor told that she needed a surgery immediately. So we stopped taking treatment.

Majority of the women came from middle class or lower middle class and it was never easy for them or their husband's to keep on paying for treatments and medicines. They always had this question in mind that how long are they going to keep on swallowing these pills and how long can they pay for it. It was a very costly affair and money was definitely a problem for these women. At some point they had to leave the treatment when they ran out of money with an unfulfilled wish. In majority of the cases, the husbands paid for the treatments. Two participants told that their husband's family made payments. But it turned out to be a big problem within the family later. Two women received help from there parents. In fact, a woman's father took loan from a bank to help her with payments.

Some of the husband's disagreed in paying up their savings for treatments. They did not show any interest in treatments nor they did not encourage their wives to take treatment. This is what Sreedevi told about her husband:

Some times when I tell my husband that we can try some treatment, he makes fun and say that with the amount he had spend for these treatments, he could have bought his own car.

Once the husband's are not ready to pay for their treatments, it is impossible for the women to go for treatments even if she wants to go, as many of them do not have an earning by themselves. Even if they have earnings, they cannot spend the money without the husband's consent. All the decisions were to be taken as a family. In nuclear families the husband and wife jointly made the decisions while in joint families the in laws always had an influential hand in decision-making.

IVF is a distant dream for many of the participants. Many of them left the hospitals when the doctor told them that IVF is the next option. Even though the hospitals advertise that they provide IVF at a lower cost, in real life that is not the reality. It costs between two-three lakhs rupees and varies between hospitals to hospital. And not only that, they might have already spend a lot before that. IVF always comes in as a last option. By that time, most of them were penniless. For Ritha, IVF was affordable but she and her husband knew that the results might not be certain, so they didn't want to take a chance at it. She adds:

They suggested IVF for us and asked us to come back for it. But we didn't go back at all. We know that it is very expensive and may not be successful also.

On the other hand two women from wealthy families were planning to take IVF while one woman was waiting for her second IVF trial.

So as far as the treatments are concerned, money is the biggest hindrance for majority of them. Most of the hospitals are privately owned and they charge a lot of money for each visit. They tried to pay with whatever they had in hand but with no definite results. Finally they were forced to discontinue their treatments unwillingly out of financial constraints.

Interference of working hours

So money was the determining factor for treatments and for that the women and their husbands had to work. Some of the women's husbands ran their own business while others were daily wageworkers. People running their own business could not stay away from their business for that long. It became a problem when they had to take treatments from hospitals that were far. When the husbands could not accompany; the wives also stopped going. Forty-year-old Parvathy's husband is a cable TV provider in a village. She adds:

My husband earns through his business as a cable TV provider. So he has to be here always. People will call him for something or the other. If he does not respond to them immediately, then that will affect his business. So we stopped the treatment, says Parvathy.

Many participants' husbands were daily wageworkers. If they miss a day's work, then they would not have any income for that day but on the other hand a lot of expenses for that day. So the husbands were reluctant to leave their jobs and accompany their wives for treatments. They could not afford to miss their livelihood. Twenty seven year old Nandini's husband works as a driver and loading labourer. She adds:

My husband came whenever possible. He is a driver and can't come always. He needs to work on all days to make money. So I tried to go with my mother if she is free. Otherwise I did not go.

It was equally difficult for the husbands working in Gulf and other small companies to take their wives for treatment. Four women's husbands were in Gulf and they could not take treatment during that time. The husbands who worked in small companies feared of losing their job if they take many leaves. So they tried not to take leaves. Three women left their jobs, as they could not get leave very often. Not only that, two of them became physically tired after taking the treatments.

It is not that common for women in Kerala to travel alone to some distant places. So the women stopped going, once their husband could not come. Not only that, nineteen women reported that their spouses suffered from either reduced count or had a reduced motility. So the women felt that there was no point in going to hospitals without their husbands.

Crowding

The women complained that the hospitals were crowded all the time. They said that they could only reach home by night, even if they left in the morning. There they met people from different parts of Kerala and even abroad.

So, when there is a huge crowd, the waiting time to see a doctor increases. One participant said that she got to see the doctor at two a.m. Most of them said that they had to stand for the whole day, as they could not get seats. Lack of facilities in the hospitals adds up their misery. Sarojam had to wait longer than anyone else when she was taking treatment from an infertility hospital. Sarojam adds: I waited for three days. I slept on the floor and used the common toilets (with tears in her eyes). I may or may not get a place to sit. Patients come from all around the world. There is such a huge crowd there always. If you want to see the doctor immediately, you will have to pay extra. The rich people come and go soon. There are rooms for renting there but I didn't have money for that, says Sarojam

There are many people like Sarojam, who came from far off places and waited for days together in the hospital corridor. In order to save the money, they do not rent a room. Instead of that they lie on the floor.

Lack of interest in Spouse

Even though the women had an undying quest for seeking treatments, it was not the same with their husbands. The husbands did not like to wait for long in the hospitals and some of them hesitated to go for treatments because of it. Three women believed that drinking and smoking was more important to their husbands. These men left the treatments, when the

doctor asked them to skip alcohol before taking medicines. They never went back again. Rekha repeatedly said about her husband's alcoholism. She adds:

My husband always had been a bit reluctant about going for treatments. I feel my husband does not think it is a must to have a child. Smoking and drinking is more important to him. He is worried that if he goes to the hospital, then the doctors might also ask him to take treatment and avoid alcohol and smoking.

Some husbands lost interest in treatment when the doctor diagnosed them with a reduced count or motility. They felt ashamed to seek treatment for it and even for giving semen for testing. They left the treatments half way through. Thirty-year-old Tresa is facing this situation. Doctor told that she is not having any problem and her husband is not cooperative with the treatments. She does not know what to do. She adds:

He wants to go and see the doctor alone. He was very hesitant to take the medicines they gave him. He told that he is feeling hot after taking it. He feels ashamed in giving semen for testing and he does not take me there with him. He always wants to go alone saying that only he is having the problem. Sometimes I compel him to take me with him but he may not listen. He took treatment only for six months. He told that going for treatment is a waste of money and stopped. He has some disturbing thoughts in his mind. It is even affecting our sexual life. I asked him many times to get counselling, but he would not listen.

As mentioned before, in majority of cases in this study, the childlessness in women was due to male infertility. So when the husband's were unwilling to take the treatments, the poor women were left to suffer in misery. There was nothing much they could do about it.

Previous experiences with the treatments

At least few of them had stopped taking treatments when there body could no longer tolerate the medications. To some, it appeared as stomach discomforts, making it difficult even to have food. They repeatedly complained about their stomach discomfort. They referred to it as a burning sensation or a feeling that their stomach is filled with gas. The stomach upset grew worse when they took more medicines Others felt that the medicines made their body weak, thereby making it difficult to carry out their daily household works. Two of them even left their jobs because of it.

Few of them faced serious side effects after procedures or interventions, which left them in fear and pain. Forty eight year old Lekshmi had to face an unfortunate experience during one of her treatments at an allopathic hospital. Lekshmi adds:

The doctor injected some dyes in my uterus. After that I developed severe infection and was hospitalized there for two weeks. It was very painful. I felt so tired and I was even scared that I might die. They gave me lots of antibiotics at that time. All I wanted was to go back to my house. I did not want to take treatment after that. Some women developed allergic reactions to the medicines they were given. Neena developed an allergic reaction to an allopathic medicine and this is what she had to say: After a few months the doctor gave some white powders to reduce weight. I developed allergy to that powder and had to take medicines for that then. I had to take many medicines and as a result of that I got acidity in my stomach. I could no longer take medicines. I also felt so tired; it was even difficult to do work.

Parvathy developed a lot of complications after her laparoscopy and she was frustrated that in spite of going through it, there was no use. She developed back pain and also has a feeling that her stomach is filled with gas. After that, she took homeopathic treatment and just after a week, developed urinary incontinence. This is what Parvathy has to say about her plight: I had many health problems. I couldn't even take medicines for a fever. I had problems with my stomach and was feeling unwell. We went to see a doctor nearby and she said that I was hyper stimulated and that my body is weak. She asked me not to take any unwanted medicines or hormones anymore. After that I never went for any treatments. Some participants were worried that the medicine's side effects destroyed their husband's health as their husbands developed diabetes and heart attack. Many of them also complained about weight gain after taking the medicines.

At least few of them spoke about the pain they had to go through while taking the treatments. Most of the diagnostic and therapeutic procedures were invasive and these inflicted a lot of pain on these women. They suffer the pain physically and also from their heart because of their helplessness. Many of them had to go through these painful procedures again and again. But most of the time, these procedures did not bring about desired results. Some of them said that they could not remember the number of pricks they have got. Razia was one of them and said that she was even scared to think about her second IVF trial as the painful memories from the first IVF trial kept on haunting her. She said that she felt as if there was not even a single place in her body without a prick. Razia adds: Last time during IVF, I had to take many injections, which was painful. I am scared of going through that pain again. I am bearing all this pain with a hope, says Razia.

Most of them stopped the treatment for a short time when their body suffered from side effects from the treatments while some of them stopped seeking treatment after that.

Lack of confidence in care providers

Most of the participants felt that they were being exploited of their distressed state. They said that the doctors and people running the hospitals and infertility treatment centres know that childless women will go to any extent to get a baby and they believed that the hospitals use their desperate situation to make money.

The general talk in the community was that infertility treatment centres were cheating people with donor sperm without the couple's knowledge. The public always looked at a baby born out of IVF with doubt. So, many of the participant's husband's were against IVF. They also see it with suspicion. The name IVF itself repels them. Rekha, who had taken treatment from the popular infertility specialty hospital in the district, is happy that she did not continue her treatment there for so long. This is what she had to say: We have heard many things about that hospital .One lady from our village worked there. She said that they give patients water instead of hormone injections. See what all they are doing to make money. Not only those, some people are also saying that you cannot trust the parenthood of children born there by IVF. It seems they are using someone's sperms to get the women pregnant.

Even when the wives wanted to take a chance with IVF, the husband's would not agree at all. It is very important for malayali men to have babies of their own flesh and blood. The women could not convince their husbands regarding this as the men strongly believed that the hospitals will use others sperms. It is an insult to the men in the society to bring up a baby born from someone else sperm. Sarojam was advised to take IVF, as her ICSI did not give any result. The doctor at the infertility hospital gave them an option. Sarojam adds: The hospital informed us that they could perform IVF to us at a lower price. Still I wanted to try but my husband didn't agree. He said it was unacceptable to him. We stopped treatment there. Because of the existing misconcepts, women who had taken or are planning to take IVF do not say it out. They are worried whether the people will criticise them and their baby once it is born. Saranya had to go through a lot of plight while taking IVF twice. I had to go to this hospital frequently and was also admitted there few times. My neighbours were curious and came and asked where we went. I told them that we are going to distant temples. Only my husband and me knew about the IVF treatment that we were taking. If we get a baby out of it, then these people will speak badly about it. They think that children born out of IVF are someone else's babies. They make fun of people going for IVF.

Some women leave the treatment when the doctor suggests that the next possible step is IVF because they also find it unacceptable. The problems are not just limited to the misconcepts

about IVF, but also about being cheated regarding treatments and medicines. Saranya had an experience of being cheated. She had to take many injections as part of her treatment and it became very difficult for her to travel all the way to the hospital to just get an injection. So she told the doctor that a nurse near her house could take the injections. He agreed to that but strongly recommended her to buy medicines only from the hospital. Saranya adds: *The doctor insisted that I should buy the medicines from the hospital. I agreed and bought it from there. When I checked the bottle, there was no MRP written on these bottles, so they can charge how much ever they want. See this is what is happening here.*

The doctors insisted their patients to buy medicines from their hospitals and they charge it the way they like. It is the same for ayurveda medicines. Many of them had to go and get the medicines directly from the ayurveda doctor and had to pay the prices they asked for.

Some of them said that the hospitals are doing like this because there is no one to look after their welfare or to get any justice for them. The women also felt that they doctors were taking unnecessary scans each and every time to take money. Nandini stopped going to a hospital when she got frustrated with the in numerous scans. Nandini adds: *Every time they did a scan. Altogether they did seven scans in four months. For each scan we had to pay. I think they are doing it simply to take money*.

Some women left the treatments when they felt that they were not being treated for their problem or when they were not convinced with the treatment. Revathy and Neena stopped going to heir doctors when they were just given syrups. Two of them were suspicious about a white powder, which their doctor gave for weight loss. Tresa was taking treatment from an infertility speciality hospital and the doctor told her that she had to reduce weight. She was surprised by the medicine he gave her. She adds: *I am surprised by the treatments they give*. The doctor gave a white powder in a packet to reduce weight. God knows what they are giving. How can a white powder reduce weight? Simply want to give something to trick people and get money. Some of them even stopped treatment when the doctor just gave them folic acid tablets on repeated visits.

Many of them did not trust their care providers. When they had to pay a lot of money without getting anything back in return, the women felt they were being cheated. In some cases, they felt that the doctors did not give proper treatments for their problem. There is always a need for the faster results. And when they do not get that anticipated result from a place, they move over to the next place.

4.1.7 Parallel religious pathway

It is interesting to note that a religious pathway runs parallel to the treatment pathway. Religion has a strong hold over the different communities and at the same time, every religion exists in harmony with each other. There is a common phrase used by malayalis, 'marunnum manthravum'. It means medicine and 'mantra' refers to a word or sounds repeated to aid in meditation or used in sacred rituals. They believe that both are needed to cure an ailment. Religious beliefs are deep rooted in the societies in Kerala. The participants in this study belonged to Hinduism, Christianity, Pentecost and Islam. Most of them stressed that 'God' determines their fate. So everyone tried to evoke the 'God's blessings through prayers and rituals.

Prayers and fasting

Daily prayers were part of their routine life. They prayed either to get result from their treatment or else to find a solution for their problems. Some of them were advised by their mothers and mother in laws to pray, while others did by their wish. There was a greater dependency on mercy of god. They feel that now only god can help them. Some of them stopped their treatments in between and prayed. No matter whichever religion they were following, everyone felt the same way. They felt that when the doctor's hands on earth cannot help them, and then only the God's hands can make a change.

The women continued with their prayers along with treatments. The prayers and belief in God gave them the confidence in their treatments and helped them to think positively.

But a few of them stopped praying when their treatment turned out to be fruitless. They felt miserable that they are left to suffer. This is what a disappointed Saranya had to say after her IVF trials failed: I prayed daily before but stopped praying after failure of my IVF trials. I lost all my hope and faith. I feel I am left out to suffer. She left her job and dedicated her life to get a baby and when it is still beyond her reach, she feels disturbed.

It is not just the prayers; some of them also indulge in fasting. A Hindu woman, Christian woman and Pentecost woman did fasting to get answer for their childlessness. Elsa, the Christian woman told that she and her husband attended fasting prayers conducted by a priest in a church for three years. They prayed to Mother Mary for her blessings. During the time of the fieldwork, an advertisement was seen in a major newspaper about a priest conducting prayers for childless couples. Molly, The Pentecost women did fasting frequently in her house, as she believed that it would help her in conceiving. Kamala, The Hindu women had

been following *Shashti Vrath* for past few years. Every month I take '*Shashti*' (fasting) as my friends told that it is good, says Kamala. She fasted every month and during that day she only took banana an at night milk. The *Shasti Vrath* is dedicated to Hindu God *Subramanya*, Son of *Shiva* and *Parvathy*. It is believed that observance of prayers and fasting to *Subramanya* with utmost dedication helps in getting a child. The sixth day after new moon is considered auspicious for doing this *vrath*.

The allopathic and ayurveda doctor also backed up the religious element in finding a solution for childlessness. The ayurveda doctor believed that spirituality was an important component of fertility. The allopathic doctor was a strong devotee of god and she considered herself to be guided by god. She advised the patients to pray well and even gave away prayer books in her consultation room. According to her, god can only help a childless woman in conceiving and doctors are a medium through which it can be implemented.

Visits to places of worship and offerings

All of them went to pray in nearby churches or temples. They all felt that praying and visiting gods was an important aspect to find results with their treatment. They gave or promised god some form of offerings when they visited these shrines. All the Hindu women who participated in this study said that they went to different near and far temples and prayed and gave some kind of offerings. Three of these women also went to pray in churches. The Christian women went to different churches and gave offerings. These women prayed and offered to take back the child to those places of worship, once their prayers are answered. Forty three year old Ritha went with her husband for a pilgrimage to *Velamkanni Church* and offered to shave off and give her baby's first hair there. Believers worship the 'lady of good health' in this church and it is one of the biggest Catholic pilgrimage Centre in India. It is situated in the neighbouring state of Tamilnadu. A deity of Mary holding her infant son is worshipped here. Devotes pray to cure them of their ailments because of their belief in miraculous healing powers of 'the lady' and many childless couples also come and pray. It is believed and said that many people have conceived after offering prayers there.

Nandini, the twenty seven year old Hindu is on her homoeopathy treatment. She had offered to do her baby's 'chooronu' in Malayalapuzha temple. Chooronu or Annaprashan is the ceremony of introducing first solid food or rice to a baby. It is during this ceremony that a baby is first taken to a temple. This ceremony is done between fifth and seventh month. Sarojam has reached on to homoeopathy treatment after trying different allopathic treatments from different hospitals. Now she has offered to give her child born to the temple as a

devotee, which she referred to as *adimakidathal*. It is a ceremony in a Shiva temple in *Kalanjoor*, where a baby born out of prayers and offerings is made to lie in front of god for a while as his devotee. After some time the parents take back the baby, considering him as a gift from Lord Shiva. She has already given other offerings in temples and churches. Most of the Hindu families in Kerala have a family deity and Nirmala said that she prays to her family deity along with her ayurveda treatment. Every woman in this study had visited places of worship during the time of treatment and even after stopping it. Three Muslim women participated in this study but they didn't mention about any kind of offerings made.

According to the ayurveda doctor, some of her patients did not have any reproductive health problems, but they could not conceive by any means. They were under a lot of stress because of the treatments and also due to their childlessness. So she asked them to make offerings in places where they liked or to give something to poor people because she believed that peace of mind is also important in conception. She claims that she had some cases, where they conceived after doing so.

Rituals

Only the Hindu women performed different rituals in temples. Three women among them said that they only pray at home and temples. They never performed any rituals or offerings particularly to resolve their childlessness. Different rituals are performed in temples to help childless couples to conceive. Some were as simple as a 'Sandanagopala Archana' done every month and others were sacred rituals like 'Noorum paalum vazhupadu' and Urulikamazhthal vazhupadu in mannarasala sree nagaraja temple. The last two rituals are elaborate and are performed only in the temples of Serpent gods. Hindu people of Kerala worshipped Serpent gods from ancient times and associated snakes with fertility. So when they failed to conceive, the women went to seek blessings of the serpent god. The manarassala temple is the oldest snake god temple in Kerala dedicated to Nagaraja, The Serpent God. The temple is situated at *Haripad* in nearby Alappuzha district. It headed by a priestess and is an exception as she performs all the major rituals. She is referred to as 'amma' or the mother. It is an important 'vazhupadu' for childless couples. In between her treatments, Rekha went with her husband to Manarassala temple. She adds: First we went to manarassala temple and did Urulikamazhthal and waited for almost a year. Since we didn't get a child after doing Urulikamazhthal, the 'amma 'or supreme priestess blessed and gave us blessed ghee and 'basmam' to consume. She has asked to take it for a year. We had to take the ghee before sunrise, says Rekha. People come from near and far to pray for getting

children, health and wealth. Out of the thirteen Hindu women in this study eight of them already performed *Urulikamazhthal vazhupadu in Manarassala* temple and Nandini who has been married for the past two and a half years has made an offering to do it as she told that they had to wait for three years after marriage to do the ritual. *Urulikamazhthal* or placing of a traditional bronze metal vessel '*uruli*' upside down in the front of the deity is the most popular offering made by childless Hindu couples and that is believed to help them in bearing a child. *Noorum Paalum vazhupadu* are also advised for childless couples. During this puja, prayers and mantras are recited and a combination of turmeric powder, rice powder and milk are offered to the serpent god.

'Sandana gopala archana' is a puja performed in temples to get a baby. The word *sandanam* means child. It is a regular offering and takes only about a few minutes to complete. Mostly the mantras are chanted in the name of the person offering the puja.

Pilgrimages

Few of them stopped the treatment for a while in between and went for pilgrimages to far off temples in Kerala and neighbouring states. When Razia got tired off her treatments and medicines, she went for a pilgrimage with her husband to a mosque of a saint In Tamilnadu. It is a famous mosque where childless people go and pray. We prayed and tied a cradle to a tree in the mosque to get a child: adds Razia. She started a new treatment after coming back. It is interesting to note that women belonging to Hinduism, Christianity and Islam practiced the same tradition of 'tying cradles on trees' in holy places. Ritha, the Christian woman went to *Velankani* church for a pilgrimage and tied a cradle there. Revathy, The Hindu woman also went to temples and tied wooden cradles. It is a common site in many temples in Kerala to see cradles hanging on to banyan tree. I also found a banyan tree in a Goddess Durga temple covered with plenty of cradles. It is a belief that tying cradles on trees after offering prayers to deities in holy places and shrines bless the childless women with a baby. In some places, wooden cradles are tied while some tie cradles with clothes. In between her treatments, Revathy went with her husband to pilgrimages to seek god's blessings. She adds: We did a puja in Thripayar temple last year. Two years before we went to Palani temple and climbed thousand steps. We had done that twice, says Revathy. Palani temple is situated on top of a hill, referred to as 'Palanimala' and it is dedicated to Lord Subramanian. It is in Tamilnadu, the neighbouring state of Kerala. One needs to climb thousand steps to reach the temple or can take a ropeway. But Revathy and her husband chose to climb the thousand steps to seek god's blessings and they did it twice. They also took strict 'vrath' before going i.e., they took

only vegetarian food and took bath and prayed daily. Kamala, the thirty-five year old Hindu woman was disheartened when none of her treatments worked out. She even had to sell her home for it. So she also went for pilgrimages with her husband to palani temple and velankanni Church.

This shows that the childless women travel to far off places not only looking for treatments, but also for seeking blessings from God to conceive. They travelled to holy places, which were frequently visited by childless couples as certain deities were prayed to get blessings for a child. Again hearing from other people's experiences of conceiving after prayers and offerings at a particular holy place encouraged the other childless women also to seek blessing from that particular place. There is also a strong feeling that god's blessings are required for a treatment to become effective. So, the treatment pathway runs in hand in hand with the religious pathway and both of them occur simultaneously.

4.2 Being childless

This chapter depicts the life of a childless woman in Kerala. Her feelings, pressures that she encounters from people around her regarding her situation, how she understands and explain her condition and the consequences that fall upon her, in her family and in the society because of her childlessness.

4.2.1 Feelings of childless women

The childless women's feeling varied from a sense of loss, sadness, depression, and regrets to insecurities. Most of the women expressed at least one of these feelings and sadness was the dominant one among them

Emotional sufferings

Few of the women mentioned that they felt a 'sense of loss', which left a void in their life. They all had a feeling that children bring happiness into life and they miss that happiness due to the absence of a child in their life. They felt their life was monotonous when compared to other people with children. It made them feel inferior, when they were around people with children as they lacked something, which others had. This made them sad to be around r people with children, especially the familiar ones. Others felt sad when they saw their friend's children or when someone talked about their children. They were hurt when they realized that they don't have one of their own and the bitter truth that they might not have

one. Sarojam's friends had got their daughters married off. She sometimes thinks that if she had one daughter, she could also have done all these for them. She adds: I feel sad when I see my friend's daughters coming back to visit them after their marriages and celebrate on various occasions together. I do not know whether I will get such an opportunity in my life. If I had one for myself, I could also have got them married, then to wait for their visits and we could have celebrated the festivals together. You know something, if I could have got married off at the right age, my daughter would have been of marriageable age now ...hmmm (sigh) Majority of the women said that they felt sad of being unable to conceive. Sadness is mostly aggravated by their loneliness. Women who stayed at home were affected more by loneliness. When they were alone, they sat and thought about their misfortunes and sufferings endured. These repeated thoughts made them more miserable.

Four women in this study mentioned of being depressed at times. Among them, Ritha took treatment for depression for a while. The other women who suffered from depression did not get any help. They just sat and cried. They felt low at times and then they could not do any work. Mental illness is also highly stigmatised and they did not want to be called a mad person. So rest of them were hesitant to get help for it, and they were of the opinion that they could not tolerate more treatments. Few of the participants said that they felt physically and emotionally broken down. The emotional hurt was brought about by the missing motherhood while the physical sufferings were endured on their quest to seek that missing motherhood.

All the three doctors and the psychologist said that the childless women who came to them were emotionally down. Some of them were desperate to find a solution while others sat and cried. They felt that this made the patients less receptive to their advices as they were disturbed most of the time.

Regrets and Insecurities

Two women said that they felt regretted at times, about their decision to stop certain treatments in between. They felt that they might have got a child if they continued with the treatments. Both of them stopped the treatment, as their husbands were not supportive. Forty eight year old Shobana was one among them. Fifteen years back, she took treatment from an infertility hospital in another district. After a consultation, her husband told her that there is no point in continuing with treatments as the doctor told that there child would be born with disabilities as both of them were diabetic. She was surprised and told him that the doctor never told her anything like that. He told her that the doctor told him in person when she went to another room to get undressed for her examinations. She adds: *It seems the doctor told that*

since we both are diabetic, the child born to us would have some abnormalities. I am a bit doubtful about that. That doctor didn't tell me anything like that. See... if a doctor is telling something like this, then he should tell to both husband and wife. I still think my husband lied to me. I regret listening to him and stopping that treatment. Somehow I should have continued. I have a feeling that if I had taken those medicines regularly and correctly, I might have got a child then.

Among the participants, four of them felt a bit insecure when they were around other people. They were anxious about what people spoke behind their back. Even though people never made any rude comments about them on their face, they were concerned whether people spoke something in their absence.

4.2.2 Pressurization faced

Every women who participated in this study encountered pressurization from their in-laws, parents or acquaintances regarding their treatments for childlessness at some point in their married life. Pressures came in the form of constant nagging, questions about their problems and on their treatments or why they were not on treatments. Many of them started treatment after they were questioned about their childlessness. The family and community expect a woman to conceive soon after marriage. People start asking the women questions a year after their marriage.

Pressures within the family

It is interesting to note that eight women said that they felt more pressure from their mothers. The mothers compelled their daughters to take treatment when they failed to conceive in a year after marriage. This usually happens when their sibling were also childless or else the mother had some difficulty in conceiving. Nandini's mother conceived her after taking treatment for many years. So when her daughter could not conceive in one and a half years, the mother got frightened and compelled her to seek treatment immediately. Nandini adds: I was born to my mother thirteen years after their marriage. I am their first child. They took many treatments. Finally she conceived after taking an Ayurveda treatment from a Vaidyan. When people started asking why I was not getting pregnant, my mother was very worried because of her difficulty in conceiving. She thinks I am also having a problem like her and asked to go to a hospital soon. She only suggested the doctor for me after asking to people around

Their mothers encouraged them to try different treatments and suggested doctors or hospitals for them. When they were lazy to seek treatment, the mothers took the initiative to put them back on treatments. An anxiety was seen in these mothers about their daughter's childlessness and this in turned out to be a pressure for their daughters.

The mother-in laws troubled a few of the participants. They never enquired whose problem was causing the childlessness; they straightaway thought that it was the daughter in law's fault. This resulted in fights and arguments in the house. Some of them even had to face verbal abuse and it was hurtful for these women to live with their in laws. Sarojam and her husband lived with her mother in law. It was not at all a pleasant experience for her. She adds: My mother in law used to hurt me a lot. She called me a matchi. Everyday she used to fight with me for something or the other. She died a few years back. I started living peacefully after her death. 'Matchi' is an abusive word used to call a childless woman. It means 'barren animal'. During my observations also, I noticed that some women referred to childless women as *matchi*. It means a barren animal and sometimes barren animals were also referred using the same name. Sarojam said that she went through all these pain and suffering to prove that she is not a *matchi*. Two women said that they were ridiculed and laughed at for being childless in their husband's home. Some of them had their husband's support and they moved out of their in-law's house. The mother in law's always pressurized the women even when it is not their problem. According to the psychologist and homoeopathy doctor, most of the women who came for treatments were under a lot of pressure from their in-laws and other family members.

Pressure from acquaintances

From my observations, I understood that it is a cultural norm to have a baby soon after the marriage especially in the rural part of Kerala and smaller towns, but professionally qualified women postpone for their convenience. Women does that for their convenience but others usually raised their brows at that decision. This concept is changing in the bigger cities and women have more flexible to delay their first pregnancy. Majority of the participants in the study felt that their acquaintances were inquisitive about their inability to bear a child. It was mainly the neighbours who taunted them the most with many questions. The first question that they faced is 'vishesham onnum ayille' from them, few months after their marriage. It is a commonly used phrase to enquire if they have any good news. This question was repeatedly asked whenever they saw the women and it continued for years. So the neighbours turned out to be a big headache for many of them. "Ningalil aarka prashnam, entha prashnam" They

wanted to know who among them is having the problem and to know what is the problem. This was the most commonly asked second question. This question came up once the couples started the treatments. They were curious about where the childless women went for treatment and what treatment they were taking. Jalaja tries to avoid these questions by hiding away from people. She adds: *The neighbours around my mothers' house ask a lot. They want to know who is having the problem. Just fearing their question, I don't go to my mother's house that often. Even when I am at home, I try to hide away from these people, says Jalaja.* Some of them feared to talk about their treatment to neighbours as they make negative comments about their treatments. Twenty seven year old Nandini is annoyed with her pestering neighbours. She adds:

My neighbors are a big headache. They always like to ask questions and hurt me. There is a lady near my house. She asked me what problem I am having and hurt me by asking so many questions. I was hurt so badly that I told her you don't have the right to tell such things, thinking that you have a daughter. Their life is not in our hands. No one knows what is going to happen in his or her life? Now I am taking homeopathic treatment. They also tell me negative comments about that treatment. They say that such treatments are not effective for infertility.

Other than the questions and comments, the participants did not report any other stigmatisation from their neighbours.

Marital harmony

It is to be noted that these women never felt any pressure from their husbands. Majority of the husbands were supportive in taking treatments and accompanied their wives for treatments. But half way through the treatment pathway, some of them lost interest in taking treatments. It was either due to the cost or out of frustration in going from one hospital to other. Some of them turned away treatment when it was diagnosed that it was their problem. The women said that their husband's were concerned about their health and they didn't want to see them get hurt. So the husband's discouraged them from taking treatments.

The husbands even moved out of their own home to protect their wives from their parent's wrath. They consoled the women and assured them that it was not a problem. But some women were a bit upset that their husbands were taking the issue too lightly.

Shobana and Jalaja said that they didn't share a close bond with their husbands, as their husbands are alcoholic and some times fights with them. But these fights were not regarding

their childlessness. Jalaja worries that he became an alcoholic because they do not have a child.

4.2.3 Women's explanation on childlessness

Interestingly, fourteen out of twenty four participants gave a medical explanation to their condition. They confidently spoke of it. Some of them could clearly describe their procedures also. They read from newspapers and magazines to know more about their health problem. Everyone tried to give some explanations. They either had an irregular ovulation, ovarian cyst or fibroids. Some of them said that it might be due to their husband's reduced count or motility.

Shobana thinks that diabetes has affected her reproductive organs. Her mother in law and sister in law enquired to a nurse and told her like that. I think it must be because of my diabetes. I have heard that diabetes affect different parts of our body. My mother in law and sister in law enquired to a nurse working at the health centre and told that diabetes will only affect women's reproductive capacity. Is it right? Will it only affect the women?

Forty three year old Sarojam was married when she was thirty years old and is angry with her parents for getting her married late and she had a different explanation for her problem. I think the main problem was that I got married late. Since I became old, I got all these health issues. My age might have affected my fertility. Sometimes I feel so angry towards parents. If they would have married me when I was 22, I would have a child now and it would be of marriageable age.

Some of them attributed their childlessness to god's will. When a woman was asked, what was causing the difficulty in conceiving, she said that it was her husband's reduced count. But along with that, she added that she would get a child only when God decides it. So many of them had a spiritual explanation with medical explanation. Three of them mentioned that they would get a child, if have the fate to be a mother, which they referred as 'vidhi'. According to them, their fate is already decided or written by God.

Rekha and Revathy consulted an astrologer when they could not conceive. It is a normal Hindu custom to visit a *jyotishan* or an astrologer before an auspicious occasion or when something goes wrong. They believe that the planets or *Grahangal* movements have an influence over their life. The astrologers make predictions based on the birth stars, birth timings of the couples and position of the stars and planets. They might also say what is causing the trouble. Among Hindus, it is a tradition to check the couples' stars before their marriage. They will get married if the astrologer says that their stars getting along well. This

is what Rekha had to say: Ours was a love marriage and so our parents didn't check. But when I failed to conceive, my parents went and checked with an astrologer. He told them there is 95% chance of not having a child in our marriage. Our stars were not matching ideally. The astrologer told Revathy that they have a Kudumba dosham and that is the reason for her childlessness. Dosham refers to something that is unfavourable or bad.

Some of them said that they still did not know their problem. They went to many care providers, but they were never given a clear answer regarding the reason behind their childlessness. Revathy sadly recollected that people made fun of her when she told them that she did not know her problem. She adds: *Every doctor says that both of us do not have any problem. So I don't know. People make fun of me when I tell like this to them. By hearing this, they laugh at me and say that if you are not having any problem whether your neighbours are having problems.*

4.2.4 Consequences faced due to childlessness

To be blamed and rejected

Every childless woman faced some sort of consequence in her life due to her inability to conceive. Seven women said that the in-laws or other people in their families blamed them for their childlessness. They were badly hurt when they were criticized. The wife is subjected to blame, even when it is the husband's problem. Nirmala had to go through a similar experience. She adds: Even though my husband had a low count, they always blame me for not having children. His family members never tried to understand that his problem could also cause this problem. Instead of that, they blindly decided that it is the woman's problem and started blaming me. His family wanted him to remarry a woman with a kid. They wanted to ensure that next time he is marrying a fertile woman. But my husband said that it would never happen.

When both the husband and wife has a problem, the husband's family tries to point out that the woman is the one with reproductive deficit. Shobana's husband's sister and mother also blamed her saying that diabetes will only affect a woman's reproductive capacity and that it will never affect a man.

Two of the participants said that they were rejected along with their husbands from the husband's home. Normally a woman resides in her husband's house with his parents. In their case, the parents no longer wanted them in the house. In both the cases, the in-laws paid for the treatments initially. But after a few years, they started showing their disagreement

towards wasting their money. Soon after that they were also asked to move out from the family home.

When people concludes that a woman cannot bear a child, then they neglect her. They face this abandonment in their homes and during functions. Three women experienced neglect in three different backgrounds. Rekha complained that her husband and mother in law neglected her, when her sister in law got pregnant. Sarojam felt neglected when she went to gatherings or functions. She thinks that people do this to her because she is a woman without a child. And Sreedevi felt neglected by the authorities, as no one had ever looked into their problems. She adds: *I know many childless women in the neighbourhood. The authorities have neglected it. They did not even do a survey. I think it is not at all important for them. Why should they care about us.*

Self imposed isolation

Weddings are the occasions during which all the family members and acquaintances get together under one roof. It is again the most common gathering with a large number of people. People meet their relatives and friends and enquire to each other about their wellbeing. All married people will be asked about their children. So when a woman says she is childless, then they enquire about their problems, who is having the problem and finally there will be a discussion on treatments. More and more people will join the discussions giving their opinions. It is annoying for the childless women. This usually happened during every gathering and eventually the childless women got exhausted of answering the same questions again and again. Seeing other women of their age with children put the childless woman in an awkward position. To avoid this confrontation, many of them decided to stay away from such gatherings. Razia do not go to any big gatherings now. She adds: I don't like to go to any functions now. When people see me, they start asking many questions about this. They ask me why I haven't conceived yet. I am tired of giving the same answers again and again. So I try to avoid going to functions now. It is difficult for the women to give answers publicly to all the questions asked. They did not feel comfortable in exposing their sexual health and life in public. Questions about children were always pointed towards the women. Kamala has something different to say. She does not attend 28th day naming ceremony of babies. She adds: I don't take small children in my hands, even my close friend's babies. Many of my friends are angry with me because of this behaviour. They think I am jealous of their baby but the truth is that I am really scared. I have never told about it to anyone. I am a woman without a child. So I am worried whether the babies' parents and relatives will not

like if I take it in my hands. For my bad luck, if the baby falls sick, then they might say that I might have caused it. She is worried that she will be stigmatized in public. No one else shared a similar opinion. She has never been subjected to such type of stigmatization, but she has a fear in her mind. So the women subjected themselves to self-isolation to avoid any sort of offensive situations.

4.3 Coping up with childlessness

Over the years of pain and suffering, the childless women devised a coping strategy for protecting them from a grief filled life. To distract or to distance her from unpleasant thoughts, questions and remarks, she try to keep herself busy, takes the role of a mother to other children from their family and indulge in self care practices. This chapter looks into each of the coping mechanisms adopted.

4.3.1 Leading a busy life

Being lonely makes the life of a childless woman wretched. So most of the women tried to lead a busy life. They tried to get involved with some sort of work. This gave them an opportunity to mingle with other people and children, which eased up their sufferings and kept their problems away. It helped them build an individuality and power status for them in the society. The women who worked appeared to be more confident and happy than those who were at home.

It was also seen that the women who stayed at home, suffered more psychologically. Kamala was getting depressed being at home and her friends encouraged her to join them in *Kudumbashree* works. *Kudumbashree* is the poverty eradication and women empowerment program started by the state government. The name itself means 'prosperity of the family'. It is a networking of the women living in the same neighbourhood and they involved themselves in joined small income generating activities. She started feeling better after getting involved in it. Kamala adds: *It made me forget my problems when I am with them*. When there is work, I do not think about anything else. In between we talk and it is good to be with others. Everyone working with me is good to me.

Nirmala is taking mathematics tuitions for children from her neighbourhood. It gives her a good income for her treatments and also keeps her busy. *I don't have time to think about anything now. I have classes on weekends also*, adds Nirmala.

Sarojam is an ASHA worker. An ASHA worker does the role of a bridge between the community and public health services. She is the first contact person for health promotion and health seeking in the community. She is trained to carry out her functions and get incentives based on her performance. Most of the days she will have fieldwork and she is busy with it. She feels that she is doing an important job and is happy with her work. She was very happy to be a part of this study hoping that her contribution could bring about a change in the attitude of public health sector towards childlessness.

Many women assisted their husband's in running their shops or other businesses. Five participants in the study reported that they felt at ease in working along with their husbands. Being a part of husband's business improved their role as a decision-maker. But the husbands always took the final decisions. These women didn't have a strict time schedule to follow. It gave them flexibility to finish off their household work and then spent time working with their husbands later. Spending time together improved their sharing of thoughts and feelings and strengthened their marital bonds. This gives them a sense of being there for each other. Women who worked far from their house were happy, that they did not have the time to think about anything

It was interesting to find that Sreedevi was the only participant who enrolled herself in sewing classes to make new friends and to improve her skills at her hobby. She seemed happy to talk about it and said that she eagerly waits to attend the classes twice a week. No one else mentioned about a hobby or interest in taking part in any leisure activities.

4.3.2 Being with children

The motherly instincts encouraged some of the participants to take in other children into their homes or to spent time with children in some other ways. To some women, it helped in filling the void left behind by their childlessness. To others it gave a relief to their grief. Neena and Mariamma work with small children as they make them happy. Pushpa worked in a hostel for girls. She stays with them and cooks food for them. She happily says that the girls love her dearly and some of them even don't want to leave her and go back to their houses. To them, she is like a mother. It is seen that these women have chosen jobs where they could enact their motherly roles. It helps them to a great extent to forget their misery and to enjoy the role of a mother.

Others have gone a step ahead and had taken in their sibling's children to live with them. Two women in this study are fostering their nephews and one is fostering her niece. These women say that even though they haven't given birth to these children, they consider them as their own. Their life revolves around these children. All the three women said that their first priority was to prepare food for the children, teach them and to take care of their needs. They went out only after fulfilling their children's needs. They tried to be back home before the children arrived from school. They have found this an alternative to accomplish their role as a mother.

Elsa happily said that her niece calls her Momma and her husband Papa. The motherly affection was seen in her eyes when she spoke of her niece. She was pleased to say that her niece relied on her for everything. Elsa's story is very interesting.

"My husband's elder brother and his family reside abroad. They already have two other kids. Soon after the second child, his wife conceived unexpectedly and they didn't want to keep the child. So they told appachan and ammachi (Christians in Kerala refer to their father as appachan and mother as ammachi) that they were coming to Kerala for an abortion. That time ammachi (mother in-law) asked them whether they could keep the child and give it to us. Ammachi told them "deivam onnine thannathalle, ivar anengil kunjungalillathe vishamikunnu. Ennal pinne athine ivarkku valarthan koduthoode." (It means God has given one, they are suffering without a child, then why can't you give that child to them to bring up). My sister in law delivered the baby and gave it to us. I feel blessed to have such a supportive family."

Rekha is so concerned about her nephew (sister's son). She even hesitated to buy him a bike as she felt that it was dangerous. We are all so concerned about him because he is the only one child in our family. We moved to the town and rented a house for his studies. I think we are pampering him a lot. He is so nice to me. He even calls me amma.

It is not just the women, their husbands also finds happiness in being with their nieces and nephews. Even when they live separately, they try to find time to be with these children.

Mary have left her job in Delhi and moved closer to her family home. She is happy to live near her sister as she gets more time to spend with her nephew. It helps her to forget her troubles. I like my nephew a lot. He is adorable and is my son. Sometimes I take him out with me and people ask me whose child is it? I will hold him closely and say that he is my son. How can they know whether I am telling the truth or not?: Asks Mary.

When they could not find a solution for their childlessness through treatments, few women started thinking about adoption. They only thought about adoption when they had serious health problems and when they realised that their chances are low to get a biological child. The adoption procedure was also strict. It is not just the strict rules, there is a long waiting list and the available children are less compared to the demand. The authority does a thorough

background and financial check before considering couples for adoption. This makes adoption also a difficult process.

Sarojam thinks that it a good gesture to give life to a baby who doesn't have anyone. She says that even if she conceives later, she will keep the child as her own. "We have been trying for three years. The officials said that it might even take up to five years. I want a small baby girl. Then only I can bring it up as our own. Bigger children will know that we are not their parents. We have to show details of our property to ensure that the child will have a good life. The procedures are very strict but we are still trying."

Pushpa and her husband have a different opinion about adoption. They feel that an adopted child can never love the parents like a biological child. Some of our relatives ask us to adopt a child. We are not interested. Now a day your own children would not take care of you in your old age, so imagine about adopted children. Later when they realize that we are not their parents, they will leave us: adds Pushpa.

It is to be noted that just two couples only thought about adoption. There is always a preference for one's own biological child and when that is not achievable, then their next choice is children of one's own kin.

4.3.3 Self care

Few of them developed different practices to take care of themselves. This included praying, refraining from talking about their condition to other people and accepting the childless life as it is as a couple. Two women said that praying makes them feel better. It gives them more confidence and helped them to look at their life with a positive attitude rather than lamenting on an unfulfilled wish. Thirty-four year old Fathima seemed to be a cheerful person. She spoke very positively throughout the interview. She adds: *I feel that there is no point in being sad and desperate because of childlessness. We have to be happy in our life. I felt sad when I could not conceive. So my parents and friends asked me to pray regularly. Now I pray every single day. It has made me feel better. I feel confident about my life. I feel that everything will happen at the right time.*

Some participants mentioned that they never talked about their problems to anyone. They thought that it was their own concern and it had to remain within them. The childless women considered that it was difficult for others to imagine their sorrows. Even if they understood, they wonder to what extent. This is what Razia had to say about it: *I am not sure whether others can understand my problems fully. I never talk about it to anyone. I don't like to talk about it.*

It is noteworthy to understand how some of the couples had come to a mutual agreement to live their life in their own way of contentment. They said that they got adjusted with this life and that they do not feel the pain anymore. Pushpa and her husband felt that it is not important to have a child. She adds: We got adjusted to this life. Now we don't think that it is very important to have a child. We are very happy together. In old age, we will be there for each other, says Pushpa.

They were not pretending to have that happiness in life. Indeed they seemed to be cheerful and pleased with their life. The couples have taken a vow to be there for each other in their old age. It is remarkable to see how these couples hold on to each other in spite of adversities. It is seen that the support from the spouses played a vital role in comforting and supporting the childless women. The emotional misery of childlessness can be surpassed in the setting of a happy and supportive marriage, no matter what the society thinks or says.

4.4 Summary of the findings

Majority of the women who participated in this study are still continuing their journey for a child. Many of them had already taken a long pathway, but the hopefulness in them drives them ahead. All the women in this study went to a medical doctor first for their treatment and most of them explained their cause of childlessness in medical terms. Some said they did not know the cause while others attributed it to God's will. They tried different doctors, infertility specialists and hospitals and different systems of medicine. Even though some said that this was going to be there last treatment, they were ready to try a new treatment when someone said that it was affordable and effective. Three women in there forties and a thirty nine year old tribal woman had given up their quest for a baby. Women in there forties stopped because of the bodily implications caused by the treatments and their loss of faith in treatments. The thirty nine year old woman thinks that it is not important to have a child now. Only one participant in this study went to a Siddha doctor. One-woman was tricked by men pretending to be herbal medicine practitioners. A Pentecost women claimed that she believed only in prayers and had not taken any treatment for her childlessness yet. One participant is taking treatment from an allopathic hospital in a neighbouring state.

Most of them did not continue a treatment for more than six months. Few of them took a treatment continuously from a doctor for a year. One participant only took a treatment continuously from a doctor for three years. They all went without treatments for months or years in between. They stopped mainly because of the cost and distance or when the doctor

said that they were not having any problem. Most of the available treatments were provided by privately run hospitals and clinics and they were not affordable for majority of them. The prices varied greatly from one care provider to the other. Besides, they had been spending all their income on treatments for years. Husbands lost their interest in going for treatments after a while, due to their job, distance, crowding, or when the doctor informed that they were the ones with the problem. Most of the husbands were hesitant in taking medications for long. Drinking and smoking prevailed as a barrier, which kept few husbands away from seeking treatments. Cost of the medicines and working hours were the most common factors, which averted them from treatment seeking.

Many women complained about the side effects of the treatment and on how the hospitals and doctors exploited them. They were subjected to repeated scans and other investigations. Many of them had wrong notions about IVF and saw IVF clinics with suspicion. Most of the husbands did not want to use a donor sperm, and in a few cases where they used, the couples kept it as a secret within them. Along with the treatment pathway, women found solace in prayers, offerings, rituals and pilgrimage. They did this concurrently with the treatments to get god's blessings and to find results in their treatments.

There exists a conflict among doctors from different care providers. The doctors practicing other systems of medicines claimed that they were not respected and accepted by the allopathic doctors and their organisations. The doctors of alternative medicines claimed that they had a good success rate in treating infertility cases. But the allopathic doctors saw that with doubt. All the doctors agreed that the childless patients were desperate, less receptive and frustrated and that is the reason they pointed out for having a treatment pathway.

The women suffered a lot emotionally and they did not share it with others. This emotional suffering was mainly caused due to their inability to attain motherhood. The financial burden and the side effects they had to bear due to the treatments, without any benefits wounded them a lot. Few of them had to face blame and neglect for their inability, which heightened up their misery. They were pressurized by their mothers, mother-in laws and neighbours to get treatments. None of the women were pressurized by their husbands nor they felt threatened about their marriage. They faced questions about their childlessness in gatherings repeatedly and some of them decided to keep themselves away from such functions.

Most of the participants found some form of coping mechanism to relieve them from the misery of childlessness. They tried to keep a busy life by working or by helping husbands in their business. Others found a way to be around children to embrace their motherly roles. They taught them or took in children from there families to live with them. Some had

adoption plans in mind and are trying. Others resorted to personal care techniques, which included praying, being silent about their problems and accepting the life, as it is as a couple.

5 Discussion

The discussion is divided into two sections. The first section examines the determinants influencing the infertility treatment pathway; the second section deals with the perception of the childless women and the self-protection strategies they had developed for contentment.

5.1 Determinants influencing the treatment pathways

The treatment pathway in the study refers to the different treatment steps taken by childless women from the time she identifies her inability to conceive, until the time of the study. The main objective of this study was to find out the different treatment pathways taken by the childless women. Studies conducted in the other parts of the world also have shown an increase in demand for the biomedical health services for infertility (19). In some parts of the world, childless women seek help for their infertility from home remedies, different providers from formal medical practitioners, both in private and public system, herbalists, traditional reproductive specialists, diviners and healers. (3,14,16). It is common for the childless women to visit various health professionals and others, simultaneously or one after the other (72). The participants in this study also moved from one care provider to the other and from one system of medicine to the other. Findings from this study showed that, out of desperation, women moved from one treatment provider to the next when they realised that it was not effective, resulting in what I classified as four general pathways and four less common pathways. In her study from Egypt, Inhorn showed that transitions of women from one level of treatment to the other are complex, ambitious and often unsuccessful (16). Moreover, Widge has pointed out from her study in Delhi and Mumbai that the childless couples life revolved around treatment seeking and that explains the evolution of different long and short treatment pathways in this study (9). The doctors who participated in our study also pointed out that the desperation and frustration of the patients with the different systems of medicines and practitioners over the years led to the formation of these treatment pathways.

I found that the women preferred allopathic treatment as a first line treatment for infertility. All the participants started their treatment at an allopathic private hospital. This finding is in line with many recent studies on infertility from different Indian states, showing a preference for allopathic treatment (20,51,52). Similar to the treatment pathway findings

from this study, participants in Unisa's study also started with allopathic treatment and then took treatment from ayurveda, homoeopathy, Unani, traditional medicines and engaged in rituals and prayers. As an alternative to the medical treatment, women in different studies followed religious practices and visited pilgrim centres to cure their infertility, not only in India, but also in Bangladesh (3,20,51,73). A complementary religious pathway was found in our study also. The childless women went for pilgrimages with their husbands when the treatment did not show any result but most of them tried to continue with some form of treatment after that. They performed rituals, gave offerings and made vows to deities, thereby reflecting a strong religious dimension to treatment seeking. However this finding was different from Singh and Shukla's findings were they stated that illiterate and less educated women sought religious treatments (52). But all the childless women in our study were educated. So, this can only be attributed to the their belief in God's will as a cause of their childlessness along with medical explanation. I found from my key informant interviews that some doctors also backed up the religious dimension of treatment seeking. They believed that the religious sphere rendered peacefulness to the patients, which helped them in conceiving with treatments. The doctors also felt that God played a decisive role in resolving childlessness.

All women sought treatment from allopathy and government accepted alternative systems of medicine. The second most preferred medical system among childless women in this study is Ayurveda, which is an indigenous system of medicine. According to Van Balen and Gerrit's, traditional medical systems have an advantage over other modern systems because of their long established traditional roots and familiarity to the area and culture (19). Even though the treatment for infertility was available from different systems of medicine, there was conflict among the practitioners and they questioned each other's efficiency in solving childless.

Women's understanding of their cause of childlessness influences their treatment pathway (16). Based on White et al.'s, analysis of various help seeking models in relation to infertility, they found that the intellectual judgment and perceptions of childlessness plays the vital role in treatment seeking (74). I found that majority of women in our study gave medical explanation for their condition and some of them could generally explain the procedures they underwent. They had a sound medical understanding that the underlying cause of their childlessness was either in their, or their husband's body. Similarly, in her study in Egypt Inhorn attributed such behaviour to people's extensive contact with biomedical personals and media. Most of the participants in the study relied on television programs, newspaper and

magazine articles to get information about their conditions and to choose their care providers. Neighbours, friends and relatives also influenced their treat seeking behaviour. More than that, the media advertisements influenced them a lot as they are designed in a way so as to make the women feel that their dreams will be realised by taking the treatment from the hospitals or clinics. The significance of motherhood is raised and showed such that a woman has no other role in the society. In addition to that, the hospitals providing infertility treatments exaggerate their results and make claims of achieving different milestones in the field of infertility. These statements easily lured the childless women to their clinics. Most of the participants in this study first approached the 'well-known' hospital providing specialised infertility care, when they experienced difficulty in natural conception. The hospital is 'well known' through advertisements in mass media, by roadside hoardings and testimonials of patients who got a child by their treatment. ART is a booming market in the Indian subcontinent and they use all kinds of marketing strategies to catch hold of childless women (23). The combination of science, journalism and advertisements is behind for the commercial success of assisted reproduction in India (75). The clinics provide packages and concessions to draw in more patients and to spread the good will of the hospital. But the women in the study confirmed that the actual prices are much higher than the prices, they advertise.

In spite of active treatment seeking, at least some of the women expressed their concern over morality of assisted reproduction provided through infertility hospitals. They worried that they might be impregnated with another man's sperm without their knowledge and hence, many chose to leave the treatment centres when they were advised to take IVF. Women from different social class and educational standards from Egypt also expressed a similar anxiety. They also doubted the mixing of procreative elements in the laboratories, which inhibited them from seeking such advanced treatments (16). Most of the women and their husbands have rejected the option of using donor materials, which is different from Widge's findings. In her study, the childless couples showed less opposition to donor materials out of misery (50). The repulsion in our study participants towards it might be due to the fear of breach in normative morals of the marriage. According to Bharadwaj, acceptability of "test tube babies" in India is low due to the social and cultural boundaries. (46). Few women revealed that they had used donor sperm but it was kept as a secret between the husband and wife. The participants in Bharadwaj's multicentre study in Delhi, Mumbai and Jaipur also preferred to keep it as a secret. This must be because of social taboo associated with clinically conceived babies, where the process of making a baby is

compromised due to external agents. From the informal talks and interviews, the mistrust on advanced infertility treatments like IVF was evident in the society. A participant said that she kept her IVF treatment as a secret from others because of the general belief that children born out of IVF are someone's children and the couples seeking IVF are ridiculed because of it.

The participants and their husbands have spent all their live savings on seeking treatment, thereby putting themselves in financial crisis. They went to the extent of selling their ornaments and house to spend for treatments. The accessibility to modern or advanced treatment is totally determined by the women's financial background. Looking in a global perspective, we see that advanced infertility care is only reachable by the affluent people in developing countries (1). Similar finding was shown in Widge's study from Delhi and Mumbai. Since the ART services are only available in the private sector, the treatment benefits reach only to the cream of the society. As the number of course and duration of treatment increased, their financial crisis also multiplied. The women who participated in Unisa's study from Andhra Pradesh and Mehta and Kapadia's study from Vadodara also had to pay substantial amounts for their treatments(20,42). It is evident from all these studies that the economic implications of infertility can be drastic. The treatment costs not only includes medicines and investigations, but also food, transportation and accommodation in some cases. This adds up to a sizeable amount over the time. Many women went looking for treatments to far off places and most of the treatment providers asked for their presence multiple times in a month. But they could not travel so long frequently due to lack of company, cost and physical weakness.

The husbands accompanied the study participants during their initial hospital visits and they also cooperated with the treatments, and this is in line with Unisa's findings from her study in Andhra Pradesh (20). However, as time went by, the husbands' often lost their interest in treatments, thereby compelling the women also to drop out of treatments. In most of the cases in our study, male infertility was also a contributing factor.

The participants raised their suspicion that the health providers were exploiting them by demanding repeated scans and investigations. The women were sceptical about the medicines given to them and they left the treatment in such circumstances. They questioned the efficiency of white powders, pinks syrups and folic acid tablets, which were given to them during each visits. A similar feeling was found among the urban childless women who sought treatment in Bangladesh. To them the doctors were part of a profit-yielding network with low concern for the patients (3). I found that all the participants in this study felt that their vulnerability was utilised for making money.

The woman also complained of being not informed about the actual process associated with infertility care. They felt that there was no one to guide them through the treatments. I also found that the women went through a lot of pain and suffering in the form of treatment side effects, needle pricks and invasive procedures during the treatments. They were not aware of the extent of sufferings associated with the treatment process until they experienced it in person. Findings from Mehta and Kapadia's study from Vadodara also pointed to a similar finding. The participants from their study also reported suffering from pain due to needle pricks and hormonal side effects (42). The ayurveda and homeopathy doctor stated that their treatment procedures were non invasive compared to allopathy treatment. This might be one of the reasons attracting childless women to these systems of medicine. More than anything, it was hope that drove the majority of the women in this study ahead from one care provider to the other, resulting in treatment pathways of varying duration and different treat options. This finding is in line with Unisa's study from Andhra Pradesh (20).

5.2 Perceptions of the childless women

This section brings out the picture of feelings of a childless women, her life within the realm of society and house and finally into the self-protection strategies devised by the women.

Life brimming with feelings and emotions

All the study participants desired motherhood profoundly. The general notion in India is that children bring in happiness, makes life interesting and add a purpose to life (9). The women in this study also shared the same notion. They felt a 'sense of loss' or emptiness in their life. This impression was worsened in the presence of friends or family members with children. According to them, they lacked the happiness in life brought by the children. Participants in Mehta and Kapadia's study from Vadodara also experienced this sense of loss and considered children as the source of happiness. The cultural mandate of motherhood and the norm of family construction is the reason for their grief (42). The women felt that their life got monotonous without a child. This is because the main duty entrusted in a woman is to nurture and being up her child. The sense of loss can also be explained in the light of the socially constructed belief that a woman becomes complete only when she is a mother. When that role is absent in life, the women are left out feeling lonely.

According to Baram et al's study, sadness, depression, hopelessness and helplessness are the foremost feelings of childlessness (76). I found all these feelings expressed in my study participants except hopelessness. Most of the women still lived with a hope of bearing a child. Li Ying et al made a conclusion based on her literature review on experiences of childlessness that women reported depression more than men (13). Three participants in our study also reported that they felt depressed thinking about their misfortune. This resulted in loss of interest in their daily activities and mood fluctuations. The underlying factor for their emotional distress was social pressure.

Childless life within the realm of society

The social pressure on childless couples is seen in many cultures (42). This pressure was exerted on them in the form of repeated questioning. Questions about their inability were raised in their home and in the society. Most of them started out to seek treatment after being asked about their childlessness. Moreover Riessman explained a similar finding from her study in Kerala. The women in her study faced constant questioning from their neighbours when they went out of their house or during functions like marriage (43). The women in our study also complained about being forced with questions on a daily basis from acquaintances and during functions like wedding, where whole family members and friends gathered. The common questions where "is there any good news?" If the answer is no, then the next questions will be about treatments. The questioning does not stop there. It will be followed by "who is having the problem and what is the problem?" The extended family and society showed a deep interest to find out these answers. Then there will be discussions and suggestions for the childless couples. The childless women tried to neglect it in the initial years, but as time passed by they felt hurt on being asked the same question again and again. Women felt uncomfortable to discuss about their sexual health in public. To escape from this plight, the helpless women embraced social isolation to protect them from confronting these questions. Self-imposed social isolation was practiced not only during social gathering but also in their daily life to avoid the questions from neighbours. A similar finding was found in Mehta and Kapadia's study from Vadodara, Bhatti et al.'s study from Pakistani and Nene et al.'s study from Pune (11,42,48). Evidence suggests that women were avoided during auspicious functions like marriages and baby functions, but none of the women in our study reported going through a similar experience (20,51). But one woman from our study shared her fears of attending baby functions and taking other women's babies in her hand. She said that even when people invited her, she avoided going to such functions. Similar finding was

expressed in Bhatti et al.'s study from Pakistan, where a woman feared being around newborn babies (11). The fear and low self-esteem experienced by these women are due to the stigmatization against the childless women by the society.

Childless life within the realm of family

Repeated pressures compelled the women to continue with their treatment seeking. They experienced this pressure from their own mother's. Mother's pressurised their daughter's out of concern, but it turns out to be stressful for the women. In most of the cases, the mother's anxiety was attributed either to her prior experience of delay in conceiving or else due to childlessness among her other kids. Four women reported that their sibling's were also childless, which added up the mother's misery.

Women around the globe took the blame for infertility. Male factors are rarely discussed. When a couple is childless, the general public and the husband's family assume that it is the women's problem. The husband's family try to find an explanation to establish that the fault lies with in the women's body. The childless women are targeted and ridiculed in a childless marriage. This happens mostly in a joint family set up. This finding is in line with Widge's study from Delhi and Mumbai, and Unisa's study from Andhra Pradesh (20,50). Similar feeling was also expressed in Riessman's study from Kerala (43). The social victimization does not stop with that. I found that two women from our study were referred to as a 'barren animal'. It is said that a childless women's body were compared equivalent to an infertile animal's body. During the time of family disputes, the mother-in law and other family members called the women 'machi'. These women from the study said that it was the most insulting name one could call them. It tarnishes their dignity. Women from Riessman's study also conveyed that they were referred to as 'machi' many times (43). (Riessman). Several other studies from India also confirm this finding, but the childless women were given different stigmatized names at different places, all meaning infertile (42,45,47).

Two women said that they were thrown out of their husband's house after being childless for few years. They were in a good relationship with their husbands and always had their support. So the husbands were also rejected along with them. It is seen that when the family have to help with treat payments, they tend to reject the couples after a few years. One of these husbands was unwilling to remarry resulting in taking wrath of his parents. The men understood that their inability also contributed to their childlessness and they always stood by their wives' side.

It is interesting to note that most of the couples shared a healthy bond with their husband. None of them blamed or compelled the women. The husbands took initiative in consoling the wives and discouraged them from taking treatments that harm their body. The harmony in their marriage was a big relief for most of the women and they shared a strong bond in their marriage. Similar evidence relating to harmony in a childless marriage was found from other studies from different parts of India and Kerala in particular (20,43,45). However the findings from Singh and Shukla's study from Haryana was different. There the childless women experienced abuse and remarriage threats from their husbands (52). A strong marital relationship helped in development of mutual support and understanding among childless couples. Childlessness is not a reason for husband's to abandon their wives in Kerala. So most of the wives received support from their husband's during family disputes (43). The husband's support and love saved the women from the social humiliations and gave them confidence and courage to live their life. So the coping up strategy of the women begins from with her husband's companionship.

5.2.1 Self protection strategies

The women developed their own self-protection mechanisms to protect themselves from emotional trauma and social stigma. These coping mechanisms were greatly influenced by their beliefs, experiences and priorities. As years went by, the women got frustrated with all forms of treatments. They gradually started to accept the reality and framed their life accordingly. The main strategies adopted by the women in this study were to lead a busy life, spend time with other children and to take care of themselves. Davis and Dearman uncovered six coping strategies from there study (77). These included leading a busy life, indulging in their hobbies, attributing their childlessness to god's will, opening up their emotions and crying, sharing their feelings with husband and other childless women.

Involvement in daily activities

Leading a busy life helped the women to forget about their worries. When they indulged in some sort of activities or occupations, they did not get much time to ponder over the troubles. Moreover it helped them to build a self-identity and generate income for their treatments.

Few of the participants were working and they exhibited a better emotional strength compared to the nonworking women. Others helped their husbands in running their own business. It gave them more flexibility to manage their household works and to develop better bonding with their spouse. Only one women in this study spoke about getting involved with

leisure activities. She had suffered a lot from loneliness before. That is when she got her selfenrolled for a sewing class. It helped her to make friends and get rid of her loneliness. The women, who stayed at home before, got them involved with some kind of activities and they claimed that it made a big difference in their lives.

Finding contentment in solitude

As a part of their self care strategy, some women decided to remain silent about their problems. It helped them in forgetting their harsh experiences with life and treatments. They felt that talking about their problems never made them feel better. In few cases, the couples decided that they do not want any child in their life. They had accepted this reality as a couple and they had assured each other companionship till their end. The women showed a lot of confidence while saying it. Some of the participants found comfort in praying. It gave them the strength to adjust with reality and develop a more positive attitude towards life.

Embracement of motherly roles

The childless couples found great comfort in being around children and taking care of them. It helped them to forget their miseries and made them happy. They took the role of tuition teachers or kindergarten teachers to spent time with children. They got to enact their motherly roles with these children. Husbands of the childless women had a preference for children from their families and they tried to spend time with them. These were the children of their siblings. Three of them are fostering their sibling's children. A similar preference among men was seen from Mehta and Kapadia's study from Vadodara (42). Adoption is the last option for childless couples. Only two women in this study thought about adoption. They decided to adopt when they felt that their body could not bear any more of the medical interventions. But that is also a complicated and time-consuming process. Evidence from other studies done in India also pointed towards the same conclusion (18,20,47). A women from our study specified that an adopted child would never love and care for their parents and would live them later when they realise that they were adopted. Participants from Unisa also shared this same opinion.

In Kerala also, children are desired to carry on the family lineage and for completion of a family born out of wedlock. The desire for a biological child arises from the existing cultural norms and the relentless treatment seeking is also based on these cultural norms.

6 Conclusions and Recommendations

The objective of this thesis was to track the treatment pathways sought by the childless women in Pathanamthitta district of Kerala, India. Altogether four general pathways and four less common pathways evolved out of this study. They were assigned these names to getter a better understanding of the popular and most sought after treatments and their order of priority.

The determinants influencing these treatment pathways were also examined. It was found that accessibility; affordability, bodily implications, lack of trust in care providers and lack of interest in spouses influenced these pathways to a great extent. A general idea of the available infertility treatments and the opinions of doctors from the three main systems of medicines helped to build a background over which the treatment pathways were build. A complementary religious pathway was also identified along with the treatment pathway.

Another aim of the thesis was to understand the perceptions of childless women regarding their life. The findings showed that childless women were always confronted with questions related to their fertility and inabilities. They also experienced a lot of pressure from their family members to take treatment and these people subjected the childless women to blame when they could not conceive. All these adversities arose from the culturally build motherhood notion. But the women shared a strong bond with their spouses and this served as their support system. They also devised other measures to protect themselves from a miserable childless life.

From this, I conclude that the childless women in Pathanamthitta, Kerala were greatly affected by their desperate treatment behaviour than the social stigmas. The unregulated private health care sector utilised their vulnerability to breed in the society. The women mostly suffered at their hands rather than the evil hands of social stigma. In fact these women were never marginalized much in the society and it was mostly the women's choice to restrict them from social circle.

Recommendations:

First of all, childlessness needs to be considered as reproductive health problem as the women are exposed to great level of vulnerabilities. There is an actual need to find out the prevalence of childlessness in Kerala. In addition to that, a treatment protocol based on the WHO designed infertility treatment protocol could be formulated, taking into consideration

its feasibility in local context. Apart from that, the sub centres and primary health centres need to provide basic information, awareness, counselling and basic treatment facilities for childless couples. There is also a need to establish a proper referral system from the grass root level of public health sector and to improve the coordination between the different levels. Eventually, more advanced infertility treatment services, infrastructure and skilled working force could be incorporated into all the tertiary level government hospitals and medical colleges to meet the growing demands and to protect the childless women from the money minting and commercialised private infertility hospitals.

7 Epilogue

During the initial phase of thesis writing, I came across a book titled 'Malicious Medicine, My experience with fraud and falsehood in infertility clinics', written by Anitha Jayadevan. Out of curiosity, I bought and read her book and to my astonishment her experiences were similar to my participant's experiences. She is a teacher from Ottapalam, Kerala. In this book, she exposes her struggle during the eight years of life, in search of motherhood. Unsympathetic doctors and hospitals subjected her to painful, invasive and expensive procedures. Just like my participants, she also went through different treatment providers to find a solution. She faced the similar questions from the society and her treatment experiences were also similar to the ones shared by my participants. Later, she conceived a pair of twins with treatments, but in between she lost them. She was gravely affected by complications, thereby putting her just in front of the coldness of death. The misfortunes did not end there. Later she found out that she was a surrogate mother and she or her husband did not have any knowledge about it, until the autopsy of her babies. She suffered physically and psychologically and more than that the betrayal broke her heart. Her story echoes the sufferings of every childless woman in Kerala. They suffer at the hands of illegal practices carried by the infertility clinics in Kerala. She initiated a fight to bring in justice for regulation of ART laws in India, but the actions have not been taken vet. The story in this book has concurred with my study findings, thereby raising the need for a greater focus on issues associated with childlessness.

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9 Appendix

INFORMED CONSENT FORM

Request for participation in a research project

Pathways Taken By Childless Women In Pursuit Of A Baby: A Qualitative Study From Kerala, India

Introduction

Dr Nayana Geetha Ravi, a master's student at University of Oslo, is conducting a study on social experiences and perspectives on cause of childlessness that influence the chronological treatment pathways sought by childless women in Kerala. This study is affiliated to University of Oslo. Estimated end date of this project is 31.12.2017. You are requested to be a part of this study as you are currently taking treatment for childlessness and is in reproductive age group. Before you decide, you can talk to the researcher about the study. If you are interested in, you will be provided with the final results of the study. You will not be provided any direct financial benefits.

Purpose of the Research

The purpose of this study is to get an insight into the your experiences regarding childlessness, how you perceive the causes and the different treatments that you have taken and experiences during this treatment. This study will also look into the different services provided by the private and government hospitals. The researcher aspires to draw the attention of stakeholders to look seriously into the issues of childlessness.

Contribution in the study

The researcher conducting this study will interview you. An interview might last between one to two hours and you might have to participate in one or two interviews. The time and venue of the interview will be according to your convenience. The interview will be audio recorded with your permission.

Advantages

You will be sharing your experiences and treatment options, which will enrich the knowledge regarding this issue in this community.

Disadvantages

You may have to share unpleasant experiences or recollect painful memories.

Confidentiality

Names of the participants will be coded with a number and only the researcher will be aware of it. All these information, audio recordings and any other data related to it will be locked up and the researcher will only handle it. These materials will be deleted

upon completion of this project.it will not able to identify you, when the results of this study get published.

Right to refuse or withdraw

It is your decision whether to participate or not. You can withdraw your consent to participate in this study at any time. This will not affect your relationship with the health care providers in this institution. If you have any questions regarding this study, you can always approach the researcher.

Thank you for your cooperation

Contact information of the researcher: Dr Nayana Geetha Ravi Mobile:0999500051

Email id: drnayanarahul21@gmail.com

Consent for participation in the study

I have read and understood the above given information sheet, and had the opportunity to ask questions. I am willing to participate in this study
(Signed by the participant/date)
I confirm that I have given information about the study.
(Signed by the researcher/date)



Heidi Fjeld Institutt for helse og samfunn Universitetet i Oslo Postboks 1130 Blindern 0318 OSLO

Vår dato: 20.06.2016 Vår ref: 48796 / 3 / HJP Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 30.05.2016. Meldingen gjelder prosjektet:

48796 Pathways taken by childless women in pursuit of a baby: A qualitative study

from Kerala, India

Behandlingsansvarlig Universitetet i Oslo, ved institusjonens øverste leder

Daglig ansvarlig Heidi Fjeld

Student Nayana Geetha Ravi

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 31.12.2017, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Kjersti Haugstvedt

Hanne Johansen-Pekovic

Kontaktperson: Hanne Johansen-Pekovic tlf: 55 58 31 18

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

NSD – Norsk senter for forskningsdata AS Harald Hårfagres gate 29 Tel: +47-55 58 21 17 nsd@nsd.no Www.nsd.no Org.nr. 985 321 884 NSD – Norwegian Centre for Research Data NO-5007 Bergen, NORWAY Faks: +47-55 58 96 50 www.nsd.no

Vedlegg: Prosjektvurdering

Kopi: Nayana Geetha Ravi n.g.ravi@studmed.uio.no

Personvernombudet for forskning



Prosjektvurdering - Kommentar

Prosjektnr: 48796

PURPOSE

The purpose of the project is to investigate the experiences of childless women in Kerala, India.

DATA COLLECTION

In the report form you have stated that you will collect datamaterial by personal interviews and observation. From the report form it appears that personal information only will be obtained through interview. We therefore assume that data retrieved through observation is done anonymously. This part of the project is therefore considered to not be notifiable. If it becomes necessary to collect personal data via observation we ask that you send supplementary information to: personvernombudet@nsd.no.

Following is evaluation of the part of the project that includes the personal interviews.

INFORMATION AND CONSENT

The sample will receive written information about the project, and give their consent to participate. The letter of information and consent is well formulated, but we ask that the following is added:

- the date for project completion

SENSITIVE INFORMATION

There will be registered sensitive information relating to religious beliefs, health, and sex life.

CONFIDENTIALITY OF PATIENTS

In the report form you have informed that you will interview medical staff/service providers. We remind you that these informants have confidentiality of patients, and that you have a shared responsibility that no personal information about third parties enter the data.

INFORMATION SECURITY

The Data Protection Official presupposes that the researcher follows internal routines of Universitetet i Oslo regarding data security. If personal data is to be stored on portable storage devices, the information should be adequately encrypted.

PROJECT COMPLETION AND ANONYMIZATION

Estimated end date of the project is 31.12.2017. According to the notification form all collected data will be made anonymous by this date.

Making the data anonymous entails processing it in such a way that no individuals can be recognised. This is done by:

- deleting all direct personal data (such as names/address/lists of reference numbers)
- deleting/rewriting indirectly identifiable data (i.e. an identifying combination of background variables, such as

residence/work place, age and gender)

- deleting digital audio files

INSTITUTIONAL REVIEW BOARD

6th floor, Mother & Child Building, Pushpagiri Medical College Hospital, Thiruvalla- 689101, Kerala, India pushpagiriirb@pushpagiri.in +91-469-2700755 (Ext-7603)

Dr Harikumar B Nair, BAMS, MHSSA Chairperson

Dr Anand Manoharan, PhD, MPH **Member Secretary**

No: IRB/1/11/2016

22nd July 2016

IRB Study Ref. No. 11/2016

To
Dr. Rajeev A
Professor & Head
Dept. of Community Medicine
Pushpagiri Institute of Medical Sciences and Research Centre,
Tiruvalla

Dear Dr. Rajeev A,

Sub: Approval of Research proposal by the I.R.B

The Institutional Review Board of Pushpagiri group of institutions, Tiruvalla, reviewed and discussed your application to conduct the research study entitled "Pathways taken by childless women in pursuit of a baby" in its meeting held on 14th June 2016.

The following documents were reviewed:

- a) Research Proposal, Patient Information Sheet and Informed Consent Form (including updates if any) in English and/or vernacular language.
- b) Principal Investigator's current CV.

The following members of the ethics committee were present at the meeting held on 14th June 2016 at Pushpagiri Institute of Medical Sciences and Research Centre, Tiruvalla.

Dr Harikumar B Nair	Medical Superintendent	Chairperson
	KNM NSS Ayurveda Hospital, Tiruvalla	
Dr Anand Manoharan	Head of R & D, Pushpagiri group of	Member
	institutions, Tiruvalla	Secretary
Prof. PS Zachariah	Retired Professor of History, Mar Thoma	Lay Member
	College, Tiruvalla	
Adv. Mini Mathew	Advocate. Member of Tiruvalla Bar	Legal advisor
Dr TP Thankappan	Principal of Pushpagiri Institute of Medical	Member
	Sciences and RC	



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Dr Harikumar B Nair, BAMS, MHSSA Chairperson

Dr Anand Manoharan, PhD, MPH **Member Secretary**

Dr Vikram Gowda	Associate Professor of Physiology	Member
Dr Sujith John Chandy	Professor and Head of Pharmacology	Member
Dr Krishnan Namboodiri	Professor of Pediatrics	Member
Dr Abraham Mathew	Assistant Professor of General Surgery	Member
Dr Nebu Mathew	Vice-principal of Pushpagiri College of	Member
	Dental Sciences	4
Dr Sheeba Chandy	Principal of Pushpagiri College of Nursing	Member
Dr Lincy Joseph	Professor of Pharmaceutical Chemistry	Member

The response to the queries of the Institutional Review Board has been (attached) responded in a satisfactory manner and approved by all IRB members.

We approve the study to be conducted in its presented form. The Institutional Research 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.

Yours sincerely,

Dr Amand Manoharan Member Secretary, IRB

Pushpagiri Group of Institutions

Tiruvalla

Date: 22/07/2016

MEMBER SECRETARY
Institutional review board
Pushpagiri group of institution
Tiruyalia - 689101, Kerala

INTERVIEW GUIDE

Interview guide for participants

Background information

Name

Age

Address

Religion

Educational Qualification

Occupation

Relationship

Age

Educational Qualification

Occupation

- > At what age did you get married?
- ➤ Have you been living together since?
- ➤ When did you decide to have a child?

Gynecological History

- Were you taking any contraceptives before that?
- ➤ What kind of contraception were you using?
- ➤ How will describe your menstrual cycle?
- ➤ Have you ever conceived before?
- ➤ What was the outcome?
- ➤ Was there any complication?

Experiences within family and Society

- ➤ When did you realize that you were having difficulty in conceiving?
- ➤ What did you do first?
- With whom did you confide this information first?
- ➤ What was your husband's response?
- ➤ How did your in-laws respond?
- ➤ How did your parents respond?
- ➤ What was the attitude of extended family members and neighbors?
- > Do you know anyone who has experienced childlessness?
- ➤ Have you received any advice from them regarding remedies/treatment?

Treatment Pathways

- What was the treatment option that you tried first?
- ➤ Who introduced it?
- ➤ What is your opinion about that treatment?
- ➤ Were you comfortable during the treatment?
- ➤ Who accompanied you for the treatment?
- ➤ Who pays for the treatment?

- ➤ How long did you try this treatment?
- ➤ Why did you stop it?
- ➤ Will you recommend it for someone?
- ➤ What are the other treatment practices that you tried?
- ➤ How long did you try them?
- ➤ How about the cost?
- ➤ What are your experiences with these treatments?
- ➤ What is your spouse's opinion?
- ➤ How long did you try?
- Why did you stop those treatments?
- ➤ When did you start treatment here?
- ➤ Who suggested it to you?
- ➤ Are you trying any other treatment options simultaneously?
- > Do you share your treatment experiences with someone?

Perception of causes

- What do you think is the reason for this difficulty in conceiving?
- ➤ Who diagnosed it?
- ➤ Was it medically diagnosed?

Consequences of childlessness

- ➤ How does this affect your day-to-day life and work?
- ➤ How do you feel while attending any celebrations or auspicious occasions?
- ➤ Have you felt any difficulties during those situations?
- Are you and your partner affectionate with each other?
- ➤ Have you experienced any kind of physical violence or abuse from your partner?
- ➤ How is your sex life?
- Do you feel that your family can understand your agony?

Additional Ouestions

- ➤ Is there something that you would like to share with me?
- Are there any other important issues that we haven't covered?

Sample probes

- Can you tell me something more about it...
- ➤ I didn't understand your point. Can you make it a little more clear
- ➤ What do you mean when you say...?
- ➤ How did you feel about...?
- ➤ Uh...interesting...

INTERVIEW GUIDE

Key informant interviews

- How many childless women do you treat in a day?
- What are their complaints?
- What do you think is the reason for their childlessness?
- What kind of treatment do you provide them?
- Tell me about the treatment seeking behavior of these women
- What do you think about their treatment seeking behavior?
- What can you tell about the health system in Kerala?
- Is there anything more that you can tell me about our topic?