

**A qualitative study to critically explore the socio-ecological determinants influencing  
screening mammography uptake amongst Kerala migrant women  
in the United Arab Emirates**

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### List of Abbreviations

| Abbreviation | Expanded Form  |
|--------------|--|
| BSE          | Breast Self Examination                              |
| CBE          | Clinical Breast Examination                          |
| CAQDAS       | Computer-assisted qualitative data analysis software |
| CBGA         | Centre for Budget Governance and Accountability      |
| CC           | Cranio- Caudal                                       |
| FGD          | Focus group discussion/s                             |
| GCC          | Gulf Cooperation Council                             |
| HAAD         | Health Authority of Abu Dhabi                        |
| MLO          | Medio-Lateral Oblique                                |
| NGO          | Non- Government Organisation                         |
| NRK          | Non- Resident Keralite (here resident in UAE)        |
| ODPHP        | Office of Disease Prevention and Health Promotion    |
| PHC          | Public Health Center                                 |
| PIS          | Participant Information Sheet                        |
| SEM          | Socio-ecological model                               |
| TA           | Thematic Analysis                                    |
| UAE          | United Arab Emirates                                 |
| U.S          | United States  |

## Glossary

| Term                | Definitions  |
|---------------------|--|
| Breast cancer       | Type of cancer that is in the breast   |
| Cancer              | Cancer is the uncontrolled growth of the cells   |
| Culture             | Culture is the way of life, especially the general customs and beliefs, of a particular group of people at a particular time and it is the learned and shared behavior of a community (Cambridge Dictionary, 2017; Sullivan & Keesing, 1981).  |
| Trustworthiness     | Trustworthiness of a study demonstrates a commitment to the degree of confidence in data, data interpretation and the research design selected to ensure the quality of a study and its ability to reflect the meaning of participant’s views as closely as possible (Guba & Lincoln, 1982, p. 218; Polit & Beck, 2018). |
| Ethnography         | “Ethnography is the art and science of describing a group or culture. The description may be of a small tribal group in an exotic land or a classroom in middle-class suburbia” (Fetterman, 1998, p. 1).   |
| Epistemology        | Epistemology is the way of understanding reality (Hudson & Ozanne, 1988; Irene, 2009; Kivunja & Kuyini, 2017; Scotland, 2012).   |
| Kerala              | Kerala is the southernmost state of India  |
| Keralites/ Malayali | Natives of Kerala  |
| Kudumbanadha        | A word used in Malayalam to convey the concept of “wife”; female head of the family  |
| Labour camps        | Place where low wages people stay together in the UAE  |

|   |  |
|---|--|
| Malayalam                               | The language is spoken in Kerala, mother tongue of Keralites   |
| Ontology                                | Ontology is the study of being, and it is concerned with “what is” the nature of reality and existence (Hudson & Ozanne, 1988; Irene, 2009; Kivunja & Kuyini, 2017; Scotland, 2012).     |
| Organised screening mammogram program   | It provides an outreach screening mammogram to all women in a target age group in a population (Anderson et al., 2017)   |
| Population 1                            | Research participants who had undergone screening mammogram  |
| Population 2                            | Research participants who had not undergone screening mammogram  |
| Paradigm                                | “a general organising framework for theory and research that includes basic assumptions, key issues, models of quality research, and methods for seeking answers” (Neuman, 2011, p. 96). |
| Screening mammography                   | Low dose X-ray examination of the breast for asymptomatic women for the early detection of breast cancer   |
| Socio-ecological determinants of health | It is the personal, social, economic, and environmental factors that influence the health (ODPHP., 2020)   |

## **Abstract**

### **Background**

Significant evidence demonstrates that undergoing screening mammography, is effective in detecting breast cancer early enabling better treatment and longer survival. Breast cancer is the most common type of cancer among females in Kerala (India) and is diagnosed at advanced stages of the disease. Keralite women residing in Kerala are less likely to undergo screening and more likely to be diagnosed with breast cancer in its advanced stages. Social, cultural and ecological factors can influence whether a woman will undergo breast cancer screening. The factors influencing the uptake of screening mammography amongst Kerala migrant women is not yet known. The principle migration destination of Keralites is the United Arab Emirates (UAE).

### **Aim**

This is the first study aimed to critically explore and identify the socio-ecological determinants for the informed uptake of screening mammography amongst Keralite women residing in the UAE.

### **Objectives**

- identify the attitudes of Keralite women residing in the UAE towards breast cancer screening using screening mammography;
- identify and categorise the influencing factors for the uptake of screening mammography as voiced by the target population;
- devise strategies for increasing the informed uptake of screening mammography for Keralite women in the UAE based on the participants recommendations.

### **Methods**

The study adopted a qualitative research approach using five focus group discussions. This enabled exploration of the collective experiences and views of participants who had undergone

a screening mammogram and those who had not undergone screening mammography in the UAE or Kerala. The socio-ecological model of health promotion that includes five levels such as individual, interpersonal, community, organisational and policy was utilised as a theoretical framework to collate and organise the findings, discuss and put forward the recommendations.

### **Findings**

The individual level socio-ecological factors were identified as self-efficacy, attitudes, beliefs, and knowledge. The interpersonal level influencers were family, peers, and friends. The community level factors were cultural beliefs, media, medical professionals, community organisations and breast cancer survivors. Further, the organisational factors were health care facilities, health insurance, specialised breast cancer screening services, and academic institutions. Finally, the policy level factors were found to be Kerala and UAE government, psychological support team, automatic invitation system and International health collaboration. Participants appreciated the initiatives by the UAE towards the health of all residents, while they highlighted the requirement of the Kerala government's initiative on the health and screening mammography of Kerala migrants in the UAE. The socio-ecological factors identified by the participants were multifactorial, reciprocal and are interconnected.

These findings indicate that a comprehensive approach is required to change health behaviour in order to increase the informed uptake of screening mammography by Keralite women residing in the UAE. Careful plans should be implemented in each level of socio-ecological influencers to alter attitudes, initiate, reinforce changes towards breast cancer early detection. The findings of this study further provide a foundation for practical plans to improve the screening behaviour among Keralite women residing in the UAE.

### **Recommendation**

The interplay between various socio-ecological factors is evident in this study. Therefore, the contemporary trend in health behavioural change involves more than simply addressing and educating individuals' healthy practices. It includes efforts to change the external factors that are beyond the control of a single individual or a community. Community organisations and



governments should initiate and develop comprehensive approaches to promote the informed uptake of screening mammography by Keralite women residing in the UAE. The study also put forward the responsibilities of the Kerala government and the importance of developing initiatives towards the health of Kerala migrants in the UAE.

**Keywords**

Breast cancer, Kerala, Keralite, Screening mammography, Socio-ecological model, United Arab Emirates

## Chapter 1: Introduction

This study aimed to critically explore and identify the socio-ecological determinants for the informed uptake of screening mammography amongst Keralite women residing in the UAE. Screening mammography is considered one of the most reliable methods for the early detection of breast cancer (American Cancer Society, 2019). It has been well-established that cases of cancer diagnosed at the first stages are easier to treat and patients have a better chance of survival (WHO, 2017d). For women forty years of age and older, regular screening is an essential part of their health care. However, many women ignore this for various reasons.

In the state of Kerala, India, the majority of patients with breast cancer are diagnosed during the very late stages (Malvia, Bagadi, Dubey, & Saxena, 2017). However, there is no statistics/database/ Kerala population based cancer directory available in UAE or in Kerala to explain the uptake of screening mammography by Keralite women in the UAE. As in many other parts of the world, this occurs for a multitude of personal, interpersonal, cultural and even socio-political reasons. In a country with a large migrant Keralite population like the UAE, estimated at 2.24 million in 2016 (Talwar, 2018), it is imperative to provide essential preventive health care services such as screening mammography to this community. It is, therefore, essential to identify the factors that affect the rate of uptake of this procedure and devise strategies to improve the uptake. This study adopts a qualitative approach using focus group interviews to explore perceived factors of the target population for undergoing screening mammography in UAE.

Chapter one of this thesis provides an introduction to the study discussing the definition and diagnosis of breast cancer, the importance of early detection, screening mammography and the rationale for selecting a particular group as research participants.

The second chapter reviews the body of research relevant to the aim and objectives of this research and the theoretical principles it discusses. Furthermore, a critical review of the literature is provided to identify the socio-ecological factors that can influence women to

undergo screening mammography. Due to the limited number of studies that focus on Keralite women in the UAE, a broader academic literature was included. Finally, this chapter also highlights the knowledge gaps in the existing literature.

The third chapter explains me as the researcher to identify my prejudices and experiences that might have influenced this research. In the fourth chapter, the methodology including the philosophical stance of the research, a description of the data collection and the process of data analysis are presented. Chapter five presents the data trustworthiness of this research and confidence in data and data analysis. Chapter six presents the findings of this research.

Further, the seventh chapter discusses and presents an analytical interpretation of the research findings in the context of relevant previous research studies and limitations in this research. In chapter eight, recommendations are made and proposed scope for further research based on concerns and suggestions expressed by the participants and my analysis of the data. Finally, chapter nine provides the conclusion of the research.

## 1.2 Background

The federation of seven emirates formed United Arab Emirates (UAE) founded by the former president, His Highness the late Sheikh Zayed bin Sultan Al Nahyan on 2nd December 1971 (Shelpai & El-Metwally, 2014). The seven member emirates are Abu Dhabi (the capital of UAE), Dubai, Sharjah, Ajman, Umm al-Qaiwain, Ra's al-Khaimah, and Fujairah (National Media Council, 2016). The official language of UAE is Arabic. With the increase in investment and job opportunities in the UAE, a considerable number of the expatriate population contributes to the total population of the UAE and most were from India (Francoise, 2015; Embassy of India, 2017), and Keralites are the major expatriate community (around fifty percent) among Indians in the UAE (Migration Information Source, 2013; Zachariah & Rajan, 2015).

Kerala is the southernmost part of India and the natives of Kerala are known as Keralites. Kerala culture is an inherent part of Indian culture, with a multi-ethnic and multi-religious state. In

India, Kerala leads the literacy rate of the country (Jana & Basu 2017). Although the official language of Kerala is Malayalam, English is widely spoken and taught in Kerala (Census Organization of India, 2015). The Kerala emigrants are far ahead compared to the general population in Kerala in terms of secondary education and higher (Rajan & Zachariah, 2018). Keralites migrated for livelihood and now it becomes a trend (Rajan & Zachariah, 2018). According to the Kerala Migration Survey, 2014 (Zachariah & Rajan, 2015), nearly 90 percent of the Kerala emigrants are going to the Gulf countries. The most popular and preferred destination of the Keralites is the UAE (John, 2016; Khaishgi, 2014; Rajan & Zachariah, 2018; The Hindu, 2013). However, there are not many sources available to confirm the accuracy of number of Keralites in the UAE (Rajan & Zachariah, 2018; Zachariah & Rajan, 2015). In 2019 the chief minister of Kerala said that the UAE is every Keralites second home (Gokulan, 2019). The maximum direct flight time from any Kerala airports to UAE airports is around 4 hours 30 minutes, mostly over the Arabian Sea (figure 1.1).



Figure 1. 1 The location of Kerala and UAE on the map

The flourishing movement of people from Kerala affected all facets of life. This means that this group makes a significant contribution to the economy of both their homeland and adopted country. However, to date, no studies have explored the socio-ecological determinants, barriers and facilitating factors to undergoing breast cancer screening by Keralite women residing in the UAE.

Breast cancer is amongst the most deadly forms of cancer diagnosed in the United Arab Emirates (Elobaid, Aw, Lim, Hamid, & Grivna, 2016). It constitutes 43% of all female cancers and 25% of all cancer in the country. In fact, it is the most common type of cancer among female UAE citizens (32.16%) and expatriates (41.41%) (Ministry of Health and Prevention, 2014). In 2014, Dr. Moza Al Hattawi, chairperson of the Dubai Health Authority (DHA) Breast Cancer Campaign reported that almost 30 percent of women who were diagnosed with breast cancer were in the third stage. Clearly, this trend needs to be changed. Dr. Al Hattawi added that although the number of awareness raising campaigns held in the country was on the raise, the rate of uptake was still low (Gulf News, 2014). The statistics on the attendance of Keralite women or other population based report for screening mammography are not published yet. It has also been established that females in the UAE are more likely to develop breast cancer at least a decade earlier than their counterparts in western countries (Chouchane, Boussem, & Sastry, 2013; Dawood, 2017; Ministry of Health and Prevention, 2014). In 2017, the president of UAE Cancer Congress and consultant medical oncologist, Dr. Shaheenah Dawood also stated that UAE's median age of breast cancer diagnosis 10-15 years younger than in the West, and its incidence is increasing and at the present rate a steep increase can be predicted by 2030 (Dawood, 2017). Around half of the women are diagnosed with breast cancer in the UAE are at an age below 46 years (HAAD, 2018). Al- Shamsi & Alrawi (2018) reported that this might be due to the failure of health providers to recognise high-risk population, patient's lack of awareness related to their family history, fear of stigma and believing that not sharing the diagnosis is protective to their families.

In India, where the subjects of this study come from, one woman is diagnosed with breast cancer every four minutes and one woman dies of breast cancer every eight minutes (Breast

Cancer India, 2018a). In addition, breast cancer incidence is found a decade younger in comparison to western women suggesting that breast cancer occurs at a younger premenopausal age and is diagnosed at a late stage (Chopra et al., 2014; Kakarala, Rozek, Cote, Liyanage, & Brenner, 2010; Shitalmala, Rajesh Singh, & Kaushik, 2014). Heredity and various etiological factors such as changes in lifestyle, industrialisation, urbanisation, advancing age, early menarche, late menopause, late age of first childbirth, exposure to pesticides and population growth contribute to epidemiological transition with an increasing incidence of breast cancer in India (Donepudi, Kondapalli, Amos, & Venkanteshan, 2014; Jaga & Dharmani, 2005; Parameshwari, Muthukumar, & Jennifer, 2013; Sathwara, Balasubramaniam, Bobdey, Jain, & Saoba, 2017). However, the reasons for the high incidence of breast cancer in younger women are not well known (Sandhu, Erqou, Patterson, & Mathew, 2016).

The breast cancer projection for India up to the year 2020 points towards an increase in the number of women who will be diagnosed with breast cancer: it will be as high as 1,797,900 and will remain to be 10% of all cancer cases in the country (Malvia et al., 2017). Thus, breast cancer figures are pertinent in the context of a developing nation such as India, where there exists an urgent need to effectively plan and give a higher priority to specialised health care services which include both diagnostic and treatment centres (Malvia et al., 2017). In Kerala, the southern state of India, breast cancer was the second most common type of cancer from 1982 to 1986 and it became the most prevalent with a proportional increase of 29% in 2007-2011 (Regional Cancer Centre, 1982- 2011). It continues to be the most common type of cancer among females in Kerala (Regional Cancer Centre, 2012-2013, 2014- 2015). However, at present, breast cancer is still commonly diagnosed at late stages of the disease (Augustune et al., 2014; George, Mohan, Parameswari, Dinesh, & Marcus, 2018; Parameshwari et al., 2013; Union for International Cancer Control, 2016) even though Kerala has exceptionally advanced health care facilities compared to the rest of the country (Jana & Basu 2017).

The Cancer Registration Centre in India was commenced in 1964 and it was extended in 1982, through the initiation of the National Cancer Registry Program (NCRP) by the Indian Council of Medical Research (Chatterjee et al., 2016). A Regional Cancer Centre (RCC) in

Thiruvananthapuram was established in 1981 by the Government of Kerala and Government of India (Augustine et al., 2014; Regional Cancer Centre, 2016) and offers a diverse range of cancer research and health education initiatives, and boasts state-of-the-art facilities meant for cancer diagnosis, palliation, treatment, and rehabilitation (Regional Cancer Centre, 2014). Moreover, a National Cancer Control Programme has been launched to support breast cancer screening services in Kerala (Gupta, Shridhar, & Dhillon, 2015; Sreedevi, Quereshi, Kurian, & Kamalamma, 2014). However, breast cancer screening opportunities are limited and the number of adequate medical facilities are insufficient in Kerala in particular and India in general. There are no national or regional breast cancer screening programmes and, therefore, organised screening mammography is limited, while opportunistic mammography is more in practice.

The UAE, where the target population resides, has a highly developed healthcare service, with a sophisticated physical infrastructure: well-equipped hospitals, specialised clinics, and primary care centres. Healthcare is free for nationals and medical insurance schemes are available to expatriates (Jaloudi, Kanbar, James, & El-Salhat, 2016). The Federal Ministry of Health of the UAE initiated several breast cancer screening programmes in 1995, and, in 2008, with the aim to increase the rate of early diagnosis of breast cancer, the Health Authority of Abu Dhabi (HAAD), the UAE's largest health district, introduced a breast screening programme (Al-Shamsi & Alrawi, 2018; HAAD, 2018). Pink Caravan is a pan-UAE breast cancer initiative that falls under the umbrella of "Kashf" or "Friends of Cancer Patients". It was launched in 2011 under the patronage of His Highness Sheikh Dr. Sultan bin Mohammed Al Qasimi (Pink Caravan, 2018). In 2018, Pink Caravan extended its services and helped 11 women to receive breast cancer treatment (Maxwell, 2018). To spread awareness and the uptake of screening among the public, Pink Caravan provided screening mammogram and information leaflets (Clarke, 2018). A series of events were held at various outlets to reach a larger number of people including RAK Mall, Al Manama Hypermarket-UAQ, Lulu Mall-Fujairah, Umm al Quwain Women's Association, Al Majaz Waterfront- Sharjah, Dubai Sports Council are to name a few (Report, 2018). Pink Caravan, is a nationalised screening mammography program that conducts free screening mammography at various Emirates of the UAE.

Furthermore, the Dubai Health Authority (DHA), the second-largest health district in UAE, introduced breast cancer screening programmes in 2014 (Al- Shamsi & Alrawi, 2018; Dubai Health Authority, 2018). Later in 2015, the Ministry of Health introduced an official breast cancer screening initiative in the remaining five health districts -Sharjah, Ajman, Ras Al Khaimah, Fujairah, and Umm Al Quwain (Al- Shamsi & Alrawi, 2018; Ministry of Health and Prevention, 2018). Elobaid et al (2016) states that there are various intervention initiatives in the UAE meant to minimise the effects of breast cancer which include free screening for all women above 40 and compulsory health insurance for both nationals and expatriates.

Other private initiatives by hospitals, clinics, such as Dr. Rami Hamed Center, launched the Breast Care unit in 2015 to conduct screening and treatment for breast cancers (Mid-East.Info, 2015). In 2012, Etihad Airways, the national airline of the United Arab Emirates, donated a mobile mammography unit to the Burjeel Hospital to provide free mammograms to the airline's female staff, employees' wives and to the general public at malls in Abu Dhabi (Mena Report, 2013; UAE government news, 2013). Other private hospitals such as University Hospital in Sharjah, Thumbay Hospital in Ajman, Zulekha Hospital in Sharjah and Ghusais, NMC Hospital in Dubai, Prime Healthcare Group, Emirates Speciality Hospital in Dubai, Medeor 24x7 Hospital in Dubai were part of the campaign which provided free screening of breast cancer throughout October. Zulekha Hospital extended its screening till the end of December and Emirates Speciality Hospital provided cervical screening in addition to breast cancer screening (D'souza 2018). Thus the availability of screening mammography to all residents is more available compared to Kerala, therefore it is worth understanding the reasons for the low uptake and the influencing factors for the uptake of screening mammography.

In order to establish the causes of late diagnosis and high incidence of cancer, an official National Cancer Registry was established in 2014 under the Ministry of Health and Prevention, providing a valuable overview of cancer case distribution. The registry boasts a number of trained professionals and a certified tumour registrar to enable the proper collection, management and production of cancer statistics. It aims to systematically collect, store, summarize, analyse and distribute information about cancer patients who are diagnosed



and/or treated in UAE. This is done with the help of Active Method, which collects data recorded by registry staff at the medical treatment abroad department at MOHAP, and the Passive Method, which organizes data from hospital information management systems and pathology reports adhering to a standardized form (Shelpai & El-Metwally, 2014).

However, in the UAE, the exact number of breast cancer incidence is difficult to establish, as the population in the UAE is transient. A multinational population with varied cultural backgrounds makes population-based public health strategies in the UAE difficult to devise and implement (Jaloudi et al., 2016). To complicate matters, a number of nationals and residents of the country receive treatment overseas (Dawood, 2017). Moreover, due to certain cultural norms, screening and diagnosis are considered taboo by many communities living in the UAE in general (Dawood, 2017).

In addition, expatriates contribute greatly to the development of different nations through the deployment of their skills. However, like migrant populations all over the globe, Keralites in the UAE may face particular challenges in accessing healthcare. It has been reported that healthcare in the UAE is quite expensive for the average expatriate (Internations.org, 2020). Not all Keralites in the UAE have well paying jobs that would enable them to live a good life. Further, expatriates do not have cost-free access to all hospitals in the UAE. As most of these migrants actively contribute financially to the livelihoods of their families back home, the average Keralite woman stands to face a number of challenges in terms of access to healthcare especially its cost.

Marceca (2017) report that expatriate experience economic challenges in the destination countries as well as discrimination or non-prioritization to access to healthcare in the host countries. This makes it hard for foreigners to access first class healthcare services; a situation that can endanger their lives. Another study conducted by Hardill, Spradbery, Arnold-Boakes, & Marrugat (2005) show that migrants in certain countries (for example Spain), including but not limited to Saudi Arabia, suffer from poor access to some healthcare facilities, limited resources and even lack of proper nationwide health information system making it very hard for them to procure meaningful healthcare services. Accordingly, it can be assumed that not all Keralite

women in the UAE have easy access to healthcare especially pertaining to breast cancer detection and treatment. Moreover, the Keralite community's perception of breast cancer screening is also a challenge that cannot be overlooked.

### 1.3 Summary of the significance of the study

Reviewing the state of breast cancer screening and diagnosis in the participants' home and destination countries suggests that in both contexts women develop the condition at a younger age compared to those in western countries, only get diagnosed at advanced stages, and do not practice routine screening mammography. Thus, there is an urgent need to identify the reasons why women do not attend breast cancer screening.

Social, cultural and ecological factors can determine whether a woman will undergo screening for breast cancer. While, the principal destination for migrant Keralites is the United Arab Emirates (UAE), little, if any, is known of which socio-ecological factors influence their decisions to undergo the procedure and how informed uptake can be increased. This study aims to provide some of this information. The knowledge gained through this research will provide useful insights that may help to identify potential interventions that could support the early detection of breast cancer among Keralite women residing in the UAE.

### 1.4 Purpose of the study

The main aim of this study is to identify the socio-ecological factors that influence the uptake of informed screening mammography among migrant Keralites' in the UAE.

The study sets to achieve the following objectives:

- identify the attitudes of Keralite women residing in the UAE towards breast cancer screening using screening mammography;
- identify and categorise the influencing factors for the uptake of screening mammography as voiced by the target population;

- devise strategies for increasing the informed uptake of screening mammography for Keralite women in the UAE based on the participants recommendations.

To achieve this, the study adopted a qualitative research approach using focus group interviews of two populations of migrant Keralite women in UAE (Population 1 is comprised of those who have undergone screening mammography and Population 2 includes those who have not undergone screening mammography). Participant selection was based on the following criteria:

- All participants are migrant Keralites
- None had previously migrated to any other country apart from the UAE
- All participants had lived in the UAE for at least 2 years
- All participants were 40 years of age and above

An ethnographic approach was utilised to collect the participants' views. The socio-ecological model of health promotion found as the most suitable framework and adopted as the theoretical framework for data analysis.

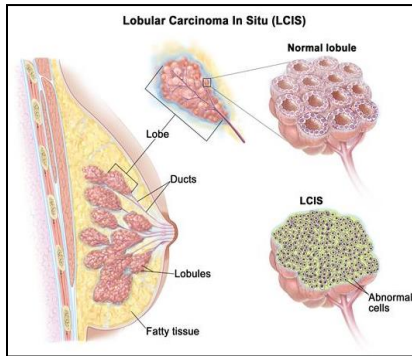
## 1.5 Key Concepts

### 1.5.1 Breast Cancer

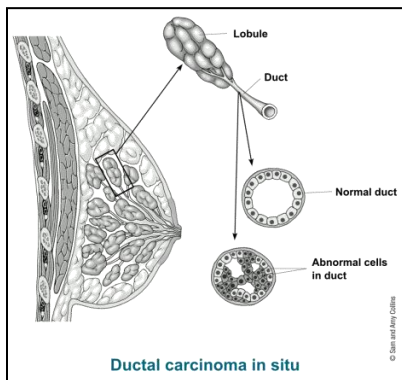
Breast cancer is one of the leading causes of death in the world and this global burden is increasing dramatically (Coughlin & Ekwueme, 2009; Fitzmaurice et al., 2018; Forouzanfar et al., 2011; Tabuchi et al., 2013). Over 1.5 million women are diagnosed with breast cancer each year (WHO, 2017a). In 2015, 570,000 women died from breast cancer and it accounts for approximately 15% of all cancer deaths among women (WHO, 2017a).

Breast cancer occurs when the cells in the breast start to grow out of control (Ebubedike, Umeh, & C Anyanwu, 2018). It can happen in any part of the breast. There are different types of breast cancer (Jose, 2015). The most common type (90%) of breast cancer, ductal cancer,

occurs in the ducts that carry milk to the nipple (figure 1.2), followed by lobular cancer (figure 1.3), 8%, which occurs in the glands that make breast milk (Vaidya, 2014). Breast cancer cells can get into the blood or lymph system and spread to other parts of the body to form secondary cancers, this is known as metastasis (American Cancer Society, 2016).



**Figure 1. 2 Ductal Carcinoma in situ (Source: ACS, 2016)**

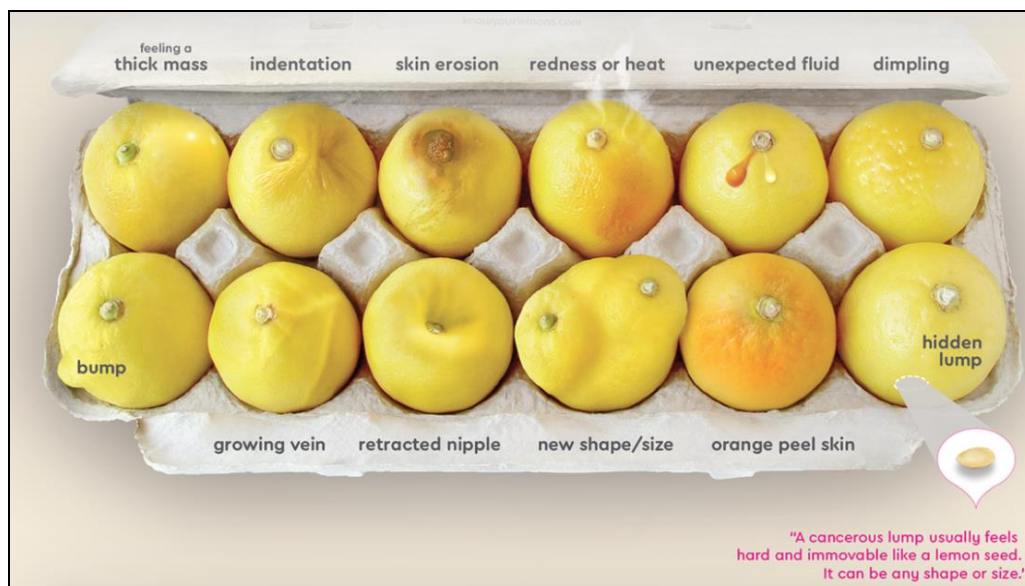


**Figure 1. 3 Lobular Carcinoma in situ (Source: NCI, 2017)**

As shown above, breast cancer occurs mainly in the internal structures of the breast, thus it may be hidden in its early stages. Early detection can be achieved through screening mammography. This research mainly aims at identifying the factors that determine the uptake of screening mammography by Keralite women in the UAE. This may help reduce the probability of fatalities due to late diagnosis (Coughlin & Ekwueme, 2009; Forouzanfar et al., 2011; Monica & Eucario, 2018; Tabuchi et al., 2013).

### 1.5.2 Symptoms of breast cancer

A new lump or mass is the most common symptom of breast cancer. Changes in the breast shape, swelling of all or part of the breast, skin dimpling, thickening of breast skin, nipple retraction, nipple discharge are the other possible symptoms of breast cancer (American Cancer Society, 2017; National Breast Cancer Foundation, 2016; Vaidya, 2014). Adapted from the Worldwide Breast Cancer organisation entitled “Know your lemons”, figure 1.4 below shows a visual representation of breast cancer symptoms.



**Figure 1.4** A metaphorical representation of breast cancer using lemons (Source:worldwide breast cancer.org, 2011)

### 1.5.3 Staging and Grading of Breast cancer

Staging represents the size of breast cancer and whether it has spread to other areas of the body (American Society of Clinical Oncology, 2018). Histopathology is used to confirm the presence or absence of breast cancer. When cancer is detected, staging and grading are used to determine the type and severity of cancer (Cho et al., 2017; Jafari et al., 2018). The appearance of cancer cells gives an indication of how quickly they may grow. Both grading and staging are

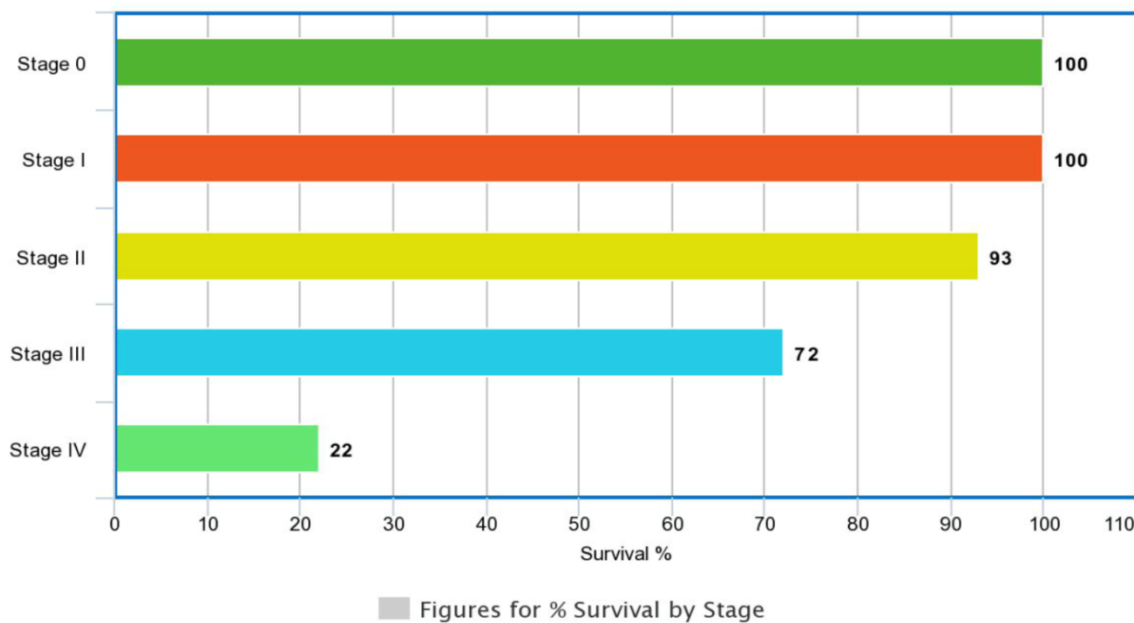
required for a physician to decide the appropriate treatment for the patient (Cancer Research UK, 2014).

The TNM staging or number staging systems are commonly used in breast cancer diagnosis and screening (American Society of Clinical Oncology, 2018; Cancer Research UK, 2014). In TNM staging system, T stands for Tumour and describes the size of the tumour, N describes whether the cancer cells are present in the lymph node and M denotes metastasis to state whether cancer has spread to any other part of the body (Cancer Research UK, 2014; Vaidya, 2014). In India, the TNM staging system is commonly used to describe the stage of breast cancer (Breast Cancer India, 2018b). The number staging system divides breast cancer into 5 stages. Stage zero (0) indicates that the cancer cells are only in the ducts and lobules of the breast and it has not invaded other surrounding tissues of the breast, also termed as non-invasive breast cancer (American Society of Clinical Oncology, 2018). Stage 1 means the size of the cancer is less than or equal to 2cm and it is involved in the breast tissue (Stage 1A) or found in the lymph nodes close to the breast (Stage 1B). It is an early stage of breast cancer where the chance of survival is greater (Berg, Hendrick, Kopans, & Smith, 2009; Cancer Research UK, 2014; Güth et al., 2008; World Health Organization, 2017). In stage 4, cancer has spread to other parts of the body (bone, lungs, liver or brain). This stage is also termed advanced cancer, secondary breast cancer or metastatic breast cancer (Cancer Research UK, 2014). This same staging process has been adopted in the UAE, though there are variations in terms of screening guidelines and in practice.

#### 1.5.4 Breast Cancer Detection

Prevention of breast cancer is still under investigation; so efforts to detect breast cancer before the symptoms occur (early detection) are paramount in fighting this disease (Dandash & Al-Mohaimeed, 2007; Hatefnia et al., 2010; Lee, 2014). Breast cancer can be detected through a screening examination before the symptoms have manifested (American Cancer Society, 2015). Screening means the application of simple tests to identify the early asymptomatic disease (Hakama, Coleman, Alexe, & Auvinen, 2008). Research continues to improve the efficacy of

treatment, however in order for a treatment to be effective early identification is required (Dandash & Al-Mohaimed, 2007; Hatefnia et al., 2010; Lee, 2014; Marmot et al., 2013). Early stage cancer detection could reduce breast cancer death rates and increase the chances for longer survival (Dianatinasab et al., 2018; Wang, 2017). Survival means the period of time a person lives after a cancer diagnosis (American Cancer Society, 2015). However, Cancer Research UK (2017) states that survival is a complex concept as the various statistics for cancer are conventionally noted as 1-year survival, 5 years or 10 years of survival scenarios. Figure 1.5, presents the 5-year survival data produced by the Surveillance, Epidemiology, and End Results (SEER) an authoritative source for cancer statistics in the United States. Additionally, these figures can sometimes be challenging to fully comprehend. They could refer to the percentage of people who are still alive after 1, 5, or 10 years post-diagnosis.



**Figure 1. 5 Five year % relative survival rate for breast cancer by stage (National Cancer Institute’s SEER database 2007 and 2013, 2017)**

Breast self-examination (BSE), clinical breast examination (CBE) and mammography are the primary measures used for early detection (screening) of breast cancer (Cho et al., 2017; Khalili & Shahnazi, 2010). The early diagnosis of a breast lesion can be made with screening

mammography as it can diagnose cancer before cancer becomes palpable (Massat et al., 2016). This contributes to the reduction of the rates of mortality and morbidity from breast cancer (Yaffe, 2018). Mammography is recommended by organisations in more than 35 countries worldwide.

Screening mammography in asymptomatic women can be either systematic mammography (organised mammography or mammography screening programme) or opportunistic mammography (Lousdal, Kristiansen, Møller, & Støvring, 2016; Sandoval et al., 2017; Teh et al., 2015). In a systematic screening programme, an organised repetitive calling in the eligible age group for a cost-free mammogram is offered regardless of the social or economic background of the client. While opportunistic mammography tends to be undertaken as a result of asymptomatic women's individual preference (Zwahlen et al., 2003).

Screening mammography has been predominantly conducted using 2 views: cranio-caudal (CC), and medio-lateral oblique (MLO) and can detect a tumour size relatively small from 1.0 to 1.5 cm (Berg et al., 2009; Güth et al., 2008). There are also other methods that can be employed during breast cancer screening using a mammographic examination, which include views such as spot compression, magnification view, cleavage view, and exaggerated cranio-caudal view (Ebubedike et al., 2018). Mammography is found to best detect breast cancer in the early stage (Stage 1) as 2cm or smaller invasive cancer would not yet have spread to the lymph nodes; whereas breast cancer detected through self-breast examination (SBE) or clinical breast examination (CBE) and for palpation can usually only detect cancers above 2 to 2.5cm (Stage 2) (Güth et al., 2008). Both SBE and CBE result in about a 20% increase in longer survival and reduction in mortality due to early diagnosis when compared to no screening at all (Ahmad et al., 2011; Berry et al., 2005; Boyle & Levin, 2008; Cancer Australia, 2017; WHO, 2017a). This development of having a longer life expectancy then goes on to support the earlier assertion by (Cariou, Rouzier, Baffert, Soilly, & Hequet, 2018a) who promoted the usage of screening mammography as a method that can enable early diagnosis and a possible prognosis.

Adopting systematic or opportunistic mammography, early detection strategies can be ensured by improving the awareness of the necessity of early detection and adoption of screening tests



in a regular and periodic manner (Yusra, Tar Ching, Michal, & Nico, 2014). This can be achieved by ensuring the availability of screening mammography, and through effective promotion (Elobaid et al., 2016; Yusra et al., 2014). Access to healthcare and referral systems without cultural or economic barriers should also be in place to serve all members of society (Shulman, Willett, Sievers, & Knaul, 2010). The World Health Organisation (WHO, 2017a), recommends systematic mammography screening of women aged 50-69 years with a screening interval of two years. The recommended age to start screening varies in different countries. This is attributed to the age of breast cancer incidence in each population and the results of screening trials (Kemp Jacobsen et al., 2015; Nelson et al., 2016).

In the UAE, the following standards (see table 1.1) are recommended for all women including expatriates. Screening of breast cancer for women in the UAE should be done in a manner that conforms to the breast screening and diagnosis pathway. This should include medical profile and risk assessment, clinical breast exam and screening mammogram (Donnelly et al., 2013).

**Table 1. 1 Summary of the UAE National Breast cancer screening recommendations<sup>1</sup>**

| Screening Category            | Age   | Screen Assessment tools  |
|-------------------------------|---|--|
| Women at average risk         | 20- 39 years  | - Breast awareness   |
|                               | 40- 69 years  | - Breast awareness<br>- Yearly clinical breast exam<br>- Mammography every two years   |
| Women at increased/ high risk | Age of initiation is individualised according to risk | - Breast awareness<br>- Clinical breast exam every 6- 12 months<br>- Annual mammography screening<br>- Annual MRI screening as indicated<br>- Referral to genetic counsellor for strong familial/ genetic predisposition |

<sup>1</sup> Adapted from: NCCN Clinical Practice Guidelines in Oncology. Breast Cancer Screening and Diagnosis. V.1.2014

However, it is argued that the advantages of population-based screening methods as used in breast cancer diagnosis might be now accepted but they have their own challenges (Kopans, 2015; Marmot et al., 2013; Myers et al., 2015; Mühlhauser, 2013; Pauwels, Foray, & Bourguignon, 2016). These medical imaging techniques may be vital, yet other some researchers are doubtful of its overall impact on the fight to limit the effect of breast cancer on societies (Gøtzsche & Nielsen, 2011). Cariou, Rouzier, Baffert, Soilly, & Hequet (2018b) claim that breast screening programmes seem as somehow lacking in terms of their overwhelming scientific influence to certain extent. Duffy & Parmar (2013) note that there are hidden complications to the procedure such as over diagnosis and treatment of possibly non-aggressive forms of tumours that would have been identified through breast cancer screening.

There are also increased risks of radiation-triggered cancers while there is a definite lack of clear information provided to women who are invited to undergo breast cancer screening. Furthermore, the specificity and sensitivity of screening mammography vary from one country to another depending on the age of the client, the density of the breast, and screening modality (Al-Shamsi & Alrawi, 2018; Kemp Jacobsen et al., 2015; Raza, 2018). Meanwhile, there is a clear absence of research addressing the specificity and sensitivity of screening mammography in the UAE. Therefore, it is important to promote informed choice of screening mammography among women, however, the fact that benefits of the procedure outweigh the risks should be conveyed to potential users.

#### 1.5.5 Categorisation of mammography diagnosis

In the UAE, the Breast Imaging Reporting and Data System (BIRADS) established by the American College of Radiology (2013, 5<sup>th</sup> edition) is followed to categorise the diagnosis of breast cancer (see table 1. 2). This is adopted by radiologists to classify each mammogram (both screening and diagnostic) by BIRADS score for a definitive treatment plan. Taher & El Sebelgy (2014) establishes a baseline to guide the patient regarding their future check-ups.

**Table 1. 2 BIRADS**

| <b>Category</b> | <b>Description</b>  |
|-----------------|---|
| BIRADS 0        | Incomplete (further imaging or information required)          |
| BIRADS I        | Negative  |
| BIRADS II       | Benign findings   |
| BIRADS III      | Probably benign (short interval follow-up suggested)          |
| BIRADS IV       | Suspicious abnormality (biopsy should be considered)          |
| BIRADS V        | Highly suggestive of malignancy (appropriate action required) |
| BIRADS VI       | Biopsy proven malignancy                                      |

### 1.5.6 Breast Cancer and Migrants

The incidence and the late detection of breast cancer among migrant women are reported in many studies. Studies of native women and immigrant women in other parts of the world such as Norway, American Indian women in Kansas and Missouri, South Asian women in England, Spain uncovered many barriers that migrant women encounter compared to native women in regard to access to breast cancer screening. Common barriers include the lack of information on breast cancer, lower positive attitudes towards breast cancer screening, lack of time to attend screening and the traditional perceptions towards breast cancer screening which are conventionally marked by an unwillingness to attend (Azeem Samera, Kumar, & Ursin, 2014; Daley et al., 2012; Maringe et al., 2013; Pons-Vigués et al., 2012). A study conducted in Spain on native and immigrant women concluded that a factor leading to migrant women having higher breast cancer prevalence could be that migrants may have less or no access to free healthcare programmes due to their temporary residency in their home country and their host country (Pons-Vigués et al., 2012; Srivastava & Giri, 2003). Several social, cultural, economic and ecological factors can also influence both native and migrant women for undergoing screening mammography (McLaren & Hawe, 2005) (see section 2.5.1). Moreover, research points out that breast cancer is one of the leading causes of death, advance stage diagnosis and its prevalence is still high among women both in Kerala and UAE (HAAD (2017b), IARC (2017), Indus Health Plus (2017) Padmavathy Amma & Sebastian (2016), The Pink Initiative (2015)) and one of the reasons may be due to low uptake of early detection methods.

### 1.6 Summary

The United Arab Emirates is one of the most desirable destinations of Keralites. Breast cancer is one of the most common types of cancer in the UAE and Kerala and expected to rise in the coming years. Screening mammography is one of the medical imaging procedures that help in the early detection of breast cancer. Opportunistic screening mammography is available in UAE and Kerala, however, women are diagnosing with advanced stages of breast cancer. The migrant population faces many challenges, including socio-ecological and cultural factors to

access health care services in adopted countries. There are no studies either in UAE or Kerala conducted in establishing the socio-ecological factors that influence attendance and non-attendance of Keralite women in UAE for breast cancer screening. Thus this research aimed to identify the socio-ecological determinants of Keralite women for the informed uptake of screening mammography in the UAE.

The next chapter will critically explore existing literature related to understanding socio-ecological determinants and its importance in the uptake of screening mammography among Keralite women residing in the UAE. Further, it makes an analysis of the health behavior theories and theoretical framework is used in this research.

## Chapter 2: Literature review

### 2.1 Background

Breast cancer incidence has increased whilst mortality among women has steadily declined especially in the developed world, due to the increase of early detection initiatives that often result in early diagnosis and treatment, subsequently helping save more lives (American Cancer Society, 2017; Tabuchi et al., 2013; Lulu Wang, 2017). In as much as this decrease in breast cancer deaths has been noted to be a result of improvements in timely breast cancer diagnosis and the initiation of treatment, not all women have managed to benefit from such breast cancer screening initiatives (American Cancer Society, 2017; Coleman, 2017; Malvia et al., 2017).

In developing countries, there is an inverse trend where there is a steady increase in breast cancer mortality rates (IARC, 2018). In fact, rates of incidence of breast cancer, and mortality thereof, have increased over the past few years in these countries. Therefore, there is a need for earlier detection and broader access to screening mammography which offers the most feasible, efficient and practical screening methods for breast cancer amongst women worldwide (Coleman, 2017; Jose, 2015; Montazeri et al., 2008).

This chapter first determines the inclusion criteria used to select sources and the methods used to find relevant references. It then gives a broad overview of previous research that explores the prevalence of breast cancer in the UAE, India and Kerala. Further it presents the barriers to, and facilitators of the uptake of breast cancer screening, with a special focus on expatriates. Next, it discusses the availability of this health service in the participants' home state and adopted country of residence. Later in this chapter, literature review done with a focus on the relationship between migration and the spread, diagnosis, and treatment of breast cancer. This chapter then explains health behaviour theories, theoretical framework highlighting their applicability to the context of Keralite women in the UAE. In addition, the chapter conveys the

apparent research gap concerning in understanding the socio-ecological determinants and their importance to the uptake of screening mammography among Keralite women residing in the UAE.

## 2.2 Literature search inclusion and exclusion criteria

Research studies older than 6 years were mostly excluded as significant changes could have occurred since the time of publication of these studies including improvements in the rates of access to screening mammography, and levels of social awareness of the issue under investigation through the media and other sources. Further key words mentioned in section 2.3 were also used to narrow down the literature search. However, a number of research papers older than 6 years were cited to support the background for this research study and they were directly relevant to either the issue under study, research methodology employed or the theories referred to here.

## 2.3 Literature search methodology and databases used

Relevant sources were identified using multiple databases to overcome the problem of inadequate indexing (Whittemore, Knafelz, 2005) and to ensure a more exhaustive scope. The databases include CINAHL, ClinicalKey, Cochrane Library, Evolve Medline (EBSCO, OVID, Web of Science), PubMed, SCOPUS, Sage Journals Online, Oxford Journals, ScienceDirect, and SpringerLink were used to collect appropriate peer-reviewed articles and e-books.

Government publications, reports, conference proceedings, news releases, abstracts, manuals, reviews were collected through Google, Google Scholar, Google alerts, websites of American Cancer Society, Breast Cancer of India, Cancer Australia, Embassy of India, Cancer Research UK, Government of Kerala, Government of India, Health Authority of Abu Dhabi, International Agency for Research on Cancer, National Breast Cancer Foundation, National Cancer Institute, U.S. Department of Health and Human Services, WHO. The search strategy was based on the terms “attitudes” OR “awareness” OR “beliefs” OR “perceptions” OR experiences AND “breast cancer screening” OR “breast cancer” OR “mammography”, “Barriers” OR “facilitators” AND

“breast cancer” OR “breast cancer screening”, “Keralites” OR “Kerala women” OR “United Arab Emirates” OR “migration” OR “socio-ecological determinants” OR “non- resident Keralites” AND “breast cancer screening” OR “breast cancer”.

## 2.4 Prevalence of breast cancer in UAE and India/Kerala

In this section, literature review around breast cancer and migration are presented after considering the incidence (new cases in a specified population over a period of time Shields & Twycross (2003)) of breast cancer in general in the context of UAE, India and Kerala respectively.

### 2.4.1 UAE context

Breast cancer is the third leading cause of death among UAE nationals and the expatriates; it accounts for 25% of all cancers according to Abu Dhabi central cancer registry database Cancer Facts and Statistics (HAAD, 2018). The condition has mostly been diagnosed in women younger than 46 years of age. In addition, approximately 170 women are diagnosed with breast cancer in the Emirate of Abu Dhabi annually (HAAD, 2017a, 2018). The Cancer Country Profiles 2014 published by the World Health Organisation (WHO, 2017c) stated that in UAE 24.1% of 500 cancer deaths among females are due to breast cancer. This is despite a background whereby the official portal of UAE government, Government.ae (2018) notes that breast cancer is the leading cause of death in women and that any woman above 40 years of age should undergo an annual screening test (HAAD, 2017b). They recommend that women in the UAE should have a monthly breast self-exam, a clinical breast exam every 6-12 months, and undergo mammography and MRI screening. The UAE government plans to reduce overall cancer mortalities by nearly 18 percent by 2021 (Government.ae, 2018) through breast cancer early detection.

In the year 2010, migrants made up a total of 88.5 percent of the population in UAE, the majority of whom come from Asia, especially India (Françoise, 2015). The number of migrants to the country increases annually, with Indians among the largest ethnic groups (Françoise,



2015). However, there is no dedicated cancer registry available to establish the extent of prevalence of breast cancer cases among Keralite women living in the UAE. Table 2. 1 provides a summary of information focusing on the breast cancer in the UAE context.

**Table 2. 1 Breast Cancer in the UAE context**

| Study         | Year  | Journal/ website  | Findings   |
|---------------|-------|---|--|
| HAAD          | 2017a | <a href="https://www.haad.ae/simplycheck/tabid/128/Default.aspx">https://www.haad.ae/simplycheck/tabid/128/Default.aspx</a>   | Annually approximately 170 women are diagnosed with breast cancer in the emirate of Abu Dhabi  |
| HAAD          | 2017b | <a href="https://www.haad.ae/simplycheck/tabid/131/Default.aspx">https://www.haad.ae/simplycheck/tabid/131/Default.aspx</a>   | A woman above 40 years of age should undergo an annual screening test  |
| WHO           | 2017b | <a href="http://www.who.int/cancer/country-profiles/are_en.pdf?ua=1">http://www.who.int/cancer/country-profiles/are_en.pdf?ua=1</a>   | In UAE, 24.1% of 500 cancer deaths among females are due to breast cancer  |
| Françoise     | 2015  | <a href="https://www.researchgate.net/publication/279910786_Demography_Migration_and_the_Labour_Market_in_the_UAE">https://www.researchgate.net/publication/279910786_Demography_Migration_and_the_Labour_Market_in_the_UAE</a>                     | In the year 2010, migrants made up a total of 88.5 percent of the UAE population and the majority come from Asia, especially India           |
| Government.ae | 2018  | <a href="https://government.ae/en/information-and-services/health-and-fitness/chronic-diseases-and-natural-disorders/cancer">https://government.ae/en/information-and-services/health-and-fitness/chronic-diseases-and-natural-disorders/cancer</a> | Breast cancer is the leading cause of death in women. UAE government plans to reduce overall cancer mortalities by nearly 18 percent by 2021 |
| HAAD          | 2018  | <a href="https://www.haad.ae/simplycheck/tabid/128/Default.aspx">https://www.haad.ae/simplycheck/tabid/128/Default.aspx</a>   | Breast cancer is the third leading cause of death among UAE nationals and expatriates  |

Many factors can influence attendance or non- attendance to screening, however, no studies were found that is conducted in the UAE that investigates the influencers for migrant Keralites attendance of screening. Studies conducted in other parts of the world show that migrants usually lack health awareness, lower positive attitude towards screening, more family commitments, and lack of time to attend screening compared to native women (Azeem Samera et al., 2014; Daley et al., 2012; Maringe et al., 2013; Pons-Vigués et al., 2012). Thus, it can be assumed that Keralites in the UAE may have a high prevalence of breast cancer and they may be diagnosed at later stages of the disease. This can be especially true because in Kerala, where the participants come from, the rate of incidence is high and levels of awareness of the disease, methods of detection and treatment are low. Furthermore, they may not be aware of or have less access to healthcare facilities where they can undergo screening mammography. However, currently, this assumption cannot be statistically confirmed as official figures from the UAE are not available.

#### **2.4.2 Indian and Kerala context**

In Kerala, among all cancers, breast cancer is one of the major causes of morbidity and mortality (IARC, 2017; Indus Health Plus, 2017; Malvia et al., 2017; Padmavathy Amma & Sebastian, 2016; Regional Cancer Centre, 2014; Sreedevi et al., 2014). Moreover, the Indian Council of Medical Research (ICMR) reports that Thiruvananthapuram, the capital of Kerala ranks the highest (43.9 per 100,000) in breast cancer crude rate (the number of new cases or deaths occurring in a specified population per year per 100,000 population) among different states of India (ICMR, 2016; Malvia et al., 2017). In addition, a survey conducted by the ICMR from 1982 to 2005 shows that breast cancer incidence rates have almost doubled during that period (Chatterjee et al., 2016). Further, the projection of breast cancer incidence in India predicts that the number of cases will double by 2020 as a result of the fact that, in developing countries, especially in the rural areas patients with breast cancer are diagnosed at a late stage with widespread metastasis (Takiar, Nadayil, & Nandakumar, 2010). The Cancer Country Profiles 2014 (WHO, 2017b) found that in India, 21% of 326300 cancer deaths among females are due to breast cancer. Therefore, an urgent need for widely providing, regulating, and

enforcing early detection of breast cancer is required in India (Malvia et al., 2017). The Pink Initiative; an Indian non-government organisation (NGO) promoting breast cancer awareness and providing support to survivors in India also stated that the incidence of breast cancer is increasing (The Pink Initiative, 2015).

In Kerala and UAE, it has also been advised that women 40 years of age and older should undergo screening mammography. If their mammogram is normal, then screening continues every year (Breast Cancer India, 2015). In the context of Kerala, Augustine et al. (2014) conducted an unmatched case-control study at the Regional Cancer Center, Thiruvananthapuram, among 660 newly detected breast cancer patients admitted for surgery during 2003-2004 and 920 controls selected from the hospital and community. The study revealed that advancing age, delayed first childbirth, nulliparity, history of previous breast biopsies and family history of breast cancer among first degree relatives were associated with increased risk of breast cancer. Furthermore, the researchers argue that breast cancer occurrence and death rates vary from region to region and there is an absence of organised screening mammogram in Kerala (Sreedevi et al., 2014). Whilst the mean age consistent incidence rate of breast cancer across the world is estimated to be around 43.3 per 100,000 women, in India, it was found to be 25.8 per 100,000. The researchers found that the figures for the Kerala state of India were higher at 30.5 in urban areas (more than the national average of 25.8) and lower, at 19.8, in rural areas. This alarming situation justifies the urgent need for the present study.

In a similar study, Mathew et al (2016) estimated trends in incidence by age from 2005-2014 to predict rates through 2020 and to assess the stage at which diagnosis of breast cancer occurs in Trivandrum. They concluded that breast cancer was mostly diagnosed in advanced stages, and rising rapidly in South India with a predicted large increase in the future, particularly among postmenopausal women. This increase might be due to aging and/or changes in lifestyle. However, their study does not assess the factors that lead to late stage diagnosis. In a recent community based cross-sectional survey John, Jose, Dhanuja, Haran, & Augustine (2018), the prevalence (factor at that single point of time Shields & Twycross (2003) of known risk factors

of breast cancer among women aged 20 years and above in Thiruvananthapuram, Kerala, India was explored. The researchers described breast cancer screening practices prevalent in the study population and established the proportion of high-risk individuals using breast cancer risk calculator. They enrolled 2000 women from Thiruvananthapuram. Their results show that the mean age of the population was 54.67. The majority of the women (82.5%) had never undergone any breast cancer screening. Clinical Breast Examination (CBE) was undergone by 9.8%. The breast cancer risk calculator showed that 65% of the women screened had normal risk, 22.2% had moderate risk, and 12.9% had high risk. The survey revealed an increased prevalence of major known risk factors of breast cancer like positive family history, low breastfeeding duration, and late age menopause.

In two independent studies, (Malvia et al (2017) and Augustine et al (2014)) noted that slightly more than a fifth of cases with breast cancer from their research samples were below 40 years, whilst 16% were above the age of 65 years. There seems to be a dramatic shift in the increase of cancer towards younger women as compared to the traditional older age group category. Menstrual irregularities were found to be a key contributor to this phenomenon and were present in 9.2% of the cases and 6.1% of controls and research subjects with a history of irregular menstrual cycles had considerably higher chances of having breast cancer.

In addition, the high mortality rate in the country is due to late presentation for diagnosis (Gupta et al., 2015; Somdatta & Baridalyne, 2008). Generally, in cancer incidence, breast cancer ranks first in the urban areas and second in rural areas of India (Parameshwari et al., 2013). This is also the case in Kerala making it a major public health concern (Parameshwari et al., 2013). In India, around 145,000 new cases of breast cancer (27% of all cancer cases in both genders) are diagnosed every year with around 70,000 annual deaths, both of which are higher than any cancer among both genders (Ferlay et al., 2013). This can be attributed to changes in reproductive factors, living standards and an increase in life expectancy. However, low levels of cancer awareness amongst Keralite women can also explain these alarming figures. Table 2.2 provides a summary of studies added in the Indian and Kerala context.

**Table 2. 2 Breast cancer in Indian and Kerala context**

| Study                         | Year | Journal/Weblink   | Findings  |
|-------------------------------|------|---|---|
| Takiar, Nadayil, & Nandakumar | 2010 | Asian Pacific Journal of Cancer Prevention  | Breast cancer incidence in India predicts that the number of cases will double by 2020  |
| Ferlay et al.,                | 2013 | European Journal of Cancer  | In India, around 145,000 new cases of breast cancer (27% of all cancer cases in both genders) are diagnosed every year with around 70,000 deaths, both of which are higher than any cancer among both genders   |
| Parameshwari et al.,          | 2013 | Journal of Clinical and Diagnostic Research   | In Kerala, breast cancer ranks higher in urban areas than in rural areas making it a major public health concern  |
| Augustine et al.,             | 2014 | Academic Medical Journal of India   | Advancing age, delayed first childbirth, nulliparity, history of previous breast biopsies and family history of breast cancer among first degree relatives were associated with increased risk of breast cancer.<br><br>Breast cancer is higher in urban areas and lowers in rural areas of Kerala. |
| Regional Cancer Centre        | 2014 | <a href="http://www.rcctvm.org/HBCR%20report%202011%20-%20Final%20(29-04-2015).pdf">http://www.rcctvm.org/HBCR%20report%202011%20-%20Final%20(29-04-2015).pdf</a> | Breast cancer is one of the major causes of morbidity and mortality in Kerala.  |
| Sreedevi                      | 2014 | Asian Pacific Journal of Cancer   | There is an absence of a population-based screening   |

|                                      |      |   |   |
|--------------------------------------|------|---|---|
|                                      |      | Prevention  | program in Kerala.  |
| Breast Cancer India                  | 2015 | <a href="http://www.breastcancerindia.net/screening/screening.html">http://www.breastcancerindia.net/screening/screening.html</a> | Screening mammography is advised to be conducted from 40 years of age. If mammogram is normal, then screening continues every year.                                 |
| Gupta                                | 2015 | European Journal of Cancer  | High mortality rate is due to late presentation for diagnosis. Breast cancer awareness programmes and early detection will cause a reduction in breast cancer       |
| The Pink Initiative                  | 2015 | <a href="http://www.breastcancerindia.net">http://www.breastcancerindia.net</a>   | The incidence of breast cancer is increasing in India   |
| Chatterjee et al.,                   | 2016 | Asian Pacific journal of cancer prevention  | Breast cancer incidence rates in Kerala have almost doubled   |
| ICMR                                 | 2016 | <a href="http://www.icmr.nic.in/guide/cancer/Breast_Cancer.pdf">http://www.icmr.nic.in/guide/cancer/Breast_Cancer.pdf</a>         | Thiruvananthapuram, the capital of Kerala ranks the highest in breast cancer crude rate   |
| Mathew et al.,                       | 2016 | Asian Pacific Journal of Cancer Prevention  | Breast cancer is mostly diagnosed in advance stages and is rising rapidly in South India with a large increase in the future  |
| Padmavathy Amma & Sebastian. et.al., | 2016 | Journal of Health Systems   | Among all cancers, breast cancer is one of the major causes of morbidity and mortality in Kerala. There is a need for breast cancer registries and public education |
| IARC                                 | 2017 | <a href="http://globocan.iarc.fr/Pages/factsheets_cancer.aspx">http://globocan.iarc.fr/Pages/factsheets_cancer.aspx</a>           | Breast cancer is one of the major causes of morbidity and mortality in Kerala.  |

|                   |       |   |   |
|-------------------|-------|---|---|
| Indus Health Plus | 2017  | <a href="http://www.indushealthplus.com/kerala-health-statistics.html">http://www.indushealthplus.com/kerala-health-statistics.html</a> | Breast cancer is the most common malignancy among women in Kerala.  |
| Malvia et al.,    | 2017  | Asia- Pacific Journal of Clinical Oncology  | Thiruvananthapuram, the capital of Kerala ranks the highest in breast cancer crude rate. There is an urgent need for strengthening and enforcing early detection of breast cancer in India hence the need for making screening and treatment facilities more available. |
| WHO               | 2017a | <a href="http://www.who.int/cancer/country-profiles/ind_en.pdf?ua=1">http://www.who.int/cancer/country-profiles/ind_en.pdf?ua=1</a>     | Cancer deaths among females are due to breast cancer.   |
| John et al.,      | 2018  | Journal of Global Oncology  | In Kerala, an increased prevalence of major known risk factors of breast cancer like positive family history, low breastfeeding duration, and late age menopause.   |



### **2.4.3 Migration and breast cancer**

Since 1945, many countries have benefited economically and socially from large-scale migration from the South Asian nations of India, Pakistan, Bangladesh, Sri Lanka, Nepal, Maldives, and Bhutan (Whitehead, 2013). As stated by Anderson de Cuevas et al (2018), the UN human development reports of 2008 show that migration has largely favored English speaking countries, although large South Asian populations also exist in non-Anglophone European, African and neighboring Asian countries. In the UK, the South Asian population constitutes the largest ethnic minority category. In all host countries, historic migration patterns have led to the establishment of South Asian communities in cities and large towns where cultural norms and practices of the countries of origin are practiced alongside those of the host country (Vartika Sharma, Lopamudra Ray, Saraswati, Das, & Sarna, 2015). Bianco, Larosa, Pileggi, Nobile, & Pavia (2017) state that women make up approximately half of the world's one billion migrants and immigrant women tend to be the most vulnerable population with respect to healthcare. In the UK, Asian migrant women have higher breast and cervical cancer mortality than the host population, worse cancer related health outcomes, with the exception of some Indian groups, and are more likely to present with advanced disease (Anderson de Cuevas et al., 2018).

While Asian migrant women and host populations may differ over a range of factors that influence mortality, such as tumour subtype and human papillomavirus status (Anderson de Cuevas et al., 2018), one potential cause of greater mortality is that Asian women show a lower likelihood of attending routine mammographic and Pap smear screening. Possible explanations for this have included poorer individual knowledge and awareness of breast and cervical cancer, lower community awareness, poor communication between health professionals and patients, health professional's background and lower access to appropriate cancer health services (Gany, Palaniappan, Prasad, Acharya, & Leng, 2019; Redwood-Campbell, Fowler, Laryea, Howard, & Kaczorowski, 2011). For example, some South Asian women cannot speak or read in the host language (Jain, Acik-Toprak, Serevitch, & Nazroo, 2009; Sokal, 2010). Another

body of research that focused on Asian women's attitudes, beliefs, and behaviors relating to cancer screening reported similar findings (Crawford et al., 2016; Wu, Lin, Chen, & Jung, 2014).

Furthermore, ample research has reported the incidence of breast cancer and late detection among migrant women. Studies undertaken in Europe and North America suggest that an increase in the incidence of breast cancer occurs when migrants move from countries with low incidence rates to countries with high incidence rates. Many studies in Australia, McCredie, Coates, & Grulich (1994); Netherlands (Visser, van Der Kooy, van Peppen, Ory, & van Leeuwen, 2004), Sweden Hemminki, Li, & Czene (2002); Germany, Zeeb, Razum, Blettner, & Stegmaier, (2002); and Canada, Yavari et al (2006) reported that breast cancer incidence rates among immigrant populations vary between those recorded in their home and host countries. Among cancer (generally) Jaehn et al (2019) conclude that incidence among migrant populations may often remain the same between the population of origin and the new host population. However, most of these studies concluded that the environment where people reside and the lifestyles they lead contribute to the increase or decrease of cancer risks amongst the population. Still, no similar studies that establish the incidence rate of breast cancer among Keralites residing in UAE are available. It is then essential to compile such records that should include the age when an individual migrated to that country and the number of years she has resided in a particular area (John, Phipps, Davis, & Koo, 2005; Maringe et al., 2013).

Inadequate awareness or access to breast cancer screening programmes in the host country is also an important factor for participation in screening services by immigrant women. For instance, these women may find it difficult to discuss breast health with health care providers (Yavari et al., 2006) and this can be due to the language barrier, and the difference in the religious, cultural or traditional customs (Azeem Samera et al., 2014). Thus, it can be concluded that migration to another country and other socio-ecological factors determine women's breast cancer screening behaviours.

WHO (2017,2020) declared that different factors (socio-ecological determinants) merge with culture to affect the health of individuals. Awareness, social and cultural behaviour, and the effect of place of residence are interdependent in the interpretation of the holistic picture of

health behaviour of an individual and society (McLaren & Hawe, 2005). Culture has an impact on how individuals relate to health beliefs, and it has an influence on what a particular group can choose to believe about a disease especially breast cancer (Cariou et al., 2018a). Culture is defined as the “complex whole which includes knowledge, beliefs, arts, morals, law, customs, and any other capabilities and habits acquired... as a member of society” (Tylor, 1871, p. 1). In fact, health perceptions and practises are shaped by the socio-cultural beliefs of the area that different people belong to (Bilikisu Elewonibi & Rhonda BeLue, 2019; Elobaid et al., 2016; Kalitzkus, Twohig, & Making Sense of Health, 2008; Waring, Allen, Braithwaite, & Sandall, 2016). For example, Harcourt et al (2014) examined the rates of cancer screening and factors associated with cancer screening behaviour among African immigrant women in Minnesota. They surveyed a community-based sample from African immigrants from 1009 households in Twin Cities. The study found that only 61 % of the age eligible women in the sample had ever been screened for breast cancer. Among these women, the duration of residence in the US and ethnicity were significant determinants associated with non-screening. It is evident that understanding these factors will help to improve the health care practices of individuals beyond improvements made to the healthcare systems alone.

Another study conducted by Bianco et al (2017) explored breast and cervical cancer screening participation to determine the levels of access to healthcare services during pregnancy, childbirth and the postpartum period among immigrant women aged 50- 69 years without history of breast cancer in Southern Italy using a structured questionnaire. The study concludes that women-centred strategies should be in place for promoting timely and regular cancer screening among immigrant women.

Furthermore, Suwankhong & Liamputtong (2018) studied early detection of breast cancer and barriers to screening programmes among Thai migrant women living in Metropolitan Melbourne in Australia. Using a semi-structured in-depth interview procedure and drawing method, data were collected from 25 Thai migrant women who had not undergone breast cancer. Their study concluded that despite seeing a breast cancer screening programme as important, the women rarely paid attention to breast cancer screening and rarely used the

mammography service provided by the Australian healthcare system. The barriers identified by their study were the location of the services, the unfamiliar pattern of healthcare provision, lack of knowledge about breast cancer, and language difficulties.

Individuals who migrate contribute diversity to their adopted countries, but they experience multiple stresses that can impact their mental well-being such as loss of cultural norms and social support systems, and changes in identity and concept of self (Bhugra & Becker 2005). Therefore, it can be concluded that, as expatriates, Keralite women residing in the UAE might have different cultural values to their compatriots still residing in their home country. The target research participants in this research comprise a unique cultural group different from Emirati nationals and from other Keralites who have been exposed to multiple cultural influences. Studies addressing this particular group in terms of cultural perceptions, socio-ecological determinants for screening mammography and health behaviour have not been identified to date. Therefore, conducting a study on screening mammography and health behaviour of this population will help all stakeholders, healthcare services and breast cancer screening organisations, to develop appropriate interventions to improve the uptake of screening mammography to these women in the UAE. Table 2.3 provides a summary of a number of studies that focused on migration and breast cancer.

**Table 2. 3 Migration and breast cancer**

| Study             | Year | Journal/ Weblink                             | Findings  |
|-------------------|------|--|---|
| McLaren et al.,   | 2005 | Journal of Epidemiology and Community Health | Awareness, social, cultural behaviour, and the effect of place of residence are interdependent in the interpretation of the holistic picture of health behaviour of an individual and society.  |
| Bhugra et al.,    | 2005 | World Psychiatry                             | Individuals who migrate contribute richness in diversity of cultures, but they experience multiple stresses that can impact their mental well-being such as loss of cultural norms and social support systems, and changes in identity and concept of self. |
| Yavari et al.,    | 2006 | Asian Pacific journal of cancer prevention   | Breast cancer incidence rates among immigrant populations vary between the rates recorded in their home and host countries.   |
| Jain et al.,      | 2009 | University Hospital of South Manchester      | South Asian women cannot speak or read in the host language making it difficult for them to benefit from existing services.   |
| Maringe et al.,   | 2013 | International Journal of Cancer              | When migrant women undergo screening mammography, the records included in the medical file should have the age when an individual migrated to that country and the number of years she has resided in a particular area.                                    |
| Whitehead et al., | 2013 | Cancer Registration Statistics, England      | Many countries have benefited economically and socially from large-scale migration from the South Asian nations of India, Pakistan, Bangladesh, Sri Lanka, Nepal, Maldives, and Bhutan.   |

|                              |      |   |  |
|------------------------------|------|---|--|
| Azeem Samera, Kumar, & Ursin | 2014 | <a href="https://www.fhi.no/globalasset/s/dokumenterfiler/rapporter/2014/incidence-and-associated-risk-factors-for-cancer-among-immigrants-2014.pdf">https://www.fhi.no/globalasset/s/dokumenterfiler/rapporter/2014/incidence-and-associated-risk-factors-for-cancer-among-immigrants-2014.pdf</a> | The difficulties immigrants face discussing breast health with healthcare providers may be due to the language barrier, and the differences in the religious, cultural or traditional customs. |
| Harcourt et al.,             | 2014 | Journal of Immigrant and<br>Journal of immigrant and<br>minority Health   | Immigrant women tend to be one of the most vulnerable groups with respect to health care.  |
| Wu et al.,                   | 2014 | International Quarterly of<br>Community Health<br>Education   | Lack of awareness, language barrier, lack of access to health care facilities for breast cancer screening.   |
| Vartika et al.,              | 2015 | <a href="https://assets.publishing.service.gov.uk/media/57a08970ed915d3cfd000246/61263Desk-review.pdf">https://assets.publishing.service.gov.uk/media/57a08970ed915d3cfd000246/61263Desk-review.pdf</a>   | In all host countries, historic migration patterns have led to the establishment of South Asian communities in the host country.   |
| Crawford et al.,             | 2016 | Health and Social Care in the<br>Community  | Language barrier, lack of access to health care facilities for breast cancer screening.  |
| Bianco et al.,               | 2017 | BMJ Open  | Women make up approximately half of the world's one billion migrants and immigrant women tend to be the most vulnerable groups concerning  |

|                            |               |   |  |
|----------------------------|---------------|---|--|
|                            |               |   | <p>healthcare.</p> <p>Women-centred strategies should be in place for promoting timely and regular cancer screening among immigrant women.</p>   |
| WHO                        | 2017,<br>2020 | <a href="https://www.who.int/hia/evidence/doh/en/">https://www.who.int/hia/evidence/doh/en/</a> | Different socio-ecological determinants merge with culture to affect the health of individuals   |
| Anderson de Cuevas et al., | 2018          | BMJ Open  | <p>South Asian migration largely has favoured English-speaking countries.</p> <p>In the UK, Asian migrant women have higher breast and cervical cancer mortality than the host population.</p> <p>Asian women show a lower likelihood of attending routine mammographic and Pap smear screening.</p> |
| Cariou et al.,             | 2018          | PLoS ONE  | Culture has an impact on how individuals relate to health beliefs; it has an influence on what a particular culture can choose to believe about breast cancer.   |
| Suwankhong et al.,         | 2018          | Asian Pacific Journal of Cancer Prevention  | Barriers to migrants were the location of the services, the unfamiliar pattern of healthcare provision, lack of knowledge about breast cancer, and language difficulties.  |
| Gany et al.,               | 2019          | Journal of Immigrant and Minority Health  | Possible reasons for lower screening rates among Asian populations are poorer individual knowledge and awareness, lower community awareness, poor communication between health professionals and patients, health professional's background and less access to appropriate cancer health services.   |

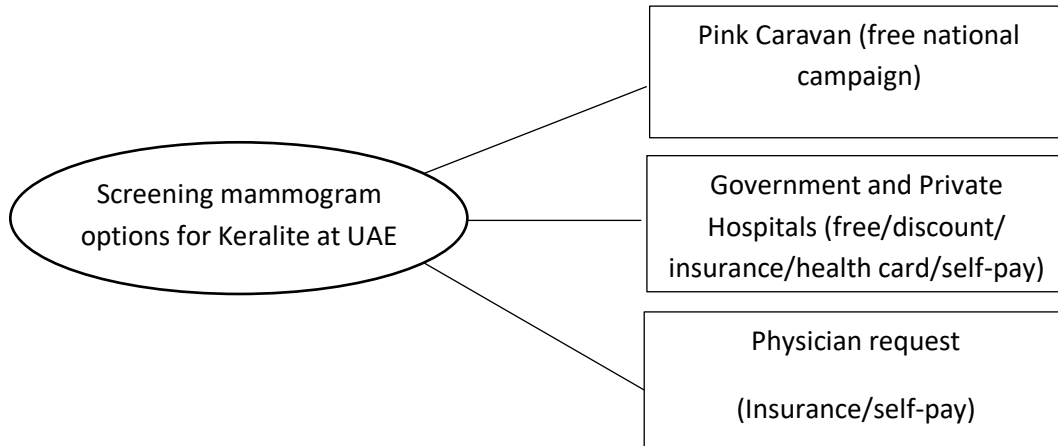
|                   |      |                    |   |
|-------------------|------|--------------------|---|
| Jaehn et al.,     | 2019 | BMC Cancer         | The incidence of cancer among migrant populations may often remain the same between the population of origin and the new host population. |
| Elewonibi et al., | 2019 | Ethnicity & Health | Health perceptions and practises are shaped by the socio-cultural beliefs of the area that peoples belong to.                             |



Thus, migration had also contributed to the richness in the variety of different cultures, perspectives, ethnicities and races (Bhugra & Becker, 2005; Bhugra et al., 2011; Bove & Elia, 2017). Studies also reveal that migrants may have increased risk of incidence of breast cancer (John et al (2005) face practical barriers and hold varied attitudes towards general health check-up and breast cancer screening (Ogunsiji, Kwok, & Fan, 2017; Robertshaw, Dhesi, & Jones, 2017). This can be due to a number of factors including linguistic, socio-cultural or religious differences between the healthcare professionals and the migrants receiving the service as well as the availability of services to the migrants in native and host country.

#### 2.4.4 Availability of screening mammography in UAE and Kerala

In UAE, for both locals and resident expatriates, free screening mammography is offered by some private and government hospitals (eg: University Hospital Sharjah, and Zulekha Hospital) as well as by Pink Caravan once or multiple times a year (2 to 3 times) through various local and national campaigns. There are also initiatives by Medclinic Hospital, Danat Al Emarat Hospital for Women and Children, Al Jalila Foundation in collaboration with Breast Friends among others who provide screening mammography facilities at various locations in UAE among both locals and migrants (Friends of cancer patients, 2018). In addition, some hospitals offer screening mammography at a discounted rate or offer self-pay options. Furthermore, depending on various health insurance policies inclusion and exclusion criteria a woman can undergo screening mammogram. The following figure 2.1 shows the possible options for a resident Keralite to undergo screening mammogram in UAE.



**Figure 2. 1 Screening mammogram options for Keralites at UAE**

Subsequently, there was a fall in the number of cancers diagnosed at the advanced stage after the introduction of free screening mammography services around UAE from 67% in 2007 to 16% in 2013 (HAAD, 2013). A report published in the Khaleej Times newspaper (Al Kuttub, 2017) offers a brief glimpse of prevailing trends in the UAE in terms of breast cancer and what the local authorities are attempting to achieve in order to limit the challenges it is posing to the society. They reported that the number of women who underwent breast cancer screening had increased in 2017 compared to previous years. However, as there is no unified UAE and Kerala national cancer registry available (Loney et al., 2013) or consolidated and up to date data reported, it is difficult to generalise and appreciate whether an increase in screening attendance relates to both the Emirati and migrant populations (Brewster, Coebergh, & Storm, 2005; Najjar & Easson, 2010).

In India, mammography and clinical breast exams are generally available in the public primary healthcare level (WHO, 2017). However the provision of healthcare facilities differ in India due to variations in levels of development from one region to the other and this deprives the majority of women of proper diagnosis (Simon, 2007; World atlas, 2017). To illustrate: the Centre for Budget and Governance Accountability (CGBA) states that comprehensive cancer care centres are not common and the quality of treatment provided vary (CBGA, 2015;

Kuraparthi et al., 2007). Because the Indian constitution states that each state government is responsible for its own health services, wide discrepancies can be noticed between different regions (CBGA, 2015; World atlas, 2017). For example, Bihar state lags far behind in terms of access to health care (Jana & Basu 2017). In fact, Kerala has an exceptionally advanced healthcare system compared to the less developed states of India, like Bihar (Jana & Basu 2017). Yet, although Kerala has strived to provide services for screening mammography and continuously aims to implement strategies that provide an advanced healthcare system (Jana & Basu 2017), breast cancer still remains a major health problem as it is the most common malignancy among women in Kerala (Kumar & Devi, 2010; Parameshwari, Muthukumar, & Jennifer, 2013). Several management challenges such as high absenteeism amongst staff at primary health centres (PHCs) and a general lack of sufficient training for effective service delivery in some Keralite rural areas have been pointed as key factors contributing to this situation (Rao, Nair, Nair, & Kamath, 2005). In a bid to reduce the discrepancies between states and also between rural and urban areas in terms of health delivery, the National Rural Health Mission (NRHM) in India has devised several strategies which take into consideration the need for providing united funds to enable and enhance local planning (e.g for breast cancer screening and treatment). Improvements to existing public health centres (PHCs) and community health centers (CHCs) can enhance their ability to tackle cases related to breast cancer through effective screening and devising appropriate and effective treatment plans.

Jana and Basu (2017) further noted that the National Rural Health Mission (NRHM) is also mandated to provide affordable, accessible, accountable, reliable and effective primary healthcare that is meant to bridge the existing gap in rural health care through the institution of accredited social health activists (ASHA). These are trained community health workers whose role is to raise health awareness among members of their assigned communities and encourage them to make full use of the health facilities available to them. All this shows that India has implemented several initiatives that are meant to help in the fight against breast cancer.

#### **2.4.5 Barriers and facilitators of breast cancer screening**

A number of factors that affect the rate of uptake of breast cancer screening have been identified in the past few years. These range from the physical, like the distance of the screening facility from a potential user's residence, to the socio-economic. One major factor that has been cited in many studies is the level of awareness of the benefits, procedures, and availability of screening among diverse populations (Elobaid, Aw, Lim, Hamid, & Grivna, 2016; Yusra, Tar Ching, Michal, & Nico, 2014).

Exploring the prevalent knowledge, beliefs, attitudes, and practices towards breast cancer and its screening methods among women living in the emirate of Ras Al Khaimah (RAK), (Salman M. Albeshan et al., 2017) interviewed 102 women. They concluded that participants' knowledge and practice of breast cancer early detection screening are currently inadequate.

Several socio-economic factors have also been identified as significant determinants of attempts to increase screening uptake. For example, (Naja, Nasreddine, Awada, El Sayed Ahmad, & Hwalla, 2019) found that the average age of breast cancer diagnosis appears to be a decade earlier in Middle Eastern countries compared to Western countries, and its incidence is predicted to further increase. They further estimated that 30% of breast cancer cases are due to environmental and lifestyle factors such as obesity, diet, and hence preventable. In addition, (Channon AA et al., 2019) attempted to provide a baseline for national estimates for mammography and Pap smear screening and to explore the association between screening uptake and socioeconomic factors. They used the nationally representative World Health Survey Plus, implemented in 2008/2009 in Kuwait, Oman, Saudi Arabia, and UAE. The percentage of women aged 40-75 years who had a mammogram were 4.9% in Saudi Arabia, 8.9% in Oman, 13.9% in the UAE, and 14.6% in Kuwait. Marital status, wealth, education, nationality and place of residence were influencers of screening uptake, with the lower educated, poor, and unmarried having the lowest percentage of uptake. Another study explored the barriers and enablers that significantly impact access to early screening, detection, and diagnosis of breast cancer both globally and more specifically in the Middle East and North

Africa (MENA) region particularly Egypt, Jordan, Oman, Saudi Arabia, UAE, Kuwait, with specific focus on health systems (Bowser, Marqusee, El Koussa, & Atun, 2017). It identified seven barriers and enablers at the health system or provider level as significantly influencing screening for breast cancer: access to insurance, physician recommendation, physician's gender, provider characteristics, having a regular provider, fear of the system or procedure, and knowledge of the healthcare system.

Prevalent beliefs and perceptions in a particular social group also have a considerable impact on a woman's decision to undergo mammography. To illustrate, a study carried out by (Youlden, Cramb, Yip, & Baade, 2014) in the Asia-Pacific region concluded that access to optimal treatment and early detection plays a vital role in survival from breast cancer. The study also established that there are several cultural and economic obstacles involved in managing breast cancer in parts of the Asia-Pacific region, including misunderstanding about the disease (such as the false belief that the surgery will cause cancer cells to spread more quickly), geographical isolation, lack of education and awareness, inadequate diagnostic equipment and treatment facilities, competing health care needs and a reliance on traditional remedies. These factors may influence treatment decisions and adherence to social implications, such as the possibility of abandonment following a mastectomy or the perception that a breast cancer patient may become a burden to her family, can also cause fear, denial, and reluctance to visit a doctor. Another study that focused on Latin American women ((Doede, Mitchell, Wilson, Panagides, & Oriá, 2018)) also deduced that perception of fear of the breast cancer screening experience, discomfort about the initial mammography, fear of pain and discomfort are some of the general forms of negative perceptions associated with breast cancer screening which caused women to delay attendance to mammography screening. The same kind of mentality may be detected among migrant Keralite women in UAE.

Other issues that may influence reported differences in breast cancer incidence between countries include the individual's socio-economic status, utilisation of mammography, and the scope and accuracy of cancer registry data. Screening uptake is generally associated with greater personal wealth, ease of access to breast cancer screening, and areas where there are

mechanisms in place for full population-based collection of all cases of cancer. The late presentation of cases may be due to factors such as fear and uncertainty of screening (Augustine et al., 2014; Ebubedike, Umeh, & C Anyanwu, 2018).

To add, being a member of an underprivileged minority or migrant group may disadvantage a woman and lower her chances of utilizing existing screening services in her host country. A recent systematic review conducted by (Jerome-D'emilia, Gachupin, & Suplee, 2019) assessed the barriers and facilitators to mammography among native/Alaskan American Indian/Alaska women. Consistent with other low-income populations, socioeconomic factors were found to be responsible for low uptake. However, some factors, such as cultural issues and traditionalism were found to be unique influencers in their study population. Similarly, (Ogunsiji, Kwok, & Fan, 2017) a descriptive, cross-sectional study that attempted to understand breast cancer screening practices of African migrant women in Australia used breast cancer screening beliefs questionnaire to collect data from women who fell into the recommended age group (50-74 years). The main research variables were breast cancer screening practices and demographic characteristics of the migrant women who had and had not practised breast cancer screening (BSE, CBE or screening mammogram). The scores obtained using multivariable logistic regression identified significant differences in the "practical barriers" between women who had and had not practised breast cancer screening. Age and employment were found to be determining factors for participating in screening mammography. The research concluded that barriers and attitudes towards health check-ups are important factors that need to be taken into consideration. However, as the participants were only recruited from migrant resource centres in Australia, this study may not be generalizable to all migrant women. Further, as they used a structured questionnaire, an in-depth understanding of the participants' views may not have been achieved.

In Indonesia, using survey data, (Anwar et al., 2018) evaluated the potential determinants for participation in breast and cervical cancer screening. Their study concluded that of the 5397 respondents, 1058 women were aware of Pap smears, of which 297 had never had the procedure. Only 251 participants were aware of mammography. A total of 605 of women

reported that they performed BSE. In their study sample, higher education and household expenditure were consistently associated with higher odds of awareness about Pap smears and mammography. The enablers identified by their study were health insurance, shorter distance to health service, and social participation. This review of the literature suggests that there are recurrent factors that affect the rate of attending screening mammography across the globe. Many of those are socio-economic and cultural in nature.

Similarly, among the common barriers currently being faced by Keralite women in Kerala are limited access to screening mammography because of a lack of screening mammograms at some hospitals and a number of cultural beliefs and perceptions. Furthermore, it has been observed that women residing in Kerala had inadequate or no knowledge regarding breast cancer, its risk factors, and the importance of annual screening. Lack of adequate finances and diagnostic equipment in hospitals are among the reasons why some women do not attend screening mammography (Sreedevi, Quereshi, Kurian, & Kamamma, 2014). However, the researchers interviewed 809 women from among residents of only one block, the Vypin block of Ernakulum. Furthermore, Ernakulum is one of fourteen districts in Kerala (Government of Kerala, 2017) therefore the findings of this study cannot be generalised to the whole population of Kerala. Poor access to health care, lack of motivation to undergo screening, lack of local screening strategies, and lack of political commitment are some of other barriers that Keralites face at Kerala (Parambil et al., 2019).

#### **2.4.6 Awareness of breast cancer early detection among migrant Keralites**

Research that specifically focuses on the awareness of the importance of early detection among migrant Keralites has yet to be identified; however, several studies have explored this issue in Kerala. Nevertheless, it is important to note that the patients in that Indian state are usually diagnosed at late or advanced stages of the disease. In fact, the majority of patients would have reached the advanced stage of the diseases when they are attended to by an oncologist (Jose, 2015). Thus, there is a need to conduct regular screening mammography amongst women in order to decrease the rate of related mortality. The positive effect of early detection is evident

from the fact that 80% of cancer incidents diagnosed in developed countries are cured due to early detection by medical practitioners hence the need to organize awareness campaigns and models that will reduce breast cancer mortality in India (Jose, 2015).

One worrying trend is that awareness levels of nature, methods of diagnosis, and treatment of the condition are very low among Keralites. To illustrate, in a population-based survey, Siddique (2017) administered a questionnaire among 302 women residing in Kerala. His study concluded that the women's awareness of breast cancer symptoms, screening methods and the importance of early detection were very low. Based on these findings, the study recommended urgent educational interventional programmes for improving women's knowledge to encourage them to undergo breast cancer screening. The study suggested that primary healthcare providers can play a major role to raise awareness among women.

In addition, a breast cancer awareness and screening programme "Snehathalam" for women of Thiruvananthapuram (the capital city of Kerala) through CBE identified that breast cancer screening is not considered a priority by the Kerala community and that members of that community are not aware of the advantages of early detection (Union for International Cancer Control, 2016). This programme was hosted in coordination with the Regional Cancer Centre (located in Thiruvananthapuram, which performs a major service in the cancer care of Kerala), Sree Gokulam Medical College and Research Foundation, Swathi Saukhya, and prominent media partners in Kerala such as Manorama and Asianet. This programme screened 9942 women by CBE, among them, 868 ladies were detected with a breast lump and out of this 868, twelve women were confirmed with breast cancer through mammography. The need to attend regular breast examinations (i.e. screening) is often overlooked by the Kerala community. Women who are aware of mammography screening programmes and their importance usually attend only once in their lifetime when free screening is being conducted as part of an awareness programme (Union for International Cancer Control, 2016). Participants in the study suggested that government and non-government organisations should arrange free screening mammography to increase screening uptake.



Critical evaluation of breast cancer incidence in areas such as Kerala can result in increased survival rates and good quality of life for breast cancer patients. Awareness campaigns and screening initiatives encourage women to attend screening mammography and also cause a decrease in psychosocial barriers (Sreedevi et al., 2014). In addition, there is a need for cancer registries that record the specific cause of death and identify the type of cancer the deceased may have suffered. Cancer registries, public education on breast cancer and encouraging women to participate in screening programmes will make breast cancer a notifiable disease in Kerala (Padmavathy Amma & Sebastian, 2016).

Unfortunately, several studies have revealed that a large proportion of women from low-income countries are still not breast aware. A feasible solution is to educate women about the screening options available to them. Of all the screening techniques currently available, mammography requires specialised equipment and technical expertise and CBE requires a hospital visit, while BSE is a cost-free, simple, non-invasive intervention carried out by women themselves (Usha, Namitha, Minimol, Salini, & Jayasree Anandabhavan, 2017). This can be highly valuable to women from economically less privileged communities. Education about SBE and early detection strategies could be easily provided to women in Kerala as they have a high literacy rate (Jana & Basu 2017; Jayalekshmi, Gangadharan, & Mani, 2006). However, studies conducted in Kerala from 1993 (Nair, Sankaranarayanan, Nair, Padmakumari, & Cherian, 1993) until 2019 (Parambil et al., 2019) found that Keralite women lack awareness of the importance of early detection and present for treatment in advanced stages (Jayalekshmi et al., 2006; Jayalekshmi et al., 2009; Kerala Women, 2012; Parameshwari, Muthukumar, & H Jennifer, 2013; Siddique, 2017; Sreedevi et al., 2014).

Certain government initiatives show some promise, although more effort is evidently required. A camp-based study by Usha et al (2017) revealed that among the 319 women who attended the camp, 301 (94%) had heard of breast cancer and 110 (34%) thought it was common for a woman to get breast cancer. Around 36% (113) had heard of it recently from Anganwadi and Kudumbashree workers during their house-to-house visit. Anganwadi and Kudumbashree workers are employed in childcare, eradication of poverty, and women empowerment

programmes in India and normally have direct contact with women in need. The study also found that around 65% of the women knew at least one symptom of breast cancer, while 73% did not know the risk factors of breast cancer.

To sum up, numerous studies conducted in Kerala and other parts of India show that the level of knowledge about the symptoms and the risk factors of the disease is inadequate (Dey et al., 2016; Sreedevi et al., 2014). Therefore, in the absence of any reliable and group-specific data from the UAE, it might be reasonable to suspect that similar trends prevail among Keralite migrants in the country.

Literature shows that breast cancer is prevalent in Asian countries including India, UAE. To reduce the mortality breast cancer screening are available in these countries yet the attendance of women for screening mammography is low and women are getting diagnosed in advanced stages of breast cancer. Furthermore, large scale migration is common and migrants face multiple facilitators and barriers to access screening mammography compared to native women.

## **2.5 Health Behaviour Theories**

Prevention and early detection of a disease are the focus of healthcare now (WHO, 2018b). However, the effectiveness of these strategies through health programmes are dependent upon the active participation and 'the health behaviour of each individual' (Tabuchi et al., 2013). Table 2.4 provides a summary of research on health behaviour theories. Health behaviour can be generally defined as performances, activities and conducts that relate to health preservation, improvement and restoration; this includes any activity undertaken by a person believing herself to be healthy such as diet, physical activity and medical adherence (Conner & Norman, 2017; Short & Mollborn, 2015). Short & Mollborn (2015) are of the opinion that health behaviours (which they refer to as health-related behaviours) are various actions individuals take which subsequently influence or have an impact on their health or mortality.

These actions may be deliberate or unintentional, and either promote or detract from the overall health of the actor or other people around them.

Michael Cummings, Becker, & Maile (1980) identified that attitudes to health care, perceptions of disease threat, knowledge about the disease, accessibility to healthcare services, demographic factors, and social networks are major determinants for health behaviour. Still, most health behaviour interventions available are based on individual cognition and rational decision making. Sabado (2014) postulated that there are several inter-related factors that are crucial in determining health behaviours and even the subsequent attitudes that may arise in an individual or community. He further stated that these health related behaviours are determined by various influences that exist at multiple levels, and these include those that are personal (for instance the variables that are biological, psychological), then factors that are organisational/ institutional and environmental (these could be both social and physical), and also at a policy level.

Several theoretical models have been developed to predict the health behaviour of an individual and explain why people do and do not adopt certain health behaviours (Conner & Norman, 2005). The oldest was the Health Belief Model (HBM), which was developed in the early 1950s by psychologists Hochbaum, Rosenstock and Kegels while working in the U.S. Public Health Services after a failure in the TB screening programme. The HBM was one of the first theories to explain the process of change in relation to health behaviour and has been successfully adapted to fit diverse cultural and topical contexts (Orji, Vassileva, & Mandryk, 2012). It focuses on an individual's behaviour in response to the perceptions of illness threat and the perceived severity of the consequences of illness (Becker & Maiman, 1975; Rosenstock, 1966).

La Morte (2018) argues that the HBM originates from the psychological and behavioural frameworks with its core basis being that of two components of health related behavioural norms which are namely (a) The overall desire in individuals to avoid illness, or alternatively to get well if one is already ill; and, (b) The belief that a definite health action will avert, or cure a certain illness. Eventually, an individual's type or nature of the response to the prevailing

circumstances is often influenced by the person's opinions of the benefits and barriers that are related to one's health behaviour. He highlights that there are six basic constructs of the HBM. The first four constructs were advanced as the original tenets of the theory, and the last two were supplemented as research about the HBM continued to evolve. These six constructs are:

***Perceived susceptibility***- refers to a person's individual perception of the risk of developing a certain illness or disease. There is extensive variation in an individual's feelings of personal vulnerability to a certain illness or disease. In the case of breast cancer, issues of perceived susceptibility can be noted in light of how some women are more prone to breast cancer diagnosis because of their family history, which could be marked by a close family member who was diagnosed with the same condition. This is also true for cases of nulliparity and those who have their firstborn after the age of 30 (Al- Shamsi & Alrawi, 2018). All these are perceived cases of susceptibility due to a higher prevalence of breast cancer among these populations.

***Perceived severity***- alludes to a person's feelings towards the seriousness of contracting a certain illness or disease (or even merely leaving the illness or disease untreated). La Morte (2018) argues that there is a marked variation in a person's feelings in relation to the perceived severity of a specific disease. Often a person might get to consider the medical consequences such as death or disability, and also any social consequences such as the impact on their family life and social relationships when weighing the severity. In the case of breast cancer, some might assume that it is a health risk that is divorced from their own lives due to the fact that maybe no one in their family would have a victim of the disease before (Ebubedike et al., 2018).

***Perceived benefits***- This alludes to a person's opinions on the effectiveness of given arrangements or actions that could limit the threat of an illness or specific disease (or to even cure the illness or specific disease). Any course of action that an average person takes to avoid (or even cure) an illness or disease is heavily reliant upon a frank consideration and evaluation of both the perceived susceptibility and benefit to that given individual in light of the risk posed by a certain disease. LaMorte (2019) argues that it is only after such an analysis that a person would accept the adopted health action if it is perceived to be beneficial.

**Perceived barriers** - this is meant to highlight an average person's perceptions of the possible obstacles to performing a recommended health action under given circumstances. Individual feelings of actual and perceived barriers do vary contextually from one community to another depending on the levels of educational background, level of economic and infrastructural development among other factors. These variables force individuals to carry out a cost and benefit analysis of the effectiveness of action against the perceptions that it may be expensive, dangerous (e.g., side effects), unpleasant (e.g., painful), time consuming, or inconvenient (LaMorte, 2019).

**Cue to action** - this is the stimulus needed to trigger the decision-making process to accept a recommended health action. These cues can be internal (e.g., chest pains, wheezing, etc.) in this case more appropriate cues would be lumps or discomfort in the breast or external (e.g., advice from others, illness of family member, newspaper articles, etc.). In the context of the UAE, there are various campaigns held by organisations such as Breast Friends, which help to promote breast cancer awareness.

**Self-efficacy** refers to the level of a person's confidence in his or her ability to successfully perform a behaviour. This construct was added to the model most recently in the mid-1980s. Self-efficacy is a construct in many behavioural theories as it directly relates to whether a person performs the desired behaviour. In this case, self-efficacy is seen as the manner in which women might opt to go for mammography or conduct BSE activities as a result of capacity building as informed by Malvia et al (2014); Park et al (2018) and Cariou et al (2018).

Another theory, the theory of reasoned action (TRA) Fishbein (1975) was developed based on the individual's assumption about the consequences of their behaviours before engaging in an action. Then in 1985, the TRA was extended as the theory of planned behaviour (TPB) (Ajzen, 1985). The TPB states that the likelihood of a behavioural change of an individual depends on the amount of control a person has over a new behaviour and the strength of their intention to change. In 1986, the social cognitive theory (SCT) was formulated (Bandura, 1986). It states that an individual behaves or learns not only through their personal experience but also through

observation and imitation of others' behaviours and actions. Another important theory that looks into health behaviour is the trans-theoretical model (TTM) or stages of change model (Diclemente & Prochaska, 1982), which analyses an individual's willingness to change their health-related behaviour. The TTM also postulates that changes and intentions to change vary among individuals.

These theories have been applied in order to fully understand how women behave when undergoing screening mammography at a certain age and in a particular environment (for example (Lawal, Murphy, Hogg, & Nightingale, 2017). The socio-economic characteristics and cultural beliefs can impact a woman's decision to undergo screening mammography and these theories seek to explain this health behaviour (Abraham & Sheeran, 2015).

A widespread health behaviour change requires effective intervention strategies focused not only on individuals but also focused on health policies (McKinlay, 1995). However, the aforementioned theories place great emphasis on an individual's behaviour whilst overlooking other important health behaviour determinants such as the influence of the environmental, socio-cultural, economic and policy factors. The socio-ecological model (SEM) of health emphasizes and identifies that an individual's health behaviour is shaped by the interaction between the individual's social and physical environment (McLeroy, Bibeau, Steckler, & Glanz, 1988). The SEM is derived from ecological systems theory Bronfenbrenner (1979), which was formulated by Urie Bronfenbrenner.

Health promotion interventions based on ecological theories were notable for planning and assessing complex health interventions (Rowley et al., 2015). However, there is no single explanation as to why some people take opportunities to manage their health, while others do not. The reasons are complex and multifaceted. Demographic variables, socioeconomic, peer influences, cultural and ethnic statuses have reliable associations with the health behaviour of an individual (Matarazzo, 1980; McNeill et al., 1989; Taylor, 1990).

Bronfenbrenner (1977) examined childhood human development focussing on three main aspects; (1) an individual's perspective of the environment; (2) the environment surrounding that individual; and (3) the dynamic interaction between the individual and the environment.

Research in human development focuses on continuous development throughout the lifetime of an individual between the growing human and the changing surroundings in which the individual is actually rooted. The surroundings not only include the individuals themselves but embraces both their formal and informal social contexts (Bronfenbrenner, 1977). The term 'development' can be defined as a continuous change in the way an individual perceives and merges or acclimates to the environment.

The naturalistic observation of human development goes beyond the direct observation of the behaviour of one or two people in the same place; it requires examination of synergy between multiple people and settings as the environment can change beyond the immediate situation involving a subject. Thus, the scientific perspective is a convergence of both the naturalistic, experimental approach and the theoretical concepts of the environment which underlie an individual and this is termed the ecology of human development (Bronfenbrenner, 1977).

Bronfenbrenner (1977) defined the ecology of human development as *'the scientific study of the progressive, mutual accommodation, throughout the life span, between a growing human organism and the changing immediate environments in which it lives, as this process is affected by relations obtaining within and between these immediate settings, as well as the larger social contexts, both formal and informal, in which the settings are embedded.'*

The ecological environment of human development can be depicted using different levels, and each level can be discussed using the following terms Brim (1975): a) microsystem, b) mesosystem c) exosystem and d) macrosystem. Microsystem involves the complex relations between the developing person and environment in an immediate "setting" containing that person. For example, in the case of screening mammogram uptake, it can be the home or workplace of the woman. A "setting" is a place where the individual performs certain activities in certain roles (e.g., wife and employee). Thus the elements of activity, place, time and role constitute the components of a setting while the mesosystem encompasses the interaction among the settings involving the individual at a particular point in their lifetime (for example, the women's interaction with the community or her spiritual network). The exosystem is an extension of the mesosystem encircling unique social structures, both formal and informal that

do not include the immediate settings in which the individual is involved or over which they have control, for examples the media and the availability of healthcare services supporting the uptake of health programs by a woman. Finally, the macrosystem refers to the overarching institutional patterns of the culture and subculture; the educational, legal, political systems and so on.

A naturalistic observation, therefore, involves both the physical and biological systems, as this progression is necessarily the approach of choice in human behaviour and development (Bronfenbrenner, 1977). However, if an investigation is considered to be ecologically valid, it needs to be undertaken in a naturalistic setting and involves objects and activities from everyday life. Thus, ecological validity can be defined as the 'extent to which the environment experienced by the subjects in a scientific investigation has the properties it is supposed or assumed to have by the investigator' (Bronfenbrenner, 1977). The current research can be ecologically valid as it is undertaken in a naturalistic setting and involves individuals and specific activities (practicing breast cancer screening).

As a result of the on-going social interest in preventing illness, many health promotion programs have led to comprehensive development and practice through various public, private and professional bodies. The term "lifestyle and health behaviour" focuses attention on changing individuals rather than changing the social and physical environment that help maintain and fortify unhealthy behaviours. However, the extent to which health promotion focuses on individuals often overlooks individual choices. This needs to be considered because the social and organisational context of health related behaviours varies among specific groups in any given society. Further, in large-scale community interventions, behavioural psychologists emphasize the individual aspects and believe patient education is the most effective method to change health behaviour of the individual. Yet, the concentration on change of an individual's behaviour requires action to change organisational, environmental and economic situations that shape human behaviour (McLeroy et al., 1988). Nevertheless, there is still a lack of health promotion activities, which consider the social association of diseases and individual choices.



Combining the theory of individual development with Bronfenbrenner's ecological model, Belsky (1980) developed another framework to study the individual, family, social and cultural influences in child abuse. Specifically, this ecological model viewed individual behaviour as being affected by and affecting the social environment. Another conceptual framework developed in 1985 to institutionalise health related activities through the involvement of the church as a "social unit" highlighted the positive influence of social support in health related outcomes (Eng, Hatch, & Callan, 1985). However, the major shortcoming of these ecological models is that they lacked specificity to guide adequate interventions. McLeroy et al (1988) used a variation of Bronfenbrenner's (1979) ecological model and adopted the Belsky's and Eng's frameworks to develop an ecological model for health promotion. In this new model, patterned behaviour is the outcome of interest, and the behaviour is viewed and determined by the following:

**Individual factors-** include the characteristics of the individual such as knowledge, behaviour, self-concept etc. This factor states the developmental history of the individual. In the context of screening mammography uptake, it can be a woman's awareness of the importance of early detection, health behaviour patterns, and self-concept regarding susceptibility to breast cancer.

**Interpersonal factors and primary groups-** the formal and informal social network and support systems that surround an individual; the family, friendship networks, etc. In connection to screening mammography uptake, it can be the support and encouragement offered by family and friends to undergo breast screening.

**Community factors-** these are the factors that developed as a result of the relationship among organisations, institutions, and other informal networks that surround the individual. These factors include churches, community centres, etc.

**Institutional (Organisational) factors** - this refers to the social institutions with organisational characteristics (both the formal and informal), rules, and regulations for operation; for example the employer of an individual. Here in this context of migrant Keralite women in the UAE, it can be the support offered by the employer in terms of work hours, health insurance and so on.

**Public policy-** this is inclusive of local, state, and national laws and policies. In connection to screening mammography, it can be the availability of conveniently located healthcare facilities, free mammograms, etc.

Taking these levels into consideration can help researchers to develop health promotion interventions based on beliefs, understandings of their participants and theories of the determinants of behaviour. Moreover, this socio-ecological framework (see figure 2.2 )can help researchers understand the different levels of a social system and the interrelationship between individuals and the environment within this system (Reifsnider, Gallagher, & Forgione, 2005).



Figure 2. 2 The socio-ecological model (McLeroy et al., 1988)

The SEM can offer longstanding applicable solutions by appraising every aspect of a given situation. The outcome is more likely to be successful if the roots of problems are identified and measures are taken to address these rather than only solving problems of immediate attention. Ecological models are now common in public health practice and centres (Golden & Earp, 2012). The U.S Centers for Disease Control and Prevention and the World Health Organisation have also started adopting the socio-ecological perspective in their programme designs (CDC, 2015; Golden & Earp, 2012; WHO, 2018b). In this research, SEM has been adopted to understand the socio-ecological determinants for breast cancer screening among Keralite women residing in the UAE.

**Table 2. 4 Studies discussing health behaviour theories**

| Study                              | Year | Journal/ Weblink                            | Findings  |
|------------------------------------|------|---|---|
| Becker & Maiman,                   | 1975 | Medical Care                                | The HBM focuses on an individual's behaviour in response to the perceptions of illness threat and the perceived severity of the consequences of illness   |
| Michael Cummings, Becker, & Maile, | 1980 | Journal of Behavioral Medicine              | Individual health behaviour is determined by attitudes towards health care, perceptions of disease threat, knowledge about the disease, accessibility to healthcare services, demographic factors, and social network |
| Matarazzo,                         | 1980 | American Psychologist                       | Demographic variables, socioeconomic, peer influences, cultural and ethnic statuses affect the health behaviour of an individual  |
| Diclemente & Prochaska,            | 1982 | Addictive Behaviors                         | The trans-theoretical model (TTM) or stages of change model evaluate an individual's willingness to change their health-related behaviour   |
| Ajzen,                             | 1985 | Springer Series in Social Psychology        | The theory of reasoned action (TRA) is based on the individual's assumption about the consequences of their behaviours before engaging in an action   |
| McKinlay,                          | 1995 | Preparation for Aging                       | A widespread health behaviour change requires effective intervention strategies focused not only towards individuals but also focused on health policies  |
| Orji, Vassileva, & Mandryk,        | 2012 | Online Journal of Public Health Informatics | The health belief model (HBM) explains the process of change in relation to health behaviour and can be successfully adapted in diverse cultural and topical contexts   |
| Tabuchi et al.,                    | 2013 | International                               | The effectiveness and success of these health care strategies depends upon  |

|                    |      |   |  |
|--------------------|------|---|--|
|                    |      | Journal of Cancer   | the behaviour of individuals   |
| Short & Mollborn,  | 2015 | Current Opinion in Psychology   | Health behaviours are various actions individuals take which subsequently have an impact on their health or mortality  |
| Abraham & Sheeran, | 2015 | McGraw-Hill   | Socio-economic characteristics, social and cultural beliefs affect screening mammography   |
| Conner & Norman,   | 2017 | Psychology & Health   | Health behaviours include any activity undertaken by a person believing herself to be healthy such as diet, physical activity, and medical adherence   |
| B. K. Kim et al.,  | 2018 | Journal of breast cancer  | Self-efficacy is seen in the manner in which women might opt to go for mammography or conduct BSE activities as a result of capacity building  |
| LaMorte,           | 2019 | <a href="http://sphweb.bu-mc.bu.edu/otlt/MPH-Modules/SB/BehavioralChangeTheories/BehavioralChangeTheories2.html">http://sphweb.bu-mc.bu.edu/otlt/MPH-Modules/SB/BehavioralChangeTheories/BehavioralChangeTheories2.html</a> | The HBM originates from the psychological and behavioural frameworks with its core basis being that of two components of health-related behavioural norms which are namely (a) The overall desire of individuals to avoid illness; and, (b) The belief that a definite health action will avert, or cure a certain illness |

## **2.5.1 The role of socio-ecological determinants in screening mammography**

This section of the literature review explores what is known about the influence of each level of SEM in health promotion in varying contexts. This helped to understand the importance of identifying socio-ecological determinants to health behaviours, and specifically breast cancer screening. Overall, there seems to be ample evidence to support the assumption that all levels in the socio-ecological model have a pivotal role in influencing women's breast cancer screening behaviour and there exists a gap in the literature among the Keralite women in the UAE.

### **2.5.1.1 Individual level**

***Language and lack of knowledge/ awareness of breast cancer:*** the language barrier can discourage women from undergoing breast cancer screening. This was revealed by a study conducted by McGarvey et al (2003) in the USA among three different ethnic groups: Hispanic, Vietnamese, and Cambodian. Their analysis exposed that 38% of the participants lacked early detection awareness of breast cancer and were in need of personalised education. Whereas, 46% of the participants had not attended breast cancer screening due to the language barrier. Participants in this study suggested that the rate of mammography uptake can significantly increase if health educators or health professionals of the same ethnicity would conduct the screening programmes in the women's first language. Lack of medical insurance was also found to be a barrier to these three ethnic groups of women. However, this study did not include women who underwent breast or cervical cancer screening, which would have helped to identify the facilitating factors as well as the barriers to undergoing cancer screening for each ethnic group.

In the context of Saudi Arabia, Alshahrani et al (2018) conducted a study on a sample of 500 women of different ages and socio-cultural backgrounds. They found that only 19% of the study participants possess adequate knowledge about BSE. Overall, a lack of knowledge about breast cancer symptoms, BSE, CBE, and screening mammography was identified as common barriers to effective breast cancer screening strategies.

Another study Ardahan, Dinc, Yaman, Aykir, & Aslan (2015) explored the perceptions of first-year nursing faculty students regarding BSE. Their study revealed that 85.5% of students had knowledge about breast cancer. In addition, 65.3% of the students stated that they knew how to carry out SBE, 19% of students were completely unaware of BSE procedure, and 15.7% had some knowledge about SBE.

In the UAE, Rahman et al (2019) conducted a cross-sectional study to explore awareness of breast cancer and BSE as a screening tool among female students at the University of Sharjah, UAE. They collected the data through a self-administrated questionnaire filled by 241 undergraduate female students (aged  $\geq 18$  years) from three campuses of the University of Sharjah. They concluded that most (99%) of the participants had heard of breast cancer. About 50% were knowledgeable about the risk factors, but only 38% were knowledgeable about the warning signs/symptoms. The most commonly identified risk factors were family and personal histories of breast cancer, and the most commonly identified warning symptom was a breast lump. The study concluded that knowledge about performing BSE was particularly low and highlighted the importance of increasing awareness of breast cancer screening among young women in the UAE.

A 10-year review of the literature by (Johnson, 2019) assessed the levels of awareness and practice of BSE among women in different countries of Africa. A major barrier identified was inadequate knowledge of BSE. In addition, a study carried out by Paul, Solanki, Shahi, & Srikrishna (2015) among a sample population of 560 women of the age group 18 to 65 residing in different locations of Varanasi city in India. They concluded that individual characteristics directly influence breast cancer screening knowledge. It was also revealed that the participants had a moderate level of knowledge of breast cancer but lacked awareness of the risk factors of breast cancer as compared to residents of other cities. Their study further showed that contemporary women are career-oriented (also noted by Augustine et al (2014), which resulted in a trend whereby some women tend to delay or avoid childbirth, and some may even neglect the need to know about breast cancer. Therefore, this research attempts to analyse the lifestyle

of Keralite women in the UAE and assess if they are failing to gain adequate knowledge about breast cancer due to variables such as career orientation.

### ***Fear of a positive diagnosis and social exclusion***

Despite advances in the early diagnosis and treatment of many cancers, a third to half of the general population in the United States and the United Kingdom say that they fear cancer more than any other disease (Vrinten et al., 2017). Recent population-based studies have consistently shown that about a quarter to half of the population worry to some extent about getting cancer, with 5%–10% experiencing extreme worry (Vrinten et al., 2017). Furthermore, Vrinten et al (2017) explored fear's behavioral effects in relation to breast, cervical, and colorectal cancer screening through a critical review of 102 studies from 26 countries using thematic synthesis. They concluded that fear of cancer emanated from a core view of cancer as a vicious, unpredictable, and indestructible enemy, evoking fears about its proximity, the lack of strategies to keep it at bay, the personal and social implications of succumbing to the disease, and fear of dying from cancer. More specifically, they found that fears about the social consequences of a cancer diagnosis were mentioned in about a third of the included studies. Half of these mentioned fears about others' reactions, such as being stigmatised or blamed (Marlow, Waller, & Wardle (2015), Misha Granada, Cornelia Guell, Ian Hambleton, Anselm Hennis, & Rose (2014), since cancer was sometimes seen as a punishment for sins or bad karma. Cervical and breast cancers were associated with promiscuous behaviour, provoking fears of social rejection and gossip: '[Women] are worried about what will people say, [...] questions will be raised, and I will have to feel ashamed'. Some, therefore, preferred to avoid screening to avoid being diagnosed (Vrinten et al., 2017).

***Fear of radiation*** : the main aim of mammographic screening is to reduce mortality from breast cancer through early detection. Radiation associated with breast imaging is a sensitive issue, particularly for women who need to undergo mammography as a screening measure to detect breast cancer. Misinformation and misunderstanding regarding the risks associated with ionizing radiation have created heightened public concern and fear, which may result in avoidance of diagnostic procedures. A study carried out by Hauge, Pedersen , Olerud , Hole , &



Hofvind (2014) estimated the potential number of radiation-induced breast cancers, radiation-induced breast cancer deaths, and lives saved due to implementation of organised mammographic screening as performed in Norway. They used a previously published excess absolute risk model that assumes a linear no-threshold dose-response. The estimates were calculated for 100,000 women aged 50–69 years, with a screening interval of 2 years, and an assumed follow-up until the age of 85 or 105 years. Their study concluded that the risk of radiation-induced breast cancer and breast cancer death due to mammographic screening is minimal. Women should not be discouraged from attending screening due to fear of radiation-induced breast cancer death.

Another study Hollada et al (2015) enrolled 1725 patients presenting for mammogram over a period of 9 months. They collected the data through a 25-point questionnaire that was composed of general knowledge regarding radiation dose in common imaging modalities, the amount of radiation associated with a mammogram relative to five radiation benchmarks, and patients' opinions of the involvement of radiation in their health care. Their study concluded that efforts should be made to accurately inform women of the risks and benefits of mammography, specifically highlighting the low dose of mammographic ionizing radiation and providing objective facts to ensure that they are making an informed decision regarding screening.

***Individual cultural and religious beliefs-*** individual religious beliefs also play a vital role in a woman's decision to undergo mammography. A study conducted by Padela et al (2016) examined religious beliefs and mammography intention among a diverse group of American Muslim women. Fifty women participated in 6 focus groups and 19 in semi-structured interviews, with near-equal numbers of African American, South Asian, and Arab Muslims. Their study concluded that religious beliefs influence the decision to undergo mammography across the ethnic/racial diversity of Muslim women. Notions about the duty to God and the stewardship of one's body appear to enhance mammography intention regarding breast cancer screening. The unjustified notions of cure and illness and varied views regarding personal beliefs also inform decisions that impact mammography intention. Given the salience of religion

among the present study participants, religiously tailored messages in interventions have the potential to enhance cancer screening.

Similarly, another study examined the relationships between religiosity—as measured by religious service attendance—and screening for breast, cervical, and colorectal cancers along with the role of social support and the potential effect of race/ethnicity (Leyva, Nguyen, Allen, Taplin, & Moser, 2015). It was concluded that religiosity was associated with greater utilisation of breast, cervical, and colorectal cancer screening. Social support fully mediated the relationship between religiosity and Pap screening, and partially mediated the relationship between religiosity and colorectal screening, but had no effect on the relationship between religiosity and mammography screening. Race/ethnicity moderated the relationship between religiosity and social support in the cervical cancer-screening model, such that the positive association between religiosity and social support was stronger for non-Hispanic blacks than it was for non-Hispanic whites. These findings have implications for the role of social networks in health promotion and can inform cancer-screening interventions in faith-based settings.

Additionally, the length of migrant women's stay in a host country can affect their attitudes to the early detection of breast cancer (Ogunsiji et al., 2017). A cross-sectional exploratory study conducted by Vahabi (2011) in one of the provinces of Canada to analyse breast cancer screening practices among Iranian women found that the length of their stay in Canada changed their attitudes towards breast health practices. The longer they had stayed in the host country, the more willing they were to take part in screening practices. Out of their 50 participants, two-thirds demonstrated limited knowledge about breast cancer, risk factors, and screening practices. About 72% of the women were not aware of the recommended time interval and age to undergo screening mammography. The participants also stated that culturally sensitive educational materials could address their lack of awareness, and sending reminders would also motivate them to undergo breast cancer screening (Vahabi, 2011). The study also concluded that Individuals' beliefs and myths also affect their readiness to participate in screening mammography. It appears, however, that the small number of

participants and the research methodology adopted (questionnaires) might have limited the quality and validity of data.

#### **2.5.1.2 Interpersonal level**

Family income plays a major role in an individual's health behaviour. The Centre for Budget and Governance Accountability (CBGA) states that in India women are expected to have a lower share of household resources (CBGA, 2015). Health expenses are also high due to increased privatisation of healthcare and the reduced availability of public facilities. These factors result in women foregoing their own health needs, unable to afford to travel long distances to undergo screening mammography in Kerala (CBGA, 2015).

Other family members' motivation and awareness of screening mammography can positively affect women's participation (Missinne, Colman, & Bracke, 2013). A questionnaire survey was conducted to measure the extensiveness of breast cancer awareness and to develop an appropriate educational program among the population in Ireland. This study showed that participation in breast cancer screening is not only influenced by the women's awareness of screening but it is also shaped by their partners' attitudes and beliefs (McMenamin et al., 2005). Similarly, friends have an important role in improving the practice of breast cancer screening (Klassen & Washington, 2008; McMenamin et al., 2005).

Moreover, spiritual networks can positively affect women's attitudes towards and rates of participation in breast cancer screening. This was demonstrated by a cross-sectional survey done to understand the influence of social integration on breast cancer control among urban African- American women. It concluded that the participants' social roles, connections with social networks, social support, and spiritual integration had a positive impact and suggested organizing interventions to utilise these social determinants for women (Klassen & Washington, 2008). However, the results were analysed using old (1997-1998) interview data conducted at the participants' homes, therefore the authors might have missed other social determinants that could have been more relevant at the time when this research was published in 2008. There may also have been changes in the participants' education, culture, or socioeconomic status.

Another study by Karimi, Rafiey, Sajjadi, & Nosrati Nejad (2018) attempted to identify the social determinants of breast health behaviour based on the social determinants model of the WHO. The data were collected from 32 participants using semi-structured interviews and focused group discussions. The participants were comprised of breast surgeons, radiologists, healthcare providers, and women over 35 years of age in Tehran. Three themes emerged from the participants' responses that shaped the women's interpersonal breast health behaviour including the context of health policy, socioeconomic status, and cultural, psychological, and behavioural factors. Another study carried out by Molina et al (2015) analysed the influence of family/friend's recommendations on mammography intentions. Their study concluded that women whose family/friend recommended they got a mammogram in the previous year were more likely to report mammography intentions, norms, and support. In their study sample, perceived mammography norms mediated the relationship between family/friend recommendations and intentions.

According to Rainey et al (2018) "anxiety/worry" play a part in influencing women's decisions about breast cancer screening and that a proactive approach together with reassurances and the dissemination of knowledge are incentives to participate in breast cancer screening programmes. Rainey et al. further noted that women tend to relate to reassurance from medical practitioners and other stakeholders. Women react to intensified screening and breast cancer programmes that would be provided if they were above average risk. Conversely, it was noted that receiving a below average risk result provided no perceived reassurance for women (Koitsalu et al., 2016). Therefore, Rainey et al. (2018) argue that there is a need for an interpersonal relationship filled with reassurance for women to be in a position to be comfortable with breast cancer screening. The interpersonal reassuring relationships will enable women to overcome feelings of anxiety and worry about breast cancer screening and will lead to increased knowledge and the facilitation of women's acceptability of personalised screening and prevention methods, particularly of risk-reducing medication (Rainey et al., 2018). There is, therefore, a need to create enabling supportive interpersonal relationships and structures such that women feel more comfortable to undergo breast cancer screening. This

research study aims to relate such perspectives to the prevailing situation of Keralite women living in the UAE.

### **2.5.1.3 Community level**

The influence of the community of the beliefs, attitudes and health behaviour of its members is significant. Community organisations, medical professionals, the media, community leaders, and trusted community figures can promote certain health practices. This is of great value to any breast cancer preventive programme. For example, a study of systematically sampled medical journals between 2000-2017, which have a collective total sample of 17,770 female participants; Saei Ghare Naz, Simbar, Rashidi Fakari, & Ghasemi (2018) concluded that at the community level, there is a need for effective health education in order to enhance breast cancer awareness which in turn would lead to early diagnosis. A study by Saei et al (2018) noted that the transtheoretical model, systematic comprehensive health education and promotion model, health promotion model and the theory of planned behaviour are among some of the key models that can be used in different educational programmes to promote breast cancer awareness such as workshops, targeted emails, billboards and peer education initiatives. It was also noted that health models are valuable concerning health opinions by women (Berkiten et al., 2012). The research further notes that health promotion models are essential in enabling medical practitioners to be in a position to decipher and also demonstrate the prevailing attitudes towards breast cancer amongst women in the wider community (Saei Ghare Naz et al., 2018). Systematic comprehensive health education and promotion are therefore critical in enhancing health literacy and also the sustained mentoring of peer health educators (Hou, 2014; Khadije, Shadan Nessari, Talat, & Mohammad Taghi, 2016; Tappe & Galer-Unti, 2001). Consequently, strategic health education initiatives are essential as they will help empower women with effective knowledge about breast cancer and its screening methods. However, there lack research studies that assessed the impact of health education initiatives in the UAE and whether they have any impact on Keralite women residing in the UAE.

In the SEM, female health advisors and breast cancer survivors are considered as important social determinants. They are useful resources to promote community based breast cancer

screening education programmes. This was confirmed by an educational programme to promote breast and cervical cancer screening conducted in New York among Latinas (Saad-Harfouche et al., 2011). In their study, training was provided to female health advisors and breast cancer survivors. The researchers then assessed the participants' post-training knowledge about breast and cervical cancer to judge whether they were capable of educating the public. A noticeable increase in knowledge among female health advisors compared to breast cancer survivors was detected, even when the survivors had baseline knowledge of breast health before attending the training. The researchers suggested developing and customising public training sessions to be held by female health advisors and cancer survivors (Saad-Harfouche et al., 2011). This study found that involving more people in creating awareness of the importance of breast cancer screening was useful.

A community-based interventional study Park et al (2011) conducted in Korea in 2011 found that pre and post-educational interventions helped to raise awareness of the importance of early detection of breast cancer through mammography. The researchers conducted educational programmes in multiple cities in Korea. Before the educational programme, participants held false beliefs about breast size, the risk of cancer, and screening practices. After six or seven months of intervention, they approached the women and collected their views about breast cancer and screening. The results of the study showed a 14.1% increase in women's intention to undergo screening mammography Park et al (2011). Thus, educational intervention contributed to changing commonly held beliefs and myths about screening mammography. Nevertheless, further studies may be required to monitor these women's behaviour towards screening mammography.

An educational initiative and nurse support and follow-up were found successful in a study done in rural Louisiana, United States (Davis et al., 2014). This study aimed to improve the rates of mammography screening among people who have no health insurance coverage. It comprised a three-arm, quasi-experimental evaluation study. The three arms were: first enhanced care and support for getting appointments next to their place of residence, the second provided appropriate educational materials and the third was education along with

nurse support. In this third arm, the nurses took appointments and provided reminders to undergo screening on a scheduled date. If the women did not participate, the nurse followed up and rescheduled their appointments. It was found that more women participated and, therefore, education and nurse support were deemed an effective tool to promote screening mammography (Davis et al., 2014). However, it would have also been useful to follow up with non-attenders and identify common reasons for non-participation.

Lu et al (2012) conducted a systematic review that assessed the effectiveness of interventions for breast cancer screening among Asian women. They found that workplace-based group education sessions and mobile screening services were an effective tool to promote breast cancer screening. They reviewed studies published as of January 2010 targeting Asian women and concluded that community, social, culture-based and additional support programmes are required. Importantly, the study showed that multiple interventions are required to promote screening mammography in a particular community rather than a single intervention. It can, therefore, be concluded that more community-based research is required to identify the barriers met by minority populations in any given country which would ultimately help reduce the rates of breast cancer mortality there. There is also a need for ongoing communication between oncologists and patients about the importance of screening mammography, wide dissemination of information about breast cancer, continuous encouragement of women to participate in discussions on screening mammography (Cariou et al., 2018a; Elobaid et al., 2016; Tolma et al., 2019).

Moreover, (Wogu, Chukwu, Ugwuoke, Ugwulor-Onyinyechi, & Nwankiti (2019)) analysed the link between breast cancer preventive/curative measures and the contents of media campaigns against it. Their study used a structured questionnaire to collect responses from a sample of 1000 women that were randomly selected from markets, churches, schools, and civil services. Relevant published materials such as books, journal articles, conference proceedings, workshop papers, and internet posts were reviewed. They concluded that despite the high level of awareness, only 31.2% of the participants learned their information through media campaign; the awareness did not orchestrate health behaviour modification among the respondents,

while lack of appropriate knowledge of breast cancer disease, lack of funds, high cost of cancer treatment, and the absence of accessible treatment facilities were the other causes of the low uptake. Culture-specific media also have a role in highlighting the importance of early detection practices among women (Love, Mouttapa, & Tanjasiri, 2009; Sabado, 2014).

A study carried out by Love et al (2009) also explored the effectiveness of a culturally sensitive video in reducing the barriers to undergoing cervical cancer screening tests among Thai-American women in Los Angeles. The actors in the video were Thai actors and spoke Thai in the video. The participants of this research filled a baseline questionnaire before they viewed the video. A post-intervention questionnaire and a 3-month follow-up programme identified that the video resulted in positive decision-making for screening and communication with the healthcare team. This study highlights the importance of culture and community specific media messages and the role of members of the community to empower women and increase their self-efficacy in a way that they would be more willing to attend the screening.

A cross-sectional survey done in Tamil Nadu, India observed low-levels of awareness of breast cancer and the importance of screening. The study enrolled women aged 30 years and above who had attended public health centres (PHC) in Jan-Mar 2013. Data were collected regarding the acceptance of screening and understanding of risk factors and treatment methods of breast and cervical cancer using a semi-structured questionnaire (Senthil Kumar, Shanmugapriya, & Kaur, 2015). However, as this study was done only among the PHC attendees, its results cannot be generalised to the whole Tamil Nadu population. Furthermore, this study failed to state which media platform was most effective. More studies may be required in other districts of Tamil Nadu and post interventional studies may also be needed to confirm the social determinants identified by the authors.

#### **2.5.1.4 Organisational level**

There is a great need for effective health insurance schemes that cover the provision of breast cancer screening activities such as mammography and other techniques. Kang et al (2018) analysed Medicare claims in the USA from 2010 to 2014. Their target sample was composed of 555,705 patients, of whom 185,625 (33.4% of the total sample) had undergone mammography.



The research highlighted the relationship between effective organisational initiatives such as the one held by the U.S Medicare (2018). Studies suggest that a large number of women become aware of various breast cancer screening methods and are more likely to attend a regular screening if the health insurance system is active and also when aggressively campaigns for breast cancer awareness are conducted in the society. This research intends to assess if the same can be said about the various systems existing in the UAE for Keralite expatriates.

The availability of health insurance has been shown to correlate with breast screening mammogram uptake in various countries (Park, Park, Choi, Jun, & Lee, 2011; Robinson & Shavers, 2008; Sunil et al., 2014). These researchers confirmed that among the U.S population more insured people utilised screening mammography than the uninsured. However, they have not examined such factors as the participants' understanding of the importance of breast cancer screening and the proximity of the screening facility. Migrants often have no or inadequate insurance cover, and so may incur sizeable debts to pay for screening mammography. Most companies cannot afford to pay for the screening process and women are left with no option other than to avoid the procedure.

Trust in the healthcare provider is also crucial for promoting breast cancer screening. Hong et al (2018) examined the effects of perceived discrimination and trust on the uptake of breast cancer screening among Korean American women. They concluded that 93% of the women surveyed had health insurance and 54% reported having a mammogram in the past 2 years. Determinants of mammography found in the study were awareness about mammography centres, having a regular doctor, attending the screening at the same place for health care, greatest trust in health care providers, and lower distrust in the healthcare system. An exploratory study conducted by Yang et al. (2011) investigated whether distrust in the health system might be a barrier to screening uptake. The study surveyed 5268 women aged 18 years and above living in Philadelphia. Based on their findings, the researchers claimed that even after control of demographic and socio-economic determinants, enhancing levels of confidence in the health system is crucial to encourage women to undergo screening (Yang, Matthews, & Hillemeier, 2011). Another qualitative community based participatory research conducted

among American Indian women in Kansas and Missouri identified a limited knowledge about the importance of breast cancer screening among the participants. The researchers reconfirmed that dedicated educational programmes are required for women who had not undergone screening mammogram. They further stated that these programmes and public involvement can help overcome such beliefs and discrimination, meanwhile improving trust in the health system (Daley et al., 2012). However, the background of the women under study, how they related to their community, culture and many other factors that may affect health behaviour were not considered in this study.

In the UAE there a lack of studies that assessed the role of medical insurance, cultural beliefs and personal attitudes (like denial), or that identify the challenges faced by the migrant Keralites in relation to the breast cancer screening initiatives in the country (Sadler et al., 2001; Yusra et al., 2014).

#### **2.5.1.5 Policy level**

The government or professional bodies in different countries formulate screening guidelines, which consider the incidence of breast cancer, evidence of studies, benefits, and potential harm as a result of screening as well as the patients' values and preferences about screening. Many developed countries such as United Kingdom, USA, Canada and France, Germany, Spain, Portugal, and New Zealand agree that they could reduce breast cancer mortality rates through early detection of breast cancer by utilizing screening mammography. The survival rate from breast cancer in developing countries is generally poorer than in developed countries, primarily as a result of delayed diagnosis (WHO, 2018b).

The Australian government Australian government department of health (2018), through their Breast Screen Australia programme, conduct free screening mammography for women aged 50-74 years. They send personal invitations biannually to invite the women for screening mammography. Their statistics show that in 1991, 68 deaths per 100,000 women occurred, while in 2010, due to early diagnosis through screening mammography, that number fell to 43 per 100,000 women. The above programme can also be adopted by the UAE government in a

bid to help women attend screening mammography sessions, leading to early detection of breast cancer saving the lives of many women.

Furthermore, in Canada, the Canadian Cancer Society invites women aged 50- 69 years in each province to undergo free screening mammography biannually. An investigation by (Dickinson et al (2011)) reports that a 21% reduction in breast cancer mortality could be achieved due to regular mammography screening. Figures from the United Kingdom (UK) also show that the rate of breast cancer-related death was reduced by almost 40-60% due to screening mammography practice (Massat et al., 2016). In the UK, the NHS send personal invitations to women aged 50- 70 years to undergo free screening mammography once every 3 years.

Considering policies, there is a need for an effective blueprint that helps to fight breast cancer (Baron et al., 2018). In the United States, the U.S National Comprehensive Cancer Network (NCCN) was established as a result of a radical policy meant to help in the fight against breast cancer. It aims at developing and instituting standards to help healthcare professionals diagnose and treat people with breast cancer. The current NCCN guidelines recommend that women with an average risk of developing breast cancer should begin screening mammography at age 40 (NCCN, 2016). This research also aims to investigate the existence of any such policies that are intended to offer guidelines for breast cancer screening and diagnosis in the UAE and also establish whether such instruments are effectively within the public domain and are known by all concerned stakeholders such as Keralite women living in the UAE.

In the United Arab Emirates, Friends of Cancer Patient provides free opportunistic screening mammography for local and migrant women aged 40 years and above once every 2 years. This has helped reduce the number of cases diagnosed with cancer at the advanced stages from 67% in 2007 to 16% in 2013 (Friends of cancer patients, 2018). Thus the provision of free mammography can support women to undergo screening reducing breast cancer mortality among UAE and migrant Keralite women.

In Japan as a trial initiative, the Japanese government introduced an intervention of providing offering free mammograms to the eligible age group of 40 and above. The availability of free screening mammography was announced through the media and vouchers were distributed

among women through mail or by hand. The overall intervention increased the attendance of breast cancer screening by 9.8%. This increase was calculated to relate to a reduction of 461 deaths by breast cancer (Tabuchi et al., 2013). However, a higher increase in attendance may have been achieved if the availability of these free services was introduced to the women in a more personalised manner or after an educational interventional program.

However, in India, there are no organised, systematic, or funded screening mammography programmes (Agrawal, Tripathi, Sahu, & Daftary, 2014; Breast Cancer India, 2015; Takkar et al., 2017). Furthermore, there are no statistics of organised screening mammography that convey a reduction in breast cancer mortality in India due to early detection of breast cancer through screening mammography available up-to-date (Singh, Shrivastava, & Dwivedi, 2015). Meanwhile, the “Breast Cancer India”, a non-government organisation recommended that women aged 40 to 50 should undergo screening mammography once annually (Breast Cancer India, 2015).

Convenient access to screening mammography is important. In India, CBGA states that reduced access to public healthcare services results in women neglecting their health. An investigation to understand social inequalities based on gender and availability of free health services can foster the uptake of breast cancer screening. A systemic review of literature from the year 1990 until 2016 affirmed the existence of health inequalities biased against Indian women and among other socio-economically vulnerable groups. Therefore, further research is required to monitor the health inequalities, evaluations of health policies and health programs (Bhan, Rao, & Kachwaha, 2016).

A study carried out by Ilaboya, Gibson, & Musoke (2018) assessed the perceived barriers to early detection of breast cancer in a district of Uganda using a socio-ecological approach. They found that there were several varied barriers to early detection of breast cancer. The major themes emerging from this study include knowledge, attitudes, beliefs and practices, health system and policy constraints, distance, poverty and limited access to media. However, this study looked at the early detection of breast cancer in general; therefore, it may include other early detection methods apart from screening mammography. Besides, data were gathered

from community health workers, health professionals, policymakers and other public health researchers. These are health care professionals, not patients, so they may have awareness about the importance of early detection. The study also failed to gather data from the women who would have benefitted from whatever service that was available. After all, a socio-ecological approach aims to find out the root cause of the problem including individual factors. Thus this study failed to explore the factors that influence women at the individual and interpersonal levels (Ilaboya, Gibson, & Musoke, 2018).

However, a gap exists in the analysis of socio-ecological determinants among Keralite women in UAE. The incidence of diagnosis of breast cancer among Keralites is increasing especially at an advanced stage. Moreover, many Keralites live in UAE; therefore, it is important to conduct a culture specific study among Keralite women residing in the UAE to determine their perceptions regarding screening mammography. To add, no studies or statistics that identify Keralite women's perceptions of screening mammography or the barriers and facilitators they encounter in UAE or Kerala exist. Therefore, the socio-ecological determinants that influence Keralite women in the UAE need to be investigated to provide them with appropriate interventional strategies in the future to increase the rate of early detection of breast cancer. Table 2.5 provides a summary of the studies included that discuss the influence of each level of SEM in health promotion.

**Table 2. 5 Studies that discuss the influence of SEM in health promotion**

| Study                         | Year | Journal   | Findings   |
|-------------------------------|------|---|--|
| McGarvey et al.,              | 2003 | Ethnicity & Health  | Language barrier discouraged women from three different ethnic groups from breast cancer screening uptake  |
| McMenamin et al.,             | 2005 | European Journal of Cancer                                  | Participation in breast cancer screening is not only influenced by the women's awareness of screening but also shaped by their partners' attitudes and beliefs   |
| Klassen & Washington,         | 2008 | BMC Women's Health  | Friends play an important role in improving the practice of breast cancer screening  |
| Vahabi,                       | 2011 | The Publication for Health Promotion and Disease Prevention | In the case of Iranian women, the length of their stay in Canada changed their attitudes towards breast health practices. The longer they stayed in the host country, the more willing they were to take part in screening practices |
| K. Park et al.,               | 2011 | BMC Cancer  | In the context of Korea, pre and post-educational intervention helped to raise awareness of the importance of early detection of breast cancer through mammography   |
| Park, Park, Choi, Jun, & Lee, | 2011 | BMC Cancer  | Health Insurance is positively correlated with the rate of breast screening mammogram uptake in various countries  |
| Golden & Earp,                | 2012 | Health Education & Behavior                                 | Socio-ecological models are now commonly adopted in public health practice   |

|                                     |      |  |   |
|-------------------------------------|------|--|---|
| Lu et al.,                          | 2012 | BMC public health                          | In the case of Asian women, workplace-based group education sessions and mobile screening services promoted breast cancer screening   |
| Missinne, Colman, & Bracke,         | 2013 | Social Science & Medicine                  | Family members' motivation and awareness of screening mammography positively affect women's participation   |
| Tabuchi et al.,                     | 2013 | International Journal of Cancer            | Increase in mammography uptake results in a decrease in deaths due to breast cancer   |
| Misha N. et al.,                    | 2014 | Critical Public Health                     | A critical review of 102 studies from 26 countries using thematic synthesis expose that fears about the social consequences of a cancer diagnosis are mentioned in about a third of the studies |
| Hauge, et al.,                      | 2014 | Acta Radiologica                           | The risk of radiation-induced breast cancer and breast cancer death due to mammographic screening is minimal  |
| Yusra, Tar Ching, Michal, & Nico,   | 2014 | PLoS ONE                                   | Insurance coverage, cultural issues, and denial behaviour are factors responsible for gaps in and challenges to breast cancer screening initiatives in UAE                                      |
| Paul, Solanki, Shahi, & Srikrishna, | 2015 | Asian Pacific Journal of Cancer Prevention | Among women residing in various locations of Varanasi city in India, individual attributes are directly related to breast cancer screening knowledge  |

|  |      |   |  |
|--|------|---|--|
| Leyva, Nguyen, Allen, Taplin, & Moser, et al., | 2015 | Journal of Religion and Health  | Religiosity is associated with greater utilisation of breast, cervical, and colorectal cancer screening  |
| Molina et al.,                                 | 2015 | Health Education Research   | Friends/family recommendation increase mammography uptake  |
| Khadije, et al.,                               | 2016 | Journal of Evidence-Based Care  | Comprehensive health education and promotion is critical for enhancing health literacy   |
| Massat et al.,                                 | 2016 | American Association for Cancer Research                              | In the case of the United Kingdom, screening mammography practices resulted in a 40-60% reduction in deaths  |
| Vrinten et al.,                                | 2017 | Psycho-oncology   | Population-based studies have consistently shown that about a quarter to half the population worry to some extent about getting cancer, with 5%–10% experiencing extreme worry |
| Ogunsiji et al.,                               | 2017 | BMC Women's Health  | The length of immigrant women's stay in a host country affect their attitudes regarding the early detection of breast cancer   |
| Takkar et al.,                                 | 2017 | Journal of Mid-life Health  | In India, there are no organised, systematic, or funded screening mammography programmes available   |
| WHO,   | 2018 | The Ecological Framework  | World Health Organisation also considers socio-ecological perspective in their program designs   |
| Alshahrani et al.,                             | 2018 | The official journal of the American Association for Cancer Education | Individual lack of knowledge about breast cancer, BSE, screening mammogram and CBE are common barriers to effective breast cancer screening strategies                         |



|                            |      |  |  |
|----------------------------|------|--|--|
| Rainey et al.,             | 2018 | PLoS ONE                                   | Women tend to relate to reassurance from medical practitioners and other stakeholders  |
| Saei Ghare et al.,         | 2018 | Asian Pacific Journal of Cancer Prevention | To enhance breast cancer awareness there is a need for effective health education that will ultimately lead to early diagnosis   |
| Kang et al.,               | 2018 | Radiology                                  | Health insurance positively influences screening uptake  |
| Hong et al.,               | 2018 | Women's Health Issues                      | They revealed that 93% of the participants surveyed had health insurance and 54% reported a mammogram in the past 2 years  |
| Ilaboya, Gibson, & Musoke, | 2018 | Globalization and Health                   | Knowledge, attitudes, beliefs and practices, health system and policy constraints, distance, poverty and limited access to media are prime determinants of breast cancer screening                             |
| Rahman et al.,             | 2019 | Asian Pacific Journal of Cancer Prevention | In their study sample of 241 undergraduate female students, 99% had heard of breast cancer   |
| Johnson,                   | 2019 | Women's Health                             | In the context of different African countries, the most commonly identified risk factors are family and personal histories of breast cancer, and the most commonly identified warning symptom is a breast lump |

## 2.6 Summary

In Kerala, breast cancer incidence is higher in the urban communities compared to rural areas making it a major public health concern (Parameshwari et al., 2013). Thiruvananthapuram, the capital of Kerala ranks the highest (43.9 per 100,000) in breast cancer crude rate (ICMR, 2016). Similarly in the UAE 24.1% of 500 cancer deaths among females are due to breast cancer (WHO, 2017). Advancing age, delayed first childbirth, nulliparity, history of previous breast biopsies, and family history of breast cancer among first-degree relatives are associated with increased risk of breast cancer in Kerala Augustine et al (2014) and breast cancer is mostly diagnosed in advance stages, is rising rapidly in South India with an expected large increase in the future (Mathew et al., 2016).

Several factors for delaying or avoiding screening have been proposed. Fear of pain and discomfort are some of the general forms of negative perceptions associated with breast cancer that caused women to delay undergoing breast cancer screening Doede, Mitchell, Wilson, Panagides, & Oriá (2018) and the late presentation of cases may be due to factors such as fear and uncertainty of screening (Ebubedike, Umeh, & C Anyanwu, 2018). In addition, poorer individual knowledge and awareness of breast and cervical cancer and lower community awareness are determinants of lower screening rates in South Asian populations Jones & Johnson (2012), while, in MENA region, marital status, wealth, education, nationality, and place of residence influence screening uptake, with the lower educated, poor, and unmarried scoring lowest percentage of uptake (Bowser et al., 2017). To counter these obstacles, it is imperative to firmly identify the determinants of breast cancer, which will improve the health care practices of individuals (McLaren & Hawe, 2005). Other cultural issues such as the language barrier and differences in religious, cultural or traditional customs between patients and healthcare professionals result in low mammography uptake (Azeem Samera et al., 2014). Similarly, the environment where people reside and the lifestyles they lead can also determine the prevalence of cancer risks amongst the population (Yavari et al., 2010).

Meanwhile, early detection of breast cancer has been shown to increase chances of a successful treatment and decrease rates of mortality due to the condition. For example, more than 80% of cancer found in developed countries is cured due to early detection by medical practitioners hence the need for India to establish awareness campaigns and models that will reduce breast cancer mortality (Jose, 2015). The focus on prevention and early detection of disease are the focus in healthcare now (WHO, 2018). However, the effectiveness and success of these strategies through health programmes are dependent upon the active participation and health behaviour of each individual (Tabuchi et al., 2013). Health behaviour can be generally defined as performances, activities and conducts that relate to health preservation, improvement and restoration. This includes any activity undertaken by a person believing himself to be healthy such as diet, physical activity and medical adherence (Conner & Norman, 2017; Short & Mollborn, 2015) and widespread health behaviour change requires effective intervention strategies focused not only towards individuals but also focused towards health policies (McKinlay, 2015).

Individual and group health behaviours have been the subject of rigorous investigation. The result was the formulation of several models and theories. The health belief model (HBM) explains the process of change in relation to health behaviour and can be successfully adopted in diverse cultural and topical contexts (Orji, Vassileva, & Mandryk, 2012). On the other hand, the theory of reasoned action (TRA) is based on the individual's assumption about the consequences of their behaviours before engaging in an action (Ajzen, 1985). Socio-ecological models are now common in public health practice (Golden & Earp, 2012). World Health Organisation also considers a socio-ecological perspective in their programme designs (Takkar et al., 2017). Consequently, this study has adapted the socio-ecological model to facilitate the identification of the factors that impact the decision of the target population to undergo screening mammography.

### Chapter 3: Researcher characteristics and reflexivity

In qualitative research, the main instrument is the researcher. The human instrument can have biases and shortcomings that may influence the research. The researcher's own prejudices and experience may influence the observation, understanding of the context and participants' views. Thus,

*“the researcher’s role further refines the definition of the problem... traditional differences that characterize each type of researcher, however, still hold, and these also characterize the relationship between the problem and how it is articulated, researched, and written about” (Fetterman, 1998, p. 4).*

Therefore, the whole research must be filtered through the views of the researcher (Creswell, 2011) because, they have a key role in interpreting the data, and recognizing the ‘subjectivity of one’s observation is of paramount importance throughout the research process’ (Miles, 1994, p. 6). Therefore, by reflecting on their own experience in context the researcher provides an added layer of dynamic reference points in relation to the process of knowledge production and the subject of investigation (May & Perry, 2013; Merriam, 2009; Nilson, 2017).

Reflexivity embraces a process of on-going interactive shaping between researcher and research (Attia & Edge, 2017; Gouldner, 1971). Fook and Askeland (2006) define reflexivity as

*“ an ability to recognize our own influence and influence of our social and cultural contexts on research, the type of knowledge we create, and the way we create it” (Fook & Askeland, 2006, p. 45).*

Thus, reflexivity is a hallmark of excellent qualitative research and it entails the willingness of the researcher to acknowledge and convey the ways they influence the research and its findings. Consequently, this reflexive chapter was written to give an explicit reflection of me as the researcher, and how I might have influenced the research.

This chapter starts with a brief explanation of me, my personal experiences, beliefs, skills, motives for this research, my position in the research context, and my philosophical perspectives. Along with these, I will provide a transparent explanation of how these features may have influenced this research to help the readers to get an account of the influence of me on the findings being reported.

### 3.1 About me

I am an Indian, Keralite, female in my mid-thirties. I was born in Trivandrum; the capital of Kerala. I am proficient in the use of multiple languages of India such as Tamil, Kannada, Hindi as well as Malayalam. Malayalam is my mother tongue and the local language of Kerala. English is the second language that I use in academic writings and in my career. I have professional and personal connections with people in almost all the states of India. Therefore, I have exposure to multiple cultural groups of people.

I hold Bachelor's (BSc) and Master's (MSc) degrees in Medical Imaging Technology in the year 2008 and 2011 respectively from Manipal University, Karnataka, India. I am a radiographer and an academic. I worked as a radiographer for around 2 years before enrolling for a master's degree. During my master's degree, I had an independent role as a radiographer in handling routine, portable, special radiographic techniques (Barium and other contrast studies such as IVU, MCU, HSG, Sialography), mammography, Computed Tomography, and Magnetic Resonance Imaging procedures and had observationship in Nuclear medicine, Ultrasound and reporting for around 4 months each. Later, I joined as a faculty member in the Department of Medical Imaging Technology, Manipal University in 2012. While working as a faculty, I had clinical postings as well, and during these experiences, I examined many patients with breast cancer and understand their pain and I was able to offer empathic care in the light of my personal experience with my parents.

In 2014, I moved to the University of Sharjah, United Arab Emirates as a lecturer in Medical Diagnostic Imaging. I teach students in radiography (theory and clinical), and conduct and organise clinical preceptor workshops and other activities in the department. I am also involved

in and organise community and school activities to educate the public (both native and expatriate) and students, about the early detection of breast cancer and osteoporosis in the UAE. I engage with students, colleagues and clinical preceptors from various nationalities and cultural backgrounds. Thus I have had experience in handling groups of people and this helped me to manage the focus group discussions to bring forth collective views from the Keralite women in the UAE.

### 3.2 The Research context

I am the principle investigator of this research and my doctoral thesis critically explores the socio-ecological determinants influencing screening mammography uptake of migrant Kerala women in the UAE. I am a split-site Ph.D. candidate at the University of Salford, United Kingdom, where my main supervisors are located, and I have a local advisor at the University of Sharjah, United Arab Emirates. The data collection took place in the UAE where I currently work and live. This enabled me to share and discuss the findings with multicultural researchers and I was able to recognise various viewpoints from varied cultural and health care contexts. For example, in the UK, the NHS invites women for screening mammography after the age of 47 years, through an automatic referral system but it is not available in UAE or India.

Along with this, as part of my role in clinical training, I was familiar with major hospitals and their free breast cancer screening services to the expatriates in the UAE. Also, I had anecdotal information from my friends in the community and worship center that some of their Keralite friends or acquaintances had been diagnosed with advanced breast cancer after residing in the UAE and have not attended screening mammography. This made me set a goal to understand the underlying reasons that prevent Keralite women in the UAE from undergoing early detection of breast cancer.

### 3.3 My motive for this research

My interest in breast cancer research started after the demise of my beloved mother with an advanced stage of breast cancer. From my childhood, I saw her always in tears and pain. Along

with my father, she worked hard to take care of us. She used to have a shock-like sensation/pain in her head and when she pressed anywhere on her head and face during periods of intermittent pain. This pain ceased but after a few minutes, she again used to have the same pain. During that time, we had little access to advanced imaging modalities, doctors assumed that it was dental problems and most of the time they used to extract her teeth and gave medications for the same. When I was 11 years old, she was diagnosed with breast cancer and immediately underwent a mastectomy and later it was diagnosed that she had a tumor in her brain as well.

My father was a retired Indian Air Force officer, and when my mother was diagnosed with breast cancer he was working with the Telecommunications of India (Bharat Sanchar Nigam Limited). He was a caring and family-oriented as well as a workaholic. He used to take me to his office after school and I dreamed of becoming an officer like him. The severe disease conditions of my loving mother and other related stress resulted in him having a diabetic foot and one of his legs was amputated while I was 15 years and he was bedridden and now he is no more. Even though my parents were going through difficult times I had noticed their empathetic care to many people in need. My parents tried their level best to educate me, implanted positive thoughts, through their life, and the days taught me valuable lessons to succeed and work among the ones deserved in the society in various ways.

During the hospital experience with my mother, I got the impression that my mother was a sample for their studies and the treating physicians used demotivating words such as “treatment is of little use in this stage as it was diagnosed very late and do not cry now”. This mentally affected my mother and our confidence in facing the disease. I did not have a voice during that time, and I was unaware that it was not professional behaviour by the treating physicians. My mother left us when I was 18 years, and later I started my bachelor's degree studies and had the interest to learn more related to breast cancer early detection. This experience with breast cancer created many challenges in our life due to the lack of awareness of the importance of early detection, non- access to advanced diagnostic modalities during that time, and demotivating words by the physician. Now the health care environment has changed,

screening mammograms and other early detection facilities are available even at the doorsteps of women in UAE. As discussed in the literature section of this thesis it is still reported that Kerala women seek medical assistance when the disease is in its advanced stages. Further, unawareness of the importance of early detection, and the use of screening mammograms among their family members and other family reasons hold back treatment options among Keralite women. These experiences suggested to me that further research is needed, and adequate interventions developed to empower Keralite women to undergo early detection of breast cancer. Therefore, I found myself in a good position to research further as I belong to the same cultural background as the Keralites, and I was aware of the most common factors that face women in Kerala and had some perception about the issues that many Keralite women face here in UAE for early detection of breast cancer, whilst at the same time being aware of my bias and perceptions. Further, the impact critical ethnography and skills developed through this research journey is presented in Appendix Q.

### 3.4 My philosophical perspectives

The researcher's philosophical perspective is important as the researcher plays an important role in qualitative research (Merriam, 2009). My philosophical viewpoint is reality and human behaviour is socially constructed and multidimensional. Because my experience made me interpret that an action (in this research context undergoing screening mammography) is not governed by one absolute reason but characterized by multiple realities to the culture and the social environment. So I adopted relativism as my ontological approach to this research. Further, I understood that these realities cannot be shared in numbers but they need to be interpreted in relation to a context. I discussed the topic of interest with my supervisors, and, I decided that a qualitative and interpretative approach would be better for arriving at an understanding of the Keralite women's view of breast cancer early detection, and to empower their informed uptake of a screening mammogram. I conducted the research process from proposing the research questions, conducting focus group discussions in different locations within the UAE, transcribing the voice records, and conducting data analysis under the valid supervision of my supervisory team. The teaching and interactive experience gained from the



university enabled me to move along the journey, starting as a complete novice and moving along a continuum towards expert over a period of time and equipped me to administer qualitative research methods. While communicating with the women, I could encourage both cohesion and confrontation of opinions within the group as well as collecting participant's views with confidence.

### 3.5 My influence in this research

According to Lincoln and Guba (1985), the human is only an instrument that is able to capture constantly changing situations and human experience. As I was the primary instrument in this whole research it was so critical for me to remain impartial as much as I could. However, I acknowledge that there will be personal bias in relation to my ontological and epistemological approach to the research. I will now explain how, and in which areas I could have influenced: a) research participants b) data collection c) interpretation of the research data.

#### ***My influence on research participants:***

I had a connection with a few of the Keralites in the UAE, such as pastors and community leaders. As I was in fulltime employment at the University I did not have many connections among Keralites in the UAE. Therefore I approached the pastors and community leaders to guide me to other potential participants for the research who attained the inclusion and exclusion criteria for this research. This personal connection directed me to get a connection with other women by attending different worship centres and community gatherings. As the women were directed to me by their known person (community leaders or pastors) and my job is in education, I was able to gain the women's trust in the research and me. This enabled me to recruit the participants and I could correspond with them to arrange locations for focus group discussion.

I used motivating gestures such as nodding my head to women's opinions, connecting a woman's view to other participants, and using probing questions (for example: FGD 3: Ok, I

understood that some of you heard about mammogram. Do you know when and how the mammogram will be done?. Another example: When women discussed the appropriate age to undergo screening mammography and when one participant stated that screening mammography can be done at 'any age after puberty or if someone have breast cancer in the family", I asked them 'Do you believe it?' to continue the discussion among the participants. These skills of facilitation were developed during the experience I gained in managing small group discussions with university students, and clinical preceptors, during my lectures and preceptor sessions at the University of Sharjah.

I dressed myself to be similar to the participants; I wore churidar<sup>2</sup> during focus group discussions. Most of the Keralites during informal gatherings used to wear sari or churidar. This would have reduced a difference in the physical identity of the participants and I. However, my age and my expatriate experience also might be influenced as the participants were older than me and they migrated before my arrival to the UAE. In Kerala culture, we express our respect to elders by standing up when they arrive, a welcome gesture of folding hands (Namaste) and shaking hands. I did the same when the participants arrived in the discussion venue. This would have made the participants feel comfortable with me as I respected their age and experiences.

### ***Data collection***

An ethnographic researcher can encounter problems, especially during data collection. During the discussion, many women expressed their doubts mainly related to a screening mammography, its availability in the UAE and radiation. But during data collection, I agreed to discuss those doubts and diverted the discussion to capture other influencers that empower the uptake of screening mammography by the participants. Thus, as an ethnographer, and being interested in more women undergoing screening mammography; I cleared their doubts after the focus group discussions.

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<sup>2</sup> A churidar is tight trousers worn by people from South Asia, typically with a kameez or kurta.

Further, I did not share my personal views about breast cancer before or during the data collection. But I used triggers that direct the discussions. For example: if they have not raised any factors related to the Kerala government's initiative for migrant women in the UAE, I asked whether the Kerala government has a role to influence them or do they have any expectations from Kerala government that may influence them to undergo screening mammography. So I directed the conversation to capture the views related to my area of research interest.

However, challenges such as "insider position", my personal aspiration to improve the early detection of breast cancer by Keralite women in the UAE, professional history, and personal connection with some Keralites in the UAE, made it difficult for me to be ethnographically strange in this research. I as the researcher, the moderator positioned myself as an "insider" as I have the same mother tongue, cultural backgrounds, possibly some similar values, influenced by similar socio-ecological influencers as the target participants. Therefore, I acknowledge that researching one's own backyard creates its own challenges and opportunities. However, if I were in an "outsider" position, I would have missed many important findings. For example, the role of the husband as a barrier to Keralite women's decision-making for health sounds strange to a western cultured person. This can be due to the fact that the researcher is new to the culture under study and the researcher needs to immerse themselves in the cultural group under investigation (Janice Jones & Smith, 2017; Sanjari, Bahramnezhad, Fomani, Shoghi, & Cheraghi, 2014). Thus when the researcher is in an "outsider position" (Chirkov, 2015, p. 287) the researcher may not know what the participants want to share about their own personal and cultural views (Chirkov, 2015, p. 287; De Chesnay, 2014) in their own language.

Thus to a great extent, the "insider" position of mine enabled me to extract participants views, obtain access to communities, social networks, and demonstrate rapport that may be difficult to outsiders (Acker, 2001; Baker, 2006; Beoku- Betts, 1994; Bositis, 1988; Chirkov, 2015; Jackson, 1983; Schwartz & Green-Swartz, 1955; Takyi, 2015). In particular, the "insider" approach can be very effective when the community under investigation is made up of migrants; the same as me, as this can facilitate access and establish rapport with the participants (Birman, 2006; Chirkov, 2015).

On the other hand, the limitation of insider position, ethnographic approach extends to the issues of bias that can happen due to the presence of a researcher; as a known person to the participants in the same culture in the environment under study. In certain cases this influenced me because women were conscious and conveyed that they did not have much knowledge about breast cancer and considered me as an educator who is thorough in the topic and not considered as a researcher. Further, some invitees thought that I may evaluate their knowledge. So I lost potential women who had undergone a screening mammogram.

Yet, compared to a researcher with an outsider position, Beoku- Betts (1994) believes that a researcher with insider status brings a special sensitivity and engagement to the research process. Thus, “sharing ethnicity, experience, and language definitely reduces the social distance between researchers and their participants and this, in turn, benefits the research” (Chirkov, 2015, p. 288). I also agree with these viewpoints, and in fact, the closeness is one of the hallmark and requirement of good qualitative research (Adler, 1987; Ambert, Adler, Adler, & Detzner, 1995; Demarrais, 2004; Maier & Monahan, 2009; Toma, 2000).

At the same time, researchers encounter a variety of emotional and interactional tensions to be ethnographically strange and find difficulties to accurately calculate when getting close becomes too close with the participants (Maier & Monahan, 2009). So the researcher has to critically analyse the relationships with the subjects. In this research, while inviting for FGD, the head of the communities/ churches/ one of the TV channels invited me to give health awareness sessions. As this invitation was before the data collection, I was forced to say “No” to them, as I do not want to intervene in participants awareness before data collection. However, because of my passion to empower Keralites and other women in the UAE to undergo early detection of breast cancer, I became available to them after the data collection. Also, the university where I work as well as the study participants promoted me and I got an invitation to share awareness in schools among parents, teachers, high school students (age above 12 years). Nevertheless, their invitation to discuss in their gatherings can be considered, as this research area was so distinctive and relevant among Keralites and others in the UAE.

### ***Interpretation of the research data***

An ethnographer can face challenges during data analysis also; an “insider position” of me can be viewed as a bias as I am from the same cultural background as the subjects and I may not identify some of the unique features of the culture, as I perceived them as a norm (Medin, Bennis, & Chandler, 2010). So, it is important to monitor the process throughout and therefore, I tried to avoid bias during data analysis by following data trustworthiness criteria (see chapter 5) and adopted thematic analysis to truly represent the views from the participants. However, I acknowledge that there is an influence to pull out, present and discuss the views that are of my interest. For example, participants also shared their influencing factors to mammography uptake in Kerala; but I have not reported them in this research because through this research I am interested to report the factors that influence mammography uptake in the UAE.

### **3.6 My Future interests**

#### ***Impact of this research on me through critical ethnography:***

Being a principle investigator, this study enabled me to understand research, the importance of studies among the migrants, and explore other various patient-centered research studies in the advancing field of medical diagnostic imaging in breast cancer early diagnosis such as mammography, fMRI (functional MRI) and in artificial intelligence. Moreover, as a radiographer, my role in the university, connections with various clinical entities in the UAE, as well as an expatriate in UAE, I am looking forward being a spokesperson, encouraging people to undergo screening tests. I also would like to communicate the availability of screening mammography in the UAE with community center’s, churches and work to arrange health care services to women with the support of appropriate officials in the UAE. Furthermore, along with creating awareness interested to work on automatic invitation/referral system that may help many women to avail early detection of breast cancer and save their lives.

### 3.7 Summary

Qualitative research situated in the researcher's use of varied interpretive lens and in this chapter, I acknowledged my introspections and incorporated my perspective in the design and interpretation of this research data. The next chapter explain the methodology adopted in this research.

## Chapter 4: Methodology

This study aims to identify the socio-ecological factors that affect the uptake of screening mammogram by Keralite women residing in the United Arab Emirates.

This chapter focuses on the methodology used, its appropriateness and the wider considerations leading to the adoption of the chosen methodology. First, it introduces the research paradigm adopted, and then discusses the ontology, epistemology and ethnography of the study. Further, it describes the choice of sample selection, data collection tool, data collection and process for data analysis.

### 4.1 Research Paradigm

Researchers have their own views of what constitutes the truth and knowledge. The term “paradigm” is ‘a general organising framework for theory and research that includes basic assumptions, key issues, models of quality research, and methods for seeking answers’ (Neuman, 2011, p. 96). Furthermore, paradigm is the basic orientation to theory and the research (Kuhn, 1970). Thus, it is the overarching framework that guides the thinking, beliefs, and assumptions of the researcher to the research. ‘Research paradigms consist of ontology, epistemology, methodology and methods’ (Crotty, 1998, p. 10; Scotland, 2012).

Table 4.1 reflects the research paradigm adopted in this research, which will be reviewed later in the context of this research study.

**Table 4. 1 Summary of research paradigm in this research**

| <b>Research Paradigm</b> | <b>Research Paradigm in this research</b> |
|--------------------------|---|
| Research questions       | Exploratory                               |
| Ontology                 | Relativism                                |
| Epistemology             | Interpretivism                            |
| Research approach        | Ethnography                               |
| Theoretical framework    | Socio-ecological theoretical model        |
| Data collection tool     | Focus group discussions                   |
| Data analysis method     | Thematic analysis                         |

This research project stemmed from two main factors that lead to the adoption of the chosen methodologies and methods. First, as a Keralite residing in the United Arab Emirates (UAE) for more than four years, and working as a lecturer of medical diagnostic imaging at the University of Sharjah, I am aware of the breast cancer screening services available for expatriate women in the UAE. Accordingly, the first aim of the study was to explore the socio-ecological factors that influence the uptake of free screening mammogram by Keralite women residing in the UAE from an emic perspective, putting myself in the position of the participant (Jeffs & Smith, 1999, p. 26).

A researcher can basically take two stand points to describe human behaviour and it is established for specific purposes: the emic and etic approach (Hoare, Buetow, Mills, & Francis, 2013; Lu, 2012; Pike, 1954). The emic approach in research is cultural and language specific; in contrast, an etic perspective is universal or divergent (Adler, 1983; Davidson, Jaccard, Triandis, Morales, & Diaz-Guerrero, 1976). In the emic perspective, the researcher attempts to describe the behaviour or pattern of a particular cultural group of people; understanding how various elements of that culture are related to each other Pike (1954) and utilises concepts employed only in that particular culture (Davidson et al., 1976). While in the etic approach, the researcher



uses external criteria imposed by the researcher and makes cross-cultural comparisons. But the researcher may overlook the most important aspects of the phenomenon inbuilt in a particular culture or group of people (Davidson et al., 1976). This is because the researcher uses pre-existing theories, hypothesis and perspectives as framework to analyse whether they apply in the culture under study (Olive, 2014).

I adopted an emic approach as I belong to the same Keralite culture of the participants and am interested to understand the socio-ecological factors from the Keralites' point of view. However, the consequence of this is that I am not a neutral observer or collector of research data, but rather a co-observer whose values also will inform this research project.

The second aim of this research is to seek the views of two populations: population 1 and 2; women who have undergone screening mammogram and women who have not undergone screening mammogram respectively. The purpose was to identify the socio-ecological determinants that influenced or might influence the uptake of screening mammography among the Keralite women in the UAE.

In so doing I attempted to answer the following research questions:

- a. What are the socio-ecological determinants that influence the uptake of screening mammography by Keralite women participating in this study?
- b. What strategies can influence the UAE resident Keralite women's uptake of screening mammogram according to the views of the participants in this study?

The main objectives of the research are to:

- identify the attitudes of Keralite women residing in the UAE towards breast cancer screening using screening mammography;
- identify and categorise the influencing factors for the uptake of screening mammography as voiced by the target population;
- devise strategies for increasing the informed uptake of screening mammography for Keralite women in the UAE based on the participants recommendations.

This research aims to identify the factors associated with the uptake of screening mammogram from the participants' perspective rather than choosing an answer to research developed contextual questions. This required the adoption of a research method that enabled me to explore the views of the participants that can influence Keralite women's voluntary uptake of screening mammogram mammography and to further share participants' views with relevant authorities through this thesis and future publications.

Careful selection of the appropriate research methodology is important for what is being investigated depending on the objectives of the research, for example, whether it requires a comparison and generalisation (quantitative) or an in-depth understanding of a particular phenomenon (qualitative) (Anderson, 2010). The above stated research aims, questions and objectives enabled me to establish from the outset that this research project would need to adopt an ethnographic, exploratory (qualitative) approach and its tools for data gathering and analysis. This is because I included only Keralite women in the UAE as research participants, I am a Keralite (sharing the participants' culture) and I am interested in how these participants make sense of screening mammography and its uptake from a cultural point of view rather than gathering answers for predetermined set of close-ended questions. This is because human behaviour is significantly influenced by the setting in which it occurs; that involve feelings, interactions, behaviours (Atieno, 2009)) and cultural values.

Qualitative research is not built upon a unified theory or methodological approach, but it adopts various theoretical, philosophical stances and methods (Flick, 2009; Gray, 2018). A qualitative study aims to explore new phenomena, capture perceptions, attitudes and behaviours (Reiter, 2017; Stebbins, 2001; Zaharia Rodica, Grundey, & Stancu, 2008). Furthermore, qualitative research also provides the freedom to understand the central phenomenon of the research by involving the participants in the research problem (Austin & Sutton, 2014; Qu & Dumay, 2011). Thus, a qualitative research approach serves as a form of social inquiry that emphasises the way participants interpret and make sense of their real lived experiences (Creswell, 2014; Given, 2008; Maltby, 2010; Mason, 2002). It is underpinned by the interpretive perspectives that make sense of a social phenomenon Pope, van Royen, & Baker,

(2002), while, quantitative research design uses numerical values and the testing of a scientific hypothesis (Muijs, 2011; Murphy & Yelder, 2010). Quantitative research aims to uncover existing realities using objective research methods and maximise objectivity and minimise the involvement of the researcher in the research (Muijs, 2011).

However, human beings are part of the world and so cannot detach completely from the research. Accordingly, qualitative (exploratory) researchers are subjectivists and claim that reality is not there to be objectively detached and observed by a researcher, but is partly constructed by the researcher and their observations. To add, the process of observation by the researcher changes reality and transforms it, and therefore subjectivists are relativistic. As has been previously observed, all the truth can only be relative and is never definitive, as a positivist researcher claims (Muijs, 2011).

I have previously noted that there were no similar studies that target Keralite women residing in the UAE to explore their views, experiences, expectations, and the socio-ecological factors, which determine their screening mammogram behaviour. I adopted an exploratory research approach because this study requires an in-depth understanding of an understudied topic, and when there is little known in a particular research area an exploratory research approach can be used (Barker, Pistrang, & Elliot, 2002).

A qualitative research method is well suited to study a research question where the researcher does not know the variables to be explored and can be data driven and context sensitive (Creswell, 2011; Mason, 2002). In addition, my review of the literature, in line with several studies, revealed that the qualitative research approach is commonly used to evaluate women's health and breast cancer screening practices (Abadir, Lang, Klein, & Abenhaim, 2014; Daley et al., 2012; Ilaboya et al., 2018).

Qualitative research findings may also be used to improve public awareness so that informed choices can be made to attend breast cancer screening. It further creates possibilities to develop adequate strategies for providing awareness and relevant actions (Taylor & Francis,

2013). Whereas a quantitative research approach limits the researcher to determine or quantify screening availability or how many people exhibit similar behaviours and it fails to comprehensively identify the views of the participants and the reasons why people behave in a particular manner (Sutton & Austin, 2015).

However, qualitative research is often criticised as biased, unscientific and lacking in accuracy (Anderson, 2010; Atieno, 2009). Additionally, as the findings of qualitative research are not tested to confirm whether they are statistically significant or due to chance, the findings cannot be generalised to a wider population (Atieno, 2009; Guba, 1981; Polit & Beck, 2014). In short, as data in qualitative research is usually collected from a few cases or participants, the findings cannot be generalised to a larger population. It can then be concluded that research quality depends heavily on the skills of the researcher and is more easily influenced by the researcher's personal biases (Anderson, 2010).

Thus qualitative research expresses a crisis of confidence from both inside and outside the field as it does not check reliability and validity as in quantitative research studies (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Further, the trustworthiness terms used in quantitative (scientific paradigm- positivistic) are replaced by postpositivistic terms (see table 5.1) in qualitative research (constructivist paradigm).

On the other hand, when qualitative research is conducted under strict adherence to verification and qualitative data trustworthiness criteria, it will, to a great extent, become less biased, dependable, valid, reliable and credible (Anderson, 2010; Atieno, 2009; Morse et al., 2002).

Verification in qualitative research is the process of checking, confirming, making sure and being certain about the dependability and credibility of data (J. M. Morse et al., 2002). The processes of verification includes ensuring methodological coherence, sampling sufficiency, developing a strong relationship between sampling, data collection and analysis, theoretical reasoning, and development of theory (Creswell, 1997; Morse et al., 2002). During this process, modifications in research question, research methodology and data analysis can happen (Morse et al., 2002).

Gorman and colleagues stated that 'qualitative research is a process of enquiry that draws data from the context in which events occur, in an attempt to describe these occurrences, as a means of determining the process in which events are embedded and the perspectives of those participating in the events, using induction to derive possible explanations based on observed phenomena (Gorman, Clayton, Shep, & Clayton, 2005, p. 3). Consequently, in 'qualitative research the researcher's power of abstraction, as well as imagination and creativity is crucial' (Danermark, 2002, p. 79). In consequence, there is no single accepted way of carrying out a qualitative research study; indeed the researcher depends on various factors such as the aim and objectives, characteristics of the research participants, positions and the background of the researcher, their beliefs about the nature of the social world (ontology), how the nature of knowledge can be acquired (epistemology) and conveyed, (Ormston, Spencer, Barnard, & Snape, 2013).

Ontology and epistemology are important elements of the philosophy of knowledge. Ontology is the study of being, and it is concerned with "what is" -the nature of reality and existence- while epistemology is the way of understanding the reality (Hudson & Ozanne, 1988; Irene, 2009; Kivunja & Kuyini, 2017; Scotland, 2012). In a research study, both ontology and epistemology emerge together to convey a meaningful reality (Crotty, 1998; Morse, 1996, 1998).

Research approaches in the social sciences make ontological assumptions about the nature of a reality Hudson & Ozanne (1988) such as that either a reality exists independent of the knower (realism) or reality is subjective and differs from person to person (relativism) (Cohen, 2007; Guba & Lincoln, 1994). Realism underpins the philosophical assumption that truth can be objectively investigated, analysed and studied (Hussey, 2000). Realism holds the belief that 'the material and the social worlds are "real" and can have real effects' (Stavropoulou & Stroubouki, 2014). Realism focuses on empirical knowledge gained from scientific inquiry and facts that can be empirically verified (Garrett & Cutting, 2015). Thus, the realists believe in the existence of universal truths that are independent of human perception of reality (Leszek, 1972; Littlejohn & Foss, 2009). In short, realism is based on scientific evidence, possessing

discoverable reality that is independent of the researcher or knower (Cohen, 2007; Pring, 2000). Conversely, relativism believes in multiple realities, embraces diversity and recognises the contextual factors in moulding the experiences of people (Baghranian, 2004; Creswell, 2007; Denzin & Lincoln, 2011)) argues that knowledge is acquired through the interactions with other members of the society (Denzin & Lincoln, 2011; Simpson, Berger, & Luckmann, 1967).

Epistemology is concerned with the nature of knowledge (Cohen (2007)), and justified belief. It deals with matters to do with the creation and dissemination of knowledge in areas of inquiry (Steup, 2018). Thus, it is concerned with the ways of knowing and learning, as how realities can be learned and what forms knowledge (Ormston et al., 2013). There are two broad epistemologies; positivism and interpretivism (Bowling, 2014; Tonelli & Zambaldi, 2017). The ontological position of positivism is realism (Scotland, 2012) and the ontological position of interpretivism is relativism (Denzin & Lincoln, 2000). Positivism is the epistemological form of quantitative research and it works according to fixed laws of cause and effect. It is used to test theories about these laws and either reject or accept them through objective evidence. The interpretive method provides insight and understanding of behaviour and it explains the participant's point of view without an individual (researcher) dominating it (Flick, 2009; Scotland, 2012). However, 'frequently relativism is defined negatively in terms of the doctrines it denies, as well as positively, in terms of what it affirms' (Baghranian, 2004, p. 2; Baghranian & Carter, 2018). This is because what is true or false is related to the concepts, culture or linguistic framework that the researcher adapts to construct the research, while it gives credence to the idea that human behaviour and beliefs could be understood and evaluated only in relation to the context, along with their social and economic background.

The epistemological, ontological approaches and relevant methodology should be adopted based on the research aim (Creswell, 2009). In this instance, the main aim of this research study is to critically understand the socio-ecological factors that influence the uptake of screening mammogram by Keralite women residing in the UAE. Therefore, relativism as ontology and interpretivism as the epistemology were found to be well-suited to the purpose of this research.

The epistemological views in qualitative research to acquire and analyse knowledge can be followed either through an inductive or deductive approach. First, in the deductive approach, a top-down process is followed; a hypothesis that is developed a priori will be confirmed or rejected in terms of the evidence collected (findings of the data) (Ormston et al., 2013). It starts with a theory from which a hypothesis is derived and applied to findings or observations about the world. Then the hypothesis will be confirmed or rejected thereby strengthening or weakening the theory (Ritchie, Lewis, McNaughton Nicholls, & Ormston, 2014). Fundamentally, it can be concluded that it is a theory-driven research approach in which the researcher compares data to the initial theoretical framework (Meyer & Lunnay, 2013). However, this provides a framework for what is a logically valid conclusion based on the boundaries set, while it excludes looking beyond those set boundaries (Danermark, 2002).

Second, in the inductive approach, a bottom-up process derives the patterns from observations of the world. In other words, it involves generating knowledge from the bottom up through observations of the world, which in turn provides the basis for developing conclusions, laws or theories (Ritchie et al., 2014). Thus, the inductive process involves the collection of data first, and knowledge and theories are derived from that data. In short, data analysis is not based on a pre-existing coding framework or the researcher's perceptions. In contrast, the deductive approach or theoretical thematic analysis is completely driven by a set of questions or theoretical framework or the researcher's interest towards a particular aspect of the data (Elo et al., 2014; Hsieh & Shannon, 2005; Michael Quinn Patton, 1990). Additionally, the inductive approach does not flow through setting boundaries and thus helps drawing conclusions beyond what is known (Danermark, 2002). But in this, as there are no boundaries set, there is a risk to draw the wrong conclusions or reach subjective conclusions (Danermark, 2002).

However, qualitative research is iterative (Murphy & Yelder (2010)) rather than linear (Guba & Lincoln, 1985). Therefore, to ensure methodological coherence, the researcher needs to move back and forth to ensure consistency between research question, literature, methodology and data analysis. These standpoints give rise to a position of choosing a research approach that would both suit the aim that underlies research, and suitable for the subject under

investigation. Therefore, the role and selection of a research approach vary depending on the research question and the philosophical stance (Creswell, 2007). These decisions and dilemmas were considered and presented in chapters 3 and 5 of this thesis.

The research approaches that could be adopted in this research are phenomenology and ethnography as the participants' cultural components as well as human experiences are significant variables in this research. Both approaches are based upon description and interpretation but there are notable differences. The phenomenological approach allows the researcher to understand the meaning of an individual's experience of a particular phenomenon or concept (Creswell, 2007). The participants are selected only if they have lived the experience under study (Goulding, 2005). This approach aims at 'understanding the 'constructs', concepts or ideas people use in everyday life to make sense of their world' (Ormston et al., 2013, p. 18). It shares an in-depth understanding of experiences by exploring the personal constructions of "individuals" of the "same or different" cultural background independently for a particular phenomenon (Creswell, 2009; Scotland, 2012). Known examples of phenomenological studies include an analysis of self-care practices and self-conceptions (Thompson & Hirschman, 1995), married women's everyday conception practices (Thompson, Locander, & Pollio, 1990), coping with breast cancer (Doumit, Huijjer, Kelley, El Saghir, & Nassar, 2010), lived experience of breast cancer survivorship (Abdollahimohammad, Firouzkouhi, & Naderifar, 2019; Lynne & Catherine, 2007; Sampooram, 2015), post-diagnosis experience of women with breast cancer (Piro, 2019), men's experience with female partner's breast cancer (Catania, Sammut Scerri, & Catania, 2019)), and the relationship between breast cosmetic surgery and the construction of identity (Seebaransingh, Patterson, & O'Malley, 2002).

Phenomenological studies adopt purposeful sampling techniques and interview as a data collection tool. Hence, the unit of analysis in the phenomenological approach is often the individual's lived experiences (Gray, 2018). Thus, this philosophical approach was not found to be appropriate for this research as it aimed to explore the 'culture, collective experience and views' of the Keralite women residing in the UAE.



Culture is an integral component in the persistence of health (Kagawa-Singer, Valdez Dadia, Yu, & Surbone, 2010) and has an important role in the presentation of distress and illness. Culture is the way of life, especially the general customs and beliefs, of a particular group of people at a particular time and it is the learned and shared behaviour of a community (Cambridge Dictionary, 2017; Sullivan & Keesing, 1981). Culture is concerned with not only shared understandings but also the actions that are based on those understandings and that explain beliefs held in common with others (Napier et al., 2014). Culture also impacts health beliefs and health-related behaviours by regulating the type of health information to which women are exposed and it shapes health and illness perceptions and practices (Elewonibi & BeLue, 2019; Ramathuba, Ratshirumbi, & Mashamba, 2015). Moreover, it has been established that culture has a strong influence on the perception of cancer by individuals, patients, and their communities (Agide, Sadeghi, Garmaroudi, & Tigabu, 2018; Gangane, Ng, & Sebastian, 2015; Kagawa-Singer et al., 2010; Karbani et al., 2011). Dein (2007) stated that *'cultural factors are involved at every stage in the journey through cancer, from preventive to palliative care. Even the definition of what constitutes cancer varies according to the cultural context'*- (Dein, 2007, p. 3).

Furthermore, culture has a major impact on the chances of diagnosis and treatment of diseases among migrant populations (see section 2.4.3). Hence, cultural differences need to be addressed when delivering or implementing healthcare programmes in a country with people of different cultural backgrounds. Further, several studies of South Asian populations also suggest that high quality research on cancer screening attendance based on cultural understandings, beliefs, norms and practices are required to address multilevel factors that may influence women's attendance of screening (Anderson de Cuevas et al., 2018; Chan, So, Choi, & Gurung, 2019). Furthermore, a number of researchers (see for example Kagawa- Singer et al, 2010; Emma et al, 2018; Isa Modibbo et al, 2016) suggest that the role of culture in health as well as in cancer care and outcomes among different cultures has been underestimated.

Ethnography, which is derived from social anthropology, aims to identify the cultural specific beliefs and practices among a particular community (Savage, 2000) and it provides ecological

validity to studies that adopt it (Hammersley, 2006; Naidoo, 2012). Ethnography focuses on small scale societies (Goulding, 2005) and it is one of the interpretative methodologies that refer to a kind of research that collects the perspectives and interaction of the participants of the social groups being studied (Naidoo, 2012; Pring, 2004, p. 106). It attempts to analyse and develop structured patterns of action that are cultural and/or social rather than cognitive (Arnould, 1998; Hughes, 1992).

Furthermore, Savage (2000) argues that ethnography is a qualitative methodology for the in-depth study of health issues in a context. She further states that ethnography could be applied to small-scale studies of communities that share culturally specific beliefs and practices and it focuses on the meaning of individuals' actions and explanations rather than their quantification (Savage, 2000). In addition, Taylor and Francis (2013) claim that it is the study of culture and cultural knowledge because it explores the structure and function of a group of people of a similar culture (Al-Busaidi, 2008; Reeves, Peller, Goldman, & Kitto, 2013; Taylor & Francis, 2013). Ethnographic research allows the understanding of the phenomenon under study from the perspective of those being studied (Nurani, 2008). In summary as David Fetterman (1998, p. 1) stated:

*“Ethnography is the art and science of describing a group or culture. The description may be of a small tribal group in an exotic land or a classroom in middle-class suburbia”.*

Over the past few decades, the qualitative ethnographic research approach increasingly emerged as a methodological approach to assess women's health screening behaviours (Abadir et al, 2014, p. 44. e42); Salman, Zoucha, & Nawafleh, 2018). Considering the varied nature of cultural beliefs and human behaviours in response to those beliefs, an ethnographic study of Keralite women proved an appropriate research approach to employ in my research. The unique aim of this research is to provide rich and exclusive insights into the views and actions of the target population towards screening mammography in connection to the location they inhabit. Moreover, an ethnographic approach was selected as it aims at 'understanding the

social world of people being studied through immersion in their community to produce detailed descriptions of their culture and beliefs (Ormston et al., 2013, p. 18).

Furthermore, similar-cultured groups of participants are the unit of analysis rather than the individual (Al-Busaidi, 2008; Taylor & Francis, 2013) so being a Keralite residing in the UAE myself, I would achieve cultural immersion and form an emic perspective (Reeves, Kuper, & Hodges, 2008). To add, I am not investigating a phenomenon that is practiced in everyday life, so I adopted ethnography as the approach of enquiry.

There are four ethnographic techniques: classical, systematic, interpretative and critical ethnography (Taylor & Francis, 2013). Classical ethnography involves the researcher's direct observation "in the field". For example, it can be used to understand the experience while participants undergoing a screening mammogram. Second, systematic ethnography focuses on the organisation of culture. For example, focusing on the experience of living with breast cancer. Third, interpretive or hermeneutic ethnography tries to find the meanings of interactions and behaviours of a culture and it allows for the interpretation of both experiences and contextual aspects (Taylor & Francis, 2013, p. 66). For example, to interpret the reasons why women from Kerala undergo screening mammogram.

Critical ethnography is used in this research because it empowers people raising awareness among individuals or cultural groups, and this awareness provides the opportunity to change behaviours (Palmer & Caldas, 2017; Taylor & Francis, 2013). It also provides the researcher with an approach to examine in-depth the cultural group and their attitude towards a particular issue (Speziale & Carpenter, 2011). Moreover, critical ethnography allows exploration with an interpretative lens to identify the internal and external relationships that influence how a particular group behaves (Taylor & Francis, 2013). Any new insight developed through an ethnographic approach will have a strong relationship between the researcher and the researched participants (Laitin, Marcus, & Fischer, 1987). Critical ethnography, therefore, helps a researcher to raise the views of silent or side-lined individuals of a society (Madison, 2011, p. 6; Rose, 1993). Moreover, the critical ethnographer uses the resources, skills and privileges

available to break the boundaries and make them accessible to the ones who are restrained or out of reach to it (Madison, 2011, p. 6). Thus

*“... the aim of critical ethnography is not simply to describe these settings as they appear to be - as in conventional ethnography - but to change them for the better”* (May, 1997, p. 197).

An improved understanding of cultural elements through various studies can augment support for the early detection of breast cancer (Ilaboya et al., 2018; Mobley, Kuo, Clayton, & Evans, 2009). Consequently, understanding the cultural perceptions of Keralite women in the UAE of mammographic screening and the underlying reasons for these views is crucial. Analysing the fundamental distinction between the cultural meaning of breast cancer screening and its clinical realities in the future may provide another framework to promote early detection of breast cancer. Therefore, identifying the role of culture and developing cultural specific intervention tools is a crucial element in addressing healthcare disparities among different ethnicities.

Based on the above, the findings of a research study should fulfill its aim and objectives. They should also either bring forth meaningful output that was previously unknown or confirm what is already known. For this reason, data collection and analysis methods should be selected accordingly and should be coherent in such a way that they are interlinked to ensure the interdependence between the paradigms of the research.

## 4.2 Data Collection

In qualitative research, the aim is not to produce statistical values about a phenomenon (Saldana, 2011; Thorne, 2000). Instead, an exploratory study is designed to yield detailed and holistic views of the participants under study (Grossoehme, 2014). The qualitative researcher seeks to answer questions of “how” and “why” providing detailed insight and understanding (Catherine Pope & Mays, 1995). Interview and focus groups are the most common data

collection methods used in qualitative healthcare research (Gill, Stewart, Treasure, & Chadwick, 2008; Moser & Korstjens, 2017) depending on the research question (Flick, 2009; Giddings & Grant, 2007).

Interviews can be used to explore the views, experiences, beliefs, and motivations of individual participants while focus group discussion uses group dynamics to generate the data (Gill et al., 2008). Interviews enable the researcher to learn about the experiences, motivations, beliefs and perspectives of an individual participant in-depth (Gill et al., 2008; Michael Quinn Patton, 2002). Moreover, interviews are conducted with diverse individual experts to obtain a broad perspective on a specific topic (De Chesnay, 2015).

In this research study, focus group discussions (FGD) were conducted in order to explore the collective experiences and views of the participants with regard to breast cancer screening. Focus groups were first used in the 1940s in market research, in the work of the Bureau of Applied Social Research at Columbia University (Bloor, 2001; Gill et al., 2008). Now, focus groups are one of the most common data collection methods in qualitative research (Krueger, 1995; Lewis, 2015; Nyumba, Wilson, Derrick, & Mukherjee, 2018; Pope et al., 2002; Stewart, 2015, p. 1; Sutton & Austin, 2015). Focus groups are structured groups with selected participants, which have the potential to reveal views, experiences, and perceptions on a defined area of interest (Litosseliti, 2003). They are similar in structure to face-to-face interviews, but a focus group discussion will have the interaction of the group to generate data (Moser & Korstjens, 2017; Parker & Tritter, 2006; Sutton & Austin, 2015). It is not an individual questioning nor is it a discussion happening in isolation; rather it is a social gathering where the participants will be members of the social group who interact with each other (Litosseliti, 2003; Moser & Korstjens, 2017; Wilkinson, 1999). This can allow the participants to share their experience with one another, discuss, and ask questions. It was also noted that it is a useful tool to gather data of a shared experience (Pope et al., 2002). It allows the researcher to ask open-ended questions such that the participants can share their own subjective views rather than being less biased by the perspectives of the researcher or available research in the field of study (Acocella, 2012; Morgan & Spanish, 1984). This can also be an empowering process for

participants where they can bring forth issues that are not discussed in the research (Culley, Hudson, & Rapport, 2007; Gibbs, 1997). The empowerment arises in the context of specific interactions between the researcher and participants within the research group (Asbury, 1995; Morgan, 1988; Ross, 2017). The synergism created between participants, and the varied views during the discussion can trigger group members or the researcher to uncover an aspect that has not been discussed and it can reduce the researcher bias (Culley et al., 2007; Gibbs, 1997; Twinn, 1998). The focus group is characterised by the explicit use of the group interaction to produce data and insights that would be less accessible without interaction found in a group (Morgan & Spanish, 1984). Additionally, focus groups have the advantage of yielding more information than other data collection methods possibly within a short period and with lower cost (Morgan, 1996; Nyumba et al., 2018; Pope et al., 2002). It has also been argued that focus group discussion can provide a democratic environment among the participants and with the researcher or moderator. Considering these advantages, focus group discussions were deemed the most appropriate data collection instrument for this research.

However, one of the disadvantages of this instrument is that the data obtained through focus group discussions render results ungeneralisable, which is one of the limitations of qualitative research tools (Leung & Savithiri, 2009; Litosseliti, 2003; Mansell, Bennett, Northway, Mead, & Moseley, 2004; Vicsek, 2010). This is because the focus group discussion results can vary with the participants, locations, time of conducting the research and the skill of the moderator (Nyumba et al., 2018; Zaharia Rodica et al., 2008). Further, the views of women can vary when they are exposed to different situations. The presence of other people in the group can also inhibit the formulation and expression of views by individual participants through fear of being judged negatively for holding that view (Acocella, 2012; Greenbaum, 1988). Other possible limitations include false consensus, as a participant with a strong personality can dominate the group discussion, as well as individual views may not be distinguished owing to the fact that the group members may try to be consistent with the interests of the others (Gibbs, 1997; Krueger, 1994; Litosseliti, 2003).

In qualitative research, the researcher can act as the moderator during the focus group discussion (Krueger & Casey, 2001; Stebbins, 2012). Participants can have multiple opinions and can develop or shift their opinions during discussion (Gibbs, 1997; Litosseliti, 2003). Therefore, the moderator, or researcher, should be able to skilfully manage these discussions and have a clear view of the topics to be covered as per the research question and focus of discussion (Acocella, 2012; Gibbs, 1997; Richard, 1993). The topic of discussion should be clear, non-academic and understandable to the participants (Côté-Arsenault & Morrison-Beedy, 2005; Litosseliti, 2003). For this reason, the research question should be clarified and key areas should be brainstormed (Litosseliti, 2003). These were anticipated before the data collection and therefore focus group discussion guides were used in Malayalam. The questionnaire addressed the participants in their own language to improve their understanding of the questions. These guides were reviewed by the supervisors (English version), peer (Malayalam version) and among the participants of the pilot study before administration to the real data collection (see appendixes B and C). Thus, content validity of the focus group discussion was analysed. Content validity concerns the degree to which the focus group discussion guide has an appropriate sample of items for the phenomenon being measured (Polit, 2008).

Furthermore, no details of the participants' educational qualifications, religion, health awareness, or employment status were discussed or gathered before or during data collection. However, during discussion some participants shared these details, for example, educational qualification, number of years of residence in the UAE. Nevertheless, the interviewees were not called by their names or asked to share their backgrounds during the focus group discussion and their identities were protected in the thesis. This was done to ensure each woman in the focus group discussion had a voice without any difference in power due to these social background factors. However, as most of them were from the same community or church they may have had some incling of each other's background. Yet, when I contacted the participants before FGD (at least one day prior to the discussion), to build some rapport, we introduced each other (if the gatekeeper shared their contacts, then I informed them and reconfirmed their interest to talk further). During this time, I just reconfirmed the inclusion criteria, time and venue of the discussion (see table 4.4). However, I collected the demographic data of the

participants personally at the end of the focus group discussion to understand their general background such as education and place of residence in the UAE (see table 4.3) as these helped to understand whether the group members shared a common identity and to understand their experience and social processes. These variables were not taken into consideration for participant selection and data analysis, as this research aimed to understand the Keralite women participants' socio-ecological determinants, in general, to undergo screening mammogram after the age of forty when they are in the UAE.

#### 4.3 Data collection tool

The research aim and key objectives that the researcher chooses guides the entire research venture (Nyumba et al., 2018). It dictates data collection tools as well (Fetterman, 1998, p. 3). This research used focus group discussion to collect the required data. In this case, deciding what and how many questions to be asked is very important. This guides the discussion and helps to ask precisely the questions in a similar format with all the FGD in a research study. Therefore, the questions in the FGD guide should be sequenced in a natural flow (Rana Muhammad Dilshad and Muhammad Ijaz, 2013) and with open-ended questions that can elicit the views and experiences of the women (Creswell, 2013). Further, a semi-structured interview guide helps both the interviewer and interviewee to control the flow of discussion (Britten, 1999; Galletta, 2013; Qu & Dumay, 2011). However, the interview guide should not be biased or leading and should make sure that it will not lead the participants to answer the questions in a structured manner (Qu & Dumay, 2011; Sargeant, 2012).

In this research study, the focus group discussion (FGD) guides (Appendixes B and C) helped to provide contextual landmarks for gathering the data and to ensure that all the intended interview topics were covered (Chang, 2008, p. 137; Litosseliti, 2003). Prior to actual FGDs, I developed these guides and conducted a pilot. In addition, modifications were based on feedback provided by academics experienced in conducting qualitative research in various health related fields and breast cancer screening (my doctoral supervisors). Furthermore, I translated these guides into Malayalam the mother tongue of the participant's (Simons & Fennig, 2018), and the discussions were conducted in Malayalam. This helped the participants



to share their views naturally as it eliminated any language barrier. Moreover, there was homogeneity, which resulted in good interaction among the participants during discussion as all the participants could share, understand the discussion, pose questions to each other and convey their views more eloquently and fully.

The FGD guides (Appendix B & C) generally covered the following areas.

- a) Health awareness and attitudes (Colditz et al., 2000)
  - This helped to understand the participants' beliefs, health practices and their ability to take decisions about their health.
- b) Understanding the importance of early detection of breast cancer and screening mammogram (Amin, Al Mulhim, & Al Meqihwi, 2009; Bener, Alwash, Miller, Denic, & Dunn, 2001)
  - This determined whether the participants were aware of the importance of early detection of breast cancer and the role of screening mammogram in the early detection of breast cancer.
- c) Awareness of breast cancer screening services available in the UAE (Vahabi, Lofters, Kumar, & Glazier, 2016)
  - This shed light on the participant's awareness of the availability of breast cancer screening in their locality or Emirate. This also clarified whether healthcare sectors publicise the availability and importance of screening services and invite women to undergo screening mammography.
- d) Significant socio-ecological determinants to undergoing screening mammography (Tuzcu, Bahar, & Gözüm, 2016).
  - This topic helped to specifically examine the factors that influenced participants in population 1 to undergo screening mammogram, and the factors that influenced women in population 2 to neglect attending screening. Moreover, this helped identifying what factors may enable them to undergo screening mammogram from a socio-ecological model point of view. Thus, it provides an insight into participants'

socio-ecological determinants in decisions about whether to undergo breast cancer screening.

- e) Recommendations to improve awareness of screening mammography among participants by the Kerala government and breast cancer screening providers in the UAE (Nielsen & Randall, 2012).
  - Elicited the participants' recommendations and views to improve healthcare facilities for the early detection of breast cancer in the UAE. In the future, when the influencers stated by the participants are addressed, a positive outcome of utilising breast cancer screening services by Keralites women in UAE can be expected.

#### 4.4 Pilot study

The clarity of questions in these focus group guides was confirmed in a pilot study as stated earlier. A pilot or preliminary study or feasibility study can be referred to as a small-scale study of a complete research project, which enables the researcher to pre-test the research methodology and research instrument (Polit, 2006; van Teijlingen & Hundley, 2002; Vogel & Draper-Rodi, 2017). The major outcome of carrying out a pilot study is that it provides the researcher with a chance to make necessary modifications in the main study. In addition, it helps to test a research protocol, data collection procedure and sample recruitment technique (Kim, 2011; van Teijlingen & Hundley, 2002; Vogel & Draper-Rodi, 2017).

The participants in the pilot study were representative of the study's target participants and recruited from the same locations as mentioned in table 4.4. The pilot study lasted for around one hour and was attended by seven participants; three in population 1 and 4 in population 2. This helped to assess the clarity of questions in the focus group discussion guide and rehearse my role as a moderator during the discussion. Also, this pilot study enabled me to identify the necessary modifications to participant recruitment and data collection.

## Reflections from the pilot study

### Participant's feedback:

- Confirmed the clarity and logical order of topics in the focus group discussion guide
- Established that no language barrier may have obstructed them from sharing their views as the discussion was conducted in Malayalam.
- Advised to avoid taking field notes. Field notes can provide valuable information in addition to voice-recorded data and can be very useful during data analysis. They can be considered and retained in the same way as the transcripts of the voice records (Sutton & Austin, 2015). They also help to provide records of the participants' paralinguistic behaviour, gestures, postures, laughter, eloquently expressed comments and so on (Litosseliti, 2003). However, participants in this pilot study seemed cautious and anxious. They conveyed that they thought that they were being observed individually even though I noted their views anonymously. This interrupted the flow of conversation. Yet, they did not find audio recording a barrier to open discussion, as they felt certain that it was done anonymously. The same observation was made by Muswazi & Nhamo (2013) who argued that note taking during discussion may prevent the participants from sharing sensitive and confidential issues, as well as disrupt communication (Michael Quinn Patton, 2002). Therefore, field notes were not taken during the actual group discussion.
  - In line with the findings of Acocella (2012), the presence of another researcher to take notes can be viewed as an interference by the participants. They expressed their suspicion that they were personally watched and that they would feel more conscious if there were two persons judging their views. In addition, this research did not have the financial resources to procure the additional support of a field note-taker.

### My reflections as a researcher and moderator

- Through the pilot study, it became clear that discussions should be conducted in separate homogenous groups; consisting only of population 1 or population 2 participants. This is

because members of each group expressed different experiences. For example, population 1 women shared experiences related to who motivated them to undergo screening mammography, and where and when they underwent the procedure. In contrast, some of population 2 participants were not aware of the importance of screening mammography, its availability in their location and so on. While they listened to the experience shared by population 1 participants, their discussion deviated to attempts to learn more about screening mammogram, the experience itself, expected pain, cost, availability, and whom to contact. These discussions impacted the focus and pace of the discussion. This drawback was countered in the main research study in accordance with Litosseliti (2003) who stated that participants in the focus group should share the common characteristics in relation to the research topic. Moreover, if participants feel equal, this will help them to express their views and thoughts spontaneously (Krueger, 2014; Morgan & Spanish, 1984).

#### 4.5 Participant selection

Sampling appropriateness and sampling adequacy must be considered meticulously to ensure the reliability and validity of the research and they are fundamental in qualitative research (Curtis, Gesler, Smith, & Washburn, 2000, p. 1002). However, the number of required samples and when and how to determine the sample size in qualitative research are debatable (Curtis et al., 2000; Fugard & Potts, 2015; Sim, Saunders, Waterfield, & Kingstone, 2018) and so it can be concluded that sample size is not generally pre-determined. Researchers such as (Bloor (2001), Litosseliti (2003) and Guest.et.al. (2017)) suggested that a focus group usually includes between six to ten participants, but it can comprise as few as two or three depending on the purpose of the study. Further, how many focus groups are required to address adequately a research objective is also in debate. Yet, it is commonly cited that a research study requires a minimum of two or three FGD (Morgan 1996; Krueger 2009; Guest. et. al 2017) to identify the prevalent themes in research.

Moreover, participant's in a FGD should be considered in terms of epistemology (Jacqueline Jones (2013)) and participant selection must be conducted in such a way that it best informs the research question and enhances understanding of the research under investigation (Creswell, 2009; Kuper, Lingard, & Levinson, 2008). Therefore, it can be summarised that decisions regarding sample selection are based on the research questions, objectives, and the research area (Sargeant (2012)) and thus subjective. Consequently, the researcher should have a predetermined sample selection criteria to cover the aims and objectives of the research question (Mason, 2002; Pope et al., 2002).

In this research, participant selection criteria were determined prior to the start of the research and participants were vetted and recruited according to a rigorous inclusion, exclusion criteria (see section 4.6). A minimum of three participants were assigned to each FGD and multiple focus group discussions were conducted. The target focus groups were; population 1, consisting of women who had undergone screening mammogram in UAE or Kerala, and population 2, consisting of women who had not undergone screening mammography. Both purposive and snowball sampling techniques were adopted in participant recruitment.

Purposive sampling signifies a series of strategic choices to select the sample according to the research questions. A purposive criterion strategy involves participant recruitment using specific criteria for entry into the sample (Palys, 2008). Thus, the participants that meet the inclusion criteria are invited to take part in the focus group discussion. Researchers purposefully seek out specific people based on the topic of inquiry (Arsel, 2017). A sampling procedure is considered as snowball sampling when the researcher accesses participants through contact information that is shared by other participants (Goodman, 1961; Noy, 2008). In this type of sampling, the informants, who are initially contacted by the researcher, refer her or him to yet other participants, and so on (Denscombe, 2014; Goodman, 1961; Noy, 2008; Sedgwick, 2013). Sometimes, it can also be used to access groups or participants who have similar experience or similar social status (Moyser & Wagstaffe, 1987). Snowball sampling is one of the most widely used techniques in research across the social sciences (Noy, 2008; Sedgwick, 2013). In this research, the Keralite women whom I accessed first directed me to other women in their

community and social networks. As (Denscombe (1997,2014)) suggested snowball sampling enabled me to quickly increase participant numbers and allowed me to approach women enjoying credibility as someone known and introduced by their acquaintances. Furthermore, it facilitated my access to participants from different Emirates of the UAE.

#### 4.6 Inclusion and Exclusion Criteria

**Population: 1** (Keralite women who underwent screening mammogram)

##### Inclusion Criteria:

a) Natives of Kerala

- Women who had directly come from Kerala to UAE without having resided in any other country. This helped to exclude any other foreign cultural influences that could have affected their attitudes to the early detection of breast cancer.

b) Keralite women who had undergone screening mammogram in the UAE or Kerala.

c) Keralite women who had resided in the UAE for 2 or more years

- This criteria was included to account for acculturation, a phenomenon that occurs when a group of people of different cultures come into contact, and as a result changes in the original culture patterns can ensue for either or both of the groups (Redfield, Linton, & Herskovits, 1935). This would have caused the women or their families to become familiar with the healthcare facilities, healthcare system and even health insurance system of the UAE. This can reveal some information about the participants' potential awareness of the availability of screening mammography for expatriates in UAE and other relevant issues.

d) Consent

- As the informed consent of the participants is an essential part of all research activities (Byrne, 2001; Nijhawan et al., 2013) and a serious ethical requirement for any scientific study.

e) Age 40 years or above

- In India, it is recommended to have annual screening after age 40 (Breast Cancer India, 2015).
- With a goal to reduce mortality due to breast cancer in UAE, the health authority of Abu Dhabi recommends women of 40 years of age and above to undergo regular screening mammogram every two years and CBE annually (HAAD, 2017a).

Exclusion Criteria:

a) Kerala women who had resided in any other country for longer than 2 years prior to coming to the UAE.

- This was to eliminate the influence of the host culture and the impact of any breast cancer screening awareness strategies of that country.

b) Those who had undergone diagnostic mammogram.

- Women would normally undergo diagnostic mammogram following suspicious results on a screening mammogram or when signs or symptoms of breast cancer are identified. Thus, screening mammogram is not a valid criteria for this group of women. Moreover, they would have been exposed to different stressors and have different fears and concerns compared to other women as discussed by (Batrawi et al., (2017)). Furthermore, their socio-ecological influencers may be different from those of other participants (non- symptomatic) in the group.
- Survivors and previously suspected cases of breast cancer. Survivors of breast cancer may feel distressed to discuss that life experience in some details with strangers. To add, survivors may be comparatively aware of the importance of screening mammogram and its availability in their locality.

c) Those who do not give their consent to participate.

**Population: 2** (Keralite women who have not undergone screening mammogram)

The inclusion and exclusion criteria were the same for both groups, those who attended and those who had not attended screening mammography. However, only women who had never undergone screening mammogram were included in these focus group discussions. Their awareness of the procedure gained through family members or friends was not considered. To explain, I did not ask whether they aware of screening mammogram through any means before the focus group discussion.

#### 4.7 Method of recruitment

Data collection was undertaken after receiving Institutional Review Board approval (IRB) from the University of Salford, United Kingdom (HSR1617-88) and University of Sharjah (REC-17-09-18-01-S), United Arab Emirates (see Appendix D & E). Two institutional review board approvals were sought because I was registered as a Ph.D. student at University of Salford, United Kingdom and I work at University of Sharjah, United Arab Emirates. In addition, research participants reside in the United Arab Emirates and this is where the data collection took place. Moreover, I had the responsibility to ensure that the research would adhere to the academic and scientific code of ethics to avoid or minimise any risks to the participants. Ethics is concerned with investigating what is good or right and how it is determined. In social research ethics means “the study of what researchers ought and ought not to do, and how this should be decided” (Hammersley & Traianou, 2012, p. 16). Data collection started from 18th October 2017 until 18th January 2018.

The principle emigration destination of Keralites is the United Arab Emirates (Fox, Sabbah, & Mutawa, 2006; Rajan, 2017). Zachariah and Rajan (2012) and Rajan (2017) report that the vast majority of migrants from Kerala who move to the UAE are Muslim, followed by Christians and then Hindus. Kerala associations, generally known as Indian associations, where Keralites (commonly both Muslims and Hindus) conduct their social gatherings and meetings exist in



every Emirate of the UAE. The Christians gather at churches in each Emirate (United States Department of State (2016)) such as the Worship Centre and Union Church in Sharjah. Therefore, Indian associations, referred to here as Kerala associations, and Malayalam worship churches, were directly approached to recruit the participants for focus group discussions.

The focus group discussions were conducted in Sharjah and Ajman, where the majority of Keralites in the UAE reside. Recent high increases in the cost of residential accommodation and living in Abu Dhabi and Dubai have compelled emigrant Keralites to live further away from their workplaces and, therefore, the majority of Keralites in the UAE reside in Sharjah and Ajman where living costs are relatively more affordable (Jain & Oommen, 2016). However, some participants in the focus group discussions lived in other Emirates such as Dubai, Fujairah, and Ras Al Khaimah.

Pastors and heads of the Kerala associations were contacted in person or by phone for their availability to discuss my research interest. The aim and objectives of the research, the invitation letter (Appendix F & G) and participant information sheet (PIS) (Appendix H) were shared with them. It is worth noting here that in Indian society, there are several aspects related to the human physicality that are viewed as taboo one of which is discussing breast cancer (Maggi, 2018; Thomas, 2017). Therefore, negotiations with these community figures had to be conducted delicately and direct discussion of the topic had to be done with the womenfolk. The pastors and community heads invited me to introduce the topic of my research at their gatherings and introduced me to the women in their communities. They also shared the contact details of the “active women” in their gatherings. Active women are those who usually coordinate women gatherings, social activities and provide community services for their compatriots. These “active women” from Kerala associations or churches; here onwards termed as “gatekeepers” Green (2014), Orb, Eisenhauer, & Wynaden (2001) and Smith (2007), served as key respondents providing information regarding members of their community and access to the venue where focus group discussions are held. Further, these gatekeepers became participants (see table 4.2) as well as helped me to gain access to the Kerala communities in the UAE to recruit participants for FGDs. Consequently, I had to coordinate with

the active women in each community (I directly approached or received their contact details from the pastor or male head of the community). As David Fetterman states:

*'The reality however, is that ethnographic work is not always orderly. It involves serendipity, creativity, being in the right place at the wrong time, a lot of hard work, and old-fashioned luck'* (Fetterman, 1998, p. 2).

I met the gatekeepers face to face or over the phone and they were all interested in the research idea, encouraged participation and stressed to me that this research could be of great benefit to Keralites in the UAE. Three of the gatekeepers (one in population 1 (FGD 1) and two in Population 2 (FGD 3, 4) were found eligible (according to participant inclusion/ exclusion criteria for each population) and, therefore were included in the focus group discussion. Those who were not eligible (two women) directed me to another active woman in their community to invite her to participate in the research and to arrange the venue for discussion. Of these one woman was found eligible to be in population 1 (FGD 2) and another in population 2 (FGD 5).

**Table 4. 2 The gatekeepers in this research**

| <b>Total Gatekeepers</b>  | <b>Found eligible in</b> | <b>No. of women</b> | <b>Recruited in</b> |
|---|--------------------------|---------------------|---------------------|
| 3 women (I approached them directly as I knew them before as head of communities and the other one from the church) | Population 1             | One woman           | FGD 1               |
|   | Population 2             | Two women           | FGD 3, 4            |
| 2 women (through snowball sampling -from pastors/ participants/gatekeepers)   | Population 1             | One woman           | FGD 2               |
|   | Population 2             | One woman           | FGD 5               |

The aim and objectives of the research, invitation letter and participant information sheet were shared with these gatekeepers. In this way, the gatekeepers were able to introduce the topic of the research, me as the researcher, and the eligibility criteria to other women in their community, who in turn informed others who were not part of their normal gatherings. The pastor's wife, a female community head or gatekeepers herself, supplied me with the contact details of interested women. At least one day before the focus group discussions, I contacted these women, and confirmed their eligibility to participate in the discussion and made sure that they received the PIS. However, three participants in population 2 (two participants in the FGD 3 and one in FGD 4) directly joined at the focus group discussion venue along with the gatekeepers and other participants without having contacted me first.

The participant information sheet was provided to those participants I could access during worship and gatherings and with the gatekeepers. Furthermore, participants I had not met directly before the FGD confirmed that they received the PIS from the gatekeeper. In all focus group discussions and before data collection, I distributed hard copies of the PIS and asked the participants to read them carefully and make sure they understand the content. Figure 4.1 below illustrates the stages of participant recruitment in this research.

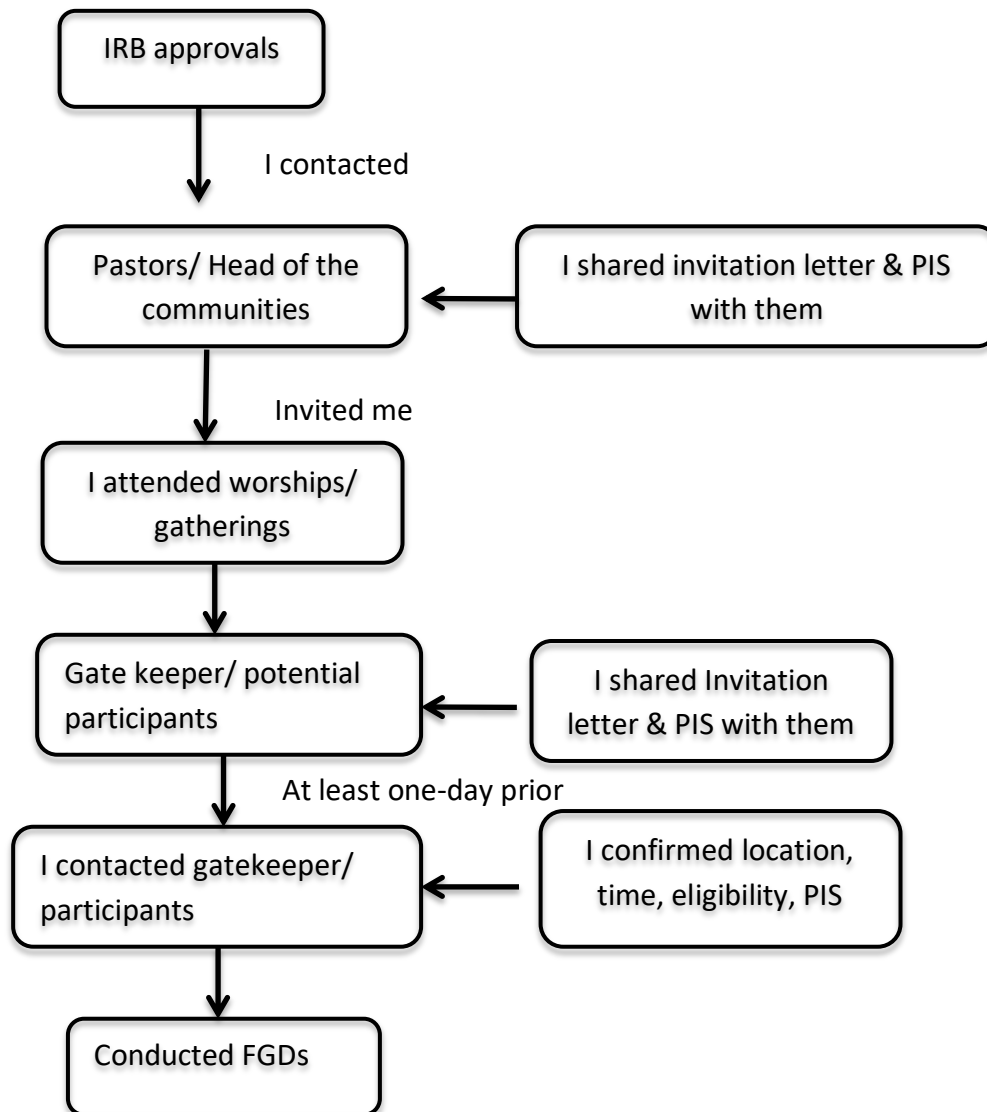


Figure 4. 1 Steps of participant recruitment in this research

## 4.8 Characteristics of participants

The focus group discussions for both population 1 and population 2 in the main study were conducted with different participants from those who attended the pilot study. Geographically, the participants were from six out of the seven Emirates of the UAE. I attended a number of gatherings in some Kerala associations or worship centres, where I invited many Keralite women to participate in the focus group discussion, so the total number of Keralite women I approached is difficult to establish. I chose this method because in Kerala culture this is a topic that is not normally publicly discussed. However, fourteen stated that they underwent screening mammogram. Due to personal reasons, six of them declined my invitation to participate in the research. For instance, one potential participant asked to be excluded as she did not know anything about breast cancer apart from the fact that it was a life-threatening disease, even though she underwent screening mammogram as part of her routine health check-up in Kerala. She informed me that she was not confident to face the topics of discussion because I, as a researcher, and other participants in the discussion may judge her on her knowledge of the subject. This limited my access to women eligible to join population 1. At the initial stage, refusal to participate can be a potential impact of incomplete data (Stuart, MacDonald, & Stawski, 2016) or can be considered as a sampling bias (Ferrer & Ghisletta, 2011). Thus, in this research, it can be considered as an instance of a lack of representativeness of Population 1 compared to population 2. Still, analysis of data collected from the two FGDs shows that participants in population 1 and population 2 shared similar views. Both population 1 and 2 FGD data were treated equally for data analysis and interpretation.

Table 4.3 presents the demographic details that I noted down in my diary before and immediately after the FGD. Table 4.4 shows the details of the focus group discussions. Table 4.5 illustrates the demographic details of the participants and Table 4.6 presents information on where participants in population 1 underwent screening mammography and the reasons for their attendance as stated by them.

**Table 4. 3 Participants details noted before (to confirm the inclusion criteria) and after FGD (to gather social background)**

| Before FGD day (either face to face/ over phone) |     |                                      |  |                         | After FGD          |                |           |            |          |
|--|-----|--------------------------------------|--|-------------------------|--------------------|----------------|-----------|------------|----------|
| Sl. No   | Age | No: of years of residence in the UAE | Undergone (1)/ Not undergone (2)<br>If 1, why, where | Interested FGD location | Place of residence | Marital status | Education | Employment | Religion |

**Table 4. 4 Details of the five focus group discussions**

| Population   | Number of FGD | Number of participants | Age range | Location of FGD | Location of participants residence               |
|--------------|---------------|------------------------|-----------|-----------------|--|
| Population 1 | Two           | FGD1 - 5               | 46-58     | Sharjah         | Abu Dhabi, Ajman, Fujairah, Ras Khaimah, Sharjah |
|              |               | FGD 2 - 3              | 49-54     | Ajman           | Ajman, Sharjah                                   |
| Population 2 | Three         | FGD 3 - 7              | 47- 54    | Sharjah         | Abu Dhabi, Dubai, Sharjah, Fujairah              |
|              |               | FGD 4 - 6              | 49- 58    | Sharjah         | Abu Dhabi, Ajman, Dubai, Sharjah, Ras Al Khaimah |
|              |               | FGD 5 - 4              | 46- 53    | Ajman           | Abu Dhabi, Ajman, Dubai, Fujairah                |

**Table 4. 5 Demographic details of all participants of both population 1 & 2**

| <b>Focus Group Discussion</b> | <b>Educational background</b>                                  | <b>Residential status (in years)</b> | <b>Employment status</b>     | <b>Marital Status</b> | <b>Religion of Participants</b>       |
|-------------------------------|--|--------------------------------------|------------------------------|-----------------------|---------------------------------------|
| FGD 1                         | Bachelor's degree - 2<br>Master's degree - 2<br>Pre-degree - 1 | 9 to 32                              | Employed- 4<br>Unemployed- 1 | Married               | Christian- 2<br>Hindu- 1<br>Muslim- 2 |
| FGD 2                         | Bachelor's degree - 1<br>Master's degree - 2                   | 7 to 25                              | Employed- 3                  | Married               | Christian- 2<br>Muslim- 1             |
| FGD 3                         | Bachelor's degree - 4<br>Master's degree - 2<br>Pre-degree- 1  | 5 to 25                              | Employed- 6<br>Unemployed- 1 | Married               | Christian- 2<br>Hindu- 2<br>Muslim- 3 |
| FGD 4                         | Bachelor's degree - 3<br>Master's degree - 3                   | 4 to 20                              | Employed- 3<br>Unemployed- 3 | Married               | Christian- 2<br>Muslim- 3             |
| FGD 5                         | Bachelor's degree - 1<br>Master's degree - 3                   | 10 to 18                             | Employed- 4                  | Married               | Christian- 2<br>Hindu- 1<br>Muslim- 1 |

**Table 4. 6 Population 1 Location of mammogram uptake and its reasons**

| <b>Population 1</b> | <b>Undergone mammography from</b>          | <b>Reason</b>   |
|---------------------|--|---|
| FGD-1               | Kerala (private hospital) – 2 participants | Part of routine health check-up during vacation to Kerala |
|                     | UAE (private hospital) – 2 participants    | Received free screening mammography voucher               |
|                     | UAE (private hospital)- 1 participant      | Received discounted coupon during health check-up in UAE  |
| FGD-2               | UAE (private hospital)- 2 participants     | Received free screening mammography voucher               |
|                     | Kerala (private hospital) – 1 participant  | Part of routine health check-up during vacation to Kerala |



## 4.9 Data Collection Venue

It is preferred to arrange a data collection venue that is convenient to the participants Herzog (2012) and Pope et al (2002) as this can maximise the number of participants. In addition, the focus group discussion venue needs to be carefully selected and should be conducted in a non-threatening environment Doody, Slevin, & Taggart (2013), Nagle & Williams (2018), and it needs to be comfortable and well furnished (Nagle & Williams, 2018). It is also crucial that the moderator creates a comfortable environment where the participants do not feel pressured to make decisions and are encouraged to express their views freely (Litosseliti, 2003). These factors can help avoid any psychological as well as physical difficulties participants may experience during the discussion, which might constrain the flow of conversation. Therefore, the gatekeepers and I arranged the seating in advance in a way similar to that illustrated in figure 4.2 below. This way the participants and I could have face-to face interaction during the discussion. Further, I dressed up in a churidar like participants to avoid creating a gap through my physical appearance.

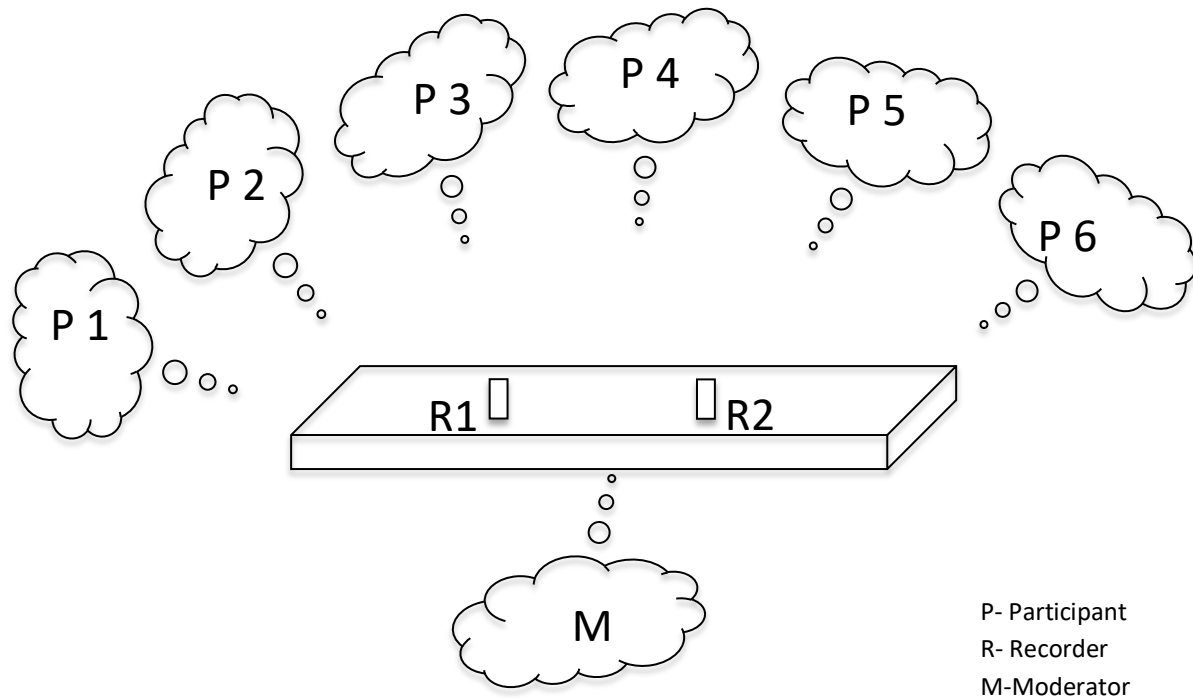


Figure 4. 2 A representation of seating arrangement at the FGD venue

Hard copies of the participant information sheet, informed consent forms (in English), and pens were available in the room. I carried a hard copy of the focus group discussion guide (in Malayalam) to guide the discussion. There was no research funding available for this research, and so no incentives or travel costs were presented to the participants. Focus group discussions were held in educational institutions, worship centres and in Kerala social network gathering venues in Sharjah and Ajman.

#### 4.10 Data collection procedure

To gain the confidence of participants and ensure the flow of discussion, open discussion is central to critical ethnographic research (Oladele, Richter, Clark, & Laing, 2012). However, these discussions should be conducted in a consistent manner free from diverting topics and chats, which can, unbeknown to the researcher, have an effect on the nature of the data. This can reduce research dependability. Dependability refers to ‘the stability of findings over time’ (Bitsch, 2005, p. 86). However, those ethnographic researchers who are “insiders” by ethnicity and race may still be outsiders by class or other identifiers such as religion, accent, personal history, and so on and may still be treated with suspicion and distrust (Chirkov, 2015; Dunbar, Rodriguez, & Parker, 2002).

In this research, even though I am an “insider” in terms of ethnicity and race, there are differences between the participants and me in age, type of and place of employment, educational background, religion, and other personal factors could potentially have instigated distrust and suspicion. Thus building rapport with the participants and gaining their trust were crucial (Chirkov, 2015; Dunbar et al., 2002). To establish a good rapport with the participants, I or gatekeeper welcomed them as they came into the venue, and I made sure to stand to show respect as is the normal culture. Once they were all settled, the gatekeepers or I introduced myself to the participants (even though I communicated with the participants before the focus group discussion day). Next, I explained the purpose of the research to the participants and handed out copies of the participant information sheets (Appendix H) and the informed

consent form (Appendix I), which highlighted the finer points of the research and its importance. The participants had a few minutes (around 8- 10 minutes) to read the documents. To ensure that the participants clearly understood the contents of these forms, I explained them in Malayalam and asked probing questions (for example: 'Did you understand that I am going to record your voice?').

Moreover, the participant information sheet explained the rights and responsibilities of the participants and the researcher. I re-confirmed their interest in participating in the discussion and informed the participants that they had the right to leave at any time during the discussion without giving any reasons. In addition, they were informed that I would transcribe the audio recordings into English. The introductory sessions of discussions may not need to be recorded Arsel (2017), as I did not want to record the participant's personal details if they happened to reveal them during the introduction. Furthermore, throughout the discussion I probed the participants in order to reach a full understanding of their perspectives and to encourage the flow of natural conversation (Ashatu, 2015; Grant, 1988; Legard, Keegan, & Wark, 2003). For example, (FGD 5: 22- 24)

|   |                       |
|---|-----------------------|
| 2. I think everyone has the cell of cancer in the body, cancer occurs when these cells become cancerous. Is it right?   | Participant statement |
| Researcher: Ok will discuss, Do you mean everyone have cancer cells in their body?  | Probing question      |
| 2. I mean the cancer cells are not the cancer disease but the cancer cells. Because of some factors, these cell becomes cancerous. These cause cancer. It has a lot of reasons to change the cancer cell into cancerous. Nowadays, breast-feeding is too low when compared with the ancient days. But at present, the doctors are encouraging to do the breast-feeding compulsorily for two years. Breast-feeding prevents breast cancer in a limited way. Women who feed the breast have less chance of breast cancer. | Participant statement |

However, there is a chance that while transcribing, some relevant information is missed. To ensure that this did not happen, my intention of doing member checking was explained (intention to share the transcriptions after translating into English to one of the voluntarily interested participants in each FGD). The participants agreed and they voluntarily identified a member from each group to do so and later I shared the transcripts with the volunteers. Further details on member check is discussed in the data trustworthiness (see chapter 5) of this thesis.

Two voice recorders were used: a Sony ICD- PX470 Digital Voice Recorder with USB (Recorder 1) and the other one was an application called “Voice Recorder” version 2.0.12 downloaded from the Google Play store on my mobile “Samsung Galaxy A8 2016” (Recorder 2). Both voice recorders were placed on a table in the middle of the room to ensure that the voices of the moderator and the participants were recorded clearly. Both devices were checked in each venue before the beginning of the discussion.

For data transcription, recordings from Recorder 1 were used as this had very good sound quality. Recordings on Recorder 2 were then erased. These discussions were saved into a password-protected computer file. Both recordings and the transcriptions were made anonymous because I had the responsibility to protect the personal information of the participants Byrne (2001), Kaiser (2009) and to safeguard the participants’ anonymity. Further, in the PIS I mentioned that I would not include their name so the participant’s statements were transcribed as Participant 1 (P1), Participant 2 (P2) and so on...

The data collection procedure at the venue was as follows (see figure 4.3):

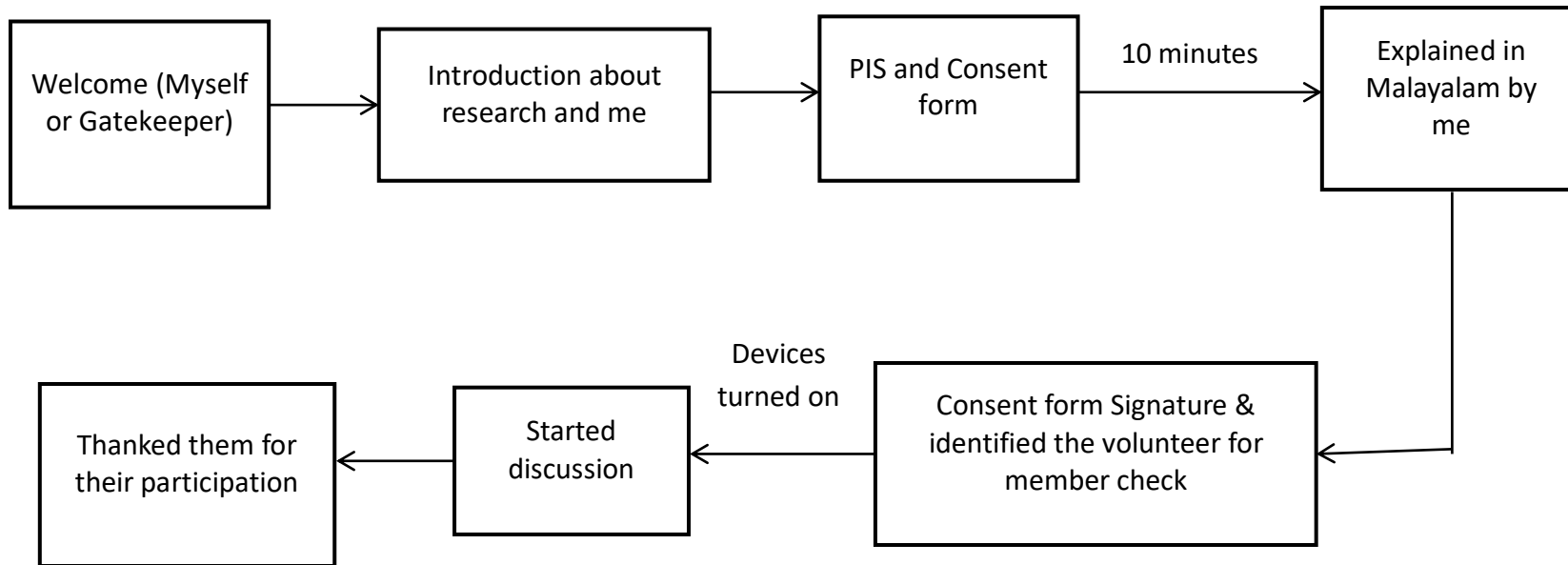


Figure 4. 3 A diagram to represent the data collection procedure

#### 4.11 Data analysis

Data analysis can be described as the process of bringing order, structure and meaning to the collected data (Marshall, 1995; Seers, 2012). It is an activity of interpreting and theorizing data that designates a search for common statements among the categories of data (Marshall, 1995, p. 150). In an ethnographic study, data analysis is strictly qualitative and draws the findings from the participants' direct statements and it relies on the researcher's ability to identify the findings from it (Nyumba et al., 2018). Yet, data analysis should follow a form of logical approach and should avoid bias wherever possible. This is because as Fetterman (1998, p. 1) states especially in ethnographic studies,

*'the ethnographer enters the field with an open mind, not an empty head. Before asking the first question in the field, the ethnographer begins with a problem, a theory or model, a research design, specific data collection techniques, tools for analysis, and a specific writing style'*

In qualitative research, the researcher becomes the instrument of data analysis, making judgments on all the stages of analysis until the results and conclusions are determined (Starks & Brown Trinidad, 2007). In ethnographic studies, the ethnographers employ a cultural lens to decode the observed behaviour from the participants (Fetterman, 1998). In this research, I explained the findings through the participants' views on breast cancer screening and its utilisation.

The careful analysis of the data using an inductive process usually identifies codes and themes and ethnographers reach theoretical explanations from their findings (Reeves et al., 2008). In addition, data collection and data analysis should form a mutual interaction between what has been established as known and what needs to be investigated to achieve rigor in qualitative research. Therefore, data collection and data analysis can be conducted concurrently to understand what needs to be known further in the topic of research (Morse et al., 2002). However, I could not do the data collection and data analysis simultaneously, but as I was the

moderator for all FGD, I had an idea what other participants stated during discussion and used the probing question accordingly. For example, In FGD 1: 89- 91

|  |                       |
|--|-----------------------|
| Researcher: Ok, let me ask some questions to you those who did mammogram from here (UAE). Apart from free mammogram what else facilitated you to do it from UAE?   | My Question           |
| P4. I don't have enough leave in the organisation where I am working. They are providing holidays once a year. If I wait for the next vacation to do check-up in Kerala, I can't do it. So, I did the check-up from here in UAE. | Participant statement |
| Researcher: Do you mean that holiday's also important for medical check-ups?   | My probing question   |
| P4. Yes, employees can do medical check-up during holidays only. One of the facts is that workers don't get holidays to go for an ordinary medical check-up even. If they get leave, they can do check-ups in the UAE itself.    | Participant statement |

From 1970s, the recorded interview became a popular research genre (Gubrium & Holstein, 2002; Jeanine, 2011). The recorded voice usually will be translated or transcribed for further analysis. I translated the recorded audio into English. Translation makes the data more transparent and accessible, enabling another researcher to read, search the data easily, and mark in it (Davidson, 2009; Jeanine, 2011). Meanwhile, transcription is the first step in analysing the data (Daley et al., 2012; Stuckey, 2014). It has also been argued that although transcribing seems a straightforward technical task (Daley et al (2012)) while transcribing, the researcher can expose more details if continuously reflecting on the data and generating initial ideas (Kvale, 1996; Oliver, Serovich, & Mason, 2005). Further, advances in technology provided new approaches for data analysis for qualitative researchers such as computer-assisted qualitative data analysis software (CAQDAS) (Cope, 2014). Since the 1990s, numerous qualitative data analysis computer programmes have been used for sorting and organising the data available (McLellan, Macqueen, & Neidig, 2003; Richards, 2002). Data analysis software also has the ability to define, organise coding, analyse relationships and themes in the data. Some of the

software available to do this includes NVivo, Ethnograph, NUD\*IST, Atlas Ti and Qualrus or it can be achieved manually (Alhojailan, 2012; Cope, 2014; Jeanine, 2011).

The use of software programmes enables researchers to save time performing manual coding and copy texts directly into the document for publication and they provide an eco-friendly approach by limiting the waste of paper, pens, storage space and filing cabinets (John & Johnson, 2000). Software coding also supports researchers who wish to quantify their data (Basit, 2003; Erik, 2016). However, equipment failure can happen, each software package is different and may not fit with the purpose of all qualitative studies and the researcher's take extensive time to learn how to use and become familiar with the software packages (McLafferty & Farley, 2006). Moreover, disengagement of the researcher from the data is a potential concern in using software packages (Banner & Albarran, 2009; John & Johnson, 2000).

Systematic manual coding ensures that all the contents of data are extracted from the transcripts (Ose, 2016) and the researcher then has the opportunity to immerse themselves in the wealth of the data (Cope, 2014). In this research, I transcribed the focus group discussion from Malayalam to English within weeks (around 2 weeks) of the discussions and adopted systematic manual coding as discussed by Ose (2016). To record the discussion digitally, extract, sort and organise the participants' views, I used Microsoft Word and Excel. I decided to code manually as both computer programmes have adequate functionality for organising and storing data. Moreover, manual coding of the data was a manageable task, and it enabled me to have an in-depth understanding and connection with the data.

Focus groups can enable the researcher to collect both verbal and non-verbal messages (for example, facial expressions, eye contact, gestures, voice, pitch, silence) (Tecu & Tescasiu, 2015). However, as my intention was to capture the meanings and perceptions from participants statements during the focus group discussions, I used a denaturalised form of transcription, in which a verbatim depiction of speech was done and avoided accents or involuntary vocalisations (Oliver et al., 2005) during transcription.

Each of the focus group discussions lasted from 45 minutes to 1 hour. I took around 10-12 hours to transcribe the voice recordings. To maintain consistency (Twinn, 1998), I translated



and transcribed all the focus group discussions. Translation here meant the transfer of meaning from the original language (the discussion happened, here in Malayalam) to a language that is understandable to the target audience (here English). During translation, the translator can face constraints such as variations in pronunciation, use of slang, and multiple word meanings (Oliver et al., 2005), or finding no word to exactly translate the concept into the target language (Twinn, 1997). It can in turn influence the trustworthiness of the research and its findings, so to minimize this, member checking was done.

However, as the discussion was in my mother tongue (Malayalam), I did not face any difficulty understanding the conversations and translating them into English. Nevertheless, one important exception was the word “Kudumbanadha”, a word that is typically used to convey the concept of “wife”; female head of the family in Malayalam. It is an important term, as it appeared to capture all the culture-specific values that represent Keralite women. During the discussions, the participants meant to say that they were often too busy taking care of their husbands and children’s needs to undergo screening mammography. In such instances, I used the term “altruism”, which means “selflessness” or “willingness to do things that bring advantages to others, even if it results in disadvantage for yourself” (Cambridge, 2019).

#### 4.11.1 Thematic Analysis

Qualitative research seeks to arrive at an understanding of a phenomenon from the viewpoint of those experiencing it. Researchers use many methods to gain insight and knowledge from the data collected (Carmel, Mark, Maggie, & Adam de, 2018). These methods enable the researcher to gain a deeper understanding and appreciation of the research data by reading, re-reading the data, writing down observations and searching for meaning to discover the pieces of relevant data for reporting (De Chesnay, 2015). Therefore, meaning and understanding of the data occurs in a non-linear fashion and it involves numerous techniques (Smith & Firth, 2011).

Thus, the data gathered through interviewing, observations or document analysis cannot be measured exactly, but must be elucidated and compiled into themes or categories (Soiferman, 2010). Therefore, the researcher should ensure which data analysis approach can answer her research questions (Speziale & Carpenter, 2011; Vaismoradi, Turunen, & Bondas, 2013). In this respect, thematic analysis (TA) and content analysis are two commonly used approaches (Vaismoradi et al., 2013). Despite many similarities between these two approaches, the main difference is that content analysis facilitates quantification of data. This makes it possible to analyse data qualitatively and at the same time quantify the data (Grbich, 2013; Powers, 2011, p. 30). Thus, it can be used to determine trends and patterns of words, their frequency, the effect of words used, and the relationship between the words (Altheide, 1987; Bloor & Wood, 2006). Thematic analysis was used in this research as it is an exploratory study intended to yield detailed and holistic views of the participants (Boyatzis, 1998; Merton, 1975). It helped to capture unique findings from the transcripts.

Thematic analysis is a widely used method that provides a descriptive presentation of the data (Attride-Stirling, 2001). It particularly helps in understanding and emphasising the perspectives of the research participants. Thematic analysis provides a direction on identifying patterns of meaning (themes) in qualitative research (Braun & Clarke, 2019). It is one of the generic skills across qualitative data analysis (Holloway & Todres, 2003). One of the advantages of thematic analysis is its flexibility (Braun & Clarke, 2006), another is that it can be used as a tool to analyse the data (Boyatzis, 1998). It also supports inductive analysis of data.

While doing thematic analysis, if the themes are completely extracted from the data with little relation to the specific questions that were asked to the participants, the approach is described as inductive (see section 4.1) (Braun & Clarke, 2006; Hsieh & Shannon, 2005; Maguire & Delahunt, 2017; Vaismoradi et al., 2013). Thus the inductive approach is not directed by the researcher's interest or theoretical knowledge (Braun & Clarke, 2006; Maguire & Delahunt, 2017). However, while doing thematic analysis, there may be pre-existing beliefs, which the researcher has gained through the literature or experience before conducting the data

collection and data analysis (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). This research followed a similar concept shared by Creswell (2014) as follows.

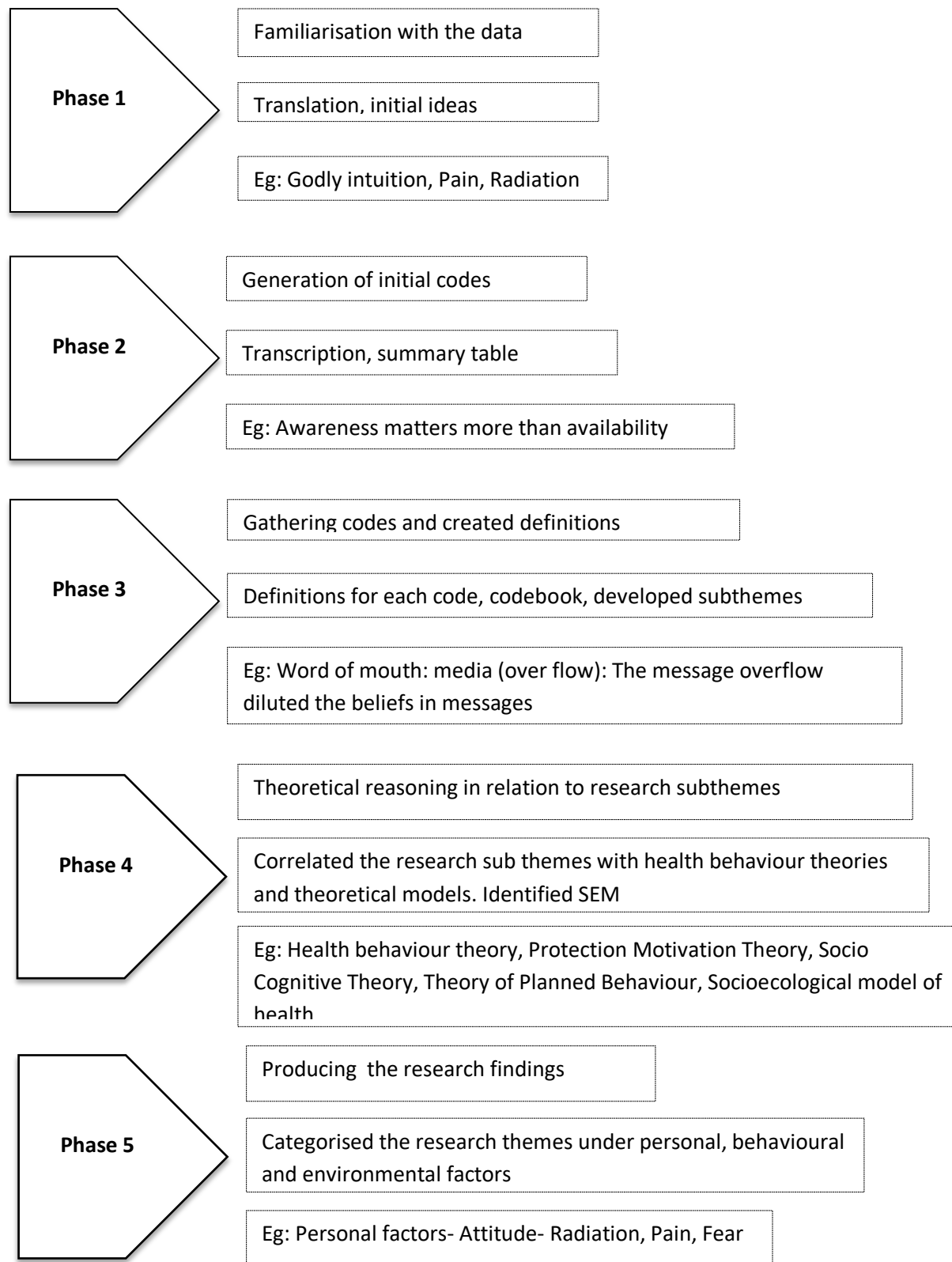
| <b>Stages</b> | <b>Concept by Creswell (2014)</b>   | <b>In this research</b>   |
|---------------|---|---|
| 1             | Researcher gathers information (eg: interviews, observation)                                | Gathered information through focus group discussion                                 |
| 2             | Researcher asks open- ended questions to participants or records field notes                | Open- ended questions were asked to the participants                                |
| 3             | Researcher analyses data to form themes or categories                                       | Analysed the data to form codes and themes  |
| 4             | Researcher looks for broad patterns, generalisations, or theories from themes or categories | Looked for the theories/models from the themes                                      |
| 5             | Researcher poses generalisations or theories from past experiences and literature           | Identified socio-ecological model of health that conveys the findings of this study |

There are many approaches to thematic analysis (Alholjailan, 2012; Boyatzis, 1998; Javadi & Zarea, 2016). In this research, I adopted the approach outlined by Braun & Clarke (2006) in a six-phase process (see table 4.7 the six phases of thematic analysis). However, not all phases were found to be relevant to the context of this research. Therefore, an adapted version of (Braun and Clarke (2006)) was been used.

**Table 4. 7 Phases of thematic analysis (Braun & Clarke, 2006)**

| <b>Phase by Braun &amp; Clarke (2006)</b> | <b>Description of the process</b>  |
|---|--|
| Phase 1 Familiarisation with the data     | Transcribing data, reading and re-reading the data and noting down initial ideas                       |
| Phase 2 Generating initial codes          | Coding interesting features of the data in a systematic fashion. Collect relevant data under each code |
| Phase 3 Searching for themes              | Identifying themes. Gathering the data that is relevant to each potential theme                        |
| Phase 4 Reviewing themes                  | Confirming whether the themes are related to the codes created   |
| Phase 5 Defining and naming themes        | Generating clear definitions and names for each theme  |
| Phase 6 Producing the report              | Final analysis of the themes and relating back to the research question and literature.                |

The description of each of these phases and how they were applied in this research are described in Figure 4.4, section 4.11.1.1 to 4.11.1.4 and in the findings chapter (chapter 6) of the thesis.



**Figure 4. 4 Thematic analysis step adapted in this research\*<sup>3</sup>**

<sup>3</sup> Adapted version of Thematic analysis (Braun& Clarke, 2006)

#### ***4.11.1.1 Phase 1 Familiarisation with the data***

The initial step in qualitative data analysis is reading and re-reading the translated document, the transcripts. In this phase, the transcripts were placed in a line numbered table format for detailed understanding and locating the data in preparation for Phase 2. As the moderator, the transcription of data and later multiple readings of the data helped me become more familiar with the data. Holloway (1996) suggests that transcribing the discussions personally allows the researcher to immerse themselves into the data. Thus, immersion in the data was achieved, which means attaining a clearer overall understanding of participants' views could be conceived. Furthermore, during the familiarisation phase, I recorded my reflections in notes. These notes helped me form a better overview of the participants' responses and proceed with the generation of initial codes. For example:

- Women depend on their husbands to undergo breast cancer screening
- Mammogram increases the risk of breast cancer
- Role of social media

#### ***4.11.1.2 Phase 2 Generation of Initial codes***

Initial code generation for all five focus group discussions began after data collection and familiarisation with the data as described in the previous section (section 4.11.1.1). In phase 2, I reviewed the transcripts line by line and identified the views expressed by the participants during focus group discussions (FGDs), henceforth referred to as 'initial codes'. The codes are the phrases or words, or units of meaning, assigned to the descriptive or inferential information compiled during a study (Harper, 1988; Miles, 1994). The codes can also be defined as

*'the building blocks for theory or model building and the foundation on which the analyst's arguments rest' (MacQueen, McLellan, Kay, & Milstein, 1998, p. 1).*

In addition, a code represents and captures the important attributes of a portion of the data from the discussion, interview, transcripts, or field notes (Braun & Clarke, 2006). However, there is no specific coding method or a particular number of codes required to report a discussion or an interview, rather this depends on how detailed the researcher wants the data analysis to be and it further varies depending on the nature of the research study and contextual factors (Saldana, 2016).

In this study, initial coding enabled me to focus on specific areas of the data collected for all five FGDs. Then, to ensure that no essential information was overlooked while extracting the codes, I reread the transcripts (Coffey, 1996) and cross-referred to the summary table created during coding; however, no new codes emerged. This was done because, in the epistemological frame of interpretivism, the emphasis is on understanding the perspectives of the participants (Ritchie et al., 2014, p. 22).

A summary table was created (see Appendix O for all initial codes and table 4.8 gives an example of the summary table) that contained six columns. The first column was labeled as the serial number (numbered list) (to know how many initial codes emerged), the second column as initial codes (the concepts shared by the participants), third column as FGD (to identify the FGD and helped to note whether the same concepts are repeated in multiple focus groups to establish data saturation), fourth column as the location of statements (to locate the codes in the raw data to ensure transparency and rigour), fifth column as notes (to note down the thoughts arise while coding) and sixth column added to give examples of the codes. At this stage, I extracted 63 initial codes and noted the key ideas whenever they emerged (Appendix O). The initial codes were created using either the participants' exact words (for example, knowledge) or a synonym reflecting the same (for example, "altruism": participant's selfless concern towards her family rather than her health).

**Table 4. 8 Example of Initial code summary**

| Sl. No | Code            | FGD* <sup>4</sup>     | Location of statements in the FGD transcript  | Researcher Notes                                    | Participant statement   |
|--------|-----------------|-----------------------|---|---|---|
| 1      | Self- dependent | 1<br>2<br>3<br>4<br>5 | FGD 1: 3,4,5,6,10, 12<br>FGD 2: 122, 136, 182<br>FGD 3: 3,5<br>FGD 4: 2<br>FGD 5: 2 | Have power over decisions and events in their lives | 'I take decision myself and go to the hospital for treatment because I can only understand my body's conditions' - FGD 3: 3 |

This stage helped to capture important elements under study and enabled me to re-confirm that additional focus group discussions would not yield any new concepts; thus data saturation was recognised (Connelly, 2016; Morse, 1991; Morse, 2010). Data saturation is a broad term that is considered a criterion for discontinuing data collection and/or analysis (Glaser, Strauss, & Strutzel, 1968; Saunders et al., 2017, 2018). This means that no additional data are found to necessitate the development of new codes or themes Coyne (1997), Fusch & Ness (2015) and the same codes are recurring in all the FGDs (see Appendix-O)

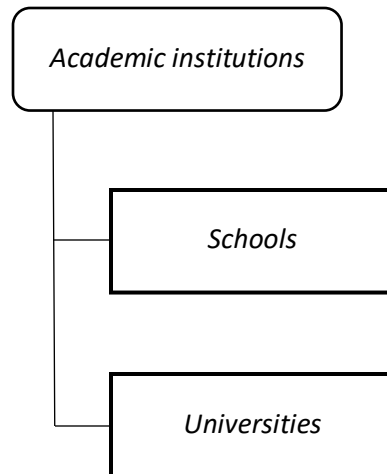
#### ***4.11.1.3 Phase 3 Gathering codes and created definitions***

Based on the previous two phases, a codebook was developed. A codebook is the first step in analysing the qualitative data. It is a set of code definitions used as a guide to analysing qualitative data. It helps to ensure reproducibility during investigator triangulation (Fereday & Muir-Cochrane, 2006; MacQueen et al., 1998). In this research, the process of developing the codebook began with compiling a list of initial codes, assigning a clear definition for each code, critically analysing participant statements and reviewing the initial codes to the FGD questions.

<sup>4</sup> FGD 1 and 2 = Population 1 & FGD 3, 4, and 5 = Population 2



Further, the initial codes were synthesised, collated, and developed as sub-themes (see figure 4.5 and table 4.9 for an example. In this instance, “academic institutions” is the subtheme and “schools”, “universities” were the initial codes.



**Figure 4. 5 Example for gathering codes under a subtheme**

**Table 4. 9 Example of Initial code summary**

| <b>Included initial codes</b>  | <b>Sub-theme</b> | <b>Definition</b>   | <b>Location of participants quotes in the transcripts</b>  |
|--|------------------|---|--|
| Participants' subjective evaluation of screening mammography such as exposure to radiation, pain, and fear | Attitudes        | Participants' settled way of feeling or thinking. It can be stated as a psychological tendency to view a particular behaviour with a degree of favour or disfavour (Ajzen, 1993; Albarracin, Johnson, & Zanna, 2005; Eirich & Corbett, 2007). | <u>Radiation</u><br>FGD 1: 25, 56<br>FGD 2: 175<br>FGD 3: 133<br>FGD 4: 65<br>FGD 5: 59, 61, 161   |
|  |                  |   | <u>Pain</u><br>FGD 1: 24, 25, 44, 45, 56, 59<br>FGD 2: 50, 51, 52, 161<br>FGD 3: 49, 65, 133<br>FGD 4: 65, 78, 81<br>FGD 5: 59, 108, 109, 111, 112 |
|  |                  |   | <u>Fear</u><br>FGD 1: 127- 129<br>FGD 3: 11<br>FGD 4: 207, 208<br>FGD 5: 122-124, 161,162  |

#### ***4.11.1.4 Phase 4 Theoretical reasoning in relation to the research subthemes***

Next, the subthemes were used to identify the theory, or theoretical model, that best suits the research findings and for developing the broad themes. A qualitative researcher uses a theory or theoretical model in several ways in their studies (Creswell, 2014). This can direct the search strategy (what to look for), intervention goals (what to achieve), and what might explain outcomes of interventions (Glanz, 1997). This phase linked the theoretical concepts available in the literature and the research data I obtained (Bradley, Curry, & Devers, 2007; Braun & Clarke, 2006; DeSantis & Ugarriza, 2000). Moreover, considering multiple theories enables a researcher to think of ideas that might have never been considered before Glanz (1997) and could interrelate the research findings with the available concepts in the research context (Glanz, Rimer, & Viswanath, 2008).

According to (Kasl & Cobb (1966)) health behaviours can be defined as any activity undertaken by a person, believing himself to be healthy, for preventing disease or detecting it at an asymptomatic stage. In fact, health behaviours such as health beliefs (Ersin, Gozukara, Polat, Ercetin, & Bozkurt (2015)), self- efficacy (Hajian-Tilaki & Auladi (2014)), perceived susceptibility (Petro-Nustas, Tsangari, Phellas, & Constantinou (2013)) and awareness (Abeje, Seme, & Tibelt, (2019); Kennedy (2018)) can impact a woman's approach to breast cancer screening, and influence her openness for the uptake of screening mammography, and therefore, need to be addressed (Noroozi & Tahmasebi, 2011).

Health behaviour theories can serve as a model to establish an understanding of research participants' thoughts, emotions and behaviours (Waterman (1988)), and predict their health behaviours (Ashing- Giwa (1999), Glanz (1997), Glanz & Bishop (2010), Noar & Zimmerman (2005)) and their response to change (Bandura, 1997). I did not focus on a single health behaviour theory or model but tried to link the subthemes of this research with available health behaviour theoretical concepts. For example: based on the health belief model (HBM) an individual would decide to undergo screening mammography if she perceives herself susceptible to breast cancer, considers the severity of the condition, and weighs the benefits of

practising breast cancer screening (section 2.5). Although similar health behaviours were identified among the subjects of this research the health behaviour theory was found to limit the factors that affect the uptake of screening mammography to socioecological factors. Most other theories that apply to health behaviour place emphasis on an individual's behaviour while excluding other important health behaviour determinants such as the environmental, socio-cultural, economic and policy factors. Such factors emerged clearly in this research and, therefore, the findings of this research seem to mostly agree with the socio-ecological model of health (McLeroy et al., 1988).

Another advantage of viewing the findings of this research within a socio-ecological model is that it helped me to understand the different levels of social system and the interrelationship between individuals and the environment within this system. Moreover, the research methodology adopted here was based on an emic, interpretivist, relativistic and ethnographic approach, therefore, the socio-ecological model of health provided a structured framework to present the personal, social and physical influencers that can initiate behavioural change towards the uptake of screening mammography. There are five hierarchical levels in SEM: individual, interpersonal, community, organisational and policy (see figure 2.2).

Interventions made at all levels of SEM were found to be an effective approach to promoting public health prevention programmes (Centers for Disease Control and Prevention, 2015). Therefore, these levels serve as the themes of this research. The term theme has been defined by (Maguire & Delahunt (2017)) as a term that refers to a pattern that gathers something significant about the data and/or research question and that can be discovered at many levels of qualitative data (Powers, 2011).

To sum up, the aim at the initial stage of data analysis was to seek as much detailed information about the participants' perception of breast cancer and the uptake of screening mammography. Then the findings of the research were related to existing theories and knowledge in the field. Phase 5, the production of the research report is presented as the Findings chapter (chapter 6) of the thesis.

## 4.12 Summary

The first part of this chapter stated the research objectives, research paradigm and the rationale for choosing specific philosophical and methodological stances. The second part discussed the methods adopted to generate data including the data collection instrument, participant sampling framework, recruitment strategy, and research ethics that informed the research process, and data collection procedures. Later the chapter explained the methodology adopted for data analysis of this research.

This qualitative research used five focus group interviews and the sample of the study comprised of two populations of expatriate Keralite women residing in the UAE: 1) those that had undergone screening mammography, and 2) those who had not. The research questions were exploratory, adopted relativism as ontology, interpretivism as epistemology.

The target research subjects of this study comprised a unique cultural group different from Emirati nationals and from other Keralites who have been exposed to other cultural influences. However, no other studies addressing this particular group of females' cultural and personal perceptions of mammography screening have been identified to date. This study aimed at revealing the underlying causes of the participants' attendance of screening mammography and the most practical and efficient ways of increasing the rate of early detection of breast cancer among them.

To achieve the objectives of this study, critical ethnography was adopted. This is because the participants' cultural components and human experiences are significant variables in this research. Both are based upon description and interpretation. For thematic analysis, the six-phase model proposed by (Braun & Clarke (2006)) was adopted and modified to suit the purpose of this particular study. The socio-ecological model of health promotion is utilised as a theoretical framework for data presentation. The next chapter reviews and evaluates data trustworthiness.

## Chapter 5: Data trustworthiness

In 1981, Guba raised trustworthiness standards that any researcher needs to address irrespective of the research paradigm, and it requires specific criteria for addressing “rigor” (quantitative) or “trustworthiness” (qualitative) (Guba, 1981; Morse et al., 2002). Trustworthiness of a study demonstrates a commitment to the degree of confidence in data, data interpretation and the research design selected to ensure the quality of a study and its ability to reflect the meaning of participant’s views as closely as possible (Guba & Lincoln, 1982, p. 218; Polit & Beck, 2018).

The quality of the research output can be measured using the concepts of reliability and validity in quantitative research (Koch, 2006; Murphy & Yelder, 2010; Rolfe, 2006). The reliability of a study describes to what extent a particular test, procedure or tool can produce a similar result when it is administered in another setting without any changes (Guba, 1989). It is the extent to which the measurements are reproducible when another person conducts the same measurements, in a different context, under different conditions or among different samples, and it is the consistency of measurement (Bollen, 1989, p. 206; Drost, 2011). The validity of a study is considered as the appropriateness of the measurement and it is the closeness of what we believe is being measured (Guba (1989) Murphy & Yelder (2010)) and the meaningfulness of the research components (Bollen, 1989, p. 184; Drost, 2011).

The nature of the knowledge in quantitative research is different from the knowledge in the qualitative paradigm and an attempt to establish quality criterion for qualitative research is unlikely to succeed as there is no unified theory, methodology or method that can collectively explain varying human perspectives (Rolfe, 2006). This is because the quantitative studies are objective, involves numerical values, and own a scientific description of reality (Sharts- Hopko, 2002). While, qualitative researches are conducted in natural settings and thus the reality is constructed by the context, and it is multidimensional, varying and cannot be measured, and

subjective to the interpretations of the researcher (Miles & Huberman, 1994; Murphy & Yelder, 2010; Roberts & Priest, 2006).

Further, the quantitative research is linear and uses statistical tests, while qualitative research is non-linear, iterative, dynamic and inductive so establishing a rigid rigor in qualitative research seem to be contradictory (Murphy & Yelder, 2010; Tobin & Begley, 2004). Therefore, qualitative research should be judged using strategies that are developed for and suit the qualitative paradigm (Cutcliffe & McKenna (1999)) to mitigate the negative effect of bias (Fetterman, 1998). Thus the qualitative research approach has specific techniques of conducting, documenting, and evaluating data analysis process. In qualitative research, the researcher is often both the data collector and data analyst giving the potential for researcher bias (Miles, 1994). Therefore, it is the individual researcher's responsibility to confirm the trustworthiness of the research findings (Nowell, Norris, White, & Moules, 2017).

In qualitative research, trustworthiness confirms the research findings are worthy of attention (Lincoln (1985)) and it is the bedrock of qualitative research (Birt, Scott, Cavers, Campbell, & Walter, 2016). Trustworthiness can be achieved by confirming the criteria of credibility, transferability, dependability, confirmability, and authenticity (Guba & Lincoln, 1982; Guba, 1989; Lincoln, 1985; Shenton, 2004) (the explanations for each one can be seen later in this chapter, see section 5.1 -5.5). These are the parallel terms that are coined for the reliability and validity in quantitative research as shown in the table 5.1

**Table 5. 1 Term in Scientific Vs Constructivist paradigm<sup>5</sup>**

| <b>Quantitative terms</b> | <b>Qualitative terms</b> |
|---------------------------|--------------------------|
| Internal validity         | Credibility              |
| External validity         | Transferability          |
| Reliability               | Dependability            |
| Objectivity               | Confirmability           |

In reality, not all of these data trustworthiness criteria may be able to be followed, but according to Creswell (2012), a qualitative researcher should engage in at least two of them in their study Creswell (2012,p. 253) and the strategies for attaining each of them can also vary between studies (Morse, 2015). The following sections of this chapter will explain the data trustworthiness criteria followed in this research.

## 5.1 Credibility

The credibility of the study is the confidence in the truth and findings of the study, and it is similar to the internal validity in quantitative research (Lincoln, 1985; Polit & Beck, 2014). "An account is valid or true if it represents accurately those features of the phenomena, that it is intended to describe, explain or theorise" (Hammersley, 1987, p. 69). Thus credibility validates whether the research findings represent true information drawn from the participants' original data and is a correct interpretation of the participants' original views (Korstjens & Moser, 2018) or it is the "fit between respondents" views and the researcher's presentation of them (Tobin & Begley, 2004).

Therefore, the credibility in qualitative research can be achieved when it represents faithful descriptions of human experience and investigator subject relationship such that the subjects

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<sup>5</sup> Adapted from Murphy & Yelder (2010)



or readers who have similar experience or interest can recognise the findings of the research (Guba, 1989; Psathas, 1973; Sandelowski, 1986). Further, the credibility; the truth-value in qualitative research is the discovery of human experiences rather than the verification of prior scientific concepts (Sandelowski (1986)) or it is the confidence in the truth and findings of the study. The term 'validity' in qualitative research is controversial and it is not a single, fixed and universal concept. It is subjective, conditional, inescapably merged in the process and intentions of particular research and the methodologies (Winter, 2000). Therefore, in reality, the truth is subject- oriented rather than research defined thus the readers or participants are the ones who can reasonably judge the credibility of the results (Slevick, 1971). It marks the issue of 'fit' between the respondent's views and the researcher's interpretation of them (Schwandt & Davies, 2002; Tobin & Begley, 2004). To conclude, the findings can vary depending on the human experience, research setting, relationship with the investigator and participants (Sandelowski, 1986; Van Maanen, 1983, p. 255).

Thus considering these, confirmation of the credibility can be achieved by adopting various strategies such as creating a reflexive journal about me (chapter 3), the interaction with the participants, and reactions to various events that happened during data collection Koch (2006) can be shared with the readers.

The events that were happened during data collection can be considered as the impact of a critical ethnographic study. To illustrate, although this was not considered as a primary objective for this study, changes in participants' breast cancer screening behaviour and the various activities they engaged in after data collection constitute an impact. This confirms a change in behaviour, awareness, and ability to utilise resources of the participants because of this research. Many participants voluntarily underwent screening mammogram and invited me to talk in their community/church/schools about the importance of breast cancer screening and screening mammogram (Appendix A). I used phantoms that show different stages of breast cancer that were available to me in the University of Sharjah during these awareness sessions. Furthermore, a television channel in the UAE invited me for an interactive session to share the importance of breast cancer screening among Keralites (David, 2018).

Along with these, prolonged engagement, persistent observation, triangulation (Data, Investigator, Method), peer debriefing (asking another researcher to code the same transcript and then can discuss the similarities and differences in the generated codes) as well as member checks can be conducted (Guba, 1981; Korstjens & Moser, 2018; Lincoln, 1985; Sim & Sharp, 1998; Sutton & Austin, 2015; Tracy, 2010).

In this research to ensure credibility (see figure 5.1); prolonged engagement (see figure 5.2), member check and investigator triangulation (see figure 5.3) were conducted, and further explanation for each of them are provided.

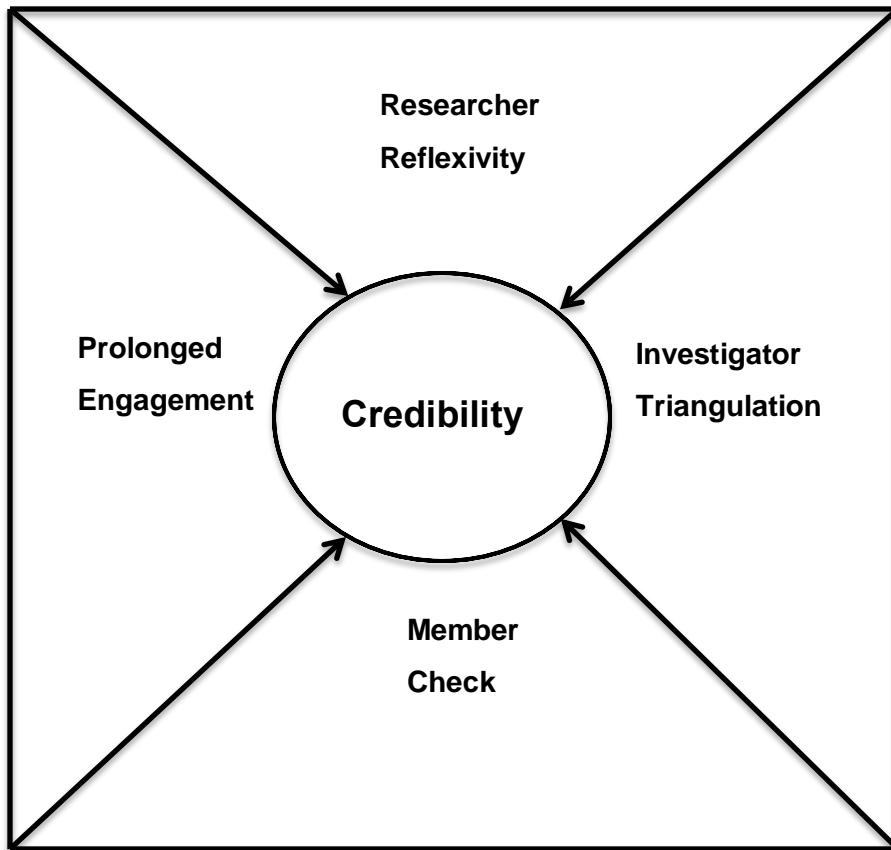


Figure 5. 1 Five ways of credibility achievement in this research

The prolonged engagement is spending enough time with the participants or community to learn the culture, social setting, or phenomenon of interest. As stated by Bitsch (2005), Creswell (2007), Onwuegbuzie & Leech (2007) prolonged engagement aids to establish trust, rapport and immerse with the participants and their communities. Because the trust is something that is voluntarily given and cannot be claimed, but it can be enhanced by creating conditions to ensure trust relationships (O'Neill, 2002). The researcher's extended time with the research setting can help the researcher to acquire an insight into the context of the study, which minimizes the distortions of information that may occur due to the presence of an unfamiliar person in the field (Onwuegbuzie & Leech, 2007).

For this (see figure 5.2), before the data collection day, I had an understanding of the participants (except three participants) and the research venue. Further, when I shared the research idea with the pastors and head of the communities, they invited me to their gatherings and I got opportunities to be in the worships, meetings, and gatherings to have a rapport, introduce the research, and invite the women for FGD. At the end of these gatherings, I shared copies of the participant information sheet and could informed them that they have opportunities to contact me over the phone or through email if they have any doubts. Furthermore, as the pastors/community leaders/or their known person directed me to the participants; they felt more trust in me (even one of the participants even expressed this during the focus group discussion). Along with these, an emic perspective (insider's view) such as participants from a single cultural group (Morris, Leung, Ames, & Lickel (1999)), I being a Keralite; enabled me to understand the Keralites culture from "the native's point of view" (Schwiedland, Malinowski, & Frazer, 1923). The discussion sites and situations also have an important role in qualitative research as the interview site itself creates "micro- geographies" of social relations and meanings (Elwood & Martin, 2000).

Careful selection, the arrangement of the interview site can offer convenience, confidentiality, comfortability and it can empower people, reduce inconsistencies in socio-spatial relations to constitute themselves as knowledgeable participants and the researcher (Elwood & Martin, 2000). Therefore, I gave priority to the participant's choice of location for example: in the

church or the community centre. The participants selected their convenient location, and accordingly I went there and arranged the interview venue. These enabled me, as the researcher, to be familiar with the interview sites, as well as the participants got knowledge about their interview neighbourhood. This further constituted to have prolonged engagement with the participants and with the research venue. Further to build trust in the trustor (researcher); the trustee (participant) has to be aware that the trust has been placed on them and this entrusting added another component that influences the fair outcome of the research (Kerasidou, 2017).

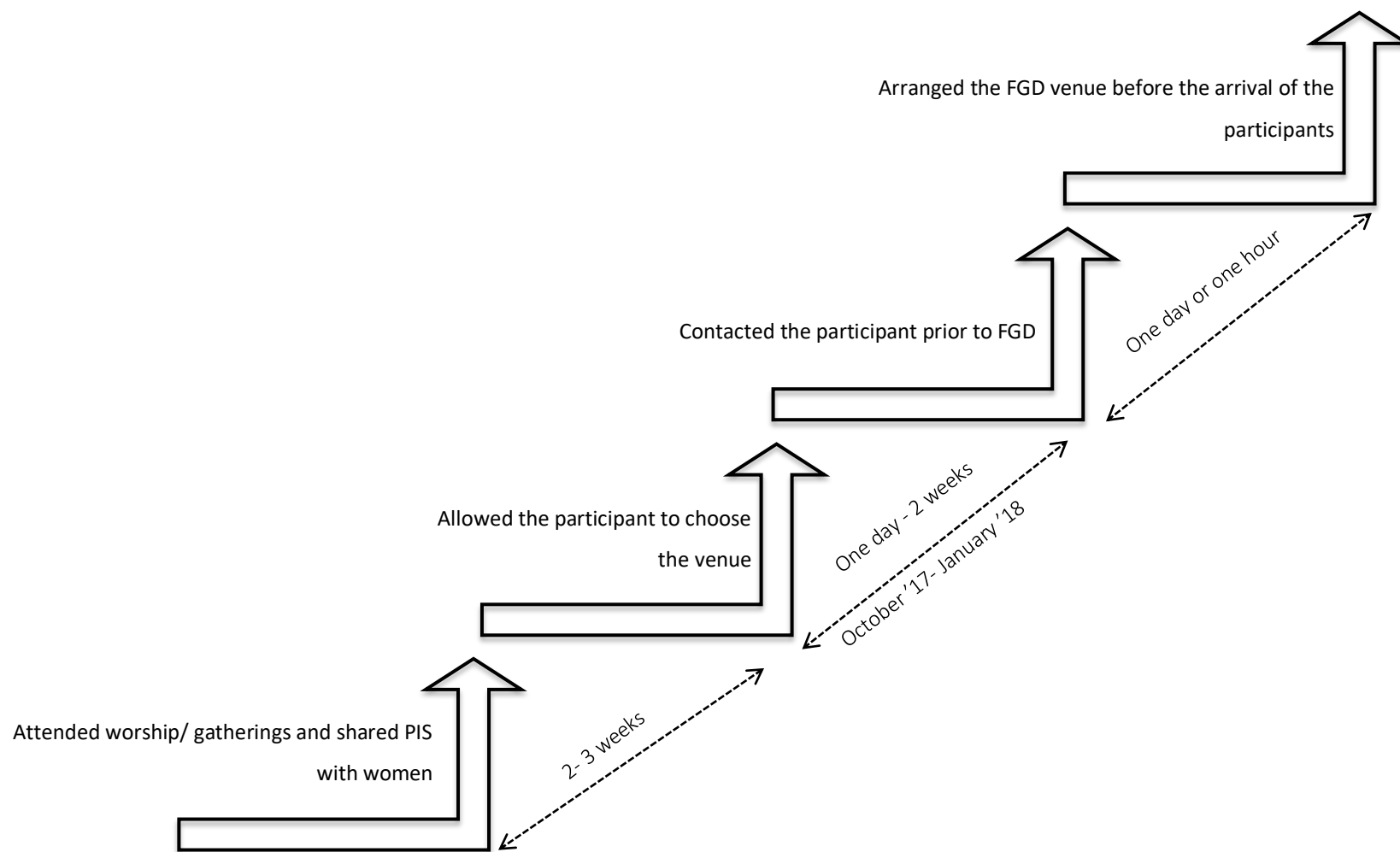


Figure 5. 2 My prolonged engagement in this research

Further, member checks Guba (1981) also known as the respondent validation Birt et al (2016) were done. Member checking is a method of confirming the exactness of the transcript confirming that the participants own meanings and prospects are presented and not curtailed by the researcher's bias in the research (Harper & Cole, 2012; Tong, Sainsbury, & Craig, 2007). This is because a qualitative researcher might impose personal beliefs and interests on every step of the research process and dominates over the voice of the participants (Mason, 2002). In the epistemological stance of Interpretivism, member check can be done by asking a participant to check the transcript of their interview (Birt et al., 2016). For this, translated verbatim transcript should be shared while the interview is still fresh in their memory (Carlson, 2010; Forbat & Henderson, 2005). I conducted member checking to obtain feedback and confirmation in the translated hardcopy version (English version) of the focus group discussion. To conduct this, I asked permission with the participants (during the discussion of participant information sheets) to share the transcribed verbatim to any voluntarily agreed participant in each focus group within two to three weeks after the FGD. Two of them returned the transcripts and the other three agreed over the phone or face to face that the transcripts resonated with the groups' views (that they remember). They did not ask to add or remove any information from the transcripts.

However, the time gap of three weeks, due to the reviewer's time constraints may have influenced to some extent the accuracy of member checking. Also, the participants checked the English version of the transcripts and they have not heard the recorded discussion while checking the transcript. Further, even though the discussion was conducted in layman language and translated as similar to the participant's statements, the understanding of the English language may vary between the participants and me as the transcriber. Nonetheless, it can be concluded that the participant's involvement in the initial interpretation of data assured that, researcher bias has been eliminated to a certain extent and gave some assurance that there is a true reflection on the participant's views.

Investigator triangulation was conducted to achieve credibility. Triangulation is the approach for 'knowing more' about a phenomenon through the use of different research methods in one

empirical investigation (Moran-Ellis et al., 2006). It is the combination of multiple data resources (data triangulation), researchers (Investigator triangulation), methodologies (methodology triangulation), theoretical perspectives (theory triangulation), and data analysis (data source triangulation) techniques to develop a comprehensive understanding of the research phenomena (Ashatu, 2015; Patton, 1999; Thurmond, 2001). It refers to the observation of a research study from a minimum of two points (Jupp (2006)) and validation of interpretations. Investigator triangulation is the use of more than two researchers in any stage of the same research study to confirm the process or findings of the research (Thurmond, 2001). When more than one researcher generates or assists in enlisting the patterns or themes from qualitative data, they can enhance the validity of the data analysis method and guard against the researcher bias (Appleton, 1995; Burnard, 1991). This could be achieved by both the researchers interpreting the data independently, producing codes, comparing, and confirming the interpretations by one another (Burnard, 1991).

In this research, investigator triangulation was achieved first by sharing randomly selected few pages (5 to 6 pages from each FGD transcripts) with one of my supervisors (British- western cultured, Male with no direct experience of mammography) who was blinded to my findings of the research. That means the supervisor did not see the codes and the theoretical interpretation of the data until he generated the initial codes in the sample pages. Then he discussed the initial codes that he generated and we discussed and correlated both of our initial codes. It was interesting to note that we agreed on the majority of the codes, and for some codes; different terms were used, for example, I marked as 'influence of family members'. He termed it as an 'influences of significant others'. Further, we merged some of the codes to represent a theme, for example, participant's beliefs for the reasons for breast cancer such as exposure to direct sun, food habits marked separately by me. But he combined it as "Myths". In addition to these, he identified additional codes for example: "Concreteness of diagnosis", where I marked it as "Fear of diagnosis". It is done under one of the participant's statements in FGD 5: 122.

*“I heard below 30 years old. Because my younger sister had breast cancer. She did mammogram before she reached 30 years old. If we think about hereditary there is a chance for siblings too. But I didn’t go for the mammography because of fear of the result/ diagnosis”*

Then the investigator triangulation continued after categorising the research themes under the themes of socio-ecological model of health by McLeroy et al (1988) as research findings conveyed that participants decision to undergo screening mammogram is driven by, interrelated and controlled by personal and environmental factors. Further, the subthemes and themes that I categorised were shared (see Appendix P) with one another supervisor to verify my categorisation before compiling the findings chapter.

However, investigator triangulation has its own challenges from the procedural level beyond the challenges from the technical, philosophical and methodological levels. Further, due to subjectivity (as an ethnographer; my interpretation of the participant’s view may be varied to my supervisor who has no experience with the Keralite culture or due to our personal opinions or feelings) sometimes may not demand the replication of results. Along with this, the selection of only a few pages from each transcript could lead to the loss of continuity of the context and participants views. Moreover, the generation of codes, themes depends on the unique creative processes between the researcher and the data and thus it is unlikely that two people will interpret data in the same way (Munhall, 2001; Schutz, 1994). Nevertheless, investigator triangulation helped to cross-check coding, themes and interpretation of data by independent researchers with fresh eyes, different time and place (Barbour (2001), Barry, Britten, Barber, Bradley, & Stevenson (1999)) as well as multiple person’s categorisation can have more diverse construction of realities than one person’s categorisation of the findings (Cutcliffe & McKenna, 1999; Johnson, 1997).



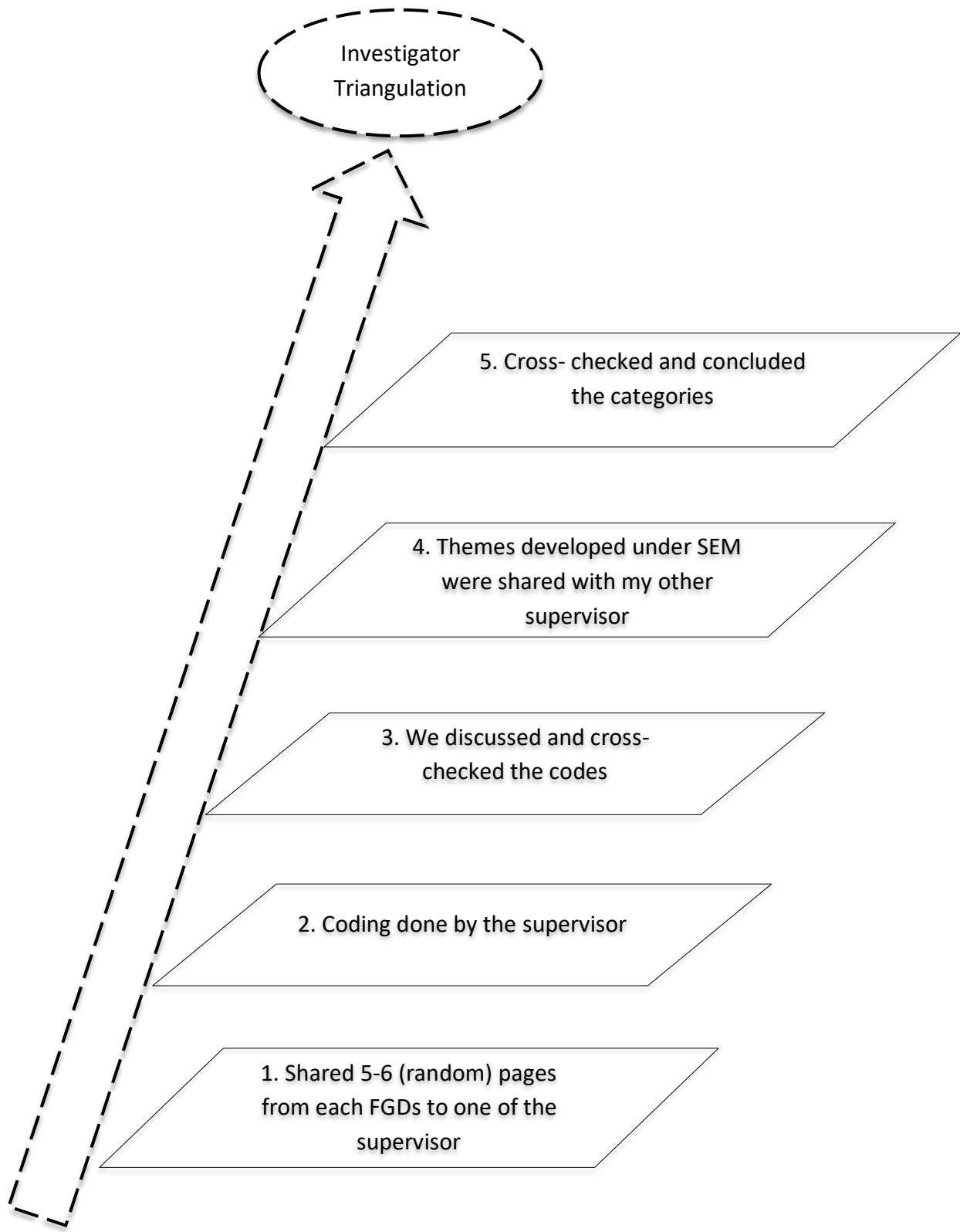


Figure 5. 3 Investigator triangulation in this research

## 5.2 Transferability

Transferability concerns the aspect of applicability Guba & Lincoln (1985) and potential for exploration (Elo et al., 2014). One of the drawbacks of qualitative research is its lack of establishing transferability, which is the extent to which findings of research are useful in other settings Polit & Beck (2014) as qualitative research is context bound Guba (1981) and specific to certain individuals (Shenton, 2004). Further, it is difficult to accomplish transferability in an Interpretivism approach, even after carrying out all the feasible measures during data collection (Guba, 1981) and research design. To some extent, the qualitative research that had been learned in-depth and richness can be transferred to other similar settings (Seale, 1999) and it can be established by sharing the evidence of research findings which could be applicable to other context with the readers (Lincoln, 1985, p. 316). Therefore, a thick description of the research context enables the readers to evaluate whether the findings are transferable to their research setting or not (Graneheim & Lundman, 2004; Korstjens & Moser, 2018). For this, a look into the descriptive data of the context in which the research is carried out, its setting, sample, sample size, demographic and socio-economic status, and inclusion and exclusion criteria of the participant, interview procedure enable the reader to make a judgement on transferability (Elo et al., 2014; Graneheim & Lundman, 2004; Korstjens & Moser, 2018; Li, 2004). Further, the description of the boundaries of the study can also aid the reader to consider the possibility of transferability (Marchionini & Teague, 1987). Yet, it will be ultimately down to the readers to make a judgement on the possibility of transferability in their research settings Graneheim & Lundman (2004) Korstjens & Moser (2018) and if researchers believe their situations are similar to a study they may be able to relate the findings to their own positions (Basse, 1981).

This research is conducted among the Keralite women residing in the UAE. The selection of migrant populations can be considered relevant to understand breast cancer screening practices among migrant women. This is because studies reveal that migrant women possess practical barriers for the uptake of breast cancer screening mammogram, (Ogunsiji et al., 2017). Further, the risk of breast cancer incidence among migrants John et al (2005), as well as migrant

women's attendance for cancer screening practices varies due to social, cultural comprehension, beliefs, norms and practices (Anderson de Cuevas et al., 2018). Moreover, the inclusion and exclusion criteria (see section 4.6) can be identified as relevant criteria's that truly represent the requirements of migrant population in this research context. The methodology, data collection tool as explained in sections 4.1 and 4.3 respectively can also found applicable in a qualitative research setting.

However, the participant's socio-economic, educational and demographic status has not been considered during participant selection. Further, in my research even though I had views from the participants who have undergone and not undergone screening mammogram, data were not analysed separately as my intention was to identify the factors that can influence the informed uptake of screening mammogram among Keralites residing in the UAE. However, the studies were conducted in separate groups to have uniformity and flow of discussion within the group. Overall, this study gains a chance of transferability in similar single cultured settings to obtain insight and correlate the factors that govern the informed utilisation of screening mammography among expatriates elsewhere. However, as similar to other qualitative research, the probability of transferability can change depending on the time, location and attitudes of the participants under a study.

### 5.3 Dependability

Dependability refers to the stability of the data over time and conditions of the study; that means whether the study could be repeated in a similar context and produce same results or not (Guba, 1981; Guba & Lincoln, 1985; Polit & Beck, 2014; Shenton, 2004). The dependability might be enhanced through conducting an audit trial by examining both the research process and product of the research. This can be done by allowing someone outside the research to follow, audit and critique the research process (Sandelowski, 1986). A detailed description of the methodology, methods employed will allow the readers to assess the extent to which appropriate research practices were followed (Shenton, 2004).

The qualitative research approach, data collection and data analysis tools adopted in this research can be counted as dependable as the research was focused to identify the thoughts and opinions of the participants rather than to test an idea or hypothesis. Further, an audit trail has been conducted and saved a copy of the data analysis phases that I conducted. Further, the research findings were cross-checked by member checks (see section 5.1) and through investigator triangulation (see figure 5.3). This enables me to state that the research findings are dependable to an extent to reduce researcher bias. Further, the participants selected for this study can also be identified as dependable to represent the Keralite expatriate population. Still, the experiences of participants can vary as the conditions can change from time to time, therefore, it is very difficult to achieve dependability in qualitative research (Collingridge & Gantt, 2008).

#### 5.4 Confirmability

Confirmability is the lack of bias that can result from the researcher's experiences and the degree of consistency that could be repeated. In short, confirmability concerns the aspect of neutrality (Guba & Lincoln, 1985). Two sources of bias can happen such as the tendency of the researcher to see what is anticipated (Morse & Mitcham (2002)) and picking only relatively small and excellent samples that exactly fit under what is being studied (Morse, 2015). I, as the researcher and FGD moderator, tried to have a neutral stance with the participants and to their views. For example, during the interviews, I did not start correcting their incorrect concepts about breast cancer, its symptoms and early detection, but continued the discussion and in some cases I agreed that I will discuss it after the FGD. For example, FGD 3: 76: *"If we see some changes immediately we must do the test (screening mammography)"*.

In addition to these to reduce researcher bias during data analysis; thematic analysis, which is one of the most common forms of step-by-step data analysis technique in qualitative research was used. This helped to use multiple steps to analyse the data. Moreover, a pilot study was conducted before the actual data collection to confirm the coherence and fidelity of the focus group questionnaire and interview strategies. Further member checks, investigator

triangulation (Figure 5.3), were conducted to confirm that the viewpoints are extracted from the data. Research team meetings with the supervisors also helped to discuss and look into the background information, data collection and process, data management and research findings that were carried out during this research and could ensure the confirmability.

## 5.5 Authenticity

Authenticity is closely linked to credibility and it involves the portrayal of research that reflects the meanings and experiences that convey participants' views (Polit & Beck, 2014; Sandelowski, 1986). In an interpretive emic approach, selection of appropriate samples, detailed descriptions of the participant's views, and characteristics of the researcher to the research (researcher reflexivity) can help the readers to understand the authenticity of a research study (Connelly, 2016; Guba, 1981; Polit & Beck, 2014; Schou, Høstrup, Lyngsø, Larsen, & Poulsen, 2012). As mentioned in the other sections of obtaining data trustworthiness, multiple considerations were made to achieve authenticity in this research.

## 5.6 Summary

This chapter demonstrated the commitment to trustworthiness of the data in this research. The nature of the knowledge in the qualitative paradigm and quantitative paradigm differs. Therefore, the chapter explained the terms used to represent the trustworthiness in both scientific and constructivist research paradigms. Trustworthiness criteria such as credibility, transferability, dependability, confirmability and authenticity are the common criteria in qualitative research. Henceforth, each of them were defined and the ways how it is established in this research were presented in the chapter. The next chapter (chapter 6) presents the findings of this research.

## Chapter 6: Findings

In this study, five focus group discussions were conducted among Keralite women who underwent screening mammogram (population 1) and who have not undergone screening mammogram (Population 2) to identify the influencing factors, perceptions and behaviours of Keralite women residing in the UAE towards early detection of breast cancer using screening mammography. The five focus group discussions involved 25 participants from six different emirates (Abu Dhabi, Ajman, Dubai, Fujairah, Ras Al Khaimah, Sharjah). All participants were married, 46 to 58 years of age, and educated to above secondary school and up to master's degree level (see table 4.5). This chapter reports the findings of the research.

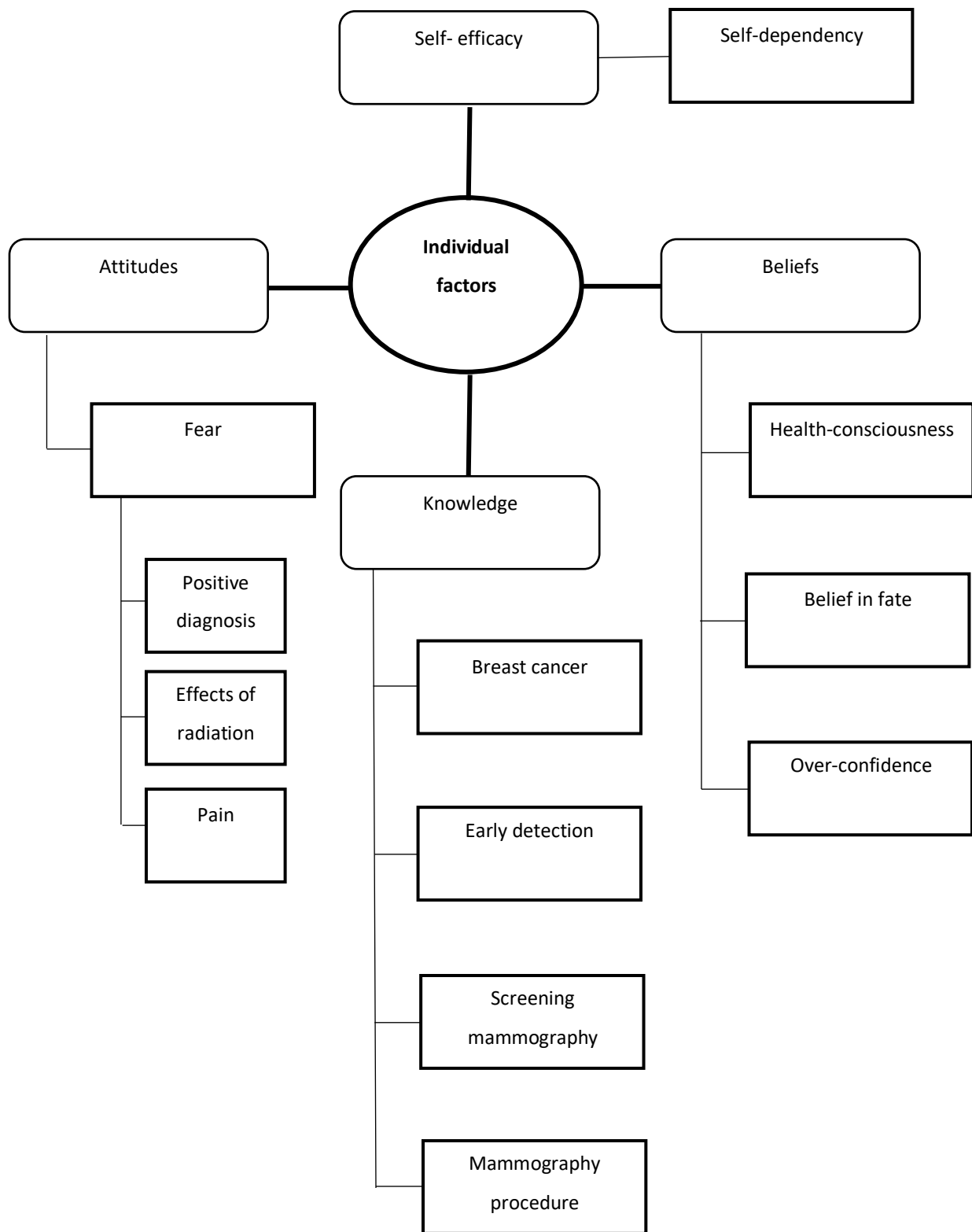
The findings of a research form the complex story of the data and this phase (phase 5) involves the final reporting of the research findings. In this section, the data collected is presented in a manner that the subthemes and themes are threaded together to convey the main findings of the research. After careful review of the common motifs that emerged in this data, it was deemed appropriate to use the different levels of the socio-ecological theoretical framework as the themes: individual, interpersonal, community, organisational and policy factors. These themes, as deduced from participants' responses, are discussed in detail below. In this part, as in the rest of this thesis, participants' statements have been translated and presented verbatim. This was intentionally done to give the participants their own voice and allow the reader to hear their views in their own words. Therefore, the local dialect and turns of phrases were kept unchanged.

### 6.1 Individual factors

Individual factors are a dynamic and interactive complex system that enables humans to be both responsive to a changing environment and proactive in regulating that environment (Bandura, 1989). People's beliefs about their capabilities to exercise control over events can affect their lives. In addition, the cognitive expectation of reward and punishment of certain

behaviours influences an individual's intention to practice or display a particular behaviour (Bandura, 1989).

In this study, self-efficacy, knowledge, attitudes, and beliefs were identified from the data collected as sub-themes of the individual factors theme (see figure 6.1)



**Figure 6. 1 The Individual level factors influencing the participants**



### 6.1.1 Self- efficacy

Self-efficacy has been found to be significant in predicting and changing an individual's behaviour towards screening mammography (Champion, Skinner, & Menon, 2005). In this context, self-efficacy is used to indicate a participant's capability or independency to implement her decisions to undergo screening mammography.

#### **6.1.1.1 Self- dependency**

Self-dependency here refers to the power participants have over events in their lives. Self-dependent subjects were found to have health consciousness and control over their decisions to be healthy.

*'I take decision myself and go to the hospital for treatment because I can only understand my body's conditions'- FGD 3: 3 (Population 2)*

Lack of time, due to family and job obligations, was reported by some of the participants as a reason that hindered them from undergoing screening mammography. This is a factor that negatively affected their self-dependence.

*'Usually here less time to manage everything together with family, kids and job'- FGD 1: 14 (Population 1)*

Moreover, not having a valid UAE driving license reduced the level of the participants' self-dependence and was suggested by them as a barrier to reaching the screening mammography venue.

*'..You know, many Kerala women won't drive here (in UAE)..'- FGD 2: 103 (Population 2)*

*'For me, husband is needed, I do not drive. If I want to go anywhere, he has to come with me. Our work schedules are different too'- FGD 3: 130 (Population 2)*

Women's perception of the cost of mammography was found to have a detrimental influence on women's uptake of screening mammography.

*'Then women will not ask their husband for money for these check-ups, as these are not considered urgent issues'- FGD 1: 164 (Population 1)*

*'In UAE, money is one of the main problems, even though we have health insurance' (everyone said) – FGD 3: 136 (Population 2)*

The participants stated that self-dependency in matters that affect one's own health is a prerequisite to being healthy and utilising available resources.

### 6.1.2 Knowledge

The level of knowledge a person possesses about a particular issue is determined by a number of cognitive factors. Cognitive factors refer to characteristics of the person that affect performance and learning. They involve cognitive functions like attention, memory, and reasoning (Danili & Reid, 2006). They are internal to each individual and guide her to regulate her behaviour and behavioural responses to external stimuli (Roy, 2013; Vaughan & Giovanello, 2010). A participant's knowledge about breast cancer, the importance of early detection of breast cancer and screening mammography were identified as influencing factors for the uptake of screening mammography.

#### **6.1.2.1 Knowledge about breast cancer**

It was noted that most of the participants, even those who underwent screening mammography were not aware of the signs and symptoms of breast cancer. However, some had a vague knowledge that breast pain, thickness, colour change and pus discharge are signs and symptoms of breast cancer.

*'Any abnormal feelings in the breast can be a sign of breast cancer. And thickness and pain are the symptoms of breast cancer'- FGD 1: 20 (Population 1)*

*'Breast cancer appears first as a thickness in the breast that's what I heard from others, I only know this much. I heard that when we touch we could feel a thickness in the breast'*  
- FGD 3: 13 (Population 2)

The depth of knowledge about the signs, symptoms and the stages of progression of the disease among the participants was found to be limited.

#### **6.1.2.2 Knowledge of the importance of early detection**

The data obtained in this research shows that some participants are unaware of the physiological changes in the breast brought on by the condition and the possibility of early detection of breast cancer. For example, one of the participants associated breast cancer with the tenderness of the breasts experienced during the menstrual cycle.

*'Sometimes I go in front of the mirror and look for any redness or anything. Before periods I get pain, so that time I clearly look that area'* – FGD 1: 33 (Population 1)

Also, some of the participants wrongfully assumed that undergoing treatment immediately after self or clinical detection of abnormalities was known as early detection of breast cancer.

*'I don't have any symptom in my body, so I didn't go for the screening mammography'*-  
FGD 3: 125 (Population 2)

*'We should not wait if we see any changes; we should press our breast and see if any thickness then immediately should go for treatments'* - FGD 4: 267 (Population 2)

However, one of the participants who had not undergone screening mammography conveyed that if breast cancer is identified early this helps prevent the growth of cancer and so the patient can live longer. This means that even though she had not undergone screening mammography for other reasons, she was still aware of the importance of early detection.

*'If we identify and do the treatment at the beginning stage itself, we can prevent cancer growth and can live longer'*- FGD 5: 28 (Population 2)

Another participant, who had undergone screening mammography, remarked that receiving immediate treatment after detecting signs or symptoms of the disease is necessary to reduce the complications. This indicates that she was not aware of the nature of early detection of breast cancer or the importance of screening mammography.

*'Most of the people are educated at present and they may know the symptom if people realise the symptoms they usually go for the check-up. If we didn't go for the treatments, it is too dangerous and harmful to our body' – FGD 2: 13 (Population1)*

### **6.1.2.3 Knowledge about screening mammography**

A number of participants who underwent screening mammography conveyed that awareness of screening mammography helped them undergo it.

*'I am aware of the test. I knew that there is an X-ray test called mammography, so I went for the same'- FGD 2: 16 (Population 1)*

Participants who had not undergone screening mammography showed little awareness of its importance to the asymptomatic population. They assumed that screening mammography was a confirmation test done after patients detect changes in their bodies or breasts. Thus, for these women, the absence of signs and symptoms rendered screening mammography an unwarranted test that might even be endangering to their health and so should be avoided.

*'I didn't feel the necessity up to now to do it, if I feel, I can go anywhere and do the check-up (test)... Yet, I did not have any sign in my body, so I did not do it '- FGD 3: 129 (Population 2)*

*'I heard it is dangerous to do these (screening mammography) tests without any reason'- FGD 4: 125 (Population 2)*

Moreover, they viewed screening mammography as a test to detect the spread of the disease. This highlights these participants' lack of awareness of the importance of screening mammography in the early detection of breast cancer.

*'It (screening mammography) can detect the extension of disease if we find some changes in the breast' – FGD 3: 121 (Population 2)*

The age of women is an important factor for determining the need for screening and follow-ups, which are essential for the early detection of breast cancer. However, only a minority of the participants correctly stated that screening mammography should be done after the age of forty. Furthermore, participants who had already undergone screening concluded they did not want to take a follow-up and were not certain when to take it if they did.

*'...I read from somewhere once in a year or two women should do, but not sure exactly. But I do not think I will do it again. Once it is enough' –FGD 1: 55 (Population 1)*

*'I did before and immediately after menopause. I did it two times because of fear, and then I asked the doctor about the next mammography. The doctor said; it is not necessary now. I heard that radiation is very harmful to our body'-FGD 2: 175 (Population 1)*

*'I think every year or once in two years have to do. I do not remember what I have heard. But I have not planned to do it again' -FGD 2: 176 (Population 1)*

*'Once I cleared that there is no disease that's enough' –FGD 1: 59 (Population 1)*

One of the participants who had not undergone screening mammography conveyed that the service should be available in locations targeting cancer survivors. This indicates that she is unaware of the difference between screening and diagnostic mammography: an indication of lack of understanding of the early detection of breast cancer and the purpose of screening mammography.

*'Find out an area, and conduct free mammography in the location where more breast cancer survivors are living. That will be helpful' –FGD 3: 172 (Population 2)*

#### **6.1.2.4 Knowledge about the mammography procedure**

Lack of prior understanding of the technical operation of a mammography machine and the procedure itself, as expressed by participants, was an influencing factor. Participants who underwent the procedure conveyed that prior to undergoing the mammography, they had incomplete and/or inaccurate knowledge about the procedure or relied on other women's views of the procedure. They had varied experiences when they finally underwent the procedure.

*'We were unaware about how it (screening mammography) is going to be and how it will be done and so on' - FGD1: 46 (Population 1)*

*'I was not aware of the machine or procedure until I experience it. Heard it presses the breast very hard and was a little worried' – FGD 2: 47 (Population 1)*

One of the participants revealed that prior to the procedure, she anticipated that it would be similar to a pregnancy scanning (ultrasound). When she underwent the screening mammography, she was unpleasantly surprised by the pressure applied to the breast and the pain induced as a result.

*'I was thinking something like scanning when I was pregnant, but when I underwent it was different and little painful, as I did not expect it' – FGD 2: 52 (Population 1)*

Furthermore, some of the participants disclosed that the exaggerated accounts of the mammography procedure related to them by other women frightened them and made them choose to avoid undergoing the procedure themselves.

*'They (friends) said that while doing mammography the nurses keep equipment and press very hard. I frightened by hearing this experience from my friend. That is one of the reasons I avoided mammography. There is a fear inside my mind about mammography procedure'- FGD 5: 109 (Population 2)*

### 6.1.3 Attitudes

The term attitude, as used in this research, refers to the participants' settled way of thinking about breast cancer and screening mammography. Eagly & Chaiken (2007) define attitude as a psychological tendency to view a particular task with a degree of favour or disfavour. Attitudes are a specific and subjective evaluation influenced by affective and emotional responses to a particular task.

In this research, a negative perception of some of the issues related to breast cancer and screening procedure could be noted among the target population. These issues particularly concerned the consequences of a positive diagnosis, the negative effects of radiation and the experience of pain during the screening mammography procedure.

#### ***6.1.3.1 Consequences of a positive diagnosis***

Participants from both research populations expressed their apprehension of a positive diagnosis and the perceived consequences of breast cancer.

*'Most people will not go because of the fear of breast cancer. If it is in UAE or Kerala; fear is fear. Those who have a fear they will not go for mammography'- FGD 5: 171 (Population 2)*

The fear of a positive diagnosis was found to revolve around partial or complete mastectomy, where a woman may lose part of her feminine signature and beauty.

*'Breast is part of women's beauty. If it is lost that will affect their beauty. It is a shame for women to lose their breast'- FGD 5: 172 (Population 2)*

The experiences of some participants dealing with dear ones who suffered from breast cancer made them believe that they will also develop breast cancer. This deterred them from undergoing any investigation or screening mammography in the absence of any troubling signs or symptoms.

*'I even don't go to a hospital for check-ups and it is because of the fear related to the death of my mother with this (breast cancer) disease' –FDG 4: 25 (Population 2)*

*'My younger sister had breast cancer. She did mammography before she reached 30 years old. If we think about hereditary there is a chance for siblings too. But I didn't go for mammography because of fear of the result/ diagnosis'- FGD 5: 122 (Population 2)*

Moreover, they concluded that if “any changes” in the breast were detected, this would result in their imminent death. Alarmingly, they concluded that a cancer survivor was like a dead person who was still breathing.

*'Death within one or two years. It is like a death notice'- FGD 3: 21 (Population 2)*

In addition, participants reported that fear was an integral part of the whole experience of undergoing screening mammography and up until they had received the medical report. They associated the procedure with the probability of being positively diagnosed with breast cancer.

*'We will be in tension for one week before and after mammography until the result comes'- FGD 1: 127 (Population 1)*

*'We considered it (screening mammography) as a complicated check-up; if any changes detected then we are going to die soon. So, will be tensed until we receive the results'- FGD 1: 131 (Population 1)*

### **6.1.3.2 The negative effects of radiation**

Fear of the effects of radiation was another concern expressed by the participants. However, they were unaware of the amount of radiation they might be exposed to during screening mammography. For example, one participant, who experienced the procedure, stated that she had some knowledge of the amount of radiation involved in screening mammography. However, when she considered the importance of early detection (benefit vs. risk), and the



availability of screening mammography for free (FGD 1: 51, 84), she decided to undergo screening mammography.

*'...I read there is radiation, which is very harmful to our body. So, thought whether to undergo or not. But did it' - FGD 1: 25 (Population 1)*

Meanwhile, women who had not undergone mammography envisaged that the risks of the procedure outweighed its benefits. They also realized that the radiation involved in the screening mammography can induce breast cancer and this influenced their decisions not to undergo the procedure. Their inadequate knowledge of the risks involved during screening mammography has negatively impacted their utilisation of screening mammography.

*'I heard mammography is not good for our health...I understand that if we do screening, the risk of getting cancer is higher'- FGD 5: 59 (Population 2)*

*'... surely we have to fear that (radiation). If there is a high chance to get cancer through screening, then we have to fear that...'- FGD 5: 61 (Population 2)*

### **6.1.3.3 Pain**

Pain is a subjective experience Hafslund (2000) Poulos & Llewellyn (2005), justifies some of the negative perceptions some women have of screening mammography (Miller, Livingstone, & Herbison, 2008). As the threshold of tolerance to pain varies from one individual to another, the experience of pain is viewed here as subjective. A number of women reported experiencing pain during the procedure especially because compression on the breasts is required in all currently available screening mammography technology for obtaining clear images of the internal structures for diagnosis.

Although some participants stated that the pain was bearable, they had not expected the amount of pain induced by the procedure. Others, on the other hand, thought the pain unbearable to the extent that they reconsidered whether it was necessary to undergo screening mammography in the absence of symptoms.

*'I did mammography, it was so painful, so I still think whether mammography was necessary or not?'* –FGD 1: 25 (Population 1)

Moreover, participants who underwent screening mammography stated that some of their friends would not undergo screening mammography because of the pain involved.

*'They (my friends) are avoiding this (screening mammography) because this test is very painful'* –FGD 1: 24 (Population 1)

However, some related that even though they had some concern about the pain before undergoing mammography, they had quite different experiences.

*'It was totally different, very much tensed. For me, the screening mammography was not painful'* -FGD 2: 50 (Population 2)

Research participants who did not undergo the procedure attributed that to how others reported the experience to them.

*'My friend said about an X-ray test. But painful it seems and radiation is used'* –FGD 4: 65 (Population 2)

*'We heard that during mammography they press the breasts very hard and it will be painful'* -FGD 5: 108 (Population 2)

Based on participant reports, it can be concluded that some had some knowledge of screening mammography, but were afraid of the pain involved, because either they had experienced pain during the procedure themselves or perceived the experience to be painful. Further, as the experience of pain is subjective, they received varying feedback from their friends which made them develop their own perception of the degree of pain they could anticipate if they underwent the procedure.

#### 6.1.4 Beliefs

A belief is defined as the mental 'reliance on or acceptance of a particular concept, which is arrived at by weighing external evidence, facts, and personal observation and experience (Bouvier, 1856). Belief is essentially a subjective feeling about the validity of an idea or set of facts.' It is gained through personal experience or the experience and/or assurances of others. In this study, health consciousness, belief in fate, and overconfidence (trust in one's will power) influenced the participants' readiness to participate in screening mammography and shaped their views towards it.

##### **6.1.4.1 Health consciousness**

Women who had health consciousness were self-motivated to undergo screening mammography.

*'If I have to be healthy I have to take care of my own health'*- FGD 1: 4 (Population 1)

*'One who has care and fear about their own health only will give importance to these messages. If a person is not bothered about their health, she never considers this information'* - FGD 2: 125 (Population 1)

*'My disease condition can affect my whole family in many ways, so must be cautious from the beginning. So, when I got a free screening mammography voucher, from (name of a hospital) hospital I utilised it'* - FGD 2: 136 (Population 1)

According to these views, the participants acknowledged the necessity for attending screening mammography to their own health and linking their health to the welfare of their families.

#### **6.1.4.2 Fate**

Participants from both populations viewed the onset of breast cancer as an act of fate.

*'I had an uncle too he died with lung cancer. He does not smoke, follow diet and does regular exercise even though he died because of cancer. Maybe like this breast cancer is also a fate'* –FGD 1: 40 (Population 1)

*'Fate, what else!'*– FGD 4: 20 (Population 2)

*'It is a deadly, non-curable disease. It is fate if someone gets it. Nothing can be done'*- FGD 2: 14 (Population 1)

Participants, seemingly unsuccessfully, attempted to relate the apparent healthy lifestyles led by their friends or relatives with the fact that these same individuals were diagnosed with breast cancer and concluded that breast cancer was simply these individuals' cruel fate.

#### **6.1.4.3 Overconfidence**

Participants were found to believe in a link between the mind and the ailments one may suffer (mind over matter!). Participants in both populations openly expressed their belief that breast cancer was not meant for them, even though it may affect others. They expressed the “not me” belief: cancer can take the lives of others but not mine.

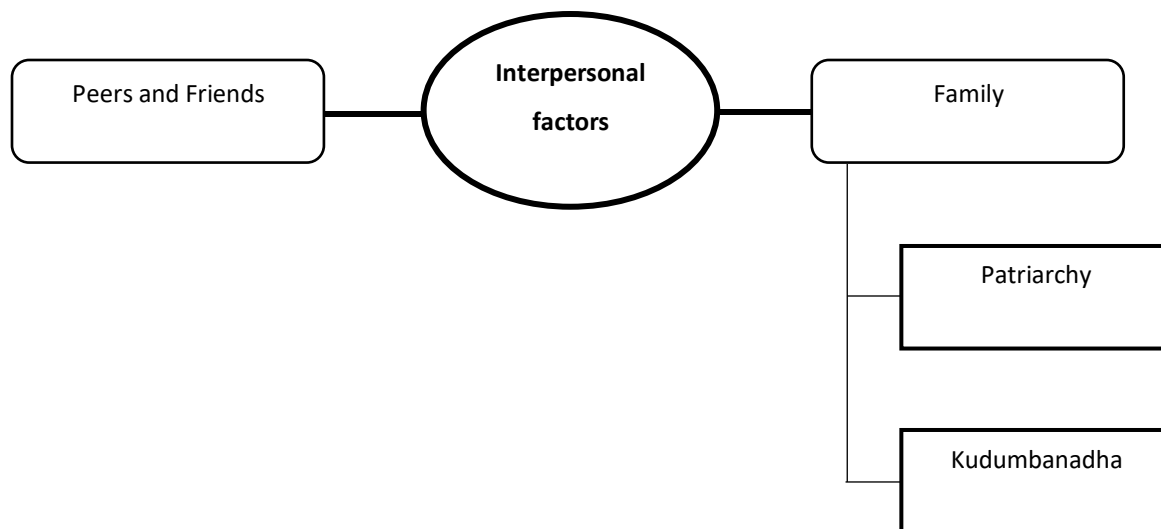
*'After I underwent mammography, I said to my friends to do it. But they neglected my words it's not easy to convey and said; breast cancer will not affect me. They found to have good belief and confidence that breast cancer will not come to their life'*- FGD 2: 124 (Population 1)

*'We all are confidently trying to believe that cancer will not affect me but it will come to others. I am also thinking like that because I am not eating such kind of food that can cause cancer'* –FGD 3: 10 (Population 2)

*'I believe and I feel that all diseases are according to our mind. If I always think that I am weak, I will be weak. It is attached to our mind and will power'* -FGD 5: 78 (Population 2)

## 6.2 Interpersonal factors

The interpersonal level concerns the informal and formal social networks or support available to an individual McLeroy et al (1988), that consequently, influence screening mammography uptake. An individual's closest social circle influences her behaviour and contributes to her experiences (CDC, 2015). In this research, the interpersonal factors include the husband, other family members, and friends and peers. Additionally, the participants communicated that friends and peers significantly influence a woman's decision to undergo screening mammography (see figure: 6.2).



**Figure 6. 2** The interpersonal level influencing factors of participants

## 6.2.1 Family

Participants from both populations expressed that their families, including husbands, children, parents, and siblings have a significant influence on their decisions to undergo screening mammography. Their husbands are considered the sole providers and decision-makers in the family and so they defer to them when making such decisions as attending screening mammography. Participants also expressed their commitment to their families.

### **6.2.1.1 Patriarchy**

Keralite women are dependent on their husbands due to cultural beliefs that surrender the responsibilities of women's lives and health to their husbands (Devika, 2019). Patriarchy, in this research, refers to a husband's influence on his spouse's decision to undergo screening mammography. Women in both populations were reliant on their husbands as they were considered the heads of the family.

*'Usually, I make the decision but will inform my husband before undergoing any health check-ups or even anything. You know that's our routine practice at home' - FGD 2: 5 (Population 1)*

*'Informing husband or family members is our routine; maybe I think it's our family routine too' -FGD 4: 14 (Population 2)*

In both group discussions, participants also conveyed that they would inform or take permission from their husbands before executing a decision related to their health. In addition, their health is important to their husbands, and so their husbands would act as facilitators for routine health check-ups. However, their husbands would feel anxious when cancer, and tests related to it, were mentioned. Therefore, these women would try to refrain from troubling their husbands and so neglect to undergo screening mammography.

*'Our health also affects our husband. Our health is important to them. I am saying for routine check-ups, if it is something like cancer check-up, he will be stressed'* - FGD 2: 8 (Population 1)

*'My husband is a stressed husband. He will get stress first. So better will not inform him or will not go for it (screening mammography)'* – FGD 3: 185 (Population 2)

In addition, participants in both populations revealed that they were financially dependent on their husbands and relied on them to bear the cost of such tests.

*'I am depending upon the husband and his salary. I usually plan to go for any check-up when he gets the salary'* – FGD 4: 170 (Population 2)

Considering the financial responsibilities of the family, women usually would not demand money from their husbands for their health, unless it is not an urgent concern.

*'Women will not ask money to their husband for these check-ups, as these are not considered urgent issues'* – FGD 1: 164 (Population 1)

### **6.2.1.2 Kudumbanadha**

Kudumbanadha in Malayalam refers to the female head of a family. The tendency of the participants from both populations to prioritize the welfare and care of their family members over their own health was found to have a major impact on their decision to undergo screening mammography. Some participants realized that they were too preoccupied with their responsibilities towards their families to spend time and money on screening mammography.

*'Family, kids are important for us (Keralites) rather than finding time for these (screening mammography) tests'* - FGD 2: 116 (Population 1)

*'I will not go for mammography because I have lots of responsibilities in the family. Because of my responsibilities, I can't spend money and time on mammography. Those who have family and job it is difficult to go' – FGD 3: 144 (Population 2)*

*'I have to take care of my children and husband. I can't leave it. It is my responsibility' – FGD 4: 118 (Population 2)*

Furthermore, the participants' concern about the possibility of a positive diagnosis and its perceived devastating consequence on the family also influenced their decision to undergo screening mammography. One of the participants concluded that it was better not to have screening mammography than to disturb the equilibrium of the family when diagnosed with the disease.

*'My sister got breast cancer; she is in Fujairah, the doctor advised me to do mammography. But scared. Worried if the result comes positive, we can't afford. The whole family will be in trouble in all means. So, live peacefully until it shows the symptoms' - FGD 3: 75 (Population 2)*

Meanwhile, for those aware of their family members' past experiences with the procedure, the importance and availability of early detection were enough motivators to undergo screening mammography. This shows that the participants were inclined to trust and follow the advice of their relatives.

*'...now we have the facility for early detection so that we can realize the disease and take medicines early. One of my cousin's daughter was affected by breast cancer. She came to know it early and took treatment. Now she is perfectly ok, then she got married and gave birth to a child. So, I thought to do screening mammography'- FGD 1: 16 (Population 1)*

*'My relative had breast cancer, so she said to me to do (screening mammography). Then my son advised me to do it. He is a doctor. So, I did it' –FGD 1: 28 (Population1)*



### 6.2.2 Peers and Friends

It was evident that the participants' peers and friends had a significant influence. In most cases, they offered them support to do screening mammography. By sharing their experiences with the participants they highlighted the importance of the procedure which, in turn, motivated them to undergo it themselves.

Moreover, the participants stated that their peers and friends were usually of the same social circle and age group making it easier for them to communicate and influence each other.

*'To influence others friendship circle is effective. Our friend also will be of our own age, so friends can easily understand our ideas and thoughts and even difficulties. Close friends can make an impact'*-FGD 2: 111 (Population 1)

*'If some friends are there, I think I would have gone'* –FGD 3: 131 (Population 2)

Furthermore, close associates who realize the significance of early detection of breast cancer are liable to encourage the woman to have the procedure. This was clearly expressed by one participants in the following quote:

*'I also heard that it (screening mammography) is important to do from my manager as her sister got diagnosed with breast cancer and she was very upset. She conveyed all colleagues to do early detection tests for it'* -FGD 2: 17 (Population 1)

In addition, moral support from family and peers encourages women to have the procedure as was stated in the following:

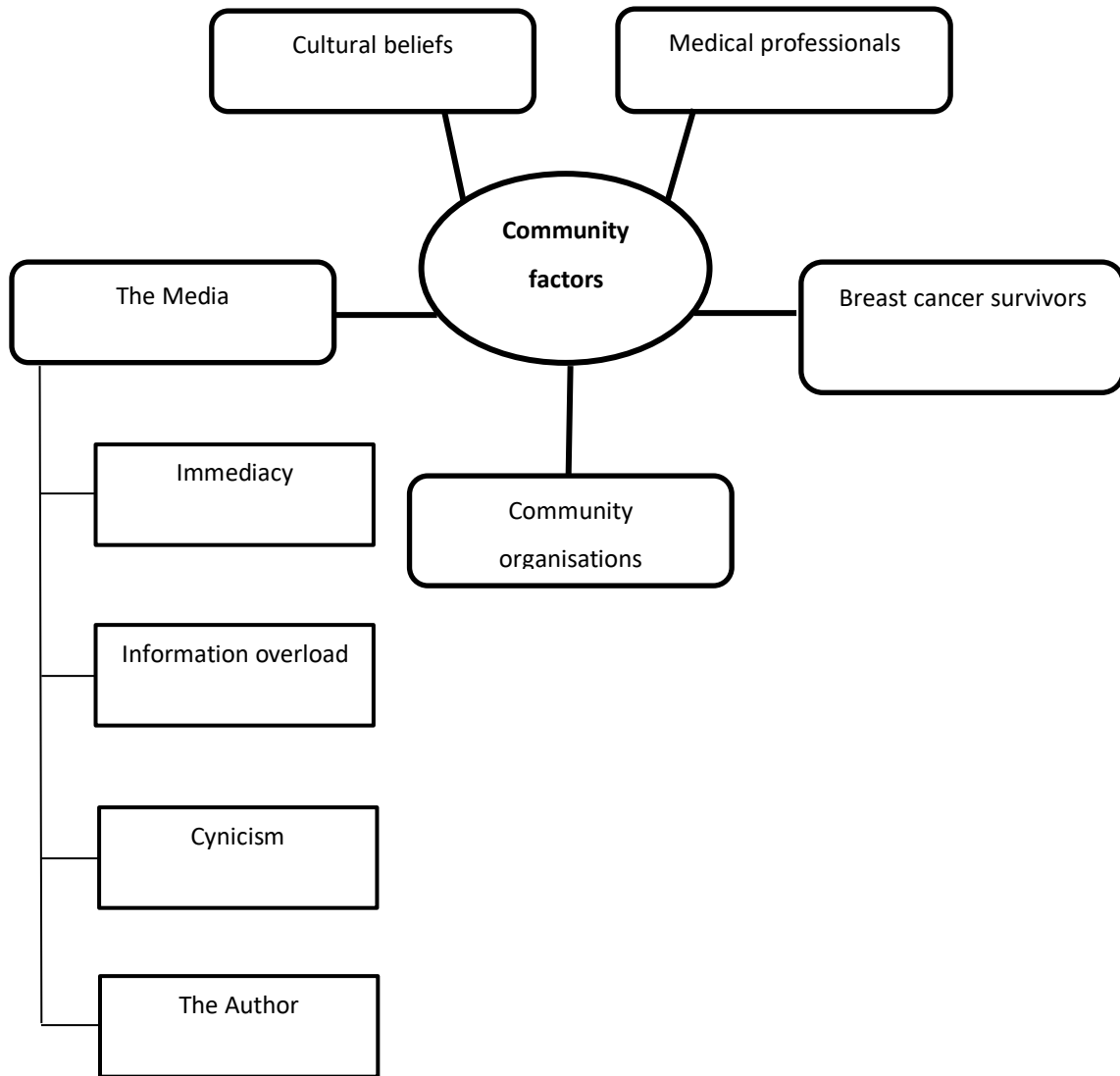
*'If some friends are there, I think I would have gone'* –FGD 3: 131 (Population 2)

However, in some cases, the attitudes of friends, peers and other associates had enough influence on some of the participants to avoid undergoing screening mammography. Some stated that if peers and superiors became aware of a woman's intention to undergo screening mammography, they would become inquisitive and suspicious that she had cancer. This would discourage her from undergoing the procedure.

*'If the woman is an employee, she should take leave in a day to go for the mammogram. If she ask to boss to get leave they will ask the reason for the leave. We have to answer their questions. If the colleagues ask about the reason for the leave, what would I say to them? These kinds of questions will come to a woman, so they usually didn't think to go for the mammogram. If we say to them the reason that I am going to do mammogram then there will be other question why do you want to go? Do you have cancer? Such kind of thinking may come to their mind and they started to think that the woman is a cancer patient' – FGD 5: 152 (Population 2)*

### 6.3 Community factors

Community in this context refers to the group of Keralites who live in UAE and share a common culture. This community, where social relationships occur, was found to have an influence on the uptake of screening mammography. The participants were also influenced by the media, the credence of their compatriots, community leaders and breast cancer survivors from their community (see figure 6.3).



**Figure 6. 3 The community level influencing factors of participants**

### 6.3.1 Cultural beliefs

Cultural beliefs, which affect women's thought processes and customs, were found to shape the participants' attitudes towards screening mammography. For example, one of the participants conveyed that in Keralite culture, women may not expose their breasts even for a medical examination; undergoing the procedure, therefore, is considered a shameful act. So an open mind-set is required to motivate Keralites to undergo these tests.

*'Our cultural background is very narrow and closed one regarding breast examination; it is a shameful procedure. Women should have an open mind and then only they will be motivated to undergo mammography'* -FGD 2: 86 (Population 1)

Moreover, another participant conveyed that in her culture women tend not to face reality.

*'Usually Malayal's keep distance from the realities, their cultural background not allow to make a decision by themselves'* –FGD 2: 88 (Population 1)

Further, one of the participants stated that as screening mammography was not a routine procedure, undergoing the procedure would lead others in her community to think that she had breast cancer. So women would not undergo screening mammography to avoid causing confusion.

*'Otherwise if someone from office hears that I have undergone this test, they think that I have cancer, otherwise have to prove to them'* –FGD 3: 230 (Population 2)

In addition, it was revealed that some cultural beliefs and discriminatory practices deterred women from accessing screening mammography. One of the participants explained that if it became known that a woman was diagnosed with breast cancer, everyone in the community would be curious. Furthermore, the community would be saddened and treat her with sympathy. This is a situation women from the community may prefer not to experience. This participant cited this as a reason women may avoid undergoing screening mammography.

*'If a person got diagnosed with cancer, soon everyone will enquire details of it. After that they used to watch through a different eye and with sympathy' -FGD 5: 92 (Population 2)*

### 6.3.2 Medical Professionals

Medical professionals were found to have a major impact on the participants' awareness of breast cancer. Medical professionals in this research include members of the medical and health profession in all fields. Members of both research populations trusted messages shared by a medical professional more than those posted by non-professionals. The participants believed that medical professionals had superior knowledge about breast cancer compared to those who are not in the medical field. This emphasized the role of medical professionals in raising the public's awareness of the importance of screening mammography to support the early detection of breast cancer.

*'My son advised me to do it. He is a doctor. So, I did it. My son said to do it maybe after 2-3 years. Maybe if he says, then I may do it again' - FGD 1: 28, 57 (Population 1)*

Furthermore, it was a fruitful moment to listen (as a critical ethnographer) to participants stating that the focus group discussion made them aware of the importance of early detection of breast cancer through screening mammography.

*'If educated people like you (me as the researcher) can influence us to undergo mammography. Now itself through this discussion we got many ideas. We can understand there is importance for screening mammography' - FGD 5: 202 (Population 2)*

Moreover, one of the participants explained that she would not undergo screening mammography even if her husband told her to as he was not a medical professional.

*'If a person like you (like me as the researcher), one who studied and learn about this disease can influence women and will surely go for the tests. I will not go if my husband*

*just immediately comes and say to do mammography. Because I do not think it is required as he is not in the medical field' - FGD 1: 104 (Population 1)*

Further, they stressed that physicians, especially gynaecologists, and medical professionals should regularly update women and be more proactive to eliminate the misconceptions related to screening mammography in the communities.

*'One of my friends shared an interview video with a doctor about breast cancer on Facebook. That doctor conveyed the way of doing a self-breast examination and shared that if it is diagnosed in early stage, no one should worry about the disease. Because of that reason I did screening mammography' –FGD 2: 35 (Population 1)*

### 6.3.3 Breast cancer survivors

A breast cancer survivor can serve as a positive influence when she highlights the importance of early detection of breast cancer through screening mammography to others. Their positive living experience due to the early detection of the condition makes other women understand what early detection is and motivates them to undergo screening mammography.

*'One of my cousin's daughter was affected by breast cancer, and she came to know it early and took treatment. Now she is perfectly ok, then she got married and gave birth to a child. So, I thought to do screening mammography' –FGD 1: 16 (Population 1)*

*'Before I thought early detection means it is done immediately after noticing anything on the breast... But now after my cousin's experience, she shared, so I thought it will be good to undergo it (screening mammography)' –FGD 1: 24 (Population 1)*

Additionally, the participants stated that they would trust messages conveyed to them by breast cancer survivors, especially because they would relate at which stage they were diagnosed, the complications they faced and the importance of early detection. Thus, it can be concluded that participants believed direct communication with breast cancer survivors could influence other women to undergo screening mammography.

*'Breast cancer survivors have a major role to influence and motivate others to do mammography. They are the living testimony among the other people those who were not undergone mammography'* -FGD 2: 166 (Population 1)

However, the participants also admitted that it may be painful for a breast cancer survivor to recall her hard experience, which may cause psychological stress to the audience and the survivor herself.

*'Sometime people will feel sad about them and they also feel difficult to face others. So, I do not think they (breast cancer survivor) should be involved'* -FGD 2: 168 (Population 1)

#### 6.3.4 Community Organisations

The participants' views call attention to the fact that the availability of and level of priority given to screening mammography among community organisations (churches, Kerala community centres, etc.) and leaders are of great significance. The participants indicated that their community leaders can serve as influencers for the uptake of screening mammography especially due to contextual reasons. These participants are away from their native land and from their relatives and friends, and so in the UAE, they would usually hold communal gatherings and rely on each other.

*'In UAE we are depending on our own communities more than our relatives'*- FGD 1: 153 (Population 1)

*'Most of the people (Keralites) who are here are there in one or another Kerala community group. Like, we have a lot of Malayali's organisations, Indian association, even churches also. If an authorized person like you, who are in the medical field can give awareness classes to these groups. It will be more influential and motivation to do mammography'* - FGD 1: 104 (Population 1)

The participants suggested that hospitals should communicate directly with their community centres with information regarding the availability of screening mammography. Otherwise, community centres should take the initiative to collect such information from hospitals to

disseminate among community members. This is because many of the participants were not aware of the availability of screening mammography in hospitals close to their places of residence.

Moreover, the participants believed that if their community leaders were aware of the importance of screening mammography, they would convey this to their community members. The participants expressed their trust in their community leaders to have a positive impact on women in their community in regards to this matter.

*'I think the pastor aunty/ pastor/community leader has a major role. Their words will consider as believable by the members in the community'* – FGD 2: 125 (Population 1)

*'I think they (community leaders) are also not aware of it (screening mammography). Otherwise, they would have informed us'* –FGD 1: 135 (Population 1)

However, a few women expressed their scepticism that a male figure of authority may not be the best person to spread awareness of the procedure. This might be because, as a male, he would not feel very comfortable to discuss such an issue with women of the community.

*'If the leader is male, maybe, they may not share with the women'* -FGD 3:210 (Population 2)

While another participant said that this would not be a significant issue.

*'I do not think that the pastor of a church has a limitation to give information. Our pastor is an open-minded man; he wants to see us healthy. He always recommends good things'* -FGD 2: 131 (Population 1)

Some women suggested that intervention should come from a higher authority, such as their church or employer, who would help them go for screening mammography as a group and so experience no shame. This, they believed, would give them more confidence especially when they might not have to answer to others in their community.



*'If it is that important, I think someone should gather everyone and take us. Like from our church, or employers. Otherwise, if we go alone then people will think that I got some disease that's why I did it and need to answer everyone' –FGD 3: 132 (Population 2)*

*'...If the colleagues ask about the reason for my leave what would I say to them? These kinds of questions will come to a woman, so they usually didn't think to go for mammography. If we say the reason that I am going to do mammography, then there will be another question why do you want to go? Do you have cancer? Such kind of thinking may come to their mind and they started to think that this woman is a cancer patient'- FGD 5: 152 (Population 2)*

### 6.3.5 The Media

Media here means mode for mass communication that involves broadcasts, social network messages, posts on the internet and published materials. Both populations acknowledged that social media, especially WhatsApp, Facebook, and Twitter affected their awareness of breast cancer, the importance of early detection and the use of screening mammography. Factors such as immediacy, cynicism, information overload and author of the media have a significant influence on the uptake of screening mammography in this population as evidenced below.

#### **6.3.5.1 Immediacy**

Immediacy in this research means the immediate accessibility and extensiveness of the content of media messages which instil a sense of urgency in the participants and hence influences their uptake of screening mammography. Participants considered that social media can deliver messages in a video format that can be quickly broadcast. One of the participants conveyed that she underwent screening mammography after receiving information through the media.

*'I went because I received a video from my friend through some media that if it is diagnosed when it is very small, it could be treated easily even maybe without surgery. But if it becomes big, the whole breast will be removed'* -FGD 2: 18 (Population 1)

*'Media have an important role because knowledge of a friend has a limitation. But media can share all in detail quickly'* –FGD 3: 192 (Population 2)

However, some participants from both groups stated that some instructions/messages posted on social media lacked detailed information on the technical aspects of the procedure and the providers.

*'My friend shared a message and I saw in it. But not sure and was not aware of how it will be done'* – FGD 1: 47 (Population 1)

*'Advertisements will be seen, but do not know whom and how to approach'* – FGD 3: 99 (Population 2)

A participant in population 2 expressed her interest to know the benefits and risks of screening mammography and added that if this information was included in the messages, this would have increased the trustworthiness of the message and motivated her to undergo screening mammography.

*'If we get clear information about the side effects and the importance of mammography, surely I will go for that. Want to know about it'*- FGD 5: 203 (Population 2)

#### **6.3.5.2 Information overload**

Countless messages on health are posted on the media every day. Many are unreliable and offer insufficient information on the topics they address. This decreases their relevance and usefulness. What compounds this problem is that the average person uses several social media applications. As a result, the participants in this research tended to ignore and distrust similar messages on breast cancer and mammography.

*'Internet also is a good media to inform others. But may not take it that seriously'*-FGD 1: 101 (Population 1)

*'We got information through WhatsApp, but we didn't take it as serious. Many messages come just as forwards'* -FGD 1: 61 (Population 1)

One participant expressed her view that such messages should include the contact details of a person or organisation that one can refer to. However, she also stated that even messages with contact details seemed unreliable. She came to the conclusion that irrelevant messages are common and health messages on social media are not to be trusted.

*'Most of the women may not believe the messages through social media, but if we give with full details and phone number, that may help them to contact. But now a day's blood required messages used to come with contact details, even hospital names, person's names are included in it. No one will consider it, I think. I usually won't. I think many others also think something like that'* -FGD 2: 121 (Population 1)

This participant refers to a worrying trend in the UAE, where members of the community might receive text messages asking them to donate blood. These are usually fake and seem to deepen the participants' mistrust of unsolicited messages on social media.

### **6.3.5.3 Cynicism**

Cynicism in this research refers to the participants' attitude towards media messages posted by hospitals and their perception that those are nothing more than marketing gimmicks used to promote the hospitals.

*'We do not know, and the importance of it. I thought might be it is their (hospital) business ad'*- FGD 3: 199 (Population 2)

*'We will doubt them that it is for the progress of their business. In some way running a hospital is a business, we think they are sending a message for their business only' -FGD 4: 262 (Population 2)*

*'But if we are not aware of the importance of it. No one is going to consider it. We get many messages, when a new doctor joins a hospital, they send messages. Therefore, if we do not have any disease related to the speciality of that doctor we would not consider those messages' –FGD 4: 209 (Population 2)*

The placement of the messages on the screen was also noted by the participants as a factor that made them assume that these messages were hospital advertisements.

*'In the media, sometimes it will be on the right side or left side just like advertisements it just flashes and goes. In the beginning, I thought that those are some advertisements for hospital facilities similar to a shopping ad' –FGD 2: 28 (Population 1)*

#### **6.3.5.4 The Author**

Participants trust official advertisements issued on the media. It was evident that announcements and information published by an official body received more trust from the participants than those posted by a private healthcare provider or individuals. In addition, the participants indicated that these official announcements had greater reach and, therefore, probably have more impact.

*'If the government give advertisement, that will be trustworthy and reach to them (Keralites)' –FGD 1: 100 (Population 1)*

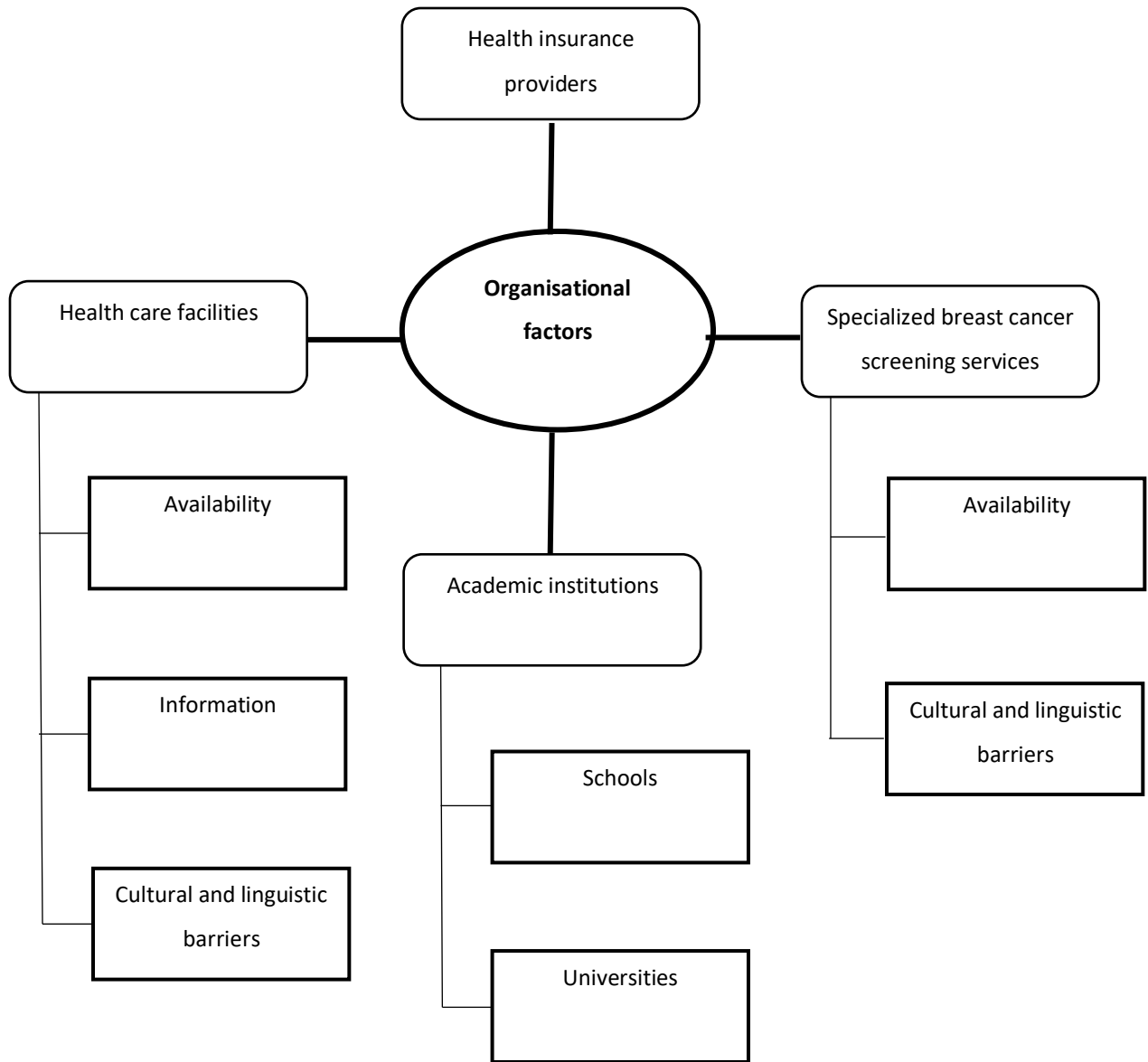
*'...otherwise if it is private hospitals we may think it is their advertisement'–FGD 4: 257 (Population 2)*

In some instances, the participants received messages on phone applications from either unknown sources or from friends who were not medical professionals. As a result, they tended to ignore the information included in these messages.

*'we get information through WhatsApp, but we didn't take it as serious. Many messages come just as forwarded. Sometimes we do not know whether it is fake or not, usually, I ignore it'* -FGD 1: 61, 62 (Population 1)

#### 6.4 Organisational factors

This part is concerned with the organisations and social institutions that provide or can provide screening mammography services in the UAE (figure 6.4). The cohesion of these facilities can enable them to successfully provide screening mammography and support the uptake of the procedure by Keralite women as stated by the participants. A distinction was made here between general health care facilities and breast cancer screening venues as the latter include specialized initiatives that may be independent of general hospitals or clinics.



**Figure 6. 4 The organisational level influencing factors of participants**

#### 6.4.1 Health Insurance providers

In the UAE, insurance companies play an important role in facilitating access to health services by expatriates. The extremely high costs of healthcare compel expatriates to acquire health insurance before consulting medical professionals. These companies determine what the insurance policies cover and dictate whether such tests as screening mammography would increase the premium they would charge. Therefore, without adequate medical cover, the cost of the procedure might be inhibiting for many women.

*'If a person has insurance that is ok, she can go for a check-up. But people like me who came many years before they do not need insurance at that time. Now for me, someone in the family must take care of me. In emergency cases only will go to the hospital'* - FGD 1: 112 (Population 1)

Many participants even stated that they would have been more willing to undergo the procedure if it was covered by their insurance policies, and proposed that the UAE government should direct health insurance providers to include it in their policies.

*'When we apply for the visa to come to UAE, Health card is compulsory for the overseas in Abu Dhabi, Kuwait, and other places. If the governments add the screening mammogram in the health package that will be good for us'*- FGD 5:219 (Population 2)

*'If UAE government adds this along with the health package in every Emirate it will be a great help'* – FGD 5:220 (Population 2)

Furthermore, it was revealed that participants in both populations were unaware whether screening mammography is covered under their health insurance policies. This is something the providers should have informed them.

*'I am not sure; I do not think it is covered. Then they would have accepted my card while I went for the test'* - FGD 1: 117 (Population 1)

*'It is not covering the entire check-up. Most of the tests can be done by health insurance. Not sure about this (screening mammography) test' - FGD 3:138 (Population 2)*

However, one of the participants who had undergone screening mammography conveyed that even though the procedure was covered by insurance, women who did not realize the importance of screening mammography would not be willing to take the test.

*'Common people usually won't worry much about mammography whether it is included in the insurance card or not because I was unaware of mammography until my son said to me' –FGD 1: 121 (Population 1)*

It is worth mentioning that some of the participants were not aware of free screening mammogram services available for all expatriates in the UAE.

#### 6.4.2 Specialized breast cancer screening services

Breast cancer screening centres in this research are the UAE government-owned breast cancer screening initiative, the Pink Caravan. Pink Caravan organizes awareness campaigns and offers free screening mammography and treatment to all residents through mobile medical clinics or free vouchers. It falls under the Friends of Cancer Patients Society for early detection of breast cancer. It was launched in 2011 under the patronage of His Highness Sheikh Dr. Sultan bin Mohammed Al Qasimi, Ruler of Sharjah and Her Highness Sheikha Jawaher Bint Mohammed Al Qasimi, wife of the Ruler of Sharjah, Founder and Patron of the Friends of Cancer Patients Society (FoCP) (Friends of Cancer Patients, 2019).

Many participants were aware of the services offered by the Pink Caravan, but none stated that they did screening mammography through them due to issues related to its availability and cultural and linguistic barriers.



#### **6.4.2.1 Availability**

The opportunistic nature of screening mammography services (if women are interested, they can use the service), the limited number of days the services are available in a particular location, lack of transportation to and from the units, and absence of prior announcements hindered the participants to benefit from the services offered by this initiative.

One of the participants conveyed that physical preparation is needed because the procedure can only be done during the sixth day of the menstrual cycle. So the duration the mobile clinic is available in any particular location is a significant factor.

*'If they (mobile van by Pinkcaravan) come to a place, they spend one or two days in a place. We didn't get information when they are going to leave that place. Maybe they are sharing it, but I didn't get that information. Maybe they should announce or email or send messages to people in that area. Now all the details are available to track people, I think' –FGD 2: 67 (Population 1)*

*'If we want to do this there are certain criteria. We have to do after the sixth day of the periods. So, we have to wait, likewise, one month will go from us. But I took an appointment in a suitable time and did from the hospital' -FGD 2: 72 (Population 1)*

*'If a woman wasn't able to go at that particular month she never tries to go anywhere else. She will wait for the next year. Then she forgets and never tries to do' –FGD 1: 163 (Population 1)*

In addition, one of the participants suggested that women should be informed in advance of the availability of the services so that they are also emotionally prepared.

*'Yes, I have seen it (Pink caravan), but will not be in a mood immediately to undergo check-up, if I see somewhere like that'-FGD 2: 63 (Population 1)*

*'I think unless and until if there is no clear explanation of the procedure to the public no one will just go like that. I think they must give some sessions before'* -FGD 2: 68 (Population 1)

Transportation was also found to be a practical barrier for some of the participants.

*'I am living here for many years I have seen 'Pink Caravan' (mobile screening mammography unit by Pink Caravan). They used to conduct this kind of check-ups in various places in a bus kind of, but for me, it was not easy to reach up to them. I couldn't go because of the lack of transportation, or I have not seen their announcements of its availability and locations. But I think now it's making available everywhere'* – FGD 2: 62 (Population 1)

*'Of course, transportation is a barrier for us. Many of us do not have a driving licence'*- FGD 4:135 (Population 2)

#### **6.4.2.2 Cultural and linguistic barriers**

Participants conveyed that they were aware of endeavours undertaken by Pink Caravan to raise awareness of the importance of early detection. However, a number of cultural and linguistic barriers obstructed their use of these services. For example, the participants and their colleagues assumed that the tests were available only for Arabs (Emiratis).

*'I have seen UAE governments rally (procession) on horses. Someone in my office told it is related to breast cancer. We thought it is for Emiratis only'* – FGD 1: 72 (Population 1)

Further, the participants perceived that the mobile vans may have only Arabic or English speaking health care professionals. This meant that they concluded that they would not be able to communicate comfortably with the medical staff, not only because of the linguistic barrier but also because a medical professional would better understand their concerns. Furthermore, they assumed that they would “stand out” in these venues as women who belong to a different

culture and speak a different language from everybody else there. Clearly, this triggered feelings of unease which further inhibited them from using the services.

*'I thought there might be only Arabic speaking doctors and health team in it (Pink Caravan). We look odd there. I feel so'* -FGD 2: 68 (Population 1)

*'If they inform that a Kerala doctor (Malayalam speaking medical professional) is available, many women feel comfortable to go. Because we will have a common understanding of our problems and concern'* -FGD 4: 240 (Population 2)

The perceptions of the participants triggered by language and cultural barriers influenced their ability to access the information and services offered by the Pink Caravan.

#### 6.4.3 Academic Institutions

Health habits are rooted in family practices; however, academic institutions have a significant role to play in promoting the health practices in a nation (Bandura, 2004). Both research populations conveyed that academic institutions (schools and universities) have a great role in raising awareness of early detection of breast cancer.

Both populations stated that information about breast cancer awareness was provided in universities and schools

*'The breast cancer awareness teams went to the university here where my daughter is studying. They provide awareness classes to the students to inform their family'* -FGD 2: 170 (Population 1)

*'In the assembly, the school authorities gave the pink ribbon to the children last year'* - FGD 4: 178 (Population 2)

Participants conveyed that awareness developed by these institutions in their students can encourage them to share important information with their families and practice early detection themselves later in life.

*'If the students get information, they will share with others as well as they get motivated through this. It will help them to prepare themselves and to do self-detection and other tests' –FGD 2: 172 (Population 1)*

*'After a few years, they will reach an age where the diseases are common and then they can avoid it and will be helpful for others too' -FGD 3: 219 (Population 2)*

The participants' trust of the academic institutions is a promising sign that these institutions can raise society's awareness of early detection. Further, it can have a wider impact on the next generations, family members and teachers.

*'Awareness class and mammography in the school and university are a better idea. Students can inform their parents. If school or university conveys this everyone will believe' –FGD 3: 235 (Population 2)*

#### 6.4.4 Health care facilities

The term “health care facility” in this research covers both private and government hospitals and primary health care centres in the UAE. Currently, private health care facilities outnumber the public ones. To use public hospitals and clinics, an expatriate needs to either pay a fee or present a health card (Internationsgo, 2020). Most private and public facilities provide breast cancer screening tests. It can be noted from the views of both populations that health care facilities in the UAE have a major impact on resident Keralite women's uptake of screening mammography.

#### **6.4.4.1 Availability**

The availability of screening mammography in general health care facilities determined the level of willingness of women to undergo it, especially when government and private institutions are actively promoting it through free/discounted vouchers.

*'I did it from Dubai...hospital (name of a private hospital). My friend shared a free voucher last November. I think it was an offer for a few days, I think, I am not sure' - FGD 1: 51 (Population 1)*

*'I did it from Sharjah through the free voucher I got from ....(name of a private hospital) hospital' -FGD 1: 58 (Population 1)*

*'There was a health campaign, conducted by ..... (name of a private hospital) in our community centre. They gave routine blood, urine tests, BP, ECG and this mammography discounted coupon. So, I did it' -FGD 1: 53 (Population 1)*

Participants also communicated that screening mammography is not conveniently available to the public in the UAE. They undergo health check-ups and, if the screening mammography is available all year round and included in their routine healthcare tests this would allow them to plan accordingly and utilise the service at their convenience.

*'I underwent as part of the executive health check-up (at Kerala). Otherwise, maybe I would have not undergone it' - FGD 1: 45 (Population 1)*

*'...thought to do mammography from Kerala during vacation as part of health check-up .... I did it from Kerala during my vacation' - FGD 2: 36, 60 (Population 1)*

#### **6.4.4.2 Information**

The ability of the participants to access accurate information about the breast cancer services provided by health care facilities in the country was also revealed as an important factor. A number of participants revealed that they were not aware of the availability of free screening mammography in the UAE and that they had not received enough information about it. Even when they received such information, it was found that the participants did not pay it enough attention.

*'I was not aware of its availability in this hospital and its importance, last year when I went for some other check-up, I have seen the advertisement. But was not aware of it and its importance'* -FGD 2: 64 (Population 1)

*'I don't know the hospital which provides free screening mammography nearby, but I got some WhatsApp messages that some hospital in Ajman is providing screening mammography'* –FGD 3: 86 (Population 2)

To add, although participants recalled the pink ribbons and other decorations available in hospitals during October, they assumed this to be a campaign to encourage women to follow a healthy lifestyle to prevent breast cancer. This further emphasises that the availability of screening mammography and/or its importance is not clearly communicated through these decorations and ribbons.

*'In the month of October (whole month) used to see pink badges and ribbon in every hospital and in shopping malls. Thought to have a healthy lifestyle and to get rid of breast cancer. Every year it reminds us about breast cancer'* - FGD 4: 107 (Population 2)

#### **6.4.4.3 Cultural and linguistic barriers**

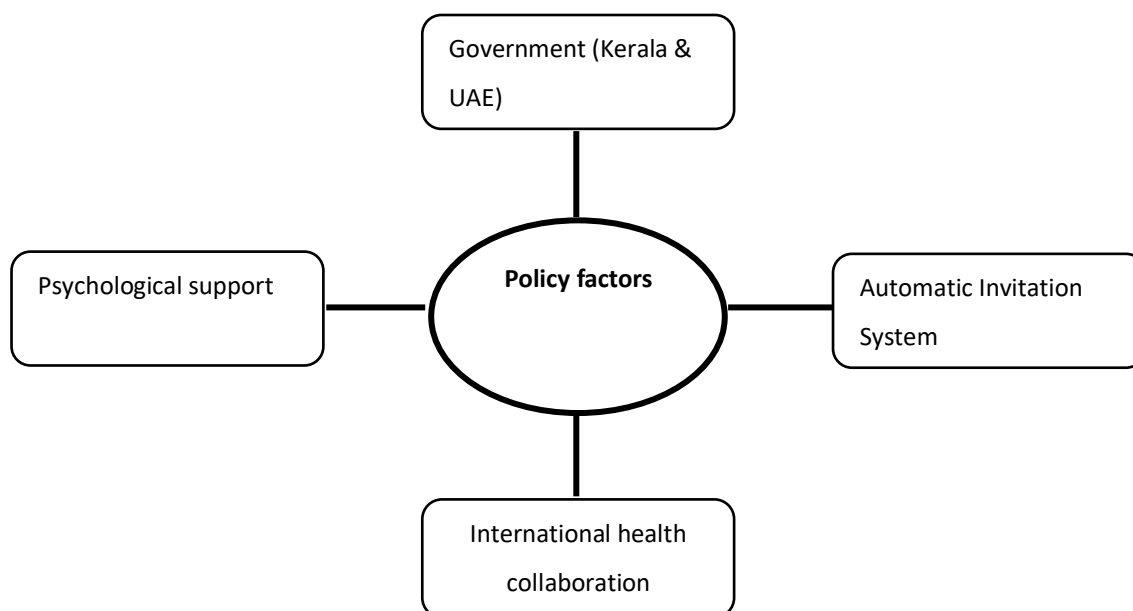
The participants also voiced that the cultural and linguistic barriers between them and the health professionals working in these facilities had a significant impact. They feel more confident to approach a doctor who can communicate with them in their own language and who can understand their feelings, culture, and food habits. They are also more receptive to their advice.

*'Understanding our culture is very important. Malayalee doctor have a clear idea about our lifestyle, food pattern, etc. we can also understand their suggestion well in our cultural context'* - FGD 2: 82 (Population 1)

*'Language found to be a barrier to communicate with the doctors. If we want to express our feeling there should be good communication. The doctor should be one who can understand the client's language and our feelings'* - FGD 2: 78 (Population 1)

#### **6.5 Policy factors**

Changing health behaviour of individuals involves more than simply educating them or addressing their health practices. It requires serious efforts to change the external factors that are beyond the control of the individual and/or community. Thus, advocating the development of policies that support behavioural changes of an individual is essential. Health policies in an expatriate's home (here, Kerala government) and adopted countries (here, UAE government) can have a significant impact on her health practices (see figure 6.5).



**Figure 6. 5 The Policy level influencing factors of participants**

### 6.5.1 Government

Some participants from population 1, those who underwent screening mammography, acknowledged the health care initiatives targeting expatriates conducted by the UAE government.

*‘UAE government gives importance to the health for all residents’ - FGD 2: 152 (Population 1)*

*‘They (UAE government) are doing many activities for breast cancer screening. Only thing I think they should be more effective to reach to everyone’ - FGD 2: 147 (Population 1)*

*‘In my limited knowledge, I didn’t hear that the Kerala government is taking such kind of initiative as the UAE government has. Kerala government are not taking such kind of initiatives for health’ –FGD 2: 144 (Population 1)*



One of the participants conveyed that many expatriate Keralites living in the UAE got diagnosed with lifestyle diseases when they returned to their home country to live there permanently. She suggested that if they were diagnosed early through the support of Kerala government health initiatives in the UAE, these individuals would have been safe when they returned home. In her view, as Keralites working in the UAE are major contributors to the Kerala economy mainly through the money they send home, the local government should provide them with the necessary health care while still residing in the UAE.

*'Many lifestyle diseases can be diagnosed early, not only breast cancer. After some years usually, when Keralite go to Kerala after finishing the job from here, most of them go with many diseases, like sugar, cholesterol, BP, heart problems and so on. If the Kerala government arrange it (tests) free of cost that will be great. We are the major source of Kerala income. They (Kerala government) can consider our wellbeing' -FGD 2: 187 (Population 1)*

Participants also intimated that awareness campaigns held by the Kerala government would enable women, and the community, to overcome their fear and concern about breast cancer and screening mammography.

*'If the government take the initiative that will help women to be confident and courage to face' - FGD 2: 159 (Population 1)*

*'If the Kerala government add free treatment to the client after diagnosis that will be a motivation to do mammography'- FGD 2: 160 (Population 1)*

*'After diagnostic tests, the Kerala government can guide the people to take the next step. If anyone finds out with breast cancer, the government should take the initiative to take the next step for further treatment. Women are thinking that also. Because once when I said to my friend about screening mammography, she asked if diagnosed where we will go. So, leave it' - FGD 2: 158 (Population 1)*

## 6.5.2 Automatic invitation system

An automatic invitation system here means a system devised by the local or Kerala government whereby women of 40 years of age and older are invited and directed to undergo screening mammography. The participants explained that such a system would support changes in women's health behaviour and increase the uptake of screening mammography. In fact, it can overcome the impact of the various influencers present at the socio-ecological level. For example, awareness and knowledge of the procedure and the actual medical condition can be raised through it. Individuals can also overcome cultural restrictions and barriers because the procedure would then be considered a formally directed and common examination.

*'It (invitation by the government) will help us to overcome the fear. Then women will start to think that we must do it' -FGD 4: 228 (Population 2)*

The participants also highlighted that government agencies have their personal details and are able to inform those at the target age group to attend screening mammography.

*'All details concerning a person are available in the insurance plan. So the government can look at it and provide treatment or check-up'- FGD 3: (Population 2)*

*'The government or hospital we visited for any reason will definitely have our date of birth. So they can inform us'- FGD 3: 223 (Population 2)*

*'Up to now such kind of SMS system concerning medical checkup is not available. If they start in UAE will be more helpful to everyone. But I do not know whether people consider it serious unless they know about it' - FGD 3: 226 (Population 2)*

*'...Data should be collected by an accredited agency and they have to inform the client. If it will be like this that will be helpful for all of us'- FGD 3: 227 (Population 2)*

*'If the government inform us to do mammogram for example during the renewal period of passport we will surely do a mammogram. People will consider it serious. They understand that it is important' – FGD 4: 256 (Population 2)*

*'In Passport and in Emirates ID very clearly mentioned about our date of birth. So they can inform us' – FGD 4 :255 (Population 2)*

### 6.5.3 Psychological support

Some participants expressed their concern that psychological support was unavailable to those diagnosed with breast cancer after undergoing screening mammography or those attending clinics for screening. They conveyed that a psychological support team should educate and assist women and their families to enable them to undergo screening mammography and manage the disease if diagnosed.

*'I think some sessions. Mainly psychological support is required' -FGD 4: 219 (Population 2)*

*'If diagnosed mental problems will arise and find difficult to face the results too' -FGD 4: 208 (Population 2)*

*'Communities need a deep awareness about the disease and psychological support' -FGD 5: 181 (Population 2)*

A strong need for psychological support was clearly evident in a number of participant statements such as

*'When we hear first, the screening mammogram causes tension' - FGD 2: 46 (Population 1)*

*'I had breast cancer awareness through hearing, so even though it is a small pain in the breast I used to worry about that and think that there is breast cancer. Tension will automatically come to our life'- FGD 2:46 (Population 1)*

*'If some friends are there, I think I would have gone' - FGD 3: 131 (Population 2)*

*'Moral or mental support is also very important. The community can encourage that person also. Now that is not available too'- FGD 3 (Population 2)*

In addition, during focus group discussion 4, the participants all agreed to a peer's suggestion that what they needed to overcome their fear of the procedure was 'awareness classes and mental support'.

#### 6.5.4 International health collaboration

Participants suggested that as there were many Keralites in the UAE and a number of community associations were linked to their homeland, these associations could work towards addressing expat Keralites' health concerns.

*'There are many mediators between UAE migrants and Government of Kerala such as Sharjah Association, Norka, Pravasi India etc. these all organisations are communicating with the government about our needs. If the government open a facility for women to do mammography and other tests that will be very helpful for each and every woman' – FGD 1: 143 (Population 1)*

*'Even they can think of arranging some community health centres for us including many facilities and can mediate between our Kerala government and UAE government' – FGD 1: 144 (Population 1)*

*'If Kerala government do a link with one of the hospitals in UAE to provide free mammography and treatment for the overseas women it may be helpful for the Keralite's here' -FGD 2: 154 (Population 1)*

## 6.6 Summary

Careful analysis of the data indicates that factors that influence the rate of uptake of screening mammography by the participants are multifactorial and reciprocal. Multifactorial as there are multiple influencers and individual variables. Reciprocal because the influencers are obliged and bound to each other and thus a single influencer cannot convince women to undergo screening mammography.

Thus, the socio-ecological factors as suggested by the socio ecological model have an influence on the decision of women to undergo screening mammography. These factors are interrelated. For example, even if health care facilities are available in accordance with the local or Kerala policy, at the individual level, if the women are not aware of the importance of early detection and screening mammography, they will not undergo screening mammography. Further, even those women who are aware of the importance of the procedure might opt to not undergo it if they do not receive the support of their families, friends and community (interpersonal factors). Moreover, the absence of adequate health care insurance (organisational factor) can deter women willing to undergo the procedure (individual factor) and enjoying the support of their relations and friends (interpersonal factor) from attending the screening tests. This interplay between the various factors is evident in this study. A single socio-ecological factor does not determine the health behaviour of the participants especially in relation to undergoing screening mammography.

The collective findings of this research are presented in figure 6.6 below where the results of the study are transposed on the SEM.

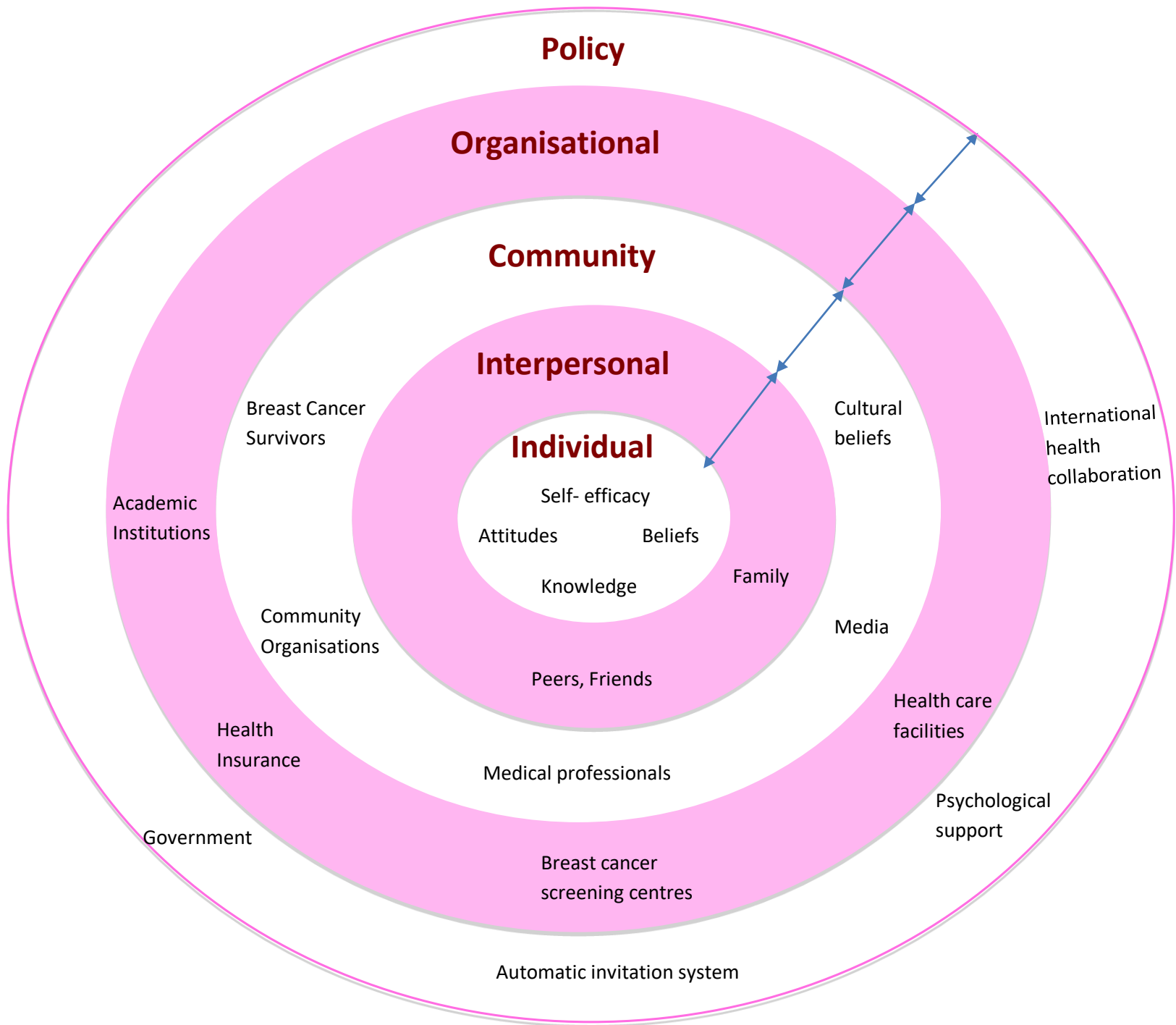


Figure 6. 6 Findings under the socio-ecological model of health

This chapter presented the findings of the data collected using 5 focus group discussions. These findings indicate that a comprehensive approach to change in health behaviour is required in order to increase the informed uptake of screening mammography by Keralite women residing in the UAE. Thus, understanding how to develop and implement changes in each level of influence is essential. Careful plans should be made to initiate and reinforce changes in the health behaviour of Keralite women residing in the UAE and alter their attitudes towards breast cancer early detection.

The findings of this study provide a foundation to practical plans to improve the screening behaviour among Keralite women residing in the UAE as presented in the recommendations chapter of the thesis (chapter 8).

## Chapter 7: Discussion

This chapter discusses and interprets the findings of the current study in context of the existing literature. The main aim of this study was to identify the socio-ecological factors that significantly influenced the informed uptake of screening mammography by Keralite women residing in the UAE. The objectives of the research were:

- identify the attitudes of Keralite women residing in the UAE towards breast cancer screening using screening mammography;
- identify and categorise the influencing factors for the uptake of screening mammography as voiced by the target population;
- devise strategies for increasing the informed uptake of screening mammography for Keralite women in the UAE based on the participants recommendations.

This chapter focuses on the identification of the participants' attitudes and beliefs and the socio-ecological factors that affect their willingness and ability to attend screening mammography. The next chapter (Recommendations) will present a number of strategies that can increase the informed uptake of screening mammography for Keralites women in UAE based on the participants' recommendations and the findings of this study.

### 7.1 The attitudes of Keralite women residing in the UAE towards breast cancer screening using screening mammography

This study identified a number of personal attitudes of the participants that influenced their willingness to undergo screening mammography. The findings of this study indicate that the participants held a slightly negative attitude towards the procedure that was generally marked by fear. Many of the participants were particularly fearful of the outcome of the diagnostic test, the pain they may experience during the procedure and the potential adverse health effects of



exposure to radiation during the procedure. While some of these attitudes are unique to this particular population, some were identified in other studies among other social groups. The following is a detailed discussion of these attitudes.

#### 7.1.1 Fear of a positive diagnosis

The fear of receiving a positive diagnosis of breast cancer discourages the participants from attending screening mammography. For them, it simply means a “death sentence”.

Further, among many members of the target community, a positive diagnosis usually carries a cultural stigma and may lead to social isolation; other members of the community may think that cancer is the result of a “sin” committed by the patient. In addition, even attending a clinic for a screening mammography carries its stigma. Regardless of the results, the woman will be viewed with suspicion. Another reason for dreading a positive diagnosis is tightly linked to their femininity. A mastectomy, even partial, is viewed as disfiguring. The perceived loss of feminine beauty and grace is not only agonizing but shaming.

Moreover, many of the participants would only undergo the procedure if symptoms were detected. The psychological impact is too strenuous for many. That fear of the consequences of a positive diagnosis inhibits women from undergoing screening mammography is in line with the findings of a study conducted by (Kobeissi, Samari, Telesca, Esfandiari, & Galal (2014)) which studies Iranian immigrant women residing in Southern California. The study aimed to describe the extent of knowledge of breast cancer and its risk factors. Their study concluded that personal attitudes had an independent significant effect on screening mammography uptake and future plan to continue screening. Further, they concluded that mortality induced attitudes influence screening behaviour and recommended to develop interventions targeting immigrant women’s personal attitudes to influence screening behaviour. The same was also found by (Somayyeh and Aydogdu (2019)) who conducted a study to explore the effects of fear from being diagnosed with breast cancer on early detection behaviour of women aged 20 and older in Turkey. They concluded that the fear of screening mammography and the chances of

being diagnosed with breast cancer negatively affect the practice of early detection behaviours. Further (Philippa, Laura, Jo, & Charlotte (2018)) conducted a population based survey among adults in England, and concluded that worries and fear highly impact breast cancer diagnosis and are the determinants of low uptake of screening. These studies suggest that the fear of a positive diagnosis is a global determinant of the low rate of uptake of screening mammography.

In this research, one reason for this fear is their lack of understanding of the condition and its treatment, and how to deal with the perceived aftermath of the diagnosis. This is clear from the more positive reports made by those participants who dealt with breast cancer survivors or received adequate information about the condition and the benefits of early detection.

#### 7.1.2 Fear of exposure to radiation

Participants aware of the screening mammography process and equipment conveyed their concern about the possibility of developing breast cancer as a result of exposure to radiation during the procedure.

*'I heard that mammogram is not good for our health; radiation it is too much painful. I understand that if we do screening, the risk of getting cancer is higher' - FGD 5: 59 (Population 2)*

This apprehension, the result of receiving scant, and often misleading, information reduced the uptake of mammography among the target population. When explaining the cause of their fear of exposure to radiation, many participants used words and phrases like "I heard," "we know that," and "surely". This indicates that their fear is based on partial knowledge of the risks involved. Yet, the fear is palpable enough to deter many of them from undergoing the procedure. It is perhaps not surprising that the findings of this study also reveal that the participants received relatively little information about the procedure or that they tended to ignore such information especially if its source is unofficial or dubious. It has been suggested elsewhere that measures should be taken to counter the lack of adequate knowledge about the

risk of developing ionizing radiation induced breast cancer fairly prevalent among women. Hollada et al (2015) advocate that women need to be well informed to overcome their misgivings towards the effects of the minimal doses of ionizing radiation such as those they would be exposed to during mammography. It is evident here that the situation is similar among the target participants of this study.

This information needs to be extensively disseminated in a language and form accessible to laywomen and men (ACR, 2019). To illustrate, although a large body of research shows that the benefits of screening mammography outweigh the risks (de Gelder, Draisma, Heijnsdijk, & de Koning, 2011; Hendrick, 2010; Miglioretti et al., 2016; Myronakis, Zvelebil, & Darambara, 2013; Seimenis, Chouchos, & Prassopoulos, 2018; Tabár et al., 2011; Yaffe & Mainprize, 2011), participants of this study believe that the risk of screening mammography outweighs its benefits. The American College of Radiology (2019), also encourages the health care providers to encourage women as well as inform them regarding the benefits of screening mammography and remove confusion related to it. The European Breast Guidelines (2020) (European Commission Initiative for Breast Cancer Screening and Diagnosis guidelines) have differences from ACR (2019) in terms of the annual screening mammography and the age of undergoing screening mammography. However, both guidelines confirm that screening mammography benefits outweigh the risk.

### 7.1.3 Fear of experiencing pain

Compression of breast during mammography improve the image quality and reduce radiation dose (Waade, Sebuødegård, Hogg, & Hofvind, 2018). However, the fear that screening mammography is a painful procedure because the machine used compresses the breasts is another determinant of low uptake among this study's participants. This was expressed by a number of participants including those who had undergone the procedure. Participants who underwent mammography prior to the study stated that they also had the perception that

screening mammography was a severely painful procedure, but realized that it was not the case when they attended screening mammography.

*'It was totally different, I was much tensed. For me, the screening mammogram was not painful'* -FGD 2: 50 (Population 1)

Some of the participants explained that they had received exaggerated reports of the pain involved during mammography. One was even told that it was similar to ultrasound screening during pregnancy. The involvement of pain, real or perceived, dissuaded some participants from undergoing screening mammography.

Previous several studies that assessed the level of pain during breast cancer screening concluded that the perception, and therefore, the amount of pain involved in screening mammography is subjective (Davey, 2007; Feldstein et al., 2010; Robinson, Hogg, & Newton-Hughes, 2013; Whelehan, Evans, Wells, & Macgillivray, 2013; Zintsmaster, Morrison, Sharman, & Shah, 2013). As has been found in other studies, the supposed level of pain involved in screening mammography is one of a number of factors that deter women from undergoing it (Chan, Lo, & Cheung, 2016; Holland et al., 2017; Suwankhong & Liamputtong, 2018). Furthermore, the findings of this study are in line with such research as that conducted by Engelman et al (2010) to assess native American women's mammography experience. The study concluded that due to the pain involved, women were not interested in undergoing the procedure again.

In the present study, a number of women who received mammography stated that it was not a painful procedure as previously expected. This can be attributed to the fact that the feeling of pain is subjective and they expected the procedure to be painful based on the reports they received from others who had previously underwent the procedure. Thus, the research presents conflicting reports of the experience of pain during mammography concluding that the experience is subjective.

## 7.2 The influencing factors for the uptake of screening mammography as voiced by the target population

This study identified a number of socio-ecological factors that determine the degree of willingness of the participants to undergo screening mammography. These factors were then divided into five categories based on the degree of influence and control the individual participant had at each level. As mentioned earlier, these categories are individual, interpersonal, community, organisational and policy factors. However, this division does not imply a separation of spheres as a significant interaction exists between these factors. The following is a detailed discussion of each of these factors.

### 7.2.1 Individual factors

#### ***7.2.1.1 Self- efficacy***

Self-efficacy refers to ‘the belief in one’s capabilities to organise and execute the sources of action to manage prospective situations’ (Bandura, 1997, 1998; Hasking & Rose, 2016). Analysis of participant responses reveals that the majority are health conscious and self-efficient. However, their lack of knowledge about breast cancer, and the importance of early detection, coupled with other socio-ecological factors, such as the fear of a positive diagnosis with breast cancer and the belief in fate, negatively affect their decision making regarding undergoing screening mammography. For example, a participant in FGD 3 was found to be self-efficient regarding organizing and attending hospital visits (FGD 3: 3), but her unfounded fear of a positive diagnosis due to simply hearing the word cancer deterred her from undergoing the procedure (FGD 3:11). Similarly, Sub-Saharan African and Chinese women were also reported to avoid talking about cancer and Chinese women associated talking about cancer with the probability of developing it (March et al., 2018).

*‘I take decision myself and go to the hospital for treatment, because I can only understand my body’s conditions... But I am scared even to hear cancer that it may come to me too’ –FGD 3: 3, 11 (Population 2)*

The link between self-efficacy and the willingness to undergo mammography is widely reported. Self-efficacy is one of the major factors that are positively correlated with the rate of screening mammography uptake (Champion et al., 2005; 2008; Gierisch, Earp, Brewer, & Rimer, 2010; Russell, Perkins, Zollinger, & Champion, 2006; Tolma, Reininger, Evans, & Ureda, 2006; Xie et al., 2019). Further, efficacy encourages action and affects the self-motivation to invest effort in an endeavour (Bandura, 2015). However, the level of self-efficacy can vary according to the situation. For some participants, the inability to conduct their affairs independently forestalls their efforts to undergo the procedure. For example, some do not have a valid driving licence in the UAE, others would need to ask their husbands for money to pay for the screening procedure.

It is difficult to be self-efficient if there is doubt in the outcome of an action. So the knowledge about an action creates a precondition for change and it constructs options to integrate predictive factors, and revise judgements against the expected outcome of a behaviour (Bandura, 1989). Further, attitudes towards the perceived risks, benefits, barriers and anxiety towards an action can affect change in behaviour Bandura (1989) and it creates an environment to execute an action (here screening mammogram) (Ramathuba et al., 2015). In the present study, participants were found to be self efficient in taking decisions, however, their lack of knowledge and other socio-ecological determinants (for example, a participant's husband's lack of knowledge of the procedure interpersonal factors or the participant's lack of awareness of the availability of screening mammography organisational factors in UAE for expatriates) are barriers for their uptake of screening mammography.

### ***7.2.1.2 The belief that breast cancer is an act of fate***

The results of this study indicate that women of the target population view the onset of breast cancer as an unavoidable act of fate.

*'Yes, it is a deadly, non-curable disease. It is fate if someone gets it. Nothing can be done'*  
-FGD 2: 14 (Population 1)

This view might not be very surprising considering the religious background of most of the participants. In fact, it can even be linked to the community's belief that cancer is visited on patients for sins they may have committed. This belief that breast cancer is an act of God corroborates the findings of a study conducted by (Lawal (2018), Sinky, Cheyney, & Dolcini (2015)) that concluded that in the case of Saudi women, fatalistic discourse, perceived threat to traditional role fulfilment, and preference for traditional therapies are responsible for the low uptake of mammography. Further, a study carried out by (March et al (2018)) determined that the culture of origin affects whether an immigrant has a fatalistic or proactive approach towards breast cancer screening, however, religious beliefs did not necessarily lead to fatalism. They analysed the level of knowledge, the barriers, and the common discourse about cancer screening among female immigrants from low-income countries (Morocco, Ecuador, China, Bulgaria, Romania, and Sub-Saharan Africa) and native women from lower socio-economic classes in Spain.

Participants of the present study confirmed that a lack of proper motivation for screening and taking preventive measures is a direct result of the perception that breast cancer is an act of fate. Similarly, some of the participants were overconfident that they were at less risk of developing the condition compared to other women.

*'I believe and I feel that all diseases are according to our mind. If I always think that I am weak, I will be weak. It is attached to our mind and will power'* - FGD 5: 78 (Population 2)

Psychological denial, particularly in relation to health, can have profound consequences (Moore & Healy, 2008). Most importantly, in the case of the target participants of this study, it poses a serious risk of missing the opportunity for early diagnosis and treatment of the condition. That these participants are in denial is perhaps clear from their belief that they can stay healthy and not develop breast cancer by will power alone. This suggests that some of them are not aware of the significance of early detection and its impact on the survival rate of patients. It also indicates some tendency to adopt unsafe health practices where regular health checks are

deemed unimportant. Perhaps it is worth mentioning that the relationship between the participants' awareness of the importance of the early detection of breast cancer and their willingness to attend screening mammography is a recurrent theme that is evident across the five categories of socio-ecological factors detected in this study.

### ***7.2.1.3 Lack of knowledge***

The participants' awareness of the importance of early detection and the role of screening mammography is one of the major factors that determined their utilisation of screening mammography. Similar results were found by a study conducted in Saudi Arabia to describe the level of knowledge about breast cancer screening and breast cancer risk factors among Saudi women. The study revealed that the subjects had sufficient knowledge about the risk factors and symptoms of breast cancer while they had insufficient knowledge about the screening methods (Binhussien & Ghoraba, 2018).

Similarly, the lack of proper knowledge about the signs and symptoms that should prompt an individual to attend screening mammography is another factor that negatively influences a woman's decision to undergo mammography. A number of studies reported the same results in other countries such as Iran (Izanloo (2018) and Hajian Tilaki & Auladi (2015)), Australia (Suwankhong & Liamputtong (2018)), (Hajian Tilaki & Auladi (2015)), Ethiopia, (Abeje et al (2019)) and Saudi Arabia (Binhussien & Ghoraba, 2018).

Analysis of the participants' responses regarding screening mammography and follow-ups reveals that women in both populations have some, albeit minimal, knowledge of the procedure. Therefore, it can be concluded that they do not have enough knowledge to fully recognize the importance of the procedure. As has been expressed elsewhere, this shows that individual factors are an internal instrument, through which external factors operate mechanistically to direct a behavioural change (Bandura, 1989). Behavioural change is possible by a personal sense of control (Conner & Norman (2005)) and control on cognitive factors such as thought processes, motivation and action. To alter an individual's health-related behaviour, exploration of behaviour triggering determinants is necessary (Ahmadian & Samah, 2013).



Hence, identifying and exploring these factors and removing these individual level barriers can lead to an increase in the rate of mammography uptake among Keralite women residing in the UAE.

## 7.2.2 Interpersonal factors

In the present study, interpersonal level determinants or factors refer to the formal and informal social networks or support that determine the rate of screening mammography uptake among Keralite women residing in UAE. The major interpersonal influencers are family members, the participant's role as 'Kudumbanatha' (female head of the family), peers, and friends.

### 7.2.2.1 Family

Being members of the Kerala community, all participants are greatly dedicated to and significantly influenced by their social circles. In traditional Kerala culture, women are expected to play the role of a mother, daughter, sister, or wife. They can be heads of the family, however, men are believed to have the greater analytical capacity (George, 2011). Further, patriarchy is the prevalent family structure, which means that the head of the family and the decision maker is the eldest male. Customarily, in marital relationships, a Kerala woman's position is that of a subordinate partner George (2011) responsible for housework such as shopping for food supplies, cooking, cleaning, washing, attending to the needs of children, husband and parents in-law (Ramanathaiyer & Macpherson, 2000). Participants in this study reported that they had the same responsibilities here in UAE as they did in Kerala. Paradoxically however, they said they were comparatively more able to make independent decisions here in UAE than they would have been in Kerala. This is evident from the following statements made by a number of participants:

*'I take decision myself and go to the hospital for treatment, because I can only understand my body's conditions'* -FGD 3: 3 (Population 2)

*'No, needs to get permission from the life partners or any family members'* -FGD 3: 5  
(Population 2)

*'I am taking decision myself'*- FGD 4: 2 (Population 2)

The influence other family members, especially the spouse, exert in such situations as deciding to undergo screening mammography has also been observed in other cultures.

*'Awareness is very important to husband and to everyone in the family, friends, and co-workers also'*—FGD 3: 188 (Population2)

For instance, a study done in Lebanon among Lebanese women (Elias, Bou-Orm, & Adib (2017)) and another study among immigrant and refugee women in (Buffalo, Newyork Gondek et al., (2015)) also reported that husband support was significant for adherence to screening mammography by women. Further an ample body of relevant work was conducted in the context of Iranian communities to explore the factors that affect the rate of uptake of breast cancer screening. This body of research also confirmed that a husband plays a significant role in his wife's decision to undergo screening mammography (Charkazi et al., 2013; Lamyian, Hydarnia, Ahmadi, Faghihzadeh, & Aguilar-Vafaie, 2007; Maryam, Mahmood, Soghra, & Zeinab, 2019). Similar findings were reported by Moses et al (2011) in their study that explored the part Nigerian husbands play in their spouses' early detection of breast lumps. Another study conducted in Saudi Arabia also concluded that husbands' knowledge, attitudes, and perceptions influence their wives' decision for pursuing opportunities for the early detection of breast cancer (Hassan, Nabil, & Ahmed, 2019). A critical review of earlier studies reveals that husbands' cooperative attitude has a positive influence on the overall health and breast cancer screening behaviour of their spouses; men who know about breast cancer, examine their wives' breasts and support them in self-examination, see for example, (Moses et al., 2011; Sambanje & Mafuvadze, 2012; Widiasih & Nelson, 2018). This behaviour was not reported by the participants of this study. The findings of this study also suggest that the husband's behaviour remarkably influences breast cancer screening uptake. Particularly, factors such as women's lack of transportation, need to be escorted to attend mammography by their husbands, financial dependency on their husbands, obligation to appreciate the work stress experienced

by the husband, and need to provide almost total family care as a result of the husband's inability and/or unwillingness to devote enough time to the family negatively affect their ability to undergo mammography. However, a number of participants reported that they could make their own health decisions relatively freely, although they needed to discuss this with their husbands first.

In Kerala, it is believed that a woman's financial independence enables woman to understand their potential and at the same time, turns her into a potential threat to the power and status of her male counterpart (George, 2011). However, freedom of choice and autonomy enable women to make their own healthcare decisions and they can be healthier (Abeje et al., 2019; Green, Wang, Ballakrishnen, Brueckner, & Bearman, 2019). Generally speaking, although Kerala women have a high level of education, their cultural norms and the restrictions imposed on them greatly limit their autonomy George (2011) even to the extent that they are unable to make independent health care choices (Green et al., 2019). Furthermore, an employed Keralite woman is unable to spend her money without the permission of her husband and is expected to attend to the needs of her family at her own expense (George, 2011; Green et al., 2019). This is in line with Akuoko et al (2017) to evaluate the contributing factors of delayed breast cancer presentation and diagnosis among African women living in sub-Saharan Africa and concluded that women sacrifice their health needs to fulfil their responsibilities towards their families. Another study that focused on the communities of the northern part of Iran aimed to investigate the factors that affect the uptake of breast cancer screening among women revealed that these women preferred to stay at home and suffer in silence rather than have their husbands or family members pay for health care (Maryam et al., 2019).

Moreover, as evident in this study, Keralite women prefer to manage their disease by themselves and not disrupt their families' peace and financial state with their sickness (Sharma, Mehan, & Surabhi, 2010; Wilson, 2010). The following statement by one of the participants in this study illustrates this points perfectly:

*'My sister got breast cancer; she is in Fujairah, the doctor advised me to do a mammogram. But scared. Worried if the result comes positive, we can't afford. The*

*whole family will be in trouble in all means. So, live peacefully until it shows the symptoms'* -FGD 3: 75 (Population 2)

These results are in line with the findings of Elobaid et al. (2016) who conducted a qualitative study of Arab and local women in the UAE which revealed that, in their respective cultures, people may consider cancer patients as a potential cause for financial difficulties and shame; a woman's bosoms are part of her beauty, if lost, that would diminish their beauty. Similar results were also reported by Sabih et al. (2012) who attempted to identify the barriers to breast cancer screening and treatment among women in the Emirate of Abu Dhabi.

However, it can then be argued that participants in this study are unaware of the importance of early stage detection and how it can help their families by reducing the emotional and financial cost they would otherwise have to bear. Furthermore, the family's financial and psychological support, especially that of the husband, is significantly important for Keralite women to be able to attend screening mammography.

#### **7.2.2.2 Peers and Friends**

Analysis of participant responses suggests that peers and friends greatly influence screening mammography uptake. This is because their peers and friends belong to their age group and similar social networks, hold the same cultural beliefs, and follow similar routines. Consequently, they discuss their problems with one another comfortably. A negative effect of this is that these people can exert some pressure on the women discouraging them from attending screening mammography. The type of pressure peers, friends and work colleagues place on the women varied from the well-intentioned concern they might have already been diagnosed with breast cancer to the stigmatizing. On the other hand, close social associates of the women can have very positive and supportive influences. For example, they would encourage them to undergo the procedure or, in the case of employers, allow them the time to attend the screening test.

Similar beliefs were reported in studies conducted in other cultural contexts, for example Chinese American women, (Wenchi et al (2008)); Korean American women (Lee, Kim, & Han, (2009)); Asian women (Ahmadian & Abu Samah, 2012). This suggests that social ties underpin the willingness of individuals to help others with health care (Lem (2013), Uchino (2004)) and breast cancer screening behaviour (Allen, Sorensen, Stoddard, Peterson, & Colditz, 1999). Further, in addition to a woman's informal social network, family members play a significant role in increasing the chances of her mammography uptake (Keating, O'Malley, Murabito, Smith, & Christakis, 2011; Smalls et al., 2018).

However, this social impact is probably less pronounced in strongly individualistic cultures like the USA. Smalls et al (2018) reported that social networks did not significantly influence breast cancer screening behaviour among the participants of their study. Similarly, a quantitative study done by Keating et al (2011) from Harvard Medical School and Boston University Medical Center using the Framingham Heart Study data to assess whether screening for breast and other types of cancer is influenced by the actual screening behaviours of siblings, friends and co-workers. Their study concluded that, aside from a slight increase in breast cancer screening among women whose sisters were screened and in colorectal cancer screening if their spouses were screened, the screening behaviour of siblings, friends, or co-workers did not influence cancer screening behaviour.

In this research, the target study population concluded that peers and friends significantly influence their mammography uptake.

### 7.2.3 Community factors

In this study, the community level determinants were community organisations, medical professionals, mass and social media, community leaders, and breast cancer survivors. Analysis of participant responses shows that they value information shared by community organisations and community leaders. Therefore, it can be concluded that community organisations play a

major role in shaping the views and health behaviour of its female members. This can be attributed to the fact that members share the same cultural values and traditions, are able to share culturally sensitive information, and can encourage their female members to commit to positive health behaviour such as undergoing screening mammography (Cardarelli et al., 2011; Jonathan et al., 2018; Macnamara & Camit, 2017).

### **7.2.3.1 Community Organisations**

Keralite women in the UAE have close links with other members of their community through various venues. As the participants expressed it, that is because they are away from their relatives and friends in their homeland. This form of close social ties inspires trust in community leaders and the organisations they head.

*'People will believe the information which is given by the community leaders. Information from the community leaders is believable. If any organisations provide free mammogram service, they can approach the community leaders and inform them to announce it'* -FGD 2:128 (Population1)

It is this broad reach of such organisations in the UAE that makes them a perfect platform for raising awareness about such health issues as the importance of early detection of breast cancer. This would be in line with several studies that explored the potential of community organisations for promoting adherence to and maintaining positive health behaviours. For example, a study done in Washington to identify methods to promote breast cancer screening recommended by primary physicians concluded that the involvement of community organisations is a promising option (Taylor et al., 1996). Another community-based intervention project to promote breast cancer awareness and screening in Korea also determined that their intervention was successful enough to create awareness, promote breast cancer screening, and decrease various myths about breast cancer (Kim et al., 2011). A similar project that focused on Asian American women also reported success in their intervention (Wu et al., 2014). This suggests that intervention through community organisations increases awareness about breast

cancer and screening in diverse cultures. As intervention programmes are designed to suit the target culture, they generally achieve their objectives.

In addition, this study reveals that, especially in this particular context, Keralite women rely on community organisations, places of worship, and professionals for information and guidance as expressed in the following statement made by one of the participants:

*'Most of the people (Keralites) who are here are there in one or another Kerala community group. Like, we have a lot of Malayali's organisations, Indian association, even churches also. If an authorized person like you, who are in the medical field can give awareness classes to these groups. It will be more influential and motivation to do mammography'-FGD 1: 104 (Population 1).*

This is not very different from the situation in Kerala, where the target population comes from. A study conducted in Kerala by Parambil et al (2019) supports the idea that community participation involving volunteers with the collaboration of the health care system and local government can increase early detection of breast cancer and can improve the chances of longer survival.

### **7.2.3.2 Medical Professionals**

A common sentiment expressed by all study participants is that they attach higher value to the advice and information shared by medical professionals compared to those communicated by other unqualified individuals.

*'...If an authorized person like you (me as the researcher), who are in the medical field can give awareness classes to these (Malayalee organisations) groups. It will be more influential and motivation to do a mammogram. If a person like you, one who studied and learned about this disease can influence women and surely will go for the tests. I will*

*not go if my husband just immediately comes and say to do a mammogram. Because I do not think it is required as he is not in the medical field'* –FGD 1: 104 (Population 1)

As has been stated elsewhere, medical professionals can positively influence the attitudes and beliefs of patients and their relatives and friends regarding mammography uptake (Akpınar, Baykan, Naçar, Gün, & Çetinkaya, 2011; Heena et al., 2019; Othman, Ahram, Al-Tarawneh, & Shahrouri, 2015; Rawashdeh et al., 2018). A study carried out in Canada among Tamil female immigrants of 50 years of age and above concluded that recommendations made by a medical physician can encourage the uptake of breast cancer screening (Meana, Bunston, George, Wells, & Rosser, 2001). Another study found that Turkish women of the age group 60 to 75 years attach high value to the advice of medical professionals (Kissal & Beşer, 2011). A critical review of the literature by Ahmadian & Abu Samah (2012) regarding factors influencing the uptake of breast cancer screening in Asian countries concluded that health professionals can play an important role in overcoming psychological barriers of women towards breast cancer screening.

Nevertheless, a health care professional is still a stranger in front of whom women should not reveal parts of their bodies. This has a considerable impact on the willingness of Keralite women to have mammography. Participants in this study conveyed their embarrassment of having to expose their breasts or be examined by a health care professional. However, in UAE, the sensitive nature of Islamic socio-religious environment promotes a preference for a female health care professional to treat women (Rizk, El-Zubeir, Al-Dhaheri, Al-Mansouri, & Al-Jenaibi, 2005; Rizk et al., 2002).

*'Our cultural background is very narrow and closed one regarding breast examination; it is a shameful procedure. Women should have an open mind and then only they will be motivated to undergo mammogram'*-FGD 2: 86 (Population 1)

A study conducted in India to explore breast cancer awareness, barriers to early detection, and prevention behaviour among women in Delhi reported that the presence of a male doctor during breast examination causes hesitation among the patients (Dey et al., 2016). Participants in this study expressed similar attitudes.



*'During medical check-up our female doctors can examine us' –FGD 4: 70 (Population 2)*

It can then be concluded that the participants believe that medical professionals can play a prime role in spreading desirable awareness about the importance of screening mammograms that will consequently promote a culture of early detection of breast cancer among community members.

### **7.2.3.3 The Media**

The study reveals that participants are exposed to cancer awareness messages through both mass and social media. However, as the majority considers these to be either marketing ploys or fake messages, they are not influenced by them. This is evident in statements like the following:

*'we get information through WhatsApp, but we didn't take it as serious many messages come just as forwarded. Sometimes we do not know whether it is fake or not, usually, I ignore it' -FGD 1: 61, 62 (Population 1)*

Based on the views expressed by some of the participants (see the FGD 3: 192 and FGD 4: 103), it can be concluded that although the media can be used to promote breast cancer screening programmes, it cannot be viewed as the most viable means to bringing health behavioural change. This is especially true in Arabian Gulf countries where holding health campaigns through the media can pose a significant challenge due to the cultural and linguistic diversity of their residents (Mansour et al., 2018). However, a study conducted in Saudi Arabia to determine the advantages and challenges of using social media in health care concluded that the use of social media is revolutionizing health care delivery and its advantages outweigh the disadvantages. This is because, people in the modern digitised world use social media on daily basis, and learning about health related issues such as the symptoms of an illness and methods of treatment can help them to take better care of their health (Al-Qahtani et al., 2018). Still, the enormous growth of information now available on the media and its varied and numberless sources can also lead to public harm or impede the achievement of the intended purpose of

providing this information (Kolusu, 2015). This is in line with the findings of the current study, where participants stated that there were too many health-related posts on electronic media and that they considered such messages a means of social marketing.

Furthermore, in line with a study that assessed the level of knowledge and practice of breast cancer detection among women aged 35 and above in Tanzania (Ng'ida et al., 2019), participants of this study trust information broadcast on television and radio programmes more than other sources. Moreover, participants trust message shared by the Kerala or UAE governments.

*'Television is one of the effective media to inform others about it. Women watch television in their free time. If the government give advertisement, that will be trustworthy and reach to them'* – FGD 1: 100 (Population 1)

Similarly, the participants stated that media messages by physicians and breast cancer survivors can greatly convince recipients to value the information.

*'But I think we are not considering it (media message) serious. If there are columns which mentioning about the person who affected by breast cancer, message by a doctor, how the client is now, how they recovered from the disease. Medias can include these all to create awareness'*-FGD 4: 197 (Population 2)

Thus, creative media messages that are culturally acceptable can influence and dissipate health related perceptions to a wider audience (Lutkenhaus, Jansz, & Bouman, 2019).

#### **7.2.3.4 Cultural beliefs**

In this context, cultural and religious beliefs and the fear of social exclusion are determinants for the uptake of screening mammography. Bedi & Devins (2016) stated cultural beliefs and values can shape a woman's experience of a disease and introduce stressors that influence

psycho-social needs and adaptation. The following statement made by one of the participants reflects this view clearly:

*'I know a woman with breast cancer, and during the vacation she went to treatment in Kerala. But the attitudes of the others towards her were different. She felt discomfort there in Kerala. So she escaped from there to UAE'* –FGD 5: 102 (Population 2)

Fear of social exclusion and the need of social support are two significant factors that affect the decision of the target population to undergo screening mammography. This is in line with a study conducted in Turkey to determine the effect of women's perceived breast cancer fear and social support on their participation in breast cancer screening (Kissal, Vural, Ersin, & Solmaz, 2018). The study observed that the supportive attitude of the community plays a significant role in promoting positive empowerment message in overall health related activities and specifically for breast cancer screening uptake (Kissal et al., 2018). Another study of immigrant Tamil women of 50 years of age and above in Canada confirmed that, for these women, cultural and religious beliefs were barriers to undergoing breast cancer screening (Meana et al., 2001). Therefore, to promote breast cancer screening, the cultural beliefs of the target groups should be identified and considered in any efforts to positively change their health behaviour.

To conclude, community related determinants play a vital role in propagating mammography uptake among this study's participants.

#### 7.2.4 Organisational factors

##### **7.2.4.1 Health care facilities**

Participants share a lack of awareness of the availability of breast cancer screening services for expatriates. Many of the participants underwent breast cancer screening during their routine health check ups in Kerala during their vacation to Kerala as they were not aware of the

screening mammogram services available at UAE. Even for those aware of the service, language, cultural and religious differences make them feel uncomfortable to undergo breast examination by a non-Keralite health care professional, which prevented the participants utilizing the breast cancer screening services available to them in UAE. Thus the participants rarely availed themselves of this service mainly because of issues related to convenience, information and cultural sensitivity.

*'I may not be prepared to undergo it, just like when we see it somewhere, no one will just go and do it. Also, I thought there might be only Arabic speaking doctors and health team are available. We look odd there. I feel so. In addition, I think unless and until if there is no clear explanation of the procedure to the public no one will just go like that. I think they must give some sessions before'* -FGD 2: 68 (Population 1)

In the UAE, free breast cancer screening services are organised by both public and private health care organisations. Furthermore, mobile screening mammography units (Pink Caravan) are available to expatriates. In many cases, women need to travel to these units when they may not be able to drive themselves or have easy access to transport. In addition, the presence of a unit in a certain area is not usually announced well in advance so that potential clients can plan their visits. This is in line with the results of research conducted in Australia on Thai migrant women which concluded that the subjects paid little attention to breast cancer screening programmes and considered them unimportant (Suwankhong & Liamputtong, 2018). Similarly, a study carried out by Brzoska and Abul-Rida (2016) examined the ease of access to cancer facilities by migrant and non-migrant women in Germany and concluded that migrant women had limited accessibility to informed screening practices. Another study conducted in Germany among migrant and non-migrant women to analyse the uptake of gynaecological cancer screening and determined that these women formed a high-risk group as they did not attend screening sessions, hence they were largely diagnosed with cancer at later stages (Berens et al., 2019). They further added that language barriers and lack of transportation could lead to lower rates of utilization of health care services. This was also confirmed by a population based registry study carried out in central Denmark to identify specific breast cancer screening non-

attending groups (Jensen, Pedersen, Andersen, & Vedsted, 2012). Participants in this study expressed the same concerns about their ability to access the free screening mammography service offered in the UAE.

*'Of course, transportation is a barrier for us. Many of us do not have driving licence here'*

– FGD 4: 135 (Population 2)

A study that explored the association between health literacy, barriers to breast cancer screening, and participation among multicultural groups in Melbourne identified that three health literacy domains assurance and support by health care facilities, social support for health, and understanding health information can lower the emotional barriers of women (Jonathan et al., 2018). Therefore, it can be suggested that health services and intervention programmes should consider in their design the socio-cultural needs of migrant women. This is because even though free screening mammography is available in the country, potential users' lack of awareness of its existence, location, and timings limit their use. Some of the participants in my study shared that screening mammogram can only be done on or after the sixth day of the menstrual cycle, so the duration of availability of screening mammogram at a location were highlighted by them. This means the participants were not aware that in pre-menopausal women, the sensitivity of screening mammography for detecting breast cancer is greater in the follicular phase (first day of the menses to 10 -16 days (Reed & Carr, 2018)) than in the luteal phase (from 14th day of the cycle) of the menstrual cycle which might be due to differences in mammographic density (Browne et al., 2020; Gayane et al., 2009; Morrow et al., 2010). Thus, the participant's view in my study revealed that free screening mammogram is not the only influential factor but it is also governed by many other socio-ecological factors.

#### **7.2.4.2 Academic Institutions**

The findings of this study suggest that academic institutions can play a significant and on-going role in spreading awareness of the importance of screening mammography. In addition,

information provided by these institutions is often valued and trusted by the community and so can initiate change in the health behaviour of its members.

*'If the students get information, they will share with others as well as they get motivated through this. It will help them to prepare themselves and to do self-detection and other tests'* -FGD 2: 172 (Population 1)

*'Awareness class and mammogram in the school and university are a better idea. Students can inform their parents. If school or university conveys this, everyone will believe'* -FGD 3: 235 (Population 2)

However, several studies show that awareness of breast cancer among teachers and students was too inadequate for them to understand the importance of early detection and practising screening mammography. In the context of Kuwait, female school teachers were shown to have in-sufficient knowledge about breast cancer, which negatively influenced their early breast cancer detection practices (Alharbi, Alshammari, Almutairi, Makboul, & El-Shazly, 2012). Similarly, female undergraduate students in Cameroon were found to be aware of breast cancer as a disease but lack knowledge of the signs and symptoms of the condition and the importance of early detection (Sama et al., 2017). Moreover, and closer to home, a number of studies carried out among female students of different universities in the UAE revealed that female students of higher education lack the knowledge of the risk factors and screening methods of breast cancer (Shaima, Lina, & Pavlos, 2017).

The participants of this study believe that academic institutions should provide training to interested students who volunteer to deliver sessions on the importance of breast cancer screening and early detection. They further added that this would help those trained students to share this information with family members and they could train other members of the public. The participants trust these institutions and believe that they are best placed to raise the public awareness of breast cancer and screening mammography.

*'From the college itself, students can go to nearby places and can make the people aware of the need for a mammogram. It can be considered as training for community service'-FGD 2: 171 (Population 1)*

These findings highlight the role of health care facilities and education and breast cancer screening organisations in changing breast cancer screening behaviour of Keralite women in the UAE.

#### 7.2.5 Policy factors

This level is concerned with policies that allocate screening mammography and health care resources to expatriates in a country. The influence of the UAE and Kerala governments can exert to increase the rate of uptake of screening mammography is highlighted by many participants in this study. They were also ready to make serious recommendations as the requirement for health service collaboration between the two states.

The participants highlighted a number of factors that they thought could affect the willingness of women to undergo screening mammography. These include official notifications issued to women of vulnerable age to attend screening mammography, and the availability of professional and informal psychological support.

They proposed that the Kerala government should make serious initiatives to care for the health of expatriate nationals. They further suggested that officials should issue instructions to encourage and facilitate the uptake of screening mammography as they expected that this would help women in the community overcome cultural barriers. Moreover, the participants were worried about receiving a positive diagnosis of breast cancer, hence their request that a psychologist be available at health care facilities, who would help women in this regard.

The participants communicated that one reason for the demand for a direct involvement of the Kerala government was that after spending some years in UAE, Keralites go back to their home country suffering from many diseases.

*'Many lifestyle diseases can also be diagnosed early, not only breast cancer. After some years usually when Keralites go to Kerala after finishing the job from here (UAE), most of us go with many diseases, like sugar, cholesterol, BP, heart problems and so on. If the Kerala government arrange it (screening) free of cost that will be great. We are the major source of Kerala's income. They can consider our wellbeing'-FGD 2: 187 (Population 2)*

Keralites do indeed seem to migrate in considerable numbers. It was once proclaimed that 'no state in India is as historically integrated and embedded with the world system economically and culturally as the state of Kerala (Jones & Mielants, 2016, p. 124). In fact, migration is the single most dynamic factor in the development of Kerala (Jones & Mielants, 2016; Zachariah, Mathew, & Rajan, 2001). At least 18 percent of households in Kerala have at least one migrant (Rajan & Zachariah, 2019). The temporary economic migration of Keralites to Gulf Cooperation Council (GCC) countries has been on the increase, especially to UAE, which is the favourite destination of Keralites since 1998 (Irudaya Rajan, 2011, pp. 299, 301; Rajan & Zachariah, 2019; Zachariah & Rajan, 2015; Zachariah et al., 2001). This significantly contributes to the economy of Kerala and the living conditions of its citizens (Irudaya Rajan, 2011, p. 303; Jones & Mielants, 2016, pp. 133-134; Zachariah & Mathew, 1999). The huge value of remittances, the enormous NRI bank deposits, and the palatial houses they build in Kerala are the potential impacts of Keralites migration to GCC (Zachariah et al., 2001). These remittances further make a substantial contribution to the annual income of the households in Kerala (Irudaya Rajan, 2011, p. 303). But this prosperity through migrants appears to come with a heavy personal price (Shahul Hameed, Kutty, Vijayakumar, & Kamalasanan, 2013), as migrant Keralites have been found to compromise on eating habits and lifestyle, and work overtime to earn more for their families (Vidyanandan, 2018). This takes its toll on their health. Many return home due to health problems (14%), or family matters (12%) (Rajan & Zachariah, 2019; Sirkeci, Cohen, & Ratha, 2012, p. 89). Such health issues Keralites suffer overseas include allergies (9.3%), diabetes (7.6%), kidney problems (6.9%), and cancer (2.4%) (Begam, Srinivasan, & Mini, 2016; Rajan & Zachariah, 2019). In short, it is reasonable that the Kerala government should be directly involved in the health issues of its very economically vibrant migrant citizens.



Nevertheless, the participants appreciate the initiatives carried out by UAE health authorities to improve the health for all residents.

*'UAE government gives importance to the health for all residents'- FGD 2:152  
(Population 2)*

Analysis of participant responses shows that the majority are not aware of the availability of screening mammography services for expatriates. Meanwhile, those aware may not attend the procedure due to lack of reliable information, information overload, or cultural differences. Furthermore, many believe the services are only offered to UAE nationals and conducted by Arabic speaking medical staff in front of whom they would feel embarrassed to expose their breasts.

*'But less Keralite's may go, I think because Malayalee's think that they will feel odd, because of language, they will not feel to go' - FGD 2: 148*

A study done to assess healthcare services accessible by refugees and migrants in European countries under migratory pressure also concluded that expatriate communities usually face many challenges accessing healthcare services in a foreign country due to such reasons as the high cost of the services, lack of reliable information, cultural differences, and lack of knowledge about the available services (Chiarenza, Dauvrin, Chiesa, Baatout, & Verrept, 2019; WHO, 2019). In the context of UAE, although a number of free services are available for Keralites, relevant information does not reach the community as needed.

To add, afraid of losing their livelihoods and, consequently, deprive their families of the extra income they provided, many women prefer not to undergo the procedure. Participants conveyed that they knew many women who were not able to undergo health check-ups or treatment, and hide their disease because of the fear that they could lose their jobs as a result.

*'Many people are working for minimum wages. They can't spend their salary for their check-up. Because they have many responsibilities to do, they have a family member who is waiting to receive money, their kid's education, and their own daily needs. They*

*may pay rent. So even though they have pain and suffering in their body they used to tolerate it'*- FGD 1: 111 (Population 1)

*'Women (women in the labour camps where low wages people stay together) report any disease and take leave from their duties when they cannot move from their bed'* -FGD 3:158 (Population 2).

Furthermore, 'the money that migrants send home is important not only to their families but also to their country's balance of payments' (Sirkeci et al., 2012, p. 96). Keralite migrant workers, including females, send remittances to their families left behind in Kerala, often with instructions on how and where the funds should be used (Sirkeci et al., 2012, p. 100). This places them in a very precarious position, where their own health needs would be secondary to those of their families and communities.

The government of Kerala initiated many programs for the welfare of migrant Keralites and has dedicated a department called Non-Resident Keralites Affairs Department (NORKA) in 1996, the first of its kind in India (Jones & Mielants, 2016; Shahul Hameed et al., 2013). The NORKA serves as a regulatory agency for foreign recruitment, especially to the Middle East, and developed liaison with the respective governments to develop new labour rules and laws to ensure decent living of the workers in the host country. Further, the Kerala government in alliance with the Government of India are helping emigrant populations in assistance during accidents or death of workers while abroad (Jones & Mielants, 2016). However, the inclusion of migrants' health, while in the host country and returned migrants health should be considered as one of the major targets and measures for the wellbeing of the population.

Cross-national collaboration between the UAE and the state of Kerala will provide wide opportunities to create culturally sensitive intervention programmes to increase expatriate Keralites' awareness of the importance of breast cancer screening mammography and provide comprehensive information of screening mammography services in UAE. A study conducted in Mexico to evaluate facilitators and barriers influencing screening mammography among Mexican women aged 40-69 concluded that local initiatives to reduce mammogram related

pain and fear of bad news should work together with national programs to increase access to screening (Cruz-Jiménez et al., 2018).

The findings of this research reveal that governments have a considerable effect on the levels of awareness of and willingness of participants to undergo screening mammography.

### 7.3 Limitations of the research and findings

Limitations usually ascribed to qualitative research such as the small size of the research population, the geographic location of focus group discussion, and the potential for researcher bias are possible in this research.

Studies reveal that higher socio-economic factors influence the higher incidence of breast cancer as well as uptake of screening mammograms (Lundqvist, Andersson, Ahlberg, Nilbert, & Gerdtham, 2016; Lyle, Hendrie, & Hendrie, 2017; Orsini, Trétarre, Daurès, & Bessaoud, 2016). The level of education of the participants is an important factor that could have been considered here as it may affect the ability of the participants to access information and services. For example Sheridan et al (2011) reported that low health literacy is associated with poorer utilization of health care services and poor health outcomes. Further, occupational status (Damiani et al (2015); Liu et al (2017); Willems & Bracke (2018)); insurance coverage Hale, (2018), also found as influential factors for the uptake of screening mammogram.

In this research, the study focused on Keralite women without considering their educational, health literacy, employment status, religion, or place of residence in the UAE. This may not be of great concern for example the majority of the migrant Kerala women in the UAE are educated. Yet, despite being educated the uptake of screening mammography as well as knowledge about the importance of early detection of breast cancer are low. Further, there are likely to be differences in the level of health education in migrant Kerala women in UAE and women living in Kerala therefore some of the findings may not be transferrable.

Furthermore, the findings of this study may not be generalized to other groups from the same community living in the UAE or elsewhere. This is because of the interrelations of human beings to their environment; emotional ties can vary due to different ecological and cultural factors (Andrachuk & Armitage, 2015). Therefore, the socio-ecological determinants for migrant women can vary. For example, it can vary depending on their place of residence and healthcare facilities available to them. Besides, a migrant's fluency in English or the language of the host country (here Arabic) can also vary.

In addition, I have not attempted to use linguistic features to analyse and clarify the data or used content analysis to highlight the most common view or statement expressed by the participants. Further, I acknowledge that the findings are only a few of many possible interpretations and realities of participant's perception.

Along with these, all focus group discussions were not conducted at the same location, time and not financially compensated. These physical features also affect the data as human behaviour is significantly influenced by the setting where an interview occurs and varies depending on the contextual variables involved (Atieno, 2009). The marital status was also not considered while recruiting the participants (but all participants are married), although there may have been an incidence of deliberate avoidance of regular healthcare check-ups by single, separated, and widowed women as reported by Regina & Michael (2018). Moreover, the level of participant's husband's education and health literacy was not considered. In a patriarchal structure of the Keralite community, this might have influenced their interpersonal determinants. Besides, differentiation between age groups, religion was not considered during recruitment or data analysis. Therefore, I cannot claim that this study will reflect the views, experiences of all Keralite women in the UAE.

## 7.4 Summary

This chapter discussed and interpreted the findings of the present study and related them to earlier studies, many of which targeted other ethnic groups. Later the chapter conveyed the limitations of this research.

At individual level, the fear of a positive diagnosis is a major reason behind women's non-attendance to screening mammography. Furthermore, the fear of exposure to radiation and experiencing pain during mammography are other individual level barriers toward screening uptake. In addition, the fatalistic discourse of the study participants highlights their strong belief that developing cancer was an act of God, thus contributing to the low uptake. Self-efficacy and lack of knowledge about breast cancer, early detection, and mammography procedure also determine the rate of mammography uptake at the individual level.

It was also found that formal and informal social networks or social support greatly influence uptake behaviour. Similar to other cultures, the family's, and especially the husband's, cooperative behaviour remarkably influence breast cancer screening uptake. Peers and close friends also have a significant influence on not only the attitude of these women towards screening but also on the type of relevant information and social support they receive.

Further, at the community level, community organisations, medical professionals, the media and the participants' cultural beliefs significantly influence their decision to undergo screening mammography. Members of the expatriate Keralite community in the UAE maintain close social relations with their compatriots (interpersonal level) and with their community organisations (community level). As has been shown by other studies (Akpinar et al (2011), Heena et al (2019), Othman et al (2015), Rawashdeh et al (2018)), they attach high value and trust to the advice and information offered by a medical professional rather than a lay person. The study further reveals that the participants see cancer awareness messages, videos, and advertisements in both mass media and social media. However, these have little effect,

because the majority of the participants view them as nothing more than social marketing or fake messages. Other factors ranging from the fear of social exclusion to the limitations imposed by cultural norms and values predictably define the attitudes of the target group and determine the likelihood of its members undergoing screening mammography. In fact, these social barriers decide their health behaviour to a very large extent.

In addition, healthcare and educational organisations have a considerable impact. Women of the target community need accurate information from reliable sources to be informed of all issues related to breast cancer from how to recognize worrying symptoms, the benefits of early detection of breast cancer to the technical aspects of the screening procedure itself. Healthcare providers can also facilitate uptake by considering the cultural backgrounds of their users. Linguistic, cultural and religious barriers to attending the screening were cited by the participants on several occasions.

Probably understandably for a transient expatriate community, whose members are expected to return home at the end of their contracts in the UAE, local and national health policies were deemed of high importance. The participants appreciate the free healthcare services provided by their adopted country. However, the lack of easily available and linguistically accessible information and culturally sensitive procedures limit their usefulness to them. Meanwhile, they expect their own local government to be more invested in their healthcare, especially as the main contributors to its gross domestic product (GDP).

All of the above clearly shows that the individual, interpersonal, communal, organisational, and policy determinants of screening mammography need to be seriously addressed if the informed uptake of screening mammography among the target population is to be increased.

## Chapter 8: Recommendations

This chapter first presents recommendations and then the scope of future studies and finally summarises these recommendations. These recommendations are largely based on concerns and suggestions expressed by the participants and my analysis of the factors that impeded the target participants from attending screening mammography and the possible opportunities in UAE to overcome it.

It is important to note that all determinants that emerge at the different levels of the socio-ecological model are interrelated. For example, the scarcity of awareness campaigns held by concerned organisations (organisational level) would lead to low levels of awareness of the issue among individuals (individual level) and would reduce the chances of a woman receiving such information and/or support and encouragement from her peers (interpersonal level). However, the community organisations (through community leaders/navigators) and both governments (Kerala and UAE) found to have a great influence to establish informed screening behaviour among the Keralite women in the UAE. Therefore the recommendations are presented under the broad umbrella of 'community organisations' and the 'governments'. The major recommendations under 'community organisation' and 'governments' were the following and this is discussed in detail latter in this chapter.

|  |   |
|--|---|
| <b>Community Organisation</b>          | Development of migrants health unit     |
|  | Community navigator/s                   |
| <b>Governments</b><br>(Kerala and UAE) | International health collaboration      |
|  | Development of migrant health directory |
|  | Risk assessment team                    |
|  | Automatic invitation system             |
|  | Development of referral system          |
|  | Development of migrant cancer registry  |
|  | Psychological support team              |

### 8.1 Community Organisations

Community organisations here include the Consulate General of India at UAE, the Indian associations (eg: Indian Association, Sharjah), worship centers, and Indian academic institutions in the UAE where Keralites found to be more connected in the UAE. Participants shared that they value the information shared among their community leaders and community members. Under these organisations, the participants used to have communal gatherings, and the members in it found to rely on each other. The success of cultural understanding (Pfeffer, 2004) involving community organisations was reported by multiple studies; for example, a study that was conducted in Washington, USA (Taylor et al., 1996), and another in Korea (Kim et al., 2011). Community based strategies found to be effective in progressing the screening behaviour in a relative short time (Parambil et al., 2019; Pasick, Hiatt, & Paskett, 2004). Therefore, I recommend possible measures as outlined below by involving community organisations such as developing migrant health units and appointing community navigator/s.



### 8.1.1 Development of migrants health unit

The development of a migrant health unit under each community organisations to gather data about the Kerala migrant's health, especially the female in this research context can lay the foundation to encourage informed uptake of a screening mammogram. The data of female expatriates in the migrant health unit can serve as a resource to develop female migrant health directory (see section 8.2.2) as well as to initiate an automatic invitation system (see section 8.2.4) and migrant cancer registry (see section 8.2.6) in the UAE. Thus migrant health units can help to organise and handle the target population in a systematic order while they are residents of UAE. However, an ethical practice should be adopted while collecting personal information of the expatriates.

### 8.1.2 Community navigators

The migrant health units should appoint community navigators. The appointment of the community navigators is to liaise between screening mammogram providers in the UAE, Pink Caravan, the health care authorities of UAE/ Kerala, the media of UAE, Kerala women breast cancer survivors and the Keralite communities in the UAE.

The distance decay effect plays a role here, which means the effect of distance or cultural or spatial interactions declines when the distance between the individual increases. The participants stated that their community leaders/members share the same or similar cultural background, and were connected to other community members as they were all away from their native place and their indigenous family members. Thus a community navigator would also be more able to target Keralite women and their families and develop culturally and religiously sensitive awareness campaigns to counter some of the deep-rooted misconceptions and encourage the uptake of screening mammography. Therefore, a community navigator, as per the findings, can serve as a creator of breast cancer early detection awareness and the conveyor of screening available in the UAE.

### *8.1.2.1 Creator of Awareness*

The participants' responses exposed how the levels of awareness and knowledge of breast cancer, the importance of early detection, and the benefits and risks of screening mammography and how it influences their social circles. Moreover, the participants highlighted several beliefs and cultural attitudes of their community that prevented them from attending a screening. Hence it was evident that awareness of this procedure and its benefits are crucial for the whole Keralite community residing in the UAE to overcome several barriers that hindered them from attending a screening.

The findings of this study show that it is crucial that the male head of the family plays a more active role and provides moral and practical support to his wife to enable her to attend screening mammography. Indians hold a patriarchal society and determine gender relations and imply inequality (Mahapatro, 2013). This is also true among Keralites (George, 2011). Furthermore, a major shift in the social practices noted due to migration, which resulted in women working and taking care of the home even at the expense of their health (Gardner A. M, 2011; John, 2017). Participants stated that it was difficult for them to take the time off from their families to undergo screening mammography. The participants also commented on their dependency on their husbands for transportation to reach the screening mammography venue. Moreover, they were not ready to sacrifice their families' peace and cause them to pay the emotional and financial price as a result of being positively diagnosed with breast cancer. Also, participants shared their belief that their husbands may feel tense if they knew that their wives had undergone or were intending to undergo screening mammography. This demonstrates that women and their husbands were not aware of the importance of early detection in reducing the emotional and financial cost their families may have to bear in the case of late detection. Therefore it is important to educate and raise awareness among the male members of the community about the issue.

#### *8.1.2.1.1 Potential resources to create awareness*

The trusted sources of information according to the participants were found to be health care professionals, media, educational institutions, breast cancer survivors, and their health insurance.

Health care professionals should actively promote the informed uptake of screening mammography during the clients' visits as medical professionals can influence the attitudes and beliefs of their clients and families (Akpınar, Baykan, Naçar, Gün, & Çetinkaya, 2011; Heena et al., 2019). In fact, the participants listen and trust advice from medical professionals especially from those from the same cultural background.

The findings of this study revealed a number of issues related to the form, mode, and means by which information about breast cancer and screening mammography availability relayed to them. It is evident that these problems seriously affected their decisions to undergo screening mammography. The governments, health providers, educational institutions can utilise traditional and social media to promote screening mammography and inform women of the location of testing facilities and the cost of the procedure. This would counter the women's cynicism towards unsourced media messages. This should be done promptly and in the languages of the target population, so it is easy for them to access the information. Thus the media can serve as a source to effectively inform women of the benefits of screening mammography, its availability in the UAE, and its cost.

In line with several studies (Alharbi, Alshammari, Almutairi, Makboul, & El-Shazly, 2012; Rahman et al., 2019; Sama et al., 2017) the participants stressed the role of educational institutions in creating awareness among them and other members of the community. Thus, it is worth considering actively involving academic institutions (here Indian schools, universities) in raising the awareness of the people they can reach. Also, they should train interested students to create awareness among their communities and peers.

In addition, breast cancer survivors should be involved in sharing their experience and the importance of early detection to enhance the value of an awareness campaign. The involvement of breast cancer survivors is recommended because the participants themselves shared that they became more aware and motivated to undergo a screening mammogram after hearing or learning about the experiences of breast cancer survivors.

To add, insurance companies should inform women, especially of the target age group, whether their policies cover screening mammography. This would enable the women and their husbands to consider the financial costs they may have to bear. This knowledge can reduce the stress the family might experience.

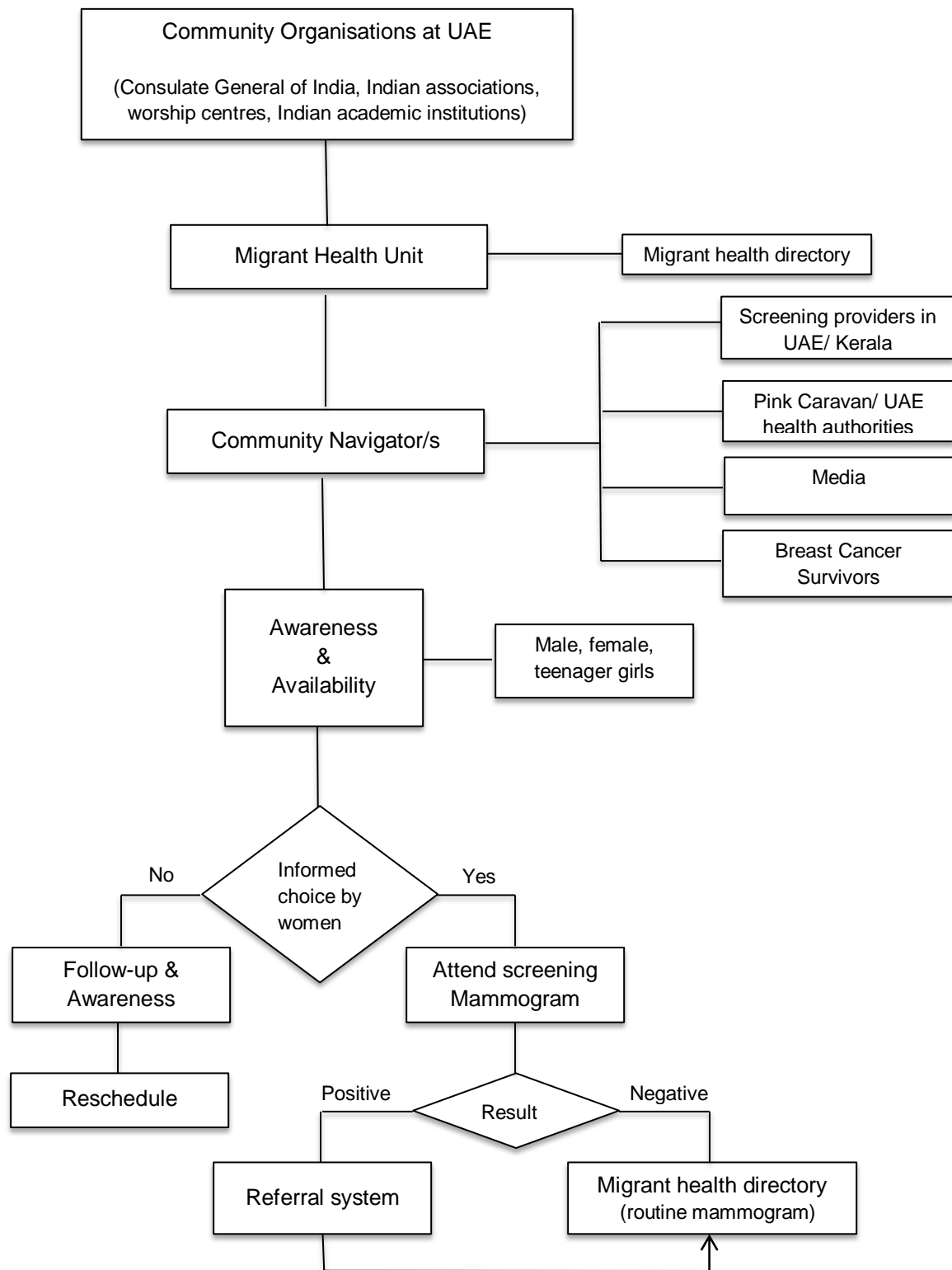
#### *8.1.2.2 Conveyor of the screening availability*

In the UAE, even though there are free breast cancer screening opportunities available to expatriates, the participants stated that they were not well aware of the services offered in the UAE. Surprisingly, none of the participants utilised available services in the UAE and they underwent screening along with their routine health check-ups when they traveled to Kerala. (Brzoska & Abdul-Rida, 2016; Suwankhong & Liamputtong, 2018) reported similar limitations of migrant women to undergo screening. For example, the availability of free screening initiatives like Pink Caravan, screening offers by medical providers was near to them but many women did not utilise it either because of the lack of information related to availability, time, or location the service was provided. Thus, it is evident that information about promotions and availability does not reach the Kerala community in an efficient and timely manner and it impeded participants from attending the readily available screening in the UAE. Moreover, participants stated that by chance if they see an advertisement they may not be immediately mentally and physically prepared to use the service.

Prompt communication by community organisations helps Kerala expatriates not to miss the opportunities to choose their convenient date and venue to undergo the procedure. Moreover, participants who underwent screening mammogram conveyed that they did it in Kerala during

their routine health check-up at their time of vacation to Kerala and they were not aware of the screening facilities available at UAE. Therefore, to improve early detection of breast cancer by expatriates, the screening providers in UAE/ Kerala can communicate with community organisations/ community navigators and can consider strategies to communicate effectively with the community members and can do follow up either for rescheduling or for treatment.

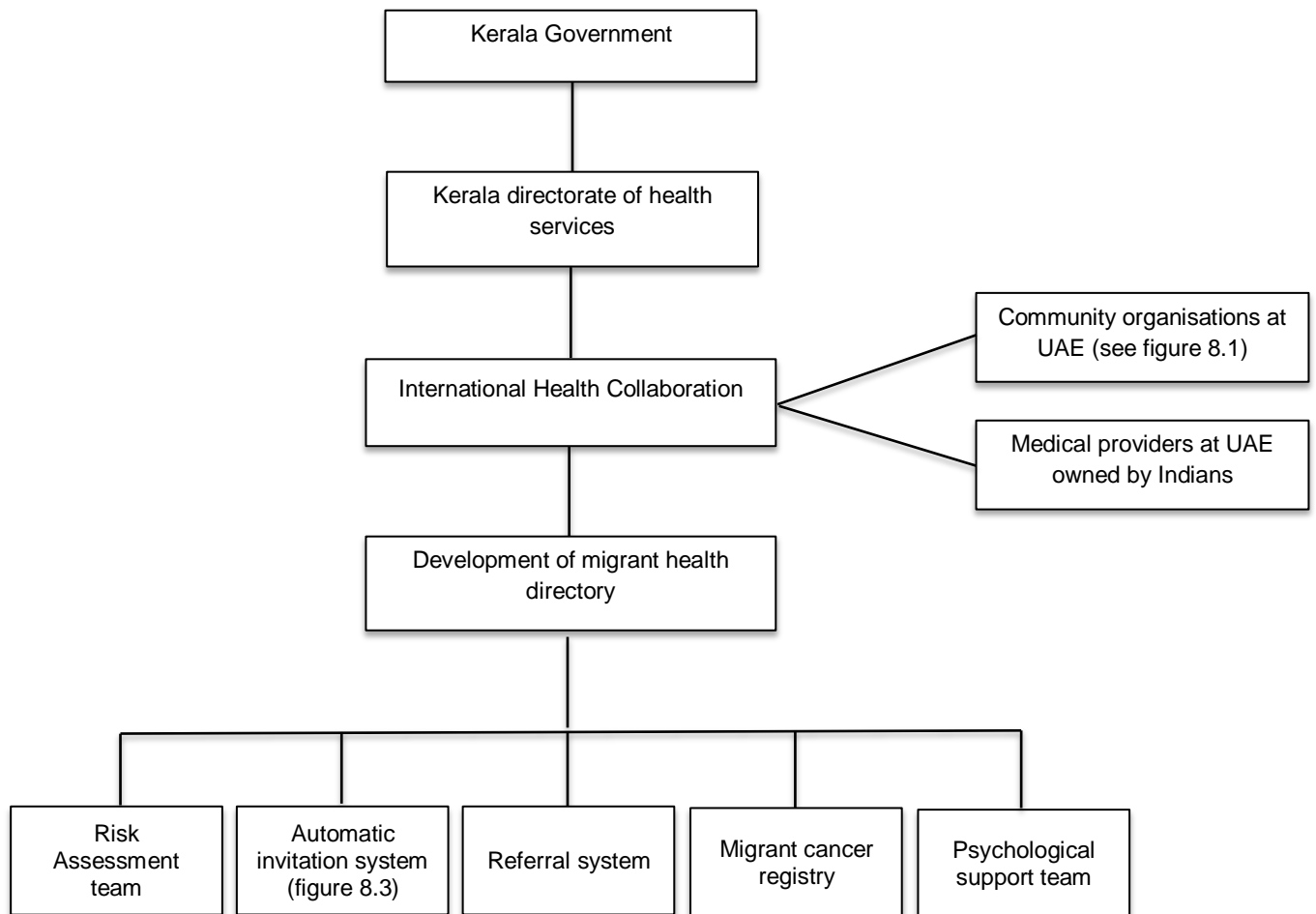
The following figure 8.1 summarises the recommendations to community organisations to enhance the informed uptake of screening mammograms by the Keralite community in the UAE.



**Figure 8. 1 Recommendations to community organisations to enhance the informed uptake of screening mammograms by the Keralite community in the UAE.**

## 8.2 Government

The contemporary trend in health behavioural change involves more than simply addressing and educating individuals' health practices. It includes efforts to change the external factors that are beyond the control of a single individual or a community. Unless countries change health care strategies, migrant's right to health care will not be enhanced (Gostin et al., 2019). The WHO global action plan ((Pant, Eder, Vračar, Mosca, & Orcutt, 2019)) and several studies (Chiarenza, Dauvrin, Chiesa, Baatout, & Verrept, 2019; Turner, 2019) states that expatriates face many challenges accessing healthcare services in a foreign country. Thus, I advocate the development of policies that support the behaviour change of an individual. Following figure 8.2 shows the overall facilities that need to be initiated by the Kerala government.



**Figure 8. 2 Facilities that need to be initiated by the Kerala government.**

### 8.2.1 International health collaboration

Government policies and regulations in an expatriate's home and adopted countries can result in positive changes in health behaviour. Therefore the governments of the Kerala and UAE should establish a collaborative approach to health care for Keralite migrants in the UAE.

The participants felt the remittances made by Keralites in the Gulf back home are high. This fact was also acknowledged in several studies (Irudaya Rajan, 2011, p. 303; Jones & Mielants, 2016, pp. 133-134; Shahul Hameed, Kutty, Vijayakumar, & Kamalasanan, 2013; Zachariah & Mathew, 1999). Therefore, the Kerala government should bear the responsibility for the health of their non-residents, including women in the labour camps. Many participants cited non-availability and non-access to health and screening mammogram services to the women residing in the labour camps.

To develop a collaboration the directorate of health services at Kerala can connect with the community organisations (see section 8.1) and medical providers owned by Indians in the UAE. Kerala governments' logistical support to these community organisations at UAE can lay a foundation for the collaboration. The (WHO, 2019) also states that to ensure migrant's health and wellbeing a coherent, joint multi-sectoral action in all public health policy is required. Although the participants appreciated the UAE's breast cancer related activities available to residents, they felt that more could be done by the Kerala government. Therefore, the Kerala directorate of health services should consider international health collaboration (connecting the medical services it provides with healthcare facilities based in the UAE), develop migrant health directory, risk assessment team, automatic invitation system, referral system, migrant cancer registry, and psychological support team for resident Keralites in the UAE.

### 8.2.2 Development of migrant health directory

I recommend the development of a UAE migrant health directory to serve as a central directory to collect the demographic and contact details of Keralite women in the UAE. This directory further can serve as a resource to initiate risk assessment and an automatic invitation system.



Again to a great extent, in collaboration with the government, the community organisations at UAE can support the development of migrant health directory.

### 8.2.3 Risk assessment team

Ongoing cancer risk assessment was found to be in demand and proved to be a useful tool that provides optimal management of breast cancer through early detection and treatment (Evans & Laloo, 2002). For example, a risk assessment team can determine the degree of risk of an individual developing cancer by evaluating the individual's family history of cancer and lifestyle risk factors such as the use of contraceptive pills, hormone replacement therapy (HRT), alcohol consumption, and weight, or any other (Alicja, Karol, Urszula, Julita, & Halina, 2018; Green, Dinh, & Smith, 2012; Modugno et al., 2006; Tazzite, Jouhadi, Saiss, Benider, & Nadifi, 2013). The participants expressed their concern related to cancer, many lifestyle diseases and general health after leaving their employment in the UAE and returning to Kerala. This causes the participants to experience serious stress while they are in the UAE at the same time, no idea what to do as well in the UAE. Thus, the risk assessment team can alert and guide Keralites at UAE to effectively undergo screening for early breast cancer detection. For example, they suggested that if an individual found to be at high risk (cancer among first-degree relatives) the risk assessment team can alert them to undergo screening.

### 8.2.4 Automatic invitation system

The participants conveyed that an automatic invitation system could initiate change in the cultural beliefs and health behaviours for the uptake of a screening mammogram. This helps to inform the target population when they reach the screening age. This will also help to overcome participants concern towards the availability, location of service along with the possibility to choose their convenient location and time either in UAE or in Kerala to undergo screening mammogram.

Participants also shared their concern towards the uncertainty for waiting for the results, so they ignored screening mammogram to not get stressed for a long period of time. So while

taking the appointment itself the expected date to obtain the result can be shared. Further, depending on the diagnosis the women can be directed accordingly either for routine follow up a screening or for treatment through a referral system.

The following figure 8.3 shows the recommendation for the development of the automatic invitation system

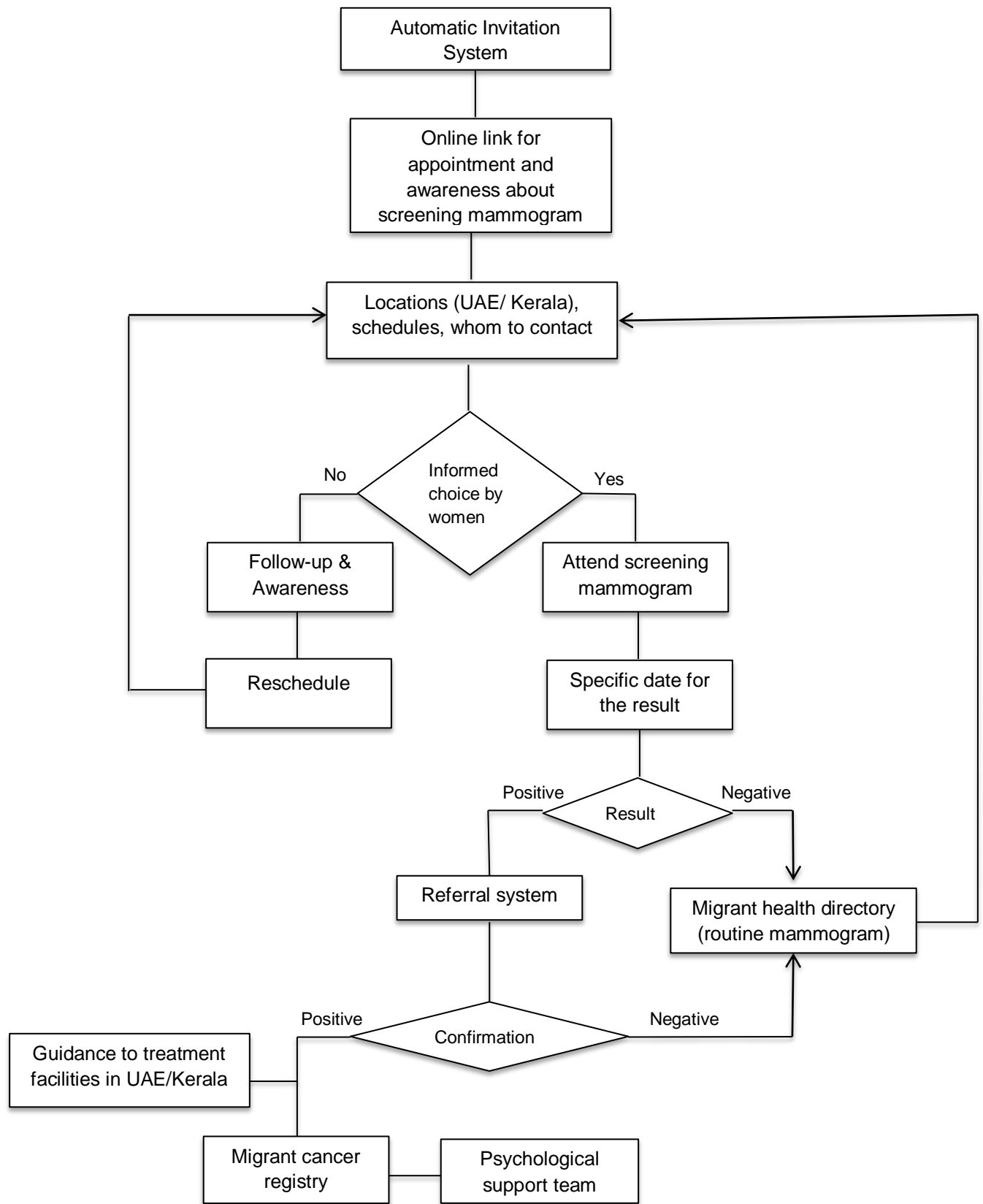


Figure 8. 3 Recommendation for automatic invitation system

### 8.2.5 Development of referral System

The findings of this research noted that women ignore screening mammography, as they are not confident in what they and their families should do if they are diagnosed with breast cancer. To counter this uncertainty, a referral system should be implemented to direct women with suspected changes in the screening mammogram or with a positive report of breast cancer. Thus the referral system can direct women for confirmation of result or for further treatment either in UAE or in Kerala. Further, the confirmed individuals can be added to the migrant cancer registry for further follow-up.

### 8.2.6 Development of migrant cancer registry

WHO also directs to have cancer registries and monitor the progress of countries in addressing the epidemic (WHO, 2018a). However, there is no dedicated cancer registry available to establish the extent of prevalence of breast cancer cases among Keralite women living in the UAE. The development of the cancer registry enables the health authorities to take appropriate action for treatment and psychological support.

### 8.2.7 Psychological support team

One important factor mentioned by the participants is the lack of psychological support for breast cancer patients. This is because when a person decides to have a screening mammography, they are concerned that their family members, especially their husband, may be under stress from the prospect of being diagnosed with breast cancer. Participants also discussed, albeit indirectly, their need for support from family and peers. The psychological support team would also enable the women to better deal with their worry about how they might be perceived by family members, peers if they underwent the procedure. Thus it would alleviate some of the stress related to attending the screening and the women's fears of a positive diagnosis.

### 8.3 Scope for further research

Further research is needed to increase the levels of awareness, importance of screening mammography and informed uptake of screening mammography and assessing the involvement of various socioecological determinants among Keralite women in the UAE.

The following studies are proposed:

1. The attitudes and beliefs of Keralite male family members, especially the husbands, towards screening mammography
2. A number of studies of the incidence rate of breast cancer among Keralites residing at UAE
3. Verification of the implementation of organised screening mammography in the UAE among Keralites
4. Studies of the importance of risk assessment team to identify breast cancer risk among Keralites including women in labour camps that resides in the UAE.
5. Studies of the effectiveness of providing psychological support team for breast cancer survivors
6. Studies on the effectiveness of community based interventions related to the early detection of breast cancer
7. Feasibility study to assess the effectiveness of assigning a community navigator for Keralites in the UAE in relation to receiving screening information and promoting awareness raising session
8. Studies to assess the levels of involvement of community organisations in promoting positive health practices such as attending screening mammography
9. Studies of the influence of media and breast cancer screening awareness in the UAE
10. Studies on the effectiveness of implementing automatic invitation system and automatic referral system at UAE for Keralites.

#### 8.4 Summary

This chapter presented the recommendations based on the findings of this study and an analysis of the factors that prevented the participants from utilising screening mammography and possible opportunities in UAE to improve the informed uptake of screening mammography among Keralites. Considering these recommendations into practice can help to initiate efficient screening and preventive healthcare options for Keralites in the UAE. The chapter also highlighted the responsibilities of the community organisations and both Kerala and UAE governments in developing initiatives towards the health of Kerala migrants in the UAE. Furthermore, the scope for further research also presented based on the findings and recommendations of the research.

## Chapter 9: Conclusion

The research explored the socio-ecological factors that influence the informed uptake of screening mammography among a sample of migrant Keralite women in the UAE. The participants of this study form a unique cultural group different from Emirati (UAE) nationals and other Keralites. Five focus group discussions comprised of two populations: Population 1: Keralite women residing in the UAE those who had undergone screening mammography and Population 2: Keralite women residing in the UAE those who had not undergone screening mammography were the participants. Qualitative research paradigm involving critical ethnography, exploratory research questions, relativism as ontology, interpretivism as epistemology used to achieve the objectives of the research. The thematic analysis for data analysis and the theoretical framework socio-ecological model of health used to present the findings. Moreover, no other studies addressing this particular group of females' cultural and personal perceptions of screening mammography have been identified to date. These gives importance to the findings and the recommendations of this research because the participants' cultural components and human experiences are important factors that need to be identified and analysed.

This study aimed at revealing the underlying reasons for participants' attendance or non-attendance for screening mammography and the most practical and efficient ways of increasing the rate of early detection of breast cancer among them. The study also explained the attitudes and health behaviours of the participants with regard to breast cancer screening. It also put forward a number of recommendations to increase the informed uptake of screening mammography including the requirements for having international collaboration and organised guidelines for breast cancer screening among Keralite migrant women in the UAE. Thus, this research deals with the unique situation of Keralite women residing in the UAE and the effects of a number of socio-ecological factors towards early detection of breast cancer screening.

Furthermore, the findings of the study established that multiple layers in the socio-ecological model of health were interrelated. A significant finding is that the level of the awareness and knowledge of the participants, and their spouses, of breast cancer, the advantages of early detection of the condition and the benefits of screening mammography has an enormous impact on their willingness to attending the procedure. It is evident that extensive awareness of the issue is required by Keralite women, their families and policy makers to counter the socio-ecological determinants that impede their uptake of screening mammography and change their health and breast cancer screening behaviour. It was shown here that awareness of the importance of early detection of breast cancer and its positive impact on the survival and recovery of patients, the importance of screening mammography, and the availability of screening mammography and treatment options if diagnosed are major factors that need to be addressed.

Another important finding was that the initiation of organised screening mammography can overcome the participants' cultural barriers, concerns, perceptions, and beliefs towards screening mammography as it will be considered as a routine health check-up procedure. The study presents some evidence that both Kerala and UAE governments can play a significant role in promoting the uptake of screening mammography. It is also important to note the participants' suggestion that the governments to establish an automatic invitation system to inform women at the target age that they need to undergo screening mammography. Based on these findings, I also recommend that the local health care system should implement an automatic referral system through which women at the risk age are automatically referred to screening during regular check-ups, or for further treatment options if diagnosed.

A further important finding is that initiatives, such as Pink Caravan, which offer free or reduced screening mammography cannot be effective in the absence of adequate promotion in the language of the target populations and in a mode that is culturally sensitive. Another determinate to the success of these initiative is logistical. If the women are unable to attend these mobile clinics due to their inconvenient location and/or operating times, they are highly underused, which defeats the purpose of offering this free service. The success of such



initiatives is also negatively impacted by lack of awareness of the importance of screening mammography on the part of the target recipients. Therefore, this study concluded that these initiatives need to be managed and promoted more effectively.

Moreover, it was found that the participants were highly sensitive to the views and attitudes of their family members, peers and members of their community. In addition, they placed a significant amount of trust in the advice and statements of government officials and entities, professionals and educators. In contrast, they mistrusted the media, especially when it broadcast unsourced messages. These attitudes can be exploited in a positive manner to more effectively to promote the informed uptake of screening mammography.

Finally the research summarised recommendations under the umbrella of 'community organisations' and 'governments'. The recommendations conveyed the development of migrants health unit, need of community navigator/s, development of international health collaboration, migrant health directory, risk assessment team, automatic invitation system, referral system, migrant cancer registry and psychological support team. Finally the research highlighted the need and importance to have future research among Kerala migrants in the UAE.

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## Appendixes

### Appendix A Research Output

| SI No | Date         | Event  | Location   | Audience  |
|-------|--------------|--|--|---|
| 1     | 14.10.2019   | Women Health Day   | University of Sharjah                                  | Faculty, staff, students  |
| 2     | 30.10.2019   | The Pink Run   | Fujairah hospital-<br>Breast care unit<br><br>Fujairah | Teachers and students from technical college and Madhab<br><br>Secondary school |
| 3     | 18.11.2019   | Breast cancer early detection  | Social service centre, Maliha                          | Public (Emirati women), Alumni students were involved                           |
| 4     | 06.07.2018   | Emotional Intelligence: using personal bereavement to increase breast cancer awareness | University of Salford, UK                              | Faculty, Staff and public   |
| 5     | 22- 10- 2018 | Think: Breast Cancer Awareness Program   | Leaders Private School, Sharjah                        | High school students, teachers, staff, parents                                  |
| 6     | 24.10.2018   | Breast Cancer Awareness  | Television (NTv)                                       | Public  |
| 7     | 02.10.2017   | Breast Cancer: Early detection   | Sharjah-Community centre                               | Pravasi Sree – Abushagara Unit  |
| 8     | 26.10.2017   | Think Pink- Awareness Session  | Engineering Company, Sharjah                           | CH2MHILL employees  |
| 9     | 28.10.2017   | Let's celebrate Pink, A Breast Cancer Awareness Campaign                               | Community centre, Ajman                                | Chill out event management members  |

|    |            |                                |  |  |
|----|------------|--------------------------------|--|--|
| 10 | 29.10.2017 | Breast Cancer Awareness        | Gulf Asian English School, Sharjah                                   | High school students, teachers, staff, parents     |
| 11 | 31.10.2017 | Breast Cancer Awareness 2018   | University of Sharjah in coordination with Zulekha hospital, Sharjah | Faculties, students, Physicians (Zulekha hospital) |
| 12 | 02.11.2017 | Early detection: Breast Cancer | Leads Education Centre, Pravasi Sree Unit, Sharjah                   | Kerala community members                           |
| 13 | 24.11.2017 | Celebrate the women hood       | CSI Worship Centre, Sharjah  | Church members, other Kerala community members     |

## Appendix B Focus group discussion Population 1



### **Focus group interview guide: for women who have undergone screening mammography.**

#### **Research Title:**

A critical exploration of perceptions and uptake of screening mammography in Kerala women residing in United Arab Emirates for the early detection of breast cancer.

#### **Introduction:**

Welcome and thank you for agreeing to take part in the study. I am working on a project to explore the perception and uptake of mammography by Kerala women in United Arab Emirates. This project is part of my research studies at the University of Salford, UK.

My supervisors are Dr. Leslie Robinson a prominent academician and researcher in the field of breast cancer screening, Dr. Lucy Walton my co-supervisor, a prominent researcher and Dr. Mohamed Abuzaid, Assistant professor from University of Sharjah

In this meeting, I would like to explore:

- a) Your awareness of mammography for breast cancer screening
- b) The people who have an influence on your decisions about your health and made you undergo mammography
- c) Your experiences of undergoing screening mammography in the UAE or in Kerala
- d) The facilitating factors made you undergo mammography
- e) Whether you have faced any barriers for screening mammography here in the UAE or in Kerala
- f) Your expectations from the Kerala government, and breast cancer screening organisations for supporting Kerala women to undergo breast cancer screening mammography



- g) Ways in which you might be made better aware of breast cancer screening mammogram availability in UAE and Kerala.
- h) How you would prefer to be reminded to undergo mammography.

**Information I will need if you agree to take part:**

You will need to sign a consent form. When you sign this consent form, you are agreeing to take part in this research. You should know that your voice would be recorded during the discussion. I will store this discussion in a password-protected computer in my office and analyse our discussion. However, your name will not be disclosed in any publications that might come from the study. I may note down some points if I feel so. I will collect basic information about your details such as your age, educational qualification, district in which you live in Kerala, how long you have lived in the UAE, marital status, whether you have a family history of cancer and your job because these details may help me make sense of the discussions. However, your name will not need to be disclosed.

**Polite instructions:**

- You can give multiple answers in Malayalam
- You can talk freely regarding the topic of discussion; no one is evaluating you but just collecting the information about your experiences and opinions
- In order for everyone to be heard, please make sure that one person talks at a time.
- Please remember to keep our discussions confidential; this respects the privacy of everyone taking part.
- Kindly turn your mobile to silent mode.
- It will be better if you remain in the room for the whole time of our discussion however, you will be free to leave at any time.
- If you have any queries please ask me.

**Let us discuss:**

**A Health Behaviour and awareness about breast cancer and its risk factors**

- 1 Who will take decisions about your health? Can you explain your answer?
- 2 What do you know about breast cancer?
- 3 Can you tell me what you know about the early detection of breast cancer?
- 4 Do you know what causes breast cancer and whether it can be avoided?
- 5 Do you know anyone from Kerala who has been diagnosed with breast cancer in the UAE or Kerala after being NRK?

**B Awareness about the importance of breast cancer screening & Mammogram**

- 1 What do you know about breast cancer screening?
- 2 Is breast cancer screening important? Can you explain your answer?
- 3 What are the ways breast cancers can be detected earlier?
- 4 What do you know about mammograms?
- 5 When do you think a woman should have a mamography? (age)
- 6 Do you think it should be repeated? If so at what age and how often?

**C Awareness about breast cancer screening services in UAE and Kerala.**

- 1 What do you know about breast cancer screening services in your Emirate?
- 2 What do you know about the breast cancer screening services in Kerala/ in your locality in Kerala?

**D Facilitating factors you could avail for undergoing a mammogram**

- 1 Where did you undergo a mammogram: UAE/ Kerala? Why and When
- 2 Who/what, made you aware of the need to undergo a mammogram? (any educational material, TV ads)
- 3 What services could you avail (free mammogram/ discount?)
- 4 How did you know about the availability of mammography in your own location
- 5 Do you think the way you got to know about the availability of mammography

was reliable? Is this the best way to communicate with Keralite women about the availability of mammography?

6 What other ways can you suggest the availability of mammography can be made known to Kerala women

7 What changes do you suggest to improve screening mammography among NRK?

**E Barriers after taking the decision to undergo a mammogram**

1 Can you tell me whether you have encountered any hindrance when you took the decision to undergo mammography? If so how you solved it.

2 Who/what can facilitate to reduce these barriers?

**F Key influencers to promote screening mammogram**

1 Who took the decision for you to undergo mammography

2 Who can take decisions or encourage you to undergo screening mammography

**G Suggestions to improve the uptake of mammography by our Kerala government and UAE breast cancer screening organisations**

1 What do you think about the Kerala government's role to promote breast cancer screening among Non- resident Kerala women?

2 What facilities or strategies do you further expect in terms of breast cancer screening mammography from Kerala government and breast cancer screening organisations in Kerala?

3 What facilities or strategies do you expect in terms of breast cancer screening mammography from UAE breast cancer screening organisations?

4 What will be the best way of communicating the availability of breast cancer screening services and mammography in UAE and Kerala?

5 Do you like to be notified yearly or biennially according to your age? If so, which will be the best way of sending reminders to undergo mammography?

Thank you for your participation, I really value all your comments and points. These findings may be used to propose recommendations to the Kerala government and UAE breast cancer screening organisations to improve breast cancer screening and mammography opportunities for women living in the UAE.

Please feel free to share or discuss if you would like to add more than what we have discussed now. If you have any anxiety regarding your input in this study, kindly contact “Local supervisor contact details”.

Further, if you are interested to know the research findings, this report may be disseminated in the form of publication or part of my doctoral thesis and even it can be discussed with you after finishing this research.

\*\*\*\*\*

## Appendix A Focus group discussion Population 2



### Focus group interview guide: women who do not undergo screening mammography.

#### **Research Title:**

A critical exploration of perceptions and uptake of screening mammography in Kerala women residing in United Arab Emirates for the early detection of breast cancer.

#### **Introduction:**

Welcome and thank you for agreeing to take part in the study. I am working on a project to explore the perception and uptake of mammography by Kerala women in United Arab Emirates. This project is part of my research studies at the University of Salford, UK.

My supervisors are Dr. Leslie Robinson a prominent academician and researcher in the field of breast cancer screening, Dr. Lucy Walton my co-supervisor, a prominent researcher and Dr. Mohamed Abuzaid, Assistant professor from University of Sharjah.

In this meeting, I would like to explore:

- i) Your awareness of mammography for breast cancer screening
- j) The reason for you for not having a mammogram
- k) The facilitating factors for you to undergo mammography
- l) The people who have an influence on your decisions about your health and whether you should have breast screening or not
- m) Barriers to access screening mammography here in the UAE or in Kerala
- n) Your expectations from the Kerala government, and breast cancer screening organisations for supporting Kerala women to undergo breast cancer screening mammography

- o) Ways in which you might be made better aware of breast cancer screening mammogram availability in UAE and Kerala.
- p) How you would prefer to be reminded to undergo mammography once you are 40 years and above.

**Information I will need if you agree to take part:**

You will need to sign a consent form. When you sign this consent form, you are agreeing to take part in this research. You should know that your voice would be recorded during the discussion. I will store this discussion in a password-protected computer in my office and analyse our discussion. However, your name will not be disclosed in any publications that might come from the study. I may note down some points if I feel so. I will collect basic information about your details such as your age, educational qualification, district in which you live in Kerala, how long you have lived in the UAE, marital status, whether you have a family history of cancer and your job because these details may help me make sense of the discussions. However, your name will not need to be disclosed.

**Polite instructions:**

- You can give multiple answers in Malayalam
- You can talk freely regarding the topic of discussion; no one is evaluating you but just collecting the information about your experiences and opinions
- In order for everyone to be heard, please make sure that one person talks at a time.
- Please remember to keep our discussions confidential, this respects the privacy of everyone taking part.
- Kindly turn your mobile to silent mode.
- It will be better if you remain in the room for the whole time of our discussion however, you will be free to leave at any time.
- If you have any queries please ask me.

**Let us discuss:**

|          |  |
|----------|--|
| <b>A</b> | <b>Health behaviour and awareness about breast cancer and its risk factors</b>                                 |
| 1        | Who will take decisions about your health? Can you explain your answer?  |
| 2        | What do you know about breast cancer?  |
| 3        | Do you know what causes breast cancer and whether it can be avoided?   |
| 4        | Do you know anyone from Kerala who has been diagnosed with breast cancer in the UAE or Kerala after being NRK? |

|          |  |
|----------|--|
| <b>B</b> | <b>Awareness about the importance of breast cancer screening &amp; Mammogram</b> |
| 1        | What do you know about breast cancer screening?                                  |
| 2        | Is breast cancer screening important? Can you explain your answer?               |
| 3        | What are the ways breast cancers can be detected earlier?                        |
| 4        | What do you know about mammograms?   |
| 5        | How is a mammogram performed?  |
| 6        | When do you think women should have mammography? (age)                           |

|          |  |
|----------|--|
| <b>C</b> | <b>Awareness about breast cancer screening services in UAE and Kerala.</b>                           |
| 1        | What do you know about breast cancer screening services in your Emirate?                             |
| 2        | What do you know about the breast cancer screening services in Kerala or in your locality in Kerala? |

|          |   |
|----------|---|
| <b>D</b> | <b>Barriers to undergoing Mammogram</b>   |
| 1        | Can you tell me the reasons why you have not had a mammogram?                   |
| 2        | Who and what can facilitate to reduce these barriers?                           |
| 3        | Where do you prefer to undergo a mammogram in the UAE or in Kerala? Why?        |
| 4        | What facilities will encourage you to undergo mammogram in the UAE or in Kerala |

|          |   |
|----------|---|
| <b>E</b> | <b>Key influencers to promote screening mammogram</b>   |
| 1        | Is there anyone in your life who takes decisions for you about whether you can undergo a mammogram or not |
| 2        | Who can influence you to undergo screening mammography  |

|          |   |
|----------|---|
| <b>F</b> | <b>Suggestions to improve the uptake of mammography by our Kerala government and UAE breast cancer screening organisations</b>  |
| 1        | What do you think about the Kerala government's role to promote breast cancer screening among Non- resident Kerala women?   |
| 2        | What facilities or strategies do you expect in terms of breast cancer screening mammography from Kerala government and breast cancer screening organisations in Kerala? |
| 3        | What facilities or strategies do you expect in terms of breast cancer screening mammography from UAE breast cancer screening organisations?                             |
| 4        | What will be the best way of communicating the availability of breast cancer screening services and mammography in UAE and Kerala?                                      |
| 5        | Do you like to be notified yearly or biennially according to your age? If so, which will be the best way of sending reminders to undergo mammography?                   |



Thank you for your participation, I really value all your comments and points. These findings may be used to propose recommendations to the Kerala government and UAE breast cancer screening organisations to improve breast cancer screening and mammography opportunities for women living in the UAE.

Please feel free to share or discuss if you would like to add more than what we have discussed now. If you have any anxiety regarding your input in this study, kindly contact “Local supervisor contact details”.

Further, if you are interested to know the research findings, this report may be disseminated in the form of publication or part of my doctoral thesis and even it can be discussed with you after finishing this research.

\*\*\*\*\*

## Appendix B University of Salford ethical approval letter



Research, Innovation and Academic  
Engagement Ethical Approval Panel

Research Centres Support Team  
G0.3 Joule House  
University of Salford  
M5 4WT

T +44(0)161 295 2280

[www.salford.ac.uk/](http://www.salford.ac.uk/)

20 June 2017

Dear Leena,

**RE: ETHICS APPLICATION–HSR1617-88–‘A critical exploration of perceptions and uptake of screening mammography in Kerala women residing in United Arab Emirates for the early detection of breast cancer.’**

Based on the information you provided I am pleased to inform you that application HSR1617-88 has been approved.

If there are any changes to the project and/or its methodology, then please inform the Panel as soon as possible by contacting [Health-ResearchEthics@salford.ac.uk](mailto:Health-ResearchEthics@salford.ac.uk)

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Sue McAndrew'.

Sue McAndrew  
Chair of the Research Ethics Panel

## Appendix E University of Sharjah ethical approval letter

Office of Vice Chancellor for  
Research & Graduate Studies  
Research Ethics Committee



مكتب نائب مدير الجامعة لشؤون  
البحث العلمي والدراسات العليا  
لجنة أخلاقيات البحث العلمي

- **Date:** 17 / 10 / 2017
- **Reference number:** REC-17-09-18-01-S
- **Title of the research:**  
A critical exploration of perceptions and uptake of screening mammography in Kerala women residing in the United Arab Emirates for the early detection of breast cancer
- **Name of the principle investigator:** Ms. Leena R David

Dear Ms. Leena,

The Research Ethics Committee has reviewed the above application, and has voted in favor of approving it from an ethical perspective.

Kindly note that this approval is based on the conditions that,

1. the research is executed according to the research protocol described in the application form, and/or its subsequent modifications, if those modifications were requested by the Research Ethics Committee
2. the information sheet and/or informed consent are those approved by the Research Ethics Committee
3. the research tools are those approved by the Research Ethics Committee

Please note that it is your responsibility, as the principle investigator, to immediately inform the Committee of any changes in the research protocol and/or the research methodologies, should the need for those changes arise prior to or during the conduct of this research study.

On behalf of the Research Ethics Committee, I wish you and your team success in your research project.

Sincerely,

**Dr. Suhail Al-Amad**  
Chair, Research Ethics Committee  
University of Sharjah

## Appendix F Invitation letter to Pastors in the church

**University of Salford**  
**MANCHESTER**

The Crescent,  
Salford, M5 4WT,  
United Kingdom  
0161 295 5000  
www.salford.ac.uk

[?]

Dear Pastor, [?]

[?]

I am a Doctoral student at University of Salford, UK. I am doing a research project titled 'A critical exploration of perceptions and uptake of screening mammography in Kerala women residing in United Arab Emirates for the early detection of breast cancer'.

You have been contacted because most of your women church members are from Kerala. This study aims to find out the barriers and facilitating factors for the uptake of mammography for early detection of breast cancer by Kerala women residing in UAE for 2 years or more. I would also like to understand their views about how various organisations in both the UAE and Kerala can support the non-resident Kerala women to undergo breast-screening mammography.

I would like to do a group discussion with non-resident Kerala women from your church. For this, I need women of 24 years and above who may or may not have undergone mammography in UAE or in Kerala during their visit to Kerala. They will be asked to share their experiences, and problems that they may have faced accessing mammography. The findings may be in future, be conveyed to the officials in Kerala and UAE who are concerned with providing support to our women in undergoing screening mammography.

Women agreeing to take part in this research will be invited to attend a meeting with a group of other women from a similar background in this worship centre or in the nearby Kerala community centre. The meeting will be conducted at their convenience at a time between 8.00am to 4.30pm. I will ask a few questions to encourage them to share their experiences and views. Their voices will be recorded without including their name or any other personal details.

It would be a great help if you could give me 5-10 minutes to share the aim of this research during any of your worship day if possible. Alternatively, could you kindly convey this message to them and encourage the women to take part? Further, if the women would like to attend this worship centre for the focus group discussion please would you allow this and provide a place for one and half-hours after the worship or any other convenient time.

[?]

If you have any queries you or the women can contact me through 0505175653 or david@sharjah.ac.ae

I have included the detailed participant information sheet for your kind perusal. I can assure you that the information your church members provide will be kept confidential. Neither your nor your organisation's name will be disclosed while disseminating the data collected through this study unless you agree to this.

[?]

Thank you for your time and understanding. I look forward to hearing from you soon.

[?]

Yours sincerely, [?]

[?]

Leena R David  
University of Salford

VERSION 2.0 (28.04.2017) [?]



## Appendix G Invitation letter to community leader



University of  
**Salford**  
MANCHESTER

The Crescent,  
Salford, M5 4WT,  
United Kingdom

0161 295 5000  
www.salford.ac.uk

Dear Sir/Madam,

I am a Doctoral student at University of Salford, UK. I am doing a research project titled 'A critical exploration of perceptions and uptake of screening mammography in Kerala women residing in United Arab Emirates for the early detection of breast cancer'.

You have been contacted because the Kerala community association you are heading includes women from Kerala. This study aims to find out the barriers and facilitating factors for the uptake of mammography for early detection of breast cancer by Kerala women residing in UAE for 2 years or more. I would also like to understand their views about how various organisations in both the UAE and Kerala can support the non-resident Kerala women to undergo breast-screening mammography.

I would like to do a group discussion with non-resident Kerala women from your community. For this, I need women of 40 years and above who may or may not have undergone mammography in UAE or in Kerala during their visit to Kerala. They will be asked to share their experiences, and problems that they may have faced accessing mammography. The findings may be in future, be conveyed to the officials in Kerala and UAE who are concerned with providing support to our women in undergoing screening mammography.

Women agreeing to take part in this research will be invited to attend a meeting with a group of other women from a similar background in this community centre or in the worship centre. The meeting will be conducted at their convenience at a time between 8.00am to 4.30pm. I will ask a few questions to encourage them to share their experiences and views. Their voices will be recorded without including their name or any other personal details.

It would be a great help if you could give me 5-10 minutes to share the aim of this research during any of your events if possible. Alternatively, could you kindly convey this message to them and encourage the women to take part? Further, if the women would like to attend this community centre for the focus group discussion please would you allow this and provide a place for one and half-hours after your event or any other convenient time.

If you have any queries you or the women can contact me through 0505175653 or [ldavid@sharjah.ac.ae](mailto:ldavid@sharjah.ac.ae)

I have included the detailed participant information sheet for your kind perusal. I can assure you that the information your community members provide will be kept confidential. Neither your or your organisation's name will be disclosed while disseminating the data collected through this study unless you agree to this.

Thank you for your time and understanding.

I look forward to hearing from you soon.

Yours sincerely,

Leena R David  
University of Salford

## Appendix H Participant Information Sheet

### **Participant Information Sheet – For Focus group interview- Women**

#### **Study Title**

A critical exploration of perceptions and uptake of screening mammography in Kerala women residing in United Arab Emirates for the early detection of breast cancer.

#### **Invitation paragraph**

I would like to invite you to take part in this research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear, or you would like more information. Take time to decide whether you are willing to take part.

#### **What is the purpose of the study?**

Across the world, there has been a lot of research undertaken to understand breast-screening practices among different regions and communities. In India, breast cancer causes the most deaths in women due to cancer. The Kerala Government also reported that breast cancer is of the most common cancer among Kerala women. Kerala women are often being diagnosed with breast cancer too late: they are discovered at the advanced stage of the disease, where the treatment becomes less effective. Thus, the incidence of breast cancer in Kerala is going up and effective early detection strategies need to be in place for Kerala women. 30% of the United Arab Emirates (UAE) population are Indians and it is the largest expatriate community in the UAE; the majority are from Kerala. The Kerala Government and service groups in UAE have adopted various measures for the early detection of breast cancer through mammography (an x-ray examination of the breast). However, an analysis of the effectiveness, perception and uptake of mammography is required especially among non-resident Keralites to develop effective policies and programs, which make the resources in Kerala and UAE accessible to all women to reduce the loss of life through breast cancer.

Therefore, this study will aim to explore the perceptions, barriers and facilitators for breast

screening for non-resident Kerala women living in the UAE. These findings will be used to propose recommendations to the Kerala Government to improve the breast cancer screening opportunities for women living in the UAE. Further, this can be shared with the breast cancer screening organisations in UAE to extend their services to Kerala women too.

### **Why have you been invited?**

You have been invited to take part in this research because you are from Kerala and residing in UAE for 2 years and above. If you have undergone screening mammography, we would like you to share your experiences, motivating factors, and further expectations from the UAE or Kerala Government in promoting screening mammography among non-resident Keralites. However, if you have not undergone mammography, we would like you to share your reasons, the possible barriers to accessing mammography, and your expectations from the government and breast cancer screening organisations in UAE and in Kerala. Finally, all the information you share will be collated into a report to give suggestions to the government and breast cancer screening organisations in Kerala and UAE. This report may be disseminated in the form of publication or part of my doctoral thesis.

### **Do you have to take part?**

Participating in this research study and focus group interview is voluntary. If you volunteer to participate in this research, you have the right to withdraw at any time and you need not give any reason for withdrawal. Your decision not to participate in the study will not affect you in any means. The researcher will also have the right to stop the research or your participation at any time without your permission.

### **What will happen to you if you take part?**

You will be invited to take part in the focus group interview, which is similar to a group discussion. You do not need to visit a clinic or any doctor to participate in this research. The discussion venue will be in the “Worship centre” or in a community centre according to your and other participant’s convenience. We expect to have 5 to 6 participants (including yourself)

for the discussion. During the discussion, everyone's voice will be recorded and later it will be translated into English for analysis and documentation. It may take around 45 minutes to 1 hour and you only have to participate once in the discussion.

### **Expenses and payments?**

There will be no gifts, vouchers, monetary or travel benefits available for you.

### **What will you have to do?**

I will collect basic information about your age, educational qualifications, district in which you live in Kerala, how long you have lived in the UAE, marital status, whether you have a family history of cancer and your job because these details may help me to make sense of the discussions. However, your name will not need to be disclosed.

Before the discussion begins, you will be asked to sign an informed consent form to document your agreement for participation. The seats will be arranged in a circular fashion and you can occupy one of the chairs. I will be present there to ask questions and record your voice during the meeting. You just have to speak freely about your experience, views, and suggestions to increase the uptake of mammography by non- resident Kerala women when they are in UAE or during their visit to Kerala. Your name will not be recorded during the discussion as well as all the information you share will be kept confidential and it will be analysed without mentioning your name. As this will be a confidential discussion, we will ask you keep everything you hear within the discussion confidential and do not share it outside the group.

### **What are the possible disadvantages and risks of taking part?**

As a participant, there is no risk involved in this study. Information you provide will be conveyed without mentioning any of your personal details in the form of publications or during a research audit. I will not ask any personal questions to you which you cannot answer in the group. However, if you are anxious about anything that is raised in the discussion you can contact any of the sources of support stated below.



**What are the possible benefits of taking part?**

We cannot promise the study will help you directly, but the information collected from you will help to provide an understanding of the facilitating factors, and barriers you are facing in UAE and Kerala to undergo mammography. The study findings may attract the Kerala Government or breast cancer screening organisations in Kerala and UAE to come up with strategies or policies that may support Kerala women residing in UAE. This may also enable increase in the participation of women for mammography and therefore reduce breast cancer mortality due to delayed detection.

**What if there is a problem?**

If you have a concern about any aspect of this study, you can contact any of the following person/s

and they will do their best to answer your questions.

Dr. Jo Cresswell

Associate Director for Research

G-08, Joule House,

Acton Square,

University of Salford,

Salford, M5 4WT.

Email: J.E.Cresswell@salford.ac.uk

Telephone: +44(0)161 295 6355

**Will your taking part in the study be kept confidential?**

Your demographic details and experiences of mammography will be recorded. However, these details, the consent form you sign and your comments will be kept confidential by the Principle Investigator (PI) of this research. Data will be stored in a password-protected computer or a shared drive. The meeting discussion will be accessed by the researchers within the team, supervisors and if required by the regulatory authorities. The informed consent and data will be stored for a minimum of 3 years by PI in the PIs office.

**What will happen if you don't carry on with the study?**

You have the right to withdraw at any time from the study. However, the data collected up to your withdrawal will be used without highlighting your name or other personal details.

**What will happen to the results of the research study?**

The data gathered from you will be reported and published. Your details will not be made identifiable to anyone unless you consent for it. If you are further interested to know the research findings, the thesis will be available in the University of Salford Institutional Research Repository and publications will be available through the research search engines.

**Who is organising or sponsoring the research?**

None

**Further information and contact details:**

Postgraduate Researcher

a) Name: Leena R David

Lecturer, Dept. of Medical Diagnostic Imaging

College of Health Sciences,

University of Sharjah, UAE

Contact Numbers: 0505175653, 065057580

## Appendix I Research Participant Consent Form

**Title of Project:** A critical exploration of perceptions and uptake of screening mammography in Kerala women residing in United Arab Emirates for the early detection of breast cancer.

**RGEC Ref No:** HSR1617-88, REC 17-09-18-01-S

**Name of Researcher:** Leena R David

*(Delete as appropriate)*

- I confirm that I have read and understood the information sheet for the above study (version 2- 28.04.2017) and what my contribution will be. 

|     |    |
|-----|----|
| Yes | No |
|-----|----|
  
- I have been given the opportunity to ask questions (face to face, via telephone and e-mail) 

|     |    |
|-----|----|
| Yes | No |
|-----|----|
  
- I agree to take part in the focus group interview 

|     |    |
|-----|----|
| Yes | No |
|-----|----|
  
- I agree to the interview being tape recorded 

|     |    |
|-----|----|
| Yes | No |
|-----|----|
  
- I agree to you keeping the recorded discussion in your password protected computer 

|     |    |
|-----|----|
| Yes | No |
|-----|----|
  
- I understand that my participation is voluntary and that I can withdraw from the research at any time **without giving any reason**

|     |    |
|-----|----|
| Yes | No |
|-----|----|
  
- I agree to take part in the above study 

|     |    |
|-----|----|
| Yes | No |
|-----|----|

Name of the participant .....

Signature .....

Date .....

Name of researcher taking consent      Leena R David

Researchers e-mail address                l david@sharjah.ac.ae

## Appendix J Transcript Focus Group Discussion 1

### FGD-1 Women undergone (Community centre Ajman )

| Identification | Participant statements  |
|----------------|---|
| 1.             | Researcher: Thank you for your time and I value your support and time you shared to me. As I said in the introduction, I would like to ask a few questions related to breast cancer, mammogram, further would like to know what are the factors motivated you to undergo a mammogram and so on. Ok, shall we start? |
| 2.             | Researcher: Who will make decisions about your health? Is it you yourselves, your husband or anyone else in the family? Why?  |
| 3.             | P1. In most of the cases, I am taking decision myself even to undergo mammogram.  |
| 4.             | P2. If I must be healthy, I must take care of my own health; however, will inform my husband before I go anywhere.  |
| 5.             | P3. I will take the decision, but usually, I tell my family, husband then, now every day we have communication through WhatsApp or phone with my mother, sister in Kerala. So usually will tell everything even before going for check-ups.   |
| 6.             | P4. Yeah, myself. My husband usually won't get time to discuss. But he will be ok with my decisions.  |
| 7.             | P5. Yes, for me husband or children must take me wherever I want to go. If I feel unwell then I will inform them.   |
| 8.             | Researcher: you mean if you feel any sickness in your body then you take decisions yourselves, right?   |
| 9.             | P1. I must take care of my health then only I can remain good.  |

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| 10. | P2. Yes, usually if I feel something wrong, I alone go to the hospital and consult the doctor.  |
| 11. | P5. In my case, it is totally opposite. I will try to tolerate the maximum if it is unbearable my husband or my children should compel me to go to the hospital and they will take me to the hospital. If they force me then only, I used to go to the hospital. If they came to know that my pressure is high, soon they will ask why you did not go to the hospital? Did you check? I need a force from them to eat medicine or to go hospital.   |
| 12. | P4. Where ever, I want to go I have to manage. Only Fridays he has an off. So we will have only one afternoon as a family time after the church.  |
| 13. | Researcher: it means some of you need a push to make a decision about your health.  |
| 14. | Usually <i>here less time to manage everything</i> together with family, kids and job.  |
| 15. | Researcher: What do you know about breast cancer?   |
| 16. | P1. Few years before I came to know that the sign of breast cancer is thickness and pain. In my family itself, there were two breast cancer patients. At last, they removed their breast. I used to go to their home when I visit Kerala and console them. Feel fear when thinking about their situation. But now the situation has been changed; now we have the facility for early detection so that we can realize the disease and take medicines early.<br><br>One of my cousin's daughter was affected by breast cancer. She came to know it early and took treatment. Now she is perfectly ok, then she got married and gave birth to a child. So, I thought to do screening mammogram. |

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| 17. | Researcher: Oh, ok will come to that, now my question is what is breast cancer? Or what do you know about it?   |
| 18. | P1. It is a thickness, tumour and pain in the breast.   |
| 19. | P2. I heard that it is not only even pain and thickness but also there are several other signs, but I don't know exactly.   |
| 20. | P3. Any abnormal feelings in the breast can be a sign for breast cancer. And thickness and pain are the symptoms of breast cancer.  |
| 21. | P4. Heard that colour change in the breast.   |
| 22. | P5. Can have severe pain, sometimes I get pain, but if it is breast cancer this will be unbearable.   |
| 23. | Researcher: Can you tell me how to detect breast cancer?  |
| 24. | P1. Before I thought early detection means it is done immediately after noticing anything on the breast. All my friends also think like this. But now after my cousin's experience, she shared, so I thought that it will be good to undergo it. I told others. If we do early detection it will be helpful, and the family members will be happy. Then they are avoiding this because this test is very painful.   |
| 25. | P2. Early detection is good. It will help to find out whether I have breast cancer or not.<br><br>In most of the cases when we hear or read some messages about breast cancer will lead us to think about the necessity of early detection and get awareness but after that, the awareness will slowly loose from us, will not bother more. It is a painful procedure, then I read there is radiation, which is very harmful to our body. So, thought whether to undergo or not. But did it. When I did the mammogram it was so painful, so I still think whether mammogram is necessary or not? Moreover, I read that there is radiation and it is very harmful. |

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| 26. | P3. I know a lot of persons those who affected by breast cancer, it led me to do mammogram or early detection. I know some women hide the symptom and that led them to death.  |
| 27. | P4. I received a message from my friend on Facebook or Twitter; about this disease and explains how painful if we keep it for long without treatment. Some pictures were also shared explaining how to do self-breast examination and the mammogram.         |
| 28. | P5. My relative had breast cancer, so she said to me to do. Then my son advised me to do it. He is a doctor. So, I did it.   |
| 29. | Researcher: Ok, do you know any other way of detecting breast cancer?  |
| 30. | P1. I read we can find out ourselves too. But it needs some technique. I did not spend much time to understand it. I am not in the medical field, so if I check also, I will not be able to find it out. Then maybe gynaecologist can check it out, I think. |
| 31. | P2. Not like routine blood check-up. But some tests are there. Doctors can check, and this mammogram only, I think   |
| 32. | P4. I saw some pictures with a description of how to find it out ourselves.  |
| 33. | P3. Sometimes I go in front of the mirror and look for any redness or anything. Before periods I get pain, so that time I clearly look that area. Then this X-ray test.  |
| 34. | P5. My son showed a video to me and my daughter. Sometimes I check myself. I think monthly it needs to be checked. I am not doing it.  |
| 35. | Researcher: Ok, do you know what helps to avoid breast cancer or do you know the reasons for breast cancer?  |
| 36. | P1. I think food behaviour needs to be changed. Cooking and keeping  |

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|     | in the fridge for many days is the main reason for breast cancer.  |
|     | P2. Yes, It is the most important reasons for any cancer. I think so. But not exactly sure. But old people also died when there was no fridge.   |
|     | P3. I started to avoid the usage of chicken. I read that the chicken grows fast after injecting some hormone/s.  |
|     | P4. I heard that lifestyle is an important cause for cancer, I started to do exercise and walking to avoid cancer.   |
|     | P5. I try to prepare everything at home. We also reduced fast food. But you know weekly once at least we used to go out.   |
| 37. | Researcher: Do you believe that if you avoid chicken and do the exercise you can avoid cancer?   |
| 38. | P3. Yes, that's what I heard. So I am following this method.   |
| 39. | Most of the people addicted to junk food. Chemicals are using nowadays to get taste and keep the food safe. Those chemicals are very important cause for the cancers. We should avoid fast food. Through this we can control cancer for a limit. |
| 40. | P3. I had an uncle too he died with lung cancer. He does not smoke, follow diet and does regular exercise even though he died because of cancer. Maybe like this breast cancer is also fate.   |
| 41. | P4. One of my friends also died because of cancer. So, I feel that cancer is a part of this human life or fate.  |
| 42. | P5. I don't know well, but I am agreeing that food is the main cause of cancer. I heard that obesity is a cause of cancer. The hormone also is a reason for cancer.  |
| 43. | Researcher: Ohk, you all undergone mammogram, what you were thinking of it. Can you please share your thinking and experience?   |
| 44. | P2. I only came to know right after I did it. Up to that time I was not aware of how to do it. Not this much pain expected.  |



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| 45. | P3. Very tightly it got pressed, there was a pain but bearable. I underwent as part of the executive health check-up. Otherwise, maybe I would have not undergone it.   |
| 46. | P5. We were unaware about how is it going to be and how it will be done? And so on.   |
| 47. | P4. My friend shared a message and I saw in it. But not sure and was not aware of how it will be done.<br>I came to know that doing mammogram in Kerala is very painful but here in UAE, it is not that much pain.  |
| 48. | P1. I knew about it because my own sister did screening mammogram. So, I was aware of the procedure, but when undergone through this, it was something a special experience. Hearing from others and experience ourselves and others are different.                                   |
| 49. | Researcher: Ok from where all you have undergone screening mammogram, why you choose to do from that place?   |
| 50. | P1. From Ernakulam, during routine health check-up when I go to Kerala, I asked the doctor about it. She then asked me to go to the X-ray department to get an appointment. Thought not to do because of time restriction. But luckily got the appointment fast, the next day itself. |
| 51. | P2. I did it from Dubai, Zuleika hospital. My friend shared a free voucher last November. I think it was an offer for a few days, I think, I am not sure.   |
| 52. | P3. Sometimes we get messages in about this test. But we will not believe think that it may be a fake one. I did it from Thrissur when I went last time.  |
| 53. | P4. There was a health campaign, conducted by Aster medical centre in our community centre. They gave routine, blood test, urine test, BP, ECG and this mammogram discounted coupon. So, I went and did it.   |

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| 54. | Researcher: Do you plan to do mammogram further?   |
| 55. | P1. I read from somewhere once in a year or two it should be repeated, not sure exactly. But I do not think I will do it again. Once it is enough. I think on Facebook, WhatsApp these messages are there.   |
| 56. | P2. I did once, it was painful and then it involves harmful radiation too. So do not think to do it again. It is a tension creating procedure.   |
| 57. | P5. My son said to do it maybe after 2-3 years. Maybe if he says, then I may do it again.  |
| 58. | P4. It is a good opportunity for us to get such availability to do screening mammogram. I did once it is expensive, even though I got a discount. Now only I heard this that there was an offer available in Zuleika. But once is enough, I think. But maybe self- breast examination can be continued. I think it needs to be done sometime. I think messages should come from the hospital. I did not notice it yet. |
| 59. | P3. No, I do not do it again. It was expensive there in Kerala, I think it was 1800 rupees. It was painful too. Once I cleared there is no disease that's enough.<br>But I heard it should be repeated sometime, read through some message.  |
| 60. | Researcher: You said about messages, through some media. Whether that motivated you to undergo mammogram?  |
| 61. | P1. Yes, we get information through WhatsApp, but we didn't take it as serious. Many messages come just as forwarded. Not get much time to see one by one  |
| 62. | P2. Yes, sometimes we do not know whether it is fake or not. Usually, I ignore it.   |
| 63. | P3. I have not seen it. For mammogram not much I think   |

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| 64. | P4. Two or three times I followed the images to do a self-breast examination and I did it but then forgot, and I missed that message too.                                    |
| 65. | P5. A video I saw from youtube. Do not know the link. Maybe my children know it.   |
| 66. | Researcher: Ok what do you know about the facilities available in UAE and Kerala. Can you explain more?  |
| 67. | P1. I have the hospital near to me like Zuleika Hospital we were not aware of the availability of it.  |
| 68. | P2. People are not much aware of these facilities.   |
| 69. | P4. After attending this discussion only, I come to know about its availability in the UAE. This hospital is near to my house, but I think many people are not utilising it. |
| 70. | Researcher: What do you think about the reason for it?   |
| 71. | P1. Yes, even though there are facilities and some people may know it. I think people are not aware of it. And not getting appropriate information from these hospitals too. |
| 72. | P2. I have seen UAE governments rally on the horse. Someone in my office told it is related to breast cancer. We thought it is for Emiratis only.                            |
| 73. | P3. Some people are not bothered about this because they don't know how horrible this disease is. So, we have to say in detail and make them aware of it.                    |
| 74. | Researcher: it means people didn't get enough information, right?  |
| 75. | Yes (All).   |
| 76. | Researcher: What do you know about the breast cancer screening services in Kerala/ in your locality in Kerala?   |

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| 77. | <p>P1. I did not know it before, but it was part of my routine health check-up. I could do it.</p> <p>Some hospitals in Kerala and here shows a similar machine along with breast diseases in their advertisements. But I was not aware of the importance of it.</p>                    |
| 78. | <p>P2. I don't know where screening mammogram service is available in Kerala.</p>   |
| 79. | <p>P3. None of us knows properly, about the mammogram service availability in Kerala. May be in big private hospitals it can be.</p>  |
| 80. | <p>P4. Maybe Keralites does not know due to financial crisis is one of the main problems in Kerala. In Kerala most of the people are living in a middle-income class so they could not go or think about the treatment and mammogram, and they are frightened to hear this illness.</p> |
| 81. | <p>P5. Yeah, I think in Pariyaram medical college, or Amrita it is there. But do not know.</p> <p>Most of the people in Kerala don't know about the screening mammogram. It is not familiar to them.</p>  |
| 82. | <p>Researcher: It means, money is a problem to undergo a mammogram, and it is not considered to be important too right?</p>   |
| 83. | <p>Yes (all).</p>   |
| 84. | <p>P2. I did mammogram in UAE. As it was free mammogram so I did it.</p>  |
| 85. | <p>P5. I did in Sharjah</p>   |
| 86. | <p>P4. from UAE</p>   |
| 87. | <p>P3. From Kerala</p>  |
| 88. | <p>P1. I did it from Kerala because all my relatives are there and I need them to be with me, especially in hospitals and during check-ups, also it was part of other tests.</p>  |

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| 89. | Researcher: Ok, let me ask some questions to you those who did mammogram from here (UAE). Apart from free mammogram what else facilitated you to do it from UAE?   |
| 90. | P4. I don't have enough leave in the organisation where I am working. They are providing holidays once a year. If I wait for the next vacation to do check-up in Kerala, I can't do it. So, I did the check-up from here in UAE. |
| 91. | Researcher: Do you mean that holiday's also important for medical check-ups?   |
| 92. | P4. Yes, employees can do medical check-up during holidays only. One of the facts is that workers don't get holidays to go for an ordinary medical check-up even. If they get to leave, they can do check-ups in the UAE itself. |
| 93. | Researcher: Ok, any other factors influenced you to do mammogram from Kerala?  |
| 94. | P1. I did as part of the executive check-up. Along with it undergone other health check-ups such as cholesterol and so on.   |
| 95. | Researcher: What do you think how can you inform about the need to do a mammogram to other Malayalee's.  |
| 96. | P1. We are interested to inform as many as we can.   |
| 97. | P2. We should inform other people especially those who are from Kerala may be through Medias. But if someone asks more about the disease or radiation or anything further, we do not know those clearly to share with them.      |
| 98. | P3. Not only through media, but we can also share each other, those who have attended the tests.   |
| 99. | Researcher: At present we have a lot of Medias, which one you will prefer to inform others about it?   |

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| 100. | P1. Television is one of the effective media to inform others about it. Women watch television in their free time. If the government give advertisement, that will be trustworthy and reach to them.   |
| 101. | P2. The Internet also is a good media to inform others. But may not take it that seriously.  |
| 102. | P3. More than these, if we can approach each one personally that will be more effective. We should plan to reach them personally.  |
| 103. | Researcher: What do you think, how we can reach to individuals and motivate them to do mammogram?  |
| 104. | P1. Most of the people (Keralites) who are here are there in one or another Kerala group. Like, we have a lot of Malayali's organisations, Indian association, even churches also. If an authorized person like you, who are in the medical field can give awareness classes to these groups. It will be more influential and motivation to do a mammogram.<br>If a person like you, one who studied and learned about this disease can influence women and surely will go for the tests. I will not go if my husband just immediately comes and say to do a mammogram. Because I do not think it is required as he is not in the medical field. |
| 105. | P2. In UAE, there have many women who are not able to go to hospitals, even not for their other diseases. There are many women in labour camps. We know many people. They are waiting to get a chance. But they are not receiving any messages like this.  |
| 106. | P3. Yes, if someone should inform them and take them for these tests it will be like a charity even. Usually, no one considers them for screening tests. I heard if they fall sick and does not attend their duties, their salary will be deducted for it. So, people hide their disease and work for their family livelihood in India.  |
| 107. | P4. True that is a good service if someone can do it.  |

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| 108. | P5. I also agree, with this, others have their family members along with them.  |
| 109. | Researcher: What is the reason behind it?   |
| 110. | The main reason is the lack of money (Most of them agreed).   |
| 111. | P4. Money is the main problem. Many people are working for minimum wages. They can't spend their salary for their check-up. Because they have many responsibilities to do; they have a family member who is waiting to receive money, their kid's education and their own daily needs. They may pay rent. So even though they have pain and suffering in their body they used to tolerate it. |
| 112. | P5. If a person has insurance that is ok, she can go for a check-up. But people like me who came many years before they do not need insurance at that time. Now for me, someone in the family must take care of me. In emergency cases only will go to the hospital.  |
| 113. | Researcher: Is the mammogram free for the people those who have insurance? Is it is also included your insurance package?   |
| 114. | P1. When I went to Kerala, they said it is included. Was not aware of it.   |
| 115. | P2. No, the mammogram is not included in the insurance package.   |
| 116. | P3. When I came to UAE Health insurance was compulsory for everyone so I could do the entire check-up along with my family.   |
| 117. | P4. I am not sure, I do not think it is covered. Then they would have accepted my card while I went for the test.   |
| 118. | Researcher: Then it means that Insurance card has a role to promote screening mammogram, am I correct?  |
| 119. | Yes (ALL)   |

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| 120. | Researcher: Are you sure that if a mammogram is included in the insurance package and informed, will you go for it?   |
| 121. | P5. I do not know. Common people usually won't worry much about the mammogram whether it is included in the insurance card or not because I was unaware of the mammogram until my son said to me. |
| 122. | No no there is no surety for it (All shouted)   |
| 123. | P3. No, we have insurance, but we did not go until we were aware of the importance of mammogram.  |
| 124. | P1. Those who are aware of the mammogram only will go for it.   |
| 125. | Researcher: You all did the mammogram; did you feel any hindrance after taking the decision to undergo it?  |
| 126. | Fear (all)  |
| 127. | P2. We will be in tension for one week before and after the mammogram until the result comes.   |
| 128. | P4. There will be much tension until the result comes (all). It is part of this check-up  |
| 129. | P1. I was being scared until I got the result. Fear is a part of the mammogram.   |
| 130. | Researcher: Ohh you had fear before you go to mammogram, am I right?  |
| 131. | P3. Yes. We considered it as some complicated check-up; if any changes detected then we are going to die soon. So will be tensed until we receive the results.                                    |
| 132. | Researcher: Ohk, Do you have any idea that someone else can also influence a woman to undergo it and reduce the tension. I mean community leaders, friends so on..                                |
| 133. | Yes (ALL)   |



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| 134. | P1. They all have an important role to influence us.   |
| 135. | P3. But I think they are also not aware of it. Otherwise, they would have informed us.   |
| 136. | Researcher: Ok what about governments?   |
| 137. | Government (all)   |
| 138. | P1. Government has a role to influence us. In each ward in Kerala, they can make an opportunity.   |
| 139. | P2. Can take consent from the women and can ask the women to undergo mammogram.  |
| 140. | P3. If the government make such a rule or facility most of them will do it.  |
| 141. | Researcher: Ok, good   |
| 142. | Researcher: Now we are here in UAE. In this situation what kind of help can Kerala Government do for us? What you are expecting from them?   |
| 143. | P1. There are many mediators between UAE migrants and Government of Kerala such as Sharjah Association, Norka, Pravasi India etc. these all organisations are communicating with the government about our needs. If the government open a facility for women to do a mammogram and other tests that will be very helpful for each and every woman.   |
| 144  | P2. Ministers are visiting UAE and meet with the community leader at that time we can give requesting memorandum for any kind of help. They are coming to identify our needs, but no one put forward such kind of needs may be. Even they can think of arranging some community health centres for us including many facilities and can mediate between our Kerala government and UAE government |
| 145  | Researcher: ok, then   |

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| 146 | P5. Up to this time, none has come among us to give us awareness about the importance to do screening mammogram. You are the first person one who came to the Malayalees and discussing this. So need to convey to more people to undergo it.   |
| 147 | P3. Yes, it is the first time. Good initiative. Hope it helps in the future.  |
| 148 | Researcher: Ok. Thank you. Happy to hear that.  |
| 149 | Researcher: This is the main point I have to highlight that we Keralites do not get proper awareness about our health and breast cancer, am I right?  |
| 150 | Yes (all)   |
| 151 | Researcher: Ok, anything more?  |
| 152 | All doctors do not have the same character as you. There are doctors those who are ready to serve the people and do the research like you. If these kinds of well-minded doctors can provide good awareness classes for ordinary people. They can make people aware of the consequence and importance of early detection. That will be a better idea (all). |
| 153 | Among the Malayalees in UAE have their own community and group. If well-educated and charitable minded doctors come to the community and arrange the classes will be good for us to know more about the diseases.   |
| 154 | In UAE we are depending on our own communities more than our relatives. If we get awareness classes in the community about breast cancer will be very effective.  |
| 155 | Researcher: OK, Do you like to add some more thoughts?  |

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| 156 | P1. In Kerala, health inspectors can give awareness classes at the ward level. Here through Medias, Community gathering and so on. But should give appropriate awareness then only it will be effective.         |
| 157 | Researcher: In Kerala, we can communicate and share the message with the help of health inspectors, right? What will be an effective method to inform in UAE?  |
| 158 | P1. In the UAE, the government can inform us through Medias and community leaders  |
| 159 | Researcher: Some organisations, eg: Pink Campaign are providing mammogram here. Do you like to add anything more about it?   |
| 160 | P2. Yeah, I think that awareness rally in hospitals, you mean?   |
| 161 | Researcher: Yes, that one, then there is a mobile clinic associated with it.   |
| 162 | P2. Not much aware of it.  |
| 163 | P1. I think for that, has to wait for next year. If a woman wasn't able to go at that particular month she never tries to go anywhere else. She will wait for the next year. Then we forget and never try to do. |
| 164 | P3. Then women will not ask money to their husband for these check-ups, as these are not considered urgent issues.   |
| 165 | Researcher: yes, the cost is the main problem not to do mammogram. Right?  |
| 166 | Yes (all)  |
| 167 | Researcher: Anything more do you like to add to this discussion?   |
| 168 | Thank you very much. I really value your views. Thank you for giving your time.  |

## Appendix K Transcript Focus Group Discussion 2

### FGD:2 Women who had undergone mammography (Sharjah)

| Identification | Participant statement   |
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| 1              | Researcher: Thank you for your time and appreciate your support for taking part in this discussion. As I said during the introduction, I would like to ask some of the questions related breast cancer, screening mammogram, factors influenced you to undergo mammogram and so on... |
| 2              | Researcher: Who is taking decision about your health?   |
| 3              | P1. About my health I am taking decision myself. If I feel any abnormality in my body, I usually take the decision and I go to the hospital and will do the needful check- ups.   |
| 4              | P2. Self-decision. If I feel uncomfortable, I used to go the hospital. It is not necessary to ask permission from the family members. Yeah sure will inform husband and family.   |
| 5              | P3. Usually, I make decision but will inform my husband before undergoing any health check-ups or even anything. You know that's our routine practice at home.  |
| 6              | Researcher: So, do you need permission from husband to go to hospital? Does his permission mandatory?   |
| 7              | P1. If I want to go to the hospital husband never says no. Hundred percent my husband will give permission. It is his need too that his wife wants to be healthy. He is also taking care of my health.  |
| 8              | P2. Our health also affects our husband. Our health is important for them. I am saying for routine check-ups, if it is something like cancer check-up, he will be tensed.   |
| 9              | P3. My husband is also very supportive to get good treatment at any   |

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|    | time. My husband usually takes one step before me to go for treatment.   |
| 10 | Researcher: Ok, good   |
| 11 | Researcher: What do you know about breast cancer?  |
| 12 | P1. Breast cancer brings many problems in our life. By hearing it we are afraid about it. It is a gene mutation.   |
| 13 | P2. Most of the people are educated at present and they may know the symptom. If people realize the symptoms they usually go for the check-up. If we didn't go for the treatment it is too dangerous and harmful to our body. It means pain and bulging in the breast.   |
| 14 | P2. Yes, it is a deadly, non-curable disease. It is fate if someone gets it. Nothing can be done.  |
| 15 | Researcher: You all did mammogram. You did it because of your knowledge about breast cancer or anything else influenced for it?  |
| 16 | P1. I went to do mammogram because I am aware of the test. I knew that there is an X-ray test called mammogram, so I went for the same.  |
| 17 | P3. Not only that but medias are also too much helpful to understand mammogram. For me, my daughter told about it. I also heard that it is important to do from my manager as her sister got diagnosed with breast cancer and she was very upset. She conveyed to all colleagues to do early detection tests for it. |
| 18 | P2. I went because I received a video from my friend through some media that if it is diagnosed when it is very small, it could be treated easily even may be without surgery. But if it becomes big, the whole breast will be removed. My aunty had breast cancer. So, the video made me more worried and did it.   |
| 19 | Researcher: Medias, Ok, both of you said Media, which one helped you to understand it.   |

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| 20 | P1. Facebook is the one of the social medias which helped me a lot. It gives information and awareness about the mammogram. Facebook is conveying lot about the breast cancer.  |
| 21 | P2. I think some are there in WhatsApp, also, I think I am not sure.  |
| 22 | P3. Yeah, even I found in Newspaper advertisements.   |
| 23 | Researcher: Which newspaper?  |
| 24 | P3. I am reading mostly "Al Khaleej", that helped me lot and social medias also helped me to do mammogram.  |
| 25 | Researcher: how the information in Facebook displayed, does it like a message or Video?   |
| 26 | P1. I have not seen in the form of video, they used to tell about the symptoms, says about the family history etc. it also discusses about the early stages, difficulties and danger of it, if it is not treated early.                                       |
| 27 | P3. Newspaper shows advertisements of its availability in the month of October.   |
| 28 | P2. In the social media, sometimes it will be on the right side or left side just like advertisement it just flashes and go. In the beginning I thought that those are some advertisements of hospital facilities similar to a shopping ad.                   |
| 29 | Researcher: From the media what attracted you to do mammogram?<br>What helped you to take decision to do mammogram?   |
| 30 | P2. First factor, which influenced me to do mammogram, was my age they stated. At the age of 40 and above every woman should do this. I heard even from the age 35 we can do mammogram. In my family no one had breast cancer, so I am now 52 and did it now. |
| 31 | P1. They said about the starting of disease and difficulties if it grows big, family history and so on.   |

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| 32 | P3. I felt that I am about to reach into menopausal age. I felt changes in my body. There were hormone changes also in my body. I did mammogram because of it. I have cysts in my ovaries too.  |
| 33 | Researcher: What do you know about breast cancer screening?   |
| 34 | P1. I was unaware about the breast cancer. But by hearing through Medias and friends about the mammogram I decided to undergo mammogram. I saw from the internet, which is shared by one of my friends that women should do mammogram in the age of 35 and above.   |
| 35 | P3. One of my friends shared an interview video with a doctor about breast cancer on Facebook. That doctor conveyed the way of doing a self-breast examination and shared that if it is diagnosed in early stage, no one should worry about the disease. Because of that reason I did screening mammogram. Even my daughter also told to do it. She is in the university now. |
| 36 | P2. During menses, I used to get pain in my breasts, and then I said to my husband about the pain. Then husband told me to undergo check-ups. I am 52 now, anyway thought to do mammogram from Kerala during vacation as part of health check-up  |
| 37 | Researcher: I come to a point that social Medias had an important role in your life to do mammogram, right?   |
| 38 | P1. Yes, social media influenced a lot to do mammogram. Because we can get many information from the social medias very quickly.  |
| 39 | Researcher: Now, do you know what we can do to avoid breast cancer?   |
| 40 | P2. We can determine through the size and shape of the breast. If there is some changes in the breast, we can find it out.  |
| 41 | Researcher: Ok my question is another one. Any idea how can we prevent this, and reasons for breast cancer?   |
| 42 | P2. If we are overweight, there will be a chance to get cancer. I read like   |

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|    | this in some articles.  |
| 43 | P1. I think need to do lot of exercises, anyway everything is in the God's hand   |
| 44 | P3. Diet is an important thing to keep our body healthy. We should avoid the fast food. But where is the time to cook every time.   |
| 45 | Researcher: What do you know about the ways of detecting breast cancer?   |
| 46 | P1. When we hear first, the screening mammogram causes tension.   |
| 47 | P2. No blood tests I think, only X-ray. I was not aware of the machine or procedure until I experience it. Heard it presses the breast very hard and was a little worried   |
| 48 | P3. I only look into the mirror to see changes, or press all the areas and check, but not really know to do it. My daughter said. Then this mammogram.  |
| 49 | Researcher: Did you felt any difference between what you experienced and heard?   |
| 50 | P1. It was totally different, was much tensed. For me, the screening mammogram was not painful.   |
| 51 | P2. I heard lot before I do mammogram that it is too painful, for me it was ok ok.  |
| 52 | P3. Yeah, I was thinking something like scanning when I was pregnant, but when I underwent it was different and alittle painful, as I did not expect it.  |
| 53 | Researcher: Can you able to recommend others to do mammogram?   |
| 54 | P1. Of course, I am ready to recommend others to do mammogram and encourage them to do. I used to tell my friends and colleagues that there will not be any harm if you do screening mammogram. If you do it once you can live peacefully. Otherwise you will be tensed all the time. |



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| 55 | P2. Everyone should do mammogram because anybody can get anything in the present life style. I think there is no side effect if we do mammogram. it will be good for everyone to do mammogram.   |
| 56 | P3. After I undergone mammogram many friends asked me; how was it? How you could do that? It was totally different between what I thought and what I experienced. They asked is it painful? I conveyed my experience and asked to get it done  |
| 57 | Researcher: From where you did the mammogram?  |
| 58 | P1. I did it from Sharjah through the free voucher I got from ***** hospital.  |
| 59 | P3. Me too from ***** with the voucher   |
| 60 | P2. I did it from Kerala during my vacation  |
| 61 | Researcher: How you came to know about the availability of screening mammogram in UAE?   |
| 62 | P3. I am living here for many years I have seen 'Pink Caravan'. They used to conduct these kind of check- ups in various places in a bus kind of, but for me it was not easy to reach up to them. I couldn't go because of the lack of transportation, or I have not seen their announcements of its availability and locations earlier. But I think now it's making available everywhere. |
| 63 | P2. Yes, I have seen it, but we will not be in that mood immediately to undergo check-up, if I see somewhere like that.  |
| 64 | P1. I was not aware of its availability in this hospital and its importance, last year when I went for some other check-up, I have seen the advertisement. But was not aware of it and its importance. One of my friends shared a voucher of Zuleika hospital.   |
| 65 | Researcher: That means even though they provided the opportunity, there were some factors hindered you to undergo it right? Can you  |

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|    | explain it.  |
| 66 | P3. Transportation was a hindrance for me to reach to them to do mammogram.  |
| 67 | P1. Another barrier was, if they come to a place, they spend one or two days in a place. We didn't get information when they are going to leave that place. Maybe they are telling it but I didn't get that information. Maybe they should announce or email or send messages to people in that area. Now all the details are available to track people, I think.  |
| 68 | P2. As said if I may not be prepared to undergo it, just like when we see it somewhere, no one will just go and do it. Also, I thought there might be only Arabic speaking doctors and health team are available. We look odd there. I feel so. Also, I think unless and until if there is no clear explanation of the procedure to the public no one will just go like that. I think they must give some sessions before. |
| 69 | Researcher: it means, you were not clearly aware when, where, how, whom to approach to do it right?  |
| 70 | P2. Yes, even though they are providing free services we didn't get clear information where and when I want to go, whom to contact. So do not feel to go may be my time will not suite or plan with their available time.  |
| 71 | P1. I did the screening mammogram from the Zuleika hospital. There was a campaign for around three months. I had an ample amount of time to plan and utilise it.   |
| 72 | P3. If we want to do this there are certain criteria. We have to do after the sixth day of the periods. So, we have to wait, likewise one month will go from us. But I took appointment in the suitable time and did from the hospital.  |
| 73 | Researcher: This is good. Right, as they provided for 3months at the hospital?   |

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| 74 | P1. Yes, if the availability of mammogram is for three months, if a woman is aware of it, they have enough time to decide, arrange, manage everything.  |
| 75 | P2. Even though the Pink Caravan is coming to our local areas, that mayn't be a suitable time for me as I have to do mammogram after sixth day of periods.<br><br>I had breast cancer awareness through hearing, so even though it is a small pain in the breast I used to worry about that and think that there is breast cancer. Tension will automatically come to our life. |
| 76 | P3. I also think it is good with more time. By the way if they keep around the year, when people go for other check-ups, they can finish this also.   |
| 77 | Researcher: I think you said only Arab speaking doctors will be there in the Pink caravan. right?   |
| 78 | P1. Yes, language is a barrier to communicate with the doctors. If we want to express our feeling there should be good communication. The doctor should be one who can understand the client's language and our feelings.   |
| 79 | P3. In Zuleika hospital we feel free because many Malayalee's are working there. So, we can communicate with them in our own language.  |
| 80 | P2. I also planned to meet a Malayalee doctor to do mammogram. Because they can only really understand our language and feelings. As I did it from Kerala that was Ok for me. They have a clear idea about our life style, food, routine habits etc. we can also understand their suggestion well.  |
| 81 | Researcher: it means that our cultural background important right?  |
| 82 | P2. Understanding our culture is very important. Malayalee doctor have a clear idea about our life style, food pattern, etc. we can also understand their suggestion well in our cultural context.  |

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| 83 | P1. May be cancer occur due to food. If the doctor is from our own culture, he can easily instruct us that which food we can eat which is not. Other doctors may not able to suggest it.                     |
| 84 | P3. Yes, we can also understand and follow the instruction without thinking many times.  |
| 85 | Researcher: Do the cultural belief can influence Kerala women? Does the culture have any role for undergoing mammography?  |
| 86 | P1 Our cultural background is very narrow and closed one regarding breast examination; it is a shameful procedure. Women should have an open mind and then only they will be motivated to undergo mammogram. |
| 87 | Researcher: Ok, Malayalee's have a different mind-set you think for screening mammogram. Right?  |
| 88 | P1. Yes, usually Malayalee keep distance from the realities, their cultural background not allow to take a decision by themselves.   |
| 89 | P2. Malayalee usually think if I do mammogram what others will think about me. Malayalee's are worrying about others more than themselves.   |
| 90 | P3. Many women are avoiding the mammogram that, if I undergo through mammogram others will think that I have breast cancer and that's why I did it. These give a fear to do it.                              |
| 91 | Researcher: How can we avoid fear?   |
| 92 | P1. I think awareness classes.   |
| 93 | P2. Awareness classes about the importance of early detection, how the test is, everything needs to be shared.   |
| 94 | P3. Awareness classes to women in their local language. The doctors, when we go for other check-ups, they can tell the women.  |
| 95 | Researcher: Whether awareness classes do we have in the UAE?   |

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| 96  | P1. We don't have only for the Malayalee's, I think.   |
| 97  | Researcher: is it will be effective if we give awareness only for the Malayalee's?   |
| 98  | P1. If one can give awareness classes only for Malayalee that will be helpful to change their attitude.  |
| 99  | P2. If we give publicity in the Malayalam newspapers and television channels, it will reach to the Malayalee's.  |
| 100 | P3. We can conduct the seminar for the Malayalee women it can easily share the importance of mammography services and breast cancer.   |
| 101 | Researcher: What will be the suitable time and place for NRK women here in UAE, you think for awareness classes?   |
| 102 | P1. Thursday 8 pm will be the suitable time for everyone, I think. If so I can inform to my friends and neighbours about the classes and can invite them to the session.   |
| 103 | P2. If we provide the transportation surely many women will come. You know, many Kerala women won't drive here. Indian association have many small groups. I am in one of its groups.  |
| 104 | P3. I think Thursdays and Fridays are best days. This is a big worship centre in Sharjah, everywhere it is there in Dubai Trinity, like so on. In Sharjah one more the Union compound many people are available there especially on Thursdays till Sunday. If we organise a dedicated breast cancer screening class many people will attend. |
| 105 | Researcher: OK. Now you all know well about the need of undergoing mammogram. How do you think you can approach others convey the same   |
| 106 | P1. I usually convey to my neighbours when I heard about its availability from (name of a hospital). But there will be limitations. Here my neighbours are not Malayalee's, so no much social connection with them. I only have friends from Church or through WhatsApp.   |

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| 107 | P2. Concerning Malayalee, they always show a difficulty to take a step like this. Someone has to push them to do these tests.  |
| 108 | P3. Some people like you, doctors, and professors can come and arrange seminars/ classes, then people will listen as you are from the university or medical field, but this kind of tests they need rethinking. If I call for shopping or other things they will join.           |
| 109 | Researcher: Ok then who have the role to share this... like friends...?  |
| 110 | P1. We can give motivation to our circle of friends. We can inform them. We can guide them to do self-examination methods to find out the chance of breast cancer. It will prevent them from the next stage.   |
| 111 | P2. To influence others friendship circle is effective. Our friend also will be of our own age, so friends can easily understand our ideas and thoughts and even difficulties. Close friends can make an impact. But as I said there may be limitations in these kinds of tests. |
| 112 | P3. Relatives can also influence to undergo mammogram. We can just give suggestions to them to do it. But in Kerala they have to pay. So no one usually will pay for it and do it, may be very less people.  |
| 113 | Researcher: There were free mammogram services here, but women are not taking it as serious. Do you think?   |
| 114 | P1. Motivation in the friend circle is very important in this case. I went to do mammogram. Most of the women are not aware about it and didn't take the breast cancer as serious. One of my friends were not aware of free mammogram availability here.                         |
| 115 | P2. The main reason behind to avoid free mammogram is that, no one is there to motivate them to do it.   |
| 116 | P3. Job is another one barrier to catch up with the time. Family, kids are important for us rather than finding time for these tests.  |
| 117 | Researcher: How we can inform them about it?   |

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| 118 | P2. We can inform them personally. I mean we can share it in the community, the community in which we are belonging to. There are many community groups in the Indian association. I am from there, she invited that's why I came here to the church.  |
| 119 | P1. WhatsApp is another important media to inform the people about the availability of the free mammogram. Now a days everyone has mobile. So, we can easily communicate with them.  |
| 120 | Researcher: If we send message in WhatsApp about free mammogram service, how much women will believe in it?  |
| 121 | P1. Most of the women may not believe the messages through social media, but if we give with full details and phone number, that may help them to contact. But now a day's blood required messages used to come with contact details, even hospital names, person's names are included in it. No one will consider it, I think. I usually won't. I think many others also think something like that. |
| 122 | P2. Self – motivation is needed along with WhatsApp messages.  |
| 123 | P3. I think inviting for awareness classes, will work. But videos and messages may not be effective to really make them to go to the hospital to do check-up.  |
| 124 | P1. After I underwent a mammogram, I said to my friends to do a mammogram. But they neglected my words it's not easy to convey and said; breast cancer will not affect me. They found to have good belief and confidence that breast cancer will not come to their life.   |
| 125 | P2. One who have care and fear about their own health only will give importance to these messages. If a person is not bothered about their health, she never considers these information. I think the pastor aunty/ pastor/community leader has a major role. Their words will consider as believable by the members in the community.   |

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| 126 | P3. Of course, community leader can influence the community members. I am going to a church. If our pastor says members will consider or take it as serious. But it depends on the community.   |
| 127 | Researcher: Ok, according to your understanding pastors/community leader can influence others and their words will be considered as valuable, right?  |
| 128 | P1. People will believe the information which is giving by the community leaders. Information from the community leaders are believable. If any organisations provide free mammogram service, they can approach the community leaders and inform them to announce it. |
| 129 | P2. Once in the Indian association there was an awareness session. I attended, made aware of the class, but from where it can be done was not told. In between classes are required. Otherwise women will forget it.  |
| 130 | Researcher: In every community there will be leaders; in the church pastor of that congregation. Does he have any limitation to give information?   |
| 131 | P1. I do not think that the pastor of a church has limitation to give information. Our pastor is an open-minded man; he wants to see us healthy and happy. He always recommends good things.  |
| 132 | P2. In our community also; if the leader members will obey. They are giving respect to leaders' reference and they will consider going for mammogram. The leaders can influence others  |
| 133 | P3. I am not sure, because in our church they may not announce it. Because they say believe in God. So, if pastor aunty says women will say that you are not believing God and can cause other related issues.  |
| 134 | Researcher: Ok, then do you know some other hospital or place there is mammogram available (free/ paid)?  |



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| 135 | P2. I have insurance coverage so I could do free mammogram from Kerala. I and my family members are covered with insurance. I am not sure that I got free mammogram because they provided it freely.  |
| 136 | P3. My disease condition can affect my whole family in many ways, so must be cautious from the beginning. So, when I got a free screening mammogram voucher, from Zuleika hospital I utilised it. I do not know other hospitals have this machine or not. |
| 137 | Researcher: As it was free you had undergone, and you have insurance card. If you didn't have insurance had insurance card/ voucher where would have you preferred to undergo mammogram in Kerala or UAE?   |
| 138 | P1. I would like to do any tests in UAE only because here we can do everything immediately but in Kerala it will take lot of time.  |
| 139 | P3. Here in UAE there is a system. We can call, take appointment, can go on at the scheduled time. No much queue.   |
| 140 | P2. As it was during vacation and there was a hospital next my house, I had undergone from Kerala. Otherwise I think I would have done from UAE only.   |
| 141 | Researcher: What is the role of our Kerala government?  |
| 142 | P1. If the Kerala government takes initiative in higher levels (it will be just in paper) it will not work. That needs to be communicated effectively among each woman.   |
| 143 | P2. Community centres should take initiative to direct women to appropriate health care facilities for a mammogram. Because the women are not aware of the importance as well as, if aware, they do not know the availability of it next to them.         |
| 144 | P3. In my limited knowledge, I didn't hear that Kerala government is taking such kind of initiative like the UAE government has. Kerala government are not taking such kind of initiatives for health   |
| 145 | Researcher: What about UAE government then?   |

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| 146 | P1. UAE government is taking initiative in all areas. Especially, for women, UAE government shows special concern.  |
| 147 | P2. They are doing many activities for breast cancer screening. Only thing I think they should be more effective to reach to everyone.  |
| 148 | P3. But less Keralite's may go, I think because Malayalee's think that they will feel odd, because of language, they will not feel to go.   |
| 149 | P2. In UAE there are hospital that are only for ladies. I think they will do  |
| 150 | P1. I think may be something Kerala government are doing. But those steps are not enough. The attitude of Kerala government is totally different from the attitude of UAE government.   |
| 151 | P1. The attitude of the Kerala government is that, if you want you can go to the hospital and get treatment for the disease. Citizens have to take care of their health themselves. But in UAE it is totally different than from Kerala. In Kerala mammogram is not available in the government hospitals, I think. In the private hospital, we can do mammogram but that will be too costly to do mammogram in Kerala. |
| 152 | P2. UAE government gives importance to the health of all residents. Comparatively all such kind of test is costly in Kerala.  |
| 153 | Researcher: You have good belief upon the government of UAE but not in Kerala government? What Kerala government can do for us? What do you expect from the Kerala government?  |
| 154 | P1. If Kerala government do a link with one of the hospitals in UAE to provide free mammogram and treatment for the overseas women may helpful for Keralite's here.   |
| 155 | P2. Kerala government is not even providing basic test like check-up of BP, Sugar. But here in the UAE, government provides these all check-up freely to their citizen. Doctors are even going to the people and providing these check-ups free to them.  |

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| 156 | P3. Kerala government can arrange awareness sessions. Because it will be in our language. Then hospitals here are providing many free check-ups during some months.  |
| 157 | Researcher: What more facilities are you are expecting?  |
| 158 | P1. After diagnostic tests, the Kerala government can guide the people to take the next step. If anyone finds out with breast cancer, the government should take the initiative to take the next step for further treatment. Women are thinking that also. Because once when I said to my friend about screening mammogram. She asked if diagnosed where we will go. So, leave it. |
| 159 | P2. If the government take the initiatives that will help women to be confident and courage to face. Otherwise, their confidence will be lost to do these tests.   |
| 160 | People here usually think that doing mammogram is not necessary. If we have disease what we will do to get treatment. Because of this reason many people avoid doing a mammogram. If Kerala government add free treatment to the client after diagnosis that will be a motivation to do mammogram.   |
| 161 | P3. Fear is one of the important causes to avoid mammogram and pain too. I think the painless machine should be made available.  |
| 162 | P1. The person who did mammogram can easily remove the fear of others.   |
| 163 | P2. In the awareness classes, there should be a woman one who did mammogram; she can motivate and encourage others to do mammogram.  |
| 164 | P3. If an undergone person says to the others about the experience of mammogram; they will mentally prepare for that. Undergone person can influence them lot to do mammogram. It is same as testimony.  |

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| 165 | Researcher: Ok whether the people diagnosed with breast cancer have any role?  |
| 166 | P1. Of course, breast cancer survivors have a major role to influence and motivate others to do mammogram. They are the living testimony among the other people those who were not undergone mammogram.  |
| 167 | P2. They can share their situation of diagnosis. Their experience and so on.   |
| 168 | P3. Sometime people will feel sad about them and they also feel difficult to face others. So, I do not think they should be involved.  |
| 169 | Researcher: Who else, can? Do you think any educational institutions?  |
| 170 | P3. Yes, school and university have a great role in breast cancer awareness. The breast cancer awareness teams went to the University here where my daughter is studying. They provide awareness classes to the students to inform their family. They are explaining through presentation etc. |
| 171 | P1. From the college itself, students can go to nearby places and can make the people aware about the need of mammogram. It can be considered as training for community service.   |
| 172 | P2. If the students get information, they will share with others as well as they get motivated through this. It will help them to prepare themselves and to do self-detection and other tests.   |
| 173 | Researcher: Whether you are planning to do mammogram again?  |
| 174 | P1. I didn't plan yet because I did mammogram once.  |
| 175 | P3. I did before and immediately after menopause. I did two times because of fear and then I asked the doctor about the next mammogram. The doctor said; it is not necessary now. I heard that radiation is very harmful to our body.  |

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| 176 | P2. I think every year or once in two years have to do. I do not remember what I have heard. But I have not planned to do it again.   |
| 177 | Researcher: Who can remind you to go for mammogram?   |
| 178 | P1. Yes, that will be good. I think can put reminder in mobile. But if I change the mobile. It's gone.  |
| 179 | P3. We have to take care of our health; I think we have to keep in our diary if I have to go again.   |
| 180 | P1. If the hospitals send any reminder messages through email, SMS and WhatsApp, I can go for the screening mammogram.  |
| 181 | P2. Hospitals only I think where we visited. But still if just messages they will think it is for advertisement.  |
| 182 | P3. We can only keep alarm in our mobile or electronic diaries if we want to take care of our own health. Now in email or in our devices everything available.  |
| 182 | Researcher: What is the role of health insurance in the field of screening mammogram?   |
| 183 | P1. If there is no free mammogram. Insurance has major role.  |
| 184 | Researcher: Have you thought of any dedicated community health organisation for Kerala women in UAE?  |
| 185 | P1. Yes, it will be a great idea. I really like that concept.<br>I am here for more than 18years, so I know most of the health care facilities here. Because my kids were taken to many hospitals in the UAE.<br>So, for Kerala women here it will be great |
| 186 | P2. Many routine check-ups can be done there. If further treatment required, they can be sent to other big hospitals.   |

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| 187 | P3. Many lifestyle diseases can also be diagnosed early, not only breast cancer. After some years usually, when Keralite go to Kerala after finishing the job from here, most of them go with many diseases, like sugar, cholesterol, BP, heart problems and so on. If the Kerala government arrange it free of cost, that will be great. We are the major source of kerala's income. They can consider our wellbeing. |
| 188 | Researcher: Do you like to add any other points more regarding our discussion today?   |
| 189 | P1. Only thing increase awareness, according to the efficiency of awareness early detection will work out. Main thing to avoid mammogram is lack of awareness. Even if it is in the UAE or Kerala.   |
| 190 | P2. For Keralites, some dedicated service should be there as well as facilities like some organisations. Here no dedicated breast cancer awareness classes for the Malayalee's.  |
| 191 | Thank you for your participation. I really value your thoughts.  |

## Appendix L Transcript Focus Group Discussion 3

(Population 2: Not undergone)

| Identifications | Participant statements   |
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| 1               | Researcher: Who make decision about your health, is it you or someone else in the family? What is the reason?  |
| 2               | 1. Our parents take decision about our health in the childhood.  |
| 3               | 2. I take decision myself and go to the hospital for treatment, because I can only understand my body's conditions.  |
| 4               | Researcher: Is there any permission needed from your life partner to go hospital?  |
| 5               | 1. No, needs to get permission from the life partners or any family members.   |
| 6               | 2. We have to inform our husband because informing life partner is our responsibility.   |
| 7               | Researcher: it means, you all will go to hospital after informing your life partner, right?  |
| 8               | Yes (all)  |
| 9               | Researcher: What do you know about breast cancer?  |
| 10              | 1. We all are confidently trying to believe that cancer will not affect me but it will come to others. I am also thinking like that because I am not eating such kind of food that can cause cancer. |
| 11              | 2. But I am scared even to hear cancer that it may come to me too.   |

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| 12 | Researcher: Ok, what do you know about the disease called cancer?   |
| 13 | 1. Breast cancer appears first as a thickness in the breast that's what I heard from others, I only know this much. I heard that when we touch we could feel a thickness on the breast. |
| 14 | 2. Pus will come out of the breast.   |
| 15 | 3. I heard that if it is a breast cancer then there would be a color change on the breast.  |
| 16 | 4. Starts pain  |
| 17 | 5. Do not know  |
| 18 | 6. Color change   |
| 19 | 7. Bulging and pus from it  |
| 20 | Researcher: What do you think about the possible causes of breast cancer?   |
| 21 | 1. Dietary supplements can be cause of breast cancer.   |
| 22 | 2. Mainly breast cancer occurs because of the modern lifestyle and practices  |
| 23 | 3. Breast cancer caused by lack of exercise   |
| 24 | 4. Breast cancer finds more among the women those who are not breast-feeding. Also heard that possibility of cancer is too less for those who are breast-feeding.                       |
| 25 | 5. No idea, I think there is no single reason   |
| 26 | 6. Hereditary is a cause of the breast cancer.  |



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| 27 | 7. Anything can cause breast cancer  |
| 28 | Researcher: Did you think of any possible way to avoid breast cancer?  |
| 29 | 1. Should consult doctors and do good check-up.  |
| 30 | Researcher: Ok, I am asking that did you ever think about how we can avoid it.   |
| 31 | 1. I heard that the breast cancer would not affect the women who are breast-feeding, so feed the child so that we can avoid it.  |
| 32 | Healthy life style (everyone)  |
| 33 | 2. Women who have given birth to three or more babies have heard that breast cancer does not affect them. That's why ancient people did not have breast cancer.                              |
| 34 | 3. Heard that regular sexual contact can defend the cancer.  |
| 35 | 4. Should avoid exposure to direct sunlight. Because exposure to sunlight is a cause of breast cancer. I heard that light color bra has to be used. Black color bra can cause breast cancer. |
| 36 | 5. Modern food items are the cause for cancers, because in the ancient times there were no such kinds of diseases. So according to me, we should be careful about our food and food choices. |
| 37 | Researcher: Do you know someone who had diagnosed with breast cancer after being resided in the UAE?   |
| 38 | 1. Yes, I know more than three cases in our community  |
| 39 | 2. In Kerala there are few people near to my local area.   |

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| 40 | Researcher: now I am asking about the Malayalee's those who were/are in the UAE  |
| 41 | 1. In my church there is a sister, her breast has been removed because of breast cancer.   |
| 42 | Researcher: Do you know how long ago they came to UAE?   |
| 43 | 1. Yes, I know, they came from Kerala to UAE before around 17 years. Just around few months or a year after me they came here  |
| 44 | Researcher: it means you know two or more women have affected with breast cancer after being in UAE, right?  |
| 45 | 3. Yes, I know more than three people those who affected by breast cancer and they are under treatment, either from Kerala or from Chennai.  |
| 46 | 4. My friend's friend she went to Kerala after diagnosing it from here.  |
| 47 | Researcher: Do you know how we can detect the breast cancer?   |
| 48 | 1. Mammography   |
| 49 | 2. Should do self-checks; if there is pain or any thickness in the breast it may help to detect the breast cancer in the beginning itself. Also, the mammography, but it is painful. |
| 50 | Researcher: As you said self-check, do you practice it?  |
| 51 | 2. I am not doing it. But I know many things but failing to apply in daily life.   |
| 52 | 3. I used to touch the breast to find out whether there are any thicknesses or not. Usually, I do it when I hear that someone diagnosed  |

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|    | with breast cancer.  |
| 53 | 4. I am not aware of the tests. May be blood tests will be available. Must check our breast more often.  |
| 54 | 3. Depending upon mensus. Must do checkup after the periods  |
| 55 | 5. No idea. Our gynecologist usually won't tell anything.  |
| 56 | 6. Mammography and whenever, we meet the gynecologist we can ask them to check our breast.   |
| 57 | Researcher: Are you doing?   |
| 58 | 3. No. we know many things but unfortunately, we are not following the procedures. That is the truth. We know something from here and there, may be through reading or hearing but does not have a proper and complete idea of it. |
| 59 | 4. Yes, when we hear will feel scared and think to do blood tests, not only for breast cancer, but also for all diseases. But do not practice it.  |
| 60 | Researcher: So, what do you think that will help you get motivated to do the tests?  |
| 61 | 4. I think like these kinds of discussions can motivate women. At least once in every year. This will help to get updated.   |
| 62 | 6. It is like we do with our children, constantly saying to do something and at least they will do some time.  |
| 63 | Researcher: Ok, I understood that some of you heard about mammogram. Do you know when and how the mammogram will be done?  |

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| 64 | 1. Heard of it but don't know, how it is tested.  |
| 65 | 2. I heard it is a painful test.  |
| 66 | 3. No idea  |
| 67 | 4. I do not know  |
| 68 | Researcher: Do you know which age group women should do mammogram?  |
| 69 | 1. Women should do mammogram at the age of 50   |
| 70 | 2. After 40 years that's what I heard.  |
| 71 | 3. Any age after puberty or if someone have breast cancer in the family   |
| 72 | Researcher: Do you agree that?  |
| 73 | 1. I doubt, I think we should do after the age of 40. Not sure anyway   |
| 74 | 2. In case of heredity a person can do checkup at any time. If someone in the family has disease, we can do the mammogram in early 40's.  |
| 75 | 3. My sister got breast cancer; she is in Fujairah, the doctor advised me to do mammogram. But scared. Worried if the result come positive, we can't afford. The whole family then will be in trouble in all means. So, live peacefully till it shows the symptoms. |
| 76 | 5. If we see some changes immediately we must do the test (screening mammogram)   |
| 77 | Researcher: Do you know when the best time will be to get an appointment for mammogram in any month?  |
| 78 | 6. A week after the end of menses that's what I heard. We don't know  |

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|    | exactly.   |
| 79 | 2. I think before periods we can do it. During periods maybe more painful that's what I think.   |
| 80 | 3. So I think a week after menses will be better but whether there will be a problem with the X-ray during that time?  |
| 81 | Researcher: Ok will tell you after our discussion. I hope that's Ok  |
| 82 | Researcher: Do you know where we have the facilities to undergo screening mammogram at UAE?  |
| 83 | 1. I don't know exactly about the place from where we can do screening mammogram. Some hospital they are conducting it, but I did not check it.  |
| 84 | 3. Everything costly, do not know  |
| 85 | Researcher: Do you know any hospital near by Sharjah which providing free screening mammogram?   |
| 86 | 1. I don't know the hospital which provides free screening mammogram nearby, but I got some WhatsApp messages that some hospital in Ajman is providing screening mammogram.  |
| 87 | 2. I think Zuleika hospital they may have, last year I heard but do not know whether this year they give it or not.  |
| 88 | 3. There are few places freely conducting the screening mammogram but don't know exactly. I will get the information through WhatsApp. They give messages about breast cancer also. But did not notice well. So, I am not sure |

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| 89  | 5. Not sure of it  |
| 90  | 6. No idea   |
| 91  | Researcher: Do you know when they conduct the screening mammography?   |
| 92  | 2. I heard that there is a cancer day, and on this particular day government conducts mammogram. It is the breast cancer day, I think in July. But it is for Arabs                               |
| 93  | 3. I think in October or November  |
| 94  | 4. Not aware of it   |
| 95  | 6. I do not know   |
| 96  | 5. Not aware of it, seen some advertisement in Facebook or WhatsApp long back  |
| 97  | Researcher: I understood that you usually get update about the facilities of screening mammogram available nearby of your place through social medias such as WhatsApp and Facebook, am I right? |
| 98  | 1. Yes, we come to know through the social medias.   |
| 99  | 2. Advertisements will be seen, but do not know whom and how to approach.  |
| 100 | 3. But I thought its part of the hospital's publicity.   |
| 101 | 4. Some hospitals give free dental checkup, glucose checkup and so on.   |
| 102 | Researcher: Do you have any idea where we can have screening mammogram in Kerala?  |

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| 105 | 3. In Kottayam there is hospital 'Bharat Hospital'. That hospital is providing screening mammogram.   |
| 106 | 4. In Trivandrum "medical college hospital" have mammogram machine. But do not know whether they are doing it or not  |
| 107 | Researcher: is the facility is available on all days and is it free of cost?  |
| 108 | 2. At Trivandrum Medical College I think it is free as its government hospital.   |
| 109 | 3. I think so, but who will have time to go there (in Kerala), for everything must wait in que for long hours.  |
| 110 | 4. Sometime the machines at government hospitals may not work, who knows, finally we will waste our time travelling long distance, waiting in the que. Cannot believe anything there not like here (UAE). |
| 111 | Researcher: It means in Kerala screening mammogram is not easily available you think, right?  |
| 112 | 1. Yeah, screening mammogram is not free in the Kerala.   |
| 113 | 2. I also have not heard about it   |
| 114 | 3. No, we don't know from where we can get a mammogram in Kerala.   |
| 115 | Do not know (all others)  |
| 116 | Researcher: I understood, you have idea about mammography and so on. Do you know the importance of it?  |
| 117 | It detects the cancer (everyone)  |
| 118 | Researcher: Do you know the importance of detecting cancer through  |

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|     | screening mammogram?   |
| 119 | 2. It detects immediately the size of it.  |
| 120 | 5. That is the test available to detect cancer.  |
| 121 | 7. It can detect the extension of disease if we find some changes in the breast  |
| 122 | 1. It can detect the disease early   |
| 123 | Researcher: I understood, you have some ideas about mammogram. Then why you have not undergone mammogram yet?  |
| 124 | 1. I don't feel that mammogram is necessary at present.  |
| 125 | 2. I don't have any symptom in my body, so I didn't go for the screening mammogram.  |
| 126 | 3. It's needed if anyone in my family has breast cancer. But scared even though  |
| 127 | 6. Did not think that still.   |
| 128 | Researcher: is there any other reason for you that you have not undergone screening mammography? Is distance of the hospital or any other reason?  |
| 129 | 1. No, no, I didn't feel the necessity up to now to do it, if I feel I can go anywhere and do the checkup (test). Distance is not a problem. Yet I didn't have any sign in my body, so I didn't do it. |
| 130 | 2. For me husband is needed, I do not drive. If I want to go anywhere, he has to come with me. Our work schedules are different too.   |



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| 131 | 3. If some friends are there, I think I would have gone, but as like she said I don't think that now I have to do, as there is no pain or bulging.   |
| 132 | 4. If it is that important, I think someone should gather everyone and take us. Like from our church, or employers. Otherwise if we go alone then people will think that I got some disease that's why I did it and need to answer everyone. |
| 133 | 3. I think there is pain and radiation in this procedure   |
| 134 | 7. If the test is important, we must go  |
| 135 | Researcher: Any barriers do you think that you face to do mammogram?   |
| 136 | Yes, in UAE money is one of the main problems, even though we have health insurance. (Everyone said)   |
| 137 | Researcher: are you covering through health insurance, does it cover this mammography?   |
| 138 | 1. It is not covering the entire checkup. Most of the tests can be done by the health insurance. Not sure about this test.   |
| 139 | 2. I do not know whether they cover this or not  |
| 140 | 3. If doctor prescribe, I think they will do after permission from the insurance as like we wait for our medicine approval. Any way I don't know   |
| 141 | 7. No idea of it. If doctor prescribe then they may give   |
| 142 | Researcher: Do you feel this as a barrier to do mammography?   |
| 143 | 1. The people those who have financial crisis, they never do such kind of checkup. Also, it is not a routine to undergo check-ups here for these, if   |

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|     | there is no problem.  |
| 144 | 2. I will not go for a mammogram because I have lots of responsibilities in the family. Because of my responsibilities, I can't spend money and time for a mammogram. Those who have family and job it's difficult to go. |
| 145 | Researcher: Ok, what is your opinion to have a health day for employees for the medical checkup including mammogram?  |
| 146 | 1. Good idea, At least once in a year a staff should get this opportunity for the medical check up.   |
| 147 | 2. Yes. Getting a holiday for the medical checkup is too necessary. Usually it is difficult to manage the time between home, job, husband job   |
| 148 | 3. Most of the employees avoid the medical checkup because of the lack of time.   |
| 149 | Researcher: Ok, that will be very useful for you all. Right.  |
| 150 | Yes, we also feel that our employers are taking care about our health also.   |
| 151 | Researcher: It means you are not being a self-efficient because of your responsibility, needs and all, right.   |
| 152 | 7. As I am having a busy life along with family, I don't have enough time to go and sit in the hospital for the mammogram or any of these tests.  |
| 153 | 1. Also, for us Ok, but if you look to the ladies in the labor camp, they have less salary, most probably they get salary in between 500 – 850 AED. In these cases, they don't have any facilities to go for such kind of |

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|     | checkups. How they can do mammogram in their salary?  |
| 154 | 1. It will be helpful for the people those who are suffering by financial crisis. As they are AED 500 to 800, it is impossible for them to do mammogram. They must take care of their family, education of their children. For them finance is an important hindrance to undergo mammogram. |
| 155 | 2. For the women in labor camps not only finance but also holidays are very important. Most of the labors do not have a holiday in a month. They are supposed to work every day.  |
| 156 | 1. Yes, they can do the medical checkup only on the holidays. One of the facts is that, even ordinary medical checkup are not available for them.   |
| 157 | 2. Medical checkup are not free for the labors even those who have health insurance, they have to pay 20 to 30 percentage of cost They deduct the money from their salaries.  |
| 158 | 6. Women they report any disease and take off from their duties when they cannot move from their bed. They are struggling a lot to survive in those small rooms even.   |
| 159 | Researcher: It needs attention. Right? Ok, if you get free screening mammogram, do you like to do at your own place in Kerala or in the UAE?  |
| 160 | 1. If we get a free mammogram, we would like to do in UAE itself.   |
| 161 | 2. Yeah here, my friend said in Kerala the test is painful, as she did it again here after she came here.   |
| 162 | 3. Wastage of time in Kerala, if we go to the hospital here (UAE) it is   |

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|     | organized.  |
| 163 | 4. Yes you know, there may not be a doctor or machine may fail in Kerala  |
| 164 | 5. UAE only. Here they use latest machines.   |
| 165 | Researcher: Someone said, yearly you are getting message about the availability of mammography in UAE. Right? So, do you think if they make it available more often, does it may allow you to think to undergo screening mammography? |
| 166 | 1. If we have some changes in the breast, must wait for one year.   |
| 167 | 2. If we get a chance for the free, that will be very helpful for many of us those who are suffering by financial crisis. Many people will come forward to do this test too.  |
| 168 | 3. Here more free facilities are available for the locals. Do not think like it is available for people like us.  |
| 169 | 3. If we get a chance at least 4 times in a year that can be for everyone (expatriates). People can utilize it during one time or other.  |
| 170 | Researcher: What are the other facilities will be helpful for you to do mammogram? I mean, transportation, cancer identification checkup in any hospital near to your home, what will be the facilitating factor for the same?        |
| 171 | 1. If I get near to my home that will be good for me. So I can easily reach there in my limited time.   |
| 172 | 2. Find out an area, and conduct free mammogram in the location where more breast cancer survivors are living. That will be helpful.  |

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| 173 | 3. There is no meaning if government provides one or two places in UAE. If free mammogram facility available far away from my home there will be transportation problem. It will be difficult to reach there. |
| 174 | 5. Transportation helps in the morning time   |
| 175 | Researcher: it means that transportation is a major factor for you? Right   |
| 176 | 1. Yes (everyone)   |
| 177 | Researcher: Who can influence you to motivate you to do mammography?  |
| 178 | 1. Friends  |
| 179 | 2. Daughter   |
| 180 | 3. Mother   |
| 181 | 4. Husband  |
| 182 | Researcher: What is the role of your husband? Do you think if he tells will you undergo screening mammography?  |
| 183 | 1. Surely I will go; it will be pleasure to hear from my husband.   |
| 184 | 2. Most of the women are waiting to hear from the husband. But most of the cases husbands are not saying it.  |
| 185 | 3. My husband is a tension husband. He will get tension first. So better will not inform him or will not go for it.   |
| 186 | 7. Husband definitely influences us to take any decision.   |
| 187 | Researcher: What can be done to remove the tension of husband?  |

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| 188 | 3. Awareness is very important to husband and to everyone in the family, friends, and co-workers also.  |
| 189 | 4. They usually won't have to time to think about these. We all will spend some time on Fridays.  |
| 190 | (All agreed)  |
| 191 | Researcher: As you all said, husband and friends have role to influence you, does media have any role to influence you?                         |
| 192 | 1. Yes, media have an important role because knowledge of a friend has limitation. But media can share all in detail quickly.                   |
| 193 | Knowledge of a friend has limitation for media will share all in detail. We can get answer to all doubt. We feel to believe on reliable medias. |
| 194 | 2. But breast cancer awareness classes are very few in the medias, in Malayalam   |
| 195 | 2. There is a program called "Let's ask to doctor" once they discussed about breast cancer in this program. I could see that.                   |
| 196 | 3. Sometime hospital adds will be there about the machines available, but I have not thought of this service                                    |
| 197 | 5. Hospital advertisements once in a while it comes.  |
| 198 | 3.TV program once I tried to call, but everyone will not get a chance to talk   |
| 199 | 7. But we do not know, and the importance of it. I thought may be it is their business add  |

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| 200 | Researcher: If someone come and say that 'I was affected by cancer. It was found early and could do the treatment and conveyed that she is doing well. Is it will be an inspiration for you to undergo screening mammography?      |
| 201 | Yes, that will be an inspiration to hear from others. (Majority of women agreed)   |
| 202 | 2. But it can cause problem to the women affected. When people ask questions about their difficult times.  |
| 203 | 3. People will look her with sympathy.   |
| 204 | Researcher: So does it means that survivor can influence others to some extent, right.   |
| 205 | Surely (Majority agreed).  |
| 206 | Researcher: Can any religious leaders (priest of your faith) influence you to guide you to undergo mammogram?  |
| 207 | 1.Yes. I personally believe that a religious leader can influence a person to undergo mammogram.   |
| 208 | 2. If any leader of small community say to the group women consider their suggestions. But they can surely influence the group of people.  |
| 209 | 3.I think, even the leaders of a small or big community can also conduct cancer awareness classes and provide the mammogram facilities. If they do so, that will be better and easy for the people, many persons can undergo this. |
| 210 | 5. If the leader is male, may be, they may not share with the women  |

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| 211 | Researcher: What about educational institutions, do you ever think that a school or university can do something for it?   |
| 212 | 1. University can do lot. They can conduct cancer awareness classes in each city so that ordinary people can understand more about breast cancer and necessity of mammogram.              |
| 213 | 2. They can provide a one-day class, so that it will give us a better understanding. They can make a tie up with our neighboring hospitals and provide medical checkup.                   |
| 214 | 3. University hospital can provide free checkup.  |
| 215 | 4. Universities have lot of transportation facilities like buses; they can provide transportation and conduct mammogram facilities in the university itself as part of community services |
| 216 | 5. Students also learn about the disease and can share with their relatives too.  |
| 217 | 1.Yes, if they are aware about this, they will go back to home and tell to their parents.   |
| 218 | 2. If they get an understanding of this, they can teach and take classes for others.  |
| 219 | 3. After a few years, they will reach an age where the diseases are common and then they can avoid it and will be helpful for others too.   |
| 220 | Researcher: What do you think if mammography is required to do, what strategy do you prefer from the government or any hospital or anyone?  |
| 221 | 1. All details concerning a person are available in the insurance plan. So the government can look at it and provide treatment or check-up.   |



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| 222 | 3. Government can collect the data through NORKA, they can come to know about our age.  |
| 223 | 5. The government or hospital we visited for any reason will definitely have our date of birth. So they can inform us.  |
| 224 | 4. NORKA can do something for us too  |
| 225 | Researcher: what kind of method they should choose to inform the women? I mean call, SMS  |
| 226 | 1. Up to now such kind of SMS system concerning medical checkup is not available. If they start in UAE will be more helpful to everyone. But I do not know whether people consider it serious unless they know about it.  |
| 227 | 2. If government start such a system that function should be secure. If the government give details about a person, that may have demerits. There is a chance to misuse our details. No one will give their details to a private organisation. Data should be collected by an accredited agency and they have to inform the client. If it will be like this that will be helpful for all of us. |
| 228 | 3. I think government has our details so that they are sending messages in special festivals day. So if government has a plan they can easily forward messages to us.   |
| 229 | 1. If the organisation itself take a step for their employees that will be very appreciable and every one will be informed.   |
| 230 | 2. Otherwise if someone from office hears that I have undergone this test, they think I have cancer, otherwise have to prove to them.   |

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| 231 | 5. I am not working, so that is Ok for me, but if someone knows that I underwent everyone will start asking about it. It is not a routine practice to undergo these tests.  |
| 232 | Researcher: you mean employer have to take a role?  |
| 233 | 1. Yes, especially in the schools more than 80% of Malayali teachers are working if management takes a decision that will be very helpful for all the staffs.   |
| 234 | 2. Not only teachers but also the students can get a chance to inform to their parents.   |
| 235 | 3. Awareness class and mammogram in the school and university are a better idea. Students can inform their parents. If school or university conveys this everyone will believe.   |
| 236 | 7. If the message comes through WhatsApp, every WhatsApp messages will not be considered as valuable. Every people have one or another community or gatherings. First of all the organizer should approach the community leader and convince them, that leader can inform the community. They can share the message to the members of their community |
| 237 | 3. Yes most of us will listen to the group leader. They usually make the message clear and share with their group members. This discussion also happened like that.   |
| 238 | Researcher: it means, you are concluding that a leader have major role to convey the information and lead others to do mammogram.   |
| 239 | 1. Yes I believe that. Today we all gathered here as a meeting because one of our community leader shared the research paper (participant   |

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|     | <p>information sheet) and about you. When a leader came to know about such kind of program, firstly the leader would enquire about the program, if it is believable he/she will inform to the community members. Today's discussion is an example for it. In our community we have many members those who are the employees of various organisations. They can collect appropriate information and convey to us. So I can strongly say that a community can influence a person to do mammogram. These leaders are living in UAE since from the long years. So they can enquire about news easily.</p> |
| 240 | <p>Researcher: What do you think about our Kerala government's role?</p>  |
| 241 | <p>1. They are not doing anything for our health. In Kerala if we go, the private hospitals have special packages for us. (Increased price)</p>   |
| 242 | <p>7. They can have tie up with the hospitals here, may be. Many hospitals are here with many facilities. Most of the time we are staying in UAE only. During vacation we go to Kerala</p>  |
| 243 | <p>3. Should provide opportunity at Kerala for us during our visit there in Kerala at various hospitals.</p>  |
| 244 | <p>4. But our relatives, neighbors there they should know about it. They will make a big publicity that there is cancer and may ignore us also</p>  |
| 245 | <p>5. Yes, most of them are scared of it.</p>   |
| 246 | <p>Researcher: How they can be influenced by the government?</p>  |
| 247 | <p>3. Can provide awareness classes to them</p>   |
| 248 | <p>6. There are PHCs in Kerala, health inspectors also</p>  |
| 249 | <p>5. Kudumbasree, where women gather and discuss many things. Not</p>  |

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|     | sure, whether it is there now, but there are many gatherings in our local community   |
| 250 | 6. Compare to women here (in UAE), they have more time and easily accessible to their location near to their houses (in Kerala).  |
| 251 | Researcher: You shared many things. Do you like to add anything more to this discussion?  |
| 252 | 1. If a person came to know that she is diagnosed with breast cancer however that person and family become panic, if so how we can approach that person and console? What they will do? These are also reasons for many women not to think of these tests and to get into trouble. No one is there to support them, apart from their close family members and friends |
| 253 | Researcher: Ok you mean there is no system or no one to follow up them?   |
| 254 | Yes   |
| 255 | Researcher: Ok, yes it is a good thought  |
| 256 | Researcher: Anything else to share?   |
| 257 | 3. Moral or mental support is also very important. The community can encourage that person also. Now that is not available too  |
| 258 | Researcher: Anything else? Otherwise, we are going to wind up this discussion. Thank you for your participation and I value your thoughts and views.  |

## Appendix M Transcript Focus Group Discussion 4

Population 2 Not undergone

| Identification | Participants statements  |
|----------------|--|
| 1              | 1. Researcher: Who will take decisions about your health?  |
| 2              | 1. I am taking decision myself.  |
| 3              | Researcher: Oh, good, What is the reason?  |
| 4              | 1. I can only know or find if there is any problem in my body. It will help me to discuss with doctors.  |
| 5              | Researcher: What about others. Are you also taking decision by yourself?   |
| 6              | 2. Normally some women are too much worried and if I tell to husband he usually says that don't worry and you don't have any problem. In this circumstance we are taking decision even if it is little or too much pain.   |
| 7              | Researcher: If you share to your husband does he support you to consult a doctor?  |
| 8              | 3. My husband normally never cares or even has time to think about my pain. So he never takes it seriously. But if it is a severe pain he used to take me to the hospital. Mainly he does not have time, he used to come late home from work and he will be tired. |
| 9              | What about others, are you taking decisions by yourself?   |
| 10             | 5. In my life, husband usually supports me to go for check-ups. He used to take me to the hospital for consultation. We are under our husband's care. If we want to go out need husband. So everything we will tell to him.  |

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| 11 | 4. In my case, I will observe for two days and check whether the pain is decreasing or increasing, if it increases I used to tell to my husband. The reason behind it is that, if I say always about my pain he will be in tension all the time. So I normally observe for two-three days. Then he will take me to the doctor. |
| 12 | Researcher: I could understand that you all are taking the the decision yourself about your health but you inform your husband. Do you agree?  |
| 13 | 3. Really, here in this meeting only we got opportunity to share these things. Always we discuss and inform our health related issues with our own family, before going for check-ups.   |
| 14 | 2. Informing husband or family members is our routine; maybe I think it's our family routine too.  |
| 15 | 3. Yeah now WhatsApp or phone calls can be made daily or each minute we can convey everything to the family in Kerala too. Even I talk with my sister every day. She is in Karnataka.  |
| 16 | 4. I think most routinely we say our concerns to our husband first then to anyone else.  |
| 17 | Researcher: Ok, good. What do you know about breast cancer?  |
| 18 | Fear (all)   |
| 19 | 2. Scared even to hear the word 'breast cancer'.   |
| 20 | 3. Fate, what else   |
| 21 | 4. Death within one or two years. It is like a death notice. My husband's colleague's wife died immediately after noticing it, within few years.   |
| 22 | Researcher: Oh, you all are fear to hear the word breast cancer?   |

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| 23 | Yes it is a word to cause fear (all).   |
| 24 | Researcher: Ok, why so what do you know about breast cancer?  |
| 25 | 1. My mother died before 14 years. She died when she was 55 years. So I am too scared about the breast cancer. My husband always says to do check- up every year. I am scared a lot about breast cancer because I was the one who saw the death of my mother. May be that will be the reason for the fear. Usually all my sisters and sister in law and my husband compel me to go for check- up. But because of the fear I even don't go to a hospital for check- ups and it is because of the fear related to the death of my mother with this disease. |
| 26 | Researcher: Oh, you feel fear in your mind, right.  |
| 27 | 3. By hearing the word breast cancer it makes me scared. Actually today I even had fear to come here for this meeting.  |
| 28 | 6. It is a deadly disease   |
| 29 | Researcher: Don't worry. Everything will be all right. We can talk about it. Ok.  |
| 30 | 4. It is a self-growth.   |
| 31 | 5. Breast cancer appears first as a thickness in the breast.  |
| 32 | 3. Yes, that is my knowledge about the breast cancer.   |
| 33 | 4. Should feel some abnormality in the breast.  |
| 34 | Researcher: Ok. What about others?  |
| 35 | 6. Fluid will come out from the breast through nipple.  |
| 36 | 3. If there is colour change in the breast. Then we should meet the doctor  |

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| 37 | 4. Scar in the breast, then we should meet the doctor   |
| 38 | Researcher: What are the possible reasons for breast cancer?  |
| 39 | 1. Food habits  |
| 40 | 2. Lack of exercise.  |
| 41 | 3. Overweight   |
| 42 | 4. Cancer can come to the women one who didn't breast feed.   |
| 43 | 5. Hereditary is another cause for the breast cancer.   |
| 44 | 6. Changes of hormones also being a cause for the breast cancer.  |
| 45 | Researcher: Do you know someone who had diagnosed with breast cancer after staying in UAE?  |
| 46 | 1. Yes, Know  |
| 47 | Researcher: How many women do you know?   |
| 48 | 1. When I went to the hospital for a check-up, I met a lady named (xxxxx).  |
| 49 | Researcher: at Kerala or UAE?   |
| 50 | 1. Here in UAE only. I felt sad about her family and I took her number we became friends and with her family. Anyway she is no more.                                |
| 51 | Researcher: How old was she? Do you know, how many years before she reached UAE?  |
| 52 | 1. She came here right after her marriage. I think at around 20 or 22 she got married. I remember like that. She was around 43-45 years when I met her at hospital. |



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| 53 | Researcher: ok, whether do you know anyone else?  |
| 54 | 3. Are you asking about the women who affected by cancer after they came to UAE?  |
| 55 | Researcher: Yeah  |
| 56 | 6. I know a teacher; she was the teacher of my daughter. She had affected by the breast cancer, I don't have regular contact with her. But my daughter used to tell about her. My daughter told me about her, and then I became curious about that teacher, one of my cousins was also teaching in the same school. So I asked about the teacher and her disease. She said to me that the teacher got breast cancer. She died in UAE and took her body to Kerala. |
| 57 | Researcher: Ok, what about others, do you know anyone?  |
| 58 | 2. I don't know about here. But in Kerala, there are many whom I know.  |
| 59 | 5. I heard about many persons through my colleagues and friends but I don't have direct contact with them. I was scared so I did not ask anything more about them.  |
| 60 | Researcher: Ok, do you know, how can we detect breast cancer?   |
| 61 | 6. Self-detection   |
| 62 | Researcher: Self-detection, do you know, how and when to do self-detection?   |
| 63 | 1. After 10 days of periods have to do  |
| 64 | 2. Should press the breast and check  |
| 65 | 3. My friend said about an X-ray test. But painful it seems and radiation is used.  |
| 66 | Researcher: ok, then  |

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| 67 | 1. My mother was diagnosed by breast cancer, she felt like boiling water pouring into her breast. She felt like burning at the beginning. Because of this she consulted the doctor. But at that time breast cancer was in its final stage. That's what she said, mom has good knowledge, and she is person one who is reading lot. Even though we couldn't realize the disease at beginning. We only came to know after my mother felt like this in her breast. |
| 68 | Researcher: Ok, according to you X-ray test and self-detection are the two tests to identify the breast cancer. Right?  |
| 69 | Researcher: Is there any other way to check the breast cancer?  |
| 70 | 1. During medical check-up our doctors can examine us.  |
| 71 | Not sure (all others said)  |
| 72 | Researcher: Did you all heard about Mammogram?  |
| 73 | 3. Yeah that is the X-ray test I think my friend said. Not sure. It is the X-ray test right?  |
| 74 | Yeah heard about it (many said)   |
| 75 | Researcher: Do you know how mammography is done?  |
| 76 | Don't know (few)  |
| 77 | 3. X-ray is used to do mammogram.   |
| 78 | 1. I know its painful (most of them agreed)   |
| 79 | 2. I actually don't know about it. They are using lots of machines.   |
| 80 | Researcher: ok, then  |
| 81 | 1. Mammogram is very painful. Because of this reasons many women are not  |

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|    | going to do it.   |
| 82 | 2. I think it is similar to how we check like when we are pregnant, like that machine.  |
| 83 | 5. It is like scanning. One type of instrument they will use to press and move over the entire breast to do mammogram. It will be too painful.  |
| 84 | Researcher: Do you know at what age mammography needs to be done?   |
| 85 | 1. After 40 years. Our family physician said to me to do it. But I am scared, I saw my mom suffering, I believe in God. God will not put the suffering to me or anyone else in the family.  |
| 86 | 2. I don't not know when we have to do  |
| 87 | 3. I think if we see some changes immediately have to do it   |
| 88 | (Most of them agreed)   |
| 89 | Researcher: Do you know where mammogram is available in UAE?  |
| 90 | 1. Zulekha Hospital.  |
| 91 | 3. Dubai Aster, they used to conduct camp in some of the clinics. They informed us that they are going to conduct free tests, so we went on that day and they just did check up by hand and informed us to go to Dubai hospital to undergo mammogram. And they offered discount in the payment for mammography. |
| 92 | 4. Yes, Zulekha   |
| 93 | 6. On behalf of some ministry organisation provides free detection program for cancer. Not sure.  |
| 94 | Researcher: Ok. On behalf of Ministry there are facilities to do mammogram in   |

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|     | some clinics. Right?  |
| 95  | 6. Some advertisements were seen in Newspaper but do not know much about it. Did not look into much detail for it.  |
| 96  | 5. I remember something like that I also saw but did not check further  |
| 97  | 2. Every October group of people is coming and conducting some tests.   |
| 98  | Researcher: Is it a mobile unit, van like thing? Is that you are trying to convey?  |
| 99  | 2. I don't know about that. Someone said that some tests are available  |
| 100 | 3. I do not know  |
| 101 | 1. That's the Pink Caravan  |
| 102 | Researcher: What do you think of conveying this message to reach all the women?   |
| 103 | 1. Information about it is also showing in the Gulf News channel, even in newspapers also   |
| 104 | Researcher: Have you all had newspaper at home?   |
| 105 | Yes many of them agreed   |
| 106 | 5. I came to know by WhatsApp or Facebook. But usually we do not take care of it much, feels not required for us  |
| 107 | 3. In the month of October (whole month) used to see pink badges and ribbon in every hospitals and in shopping malls. Thought to have healthy life style and to get rid of breast cancer. Every year it reminds us about breast cancer. |
| 108 | 5. But no one is following it   |

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| 109 | Researcher: Do you know any place near to do mammogram in Kerala?   |
| 110 | 1. In Thrissur hospital: they are providing mammogram. It is not free. My mother went there for all tests. We have to pay for everything.   |
| 111 | 4. I am here for 14 years. I am not aware of any thing there  |
| 112 | Do not know (many of them)  |
| 113 | Researcher: Why you have not undergone mammography?   |
| 114 | Researcher: Do you think if you get any facility near to your house whether you would have undergone mammography?   |
| 115 | 1. See, I am scared because of my mom. She noticed some burning sensation and redness and she went for just check- up. But ended up with breast cancer and I trust in God                                       |
| 116 | 3. My friend told about this test. But as there is no changes do not think that I may go  |
| 117 | 4. Mainly I think women are not much aware of this. If we hear also we do not know what needs to be done and how and when   |
| 118 | 6. In the evening most of the women cannot leave the house. Every woman have lots of responsibilities in their home, I have to take care of my children and husband. I can't leave it. It is my responsibility. |
| 119 | 3. My friend did the tests from UAE only. Through **** hospital. But I do not know much about their time and availability.  |
| 120 | 6. I think in Ajman nothing. If it is next to our home I may be able to know it   |
| 121 | 3. I think tests are there in October. But like me many are not serious about it  |

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| 122 | Researcher: Ok in UAE; you are getting the facilities to do mammogram in the month of October, right?  |
| 123 | 1. In one or other way it is fear.   |
| 124 | 2. Actually many knows about these tests from here and there. But no clear idea. When we are discussing now, I am trying to recollect those.   |
| 125 | 5. Also, I heard it is dangerous to do these tests without any reason  |
| 126 | Researcher: Well, some of you know about it then why you didn't undergo mammogram. I understood that you have seen advertisements, or friend informed and so on...   |
| 127 | 1. Some people also told that it would affect the body and harm for our body.  |
| 128 | Researcher: You find it as a reason, what about others?  |
| 129 | 1. Once when I went to Kerala for routine check-ups as usual every year we do, even though i was scared. My doctor said to do mammogram along with health check-up. But I did not get appointment. Actually i became happy and there is lack of time to wait. Thus I didn't undergo mammogram. |
| 130 | Researcher: You didn't undergo mammogram because you couldn't get the chance to do mammogram along with your routine medical check-up, and lack of time, am I right?   |
| 131 | 1. Yes.  |
| 132 | 2. Time for us there in Kerala is very important   |
|     | Researcher: Here in UAE free mammograms are available then what time will be good for you?   |

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| 133 | 1. Morning time. (Many). But for working women according to their holidays. If it is available throughout can manage ourselves and even can get it when we go for other tests.           |
| 134 | Researcher: Ok what about reaching to the hospital?  |
| 135 | Of course, transportation is a barrier for us. Many of us do not have driving licence. (Many agreed). (Noisy could not hear completely)  |
| 136 | Researcher: if it is important to do. Where do you prefer to do it while you go to Kerala or in UAE?   |
| 137 | 1. Like to do the tests in Kerala.   |
| 138 | 2. Money is factor to do check-ups in Kerala.  |
| 139 | 3. No, for me in UAE, here everything available and they are caring  |
| 140 | 6. Private hospital takes lots of money. If insurance is there that's ok   |
| 141 | Researcher: What facilities will encourage you to undergo mammogram in the UAE or in Kerala?   |
| 142 | 1. To do check-up in UAE is very expensive comparing to Kerala. So we use to plan to do all check-ups in Kerala. During the time of vacation most of us do routine check- ups in Kerala. |
| 143 | Researcher: Ok. You are expecting to do the entire check-up while you go to Kerala during the Vacation. Right?   |
| 144 | 1. Yeah  |
| 145 | Researcher: Most of the Keralites go to Kerala from UAE during the month of June, July and August.   |

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| 146 | Researcher: In order to do mammograms do you expect any special facilities from Kerala government to the Keralites from UAE? Example: if I get these types of facilities, I would go. If these facilities were available to me when I went to Kerala, I would have undergone.                                       |
| 147 | 5. I expect to get free check- ups. That will be helpful for those who have financial crisis.   |
| 149 | 1. Appointment system for the expatriates during our limited time in Kerala is difficult. The hospitals should consider it.   |
| 150 | 1. A special counter for expatriates (avoid appointment waiting time for us)  |
| 151 | Researcher: What kind of help do you expect from government?  |
| 152 | 4. Kerala government is not providing any facilities for us. If we go to a hospital, government offices to get certificates there are lot of procedures to go through. We can't do it all with our limited vacation. If government started to consider us. It will be really good help from the side of government. |
| 153 | 2. Now there are many ID cards are emerging day by day in India. We have only limited days there. During those periods we have to complete all formalities to get Aadhar Card and so on.  |
| 154 | 3. If I want to get a medical certificate and for check-ups, we have to wait in long queues. Because of this reason I do not like to go to hospital for check-ups there.  |
| 155 | 4. For check-up we have to show our ID, Ration Card, etc. even in hospitals too.  |
|     | Researcher: Do you want to show these proofs in the hospital too?   |
| 156 | Yes (many agreed)   |



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| 157 | 4. There should be a facility to get special consideration in hospital by showing the passport.   |
| 158 | 1. In small hospitals if they come to know that we are coming from abroad they will increase the charge of check-up. During last vacation I went for the routine check-up. I was in the queue. Because of the lack of time I went to the officer room and said that I am in need to do check-up urgently because in need to go UAE. They considered me, provided a smart lady along with me and took me everywhere without a queue everything done but billed too much. |
| 159 | 2. Even if the doctors came to know that we are NRI then they will increase the fee.  |
| 160 | 3. They prescribe for unnecessary investigations to earn money.   |
| 161 | 5. If we approach a dental doctor, we have to convey our need to go back to the UAE. So dental doctor always charge high fee.   |
| 162 | Researcher: You experienced these almost in all private hospital and clinic, am I right?  |
| 163 | 1. Yes, they are thinking that we have lots of money.   |
| 164 | 2. Many of us undergo routine health check- ups. It is a fixed package. May be the hospital can add into it with little more charge if this test is very good.  |
| 165 | Yes (everyone agreed)   |
| 166 | Researcher: Now free mammogram is available in the UAE. It is free and almost near to your places then why you didn't do it? I can understand that you are living near to those facilities  |
| 167 | 4. No one clearly told to us about it. In the morning we are going to office and coming back, it is our daily routine.  |

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| 168 | 2. We also did not get information about the availability of mammography. As said I have seen some ads, but not aware of the importance of it.   |
| 169 | Researcher: Ok, lack of information about the availability is one of the problems then,  |
| 170 | 5. I am depending upon husband and his salary. I usually plan to go for any check-up when he gets the salary.  |
| 171 | Researcher: I think, there are Muslims, Hindus, Christian communities, and schools are here. Can they influence or inform you to do mammography? What is your opinion?   |
| 172 | 1. In case of our disease these leaders do not have any role. But we may consider their suggestions  |
| 173 | 2. They can inform us. However, we should have our own desire and will. If I have any disease I, myself have to decide whether I want to go or not.  |
| 174 | 3. If I need to go for medical check-up, I shall go for that. No need to wait for leaders.   |
| 175 | 5. They can also influence largely.  |
| 176 | 4. I agree with it.  |
| 177 | Researcher: Do you think the school has any role?  |
| 178 | 4. In the assembly the school authorities gave pink ribbon to the children last year. They can inform about the availability of the tests.   |
| 179 | Yes (many of them). But didn't have that much importance for it. They should give awareness classes about the disease to the parents and students. There are many Indian schools; even Kerala management schools are there. They can |

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|     | teach us.   |
| 180 | Researcher: Do you feel that if the universities provide awareness classes there can be any influence?  |
| 181 | 1. Teenagers, they can influence their mother to do mammogram. They will help us to recall the necessity of it. They also will know about it  |
| 182 | 2. If universities provide awareness classes for the teenage girl, that will be useful, I don't know about boys, they do not share anything at home.  |
| 183 | Researcher: We have many Kerala community organisations; Do they have any role?   |
| 184 | Yes (all)   |
| 185 | 2. In our Indian association or churches if classes are there many people will come. In one or other place Kerala women get awareness about it.   |
| 186 | Researcher: Ok, you are thinking that community centres can influence, right?   |
| 187 | 1. Yes  |
| 188 | Researcher: Are you all agreeing with this point?   |
| 189 | Yes (all)   |
| 190 | 3. This community even started few days before only. It is functioning very smoothly, conducting many health activities. All members are very active and gather together whenever our leaders inform us.  |
| 191 | 2. One day while all community members gathered in a park for funny games, a person from a clinic approached our leader and offered an awareness class about some topic (I don't know what was the topic). Our leaders agreed to invite them to one of our gatherings. But when we gathered next time the |

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|     | clinic people were not available.   |
| 192 | 5. Of course, today we could gather as our community leader introduced you to us.   |
| 193 | 4. Usually, she informs us about the important events, then we used to gather.  |
| 194 | Researcher: Can the media influence you to undergo mammography? Many of you came to know about the facilities of mammogram through newspaper advertisements and so on right?  |
| 195 | 1. Yes (all)  |
| 196 | 2. Yes, because, media can reach to many people   |
| 197 | 3. But I think we are not considering it seriously. If there are columns mentioning the person who affected by breast cancer, message by a doctor, how the client is now, how they recovered from the disease. Media can include these all to create awareness. |
| 198 | 4. Yes if it is just advertisement Women will not consider it. Something, like she said, is added, then it may catch the attention (many agreed)  |
| 199 | Researcher: Ok, Which are the Medias you normally use?  |
| 200 | 1. Newspaper, magazines   |
| 201 | 2. Television, Radio  |
| 202 | 3. Internet   |
| 203 | 6. Facebook and WhatsApp, most of us use.   |
| 204 | 4. Facebook, WhatsApp   |
| 205 | 5. Now I think more common is the Whats app   |

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| 206 | Researcher: Ok, what else do you think?  |
| 207 | 1. Fear is a reason that is not allowing us to go for mammogram.   |
| 208 | 2. If diagnosed mental problems will arise and find difficult to face the results too.   |
| 209 | 6. But if we are not aware about the importance of it. No one is going to consider it. We get many messages. When a new doctor joins a hospital, they send messages. Therefore, if we do not have any disease related to the speciality of that doctor we would not consider those messages. |
| 210 | Researcher: yeah correct. I think you are trying to convey that some strategies should be there to convey relevant messages. Right?  |
| 211 | Yes correct (everyone agreed)  |
| 212 | Researcher: Do health insurance have any role?   |
| 213 | 5. If all check-ups are covered in the health insurance, it is good.   |
| 214 | Yes (all)  |
| 215 | 2. It is sure that we will go and do the check-up.   |
| 216 | Researcher: or may still be afraid?  |
| 217 | 1. Yes, fear is there.   |
| 218 | Researcher: What can change your fear?   |
| 219 | 1. I think some sessions. Mainly psychological support is required.  |
| 220 | 4. Awareness classes and mental support  |
| 221 | All agreed   |

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| 222 | Researcher: What about the role of our Kerala government? Do you think they have any role?  |
| 223 | Yes (all)   |
| 224 | 2. At present, when we come to UAE chest x-ray is compulsory. if the government makes it as compulsory everyone will do it                      |
| 225 | 3. The government should inform then women will do it.  |
| 226 | Yes   |
| 227 | Researcher: Is it will be good? What is your opinion?   |
| 228 | 1. That (invitation by the government) will be better; it will help us to overcome the fear. Then women will start to think that we must do it. |
| 229 | 3. Otherwise, we feel that only the women who are interested to know their breast only will do it.  |
| 230 | 6. The government should inform about the importance of it and should give facilities without time constraints.                                 |
| 231 | Researcher: Do you mean, appointment date is a problem, right?  |
| 232 | Yes (many of them agreed)   |
| 233 | Researcher: What are you expecting from the health organisations? DO you expect any health care facilities for Malayalees?                      |
| 234 | Yes (all)   |
| 235 | 2. But doing mammogram in UAE is very expensive.  |
| 236 | 3. Provide free mammography for the non-locals in UAE throughout the year.  |

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| 237 | Researcher: But, we have a free mammogram in UAE? Apart from this, what do you think a health organisation can do for the Malayalees in the UAE?  |
| 238 | 1. Bring well experienced gynaecologist from Kerala. If these doctors open a clinic for Keralites, it will be more comfortable for us.  |
| 239 | Researcher: Ok, how the health care organisation can involve in bringing qualified doctors to UAE?  |
| 240 | 1. If the health care organisation conduct such camps in any clinic or hospital it will be helpful.<br><br>If they inform that a Kerala doctor is available, many women feel comfortable to go. Because we will have a common understanding of our problems and concerns.                                   |
| 241 | 2. But here the doctors who are not Malayalees, it is difficult to share our concerns.  |
| 242 | Researcher: Do you prefer Malayalee doctors for the Malayalees?   |
| 243 | Of course (all)   |
| 244 | 2. It will help us to communicate easily and we can talk to them, and share our exact feeling to them.  |
| 245 | 3. We can say our disease openly to Malayalee doctors.  |
| 246 | 4. We are expecting good care from them.  |
| 247 | Researcher: When the screening mammography is available, how can it be informed to you? What methods do you expect to get information? You already said about newspaper but it did not influence you to go for mammogram. What will encourage you to do mammogram? Is it newspaper alone, or anything else, |

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|     | which media can influence you a lot?  |
| 248 | 1. WhatsApp is a good media mostly all of us are using it. All messages of our community activities and other messages are shared through WhatsApp.   |
| 249 | 2. If a person in our group comes to know about it, especially our xxxxxx (name of their community head), she will share this information to the group that will help us to know well.                |
| 250 | Researcher: Do you like to get information to do mammogram when you reach the appropriate age, I mean at 40 or after that?  |
| 251 | Yes (all)   |
| 252 | 2. Now I started to think about doing mammography. I already passed 40  |
| 253 | 3. Normally women will not say their age in public.   |
| 254 | 4. Automatic calling system can help us.  |
| 255 | 6. In Passport and in emirates ID very clearly mentioned about our date of birth. So they can inform us   |
| 256 | 1. If the government inform us to do mammogram for example during the renewal period of passport we will surely do a mammogram. People will consider it serious. They understand that it is important |
| 257 | Yes, otherwise if it is private hospitals we may think it is their advertisement.<br>(most of them agreed)  |
| 258 | 1. When we first go to a hospital they will collect our details the hospitals can remind us   |
| 259 | 2. Yes, if they send the message to remind what have to do in particular age  |



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|     | that will be a good media to do our check- up on time.  |
| 260 | 3. If they do so that is good.  |
| 261 | 4. There is another one side for it, if they send the message to remind us. We will think that now check- up is not necessary because I don't have any problem.                 |
| 262 | 5. Yeah, we will doubt them that it is for progress of their business. In some way running a hospital is a business, we think they are sending message for their business only. |
| 263 | Researcher: You mean the message should come from the reliable organisations like government. Right?  |
| 264 | Yes (all)   |
| 265 | Researcher: Do you know about the importance of detecting the breast cancer early?  |
| 266 | 1. My mother felt redness and heat in her breast; she went within a week to do check- up.   |
| 267 | 2. We should not wait if we see any changes. Should go immediately for check-ups. We should press our breast and see if any thickness. Should not wait                          |
| 268 | (Many conveyed that immediately after finding any changes in the breast, should undergo tests).   |
| 269 | Researcher: Do you have anything to say more?   |
| 270 | No (all). It was a good discussion  |
| 271 | Researcher: Thank you for your participation. These were the topics I planned to discuss. Through your answers I got more thoughts  |

## Appendix N Transcript Focus Group Discussion 5

Population 2- Not undergone

| Identification | Participant statements   |
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| 1              | Researcher: Who will take decisions about your health? Is it you yourselves, or anyone else in the family?   |
| 2              | 1. Self (all)  |
| 3              | Researcher: you all are agreeing that you yourself take decision, good.  |
| 4              | Researcher: then, who else can influence you?  |
| 5              | 1. Children, especially daughter   |
| 6              | 2. Husband, Daughter   |
| 7              | 3. Husband   |
| 8              | 4. Mother, Sister, daughter- in- law   |
| 9              | Researcher: Ok, you know we are here to discuss about the breast cancer and related to it. Now, what do you know about breast cancer?  |
| 10             | 1. I heard that breast cancer is an excess growth; it is the growth of some kind of cells.   |
| 11             | Researcher: Ok, What about you?  |
| 12             | 2. I was aware about the breast cancer, by reading books concerning the cancer. Even my sister also had breast cancer. Because of her I am scared of it.   |
| 13             | Researcher: You said that you read about cancer from some book. What you know about cancer after you read the book?  |
| 14             | 2. I am aware how I have to do self-check. I understood through reading. When I consult a doctor, few years before he also said the importance of practicing it. But I am not doing it. Not confident to practice it. Book won't tell that very clearly, but gave some idea.<br>Now reading about mammography too. |

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| 15 | Researcher: Ok, what you mean by breast cancer?   |
| 16 | 2. It is a tumor/ thickness in the breast.  |
| 17 | 1. Breast cancer is a very dangerous disease it comes once in the life, it will take away our life. I am personally scared about this disease. I think that if it comes our full courage will lose.   |
| 18 | 4. Some kinds of bacteria are causing the breast cancer. I believe and know that cancer is equal to death. (Like a person is dead but living).  |
| 19 | Researcher: You meant that tumors are due to bacteria?  |
| 20 | 3. I heard that breast cancer occurs when cells are divided into pieces.  |
| 21 | 2. There is a thought among the people that if the breast has any kind of thickness or tumor that is cancer. Soon after we realize the thickness in the breast we started to worry and think.   |
| 22 | 2. I think everyone have the cell of cancer in the body, cancer occurs when these cells are become cancerous. Is it right?  |
| 23 | Researcher: Ok will discuss, Do you mean everyone have cancer cells in their body?  |
| 24 | 2. I mean the cancer cells are not the cancer disease but the cancer cells. Because of some factors these cell becomes cancerous. These cause the cancer. It has lot of reason to change the cancer cell into cancerous. Nowadays, breast-feeding is too low when we compared with ancient days. But at present the doctors are encouraging to do the breast-feeding compulsorily for two years. Breast-feeding prevents the breast cancer in a limited way. A women who feed the breast have less chance to breast cancer. |
| 25 | Researcher: Ok, and what about your understanding?  |
| 26 | 3. According to our physical activity or appearance symptoms can display in our body. Some women can realize at the beginning itself, some women can't realize at the beginning.  |
| 27 | Researcher: Ok, Good, What do you think?  |

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| 28 | 2. Yes, if we identify and do the treatment at the beginning stage itself, we can prevent the cancer growth and can live longer.   |
| 29 | Researcher: Ok good, if we find out cancer at beginning stage, we can overcome, well then?   |
| 30 | 4. We need will power and that can prevent the cancer.   |
| 31 | Researcher: You mean, if one has self-confidence can overcome the cancer disease?  |
| 32 | 1. No, a cancer patient as well as normal women with self-confidence can overcome the cancer.  |
| 33 | 3. If we eat selected food which is good for health can prevent the cancer. I heard that by adding more turmeric in the food could prevent cancer.   |
| 34 | Researcher: Ok, you believe that if you add turmeric in your food can prevent cancer?  |
| 35 | 1. Regular exercise can also prevent the cancer.   |
| 36 | 3. I have a relative, he had cancer in the stomach and undergone many treatments at last he gone through a turmeric treatment. Doctor suggests him to use lot of turmeric. Now he is free from the cancer. That is my personal experience. So I believe that if we use turmeric in our food we can avoid the cancer. |
| 37 | Researcher: Do you know anyone who detected with breast cancer after living in the UAE?  |
| 38 | 1. I know my close friend here who died recently because of the breast cancer. She was the member of our church. After diagnosing within few months she died.  |
| 39 | Researcher: ok, was the cancer found in later stage?   |
| 40 | 1. No idea about that, she had completed her Ph.D. from UAE few years before. She was working here in UAE. She found some budging in her breast. She went to the doctor immediately.   |

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| 41 | Researcher: Oh, How old was she?   |
| 42 | 1. She is around my age or few years younger than me. I am now 46 years now.   |
| 43 | 4. I know a classmate; she studied with me in the Islamic study center. She found some changes in the breast but immediately she went from here, for the treatment at Kerala at Trivandrum RCC. She is Ok now.   |
| 44 | Researcher: How old is she when detected?  |
| 45 | 4. I am not exactly sure, may be of my age or one year difference.   |
| 46 | 2. I don't know anyone here. My younger sister had breast cancer. But she is in Kerala.  |
| 47 | 1. I know one of my friends' friends here in Ajman. She was diagnosed by breast cancer. She underwent surgery.   |
| 48 | Researcher: Does she diagnose by cancer after residing in the UAE?   |
| 49 | 1. Yes, she was here for many years before. They are well-educated and taking care of their health. She also did self-detection. She felt symptom in her body so she went to do mammogram but while she went for the mammogram her doctors not allowed her to do mammogram. The doctors said to her that she don't have any problem. When she went to Kerala during vacation she checked there and found out that it is cancer. She had self-confidence so she could overcome the disease soon. Even she got well support from the family and her friends. |
| 50 | 2. I feel that in the UAE we don't have sufficient equipment to detect the cancer.   |
| 51 | Researcher: Ok, I will come to that point.   |
| 52 | Researcher: What do you know about breast cancer detection tests?  |
| 53 | 1. I do not know much about how to detect it.  |
| 54 | 2. I don't have more knowledge about it. I had no much idea but like self-checkup and the mammography. That's what I read.   |

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| 55 | 3. I do not know. My friend said you know how to do self- detection, and mammography. Waiting to attend your session.   |
| 56 | 4. I am not much aware, but self-detection is first and important. But do not know how to do it.  |
| 57 | Researcher: do you know about breast cancer screening?  |
| 58 | 1. I heard about breast cancer screening because at present breast cancer becoming a common and widespread disease. But I don't know exactly about it. I knew that breast cancer screening is a test to detect breast cancer.       |
| 59 | 2. I heard mammogram is not good for our health; radiation also and it is too much pain. I understand that if we do screening the risk of getting cancer is higher.   |
| 60 | Researcher: Ok you heard that the chance of getting cancer is very high; so you did not do the mammography? Am I right?   |
| 61 | 2. Yes, that is a reason; surely we have to fear that. If there is a high chance to get cancer through screening then we have to fear that. Screening also a painful test, that is another one reason to avoid screening mammogram. |
| 62 | 4. I do not know.   |
| 63 | 3. Even I do not know how to do the self-test.  |
| 64 | 2. I read it, but not confident to do it.   |
| 65 | Researcher: it means, you know about the self-detection but you do not know how to do the self-detection, am I right?   |
| 66 | Yes (all)   |
| 67 | 4. We don't have any idea to do self-detection.   |
| 68 | Researcher: ok, then  |
| 69 | 1. We all heard about the word self-detection but we do not know how to do self-detection.  |
| 70 | 2. I used to check simply by pressing with my hand.   |

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| 71 | Researcher: ok then  |
| 72 | 3. I heard that, without any reason losing the weight of our body would be a sign for cancer. I did not go for any kind of test but I am controlling myself through keeping healthy weight. I have a faith that, such kind of diseases will not affect me ever. That faith only helping me to live now I am 53 years. Up to now I didn't do any kind of checkup concerning cancer. I will not be affected by this kind of disease that is my faith and hope. |
| 73 | Researcher: ok. You have a good faith and self-confidence. Do you decide to avoid such kind of checkup like screening mammogram?   |
| 74 | 3. Yes, I decide myself to be away from the checkup. My daughter is an Ayurveda doctor. She used to advise me to do checkup but will ignore her, and say that I don't have such kind of diseases, I don't want to do checkup. I am a BSc graduate in Zoology, I have little knowledge about anatomy too.   |
| 75 | Researcher: ok   |
| 76 | 3. At present we have lot of Medias to get information such as WhatsApp and Facebook. Through that we can get lots of information. Then I have good believe in the almighty God. I have a good will power. My father is 84 years old man still he is healthy and do not have any problem. May be I got his will power as hereditary.   |
| 77 | Researcher: Ok, good according to you, screening is not necessary if we have will power, am I right?   |
| 78 | 3. Yes, that's what I believe and I feel that all diseases are according to our mind. If I always think that I am weak, I will be weak. It is attached to our mind and will power.   |
| 79 | 1. I also think so it is depending on our mind, everything in our life.  |

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| 80 | 3. I know a person who had died with stomach cancer. She was here in UAE after detected the cancer. She was too much active and smart even though she affected by cancer. She was an employee in a school here.   |
| 81 | Researcher: ok  |
| 82 | 3. During the time of vacation she went to Kerala for further treatment but it became worse immediately. I heard that there was lots of friends visited her and discussed about the experience of other persons to her that influenced her negatively. The information that she got from her friends was negative that discouraged her. The discouraging experience influenced her a lot and she was discouraged and died within two month.   |
| 83 | Researcher: According to you then the friends, relatives, family members have a role to give psychological support for a patient to overcome the disease, am I right?   |
| 84 | 1. Yes, it is an important issue at present. If anyone affected by breast cancer her relatives and friends usually come to see the patient. At that time these friends or relatives have lot of things to say to the patient from their experience like other's testimony. If these experiences/testimony are negative that will negatively affect the patient and lose her courage. If we like to say positive testimony and encouraging testimony that will be helpful for the patient to get more confidence and courage. We should not reveal the discouraging testimony in front of a patient. |
| 85 | 2. There should be good awareness to the friends and relatives to reveal positive and encouraging experience in front of the patient. Sometime these influences woman not to disclose their problems.   |
| 86 | 3. I know few breast cancer patients in Kerala. They are going to Chennai for treatment and staying there. Because if they come back to the society she has to answer all the questions and will only get discouraging  |



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|    | words from their friends and community.  |
| 87 | 4. I too agree, if a person affected by the cancer, she never like to say to others about her disease. Because if they say people use to watch her with sympathy but not with empathy and that will feel herself that she got a dangerous disease. It will cause discouragement. |
| 88 | Researcher: Through your talk, I got a point that; our society has a major role towards the breast cancer, right?  |
| 89 | Yes of course (all)  |
| 90 | 1. Society has a major role towards breast cancer patient. Many time women are scared of it, because of these issues.  |
| 91 | 2. Society has negative attitude towards this disease.   |
| 92 | 3. If a person got diagnosed with cancer, soon everyone will enquire details of it. After that, they used to watch through a different eye and with sympathy.  |
| 93 | 4. Everyone talks each other, when they see the person and others also started talking to her with sympathy.   |
| 94 | Researcher: oh, good to know those.  |
| 95 | 1. The relatives and friends are discouraging and taking away the confidence, which the patient have. So we should avoid sharing the negative and discouraging testimony in front of a cancer patient.   |
| 96 | 2. If we say the encouraging testimony that will be helpful for the patient.   |
| 97 | 4. I agree these all makes women not to think about this disease and tests.  |
| 98 | Researcher: Interesting to hear these. You are thinking or the experiences shared by your friends or relatives?  |
| 99 | 2. I heard of these experiences.   |

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| 100 | 4. I agree with you all.  |
| 101 | Researcher: Ok, then Because of these reason the cancer patient usually will not reveal to the public about their disease. Right?   |
| 102 | 1. I know a women with breast cancer, and during the vacation she went to treatment in Kerala. But the attitudes of the others towards her were different. She felt discomfort there is Kerala. So she escaped from there to UAE.   |
| 103 | 2. We should not allow the visitors to visit the patient.   |
| 104 | 1. We never disturb the patient and discourage them.  |
| 105 | 2. Now the Patients are leaving the Kerala became common practice.  |
| 106 | 1. Even though they get good treatment in Kerala the societies are not treating them well. So they like to leave the Kerala to get peace and avoid the rush of the visitors. Mentally they are feeling discouraged  |
| 107 | Researcher: ok, Do you know about mammogram? How is a mammogram performed?  |
| 108 | 1. We heard from others but we don't experience. We heard that during mammogram they press the breasts very hard and it will be painful.  |
| 109 | 2. Yes, I heard from my friend those who did the mammogram. They said that while doing mammogram the nurses keep equipment's and press very hard. I frightened by hearing this experience from my friend. That is one of the reasons I avoided a mammogram. There is a fear inside my mind about the mammogram procedure. |
| 110 | Researcher: OK. then  |
| 111 | 1. According to my friends those who undergone mammogram, they said they keep our breast inside a machine and press; as like we press the atta to make chapatti's.  |
| 112 | 1. It will be too hard and painful for the patient.   |
| 113 | Researcher: What about others what you are thinking of?   |

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| 114 | 2. I thought that it is something like we do x-ray for other body parts, like chest X-ray for the security clearance.   |
| 115 | Researcher: Do you know when women should undergo screening mammography?  |
| 116 | 1. I heard at the age of 35.  |
| 119 | Researcher: you heard that at the age of 35, oh what about others?  |
| 120 | 1. 35 and above that's what I heard.  |
| 121 | 2. I heard that mammography should do at the age of 40 and above.   |
| 122 | 3. I heard below 30 years old. Because my younger sister had breast cancer. She did mammogram before she reached 30 years old. If we think about hereditary there is a chance for siblings too. But I didn't go for the mammography because of fear of the result/ diagnosis. |
| 123 | Researcher: Oh, you fear to do mammogram, right? is it because of fear are you avoiding mammography?  |
| 124 | 1. Yes (all)  |
| 125 | 9. Researcher: What do you know about breast cancer screening services in your Emirate? Do you have any idea about the facility of screening mammogram in the UAE?  |
| 126 | 1. Not much. There are some camps conducting the tests in between the years.  |
| 127 | 2. I think the mammogram available in the most of the hospitals, but I don't have a clear idea.   |
| 128 | 3. I thought that the facility of screening mammogram is available in all the hospital like we do x-ray and scanning.   |
| 129 | 4. I heard from some of the friends that some hospitals are also providing the free screening mammogram. But I did not ask about it. Not sure   |
| 130 | Researcher: What are you mean by in between? When it will be  |

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|     | conducting in a year?   |
| 131 | 1. I think in the month of November they used to conduct the camp. There is a day called 'Pink Day' on this day some hospitals are providing free mammogram |
| 132 | 2. I also seen some advertisement of the hospital, but did not read much about it.  |
| 133 | Researcher: Ok in any of these months right?  |
| 134 | 1. Advertisements used to come through medias about it. But I don't know whether it is in the month of October or November.                                 |
| 135 | 2. We don't know the exact date of the pink day.  |
| 136 | Researcher: Do you know what kind of services they provide in the camp or on 'Pink Day'?  |
| 137 | 1. It is known as pink day. No other idea   |
| 138 | 3. We don't know exactly about the services   |
| 139 | 2. Because up to now we didn't attend such camps. So we don't know about their services.  |
| 140 | Researcher: Have you had any idea about the availability of screening mammogram in any Hospital before?   |
| 141 | 1. Yeah heard of, but do not know clearly   |
| 142 | 2. Yes. Some advertisement they are giving. But no much idea about it.  |
| 143 | 1. I think they provide mammography also  |
| 144 | 2. They provide breast check-ups, but I did not tried to know more about it.  |
| 145 | Researcher: Are they providing free of cost? Do you know that?  |
| 146 | 1. We don't know whether they are providing it freely or not.   |
| 147 | Researcher: You all said that the main barrier to do mammogram was fear.  |
| 148 | 1. Yes.   |

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| 149 | 2. Not only fear of the result but also pain, radiation  |
| 150 | 3. Fear and pain (all)   |
| 151 | Researcher: Do you feel any other barriers for you to undergo mammogram? Related to job something like that  |
| 152 | 1. Yes, if the woman is an employee, she should take leave in a day to go for the mammogram. If she ask to boss to get leave they will ask the reason for the leave. We have to answer their questions. If the colleagues ask about the reason for the leave what would I say to them? These kinds of questions will come to a woman, so they usually didn't think to go for the mammogram. If we say to them the reason that I am going to do mammogram then there will be other question why do you want to go? Do you have cancer? Such kind of thinking may come to their mind and they started to think that the woman is a cancer patient. |
| 153 | Researcher: Then do you think that your employees or coworkers have a role to do mammogram?  |
| 154 | Of course (everyone)   |
| 155 | Researcher: them how we can make them aware about it?  |
| 156 | 1. Each and every individual should get proper education and knowledge about the cancer.   |
| 157 | 2. Should avoid the discrimination between each other. If a person has cancer others are thinking that it is a dangerous disease so they are separating the patient from them. Discrimination in the disease should be avoided.  |
| 158 | Researcher: Ok, anything else?   |
| 159 | 1. Time is another one factor for women. Usually, women have a lot of responsibility to do at their home. They have to take care of children; husband and household works etc. after these all works the woman don't get enough time to go to a hospital for a check-up.   |

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| 160 | Researcher: As I know you all are living here since many years. So you know most of the health facilities in the UAE. Am I right?  |
| 161 | Yeah, Yes (all).<br>We have kids so even small hospitals also we know  |
| 162 | Researcher: Do you know about the facilities of mammogram in Kerala?<br>What do you know about the breast cancer screening services in Kerala or in your locality in Kerala?   |
| 163 | We don't know  |
| 164 | 4. Cancer patients are too much in Kerala that only I know.  |
| 165 | Researcher: Ok   |
| 166 | 1. Yeah, Cancer patients are increasing day by day   |
| 167 | 1. In the radio and television they used to give health awareness classes, sometimes they also take class about the cancer too. A person can get awareness about the cancer through that. That is good. If face-to-face interaction is there, that will be more useful to women. |
| 168 | Researcher: Even if they are aware about the cancer, do they go for the screening mammography?   |
| 169 | 1. May be. No idea. But if there is face to face classes that will motivate women. They can ask doubt confidently too.   |
| 170 | 2. Few people may go. But needs constant awareness. Otherwise women will hear and forget. But I think like here it is not that common practice to go for check-ups. Till they fall sick they will manage with their home remedies. This is usual in my families and relatives.   |
| 171 | 4. Most people will not go because of the fear of breast cancer. If it is in UAE or Kerala. Fear is fear. Those who have a fear they will not go for mammogram.  |
| 172 | 1. Breast is part of a women's beauty. If it lost that will affect their beauty. It is a shame for women to lose their breast.   |

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| 173 | 1. Another one reason is if we go for these tests or checkup if others come to know about it, they consider me as a breast cancer patient. We may go for the test but they try to prove that we have breast cancer.   |
| 174 | Researcher: Oh you think that the society may consider you as a breast cancer patient?  |
| 175 | 1. Yes. Those kinds of attitudes are destroying our inner confidence. It increases the tension.   |
| 176 | Researcher: Ok let me ask; in order to avoid such kind of attitude, what needs to be done, what do you think?   |
| 177 | 1. Government should educate the people.  |
| 178 | 2. We should avoid looking to the community.  |
| 179 | Researcher: ok, Should avoid others view. Right? That's good.   |
| 180 | 4. Father, mother, daughter, son and husband they never separate us or discourage us.   |
| 181 | 1. Communities need a deep awareness about the disease and other psychological support.   |
| 182 | Researcher: How can it be possible to give awareness to the community?  |
| 183 | 1. It is not possible to give awareness for community together. We should divide the community in panchayat level or ward level then we should make them aware.   |
| 184 | 2. Kudumbashree, and other women gatherings are there   |
| 185 | 3. That is correct. We have to follow that method.  |
| 186 | Researcher: ok.   |
| 187 | 1. The people those who are living in the village area, they don't know about the breast cancer and related. Those who are living in the urban area may have good knowledge about the breast cancer. In the rural area should be divided in to small part as one among us said before. We have to divide the village and teach them separately about the breast |

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|     | cancer and its consequences and the way to behave to a person if one is identified with the disease.  |
| 188 | 2. We should make a small community or group.   |
| 189 | Researcher: ok, we have to separate small community or group, then;   |
| 190 | 1. There we can do lot of things. We cannot do anything in a vast community. If we give awareness in the Ward level that will be very useful and helpful for the people. Ward members can take initiative of it.  |
| 191 | 2. Now there are many women community such as; 'Adukala Kootam', 'Kudumba Sree' in Kerala. We have to arrange classes among them and call them together and make them aware about it.   |
| 192 | 3. This is really correct point.  |
| 193 | 4. That is really a Plus point. Because there is no any knowledge among the downtrodden people about the cancer. If we provide such kind of classes it will be very useful.   |
| 194 | Researcher: So how this can be influential to women living here in UAE?   |
| 195 | 1. Yes there is a major influence to Kerala women here. Because everyone have their family members or close friends there in Kerala. Daily there are communications happening between them and us. So if they say we can utilize the service from here. |
| 196 | 3. Through giving the classes for them their views will change and even they will share with us.  |
| 197 | 2. Then their outlook towards the person's one who go for the mammogram will change and also the attitude and thinking pattern also will change.  |
| 198 | Researcher: Oh yeah that's good to hear   |
| 199 | 1. Yes. It will help us to change the attitude towards the affected   |



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|     | person and one who is going to do mammogram too.  |
| 200 | Researcher: OK, anything else?  |
| 201 | 1. Another one thing among the new generation women that they give lot of preference for their beauty. They stop breast-feeding as much as earlier as they can, it may lead to breast cancer. Bottle-feed needs to be compulsorily prohibited for the babies. That is a good advice for the new generation women. |
| 202 | 1. If educated people like you can influence us to undergo the mammogram. Now itself through this discussion we got many ideas. We can understand there is importance for a screening mammogram.  |
| 203 | 3. If we get clear information about the side effects and the importance of a mammogram, surely I will go for that. Want to know about it.  |
| 204 | Researcher: I would like to ask, for the non-resident Kerala women, like us, What could our Kerala government do for us? Please share your expectation from the Kerala government.  |
| 205 | 1. Government can conduct the awareness class among the non-resident women. That will be helpful for the women those who live in the other country by people like you know Malayalam.   |
| 206 | 2. Arrange the awareness class in community centers and give information again and again. I mean repeat the awareness classes in between with limited break.  |
| 207 | 4. Provide some campaigns in UAE. I mean with check-ups and mammogram service.  |
| 208 | Researcher: what you are expecting about the awareness? Even though women are aware, some women mayn't go for that.   |
| 209 | 1. Government can provide the facilities of screening mammogram to the overseas women. If the Government opens the clinic in every Emirate, means facility of mammogram in all the areas of UAE that will   |

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|     | help the women to undergo screening mammogram. If it's so, many people can know about it. The women can also go for the treatment in that clinic itself. Than private if it is government people will believe.   |
| 210 | Researcher: What you mean by every area or every part of the UAE?  |
| 211 | 1. Every area means, if government arranges the facility of doing mammogram in every 100km distance that can encourage the women to do mammogram. Because here the transportation is a big issue.  |
| 212 | 1. Most of the women don't know the method of treatment and expense if diagnosed.  |
| 213 | Researcher: Ok what is the role of health insurance?   |
| 214 | 2. Few have the concern about the expense and method of treatments. They don't know whether the facility of mammogram is included or excluded in their insurance card! In this situation they started to think that do I really want to go for the mammogram check or not. |
| 215 | 15. Researcher: What UAE Government can do for the Malayalees here? What are you expecting from the UAE government?  |
| 216 | 1. In UAE, organisations are doing something for the women. There are Malayalees organisations that provide some kind of help. Government should inform the organisations.   |
| 217 | 2. UAE government is providing privileges, but it should reach to the Keralites too.   |
| 218 | Researcher: OK anything else?  |
| 219 | 1. When we apply for the visa to come to UAE, Health card is compulsory for the overseas in Abu Dhabi, Kuwait, and other places. If the governments add the screening mammogram in the health package that will be good for us.  |
| 220 | 2. If UAE government adds this along with the health package in every  |

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|     | Emirate it will be a great help.  |
| 221 | Researcher: Ok If the government provide free mammogram checkup for the above 40 years old women, that will be a help for you, right?   |
| 222 | 1. Yes (All)  |
| 223 | Researcher: you said that here (near to you) there is hospital which provides mammogram. But most of the women from the same area didn't heard about the facility provide by the hospital. How can they inform about the availability of mammogram to the women one who is not a member of a community? |
| 224 | 1. Through medias (all)   |
| 225 | Researcher: Which media do you think that it can help to reach the maximum people?  |
| 226 | 1. Newspaper. Malayalam newspapers are there.   |
| 227 | 2. Radio.   |
| 228 | 3. Television. There are many Malayalam channels in the Television  |
| 229 | Researcher: Do you expect to get a call or reminder once after a women reaches the age of 40.   |
| 230 | 1. NORKA or other government authorities should contact with the community centers or churches. Along with them they can handover the message women of eligible age.  |
| 231 | 2. As we discussed before, normally all people are availing health cards, right? Health cards have one-year validity. After one year we have to renew the health card. During the time of renewal we have to link our details along with that card.   |
| 232 | 3. But the people those who are going to Kerala from UAE, they usually do body checkup in Kerala, the executive check-ups. But people are not interested and do not know about the screening mammography to do along with it.   |

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| 233 | Researcher: What you feel about time you get in Kerala? As you said that time is an important reason. Overseas women do not get enough time to get an appointment in Kerala. How you can manage your limited vacation time? |
| 234 | 1. It is routine in our community to undergo routine health check-ups when we go to Kerala. It is common.   |
| 235 | 2. Open a hospital in Kerala for all the Indians living outside India. Government can allow a particular time for the migrant to get appointment in that hospital.  |
| 236 | 3. Kerala government do not showing any kind of responsibility like UAE government shows to us.   |
| 237 | Researcher: Ok  |
| 238 | 1. If we go to passport office at present we can get immediate response and action from the passport office. That same system government has to apply for migrants in the hospital. Government have to think about us too   |
| 239 | Researcher: Ok, Government has to consider their people, right?   |
| 240 | 1. Yes (all)  |
| 241 | Researcher: Do you like to add something to this point?   |
| 242 | 1. Kerala government only needs the money of the migrants. We are the major source of income to Kerala  |
| 243 | 1. Kerala government is not at all doing anything for the betterment of the non-residents. I feel that the Government is not worried about our health. Government's outlook towards the non- residents should change.       |
| 245 | Researcher: What about you?   |
| 246 | 1. If the government makes a rule to open new counter for the expatriate in all hospital that will be very helpful for the expatriate. Because we usually go to Kerala during the time of our limited days of               |

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|     | vacation. In that occasion one may not be able to reach at exact time, as per the hospital's appointment time. In such case we have to go and wait for a long time. It will be very difficult for the non-residents those who are going for a short period. Government should give preference for them.   |
| 247 | 2. Yes, the government can open new counter for the migrants in the hospitals. I don't think it is possible in the present days condition. If government do the same that will be appreciable.  |
| 248 | Researcher: Do you like to add something more?  |
| 249 | 1. If the government make the mammogram compulsory for above 40 years old women. Government has to provide a rule to make mammogram compulsory.   |
| 250 | 2. Firstly try to remove the fear from the mind.  |
| 251 | 3. Fear can remove through these kinds of discussions delivered by experienced scholars like you. If the people get awareness about the mammogram, that will give them courage to do. We would fear if we go without a clear knowledge about screening mammogram.   |
| 252 | Researcher: Does someone wants to add something?  |
| 253 | 1. Yes. When we go to meet a doctor in a clinic for any kind of disease. The communication between the doctor and victim is important. If the doctor speaks toughly the victim can't say frankly to the doctor about his/her disease. So all the time the doctor should be a person who is calm. Then only we can open our mind in front of him/her. Doctor should be available to understand us and he/she must listen us carefully, that will help us to open our mind. We usually say that if we go to that doctor we get half relief. |
| 254 | Researcher: How it will helpful in the field of mammogram.  |
| 255 | 1. I will explain that. While we undergo through the process of mammogram the doctor can convert our mind through the positive  |

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|     | attitude. If the doctors do the same, they can change our mind from the fear of mammogram. Then can forget our inner fear.  |
| 256 | Researcher: What you mean by inner fear?  |
| 257 | 1. When we go for mammogram there will be lots of doubt that whether I have breast cancer or not, about pain and so on. We are going for the mammogram along with that doubt. By the positive approach of the doctors can divert our mind from such type of inner fear. If the doctor speaks encouraging words automatically our fear will go away from us. I think, that will be comfortable for the victim. |
| 258 | Researcher: ok do you like to add something more?   |
| 259 | No (everyone).  |
| 260 | Thank you so much for your input. Appreciate it.  |

Appendix O Code book

**Population 1 (FGD 1, 2) & Population 2 (FGD 3,4,5)**

| Sl. No | Code                   | FGD | Location of statements  | Notes   | Participants statement example  |
|--------|------------------------|-----|-------------------------|---|---|
| 1      | Self- dependent        | 1   | FGD 1:<br>3,4,5,6,10,12 | Have power on their decisions and events in their lives | 10. Usually if I feel something wrong, I alone go to the hospital and consult the doctor.   |
|        |                        | 2   | FGD 2: 4, 122, 136, 182 |   | 4. If I feel uncomfortable, I used to go the hospital. It is not necessary to ask permission from the family members. Yeah sure will inform husband and family. |
|        |                        | 3   | FGD 3: 3,5              |   |   |
|        |                        | 4   | FGD 4: 2                |   |   |
|        |                        | 5   | FGD 5: 2                |   |   |
| 2      | Self- health conscious | 1   | FGD1: 4, 9              | Self-consciousness towards their own health             |   |

|   |   |   |                   |   |  |
|---|---|---|-------------------|---|--|
|   |   | 2 | FGD 2: 3, 4, 8,32 |   | 3. About my health I am taking decision myself. If I feel any abnormality in my body, I usually take the decision and I go to the hospital and will do the needful check- ups. |
|   |   | 4 | FGD 4: 4          |   |  |
| 3 | Cultural influence to inform husband (Patriarchy) | 1 | FGD 1: 4, 5, 164  | Husband is the head of the family.<br><br>Do not ask money as well as this test is not an urgent one. |  |
|   |   | 2 | FGD 2: 4, 5       |   | 5. Usually, I make decision but will inform my husband before undergoing any health check-ups or even anything. You know that's our routine practice at home.                  |
|   |   | 3 | FGD 3: 6          | We have to inform our husband because informing life partner is our                                   |  |



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|   |  |   |                                  | responsibility.                      |   |
|   |  | 4 | FGD 4: 10, 11, 14, 16, 170       |                                      |   |
| 4 | Involvement of significant others (positive) | 1 | FGD 1: 5,7,11, 24,28, 48, 57, 88 | Positive influence of family members | 48. I knew about it because my own sister did screening mammogram. So, I was aware of the procedure, but when undergone through this, it was something a special experience. Hearing from others and experience ourselves and others are different. |
|   |  | 2 | FGD 2: 7, 17, 35, 48, 112        |                                      |   |
|   |  | 3 | FGD 3: 178-181                   |                                      |   |
|   |  | 4 | FGD 4: 13, 181                   |                                      |   |
|   |  | 5 | FGD 5: 1- 4, 180                 |                                      |   |

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| 5 | Involvement of significant others (negative) | 1 | FGD 1: 16,           | Negative influence of family members | 16 (first part): Few years before I came to know that the sign of breast cancer is thickness and pain. In my family itself, there were two breast cancer patients. At last, they removed their breast. I used to go to their home when I visit Kerala and console them. Feel fear when thinking about their situation. But now the situation has been changed; now we have the facility for early detection so that we can realize the disease and take medicines early. |
| 6 | Husband- a facilitator                       | 1 | FGD 1 : 6, 9         |                                      |  |
|   |  | 3 | FGD 3: 183, 184, 186 |                                      |  |
|   |  | 4 | FGD 4: 10            |                                      | 10. In my life, husband usually supports me to go for check-ups. He used to take me to the hospital for consultation. We are under our husband's care. If we want to go out need husband. So everything  |

|   |                               |   |                      |  |  |
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|   |                               |   |                      |  | we will tell to him.   |
| 7 | Husband- a barrier            | 2 | FGD 2: 8             | Husband's tension, lack of knowledge towards breast cancer and breast cancer screening served as a barrier | 8. Our health also affects our husband. Our health is important for them. I am saying for routine check-ups, if it is something like cancer check-up, he will be tensed. |
|   |                               | 3 | FGD 3: 185           |  |  |
|   |                               | 4 | FGD 4: 6             |  |  |
| 8 | Lack of family time           | 1 | FGD 1: 6, 14         |  |  |
|   |                               | 3 | FGD 3: 130, 189      |  | 130. For me husband is needed, I do not drive. If I want to go anywhere, he has to come with me. Our work schedules are different too.                                   |
|   |                               | 4 | FGD 4: 8             |  |  |
| 9 | Un/awareness- Early detection | 1 | FGD 1: 7, 10, 11, 24 |  |  |
|   |                               | 2 | FGD 2: 13            | After symptoms   |  |

|    |                                    |   |  |  |  |
|----|------------------------------------|---|--|--|--|
|    |                                    | 3 | FGD 3: 49, 58, 76,125, 126, 172          | 76- Early detection for them means taking treatment immediately after finding symptoms |  |
|    |                                    | 4 | FGD 4: 87,88, 125, 168, 267              |  | 87. I think if we see some changes immediately have to do it |
|    |                                    | 5 | FGD 5: 28                                |  |  |
| 10 | Un/awareness - breast cancer       | 1 | FGD 1: 16, 18-22                         |  |  |
|    |                                    | 2 | FGD 2: 12, 13                            |  |  |
|    |                                    | 3 | FGD 3: 13- 19                            |  |  |
|    |                                    | 4 | FGD 4: 30, 37                            |  | 37. Scar in the breast, then we should meet the doctor       |
|    |                                    | 5 | FGD 5: 10, 16, 20, 21, 24, 26            |  |  |
| 11 | Un/awareness – screening mammogram | 1 | FGD 1: 24                                | Unawareness  |  |
|    |                                    | 2 | FGD 2: 16, 47                            | awareness  |  |
|    |                                    | 3 | FGD 3: 48, 53-56, 75, 168, 117- 122, 134 |  |  |

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|    |   | 4 | FGD 4: 73, 86, 87, 88     |  | 73. Yeah that is the X-ray test I think my friend said. Not sure. It is the X-ray test right?                      |
|    |   | 5 | FGD 5: 53, 54, 58         |  |  |
| 12 | Un/awareness-screening mammography procedure  | 1 | FGD 1: 46-47,             |  |  |
|    |   | 3 | FGD 3: 69- 74, 78- 80     |  |  |
|    |   | 4 | FGD 4: 82, 83, 117        |  | 82. I think it is similar to how we check like when we are pregnant, like that machine.                            |
|    |   | 5 | FGD 5: 108, 109, 111, 114 |  |  |
| 13 | Unawareness – breast cancer detection methods | 1 | FGD 1: 31                 |  | 31. Not like routine blood check-up. But some tests are there. Doctors can check, and this mammogram only, I think |
| 14 | Un/awareness of self-breast examination       | 1 | FGD 1: 33, 34             |  |  |
|    |   | 2 | FGD 2: 48                 |  |  |
|    |   | 4 | FGD 4: 61, 63, 64         |  | 63. After 10 days of periods have to do  |
|    |   | 5 | FGD 5: 14, 56, 63, 69     |  |  |

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| 15 | Un/awareness of screening mammography follow up | 1 | FGD 1: 55, 58, 59   |   |   |
|    |   | 2 | FGD 2: 54, 174, 176 |   | 54. Of course, I am ready to recommend others to do mammogram and encourage them to do. I used to tell my friends and colleagues that there will not be any harm if you do screening mammogram. If you do it once you can live peacefully. Otherwise you will be tensed all the time. |
| 16 | Altruism  | 1 | FGD 1: 14           | Concern towards family.<br><br>Well being of family is women's responsibility |   |
|    |   | 2 | FGD 2: 116          |   |   |
|    |   | 3 | FGD 3: 75, 144, 152 |   |   |

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|    |   | 4 | FGD 4: 118        | Family is my responsibility | 118. In the evening most of the women cannot leave the house. Every woman have lots of responsibilities in their home, I have to take care of my children and husband. I can't leave it. It is my responsibility. |
|    |   | 5 | FGD 5: 159        |                             |   |
| 17 | Word of mouth- Breast cancer survivor (+ ive) | 1 | FGD 1: 16, 23, 26 | Positive influence          |   |
|    |   | 2 | FGD 2: 166, 167   |                             | 166. Of course, breast cancer survivors have a major role to influence and motivate others to do mammogram. They are the living testimony among the other people those who were not undergone mammogram           |
|    |   | 3 | FGD 3: 52, 201    |                             |   |
|    |   | 4 | FGD 4: 197, 198   |                             |   |
| 18 | Word of mouth- Breast                         | 1 | FGD 1: 16         | Negative influence          |   |

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|    | cancer survivor<br>(- ive) | 2 | FGD 2: 168  | Can have negative influence on the audience as well as the survivor       | 168. Sometime people will feel sad about them and they also feel difficult to face others. So, I do not think they should be involved. |
|    |                            | 3 | FGD 3: 202-203  |   |  |
|    |                            | 4 | FGD 4: 115,   |   |  |
|    |                            | 5 | FGD 5: 12   |   |  |
| 19 | Word of mouth<br>- Media   | 1 | FGD 1: 27, 47, 64, 65   | Influenced to undergo as well as shared the importance of early detection |  |
|    |                            | 2 | FGD 2:17, 18,20, 21, 22, 24, 26, 30, 31, 34, 35, 38, 119, 182 |   |  |
|    |                            | 3 | FGD 3: 86, 96, 98, 192  |   |  |
|    |                            | 4 | FGD 4: 95,96, 103, 106, 196, 248                              |   |  |
|    |                            | 5 | FGD 5: 76, 134,   |   | 76. At present we have lot of  |



|    |                                  |   |                           |   |   |
|----|----------------------------------|---|---------------------------|---|---|
|    |                                  |   | 224                       |   | Medias to get information such as WhatsApp and Facebook. Through that we can get lots of information. Then I have good believe in the almighty God. I have a good will power. My father is 84 years old man still he is healthy and do not have any problem. May be I got his will power as hereditary. |
| 20 | Word of mouth – Media (overflow) | 1 | FGD 1: 61, 62, 77, 101    | Shared that it dilutes the importance as well.  |   |
|    |                                  | 2 | FGD 2: 28, 121            |   |   |
|    |                                  | 3 | FGD 3: 99 -101, 196, 199  | Do not know whom to approach  |   |
|    |                                  | 4 | FGD 4: 197, 198, 209, 262 | Physician or breast cancer survivor can write to add value on the advertisement<br><br>209- similar to new doctor joins | 197. But I think we are not considering it seriously. If there are columns mentioning the person who affected by breast cancer, message by a doctor, how the client is now, how they recovered from the disease. Media can include  |

|    |   |   |                                |   |   |
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|    |   |   |                                | ad<br><br>203: should include the benefits and side effects in the ad | these all to create awareness.  |
|    |   | 5 | FGD 5: 203                     |   |   |
| 21 | Word of mouth- Trust in government advertisements | 1 | FGD1: 100, 137- 140            |   |   |
|    |   | 4 | FGD 4: 224, 225, 228, 256, 257 |   | 228. That (invitation by the government) will be better; it will help us to overcome the fear. Then women will start to think that we must do it. |
| 22 | Word of mouth- by professionals                   | 1 | FGD 1: 104                     | Wont trust husbands word for medical advice                           |   |
|    |   | 2 | FGD 2: 35                      |   |   |
|    |   | 3 | FGD 3: 195                     | TV program by doctor  |   |
|    |   | 5 | FGD 5: 202, 251                | Role of critical ethnographer   | 202. If educated people like you can influence us to undergo the mammogram. Now itself through this discussion we got many ideas.                 |

|    |   |   |                                     |  |   |
|----|---|---|-------------------------------------|--|---|
|    |   |   |                                     |  | We can understand there is importance for a screening mammogram.                                      |
| 23 | Word of mouth- Peer                                       | 2 | FGD 2: 17, 34, 110,111, 114,        |  |   |
|    |   | 4 | FGD 4: 116                          |  |   |
| 24 | Word of mouth – community leader                          | 2 | FGD 2: 125, 126, 128, 131, 132, 133 | But it depends on the community  |   |
|    |   | 4 | FGD 4: 172-176, 190, 192, 249       |  | 172. In case of our disease these leaders do not have any role. But we may consider their suggestions |
| 25 | Word of mouth- undergone screening mammogram (one to one) |   | FGD 2: 162-164                      | Participants who had undergone screening mammogram found enthusiastic to convey the message even one to one. | 162. The person who did mammogram can easily remove the fear of others.                               |

|    |                                |   |                               |   |   |
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| 26 | Painful procedure - Unbearable | 1 | FGD 1: 24, 25, 44, 56, 59     | Call for a painless machine!!<br><br>(Pain during mammogram unbearable) | 24. Before I thought early detection means it is done immediately after noticing anything on the breast. All my friends also think like this. But now after my cousin's experience, she shared, so I thought that it will be good to undergo it. I told others. If we do early detection it will be helpful, and the family members will be happy. Then they are avoiding this because this test is very painful. |
|    |                                | 2 | FGD 2: 52, 161                |   |   |
|    |                                | 3 | FGD 3: 49, 65, 133            |   |   |
|    |                                | 4 | FGD 4: 65, 78, 81             |   |   |
|    |                                | 5 | FGD 5: 59, 108, 109, 111, 112 |   |   |

|    |  |   |                    |                                |   |
|----|--|---|--------------------|--------------------------------|---|
| 27 | Painful but-bearable                           | 1 | FGD 1: 45          | Pain during mammogram bearable | 45. Very tightly it got pressed, there was a pain but bearable. I underwent as part of the executive health check-up. Otherwise, maybe I would have not undergone it.               |
|    |  | 2 | FGD 2: 50, 51      |                                |   |
| 28 | Radiation                                      | 1 | FGD 1: 25, 56      | Involvement of radiation       |   |
|    |  | 2 | FGD 2: 175         |                                |   |
|    |  | 3 | FGD 3: 133         |                                |   |
|    |  | 4 | FGD 4: 65          |                                |   |
|    |  | 5 | FGD 5: 59, 61, 161 |                                | 59. I heard mammogram is not good for our health; radiation also and it is too much pain. I understand that if we do screening the risk of getting cancer is higher.                |
| 29 | Unaware of radiation involved in the mammogram | 2 | FGD 2: 54- 55      |                                | 55. Everyone should do mammogram because anybody can get anything in the present life style. I think there is no side effect if we do mammogram. it will be good for everyone to do |

|    |   |   |   |   |  |
|----|---|---|---|---|--|
|    |   |   |   |   | mammogram.   |
| 30 | Myths-<br>reasons/breast<br>cancer  | 1 | FGD 1: 36-39,<br>42                         | Food habits,<br>exposure to sun,<br>black coloured<br>bra | 36. I heard that lifestyle is an<br>important cause for cancer, I<br>started to do exercise and<br>walking to avoid cancer.  |
|    |   | 2 | FGD 2: 42- 44,<br>83                        |   |  |
|    |   | 3 | FGD 3: 10, 21-<br>27, 31- 36                |   |  |
|    |   | 4 | FGD 4: 39- 42                               |   |  |
|    |   | 5 | FGD 5: 24, 26,<br>30,33, 35, 36,<br>72, 201 | 30- self<br>confidence                                    |  |
| 31 | Myth- more<br>pain while<br>undergoing<br>screening<br>mammogram in<br>Kerala | 1 | FGD 1: 47                                   |   | 47. My friend shared a<br>message and I saw in it. But<br>not sure and was not aware of<br>how it will be done.<br><br>I came to know that doing<br>mammogram in Kerala is very<br>painful but here in UAE, it is<br>not that much pain. |
|    |   | 3 | FGD 3: 161                                  |   |  |
| 32 | Fate & Fatal  | 1 | FGD 1: 40-42,                               | Breast cancer as<br>a token of death                      |  |

|    |                              |   |                               |                           |  |
|----|------------------------------|---|-------------------------------|---------------------------|--|
|    |                              | 2 | FGD 2: 14                     |                           | 14. Yes, it is a deadly, non-curable disease. It is fate if someone gets it. Nothing can be done.  |
|    |                              | 4 | FGD 4: 20                     | Fate what else!           |  |
| 33 | Godly intuition              | 2 | FGD 2: 43                     | Breast cancer – Gods plan |  |
|    |                              | 4 | FGD 4: 85, 115                |                           | 85. After 40 years. Our family physician said to me to do it. But I am scared, I saw my mom suffering, I believe in God. God will not put the suffering to me or anyone else in the family.  |
| 34 | Health check-ups (in Kerala) | 1 | FGD 1: 45, 50, 52, 77, 88, 94 |                           |  |
|    |                              | 2 | FGD 2: 36                     |                           | 36. During menses, I used to get pain in my breasts, and then I said to my husband about the pain. Then husband told me to undergo check-ups. I am 52 now, anyway thought to do mammogram from Kerala during vacation as part of health check-up |

|    |  |   |                                |   |  |
|----|--|---|--------------------------------|---|--|
|    |  | 4 | FGD 4: 129, 142, 149, 158, 164 | Usually go for health check-up. But did not undergo<br><br>158- health check-up charge too much of knows that we are from UAE |  |
|    |  | 5 | FGD 5: 232,234                 |   |  |
| 35 | Un/aware of screening mammogram availability in Kerala | 1 | FGD 1: 78- 81                  |   |  |
|    |  | 3 | FGD 3: 105,106, 112-115        |   | 106. In Trivandrum “medical college hospital” have mammogram machine. But do not know whether they are doing it or not |
|    |  | 4 | FGD 4: 110, 111, 167           |   |  |



|    |  |   |                        |   |   |
|----|--|---|------------------------|---|---|
| 36 | Experience Vs testimony                              | 1 | FGD 1: 48              | What they heard about screening mammogram was different when they experienced it. | 48. I knew about it because my own sister did screening mammogram. So, I was aware of the procedure, but when undergone through this, it was something a special experience. Hearing from others and experience ourselves and others are different. |
| 37 | Experienced are willing to convey the message/ but.. | 1 | FGD 1: 97, 98, 102     |   | 97. We should inform other people especially those who are from Kerala may be through Medias. But if someone asks more about the disease or radiation or anything further, we do not know those clearly to share with them.                         |
| 38 | Free screening mammogram                             | 1 | FGD 1: 51, 53, 58, 84  |   | 58.. I did it from Sharjah through the free voucher I got from ***** hospital.  |
|    |  | 2 | FGD 2: 58, 59, 64, 136 |   |   |
|    |  | 3 | FGD 3                  |   |   |

|    |   |   |   |   |  |
|----|---|---|---|---|--|
| 39 | Unaware of free screening availability in the UAE | 1 | FGD 1: 67- 69, 71, 72, 163,                         | But FGD made them aware of the availability   |  |
|    |   | 2 | FGD 2: 62, 63, 64, 67, 114                          | Aware but not aware, do not feel to just go in as they see pink caravan on road.              |  |
|    |   | 3 | FGD 3: 83, 84, 86- 90, 167                          |   | 83. I don't know exactly about the place from where we can do screening mammogram. Some hospital they are conducting it, but I did not check it. |
|    |   | 4 | FGD 4: 90- 92, 97, 99,100, 120, 121, 124, 235, 236  |   |  |
|    |   | 5 | FGD 5: 50, 54, 126-132, 139, 141,142, 143, 161, 209 | 161- Even though they know the hosp. but they are not aware of screening mammography service. |  |

|    |  |   |                               |   |   |
|----|--|---|-------------------------------|---|---|
| 40 | Duration of free mammogram availability in the UAE | 2 | FGD 2: 70, 71, 72, 74, 75, 76 |   |   |
|    |  | 3 | FGD 3: 166, 169               |   | 166. If we have some changes in the breast, must wait for one year.   |
| 41 | Tension creating procedure                         | 1 | FGD 1: 56, 127-129            | Mammogram causes tension before and after the procedure till receives the result. |   |
|    |  | 2 | FGD 2: 46, 47                 |   | 46. When we hear first, the screening mammogram causes tension.   |
| 42 | Role of health care facilities: for follow up      | 1 | FGD 1: 58                     | Suggestions for follow up by the health care facilities                           |   |
|    |  | 2 | FGD 2: 180, 181               |   | 180. If the hospitals send any reminder messages through email, SMS and WhatsApp, I can go for the screening mammogram. |
|    |  | 3 | FGD 3: 252                    | Women shared their concern  |   |
|    |  | 4 | FGD 4: 117,                   |   |   |

|    |                                    |   |                                     |   |  |
|----|------------------------------------|---|-------------------------------------|---|--|
|    |                                    |   | 252, 254, 258                       | that no follow up available if diagnosed  |  |
|    |                                    | 5 | FGD 5: 212                          |   |  |
| 43 | Need of holiday/ leave/ health day | 1 | FGD 1: 90, 92                       | Family and job takes their time and have no time to under a screening mammogram. So a screening/ health day helps them.   | 90. I don't have enough leave in the organisation where I am working. They are providing holidays once a year. If I wait for the next vacation to do check-up in Kerala, I can't do it. So, I did the check-up from here in UAE. |
|    |                                    | 2 | FGD 3: 146-150, 229                 |   |  |
| 44 | Role of social organisations       | 1 | FGD 1: 104, 105, 111, 135, 154, 158 | Awareness sessions, charitable services in labour camps, trust in their community leaders. They depend on these organisations here rather than their relatives. |  |
|    |                                    | 3 | FGD 3: 153,                         |   | 153. Also, for us Ok, but if you   |

|    |                   |   |                               |  |   |
|----|-------------------|---|-------------------------------|--|---|
|    |                   |   | 154, 207- 209,<br>236-237     |  | look to the ladies in the labor camp, they have less salary, most probably they get salary in between 500 – 850 AED. In these cases, they don't have any facilities to go for such kind of checkups. How they can do mammogram in their salary? |
|    |                   | 4 | FGD 4: 185                    |  |   |
|    |                   | 5 | FGD 5: 205,<br>216            |  |   |
| 45 | Role of insurance | 1 | FGD 1: 112,<br>114- 117       | Should add and should convey to women.               |   |
|    |                   | 2 | FGD 2: 183                    |  |   |
|    |                   | 3 | FGD 3 : 136,<br>138, 139, 140 |  |   |
|    |                   | 4 | FGD 4: 213,<br>214, 215       |  | 213. If all check-ups are covered in the health insurance, it is good.  |
|    |                   | 5 | FGD 5: 214                    | Do not know whether included or not under insurance. |   |

|    |   |   |                                |                                       |  |
|----|---|---|--------------------------------|---------------------------------------|--|
| 46 | Role of academic institutions   | 2 | FGD 2: 170, 171, 172           |                                       |  |
|    |   | 3 | FGD 3: 212, 213- 219, 233- 235 |                                       |  |
|    |   | 4 | FGD 4: 178- 179, 181           | Teens major influence                 | 181. Teenagers, they can influence their mother to do mammogram. They will help us to recall the necessity of it. They also will know about it                 |
| 47 | Role of Physician   | 3 | FGD 3: 55, 75                  |                                       | 55. No idea. Our gynecologist usually won't tell anything  |
|    |   | 4 | FGD 4: 70, 85, 129             |                                       |  |
|    |   | 5 | FGD 5: 49, 253                 |                                       |  |
| 48 | Awareness and awareness sessions matters along with free availability | 1 | FGD 1: 121- 124                |                                       |  |
|    |   | 2 | FGD 2: 92-94, 123, 189         | All of them said awareness is crucial | 123. I think inviting for awareness classes, will work. But videos and messages may not be effective to really make them to go to the hospital to do check-up. |
|    |   | 3 | FGD 3: 61, 62                  |                                       |  |

|    |                       |   |  |   |  |
|----|-----------------------|---|--|---|--|
|    |                       | 4 | FGD 4: 261   |   |  |
|    |                       | 5 | FGD 5: 167,<br>170   |   |  |
| 49 | Fear of results       | 1 | FGD 1: 127-<br>129   |   | 129. I was being scared until I got the result. Fear is a part of the mammogram.                                 |
|    |                       | 4 | FGD 4: 207,<br>208   | Needs psychological support   |  |
|    |                       | 5 | FGD 5: 122-<br>124, 161,162                                  | 122-<br>Concreteness of diagnosis- will get diagnosed with breast cancer. |  |
| 50 | Fear of breast cancer | 2 | FGD 2: 12, 161   | A death note!   | 12. Breast cancer brings many problems in our life. By hearing it we are afraid about it. It is a gene mutation. |
|    |                       | 3 | FGD 3: 59  |   |  |
|    |                       | 4 | FGD 4: 18, 19,<br>21, 23, 25, 27,<br>28, 67, 85, 204,<br>217 | Mom's suffering-<br>4: 85   |  |

|    |                |   |                              |  |   |
|----|----------------|---|------------------------------|--|---|
|    |                | 5 | FGD 5: 17, 18, 148, 171, 172 | 172- part of beauty. So if a woman loses their breast it is shame. |   |
| 51 | Transportation | 2 | FGD 2: 62, 66, 103           | Lack of public as well as own transportation                       |   |
|    |                | 3 | FGD 3: 173, 174              |  | 173. There is no meaning if government provides one or two places in UAE. If free mammogram facility available far away from my home there will be transportation problem. It will be difficult to reach there.   |
|    |                | 4 | FGD 4:135                    |  |   |
|    |                | 5 | FGD 5: 211                   |  |   |
| 52 | Expatriation   | 2 | FGD 2: 68, 96, 104,          | 68- We look odd there!!  | 68. As said if I may not be prepared to undergo it, just like when we see it somewhere, no one will just go and do it. Also, I thought there might be only Arabic speaking doctors and health team are available. We look odd there. I feel so. Also, I |



|    |                      |   |   |   |  |
|----|----------------------|---|---|---|--|
|    |                      |   |   |   | think unless and until if there is no clear explanation of the procedure to the public no one will just go like that. I think they must give some sessions before.   |
|    |                      | 3 | FGD 3: 92, 168  |   |  |
| 53 | Language/<br>culture | 2 | FGD 2: 78, 79, 80, 82, 83, 84, 94, 96-98, 100, 148, 190 | Feel more confident with a doctor who can communicate in same language and who can understand the feelings, culture, food habits of the women |  |
|    |                      | 3 | FGD 3: 194  |   |  |
|    |                      | 4 | FGD 4: 240, 241, 243, 244, 245, 246                     |   | 240. If the health care organisation conduct such camps in any clinic or hospital it will be helpful.<br><br>If they inform that a Kerala doctor is available, many women feel comfortable to go. Because we will have a common understanding of |

|    |  |   |                                    |  |   |
|----|--|---|------------------------------------|--|---|
|    |  |   |                                    |  | our problems and concerns.  |
|    |  | 5 | FGD 5: 205                         |  |   |
| 54 | Keralites trust and interested with UAE government initiatives and hospital services | 2 | FGD 2: 138-140, 146, 147, 151, 152 |  |   |
|    |  | 3 | FGD 3: 109, 110, 160, 162-164      |  | 162. Wastage of time in Kerala, if we go to the hospital here (UAE) it is organized.  |
|    |  | 4 | FGD 4: 139                         |  |   |
| 55 | Keralites with breast cancer (known to the participants)                             | 3 | FGD 3: 38, 41, 43-46               |  |   |
|    |  | 4 | FGD 4: 48, 56                      |  | 56. I know a teacher; she was the teacher of my daughter. She had affected by the breast cancer, I don't have regular contact with her. But my daughter used to tell about her. My daughter told me about her, and then I became curious about that teacher, one of my cousins was also teaching in the same school. So I asked about the teacher and her disease. She said to me that the teacher got breast cancer. She died in |

|    |                       |   |                                 |  |   |
|----|-----------------------|---|---------------------------------|--|---|
|    |                       |   |                                 |  | UAE and took her body to Kerala.  |
|    |                       | 5 | FGD 5: 38, 43, 47               |  |   |
| 56 | Ethnographic credence | 2 | FGD 2: 86, 88-90, 94, 106 - 108 | 86- open mind required.<br><br>Not a routine then??!!                          |   |
|    |                       | 3 | FGD 3: 132, 210, 230, 231       |  | 132. If it is that important, I think someone should gather everyone and take us. Like from our church, or employers. Otherwise if we go alone then people will think that I got some disease that's why I did it and need to answer everyone |
|    |                       | 5 | FGD 5: 84- 85, 152, 195         | Friends share negative experience that affects a women, breast cancer survivor |   |
| 57 | Overconfidence        | 2 | FGD 2: 124                      | Oh! Its not for me, confidence matters!!                                       |   |

|    |  |   |  |                                     |   |
|----|--|---|--|-------------------------------------|---|
|    |  | 3 | FGD 3: 10  |                                     |   |
|    |  | 5 | FGD 5: 72, 78  |                                     | 72. I heard that, without any reason losing the weight of our body would be a sign for cancer. I did not go for any kind of test but I am controlling myself through keeping healthy weight. I have a faith that, such kind of diseases will not affect me ever. That faith only helping me to live now I am 53 years. Up to now I didn't do any kind of checkup concerning cancer. I will not be affected by this kind of disease that is my faith and hope. |
| 58 | Carcinophobia                                | 2 | FGD 2: 75  |                                     |   |
|    |  | 3 | FGD 3: 11  |                                     | 11. But I am scared even to hear cancer that it may come to me too.   |
|    |  | 4 | FGD 4: 25  |                                     |   |
| 59 | Kerala government should take initiatives to | 2 | FGD 2: 142-143, 150,151, 156, 158-160, 185, 186, 190 | Expectations from Kerala government | 150. I think may be something Kerala government are doing. But those steps are not enough. The attitude of Kerala government is totally   |

|    |   |   |                                |                                 |  |
|----|---|---|--------------------------------|---------------------------------|--|
|    | serve Keralites                                   |   |                                | towards migrant women's health. | different from the attitude of UAE government.   |
|    |   | 3 | FGD 3: 222-224, 226, 227, 241  |                                 | 222. Government can collect the data through NORKA, they can come to know about our age.   |
|    |   | 4 | FGD 4: 256, 257                |                                 |  |
|    |   | 5 | FGD 5: 177, 242, 243, 246, 247 |                                 |  |
| 60 | At Kerala (women's expectation)                   | 3 | FGD 3: 244-250                 | Expectations at Kerala          | 250. Compare to women here (in UAE), they have more time and easily accessible to their location near to their houses (in Kerala).             |
|    |   | 5 | FGD 5: 205, 230, 232, 234      |                                 |  |
| 61 | Research enabled them to recollect and motivation | 1 | FGD 1: 69                      | Me a critical ethnographer!!    |  |
|    |   | 4 | FGD 4: 124                     |                                 | 124. Actually many knows about these tests from here and there. But no clear idea. When we are discussing now, I am trying to recollect those. |

|    |  |   |                        |               |  |
|----|--|---|------------------------|---------------|--|
| 62 | Psychological support  | 4 | FGD 4: 219-221         | If detected   | 219. I think some sessions. Mainly psychological support is required.  |
|    |  | 5 | FGD 5: 74, 99-106, 181 | For survivors | 106. Even though they get good treatment in Kerala the societies are not treating them well. So they like to leave the Kerala to get peace and avoid the rush of the visitors. Mentally they are feeling discouraged |
| 63 | Discussion about what can be done in Kerala to improve awareness | 5 | FGD 5: 183-193         |               | 183. It is not possible to give awareness for community together. We should divide the community in Panchayat level or ward level then we should make them aware.  |

## Appendix P Example of Investigator triangulation

### Subthemes Vs Research Themes

| Sl. No | Subthemes  | Research theme (Self- efficacy/Knowledge/Attitude/ Beliefs/ Social factors/ Environmental factors)   |
|--------|--|--|
| 1      | Altruism   | Self-efficacy but could be social too – expectation of the culture influences the way women feel, could also be attitude?? Need to look at specific quotes |
| 2      | Breast cancer  | Knowledge  |
| 3      | Carcinophobia  | Belief   |
| 4      | Community Organisations/ members (religious/ Kerala community organisations) (you have called this social organisations not community organisations) | Social factors (Social Norms not social factors)   |
| 5      | Early detection awareness  | Knowledge  |
| 6      | Ethnographic credence  | Social factors   |
| 7      | Expatriation   | Environmental factors (this is called Physical Factors not environments factors)   |
| 8      | Fear   | Attitude   |
| 9      | Media  | Environmental factors  |
| 10     | Over confidence  | Beliefs or attitudes?  |
| 11     | Pain   | Beliefs  |
| 12     | Patriarchy   | Self-efficacy  |

|    |  |  |
|----|--|--|
| 13 | Radiation                                  | Knowledge  |
| 14 | Screening mammography                      | Knowledge but this influences beliefs and attitudes.<br>Need to check quotes |
| 15 | Self-dependency                            | Self-efficacy  |
| 16 | Token of death (Godly intuition, Fatalism) | Belief   |
| 17 | UAE health care facilities                 | Environmental factors  |
| 18 | Word of Mouth                              | Social factors   |

### Research themes Vs. Themes

| Research themes   | Themes (Personal/ Environmental/ Behavioural) |
|---|---|
| Attitude  | Personal                                      |
| Beliefs   | Personal                                      |
| Environmental factors (should this be physical factors??) | Environmental factors                         |
| Knowledge   | Personal                                      |
| Self- efficacy  | Behavioural                                   |
| Social factors (should this be Physical Factors)          | Environmental factors                         |



## Appendix Q Skills developed and impact of this research through critical ethnography

This doctoral research helped me to develop many skills in research, technology, and teaching and learning skill.

**Research Skills:** such as presenting the report, qualitative data analysis, literature search strategy in relation to the research context such as PICO, PICOS & SPIDER (Methley, Campbell, Chew-Graham, McNally, & Cheraghi-Sohi, 2014); I used SPIDER and analysing research findings in relation to the available literature that I value the most as a new researcher in this field.

**Technological skills:** The referencing tool EndNote played an important role in saving time and storing the required references under each category. I was familiar with other referencing tools but EndNote was more useful to directly save the references from the library. I could also provide hands-on training to a group of students at the University of Sharjah.

I learned and tried to use a qualitative data analysis software; “NVivo” in this research. I understood that it could serve to store and sort data in one platform. However, I did not use it throughout this research, Microsoft Word and Excel served with its available features that are adequate for this research.

**Teaching and learning skills:** The opportunities and sessions provided at the University of Salford enabled me to progress in my teaching career pathways. Consequently, I started using handouts, questionnaires, and pre and post surveys in my lectures. Moreover, I could get an idea of the teaching and assessment styles at the Directorate of Radiography, University of Salford. These changes helped me to incorporate critical thinking into the topics of discussion among students. The digital learning resources that were available encouraged me to utilise and encourage to develop online teaching materials.