

**University of Southampton**

Faculty of Environmental and Life Sciences

Health Sciences

**Malaysian women and family members' narratives of their  
breast cancer decision-making experiences**

by

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Thesis for the degree of Doctor of Philosophy

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**University of Southampton**

## **Abstract**

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Breast cancer is one of the most prevalent cancers among women worldwide. Disharmony and imbalance can be created in the lives of women diagnosed with breast cancer as well as in those of their family members. They may face many decisions related to breast cancer, including on symptom interpretation and treatment, and on their own lifestyle and career. The decision-making experiences might be different across nations. Previous research literature has tended to focus on specific aspects of decision-making regarding breast cancer, but no study has sought to recruit women with all stages of breast cancer (together with their family members) with the aim of providing an understanding of their decisions. Little is understood regarding this issue and how the process takes place among Malaysian women with breast cancer and their family members.

The purpose of this study is to explore the decision-making experiences of Malaysian women and their family members, focusing on the time between first realising that something is

abnormal in the breast and the women undergoing their first conventional treatment in hospital.

The study participants took part in in-depth, one-time, face-to-face, audio-recorded interviews conducted by the researcher. All of the interviews were subsequently transcribed verbatim and analysed using narrative analysis. This research is underpinned by a social constructivism epistemology and narrative approach since these provide the opportunity to gain an in-depth understanding of the participants' experiences and enable us to derive meaning from their decisions.

The participants comprised 14 women with breast cancer (in the age range of 28–62 years) and 14 of their family members recruited from two hospitals in Malaysia. The women's breast cancer ranged from stage one to stage four. The length of time between realising that something was wrong and the first conventional hospital treatment ranged from almost two months to three years.

Four major narrative themes were presented based on Scott's pathway to treatment: 1) Appraisal interval, 2) Help-seeking interval, 3) Diagnostic interval, and 4) Pre-treatment interval. The findings reveal that each participant described the range of decisions that they made within that period of time. The participants also constructed their own justifications regarding their decisions. The decision-making process was ongoing, complex and not necessarily in sequence, with many influencing factors. Acknowledging the uniqueness and specific concerns of the women and their family members may assist health care providers in providing appropriate support during their difficult situations.



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# **DECLARATION OF AUTHORSHIP**

I, Wan Hasliza Wan Mamat declare that the thesis entitled:

Malaysian women and family members' narratives of their breast cancer decision-making experiences

and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- none of this work has been published before submission, or parts of this work have been published.

Signed: .....

Date:.....



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# Definitions and abbreviations

Term	Definition
Alternative treatment	Complementary or alternative medicine refer to a broad set of health care practices that are not part of that country's own tradition or conventional medicine and are not fully integrated into the dominant health-care system (WHO 2013)
Appraisal delay	The time between the point at which a person first detects an explained symptom until s/he concludes s/he is ill based on Andersen's model (Scott et al. 2013)
Behavioural/ referral delay	The time between a person deciding an illness requires medical care and deciding to act on this decision based on Andersen's model (Scott et al. 2013). Taib et al. (2014) had proposed that during this time, the health referral system also contributed to the delay.
Breast cancer	A disease characterised by abnormal cells growth out of control begin in the breast and the cells can invade surrounding tissues or spread to distant areas of the body (American Cancer Society 2018)
Conventional treatment	Treatment for breast cancer including surgery, chemotherapy, radiotherapy, hormone treatment, or palliative treatment
Culture	An integrated pattern of learned beliefs and behaviours that are shared among groups and include thoughts, styles of communicating, patterns of interaction, views of roles and relationships, values, practices and customs (Donini-Lenhoff and Hedrick 2000)
Decision-making	The process by which the women or family members make decisions
Family members	The members that are related by blood or marriage such as father, mother, husband, daughter, son, brother, sister, grandfather, uncle or aunt
Islamic treatment	Treatment that had basic paradigm, concepts, values, procedures conforms to or do not contradict the Holy Quran and <i>Sunnah</i> (recorded and authenticated saying and traditions of the Prophet Muhammad) (Kasule 1997)
Primary breast cancer	The first breast cancer diagnosis and not a metastasis of a previous cancer
Traditional treatment	The sum total of the knowledge, skill, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the

	maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness (WHO 2013)
Treatment delay	The time between the first appointment with a HCP and the onset of treatment based on Andersen's model (Scott et al. 2013)

BCS	Breast conservative surgery
CAM	Complementary and alternative medicine
CBE	Clinical breast examination
e.g	example
FGD	Focus group discussion
FH	Family history
GP	General practitioner
HBM	Health Belief Model
HCP	Health care professional
HLOF	Health locus of control
HOD	Head of Department
HRRC	Hospital Research Review Committee
MOH	Ministry of Health
MREC	Ministry of Health Research and Ethics Committee
MWFCD	Ministry of Women, Family and Community Development
n.d	no date
NIH	National Institute of Health
NMRR	National Medical Research Registry
PIS	Patient information sheet
SOCSO	Social Security Organisation
UK	United Kingdom
USA	United States of America
VPN	Virtual private network



# Thesis layout and contents

This PhD thesis comprises eight chapters. The structure of the thesis is outlined as follows:

- Chapter 1: Background to the study

Chapter 1 provides the reader with contextual and background information regarding breast cancer and decision-making. Theoretical frameworks such as the Model Pathway to Treatment, Health Belief Model and health locus of control are reviewed pertaining to breast cancer decision-making. The chapter continues with a description of Malaysia, including the context, culture and health care system in which the study takes place.

- Chapter 2: Literature review

Chapter 2 presents a review of the literature concerning breast cancer decision-making in Malaysia using a scoping review. This serves to reveal gaps in the knowledge and justifies the importance of conducting this research. As a result, research questions and objectives are generated to respond to the identified gaps.

- Chapter 3: Methodology

Chapter 3 presents the ontological and epistemological stance underpinning the study through the choice of social constructivism and narrative approach.

- Chapter 4: Method

Chapter 4 describes the research design, sample and recruitment process, in addition to justifying the inclusion and exclusion criteria. The data collection procedures are then presented using narrative

interview. The chapter then moves on to a discussion of the ethical issues, data analysis and rigour.

➤ Chapter 5: Introduction to the participants

Chapter 5 provides an overview of the women and family members who participated in the study and outlines the emerging themes.

➤ Chapter 6: Findings

Chapter 6 illustrates the research findings obtained from the 28 participants comprising women with breast cancer and their family members. The findings are presented according to the Model Pathway to Treatment: Appraisal interval, help-seeking interval, diagnostic interval and pre-treatment interval.

➤ Chapter 7: Discussion

Chapter 7 contains the discussion for this study. The four main findings and other sub-themes are explored by drawing on the supporting literature. This chapter also presents the discussion based on the Model Pathway to Treatment, Health Belief Model and health locus of control that influenced the decision-making process.

➤ Chapter 8: Conclusions, implications and limitations

Chapter 8 contains the overall conclusion of this study including the contribution to the knowledge, research implications for health care providers and possible directions for future research. The strengths and limitations of the study are also discussed. The reflexivity and reflection for this study are presented prior to a conclusion.



# **Chapter 1: Background to the study**

## **1.1 Introduction**

The purpose of this first chapter is to provide an overview of breast cancer around the world and, more specifically, in the Malaysian population. This is followed by a review of the Malaysian context, including its demography, culture, health care system, oncology services, and policies. A discussion of the factors that influence treatment decisions and the presence of alternative treatments has been included. This is followed by brief descriptions of the theoretical frameworks, namely the Model Pathway to Treatment, the Health Belief Model and the health locus of control. Finally, my view regarding this study has been presented.

## **1.2 Overview of breast cancer**

Breast cancer is perceived as a devastating and life-threatening illness associated with suffering, pain and death (Fu et al. 2008; Taleghani et al. 2008), in addition to being seen of as a long-term illness (Kralik et al. 2001). Individuals with breast cancer may experience significant physical and emotional effects such as fatigue, sleep problems, depression and cognitive disturbance (Bower 2008). The patients' uncertainty about breast cancer, their loss of independence and concerns about their family also serve to create significant amounts of stress and this influences the patients' quality of life (Turner et al. 2005).

Breast cancer is the most prevalent cancer among women globally. An estimated 1.67 million new cases were diagnosed in 2012 (Ferlay et al. 2015). More than half of new breast cancer cases and deaths are now

occurring in economically developing countries (American Cancer Society 2015a). In these countries, breast cancer tends to be diagnosed in the advanced stage, with subsequent poorer outcomes [ibid]. This is compounded by relatively low numbers of trained medical staff, a lack of modern equipment, such as radiotherapy machines and the high cost of cancer drugs which restricts the effectiveness of breast cancer treatment in low- and middle-income countries (Anderson et al. 2008).

In Malaysia, the incidence rate of cancer is expected to rise due to an ageing population, an increase in the population's exposure to cancer risks, the rapid process of modernisation and the growing adoption of unhealthy lifestyles (Ministry of Health Malaysia 2017). The most recent figures issued by the National Cancer Registry in Malaysia revealed that breast cancer is the most common cancer among women from all three of the major ethnic groups in Malaysia, accounting for a total of 32.1% of all cancers in the 2007 – 2011 period (Azizah et al. 2015). The peak age-standardised rate of breast cancer among Malaysian women is in the 50 – 59 age group (see Figure 1.1, p.3) which is younger in comparison to the 65 – 69 age group as in the United Kingdom (UK) (Cancer Research UK 2016) and the 70 – 79 age group in the United States of America (USA) (Komen 2016). The lifetime risk of developing breast cancer at some stage for a woman in Malaysia is 1 in 30 (Azizah et al. 2015), compared to 1 in 8 in the UK and USA respectively (National Cancer Institute 2012; Cancer Research UK 2014). Although Malaysian women face a lower lifetime risk, they tend to present late, with more than half of newly diagnosed women already having an advanced stage of breast cancer (Leong et al. 2009). The large number of Malaysian women presenting with an advanced stage of breast cancer during diagnosis has an effect on their prognosis and survival (Norsa'adah et al. 2011).

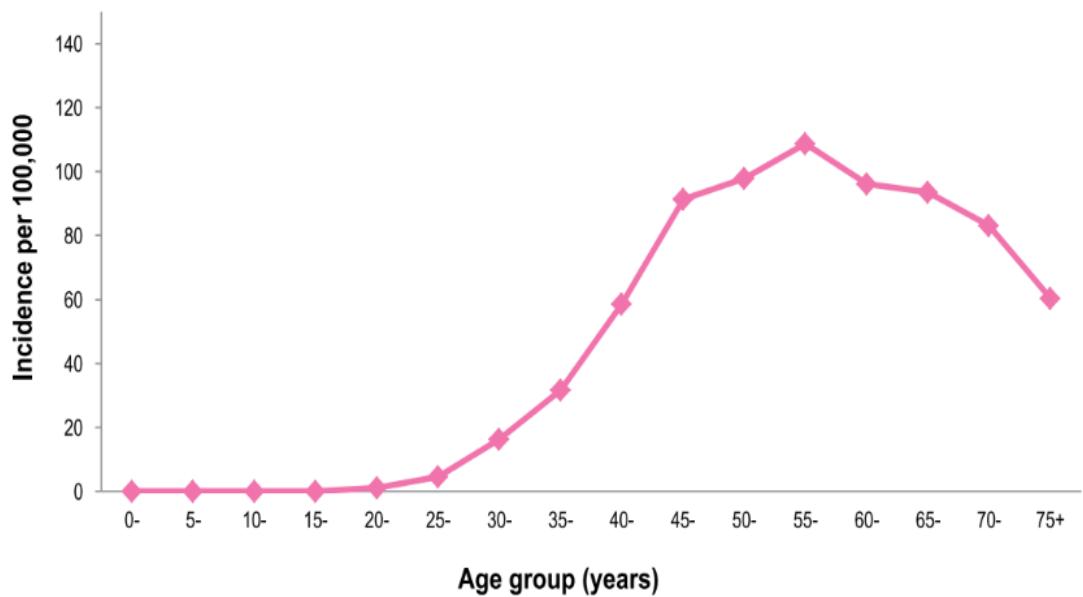


Figure 1.1: Age-specific breast cancer incidence per 100,000 of the population in Malaysia 2007–2011 (Azizah et al. 2015)

Internationally, the presence of advanced stages and the late diagnosis of breast cancer has been investigated through the concept of “delay”, looking into the health system and patient-related influences (Unger-Saldaña and Infante-Castañeda 2011; Caplan 2014; Khan et al. 2015a). Caplan (2014) defined a system delay as a “delay within the health care system in getting appointments, scheduling diagnostic tests, receiving a definitive diagnosis, and initiating therapy” (p.1), while patient delay was defined as a “delay in seeking medical attention after self-discovering a potential breast cancer symptom” (p.1). However, it is important to note that there is no agreement between authors of the time gap analysis between a patient and system delay (Freitas and Weller 2015). In the case of breast cancer, some researchers have defined patient delay as a duration of more than three months commencing from when the patient first discovers the symptom (Unger-Saldaña and Infante-Castaneda 2009; Jones et al. 2015). Other researcher has defined patient delay as one month (Memon et al. 2013) while some authors have not specified a time (Andersen et al. 1995; Scott et al. 2013). An alternative approach

was taken by Scott et al. (2013) who described the intervals between the different steps of the process from the recognition of a symptom through to treatment, which has the advantage of integrating the patient, disease and system factors that influence help seeking behaviour, diagnosis and treatment. Andersen et al. (1995) conceptualised delay as factors, which impede the actions taken between the detection of bodily changes and beginning the treatment.

Other than focusing on the concept of “delay”, several studies from the international literature have also identified a variety of factors that influence the decision-making among women with breast cancer. These factors including age, family history, having children, lactation, marital status (Gumus et al. 2010), education level, values and cultural background (Michelson et al. 2000), other people such as doctors, family and friends, alternative treatment, faith in God, knowledge about breast cancer, changing the mind (Aziato and Clegg-Lamptey 2015), past experiences of cancer, conventional treatment itself (scope for choice, risks, benefits and consequences), and the instincts concerning treatment choice (Lifford et al. 2015). It seems that most of the influential factors are related to the patients’ background.

However, it is important to note that decisions will also be influenced by patient’s beliefs and values, which are shaped by culture. Therefore, it is important to have an operational definition of culture for this study, so then these influences can be accounted for within the analysis and interpretation process later on. Chiok et al. (2012) stated that there is diverse definition of “culture”, ranging from a way of life to historical inheritance through to knowledge and value transmission. Hofstede (1993) defined culture as a “collective programming of the mind which distinguishes the members of one category of people from another” (p.89). Hofstede (2011) also explained that culture is a construct, which

is the product of people's imagination. Like Hofstede (1993), Donini-Lenhoff and Hedrick (2000) concluded that culture is an integrated pattern of learned beliefs and behaviours that are inter-connected or shared among groups, including thoughts, styles of communicating, patterns of interaction, view of roles and relationships, values, practices and customs. Thus, culture differentiates each group of people, through their relationships with other people, the environment and God.

Rijamampianina (1996) combined the definitions of culture from Harris and Moran (1987) and Kohls (1981) in his work, which results in the definition that "culture is created, acquired and/or learned, developed, and passed on by a group of people, consciously or unconsciously, to subsequent generations. It includes everything that a group thinks, says, does, and makes—its customs, ideas, mores, habits, traditions, language, material artefacts, and shared systems of attitudes and feelings – that help to create standards for people to coexist" (p.124). This definition was also selected as the most relevant to this study because it captures two domains that Triandis (2004) has called objective (all tangible or observable variable) and subjective (e.g.: values, beliefs, attitudes) culture respectively. Moreover, it consists of a number of components that most scholars from different disciplines agree upon to be constitutive of culture (Triandis 2004; Fischer 2009; Taras et al. 2010; Schein 2011; Bala et al. 2012).

There are multiple factors that influence changes in culture such as different environments, interactions (Tuohy 1999), contact with another culture, technology, ecology and geography (Nagaraja and Rashmi 2017). Dressier and Carns, as cited by Nagaraja and Rashmi (2017), reported through their observations that sometimes people are often controlled by customs that might differ from those that they have learnt to accept. This scenario makes them adopt some of the new customs,

reject others, and follow modified versions of others still. This is because culture also part of the learning process and is not genetically inherited. Moreover, there is still a continual borrowing and integration of cultural aspects between and among cultures, as culture itself is not static nor is it a single entity (Tuohy 1999). Hall (1976) claims that no culture is more superior nor better equipped than others. The following sections provide an overview of the Malaysian context, culture and health system, and the influence of complementary and/or alternative treatments for breast cancer.

## **1.3 Malaysian context**

### **1.3.1 Demography**

Malaysia is a country in South East Asia comprised of two land masses separated by the South China Sea. These land masses are Peninsular Malaysia and West Malaysia, bordered by Thailand to the north and Singapore to the south, and East Malaysia, which is comprised of the two provinces of Sabah and Sarawak on the island of Borneo (see Figure 1.2, p.7). The capital city of Malaysia is Kuala Lumpur. Malaysia is a multi-ethnic and multicultural country with a total population of 32.4 million people as of the first quarter of 2018 with an average life expectancy of 74.8 years (Department of Statistics Malaysia 2018). The main ethnic groups are Malay, Chinese and Indian, who are Muslim, Buddhist and Hindu respectively. The official language of Malaysia is Bahasa Malaysia. Malaysia is considered to be an upper middle-income country and the Malaysian people benefit from advantages including a “well-developed health care system, good access to clean water and sanitation, and programmes to reduce poverty, increase literacy, improve the status of women, and build a modern infrastructure” (Jaafar et al. 2012, p.1).



Figure 1.2: The map of Malaysia (Worldatlas 2017)

### 1.3.2 Malaysian Culture

Each of the ethnic groups in Malaysia has a mutual respect for each other's culture, traditions, religious beliefs and way of life (Mustaffa et al. 2014). Similar cultural values exist in certain areas within these multiple ethnicities such as the concept of social hierarchy (Lim and Asma 2001), expressing refusal (Kuang 2009) and the forms of address used (Kuang et al. 2012). However, they are different in terms of the degree and priority of the values. For example, Malays rank honesty as their priority value, the Chinese favour courtesy and Indians regard family as their main priority (Fontaine et al. 2002).

Malaysian culture can be categorised as a high-context culture (Mustaffa et al. 2014), which means that communication is often more implicit and less direct than in many Western cultures (Communicaid 2017). For example, Kuang (2009) found that Malays, Chinese and Indians are more prone to using indirect strategies when

communicating refusal, preferring to maintain the face of the hearer to avoid any unforeseen misunderstandings or miscommunication.

Asma (2009) stated that Malaysians are collectivist, hierarchical, relationship-oriented and religious. Bhawuk (1992) noted that the collectivist culture reflects a sense of oneness with other people, tying relationships both in the family and in society together. Based on this collectivism concept, Malaysian culture tends to be family-based, whereby people devote their lives to their families and like to be with them (Halili 2011). Malaysian culture is also very concerned with respect. According to Kuang et al. (2012), respect for authority, seniority or elders is the norm in Malaysia.

Malaysian people attempt to maintain the concept of 'keeping face' and seek to avoid shame to maintain harmonious relationships among the community members. Face can be defined as a "personal concept that represents qualities such as a good name, good character and being held in esteem by one's peers" (Commisceo 2017, p.2). Malaysian people will endeavour to avoid criticising and insulting others, doing something that brings shame to the group, displaying anger toward another person, refusing a request, not keeping a promise or disagreeing with someone publicly as it results in a loss of face [ibid].

Many Malaysians still maintain strong traditional beliefs, thus the socio-cultural influences on decision-making may be unique to the Malaysian population. Puteh-Behak (2013) stated that it is important to acknowledge that each ethnic group in Malaysia is distinctive and rich, with its own cultural values, and that each group has different interpretations of the world around it. Briley (2007) stated that people with different cultural backgrounds have different expectations, norms and values that have the potential to influence their judgements and

decisions, as well as their subsequent behaviour. Therefore, to understand a person and the culture from which that person derives, one has to look around, past and inside that person because there are values and thoughts present that have shaped that person's behaviour (Salleh 2005).

The diverse cultures present in Malaysia might influence people's behaviour with regard to their health and illness. For instance, it is a common belief that certain foods, including eggs and seafood, should be avoided after surgery as they are considered to be toxic and consumption would result in wound itchiness and festering (Lee et al. 2017). As such, these food types delay the wound healing process. Some ethnic groups also believe that supernatural agents such as witchcraft and possession by evil spirits can cause certain diseases (Razali et al. 1996). These cultural beliefs have an influence on the health practices adopted regarding disease. People from one culture can often be surprised by the decisions that people from another culture make because they are unaware of the factors that people from another culture consider regarding their actions (Noble et al. n.d). The core characteristics of decision-making are the decision itself and the behaviour of the decision maker, which involves the processes of thinking and reacting to external factors such as previous and future events, the psychological consequences, self-belief and the reactions to those events (Oliveira 2007).

### **1.3.3 Social positioning of the Malaysian women**

In many Asian countries including Malaysia, some women are strongly committed to the family responsibilities prescribed by their gender role, which includes taking care of the children and housework (Abdullah et al. 2008). Abdullah et al. (2008) also found that some Malaysian women, especially Malay, still closely adhere to their traditional cultural values.

They are expected to be strong as a mother, while remaining effeminate and subservient as a wife. Additionally, Malay women still influenced by a traditional patriarchy system, in which male in the family, especially husband controlled the decision (Norsa'adah et al. 2012). Malaysian women still face many challenges due to their work-life balance, in addition to cultural issues and religious interpretations that stereotype women's roles (Syahirah and Hussain 2016). Several studies have suggested that the women's roles prescribed by the society were they socialised and the religion (Abdullah et al. 2008). Indeed, a woman's level of autonomy is considered to be one of the factors that may affect health-seeking behaviour (Sharan et al. 2005). Referring to the social norms in South Asia, young married women prefer to consult their mother-in-law, husbands and household elders in all matters, including those related to their own health and well-being [ibid].

However, the women's lives in relation to the position and status of women in Malaysia could change due to modernisation processes (Lie 2000), rapid economic changes and industrialisation (Ariffin 1997). With the changes that are occurring in the social context, the women are being given more freedom of action and acknowledging their higher status may affect the distribution of privileges and status among them (Lie 2000). According to the Ministry of Women and Family Development (2003), Malaysian women have progressed and participated effectively in many areas such as "education, health, employment, and participation in power sharing, and in the decision-making process" due to their increased access to education, employment opportunities and changes in the socio-cultural environment (p.14). This situation empowers the women's position and they became autonomous in terms of their health, especially related to their breast cancer because they have the ability to make their own decisions. According to Osamor and Grady (2016), autonomy is essential for the health decision-making process, starting from seeking out and utilising health care services up

to the point of choosing the treatment. This is because autonomy that supports health care decision-making is associated with better health outcomes.

### **1.3.4 Health care system**

The Ministry of Health (MOH) is the main provider of health care services to the Malaysian community, but private services are also growing rapidly (see Figure 1.3, p.12). Thus, access to health care facilities should not be a problem. The nearest government clinic has been reported to be within 5.3 km of households in rural areas (Institute Public Health 2008), but despite their relative ease of access, most of the clinics are run by a *jururawat desa* (health nurse holding only a midwifery certificate), with a medical assistant or doctor conducting weekly or monthly visits based on a pre-determined schedule (Quek 2009).

The health care system in Malaysia is divided into two; the government-funded public sector and the private sector. People from low socio-economic backgrounds tend to use the public health service because the government subsidises most of the medical care or the patient pays only a minimal fee (Norsa'adah et al 2012). If a patient is unable to pay, they will usually be referred to the welfare department, which may be able to assist [ibid.]. Public hospitals comprise of both small and large district hospitals. Small district hospitals provide general medical and nursing care and have medical officers, while larger district and regional hospitals provide a wide range of services and feature specialist staff,

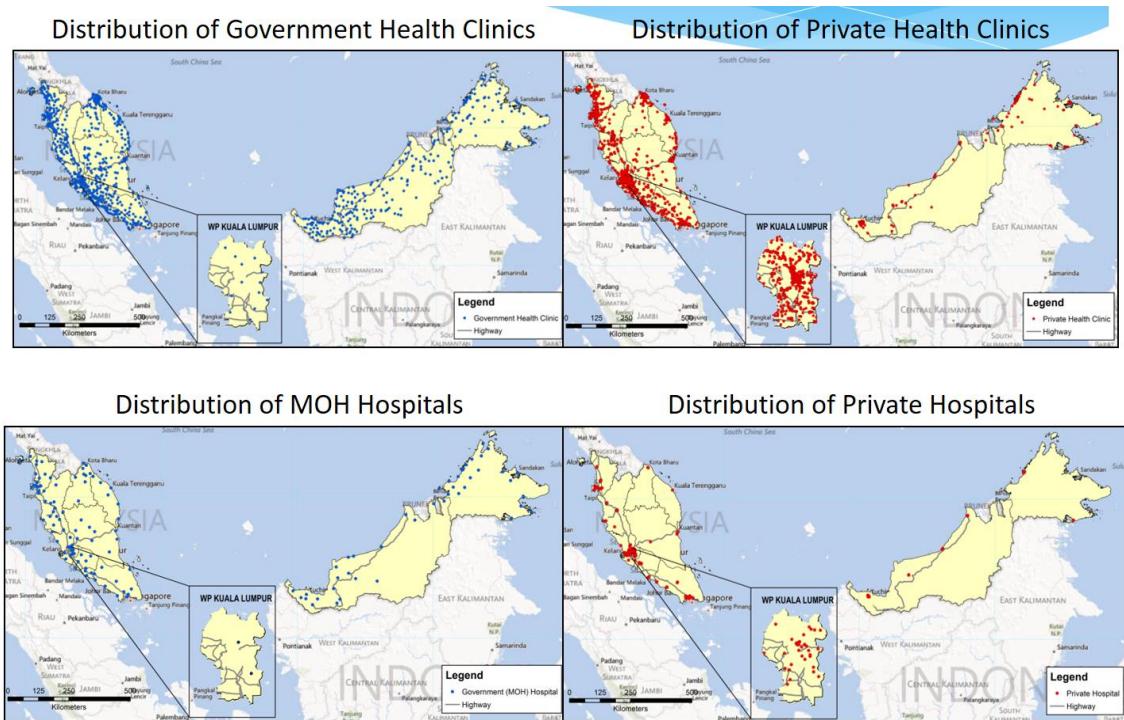


Figure 1.3: The distribution of public and private health services in Malaysia (Malaysia Ministry of Health 2014)

with the facilities being easily accessed by the public via a walk-in or referral system (Juni 1996).

A public hospital is considered to be a social obligation and it is a need for all citizens (Hameed et al. 2017), but it also experiences a lack of treatment facilities and doctors, overcrowding and long waiting lists (Rasiah et al. 2010). The shortage of professional experts, especially doctors and specialists in the public hospital, arises because they prefer to work in private hospitals and this leads to long waiting time among the patients to obtain treatment and medication (Hassan et al. 2015). This situation might delay and affect the care that the patient receives in the public hospital. However, Manaf (2012) found that the patients were satisfied with the inpatient service of public hospitals and that this might be due to the low expectations of the patients regarding their care and the services available because they were aware that they only

pay a small fee compared to private medical care [ibid]. Senarath et al. (2013) stated that patients with a higher level of education and income tended to be less satisfied with public hospitals because they have higher expectations.

The private health service offers easier access, simpler registration and appointments, shorter waiting times and possibly a greater continuity of care with better personal attention, although the costs are higher for both a consultation and medicine (Quek 2009). Private healthcare is profit-oriented and it is based on fee-for-service or out-of-pocket (Hameed et al. 2017). The private sector therefore is usually accessible to those who are willing and able to afford to pay for the services and care. However, Quek (2009) stated that the private clinics provide easy care for certain illness at very reasonable costs, especially for areas outside of the main city and that they complement the public sector in helping to alleviate the patients coming to severely overloaded outpatient government clinics. Therefore, redistributing the public sector patients that sometimes have to wait for several hours to private clinics nearer to their home provides them with better options related to patient care and attention [ibid]. Sohail (2003) reported that Malaysian patients were generally satisfied with the quality of the services that they received from private hospitals.

### **1.3.5 Oncology services**

Based on the National Healthcare Establishment & Workforce Statistics 2010 report, oncology services in Malaysia are provided by resident or visiting oncologists in both public and private hospitals (Gubrium and Holstein 2009). The same report showed that up to 2010, there were 55 hospitals providing oncology services, with 28 in the public sector including 3 university hospitals and 27 private sector hospitals [ibid.]. Out of these 55 hospitals, 50 had resident or visiting oncologists, while

the remaining 5 hospitals did not have a clinical or radiation oncologist, with the patients instead being supervised by physicians, surgeons or gynaecologists with a special interest in oncology. Most oncology services are located in urban areas, primarily in the west coast region of Peninsular Malaysia. It is estimated that the ratio of oncologists to patients in Malaysia is 1: 650,000, compared to 1: 250,000 in England (Suhami et al. 2016). This indicates that Malaysia may come to enter a situation of resource constraints with regard to the number of oncologists required to cover the growing number of patients with cancer.

Currently, there is no standard operating procedure (SOP) for the timeline to treat breast cancer in either governmental or private hospitals. The timeline for the investigative procedures and treatment, especially in government hospitals, depends on the severity of the symptoms, the stage of the breast cancer, the staff, patients and the availability of facilities such as diagnostic equipment, an operating theatre, radiotherapy machine or a bed in a ward. Thus, the flow chart (see Figure 1.4, p.15) was based on interviews with the nurses who work in the oncology clinic in a government hospital, where the study was conducted.

### **1.3.6 Breast cancer health care policy**

The Malaysia Ministry of Health (MOH) has conducted various activities regarding the prevention and early detection of breast cancer, including the national promotion of the Healthy Lifestyle Campaign and breast health awareness (Malaysia Ministry of Health 2011). As part of the breast awareness programme for public health education, the MOH had suggested for women to follow three simple steps: 1) look for any

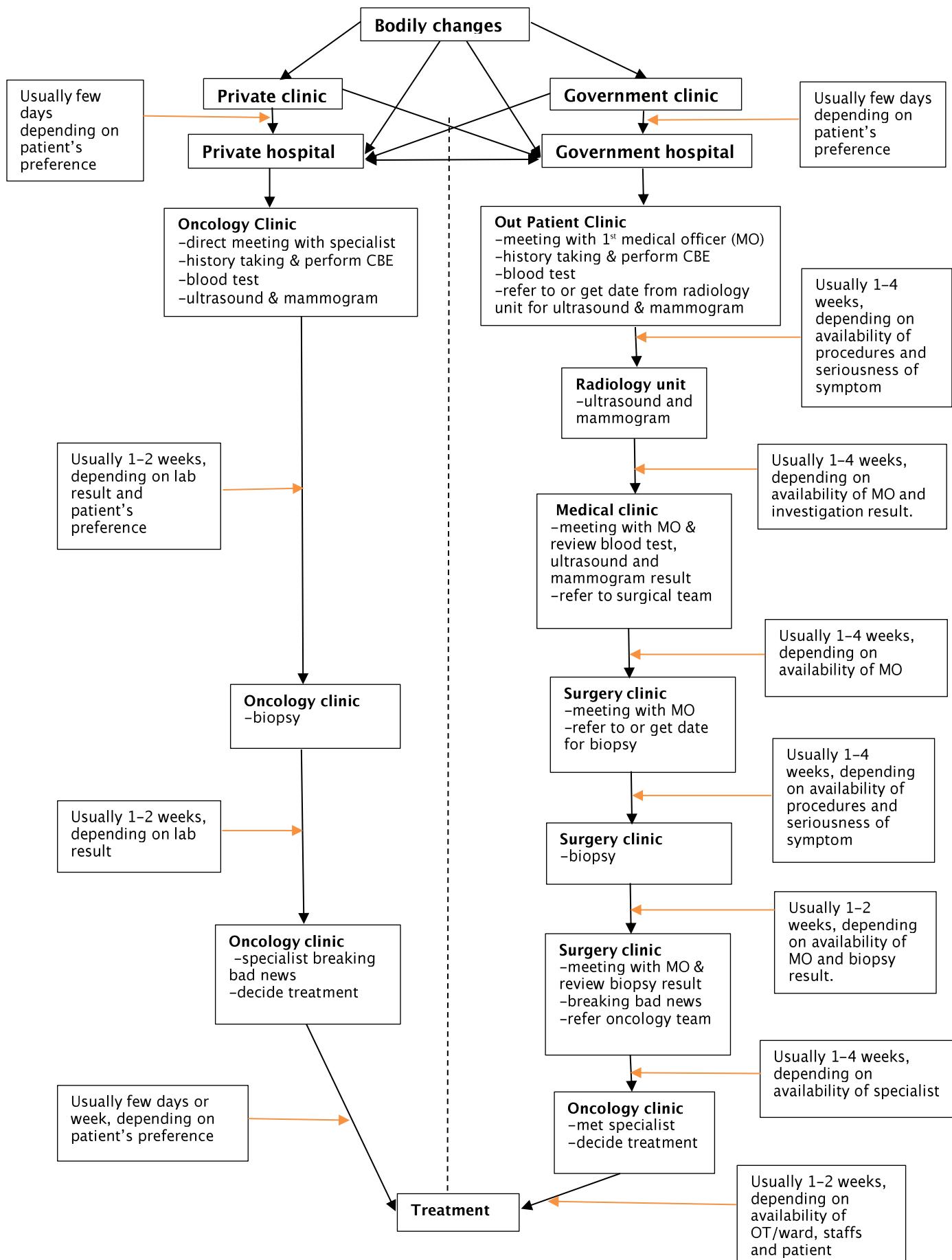


Figure 1.4: The general flow chart and time line for breast cancer treatment in government and private hospital

breast changes, 2) feel for any lumps, and 3) respond by reporting any changes found in the performance of their breast self-examination (BSE) to enable them to detect early changes in the breast and to present themselves immediately to the clinic for confirmation and treatment.

The MOH also encourages women aged 20 years and above to attend a clinical breast examination (CBE) by trained health staff (Malaysia Ministry of Health 2011). The frequency for the CBE depends on the age of the woman; women aged 20 – 39 years are invited to attend a triennial CBE, while for those aged 40 years and above, they are encouraged to have an annual CBE, and for women at a high risk regardless of age, they are encouraged to have a CBE every year [ibid.].

Based on the Malaysian Clinical Guideline Practice (CGP) for the management of breast cancer, population-based screening for breast cancer is not recommended in Malaysia due to the limited resources (Ministry of Health Malaysia 2002). Thus, the current approach for cancer screening is selective opportunistic (Ministry of Health Malaysia 2017). The implementation of opportunistic screening was in line with the recommendation from Breast Health Global Initiative (BHGI) for the lower and middle-income countries including Malaysia, in which the method for breast cancer screening depends on the available resources (Smith et al. 2006). Opportunistic screening means that a woman's attendance for a mammography is based on an individual's decision or an encounter with a health care professional (HCP) who recommends the screening (Mahmud and Aljunid 2018a). Thus the ability to obtain an early breast cancer diagnosis is dependent on the patient self-referring after they have discovered a problem with their breasts, or on them seeing an HCP that practises opportunistic screening (Taib et al. 2011).

The Malaysian government had provided mammography screening free of charge at government facilities for women considered to be at high risk, such as if they are aged 40 years and over and have the criteria A or B as listed in Table 1.1 below.

Table 1.1: The criteria and frequency for mammogram screening

Criteria	Frequency
At least one (1) criteria A below: 1. have a family history of breast cancer, mother, sister, younger sister or daughter suffering from breast cancer 2. has never given birth or given birth to a child after 30 years of age 3. has ever had atypia breast biopsy	Need to undergo annual mammogram screening
At least two (2) criteria B below: 1. carrier of genetic mutants, BRCA 1 and BRCA 2 2. first menstruated aged less than 12 years old 3. menopause at age or more than 55 years old 4. receive hormone replacement therapy (HRT) 5. a body mass index (BMI) $\geq 27.5$	Need to undergo mammogram screening every two years

(Malaysia Ministry of Health 2011)

Mammograms are also available at private health care facilities for any woman, but they have to be paid for and can cost RM230 or more (Mahmud and Aljunid 2018a). To reduce the financial burden, a number of entities offer subsidised funding because they do not have their own mammogram facilities, such as the Ministry of Women, Family and Community Development (MWFCD), and the Social Security Organisation. For example, in 2007, the MWFCD provided a subsidy of RM50 for every mammogram performed at a private health care facility registered with the National Population and Family Development Board Malaysia (LPPKN) for those who met the eligible criteria, who were at a high risk of breast cancer and who had a low of household income (Kementerian Pembangunan Wanita Keluarga dan Masyarakat 2014). However, in 2011, the MWFCD reviewed the eligible criteria and introduced free mammography screening at registered clinics for Malaysian women and

permanent residents who had a high risk of breast cancer, aged between 40 to 70 years old, and had a household income of less than or RM5000 per month, while they subsidised RM50 for the women with a household income of more than RM5000 [ibid]. Based on a report from MWFCD, the government allocated a total of RM54.2 million for a free mammogram subsidy program, but only 1.5% out of the 14.8 million eligible women with a household income below RM5000 participated in the program (Hamudin 2014). This scenario showed that even though the Malaysian government initiated a free screening programme with a huge budget allocation, the response from the target population was still relatively low.

Mahmud and Aljunid (2018b) conducted a systematic review regarding mammogram screening in Malaysia and they reported that the rate of mammogram uptake among the Malaysian general population was between 3.6% to 30.9%. This range is still lower when compared to Brazil, which has also implemented an opportunistic mammogram program, with the uptake being 12% through to 31.3%. In Malaysia, several factors were associated with mammogram uptake such as previous CBE, knowledge about breast cancer, age, education level, family history, employment status and social support (Mahmud and Aljunid 2018b). In contrast, the barriers to mammogram screening were a lack of knowledge on mammograms, not knowing the place for the test, embarrassment, fear of getting a cancer diagnosis, the women's perception that breast screening was unnecessary, low confidence in the radiologist/radiographer, low coping skills, fear of it being a painful procedure, a lack of time and cost [ibid]. Moreover, most of the facilities for mammography screening are located in the central and west coast regions in urban areas, so for those in the eastern coastal region, there is a typical travelling distance of more than 48 km (Mahmud and Aljunid 2018).

### **1.3.7 Factors influence decision-making among women with breast cancer**

#### **i. Patient-factors**

A lot of research has focused on patient decision-making to seek a medical opinion, as this influences a person's access to diagnosis and treatment. In a cross-sectional study in Malaysia (n=328 respondents), Norsa'adah et al. (2011) identified that women typically waited 2 months (median) between symptom recognition and consulting a general practitioner (GP) (range 0-11 years), 33.2% of the sample had a medical consultation with one month and 43.3% of respondents had a consultation after three months. The authors found similar results in a later study (Norsa'adah et al, 2012), with the consultation times ranging from 0.2-72.2 months (median=1.7 months). These studies demonstrated a significant relationship between these delays and prognosis. Other individual factors that influenced the delay in seeking medical help were personal beliefs, knowledge, attitude, emotions, and other priorities (Norsa'adah et al. 2012).

#### **ii. Social-influence**

In Malaysia, a person who has a close relationship with the patient, such as their partner, parents, children, siblings, friends and peers, influences the patient's treatment choices and their management of the illness (Low et al. 2016). However, the impact of this influence on the decision-making process depends on the closeness of the relationship between the patient and that person, the level of trust and the patient's perception of being cared for [ibid.]. Of particular note some Asian cultures believe that cancer, particularly breast cancer, comes with a social stigma, with the effect that the seeking of medical help and support outside of one's immediate circle tends to be discouraged (Cerimagic 2013). Some patients hold the traditional belief that the family must bear the responsibility for protecting the patients from any

unnecessary emotional burden by making decisions on their behalf (Shaw et al. 2015).

Vivien et al. (2013) found that several Chinese patients with cancer in Malaysia decided to seek guidance from a religious counsellor in a Chinese temple because they believed that their cancer was related to divine punishment, possession by an evil spirit or bad luck. This revealed that the social network comprised of the Chinese religious therapists who lived within the community influenced the participants' decisions related to their cancer treatment.

Women with breast cancer in Malaysia often obtain information and recommendations about the potential treatments available for their breast cancer from their family, neighbours and friends (Yusoff et al. 2011; Muhamad et al. 2012b; Norsa'adah et al. 2012; Abdullah et al. 2013). Some of the advice given to the women by such individuals may include to consult traditional healers (Yusoff et al. 2011; Muhamad et al. 2012b; Abdullah et al. 2013), to avoid surgery (Norsa'adah et al. 2012), to eat a sparrow's nest or to drink the juice from papaya branches (Yusoff et al. 2011). Although a woman with breast cancer in one of the studies did not believe in the effectiveness of traditional treatments, she nevertheless followed them as they had been recommended by her sister (Muhamad et al. 2012b), thus indicating that recommendations from a family member can greatly influence the decision to seek help from a traditional healer even though it was against her beliefs. Additionally, Shaharudin et al. (2011) found that 31.5% of the 114 Malaysian women participants with breast cancer mentioned that their friends were their primary source of information and that they influenced their decision to try complementary and alternative treatment (CAM).

### **1.3.8 Other treatments**

The important factors that influence treatment decisions in Malaysia are the availability and significance of complementary and/or alternative treatments, Islamic treatments and traditional healing. There is some evidence that such treatments can significantly delay access to medical consultations (Lexshimi et al. 2013; Mujar et al. 2017) because of being organised outside of cancer treatment services available. People also have faith and traditional methods have culturally significance (Osamor and Grady 2016).

#### **i. Complementary and/or alternative treatment**

According to the Ministry of Health Malaysia (2007), there is still no standard definition of “traditional” and “complementary treatment” in Malaysia, (p.5). Women with breast cancer in Malaysia can choose from a range of complementary and alternative treatments (CAM) such as dietary supplements, herbs, and homeopathy through to traditional medicines (Zulkipli et al. 2018). Approximately 34.8% to 88.3% of Malaysian women with breast cancer use one or more of these treatments (Lexshimi et al. 2013; Knight et al. 2015; Mujar et al. 2017; Zulkipli et al. 2018). However, the usage of CAM among Malaysian women with breast cancer was significantly associated with a delay in presentation, diagnosis and treatment in the univariate logistic regression analysis and this negatively impacted disease prognosis (Mujar et al. 2017).

#### **ii. Islamic treatment**

In addition to CAM, a growing number of Malaysian Muslims practice Islamic treatments (Arifin et al. 2016; Suhami et al. 2016). Kasule (1997, p.1) defined Islamic treatment as “treatment[s] that have basic paradigm, concepts, values, procedures conforms to or do not contradict the Holy Quran and *Sunnah* (recorded and authenticated

saying and traditions of the Prophet Muhammad)". Muslim people believe that cancer is a test from God, so some might prefer the religious healer to treat their illness (Merriam and Muhamad 2013).

Islamic treatment promotes faith healing through prayer and the recitation of Qur'anic verses, which are believed to bestow *baraka*, or blessing power (Asman 2008). Islamic treatments are provided in Islam-orientated healing centres by Islamic healers, who might be (1) healers with an inherited gift (for example, as a descendant of the Prophet Muhammad SAW), (2) healers who have learned the work of healing through a teacher, and (3) healers who have taught themselves (Hoofer, 2000).

Malaysian Muslim people with cancer choose to undertake Islamic healing for a variety of reasons: recommendation from their family and friends, family sanctions, a belief in Islamic healing (Yatim et al. 2014; Suhami et al. 2016), the credibility of the healer, economic factors (Yatim et al. 2014) and dissatisfaction with conventional treatments (Suhami et al. 2016).

### **iii. Traditional healer**

Malaysian people have easily access to traditional healers. Helman (2007) describes traditional healers as individuals or folk [traditional] healers that have specialized in certain forms of healing, either sacred or secular, or a mixture of the two, that are not part of the official medical system. Usually, these traditional healers have similar basic cultural values and worldviews with the communities where they live such as "beliefs about the origin, significance and treatment of ill health" (Helman 2007, p.85).

In Malaysia, the presence of a Malay traditional healer or “*bomoh*” is famous, with such individuals being highly regarded as an indigenous medicine healer in society (Othman et al. 2016). They are classified into four categories; spiritual healer, religious healer, herbalists and bone setters, based on their mode of practice (Razali and Yassin 2008). “*Bomoh*” usually believe that the causes of illnesses are physical or supernatural factors like food, heat, wind, evil spirit, witchcraft, black magic, the loss of inner strength and severe mental stress (Razali 1995). They usually perform incantations, use holy water and provide herb prescriptions, and they sometimes use the supernatural as part of the healing processes depending on the specific ailment and the needs of the patients [ibid].

According to Othman et al. (2014), people seek “*bomoh*” rather than conventional treatment due to its simplicity, use of non-invasive procedures, conducted in a familiar setting, involvement of family members, easily accessible, personalised, and involves convincing communication. According to Merriam and Muhamad (2013), traditional healers play four roles as a medicinal healer, emotional comforter, spiritual guide, and palliative caregiver in the context of cancer treatment for the Malay patients. Most of the traditional healers claimed that they able to cure the cancer with their own approach especially for the early stages of cancer even though there is no scientific evidence to support their claims [ibid.]. Moreover, their presence is accepted within the Malaysian culture as one of the ways to treat cancer. However, this type of consultation can delay seeking medical treatment (Othman et al. 2014; Merriam and Muhamad, 2013). Ariffin et al. (1997) reported that one third of the patients who attended oncology treatment had initially consulted traditional healers accounting for delay in 13% of the sample. However, not every traditional healer is against Western medicine. Some of them still advised and encouraged their patients with cancer to seek hospital treatment (Muhamad et al. 2012a; Knight et al. 2015).

#### iv. Food and dietary practice

Food is of important cultural relevance in Malaysia in relation to understanding the cause and significance of cancer, although it is not related to treatment delay. Culturally, food is categorised into two groups, which are “hot” and “cold” among the Islamic world, the Indian subcontinent, Latin America and China (Helman 2007). The term hot and cold does not refer to actual temperature, spiciness or its raw or cooked state, but “its reputed physical effect” on the body (Manderson 1981, p.950) and the “symbolic power contained in foods, herbs, medicines, mental state, illnesses, natural and supernatural power” (Ariff and Beng 2006, p.3). Since health is defined as a balance between the elements, illness can thus be treated by either adding or removing hot or cold foods from the diet to restore the health balance (Arif and Beng 2006).

In Malaysia, people distinguish foods into six categories: 1) hot food, 2) cold food, 3) itchy food, 4) windy food, 5) sharp food, and 6) poison food (see Table 1.2 below). However, there is no standard or consistent principle to classify food into each category, as it depends on the culture or region (Manderson 1981; Helman 2007).

People also may change their dietary practices, such as their eating habits, in response to the diagnosis of breast cancer to reduce the probability of cancer recurrence and to prevent cancer metastasis (Beagan and Chapman 2004). This is because some patients consider diet to be a contributing factor of their breast cancer (Zainuddin et al. 2017).

Table 1.2: Classification system of traditional food

Type of food	Description	Example of food
Hot	Regarded as healthy and supposed to warm the body, but may cause fever,	Durian ( <i>Durio zibethinus</i> ), beef, chicken, mutton, rambutan ( <i>Nephelium lappaceum</i> ), ginger,

	sweating, stomach ache, diarrhoea, and insomnia.	chilli, black pepper, herb, spice, curry, fried food
Cold	Cool the body and usually have no ill effects, but may cause in stomach upset, weakness, and wind (either flatulence or bloating).	Banana, mangosteen ( <i>Garcinia mangostena</i> ), papaya, cucumber, kangkong ( <i>Ipomoea aquatic</i> ), mustard green, spinach, bean sprout
Windy (often classified as cold)	Believed to cause flatulence, to create a full or bloated feeling, to cause oedema and vertigo.	Cempedak ( <i>Artocarpus champedon</i> ), jackfruit ( <i>Artocarpus integrifolia</i> ), tubers in general, cassava, sweet potato, ginger, brinjal, gourds, petai ( <i>Pithecellobium microcarpum</i> ), jering ( <i>jiringa</i> )
Itchy	Believed to cause general and localized body itching and rashes, pimples and pustules, and to prevent the healing of wounds.	Ikan caru ( <i>Megalaspis cordyla</i> ), ikan kembung ( <i>Scomber microlepidotus</i> ), ikan tamban ( <i>Dussumieri a cuta</i> ), ikan tongkol ( <i>Thynnus thunnina</i> ), shrimp paste, cockles, crab, cuttle fish, prawns, yam
Poison (may also be hot/itchy food)	Inhibit healing or exacerbate illness	Chicken, ikan caru, ikan kembung, ikan duri ( <i>Tachysurus thalassinus</i> ), ikan sembilang ( <i>Plotosus canibus</i> ), cockles, prawns, mango family
Sharp	Retard recovery from illness and reputedly abortifacient	Lemons/limes, mango family, pineapple, vinegar, tapai (a fermented sour-dough)

(Manderson 1981)

According to Salminen et al. (2000), patients with cancer usually focus on how their living habits might contribute to their disease and how they can gain control of their situation. In Malaysia, Shaharudin et al. (2013) reported that more than half of the women with breast cancer changed their dietary habits to a healthier diet through reducing their consumption of red meat, seafood, noodles, and poultry, while increasing their consumption of fruits, vegetables, fish, low-fat milk and soy products. Patients still prefer to change their food consumption even though there are no survival advantages among women who practise a low-fat diet after their diagnosis of breast cancer (Holmes et al. 1999).

## 1.7 The theoretical framework

This study is based upon The Model of Pathway to Treatment (MPTT) (Scott et al. 2013), the Health Belief Model (HBM) and the health locus of control (HLOC). The MPTT provides a framework that helpful in understanding where the decisions are made and identifying the contributing factors such as system, disease and individual. In order to provide more understanding regarding the patient as a contributing factor, the HBM and HLOC will be use to support the findings. Understanding women's experiences and their decisions, enables health care service improvement and the design of effective support for women so that early diagnosis can be facilitate and navigate the difficulties they might experience.

### 1.7.1 The Model of Pathway to Treatment (MPTT)

The MPTT is a revised descriptive framework proposed by Scott et al. (2013). It addresses criticisms of previous framework of the General Model of Total Patient Delay (Andersen et al. 1995), which had several issues such as the linear stage model, no alternative responses to help seeking, did not take consideration about the role of emotion and must infer illness to help seeking. The MPTT has the advantage by integrate the complex and dynamic nature of the process within the pathway to treatment. The MPTT has five key events in the pathway; 1) the detection of bodily changes, 2) the perceived reasons to discuss their symptoms with a health care provider, 3) the first consultation with a health care provider, 4) diagnosis and 5) the start of treatment. There are four intervals between the events; 1) appraisal, 2) help-seeking, 3) diagnostic and 4) pre-treatment. The MPTT also identifies the patient, the health system and the disease itself as the contributing factors that might influence the events and duration of the intervals. The MPTT has been proven useful in identifying where interventions can be targeted to enhance timely diagnosis (Moodley et al. 2018).

### 1.7.1 Health Belief Model

The HBM was briefly examined with the aim of understanding an individual's health-related choices, particularly with regard to the decision-making process among women with breast cancer and their family members. The HBM was developed in the 1950s by social psychologists Hochbaum, Kegeles, Leventhal and Rosenstock in response to the failure of a free tuberculosis health screening programme in the USA (Glanz et al. 2008). The HBM was used to predict the likelihood of a person's action concerning the recommended preventive health problem and to understand a person's motivation and decision-making regarding seeking health services (Hochbaum cited in Rankin et al. 2005). The HBM comprises a number of components, as outlined in Table 1.3 below).

Table 1.3: The core components of the Health Belief Model (Burke 2013)

Variable	Detail
Perceived susceptibility	An individual's perception of the risk of developing a particular disease or health outcome
Perceived severity	An individual's perception of the degree of the seriousness of the disease
Perceived benefit	The positive benefit of taking action to offset a perceived threat
Perceived barrier	The negative aspect of taking the action
Cue to action	The triggers for taking action
Modifying variables	The individual characteristics that influence personal perceptions, such as age, education level, experience, job and income

The HBM proposes that a person will take an appropriate action to avoid a disease if they believe that the following conditions are met: i) they are personally susceptible to the disease, ii) the severity of the disease would have an impact on certain aspects of their life, iii) taking the action would be beneficial, and iv) they are capable of overcoming the physical and psychological barriers (Rosenstock 1974).

The HBM has been used in the study of preventive health behaviour, sick-role behaviour and clinical utilisation (Glanz et al. 2008). Some studies have used the HBM as the conceptual framework for the construction of their questionnaires, with such questionnaires having subsequently been accepted as reliable tools (Coe et al. 2009; Soleymanian et al. 2014; Masoudiyekta et al. 2015). Moreover, the HBM is also used in conjunction with patients who have a wide variety of complaints such as heart disease (Jones et al. 2006), osteoporosis (Ali Khani et al. 2016), prostate cancer (Odedina et al. 2011), breast cancer (Jirojwong and MacLennan 2003; Aflakseir and Abbasi 2012; Abolfotouh et al. 2015), obesity (Romano and Scott 2014), and mental health problems (Gipson and King 2012).

However, the theory has been criticised for its emphasis on the rationality of decision-making while ignoring emotional factors, simple habit or society's approval (Walker 1999). Other weaknesses of the model are its lack of clear rules for the combination and relationship between components and the low predictability of determinants for behaviour (Orji et al. 2012). Additionally, the cue to action component of the HBM has not been well investigated, although it has been found to be related to behaviour change (Finfgeld et al. 2003). Poss (2001) suggested that HBM does not take into account the influence of normative or cultural factors that may have an effect on health-seeking behaviour.

The HBM has been used in this study to understand how the beliefs of women with breast cancer pertaining to abnormal symptoms, benefits, threat and cues to action play a role in their decision-making behaviour. The theory is relevant because it focuses on the beliefs and behaviour of women. For example, some women will rely on their beliefs when they find a lump in their breast and this will consequently influence their behaviour and decisions. In Malaysia, there has been limited research regarding the use of the HBM and breast cancer decision-making. Two

quantitative studies have been conducted on the application of the HBM in the context of breast cancer screening among young educated women (Akhtari-Zavare et al. 2013) and women with a family history of breast cancer (Subramanian et al. 2013), while there has only been one qualitative study on the health-seeking trajectories among women with breast cancer (Yusoff et al. 2011). Although Yusoff et al. (2011) used the HBM in their study, no information was presented in their findings regarding the application of the model.

### **1.7.2 Health locus of control**

The health locus of control (HLOC) is considered to be an important psychological concept that influences an individual's health behaviour in relation to illness, sickness and health (Otto et al. 2011). The concept was first introduced by Rotter as part of social learning theory (Rotter 1966) and it has subsequently been extended by Wallston et al. (1978) to cover the multidimensional aspects of health-related behaviour. The individuals' perception of their power to change or control their health-related behaviour is influenced by internal, external and chance factors (Wallston et al. 1978). People with an internal HLOC believe that their own actions determine the consequences of their health outcomes, while people with an external HLOC believe that powerful others (e.g. health professionals or family members) determine their health. People with a chance HLOC, meanwhile, believe that their health depends on fate, luck or chance [ibid.]. People who feel that they can control their circumstances or environment have higher perceived control, whereas those who believe that they have little control over their lives have lower perceived control. Waller and Bates (1992) reported that those with a high internal locus of control are more likely to take control of their own health, to seek health information and to make an effort to maintain their physical well-being.

There are two main criticisms regarding this locus of control variable: methodological and theoretical. The methodological criticism claims that there are flaws in the scales employed to measure the construct (Levenson 1981), while the theoretical criticism claims that the variable is to some extent related to other variables such as self-efficacy (Judge et al. 2002).

Many studies have been conducted regarding the role of the HLOC in breast cancer screening behaviour (Bundek et al. 1993; Murray and McMillan 1993; Team et al. 2013). However, there has been a lack of studies in the Malaysian context regarding the association between the concepts of the HLOC and decision-making about breast cancer.

## **1.8 Researcher's perspective of the current study**

Initially, this study was quite challenging for me as a nurse educator and statistician at one of Malaysia's universities. Along with the requirement to undertake a PhD, I was recommended by my scholarship sponsor to select a topic related to cancer and to employ qualitative approaches. Following some background reading, I opted to focus on breast cancer since the literature suggested that many Malaysian women were presenting to the medical system relatively late, meaning that they were often being diagnosed with advanced-stage breast cancer. I was curious as to why this was the case and how the women made their treatment decisions. I planned to use a qualitative design and to conduct interviews to further explore this issue.

After completing my first degree, I worked as a nurse on a medical ward before deciding to pursue a career in academia. I was employed as an assistant lecturer at a public university in Malaysia. During my Master's study, I chose statistics since at that time there was no statistician in our faculty. For my PhD, I realised that I did not have a working background

of cancer; instead, what I had acquired was based on my own reading and discussions with colleagues who had worked with cancer patients. I acknowledge that my existing knowledge and experiences related to breast cancer were limited prior to commencing this study.

Transitioning from a quantitative background to the state of being a qualitative researcher has proven to be a great challenge. It was a new experience, as I had never previously had any involvement in qualitative research. I struggled to understand the concepts in qualitative research such as ontology, epistemology and methodology, which are completely different knowledge bases from my prior learning. Reading about research designs such as grounded theory, phenomenology, case study, ethnography and narrative inquiry added to my stress as a novice researcher in attempting to determine the best design to suit my research. Initially, I was concerned about the sample size while preparing the research proposal rather than the quality of the interviews. By attending several courses and talking about qualitative research, especially the narrative, I was able to learn how to focus solely on the talk and to look for patterns regarding the decision-making process.

However, the challenge did not end there. Studying in an English-speaking country, especially since my English was not of a very high standard, notably my written and spoken English, made me feel inferior. However, with the help of my colleagues, whether native or non-native speakers, I forced myself to communicate with them to improve my English. Moreover, with help and encouragement from both of my supervisors, I have presented various parts of my research findings at academic conferences to gain self-confidence. However, I cannot deny that this study has gradually developed my interest in qualitative studying, especially following the data collection process, which allows for a rich understanding of the people surrounding us.

In this study, the Malaysian women and their family members live within a multicultural community and so they might have the same or different views regarding breast cancer. As a Malaysian researcher, I may be regarded as having advanced cultural knowledge of the Malaysia community by having a shared understanding of the normative rules, values, belief systems, and traditions, which serves as a source of understanding that informs the research process or that might influence the data interpretation of this study. The shared points of cultural commonality and language allowed me to attain an emic view. Emic is the concept of insider perspective; that is, having a personal experience of a culture/society (Young 2005). Emic researchers search for meaning to understand the significance of a certain phenomenon within a certain culture (Magnusson 2012). In contrast, my role as a researcher or PhD student was to gather data in the breast cancer community. I felt that I adopted what I perceive to be as an etic view because I entered the settings with no feelings of a sense of ownership as I did not have breast cancer personally, nor had participated in any breast cancer research prior to this study or had a close relationship with the participants and hospital, where the patients were recruited. According to Young (2005), etic is the idea of an outsider perspective; that is, the perspective of a person who has not had the personal or lived experience of a particular culture/society. However, having a background as a nurse, even I did not work in the oncology setting, the knowledge that I gained during my nursing studies and work experience before might influence how I looked for the data, posed the questions and interpreted the nature of culture among the Malaysian women with breast cancer. Therefore I need to be careful regarding my position in the research process, because the process of inquiry and interpretation can be influenced by the researcher's education, ethnicity, social, and cultural identities (Muhammad et al. 2015).

## **Chapter summary:**

This chapter has outlined that breast cancer is a rising concern in Malaysia that is often diagnosed late with a resulting poor prognosis. This has demonstrated the necessity for breast cancer research in Malaysia. The patient's characteristics, health care system, social and cultural factors that influence decisions have been presented along with some of the other treatment options that available in Malaysia. It is important to understand how women navigate the social and cultural factors so then they can be supported to make appropriate decisions. This chapter has also outlined an appropriate theoretical framework for this investigation, and recognised the emic and etic challenges that the study poses to the researcher. Furthermore, the people that typically influence a woman's decision-making are their family members. Therefore, this study will explore the decision-making process among Malaysian women with breast cancer and their family members. The next chapter will review the current literature relating to breast cancer in the context of Malaysia.

# Chapter 2: Literature review

## 2.1 Introduction

A substantial amount of international literature currently exists on breast cancer and decision-making that have tended to focus mainly on treatment decision-making (Halkett et al. 2007; Caldon et al. 2011; Pieters et al. 2012; Covelli et al. 2015; Obeidat 2015; Tőkés et al. 2015; Beryl et al. 2017; Kim and Yang 2017), shared decision-making (Mandelblatt et al. 2006; Pass et al. 2012; Lam et al. 2014; Durif-Bruckert et al. 2015) and the disclosure of diagnosis (Back and Huak 2005; Angela et al. 2013). Other studies have highlighted various aspects of treatment decisions itself, such as information needs (Spittler et al. 2012), knowledge (Fagerlin et al. 2006), surgical options (Lee et al. 2012), patient involvement (Hawley et al. 2007), and patient preference (Mancini et al. 2007). Breast cancer narratives have also become prevalent in Western culture (Thomas-Maclean 2004; Sadati et al. 2015; Cuellar-Pompa et al. 2016).

However, the findings are mostly from a Western perspective and may thus differ from those adopting a Malaysian perspective due to differences in socio-economics, health care systems and cultures. Therefore, a scoping review was employed to search for existing literature about decision-making undertaken by Malaysian women and their family members with regard to breast cancer. The final section of this chapter provides the justification for conducting this research and outlines the research questions and objectives.

## 2.2 Scoping review

Davis et al. (2009) define scoping as involving the “synthesis and analysis of a wide range of research and non-research material to provide greater conceptual clarity about a specific topic or field of

evidence" (p.1386). The aim of this scoping review was to identify the nature of research relevant with decision-making, consequently identifying the research gaps within the literature regarding breast cancer in Malaysia. According to Moher et al. (2015), a scoping review allows for more general questions and exploration of the related literature, rather than focussing on providing answers to limited questions. Moreover, this scoping review was an appropriate approach as it aimed to map literature on a particular topic, explore the underpinnings of the research area, identify and clarify the key concepts, theories, sources of evidence and gaps in the research (Arksey and O'Malley 2005; Davis et al. 2009; Daudt et al. 2013; Halas et al. 2015).

In this review, a collection of literature on broader topics was provided, thus scoping review was more appropriate compared to the systematic review that focuses on a narrowly defined question and scope of study (Peterson et al. 2017; Misra and Agarwal 2018). The scoping review requires a comprehensive and structured search of the literature as compared to a narrative review, which does not describe the methods used in the review that may lead to bias (Cipriani and Geddes 2003; Noble and Smith 2018). Although a scoping review is not as in-depth as a systematic review, it still considered at a higher level than a traditional literature review or an integrative review (Arksey and O'Malley 2005; Levac et al. 2010; Gough et al. 2012).

The framework developed by Arksey and O'Malley (2005) was adopted to provide guidance on how to undertake a scoping review. Their five-stage methodological framework comprises the following: 1) identify the research question, 2) search for relevant studies, 3) select studies, 4) chart the data and 5) collate, summarise and report the result.

## **Stage 1: Identify the research question**

A review of the literature was undertaken to explore the base of evidence underpinning the current knowledge of decision-making among Malaysian women and their family members in the context of breast cancer. The review was guided by the following questions:

What is known from the existing literature about:

- a. Decision-making among Malaysian women and their family members in the context of breast cancer
- b. The influence of culture and beliefs on decision-making among Malaysian women with breast cancer
- c. The current role of nurses in decision-making regarding breast cancer in Malaysia.

## **Stage 2: Search for relevant studies**

A range of databases was accessed: Cumulative Index of Nursing and Allied Health Literature (CINAHL), MEDLINE, PsycINFO, Allied and Complementary Medicine Database (AMED), EMBASE, Web of Science and Scopus. Multiple keywords were used in the search strategy to generate a breadth of coverage and ensure it was as comprehensive as possible in identifying the relevant studies. Moreover, the Boolean operators AND OR, Truncation \* or “ ” and/or limiters were applied to further refine the search. The start date of 2005 for retrieving studies was chosen because a maximum time frame of five to ten years is usually placed on the age of the evidence to be included (Cronin et al. 2008). However, since only nine papers were retrieved regarding the third objective about the “nurses” role, a search through google scholars was conducted, identifying one relevant article regarding oncology nurse in Malaysia. The results of the retrieved articles are shown in Table 2.1 (see Appendix 1, pp.281–287).

### **Stage 3: Select studies**

1,765 papers were identified from the search process and exported to Endnote software, from which 1,253 duplicate papers were subsequently removed. The remaining 512 papers were then reviewed based on their title and abstract using the inclusion and exclusion criteria as set out in Table 2.2 (see Appendix 2, pp.288–289). Copies of the full paper were obtained for those studies that met the inclusion criteria about the research question. The full paper was also retrieved if the content of the relevant study was unclear from the abstract alone. Later, all of the full papers were read to make a final decision on whether they should be included in the review. Additionally, some studies were retrieved based on the reference lists in the selected papers that were also deemed relevant, and these were also reviewed. The papers were appraised based on their quality; however, due to the limited number of related relevant studies, papers were not excluded solely on quality grounds in order to be inclusive and include all of the relevant research. Finally, 18 papers were selected for inclusion in the review. The flow chart of paper rejection and selection is shown in Figure 2.1 (p.38).

### **Stage 4: Chart the data**

A summary of the selected studies is shown in Table 2.3 (see Appendix 3, pp.290–297). The 18 papers selected comprised 17 separate studies since one study had published two papers.

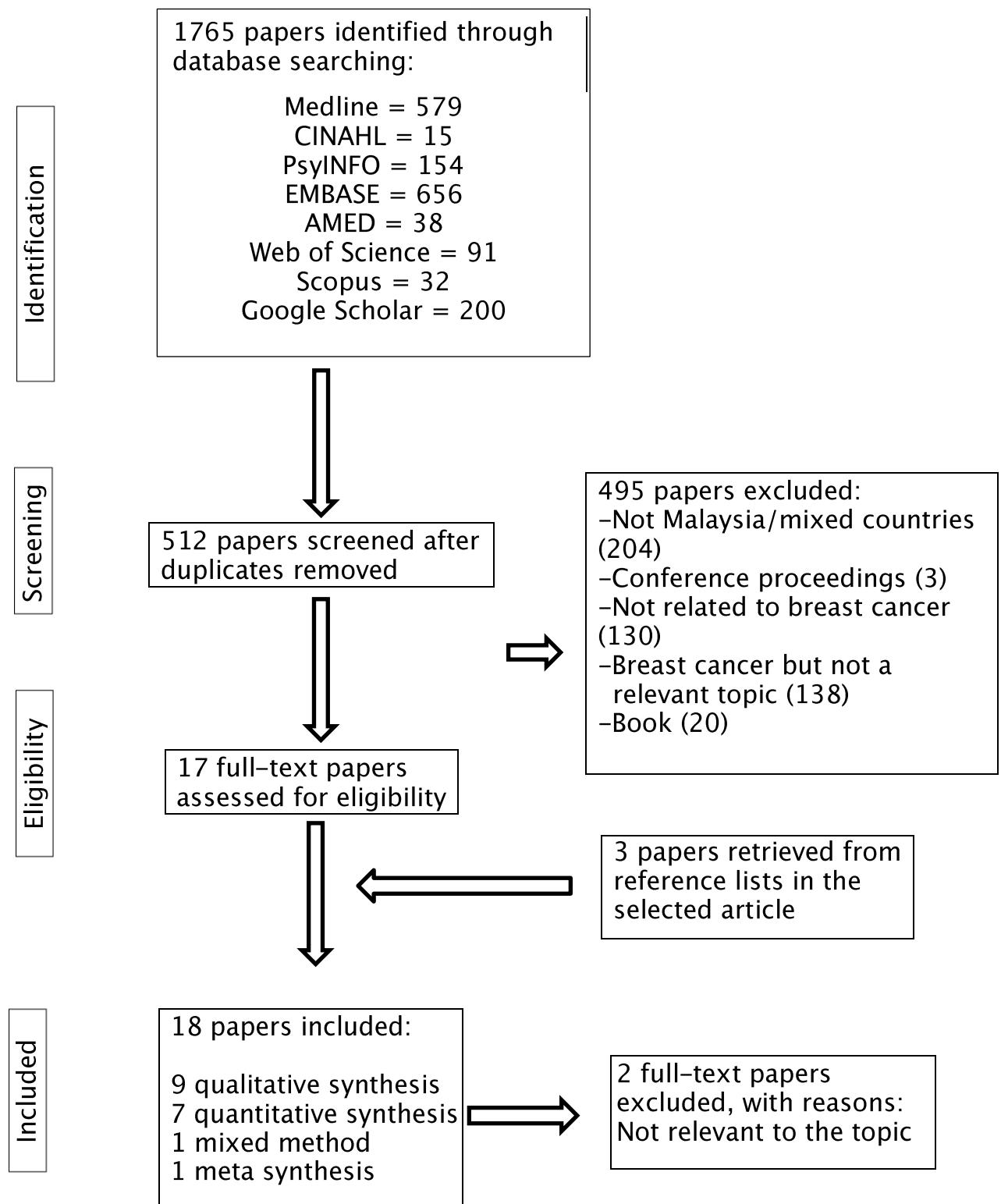


Figure 2.1: PRISMA flow chart of the data selection process

## **Stage 5: Collate, summarise and report the results**

### Research design

Eight studies were found for qualitative approach (Shariff et al. 2008; Taib et al. 2011; Yusoff et al. 2011; Muhamad et al. 2012b; Norsa'adah et al. 2012; Abdullah et al. 2013; Maskor et al. 2013; Yusuf et al. 2013; Taib et al. 2014), and seven studies for quantitative approach (Shameem et al. 2008; Leong et al. 2009; Muhamad et al. 2011; Norsa'adah et al. 2011; Shaharudin et al. 2011; Mohamed and Muhamad 2013; Teh et al. 2014). The remaining two studies used mixed methods (Taib et al. 2007) and meta-synthesis (Yu et al. 2015). Although nine papers are cited above for the qualitative approach, two were from the same study (Taib et al. 2011; Taib et al. 2014); therefore, they are considered as one study.

### Sampling

Seven studies used purposive sampling (Shariff et al. 2008; Taib et al. 2011; Yusoff et al. 2011; Norsa'adah et al. 2012; Abdullah et al. 2013; Maskor et al. 2013; Yusuf et al. 2013; Taib et al. 2014), two studies employed convenience sampling (Muhamad et al. 2011; Shaharudin et al. 2011), one study used snowball sampling (Muhamad et al. 2012b) and one study used systematic sampling (Norsa'adah et al. 2011). However, five studies did not state the specific sampling method but did mention the inclusion and exclusion criteria of the participants (Taib et al. 2007; Shameem et al. 2008; Leong et al. 2009; Mohamed and Muhamad 2013; Teh et al. 2014).

### Participants

The participants were women with newly diagnosed breast cancer (Leong et al. 2009; Yusuf et al. 2013), early stage breast cancer (Abdullah et al. 2013; Teh et al. 2014), advanced-stage breast cancer (Taib et al. 2007; Taib et al. 2011; Taib et al. 2014), women who were

post mastectomy (Shameem et al. 2008), women who had delayed in seeking help (Yusoff et al. 2011; Norsa'adah et al. 2012), those with primary breast cancer (Norsa'adah et al. 2011), and survivors of breast cancer (Shariff et al. 2008; Muhamad et al. 2011; Shaharudin et al. 2011; Muhamad et al. 2012b; Mohamed and Muhamad 2013). Only one study each involved husbands as the participants (Yusoff et al. 2011) and oncology nurses (Maskor et al. 2013).

### Data collection

The majority of the studies gathered information through face-to-face interviews using either questionnaire (Taib et al. 2007; Shameem et al. 2008; Leong et al. 2009; Norsa'adah et al. 2011; Mohamed and Muhamad 2013; Teh et al. 2014) or interview guides (Taib et al. 2011; Yusoff et al. 2011; Muhamad et al. 2012b; Norsa'adah et al. 2012; Abdullah et al. 2013; Yusuf et al. 2013; Taib et al. 2014). Two studies each used a self-administered questionnaire (Muhamad et al. 2011; Shaharudin et al. 2011) and focus group discussions (Shariff et al. 2008; Maskor et al. 2013).

It was difficult to appraise the quality of research due to the lack of information provided. The quality of the research appeared weak and unclear. For the qualitative studies, there was typically a lack of information concerning how the recruitment process was conducted (Taib et al. 2011; Yusoff et al. 2011; Norsa'adah et al. 2012; Abdullah et al. 2013), how the themes were derived from the data analysis (Shariff et al. 2008; Taib et al. 2011; Norsa'adah et al. 2012; Abdullah et al. 2013), the inclusion criteria used for participant selection (Shariff et al. 2008; Yusoff et al. 2011) and the data collection process (Taib et al. 2011; Yusoff et al. 2011). For the quantitative studies, there was a lack of information regarding the study design (Leong et al. 2009; Mohamed and Muhamad 2013; Teh et al. 2014), sampling method (Shameem et al. 2008; Leong et al. 2009; Muhamad et al. 2011; Mohamed and Muhamad

2013; Teh et al. 2014), recruitment process (Shameem et al. 2008; Leong et al. 2009; Muhamad et al. 2011; Norsa'adah et al. 2011; Shaharudin et al. 2011; Mohamed and Muhamad 2013; Teh et al. 2014), validation of questionnaires (Shameem et al. 2008; Leong et al. 2009) and data collection processes (Shameen et al. 2008).

In contrast, certain quantitative studies contained evidence of methodological strengths, such as the development of a questionnaire from multiple sources tested through a pilot study (Muhamad et al. 2011; Norsa'adah et al. 2011; Shaharudin et al. 2011; Mohamed and Muhamad 2013), the use of systematic sampling (Norsa'adah et al. 2011) and a large sample size (Shameem et al. 2008; Leong et al. 2009; Muhamad et al. 2011; Norsa'adah et al. 2011; Shaharudin et al. 2011; Teh et al. 2014). For the qualitative approach, the research objectives, sampling strategy and data collection methods were clearly described and included triangulation as a rigour strategy (Muhamad et al. 2012b; Norsa'adah et al. 2012; Abdullah et al. 2013) and peer reviews (Maskor et al. 2013). Overall, some of the selected papers were of a good quality, containing a clear purpose, methodology and convincing findings, while other papers did not adequately describe the studies undertaken.

#### Findings:

Objective 1: Decision-making among Malaysian women and their family members in the context of breast cancer.

The findings for decision-making from the 16 studies were grouped into two themes: 1) treatment decision-making and 2) barriers to seeking help/diagnosis/treatment.

## **Theme 1: Treatment decision-making**

Nine studies concerning treatment decision-making for women with breast cancer. Two studies reviewed the use of alternative therapy and explored the reasons for its use (Shaharudin et al. 2011; Muhamad et al. 2012b). Seven studies were related to conventional treatment (Shameem et al. 2008; Shariff et al. 2008; Leong et al. 2009; Muhamad et al. 2011; Abdullah et al. 2013; Mohamed and Muhamad 2013; Teh et al. 2014). Two of these seven studies explored the treatment decision-making process (Shariff et al. 2008; Abdullah et al. 2013), one study determined the reasons for breast reconstruction (Shameem et al. 2008), three studies assessed the trends of breast cancer treatment (Leong et al. 2009; Mohamed and Muhamad 2013; Teh et al. 2014), and one study was about the role of family members in providing support for treatment decision-making (Muhamad et al. 2011). Additionally, one study that explored the lived experience of having newly diagnosed breast cancer (Yusuf et al. 2013) was included in this theme as some of the findings were relevant to treatment decision-making.

Most of the women had undergone a mastectomy as opposed to breast-conserving surgery (BCS) (Leong et al. 2009; Mohamed and Muhamad 2013; Teh et al. 2014). The factors that influenced the type of treatment decision-making were interference with the participant's sex life, the importance of partners and the opinions of family members (Teh et al. 2014). However, these studies used a quantitative approach; indeed, no study was found that illuminated in depth the reasons why participants chose a mastectomy over BCS.

Many women also opted for complementary and alternative medicine (CAM). Shaharudin et al. (2011) found that 64% of women with breast cancer used CAM because they felt it enhanced the body's innate healing ability, cure and prevent their cancer from spreading and encouragement from family. Further reasons that encouraged women to

seek traditional healers were the healer's credibility, not being confident with Western medical practice and health care system delay (Muhamad et al. 2012). Both of these studies tended to focus only on the Malay ethnic group and breast cancer survivors. However, the extent of the practice of alternative treatment among other ethnic groups remains unknown.

Twenty-three out of 136 women had undergone immediate breast reconstruction because they wanted to feel whole again, regain their femininity and to feel more balanced (Shameem et al. 2008). In contrast, the main reasons for not having breast reconstruction were fear of the complications of surgery, it not being considered essential for physical/emotional well-being and/or felt too old for it [ibid.]. This is the only study that specifically focused on breast reconstruction and was limited in terms of the in-depth understanding of decision-making or experiences due to its adoption of a quantitative approach. Additionally, Leong et al. (2009) stated that breast reconstruction could not be performed due to the limitation of plastic and reconstruction services in the hospital.

The study by Abdullah et al. (2013) provided information on the four phases (discovery, confirmation, deliberation and decision) of the treatment decision-making process among eight women with early stage breast cancer. The findings revealed that the process of making a treatment decision began after the women had first suspected that they might have breast cancer following the discovery of a breast lump or an abnormal mammogram but prior to any diagnosis of breast cancer being made. One of the early decisions is seeking for alternative treatment, either taking herbal medicine or meet a traditional healer. Having received a diagnosis, the women then began searching for more information either conversation with patient with breast cancer, the Internet or the mass media. The result also showed that four women preferred surgery, three women chose CAM and one woman chose no

treatment. However, there was no description revealing the reasons why these women opted for their respective treatment choices. The strength of this study was that it recruited participants from all of the major ethnic groups in Malaysia. A limitation noted was that the women had not yet undergone any hospital treatment and that their early decisions regarding treatment might change when it was time to make a final decision. Additionally, the study lacked information on both the participant recruitment process and the data analysis process.

Shariff et al. (2008) conducted another qualitative study about breast cancer treatment decision-making. They found that the factors that influenced women's decisions to undergo treatment were to live longer, prevent a recurrence, trust in the physician and the experience of a friend and/or family member with cancer. They also reported that the women searched for information on breast cancer via books, magazines, newspapers, the Internet or the experiences of a family member. A strength of this study was that it recruited from all of the major ethnic groups in Malaysia. A limitation was noticed based on the findings, in which the authors included women who had lived with breast cancer for up to ten years and this presents the possibility of recall bias that may have influenced the women's explanations about their treatment decisions.

After having received their breast cancer diagnosis, Malay women have been described as being in a dilemma regarding whether to choose conventional or alternative treatment, while Chinese women were reported as being more concerned about what would happen to them during their breast cancer treatment (Yusuf et al. 2013). This reveals that each of the ethnic groups in this study harboured different worries with regard to their treatment. Both groups of women claimed that they needed to change their dietary pattern in a bid to control and treat their breast cancer. Positive attitude and family priorities made these women agreeing to accept conventional treatment. Although the study did not

look primarily at the treatment decision-making process, it does add to the evidence of the experiences of breast cancer among Malay and Chinese women in Malaysia.

The opinion of family members was also found to be important in treatment decision-making for women with breast cancer (Shariff et al. 2008; Muhamad et al. 2011; Shaharudin et al. 2011; Muhamad et al. 2012b; Yusuf et al. 2013; Teh et al. 2014). Mohamed and Muhamad (2013) stated that 6 out of 69 women left it up to their family members to make the final decision for them concerning treatment. Shariff et al. (2008) found that one woman claimed her husband had made the decision without asking her, while Yusuf et al. (2013) noted that one woman reported that her family were against her decision to pursue conventional treatment. These studies reveal that the families of the patients played a significant role in the decision-making. However, none of the studies had actually recruited husbands or family members as participants in order to gain information about their views on the matter.

## **Theme 2: Barriers to seeking help/diagnosis/treatment**

Six studies were associated with barriers to or delay in seeking help/diagnosis/treatment, as follows: Delay to treatment (Yusoff et al. 2011), delay in diagnosis (Norsa'adah et al. 2011), delay in presentation (Taib et al. 2007; Taib et al. 2011; Taib et al. 2014) and delay in seeking help (Norsa'adah et al. 2012; Yu et al. 2015). Although three studies related to delayed presentation, two were from the same study by Taib and colleagues. One concentrated on women's interpretation of breast cancer symptoms and presented a psycho-socio-cultural model (Taib et al. 2011) while the other presented a total breast cancer delay model (Taib et al. 2014). The final selected study was conducted to identify the magnitude of the delay in breast cancer diagnosis and its associated factors (Norsa'adah et al. 2011).

There were many reasons for the delays, whether in relation to help-seeking, diagnosis, treatment or late presentation with advanced-stage breast cancer. The reasons included lack of knowledge about breast cancer and weakness of the health care system (Norsa'adah et al. 2011; Taib et al. 2011; Yusoff et al. 2011; Norsa'adah et al. 2012), a fatalistic view (Taib et al. 2007; Taib et al. 2011), the use of CAM (Taib et al. 2007; Norsa'adah et al. 2011; Yusoff et al. 2011; Norsa'adah et al. 2012), the role of family members or friends (Taib et al. 2007; Taib et al. 2011; Norsa'adah et al. 2012), the negative experience of role models regarding conventional treatment, plus fear (Taib et al. 2007; Taib et al. 2011; Yusoff et al. 2011; Norsa'adah et al. 2012), lack of disclosure (Taib et al. 2011) and other priorities such as job commitments, financial problems or having young children (Norsa'adah et al. 2012). Most of these findings were similar to those outlined in the meta-synthesis study by Yu et al. (2015) as the majority of the papers examined here were also included in that review. However, none of these studies describes the range of decisions that women are likely to face when they delaying help-seeking, diagnosis or treatment, and what the experience is like of making these decisions.

Women showed a lack of knowledge and low levels of awareness when they misinterpreted their presenting symptoms as being a benign disease, a sign of menses, a milk clot (Norsa'adah et al. 2012) or a blood clot (Taib et al. 2011). They assumed that family history is needed to develop breast cancer. Moreover, the women felt that a painless lump would be harmless (Taib et al. 2011; Norsa'adah et al. 2012). The women's family members, such as their husbands and siblings, also had a lack of knowledge of breast cancer when the women told them about their breast lump (Taib et al. 2011). It seemed that both the women and their family members had a lack of understanding of breast cancer, especially with regard to its symptoms.

Fear of the consequences of cancer, such as pain, death, the side effects of chemotherapy and physical disability resulting from surgery were reasons for delaying treatment (Norsa'adah et al. 2012; Taib et al. 2014). Participants felt that they would suffer due to a poor quality of life after their treatment (Taib et al. 2011). Moreover, some had known breast cancer patients who had died after undergoing conventional treatment (Taib et al. 2011; Norsa'adah et al. 2012). These patients' experiences had a significant influence on the women's decisions to delay treatment.

The other reason that served as a barrier to women delaying treatment for their breast cancer was their belief in an alternative treatment (Norsa'adah et al. 2011; Norsa'adah et al. 2012). Women believed that traditional treatment was capable of shrinking a lump, so that no need to undergo surgery (Norsa'adah et al. 2012). A traditional healer administer remedies such as chanted water, lime juice, flour and leaves for them to drink and apply to the lump [ibid.].

Some women had received false reassurances about their symptom from their HCP (Taib et al. 2011; Norsa'adah et al. 2012). They were told that the lumps were symptom of normal growth, milk abscess (Taib et al. 2011; Norsa'adah et al. 2012), veins, wind, muscles or knots (Norsa'adah et al. 2012). These potential diagnoses led to the women feeling satisfied and no longer being concerned about their condition.

Taib et al. (2007) reported that the women in their study took between two months and three years to inform others after they had found a breast lump, while 60 per cent of them turned to alternative therapy before seeking medical treatment. This study revealed certain gaps regarding how women engage in decision-making; as a result, delay in disclosure about a breast lump and delay in seeking medical treatment are areas for further exploration. Thus, research into the main decisions

taken by Malaysian women with breast cancer during the time between when they found the lump in their breast to undergoing medical treatment is important to identify the range of decisions that they have to face and the turning points that led to them deciding to accept hospital treatment.

The total breast cancer delay (TBCD) model as proposed by Taib et al. (2014) was derived from the journey of Malaysian women who presented with advanced breast cancer. The model was actually adapted from the total patient delay (TPD) model by Andersen et al. (1995) that identified the following five types of delay: appraisal delay, illness delay, behavioural delay, scheduling delay and treatment delay. The unique contributions of the TPD model were the addition of other points of delay such as disclosure delay, referral delay, diagnostic delay and treatment decision delay. Other than adding new points of delay, the authors also presented the following four concepts that emerged from their study: 1) pluralistic health systems; 2) points of delay; 3) presence of patients or system delays; and 4) patient decision-making at each stage. Their findings showed that Malaysian women delayed at different and multiple points with regard to their breast cancer. Moreover, the presence of pluralistic health systems, meaning the availability of many other alternative options such as traditional treatments, supplements, herbs, alternative medicine and homoeopathy, also served to increase the cases of delays among women with breast cancer in Malaysia. However, the authors did not provide a clear definition of the terms or concepts they proposed, although they did give examples of the cases raised to convey the point of delay. This model could also be criticised in terms of the delay process because not all of the decisions involved a linear progression, as suggested by the model.

Husbands had an influence on women's decisions, and majority of women would obey their husbands' decision (Norsa'adah et al. 2012). Some husbands also made the decision for the women to try alternative

treatment and thus delay hospital treatment (Taib et al. 2011; Norsa'adah et al. 2012). In the case of one woman, her husband refused to give his consent for hospital treatment (Norsa'adah et al. 2012). Other family members, such as mothers and uncles, were found to be opposed to conventional treatment (Norsa'adah et al. 2012) while others were in denial about the presence of breast cancer (Taib et al. 2011). These studies revealed that women's families played a significant role in the decision-making process. However, none of these studies recruited the women's husbands or family members as participants in a bid to gain information about their views on this matter.

The only qualitative study that recruited both the women with breast cancer and their husbands as the participants was conducted by Yusoff et al. (2011). They found that most of the women and their husbands sought a traditional healer because they did not expect the symptoms to be cancer, the belief that a traditional healer would be able to cure the symptoms and following other people's suggestions. There were also various barriers to the husbands taking their wives to the hospital owing to limited time, financial constraints and the shifting of household tasks. This study supports the need for further exploration regarding how the husbands made their decisions. A limitation of this study was that it recruited women who had a range of medical histories, although there was no detailed information about them. These varied medical histories may thus have influenced the women's interpretations of their symptom and the delays in seeking help about breast cancer.

Objective 2: The influence of culture and beliefs on decision-making among Malaysian women with breast cancer.

Each ethnic group has strong ties to its culture and religious beliefs about breast cancer. Malay women have been shown to consider having breast cancer to be the will of God (Yusoff et al. 2011), Chinese women

to believe that having breast cancer will bring bad luck for the whole family (Yusof et al. 2013), while Indian women have been found to fear not being able to marry off their daughters if others know that the mother has had breast cancer (Taib et al. 2011). These examples reveal that socio-cultural factors may play a role in decision-making among women with breast cancer that might differ from the findings obtained in other countries. Malay and Indian women placed greater importance on the opinions of their husbands and family members in comparison to Chinese women (Teh et al. 2014), thereby indicating differences between the different ethnic groups that otherwise share an Asian family-oriented culture. Some of the women chose to avoid conventional treatment and instead opted for CAM due to the strong influence of traditional and cultural beliefs (Leong et al. 2009). They also felt that their role as a wife, mother and female as a whole would be jeopardised if they were diagnosed with breast cancer [ibid.]. However, there was only a limited detailed explanation in the study by Leong and colleagues since it employed a quantitative approach.

Objective 3: The current role of nurses in decision-making regarding breast cancer in Malaysia.

Maskor et al. (2013) identified the importance of oncology nurses in Malaysia communicating with their patients and their family members to provide information about the cancer, treatment, diet, cancer recurrence and side effects. The authors argued that communication is an important element because it contributes to close relationships and builds trust between nurses, patients and their family members. Therefore, this study recommends that the nurses should have good communication skills combined with non-verbal communication approaches, such as smiling, facial expression, touch and maintaining eye contact when communicating with the patients and their family members. In contrast, Norsa'adah et al. (2013) reported that the

participants felt that the nurses did not provide any information after they performed the breast examination.

However, none of the reviewed papers provided specific information or recommendations about the nurses' roles in decision-making in an oncology setting. Therefore, the scoping parameters were extended for this objective to include other Malaysian sources such as health policy and international quality standards about the role of the nurse in breast cancer presentation, diagnosis and treatment using the same databases as in previous search. The flow chart of paper rejection and selection specifically for this objective is shown in Figure 2.2 (see Appendix 4, p.298), the search strategy in Table 2.4 (see Appendix 5, p.299–300), and the results of the retrieved articles regarding the policy and role of nurses outside Malaysia had been shown in Table 2.5 (see Appendix 6, pp.301–305).

Sixteen papers and one Malaysia nurses regulation were included as relevant to the roles of nurses in decision-making in an oncology setting. Five of these sixteen papers are literature reviews (Eicher et al. 2006; Koutsopoulou et al. 2010; Vaartio–Rajalin and Leino–Kilpi 2011; Ahern and Gardner 2015; Tariman and Szubski 2015), five qualitative studies (Halkett et al. 2006; Barthow et al. 2009; Admi et al. 2011; Tariman et al. 2016; Pongthavornkamol et al. 2018), three quantitative studies (Kadmon et al. 2015; Luck et al. 2017; Makabe et al. 2018), two mixed-method (Eley et al. 2008; Jones et al. 2010) and one review paper regarding the role of the oncology nurse (Quinn 2008).

Based on the Code of Professional Conduct for Nurses by the Nursing Board Malaysia (1998), there is no specific description of nurses' roles in the patients' decision-making process, except that "the nurse works co-operatively with the patient and his family and respects their decisions about his[/her] care" (p.1). Even Quinn (2008) stated that there is lack of

clarity regarding the role of oncology nurses in Asian countries and they generally function as caregivers, focussing on delivery of treatment, education and symptom management. Moreover, the backgrounds of nurses throughout Asian countries are rather different due to cultural, education, health services and internal problems in each country (Makabe et al. 2018), that might lead to different roles among the nurses.

However, a systematic review of 33 international published studies summarised seven roles of the nurse during the cancer treatment decision-making process; 1) advocacy for the patient's right to autonomy and informed decision-making, 2) psychological support during decision-making and throughout the continuum of cancer care, 3) patient education regarding cancer, investigation tests and treatment related information, 4) outcome evaluation of efficacy and cost-benefit of treatment, 5) information-giving to the oncology multidisciplinary team regarding patient's clinical situation, anticipated problem, preferences for treatment, and verify medical decisions, 6) complex role mainly during uncertainty, and 7) symptom assessment, monitoring, and management of treatment (Tariman and Szubski 2015). Other studies also reported similar roles of nurses in oncology setting (Tariman et al. 2016) or more specifically as patient's advocates (Vaartio-Rajalin and Leino-Kilpi 2011), and information providers (Koutsopoulou et al. 2010).

In developed countries such as Australia, UK, USA and Canada, they have breast care nurse (BCN), which specifically support the patients diagnosed with breast cancer (Halkett et al. 2006; Eley et al. 2008; Jones et al. 2010; Admi et al. 2011; Luck et al. 2017). Their roles include all the elements described by Tariman and Szubski (2015) with the addition of the ability to refer patient to other services that may be required (Ahern and Gardner 2015).

Barthow et al. (2009) suggested that nurses should know about “specific cancer disease processes, how treatments work, process of administration, range of treatments possible, likelihood of both therapeutic and unintended effects of such treatment, and possible range of patient responses to treatment” (p.24) in order to assist patients regarding their treatment decision. Nurses also may also “clarifying or providing information, coaching, facilitating and offering choices” towards patient’s treatment decisions (p.25) [ibid]. This showed that nurses required extended knowledge, skills and training.

The systematic review revealed that nurses can contribute to improvement of decision-making process, by which patients may be more confident to make decisions when counselled by nurse and resulting in higher rate of choosing conventional treatment among patient with breast cancer (Eicher et al. 2006). However, some nurses were aware the challenge that raise a potential conflict to balance between patient autonomy and professional responsibility especially when patient make decisions that are contrary to the hospital treatment plan (Pongthavornkamol et al. 2018).

### **Scoping review summary:**

Overall, the research literature suggests that there were two decision points among Malaysian women with breast cancer: treatment decision-making, and barriers to seeking help, diagnosis or treatment. These findings have been integrated with the HBM to provide a structure and framework for considering decision-making among Malaysian women with breast cancer (see Figure 2.3, p.54).

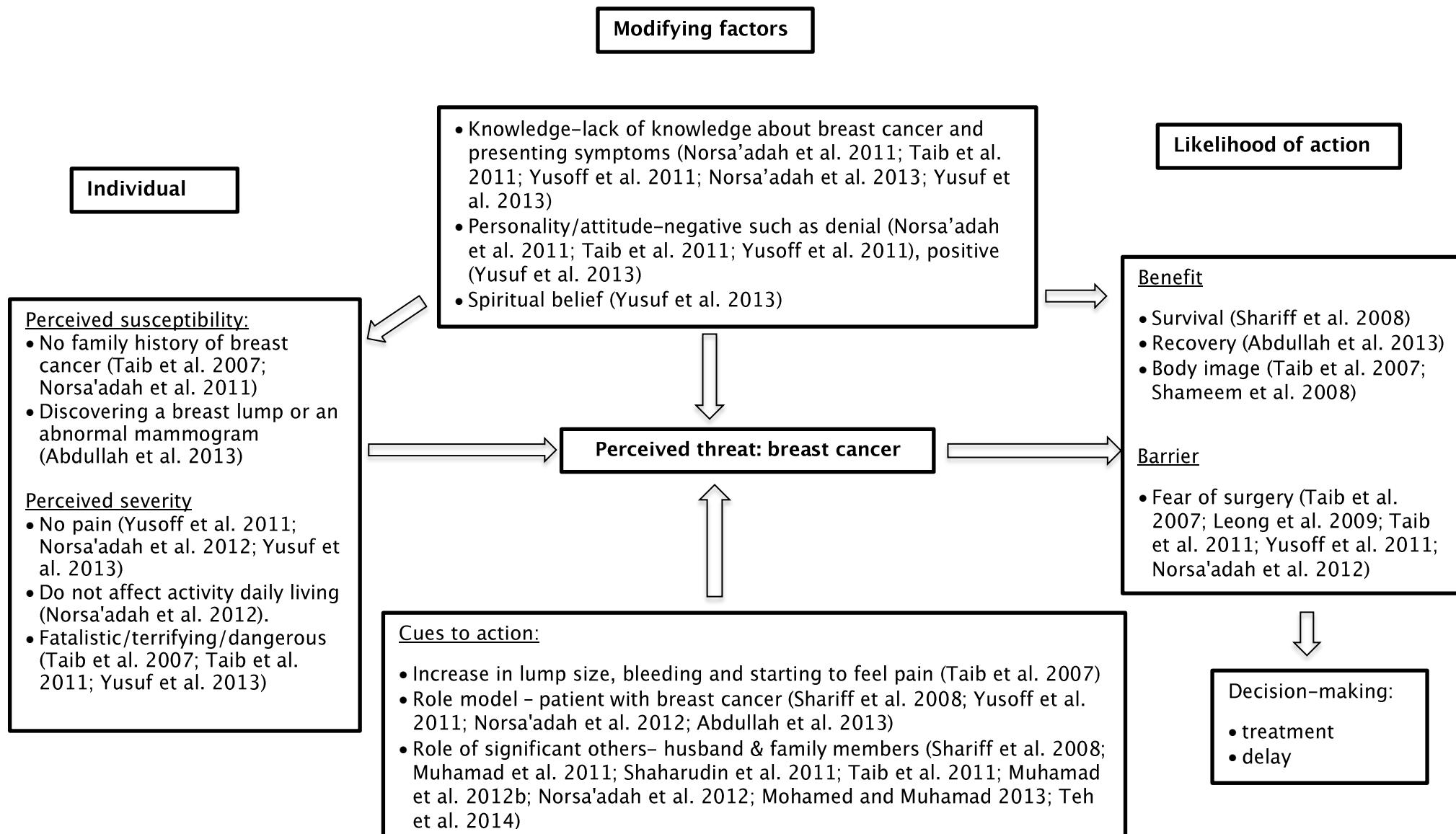


Figure 2.3: Literature mapped to the HBM about decision-making among Malaysian women with breast cancer

Despite the increasing rate of breast cancer among Malaysian women, research investigating their decision-making process remains limited. The limitations within the literature are outlined as follows:

- a. There were only two qualitative studies that specifically focused on the decision-making process and breast cancer treatment (Shariff et al. 2008; Abdullah et al. 2013). A limitation was identified based on the lack of information on the data analysis processes for both studies, while no information on the participant inclusion criteria was provided by Shariff et al. (2008).
- b. There were no qualitative studies examining why and how women made decisions regarding their breast cancer treatment, such as mastectomy, BCS or breast reconstruction.
- c. Two studies specifically focused on alternative treatment among Malay people (Shaharudin et al. 2011; Muhamad et al. 2012b). Therefore, there was limited information about the practice of alternative treatments for other ethnic groups.
- d. There were only three qualitative studies that focused on the reasons why women delayed. However, in terms of sampling, one study included all of the main ethnic groups (Taib et al. 2011), one study recruited all of its participants from the Malay ethnic group (Norsa'adah et al. 2011), while the other study recruited from both the Malay and Chinese ethnic groups (Yusoff et al. 2011).
- e. Most of the studies found that family members played a significant role in the decision-making process among women with breast cancer. However, only one qualitative study recruited husbands as participants (Yusoff et al. 2011).
- f. There were no studies that examined the decision-making process from the time women first found the problem in their breast until they underwent their first treatment in hospital.
- g. Even though none of the studies in Malaysia focused on the role of nurses in helping with the decision-making processes, the paper by Maskor et al. (2013) emphasises the important of

communication skills while dealing with the patients and family members. However, international literature had revealed some specific roles of nurses during decision-making process.

- h. None of the studies used the narrative approach as a method to understand the decision-making experience among women with breast cancer.

Despite the limitations noted in the existing literature, this study will focus only on the decision-making experience among women with breast cancer and their family members within a specific time frame – that is, from finding the problem in the breast until the women underwent their first conventional treatment in hospital – using a narrative approach. The study will focus on this specific time frame to explore the range of decisions that the participants had made within that period and integrate the findings later with the MPTT. This will enhance an understanding regarding the decision-making process and factors that influences the decision within the pathway to treatment. These decisions may have a potentially significant impact on their mortality and survival time as they will determine whether the women delay or do not delay prior to obtaining hospital-based treatment. At the same time, the turning point and factors that triggered their decision to undergo hospital treatment can also be explored in detail. Indirectly, health care service could be improve to identify early diagnosis and HCPs could supported the women when they understand women's experiences and their decisions. Since this study uses a narrative approach, the nurse will be considered as a person or key character that may be influential in the patient's decision if they are mentioned by the participant in their narrative. However, no specific questions will be asked pertaining to nurses if a participant fails to raise it initially in their account.

## 2.3 Justifications for conducting the study

The literature revealed that there is still relatively little knowledge pertaining to the decision-making experiences and how the process of decision-making takes place among Malaysian women with all stages of breast cancer. The quality of some of the existing studies appears to be weak or unclear, due mainly to a lack of information about the methodology used. To date, this is the first study to have explored its participants' stories about how they perceived their experiences of making decisions on breast cancer after they had come to realise there was a problem with their breast up to the time of undergoing their first treatment in hospital. In Malaysia, there is a need for future research on breast cancer to fully understand women's decision-making processes as this is one of the areas that has been identified as a reason for delay (Yip et al. 2014).

Although the research suggests that family members have an influence on women's decision-making, most of the studies examined neglected to include the perspectives of the women's family members in their design. In response to this situation, this study explored the perspectives of family members because their involvement in decision-making is an important feature in Malaysian culture. Family members provide daily support to a person with cancer, although the decision-making research has rarely sought to include their involvement (Hubbard et al. 2010). There have also been limited international studies that recruited family members as participants, although most of the findings revealed that the participants' family members had influenced the women's decisions (Halkett et al. 2007; Pieters et al. 2012; Sims 2014).

Most of the available information originates from studies conducted in Western countries, thereby limiting the transferability of their findings to the Malaysian setting due to the different beliefs, norms and socio-cultural values. There is a pressing need to examine differences in how women from various cultures make sense of breast cancer (Lam and Fielding 2003).

## **2.4 Aims**

To explore the experience of Malaysian women with breast cancer and their family members when making decisions during the time between women realising there is an abnormality in their breast until undergoing their first conventional treatment in a hospital.

## **2.5 Research questions**

1. What are Malaysian women's narratives of decision-making from the time between realising there is an abnormality in their breast until undergoing the first conventional treatment for cancer in a hospital?
2. What are the family members' narratives of decision-making from the time between them knowing there is an abnormality in the woman's breast to the woman undergoing the first conventional treatment for cancer in a hospital?
3. What are the key features, events, people and decision points in these narratives that prompt Malaysian women and their family members to pursue hospital treatment?

## 2.6 Objectives

1. To explore the experience of decision-making among Malaysian women starting from the realisation of an abnormality in their breast until undergoing their first conventional treatment in a hospital.
2. To explore the experience of decision-making among family members from the time between them knowing there is an abnormality in the woman's breast until the woman undergoes the first conventional treatment for cancer in a hospital.
3. To identify the key features, events, people and decision points in these narratives that prompt Malaysian women and their family members to pursue hospital treatment.

# Chapter 3: Methodology

## 3.1 Introduction

The purpose of this chapter is to present the methodological perspectives of qualitative research, social constructivism and narrative that guide this study, along with the rationale for these choices.

In choosing a methodology for a study, it is important to begin with the researcher's personal paradigm, as every researcher has their own view of what constitutes truth and knowledge. A paradigm refers to "a set of very general philosophical assumptions about the nature of the world (ontology) and how we can understand it (epistemology)" (Maxwell 2005, p.36). According to Schwandt (2001), the paradigm guides people's thinking, beliefs, and assumptions about society and selves, framing how people view the world around them. In the context of this study, my own personal belief is that the experience of decision-making is a subjective, complex process and that reality is never singular as it depends on the participants' perspectives. The experience of decision-making may vary between each participant, thus potentially leading to the construction of multiple perspectives despite the participants suffering from the same illness, which, in the context of this study, is breast cancer. This ontology is consistent with a constructivist paradigm, where individuals co-construct their understanding of the world through their interactions with others and their experiences (Cohen et al. 2017). Thus, experience consists of multiple realities and meaning (Creswell 2007), which are expressed through participants' narratives of the uniqueness of each action and event. In terms of epistemology, I could foresee an interactive conversation between the participant and myself as researcher because I believe that there are shared experiences in this multiple reality that co-construct between us during the storytelling. With these views in mind, the appropriate

philosophical position that relates to my understanding is social constructivism, to gain an understanding of how Malaysian women with breast cancer and their family members make their decisions. According to Prawat and Floden (1994), social constructivism views knowledge as the result of social interaction and language usage, thus is a shared, rather than an individual experience.

This study also focuses on personal experiences presented through oral narratives, as they offer the opportunity to explore the richness and nuances of meanings within a story about breast cancer decision-making experiences, which is appropriate to address my research questions. Moreover, narrative research aligns with this position because not everyone will have the same story or experience. They will tell a different story depending on what captures their attention and how they make sense of the event about their experiences even if they are witnessing or experiencing the same event (Bold 2012). According to Bailey (1996), the goal of personal narratives is to understand the story from the perspective of the teller in the context of their lives.

### **3.2 Qualitative research**

For the purpose of this research, I sought to ascertain a detailed portrait of “what”, “why” and “how” the decision-making process occurs among the Malaysian women and their family members in relation to breast cancer. Thus, this current project is qualitative research. According to Krathwohl (2009), qualitative research is most appropriate for these kinds of questions because it provides a contextualised further understanding of people’s experiences of the situation and their response. Qualitative research therefore focuses on “the processes by which people construct meaning and to describe what those meaning are” (Bogdan and Biklen 2007, p.43). Thus, qualitative research attempts to interpret the phenomena or event in relation to the meanings that

people describe to them. Qualitative research, enable an in-depth understanding through listening, interpreting, and retelling participants' accounts in a vicarious manner in order to engage the reader emotionally as well as intellectually in the account (Crotty 1998; Glesne 2015). By exploring the experiences from the participants in this study, it was possible to obtain multiple perspectives that further our understanding regarding decision-making processes related to breast cancer.

A qualitative design is appropriate as a means of providing detailed descriptions of research processes and ensuring a more comprehensive understanding of the phenomenon of interest (Curry et al. 2009). Since these participants had experienced or dealt with breast cancer, offering them an opportunity to narrate their experiences allowed the researcher to re-tell the participants' stories through a shared experience of meaning making. As such, qualitative research makes it possible to "stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry" (Denzin and Lincoln 2011, p.14).

### **3.3 Social constructivism**

Social constructivism usually refers to research that is interpretivism in nature (Lincoln et al. 2011). According to Hruby (2001), social constructivism refers to "the influence of social processes upon an individual's psychological construction of meaning" (p.51). In social constructivism, individuals seek to understand the world by developing subjective meaning with regard to their experiences that is negotiated both socially and historically (Creswell 2013). In other words, social constructivism sees an individual as the agent who controls the construction process of the meaning of knowledge within a social

context. In a social constructivist approach, factors such as religion, culture and social may be relevant to understanding the world or reality. For example, Muslims usually interpret or accept that breast cancer is a test from God, yet some Chinese people interpret breast cancer as a punishment from God. However, both of these interpretations are socially and culturally accepted within each ethnicity, thus indicating that people in Malaysia may attribute different meanings to their illness.

Esin et al. (2014) emphasised that a constructivist approach among narrative researchers stresses the position of tellers and listeners, and how their interaction is influenced by their personal, social, culture and politics. In this study, the participants related their stories to me, as a researcher, at the time of being interviewed for a particular purpose. Therefore, the context of the interview was influenced by how the participants narrated their experiences, which stories they elected to tell and how they presented the meaning of their experiences (Bold 2012).

Social constructivism encourages people to look at the world from a different perspective, rather than to focus on an “objective” reality. It implies that not everything in this world can be explained through scientific experimentation in a laboratory designed to test a hypothesis. This is because individuals’ experiences are personal and subjective, thus meaning it is not possible to replicate an exact experience. Therefore, the aim of social constructivism is not to prove a hypothesis but rather to attempt to understand how participants construct the meaning of their experiences and actions in a specific situation and at a specific time. As a researcher, I am aware that the participants’ narratives provided insight as to why this situation happened, the decisions that the patients made, and how they made their decisions. This is because each patient’s story in the present study was a “subjective” presentation of their experiences that became important in addressing my understanding regarding decision-making experiences

among women with breast cancer. Generally, I acknowledge that both views, “objective” and “subjective”, are important for understanding the truth of reality because it depends on the type of study being conducted, even though this study was not related to “objective” reality.

## **3.4 Narrative**

### **3.4.1 Introduction to narrative**

Narrative is one of the research approaches that falls under the umbrella of qualitative research. Narrative shares some similarities with other qualitative methodologies regarding its ontology, epistemology and/or data collection process. For example, the ontology underpinning narrative is the constructivist paradigm, which recognises that the ‘truth’ is considered as multiple and subjective realities, and this paradigm is also commonly seen in ethnography and phenomenology (Finlay 2006). Another similarity of narrative to other qualitative methodologies is that it often uses interviews for its data collection process.

The precise definition of the narrative itself remains a topic of dispute among researchers (Riessman 1993), with some researchers employing a broad definition of narrative. A simple definition, credited to Aristotle in *Poetics*, is that a narrative has a beginning, middle and end (Chainani and Miller 2006). Patterson (2008) defined a narrative as a first-person personal oral story about his/her past, present, future and imaginary experiences. Richardson (2000) emphasised that a narrative is the representation of verbal and non-verbal stories that are generally connected to a series of events. Hinchman and Hinchman (1997) described a narrative as a clear sequence of events that connect in a meaningful way for a particular audience. However, Labov (1972) proposed a restrictive definition of a narrative as a representation of specific past events that happened to the teller in chronological order.

Riessman (2008) argues that events are consequential but not necessarily told chronologically. The difference between these definitions in terms of them lacking clarity and agreement between narrative researchers may be because they are derived from an interdisciplinary background. Therefore, based on these views, the working definition of a narrative adopted for the purpose of this study is that it is a personal oral story related to a series of meaningful events, which does not necessarily follow a chronological sequence and is constructed by the teller for a particular audience and to convey meaning about the experience under investigation.

There are several features that distinguish a narrative from other qualitative methodologies. A key feature concerns the assumptions underpinning narratives that selves and identities are constructed in stories via the interaction between the teller and listener (Riessman 2008). This means that in a narrative, the focus is on the construction of the identity and personality of the teller. Clandinin and Connelly (2000) stated that a narrative has been considered as a useful approach for exploring the detailed life experiences of an individual or a small number of people through their storytelling. Therefore, in this study, I acknowledge that some of the participants had constructed their identity to inform how they made their decisions regarding treatment for breast cancer.

Another assumption about narrative is that it is influenced by the socially situated nature of the interaction (Maitlis 2012) which will vary and is affected by the setting, time, audience and purpose of the interaction (Etherington n.d); consequently, many factors may influence the teller's stories. Lieblich et al. (1998) stated that each story told is influenced by the context within which it is narrated, such as the teller's aim in participating in a study, the nature of the audience, the relationship formed between teller and listener and the mood of the

narrator. Therefore, in the context of the research interview, the way in which the research and its aims are presented to the participant is one of many aspects that may influence how the participants tell their stories, which stories they select, what they choose not to tell and how they present the meaning of their stories to bring the uniqueness of each action and event. In this study, the participants were given a patient information sheet (PIS) that indicated the topic of interest and set out the formal interview context. However, the interview was conducted in a conversational style that aimed to help the participants feel relaxed and informal in general. Additionally, the interview session was conducted at the participants' convenience, time and preferred location, with the assumption that they were ready to share their stories.

Narrative is about talk or interaction. Regarding the listener, Riessman (1993) argued that stories are designed for the individual listener, as the teller will create different stories depending on whom they are relating the story to. During my interaction with the participants, the retold experiences were influenced by how I engaged with them. Experience is considered to be a dynamic force, as stated by Scott (1991):

Experience is at once already an interpretation and is in need of interpretation. What counts as experience is neither self-evident nor straightforward, it is always contested and always therefore political (p.797).

This statement means that different emphasis occurs, depending on what is said about the experience and to whom the story is being told, potentially leading to different interpretations of the same event. Additionally, people will tell a different story about themselves if they know or have a relationship with the listener. For example, the story told to a close friend may be quite different from that which is being told to the researcher. In this study, I presented myself as a PhD student who

was conducting the interview as part of the study. However, I acknowledge that participants might talk about what I would like to hear as a student or researcher, especially as they knew about the objectives of the study.

Culture, a socially constructed concept that becomes an inherent part of a person, has an impact on personal experiences and interprets events. Some narrative researchers consider culture as an important factor within the context of storytelling (Squire 2008). According to Aneas and Sandín (2009), culture provides a platform for an individual to interpret, understand and negotiate the world. Therefore, culture might influence the way that a story is told and how the story and meaning is constructed by the narrator.

Clandinin and Connelly (2000) identified three concepts related to narrative research; temporality, sociality, and place.

i. Temporality

Temporality refers to the placing of events in time, which in this concept is related to the past, present and future of events and people (Clandinin and Connelly 2000). It means that the events that people experience are happening over time. For example, when people experience certain events, they think of an event as not just happening at that moment but instead try to relate it to previous or/and future time. People see events as they are experienced either by themselves or by other people as a process in transition with time (Connelly and Clandinin 2006). Time becomes an important element in organising the narrative experiences as there are strong correlations between the narrative and temporality (Martino and Freda 2016). Therefore, the concept of temporality enables a researcher to understand how the participants are telling their stories that are happening over time.

## ii. Sociality

The concept of sociality emphasises the relationship between a researcher and a participant, in which the researcher must acknowledge both the participant's and researcher's "feelings, hopes, desires, aesthetic reactions and moral dispositions" and the social condition such as "the existential conditions, the environment, surrounding factors and forces, people and otherwise, that form each individual context" (Connelly and Clandinin 2006, p.480). This relationship is important because the story is constructed between the listener and teller through negotiation that conveys meaning (Wang and Geale 2015).

Some narrative researchers acknowledge the role of the researcher during the interview process to co-construct or generate the data because the responses of the interviewer to the interviewee may shape the direction of the interview (Benwell and Stokoe 2006). Wells (2011) claims that the narrative represents an attempt to co-construct meaning between the teller and the listener. Thus, the interactional context within which the narrative evolves is considered necessary for some researchers (Fina 2009). Therefore, I was involved in jointly constructing the data, where I inevitably responded and asked for additional explanations about certain information during the interview process.

## iii. Place

Place is referred to as "the specific concrete, physical and topological boundaries of place or sequence of places where the inquiry and events take place" (Connelly and Clandinin, 2006, p. 480). Place is necessary to convey meaning about a person, event or thing (Clandinin and Connelly 2000). The researcher should look for a specific context or place in the participants' stories during the data analysis that gives meaning to the narrative and

how the activities that happened influenced the participants' experiences (Wang and Geale 2015). In this study, I attempted to create the right place for the interviews and gave the participants the opportunity to choose where they preferred to be interviewed. This gave them control and comfort in choosing a familiar place.

Another important element in the narrative is the presence of a plot (Polkinghorne 1988). Narrative researchers agree that there would be no identifiable narrative or story without a plot (Freeman 2017). According to Brooks (1984, p.5), the "plot is the principle of interconnectedness and intention which we cannot do without in moving through the discrete elements – incidents, episodes, actions – of narrative". In order to understand the plot, the researcher needs to understand the way the action unfolds in a given account, and the complex ways various events and characters intersect with these actions (Freeman 2017). Therefore, connection within the plot enhances the researcher's understanding of the events because the plot gives coherence to a narrative (Goldie 2012).

### **3.4.2 Narrative and illness**

Narrative is not only a powerful medium through which to express suffering and experiences but may also provide a context that could connect illness and surrounding life events (Hydén 1997). In this section, I will describe the concept and relationship between narrative and illness based on the perspective of three narrative researchers – Frank, Hydén and Bury.

Frank (2013) identified that there are three types of illness narrative: restitution, chaos and quest narratives. Restitution consists of three themes – being healthy, illness and seeking a return to health. The stories revolve around treatment, investigative tests and results. A

restitution narrative can be either helpful or harmful to a patient with cancer. For instance, knowing that other sufferers have regained their health is positive but it is also a reflection of Western medicine, in which the entire process emphasises diagnosis, treatment and cure. In this regard, Frank (2013) argued that restitution acts as a social imperative to return to health, in the process missing the subtle nuances of the meaning of illness and its effects.

Chaos narrative is different; it involves a belief that life will never improve and reveals a sufferer's "vulnerability and futility" (Frank, 1997, p.97). This type of story lacks a narrative sequence and time but still has important value with regard to understanding the particular experiences that are of great significance to the narrator. For example, different ethnic groups may have different views of cancer despite living in the same community. Some of them may portray a narrative of having breast cancer as being out of their control and relate it to the will of God, thereby indicating a sense of inevitability or that they are deserving of punishment. These beliefs may make patients feel powerless and indirectly influence their decisions.

Quest narrative relates to the patient's belief that something could be gained by their experiences (Frank 2013). They accept that illness is a journey because "quest stories meet suffering head on; they accept illness and seek to use it" (Frank 2013, p.115). It seems that the patient is the agent and that the goal is not to return to health but to live with the illness. These ill people also believe that they will gain something through their experiences. Quest narrative has three facets – memoir, manifesto and automythology. Memoir "combines telling the illness story with telling other events in the writer's life" (Frank 2013, p.119). In manifesto, the life story of suffering carries demands as truth to society. Automythology is associated with the transformation of suffering through metaphor that mediates the experience of illness to others.

In contrast, Hydén (1997) proposed three different typologies to understand and interpret illness narrative. The first type refers to “illness as narrative”, in which the same person is able to combine narrator, illness and narrative. The illness is spoken about and articulated in and through a narrative. The narrative plays a central role in the illness and shapes the occurrences that impinge on the individual’s life [ibid.]. This type of narrative represents the teller’s personal experience of events and the problems that are posed for that individual. It means that the illness is the narrator’s story and others (researchers) are retelling that story to give coherence to events and suggest possible action. Thus, the narrative could be considered as a way of integrating or solving the problems. Hydén (1997) claims that illness narrative makes it possible to integrate the symptoms and their consequences into a new whole as part of a new social reality. For instance, in the case of breast cancer, the experience of the diagnosis could form a whole story that the sufferer wishes to share, expressing the effect of the diagnosis and how the present life is viewed, thus giving new meaning to a new world.

The second type of illness narrative is “narrative about the illness”. Hydén (1997) states that this narrative delivers information about the illness and primarily relates to professional discussion between a doctor and other health care staff, in a clinical context, regarding the patient’s condition. Hunter (1991) suggests that this type of narrative has a central role in medicine to formulate and convey clinical knowledge. Sacks (1993) recognises that illness narrative is important because a doctor is able to gain detailed clinical information from the patient. For instance, during ward rounds, professional teams usually discuss the patient in order to make a correct diagnosis and suggest possible treatment that is acceptable to the patient.

The third type is known as “narrative as illness”. According to Hydén (1997), this narrative occurs when the presenting of narrative or insufficient narrative generates the illness. This type of narrative may be observed among people with neurological or mental disorders who face challenges in their ability to develop coherence in their story. A similar narrative could relate to people with learning difficulties who lack the narrative ability to express past or current experiences and events. In contrast, in a study of adults with Down’s syndrome, Brown et al. (2010) found that using narrative analysis illustrates that having the patience to listen to a patient’s life story offers meaningful learning to health care staff. This finding could be achieved through careful consideration of how data are collected and the use of an appropriate analytical approach.

Another narrative researcher, Bury (2001), suggested three broad forms of illness narrative; contingent narratives, moral narratives and core narratives. Contingent narrative is concerned with a certain part of the patient’s story associated with their beliefs and knowledge about factors that influence the start of the disease, its emerging symptoms and its effects on the body, self and others [ibid]. Contingent narrative, with particular regard to chronic illness, concerns the patient’s and family’s emotional reactions and the development of coping mechanisms to deal with the challenges of chronic illness (Bury 2001). Normalisation and coping are the two common aspects of contingent narrative. According to Bury (2001), the concept of normalisation may produce two interpretations of illness experiences. On the one hand, patients try to normalise their pre-illness lifestyle and identity through maintaining as many activities as possible, and disguise or minimise the symptoms through their behaviour. On the other hand, patients may adapt their lifestyle according to their illness, being open and likely to disclose it. Another important concept in chronic illness is coping, which refers to

people's ability to maintain some sense of worth in the face of intrusive symptoms (Bury 2001).

The second illness narrative suggested by Bury (2001) is moral narrative, which is based on a moral judgement of the illness between the individual and the wider society, set within a cultural context. According to Williams (1993), the theme of morality was identified by locating stories within a cultural framework among chronic disease patients who portrayed health as a virtuous state. For example, the presence of certain diseases was culturally related to what was viewed as inappropriate behaviour, even if they resulted from a potentially accidental occurrence, such as HIV infection. This is one of the reasons why certain women who contract HIV after being raped are unlikely to disclose their diagnosis, fearing isolation and rejection by their society (Watch 2004).

The third illness narrative refers to core narratives (Bury, 2001), which relate to the function of narrative, such as how an individual talks about illness based on the culture, social norms, language and context that shape the stories. Kelly (1994) identified several core narratives, such as heroic, tragic, comic, disembodied or romantic, while Robinson (1990) presented three categories of core narrative based on a story's sequence; progressive, regressive and stable. Progressive narrative reveals that the narrator has positive personal goals, in contrast to a narrator with a regressive narrative, who tends to have negative goals. Stable narrative, meanwhile, means that the narrator has remained in the same position [ibid]. Bury (2001) argued that regardless of which narrative form a narrator chooses (people may draw upon one or more), their forms of narrative may switch from one to another while telling their stories.

### 3.4.3 Critics of narrative research

Narrative research has its limitations. I will discuss three main points of potential criticism or debate that I consider must be addressed with regard to narrative research and which relate to crisis of truth claims, crisis of representation and linguistic.

#### i. Truth claims

As stated earlier, narrative involves the reconstruction of stories about experiences of the world. As such, narratives are not a precise replication of events. This is because the storytelling might change over time as the meaning of an experience is understood in context and in order to meet the needs of both the storyteller and the listener on each occasion. Ellis and Bochner (2000) stated that narrative should not be considered purely as a memory storage device, although it does aid in organising memory. For example, in the case of breast cancer, how the patients reflect on their illness today and again in the future will be affected by what has happened during the transition and intervening period to shape their experiences. However, this does not mean that a story told today, which may subsequently be told differently, was not the 'truth' as the person believed it to be so at the different times at which they told the story.

Some narrative researchers have different views regarding the language used to represent truth claims. Cortazzi (1993) stated that the participants' language captures the reality of lived experiences while other researchers consider language as constituting that reality (Gilbert 1993; Denzin 1997). Riessman (1993) believed that people may fabricate certain elements of their stories, not so much with an intent to deceive but rather according to a desire to make their fictions become realities and as a

requirement of their interpretation, as described by The Personal Narrative Group:

When talking about their lives, people lie sometimes, forget a lot, exaggerate, become confused, and get things wrong. Yet they *are* revealing truths. These truths don't reveal the past "as it actually was," aspiring to a standard of objectivity. They give us instead the truths of our experiences ... Unlike the truth of the scientific ideal, the truths of personal narratives are neither open to proof nor self-evident. We come to understand them only through interpretation, paying careful attention to the contexts that shape their creation and to the world views that inform them. Sometimes the truths we see in personal narratives jar us from our complacent security as interpreters "outside" the story and make us aware that our own place in the world plays a part in our interpretation and shapes the meanings we derive from them (The Personal Narrative Group as cited by Riessman 1993, p.22).

Participants thus select certain events and arrange them in such a way as to form a whole story that gives meaning and might be the truth of the events to them. Ali et al. (2015) argued that the participant may fake the stories or relate horrific experiences, while Ezzy (2000) stated that the teller may exaggerate some aspects of the stories. In contrast, Polkinghorne (2007) points out that the aim of narrative research is to understand the meanings constructed by people in relation to those events, not to discover whether the stories are accurate reflections of actual events. Therefore, in this narrative research, the argument is not whether the stories or narratives are facts, opinion or lies, but that they enable people to understand the tellers' situations in terms of how

they say they experienced and responded to those events. The position taken is that this is the story that the participant has chosen to tell at this time and in this context.

## ii. Crisis of representation

Crisis of representation refers to the challenges of describing and capturing lived experiences in text (Denzin 1994). This criticism arises because it is difficult to suppress people in the written text, as commented upon by Denzin:

When a writer writes a biography, he or she writes him[self] or herself into the life of the subject written about. When the reader reads a biographical text, that text is read through the life of the reader. Hence, writers and readers conspire to create the lives they write and read about. Along the way, the produced text is cluttered by the traces of the life of the “real” person being written about (Denzin as cited by Alvermann 2002, p.56).

While presenting narrative research, one key point is the power of the researcher over the participant’s voice. According to Alvermann (2002), narrative researchers have to decide whose stories to tell, which parts of the stories to omit and how much of the narrator’s voice to include in the publication or writing. As a researcher, I am aware of the imbalance in the power relationship between the participant and myself. During the data analysis, I was in the dominant position of being selective and in control of the transcript. The decisions I made were based on my research objectives. Boundaries must therefore be established to guide the writing. I acknowledge that by using narratives, I would be looking at and treating the stories as a whole, but only presenting extracts of the data to in the thesis, to demonstrate process of analysis

and resulting interpretations. Nevertheless, I attempted to do this in such a way as to include and represent the voice of the participants by using their words and meaning constructions.

### iii. Linguistic

Riessman (1993) stated that analysis of narrative data requires precision, including “nuances of speech, organisation of a response, local contexts of production, social discourses that shape what is said and what cannot be spoken” (p.69). However, not every narrative scholar agrees with this. Gubrium and Holstein (2009) argue that a narrative that provides a complete and accurate understanding of the topic is considered to be a good story, as opposed to being judged by the quality of its linguistic elements. Concentrating on the quality of the story is a more appropriate focus for the proposed research because in this research, interviews will be conducted in the participants own language. Thus, interviews and data analysis was conducted in the Malay language to avoid any confusion or misinterpretation of what the participants had said. Translation into English was undertaken later for the purposes of sharing the initial analysis with supervisors and then for the presentation of illustrative quotations in a thesis for an English university. Riessman (2008) stated that finding equivalent words in English for referential content is never easy in any translation. Thus, whenever there was not a direct, literal translation, the Malay terms or words were kept and explained in English as accurately as possible using my native understanding of the broader social and cultural meaning of the words and phrases used. Discussion with other Malay PhD students also enhanced the interpretation of the meaning and English translation in order to convey as similar text as possible, provided there was no loss of the authentic meaning of the story (Plummer 1995).

### 3.4.4 Rationale for selecting a narrative approach

Before deciding on an appropriate research design for this study, five approaches were compared to determine the suitability and ability to answer the research questions (see Table 3.1 below).

Table 3.1: A comparison of criteria between five research approaches (Creswell 2013)

	Narrative	Phenomenology	Grounded Theory	Ethnography	Case study
Focus	Exploring the life of an individual	Understanding the essence of the experience	Developing a theory grounded in data from the field	Describing and interpreting a culture-sharing group	Developing an in-depth description and analysis of a case or multiple cases
Type of problem best suited for design	Needing to tell stories of individual experiences	Needing to describe the essence of a lived phenomenon	Grounding a theory in the views of participants	Describing and interpreting the shared patterns of culture of a group	Providing an in-depth understanding of a case or cases
Research questions/aims	What is injured persons' experience with health care following traffic collision-caused injury? (Lindsay et al. 2016).	What is the meaning of the experience of healthcare decision-making for Chinese women with breast cancer? (Xiong et al. 2016).	To propose a model of the transition from perceptions of women's health diagnosed with cancer (Maude et al. 2016).	To explore the cultural practises, which shape the culture of transfusion, and to identify the key elements, which influence clinical decision making in blood transfusion in haemato-oncology and lung cancer patients (Bishop et al. 2011)	The aim of this case study is to examine the cognitive and language abilities of a bilingual/bicultural adult diagnosed with possible Alzheimer's dementia (Brice et al. 2014).

Based on table 3.1 above, the grounded theory, ethnography and case study were rejected because the present study did not aim to develop theory or was fully focused on cultural aspects or analysis of cases. Narrative and phenomenology were pre-selected because both methods investigate lived experiences (Riessman and Quinney 2005; Finlay 2011),

both have the potential to understand the decision-making experiences among women with breast cancer and their family members. However, while phenomenology is helpful in understanding the meaning of experience and the impact of this on identity, it “does not aim to explicate meanings that are relevant to understanding cultures or social groups” (Van Manen et al. 2016, p.6). Therefore, narrative is more appropriate for the intended research because of its focus on how the participant constructs and understands their experiences in relation to the social context of that. A narrative is created within a broader socio-cultural context (Murray 1999), and the resulting socio-cultural template provide a store of meaning for people to live by and to explain their experience (Richardson 1990). Therefore, narrative is a viable method to understand how the social context of Malaysia influence women and family’s experience of breast cancer and their associated decisions through examination of the social, cultural, linguistic, family and institutional construction of experiences (Clandinin et al. 2013).

Thus narrative will enable me to make sense of how the social context influence how women with breast cancer and their family members decision-making experiences related to breast cancer because, when the women were diagnosed with breast cancer and underwent treatment, they carried the stories of their experiences with them. According to Smith (2000), a narrative enables the researcher to understand how individuals construct meaning, identity and personality through oral, written and non-verbal communication. Additionally, the personal story is the best method for understanding and learning from an individual’s experience (Lieblich et al. 1998).

A narrative can be considered as a vehicle for the transfer of knowledge by communicating understanding and thereby the meaning of experience (Webster and Mertova 2007). Narratives are co-constructed through the story-telling relation, in other words by a researcher

working together with a participant, jointly constructing the stories relevant to the research project, based on the participant's situation (Squire et al. 2014). Consequently, in this study, the interaction between the researcher and participants led to the joint construction of the stories about breast cancer decision-making experiences, thereby helping the researcher to understand how the stories were put together and make sense of the events and actions in the participants' lives, based on what they said.

The narrative method allows the researcher to present the story holistically, including its complexity and the richness of the experience (Bell 2002). Through their stories, people create order and construct texts in a particular context (Riessman 1993). Therefore, narrative enables an understanding of the whole structure of the stories among women with breast cancer and their family members when they constructed their experiences in sequence. This makes the narrative a valuable approach to understanding people's experiences through the construction and reconstruction of personal stories because of its ability to record and retell the most influential events that happened to the teller (Webster and Mertova 2007).

Furthermore, narrative is recognised as having the potential to give a voice to people through the ability to bring out hidden and marginalised stories that may reveal a deeper understanding of the tellers' own lives (Susinos 2007) and more importantly, of what is considered socially acceptable and unacceptable narratives. This means that a narrative provides opportunities to hear how individuals interpret the meaning of their own experiences, in relation to the social context through the retelling of their experience—how they assemble the meaning of this experience, socially. For this reason, an in-depth interview technique, inviting participants to tell their story of a particular experience is an appropriate approach to understand how stories convey meaning about

something in the world (Ospina and Dodge 2005). Therefore, a narrative has a greater potential for participants to lead an interview, by choosing and constructing a story that best conveys their understanding about the issue under examination, in comparison to other approaches where the researcher would pre-determine areas for exploration.

In this study, Riessman's approach was chosen because her narrative research applied social construction perspective is in line with the paradigm of this study, while other forms of narrative analysis adopt a humanistic approach (Radley 1996; Frank 2013). In terms of narrative analysis, Labov (1972) focused on analysis regarding the structure of stories in chronological order, while Riessman (1993) focuses on both content and structure that might give more understanding regarding the decision-making process experiences.

### **Chapter summary:**

This chapter has provided an explanation of the qualitative and social constructivism paradigm that underpins this research. The narrative concept was explored, including a critique of and the rationale for selecting a narrative approach. The following chapter outlines and justifies the methods that were applied in this study.

# **Chapter 4: Method**

## **4.1 Introduction**

This chapter provides an explanation regarding the study setting, participants, recruitment process, data collection, data analysis, ethical issues and rigour.

## **4.2 Study setting**

This study was conducted in two government hospitals (one public and one teaching hospital) in a large city in Malaysia. Both hospitals provide comprehensive services in the field of cancer care. These hospitals were selected due to their location in a highly populated, multi-ethnic and religiously diverse part of Malaysia, thereby increasing the likelihood of accessing participants from a range of socio-economic backgrounds and from all three main ethnic groups.

## **4.3 Access to and identification of participants**

The participants were recruited at six locations within two hospitals, namely two oncology clinics, two oncology wards and two radiology units. The objective was to recruit women who had had different treatments for breast cancer. For example, in both hospitals, a woman receiving only chemotherapy as a form of treatment will usually go directly to the oncology ward or clinic, while someone having only radiotherapy will go to the radiotherapy unit. The researcher attended all of the relevant locations and spent some time in them getting to know the staff and becoming familiar with the surroundings.

Prior to the recruitment starting, the researcher informed and held discussions with the oncology/radiology staff regarding the study

overall, showed them the written information packs and explained the inclusion and exclusion criteria (see Table 4.1 below) to assist in the identification of potential participants.

Table 4.1: Participant inclusion and exclusion criteria

<b>Inclusion criteria</b>	<b>Rationale</b>
Women	Breast cancer is the focus of this research and patients with other types of cancer will have different experiences
Diagnosed with primary breast cancer	
Have undergone their first conventional medical treatment within the last year	To enable the interview to focus on the time period of interest, minimise other events and treatments that were not in the time period and reduce memory effects
18 years old and above	Adult
Able to speak Malay or English	The researcher is fluent in both languages.
<b>Exclusion criteria</b>	
Moderate and severe cognitive impairments (for example, Alzheimer, dementia)	People with moderate and severe cognitive impairment may be unable to describe their experience (Goldberg and Harwood 2013). Their decision-making experiences are likely to differ, and they may not be able to give informed consent to participate
Patients who are unable to communicate verbally	Inability to communicate
Patients who are very unwell mentally or physically (for example, terminally ill, patient on a ventilator, under sedation)	

The hospital staff approached eligible participants, introduced the research and gave them a recruitment pack that consisted of an invitation letter (see Appendix 7a and 7b, pp.306–309), patient information sheet (PIS) (see Appendix 8a and 8b, pp.310–319) and

consent form (see Appendix 9a and 9b, pp.320–323). If the participants expressed an interest and indicated they would like to know more about the study, the staff introduced the researcher to them when the researcher was available at the location. The researcher then spent a few minutes explaining the study in more detail and providing eligible participants with the opportunity to ask questions. The researcher invited them to think about participating in the study, to discuss the matter with family and friends if they wished, before making a decision. If the participants agreed, the researcher would contact them by telephone, after at least 48 hours had elapsed, to discuss any further questions. If they were interested in proceeding with participation in the study, the researcher then made an appointment for the research interview. If the researcher was not available at the location, the PIS contained information on how to contact the researcher directly. The flow chart of participant recruitment is shown in Figure 4.1 (see p.85).

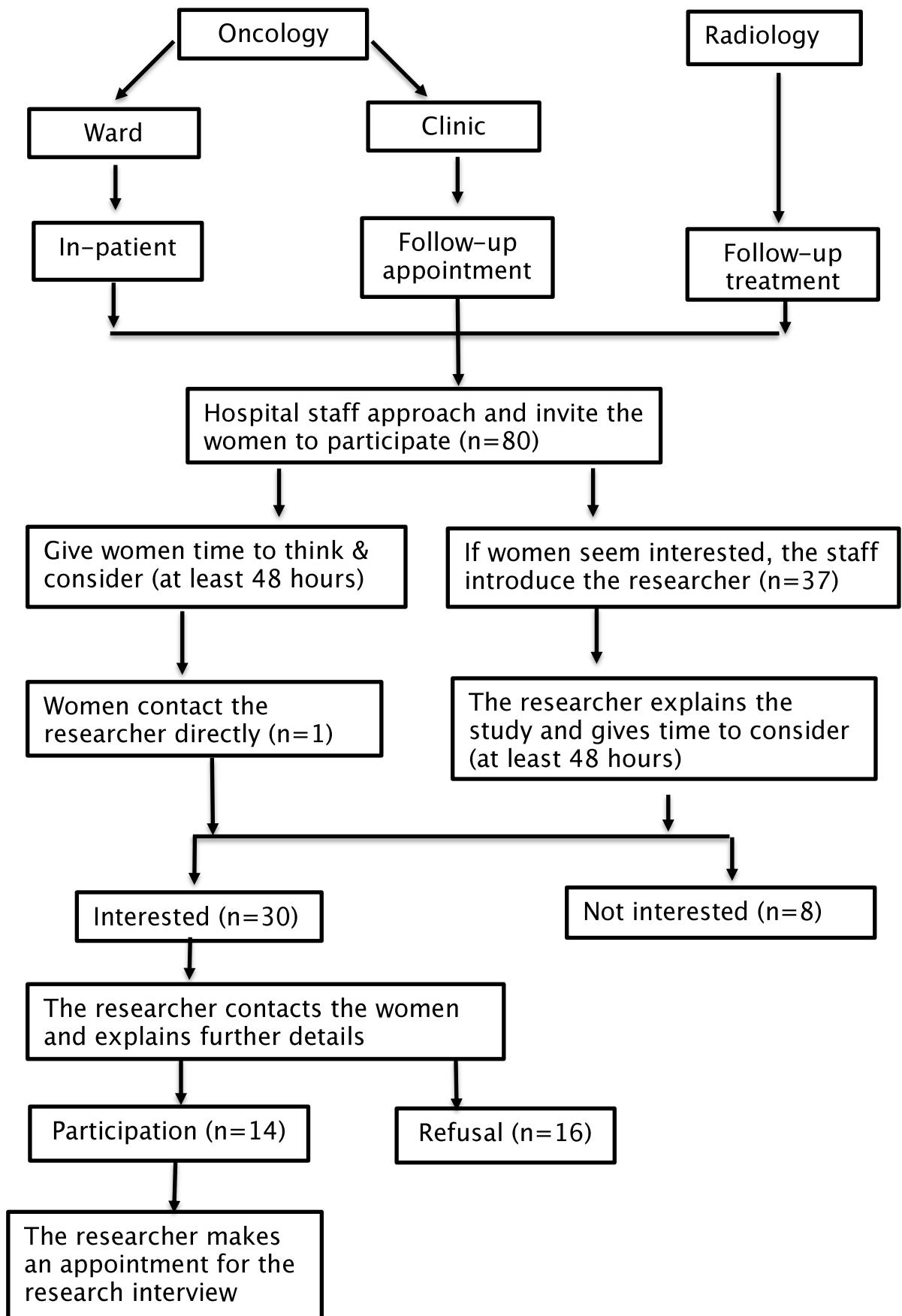


Figure 4.1: Flow chart of recruitment of women

Throughout the period August–October 2016, 80 recruitment packs were distributed to women with breast cancer in both hospitals. The first contact was made by staff, so that the participants would have the opportunity to decline to talk with the researcher if they so wished. From my observation, four participants declined immediately after the staff informed them about the study and before receiving an information recruitment pack. Thirty-seven participants agreed to talk with the researcher from all the locations. Eight participants subsequently declined to take part in the study due to personal reasons, such as not feeling ready to share their story.

Out of the 29 participants who initially agreed to be contacted, 16 participants subsequently declined or were unable to take part in the study. Seven of them declined because they were unwell and two women requested to reschedule the interview due to work commitments; however, they never rescheduled. Another woman said that she had to follow her husband to another country due to his job and was unsure when she would return. Three women agreed to take part in the study and arranged an interview date but then subsequently changed their minds, while a further three women agreed but could not be contacted (e.g. the telephone number was not connected). Therefore, 14 participants were interviewed, including one participant that contacted the researcher directly.

### Identification of family members

When the women initially agreed to be interviewed, the researcher asked them to nominate the most important or supportive family member during their decision-making whom they were happy to be included in the study. Inclusion criteria for family members comprised: i) men or women, ii) had personal experience dealing with selected women with breast cancer, iii) able to speak Malay or English, and iv) 18 years old and above.

Of the 30 participants who initially agreed to be contacted, the researcher gave them a further 11 recruitment packs containing an invitation letter and the PIS (see Appendix 10a and 10b, pp.324–332) to be passed to their family members since the family members were not present at the site. For others, the researcher distributed the recruitment packs by hand since they were present at the locations during recruitment. Each woman nominated only one family member. The same recruitment process was repeated for the family members as had been previously conducted for the women with breast cancer. The flow chart of family member recruitment is shown in Figure 4.2 below.



Figure 4.2: Flow chart of recruitment of family members

#### **4.4 Sampling method**

Purposive sampling was used to recruit volunteer study participants who were able to tell their stories of interest under study. Patton (1990) simply points out that all qualitative research designs use purposive sampling. The justification for purposive sampling is that it involves the selection of participants with specific characteristics (Higginbottom 2004). The participants were selected purposefully to fit the study for information-rich data and at the same time to achieve maximum variation, selecting participants based on a wide range of variation in their backgrounds (Polit and Beck 2016), in terms of their disease stage, treatment, decision-making and demographic by recruiting at six different locations.

#### **4.5 Sample size**

In qualitative research, there are no rules for sample size and it should be based on the information needed or research aims set (Polit and Beck 2008). The sample size used in previous qualitative studies on breast cancer in Western countries that employed a narrative method ranged from 8 to 12 participants (Thomas-MacLean 2004; Sadati et al. 2015). A total of 28 people participated, thus giving a variety of decision-making experiences about breast cancer. Ethical approval was granted for this study to be conducted with 15–35 participants.

#### **4.6 Data collection**

Narrative interviews were conducted to gain the participants' stories. The narrative interview “envisages a setting that encourages and stimulates an interviewee or informant to tell a story about some significant event in their life and social context” (Jovchelovitch and Bauer 2000 p.2). Before starting the interview, the researcher reminded participants of what the study was about and the aim of the study, which

was looking for what, when, who, why and how they made the decisions about breast cancer within a specific period of time. Thus, the participants already had pre-conceived ideas about the focus of the interview. Dempsey et al. (2016) stated that having thorough knowledge of the interview questions and topics prior to data collection is crucial. The researcher started each interview with the same narrative script that had been developed with the help from supervisors and already tested during pilot study (see Appendix 11, p.333). The purpose of using this script enable the participants to have the same context of starting the interview. The researcher memorised the narrative script and asked participants at the end of each script, for example, to “share with me your story since you first thought that you may have a problem with your breast?” This broad question allowed scope and flexibility for each participant to tell their story as they wanted and at the same time, the question did not lead to any decision that the researcher would like to hear, thus, it depended on the participant to start to share their stories. During the first part of the interview, the researcher listened carefully to what they were saying and used encouraging sounds (“mmm”, “ha-aa”), head nodding and eye contact in a way that was appropriate. No interruption was made nor guidance given as this may have influenced the direction of the story towards the researcher’s interests, rather than encourage the participants to keep talking until they had nothing further to say. As the interviews progressed, the researcher wrote a timeline and field notes based on each participant’s story. When participants told stories that were of particular interest to the research but not in detail, the researcher wrote key notes, so that further clarification could be sought later through probing. Probing is a technique used by the interviewer aimed at eliciting more useful or detailed information from a respondent (Polit and Hungler 1997). An example of probing in this study, “Can you tell me a little more about the traditional treatment?” or “You mentioned you need “some times”, can you explain what these means are?”

After the initial narrative from the participant, the researcher used the timeline with the participant to check the key events and decision points, which then became a checklist that was used to ensure all of the key events relevant to each of them had been captured. Sometimes, during checking the time lines, some participants had recalled more details stories about the issues. An example of a timeline from one of the interview is shown in Figure 4.3 (see Appendix 12, p.334).

All of the interviews were conducted in an informal, unstructured, face-to-face and conversational style. Most of the interviews took place in the participants' homes through their own choice. Only two interviews were conducted at the participants' workplace. Two of the interviews were conducted jointly with the woman and her family member. In the majority of cases, the women and family member interviews were conducted separately, one after the other, at the same place and on the same day. The interviews with one woman and her family member were conducted at a different place and time. A maximum of two interviews were conducted in one day. The interviews were conducted in the Malay language in the first instance. A total of 16 participants responded to the questions in the Malay language, with 12 responding using a mixture of the Malay and English languages.

Each interview lasted for between 20 minutes and 90 minutes (with an average length of 32 minutes). Narrative interviews can vary considerably in length since they depend on the storytelling of the participant (Holmberg et al. 2015). Written consent was obtained from each participant at the time of the interview. The interviews were audio-recorded with permission, and field notes were taken during the interviews. Background experience as a registered nurse, attendance at interview skills training as well as piloting and practising with colleagues all played an important part in helping the researcher to establish a relationship with the participants and conduct the interviews.

### Field notes

In this study, the researcher wrote field notes concurrently with the interviews, capturing things such as the participant's emotion (e.g. crying, silent moment), body language (e.g. used thumb to show the size of the lump) and the surrounding environment (e.g. the presence of other family members during the interview, setting). Field notes are used to document the timing and demographic details of the interview and any observations and reflections that are made during the interview (Minichiello et al. 1995).

### A reflective diary

The researcher wrote in a reflective diary after finishing an interview and while listening back to the audio recording if necessary. A reflective diary was used to record the private thoughts, emotions and feelings of the researcher and also anything that had been unexpected, surprising or unusual about the interactions during the fieldwork (Allin and Turnock 2007). For example, the researcher reflected on the way the interview had been conducted with the participant so that she could acknowledge any weaknesses to improve for the next interview. Therefore, the use of a reflective diary assisted the researcher in monitoring the process and progress of the data collection and supported the researcher in preparing for the next interview.

## **4.7 Pilot study**

A pilot study was conducted with one Malaysian woman with breast cancer who was recruited through a personal introduction from a friend. The participant was interviewed on the telephone due to distance issues. The purpose of this pilot study was to test and if necessary amend the interview process, transcription and analysis of the data, in addition to gaining confidence in conducting qualitative research. However, nothing was changed after the pilot study since no issues were identified. The

piloting of qualitative approaches can be carried out if “the researcher lacks confidence or is a novice, particularly when using the interview technique” (Holloway 1997, p.121) and to identify any potential practical problems in following the research procedure before the main research begins (Teijlingen and Hundley 2001).

## 4.8 Ethical issues

Ethical issues are important when conducting research involving humans due to the need to safeguard their rights and safety (Parahoo 2014). There are three main ethical issues that need to be considered when conducting qualitative research. The first issue is anonymity. The participants were thus assigned unique codes (e.g. PT1, PT2) and any identifying information (e.g. Town A, Dr H, job title) was either altered or omitted to protect both their identity and setting. The second issue is confidentiality. The researcher must keep private all of the information gathered. The final issue is informed consent, which concerns each participant’s agreement to take part in the research without threat or persuasion and their right to withdraw from the study at any time. The women and family members were provided with detailed written information about the study. This included an invitation letter and information sheets. Moreover, all of these documents had been translated into the Malay language, thus rendering them appropriate for the Malaysian population. Prior to starting each interview, the researcher asked and checked with the participant regarding the consent form.

However, according to Elliott (2005), any research that comprises human subjects requires consideration of the potential impact of that research to all those involved. The researcher is required to ensure that the participants should not be worse off at the end of the research process (Hynson et al. 2006). Therefore, the researcher needs to consider and judge what provisions must be made for the participants’ well-being due

to the sensitivity of the topic being discussed (McIlfatrick et al. 2006). According to Elmir et al. (2011), it is important for participants to feel at ease, safe, and comfortable during the interview, so all the interviews were conducted at a time and location based on the participants' preference. Dempsey et al. (2016) suggested that the environment for interview should be private and free from interruptions, particularly when discussing sensitive issues. However, in this study, some interviews were conducted with the presence of other family members, who were not participants. This was out of researcher's control because the participants gave permission and were not concerned about them being present even though the researcher hinted that the interview should be private.

In this study, the participants were given contact information of the hospital, where the participants were recruited and counselling services if they required further support after the interview. If the participants became emotional or distressed during the interview, they were given more time and if required, the interview was terminated. Some participants appeared upset during the interviews, but they continued talking even though they were given the option to take a break or to end the interview.

In case the participants disclosed information that might indicate serious concern such as harm to themselves or other, the researcher would disclose this information to the appropriate authorities. This would be made known in the PIS. Moreover, the experience as a nurse and having training for interviewing enable the researcher to be sensitive to potential distress among the participants during the interview process.

### Data protection and management

During the time when the study was being carried out in Malaysia, the entire body of documentation, including the consent forms, interview transcripts and field notes, were anonymised and stored in a locked cabinet in the researcher's home. The electronic data, such as the digital voice recordings of the interviews, were transferred to and kept on the researcher's laptop with a security password as soon as possible after each interview was completed. The researcher also stored the electronic data in personal file space on the University of Southampton server via a virtual private network from Malaysia. Only the researcher and supervisory team were able to access these data. The researcher kept the digital voice recordings and laptop in the researcher's car boot while travelling to and from the researcher's home. Any personally identifiable data, such as the participants' names and home addresses, were destroyed following their participation or in the event they decided not to participate in the study.

The consent forms were transported to the University of Southampton as securely as possible and stored in a locked office. The researcher kept the laptop with her at all times while returning from Malaysia to the University of Southampton. The researcher kept all of the relevant data in accordance with the University of Southampton research data management policy, which also requires that all significant research data be kept for a period of ten years after the study has finished (LibGuide@Southampton 2016).

### Ethical approval

This study underwent a peer-review and ethical approval process within the Faculty of Health Sciences, University of Southampton. After the Faculty ethics board had approved the study protocol, the researcher applied for ethical approval in Malaysia. This study was conducted in

two different hospitals in Malaysia. Therefore, it required approval from the Ministry of Health Research and Ethics Committee, public hospital ethics committee and the teaching hospital Medical Ethics Committee. Firstly, the researcher registered with the National Medical Research Registry of the Ministry of Health (NMRR) and submitted the study protocol to the National Institute of Health for their review and approval. Then, the researcher had to attend a meeting with the public Hospital Research Review Committee to present and defend the proposal. The committee requested that the researcher add one local supervisor, and it was agreed that this would be an oncologist working at the public hospital. The purpose of the local supervisor was to act as a reference person who would be able to guide and help the researcher if anything should happen in the hospital during the data collection process. At the same time, the researcher submitted an online application to the teaching hospital Medical Ethics Committee for their approval. The proposal was approved and a breast surgeon agreed to be a local supervisor for the teaching hospital. The flow chart of ethical approval in Malaysia is shown in Figure 4.4 (p.96) and for the approval documents in Appendix 13 (pp.335–337).

## 4.9 The process of data analysis

The research aim is to understand the decision-making experiences of women with breast cancer and their family members, in addition to how they had been constructed. Narrative analysis by Riessman (1990) was chosen to guide the data analysis. The rationale for selecting Riessman's approach was because it analyses both the content and structure of talk. This type of analysis enables an understanding of what the participants are trying to say and how personal meanings in the context of decision-making are constructed.

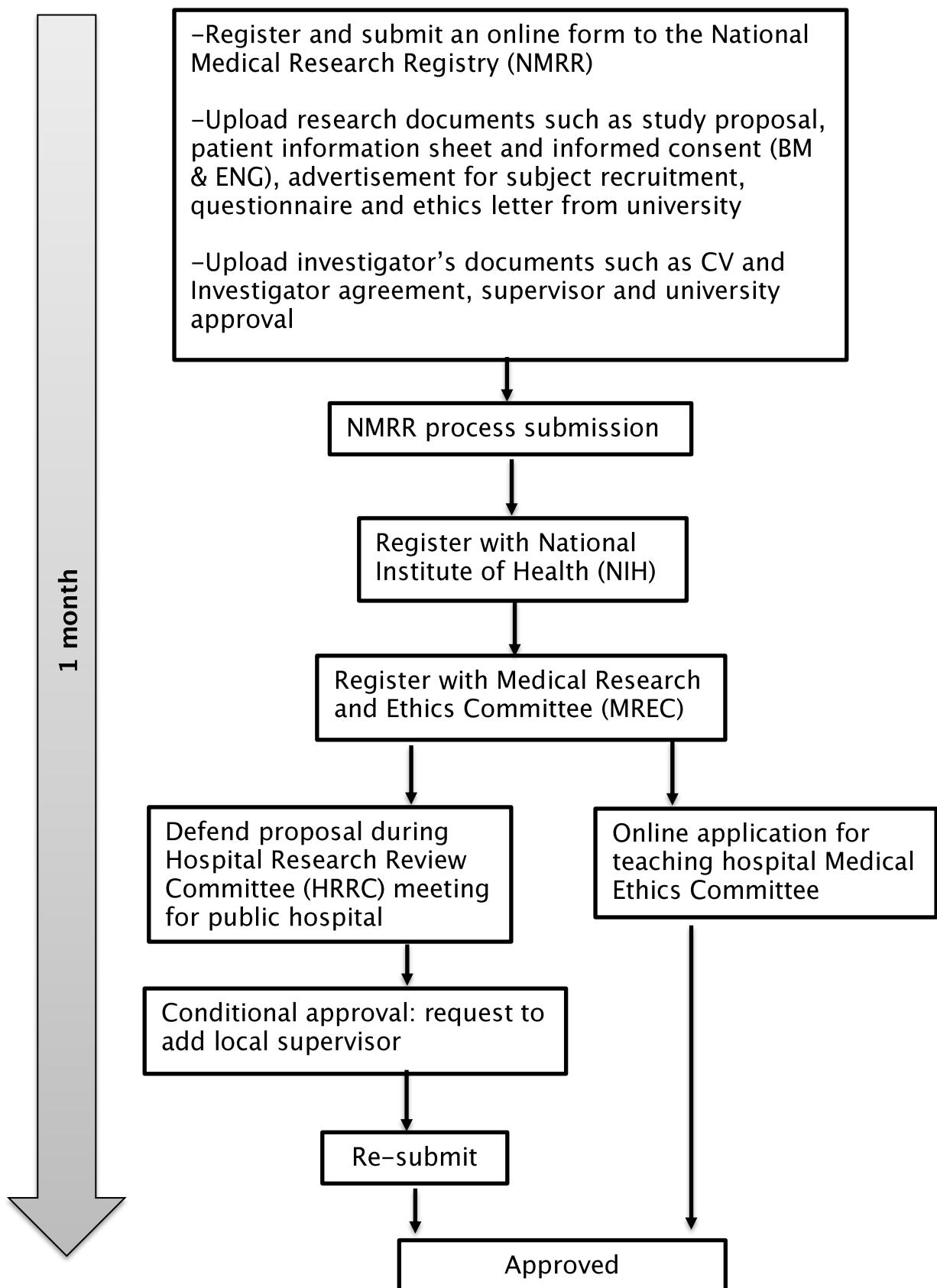


Figure 4.4: Flow chart of ethics approval process in Malaysia

The data processing comprised three stages: 1) verbatim transcription, 2) analysis and 3) interpretation.

### **Stage 1: Verbatim transcription**

All of the interviews were transcribed verbatim in the language used by the participants during the interviews. Verbatim transcription refers to the process of reproducing spoken words, such as those from an audiotaped interview, into written text (Halcomb and Davidson 2006). Riessman suggested that the transcribing process begins with a first draft comprising a rough transcription of the entire interview to “get the words and other striking features of the conversation such as crying, laughing or very long pauses” (Riessman 1993, p.56), episodes and turning points in the plot (Riessman 2008). This is followed by a re-transcribing of selected portions for detailed analysis. However, there are no universally agreed rules for representing speech as written text (Riessman 1990). Riessman also states that the effort involved in transcribing is to strike a balance between providing a readable transcript and including the detail necessary to facilitate a narrative analysis. Therefore, Riessman’s (1990, p.245) suggestions were adopted as a guide in the transcription process. Punctuation marks are used when intonation clearly marks the end of an utterance, such as a full stop, in addition to a question mark or quotation marks indicating a conversation with someone. Italics indicate a marked increase in loudness and/or emphasis. A dash is used to indicate a break-off, interruption or overlapping speech. Pauses are distinguished as (p) for a pause of 3 seconds or less and (P) for a pause of more than 3 seconds. Non-lexicals are interviewer utterances during the narrator’s speech and are enclosed in parentheses and indicated by / (for example, /: mmm). The lines are numbered for ease of reference. Each transcript was composed in a Word document, with participant anonymity maintained as described earlier in Ethical issues.

The transcription documents were re-read a number of times to check their accuracy against the audio files using Audacity transcription software. This software enables digital audio files to be played back while controlling the speed and volume, in addition to the ability to rewind as required. All of the transcriptions were carried out by myself. See Figure 4.5 below for an example of a Malay transcript.

1 PH-PT4-M-S4-CT

2 P.: Kak dah biasa dah cerita. Memang dengan doktor pun itu lah ceritanya.

3 Mula-mula, mula-mula kak sakit, mula-mula kak sakit lepas kak bersalin ko,

4 anak kak ni lah (/: ok). Mula mula tu, memang kak sedar ada ketulan akak

5 punya bawah putting (/: ok). Lepas tu ingatkan aaa susu. Ingatkan susu beku

6 tau (/: ok, ha-ah). Lepas tu, lama-lama aaa lama-lama tu. Mula-mula kak picit-

7 picit dia hilang. Pastu kali kedua, dia ada pulak (/: ok). Hah yang tu memang

8 tak hilang (/: ha-ah). Dia tak hilang. Lepas tu lama jugak kak, kak biarkan.

9 Ingatkan, kot kot nati hilang sendiri ke apa kan (/: hm-mm). Lepas tu, suami

10 kak suruh pergi hospital kan (/: ok). Bagitahu dia. Suruh pergi hospital.

11 Bukan pergi hospital lagi. Pergi klinik swasta dulu (/: ok).

12 Dia buat ultrasound tu. Pastu dia kata, memang doktor tu kata ‘Ni memang

13 tok comel, memang tak lawa ni’ dia kata (/: mmm). ‘Mungkin kanser’. Dia,

14 dia suspek kanser la (/: ok). Lepas tu dia buat surat, pergi rujuk. Suruh rujuk

15 ke, hospital lah suruh jumpa pakar kat Town P (/: ok). Pastu pergi hospital P

16 (nama hospital). Doktor tu pun dia buat, buat mammogram, buat ultrasound

17 lagi (/: mmm). Kemudian lagi dia amik biopsy (/: ok). Lepas tu, dia ambil

18 semua sample tu dia buat. Akhirnya, dalam bulan, dua ribu, dua ribu empat

19 belas, bulan Julai ko Ogos, kak disahkan kanser (/: mmm). Hah kak memang

20 ingat lagi pada masa tu, doktor H (nama doktor) (/: mmm). Jumpa doktor

21 pakar lah (/: ok). Pakar bedahkan (/: mmm). Memang dia suruh bedah lah (/:

Figure 4.5: Example of a Malay transcript

### Translation

For the purpose of discussion with supervisors, three Malay transcripts were translated into English. After translation, there were certain sentences in the Malay language that had either a different meaning or a potentially different interpretation, especially when the participant was talking in a local dialect. For example, when a participant spoke in the Malay language, “*Ni memang tak comel, memang tak lawa ni*” (PT8).

This Malay sentence can have two different meanings, depending on the context:

- i. *this is not beautiful, not pretty* – used to refer to a thing that is not beautiful, such as cloth.
- ii. *this is not good, not fine* – used to refer to something that is considered bad or negative.

To avoid any confusion or misinterpretation of what the participants were saying, it was important that the data analysis was conducted in the Malay language. According to Riessman (2008), to find equivalent words in English for referential content is never easy in any translation. Therefore, after completing the analysis, the Malay transcript was translated into English for all selected excerpts.

The Malay language does not feature specific pronouns as in English that are used when referring to a specific gender while talking. This therefore made it difficult to determine the gender of the person being mentioned if the researcher did not ask for further clarification. Therefore, in terms of writing, the researcher used s/he, as in the example below, to illustrate that the gender could be either male or female.

PT10 said:

The doctor said, “It’s nothing. Lymph nodes only”. S/he gave a medicine. S/he gave an antibiotic.

In terms of culture, Malaysian people tend to acknowledge other society members in a friendly manner by using non-formal terms such as uncle, aunty, brother or sister. For example, the doctor called the patient aunty rather than her real name of Mrs PT1. This would commonly occur,

without considering the religion or ethnicity, and is illustrated in the example below.

PT1 said:

Then, the doctor said, “You cannot be like that, aunty”, the doctor said. “You cannot be like that aunty. It is dangerous”,

## Stage 2: Analysis

In general, the narrative analysis is not easily defined since there are multiple approaches to analysis that have been developed within different disciplines and which have different theoretical underpinnings (Benwell and Stokoe 2006). However, one method of narrative analysis that has gained popularity among narrative scholars is the work of William Labov and Joshua Waletzky (Riessman 2008). They presented their structural analysis of narrative with a precision capable of explaining the organisation of a story in chronological order. The only issue is that the approach is not effective for a complicated story (Riessman 2008). This refers to a situation where the teller does not simply tell a story from start to finish, but rather jumps around from one point to another. I faced the same situation in this study, in which not all of the participants told their story about breast cancer decision-making in chronological order. At times, talking about one issue would trigger memories of other experiences that the participants considered important to include in the stories they were sharing. Thus, in this study, I chose narrative analysis as proposed by Riessman (1990) to guide my data analysis.

Riessman (1990) did not provide any clear-cut or specific steps for conducting data analysis. Therefore, it is not an easy task to conduct this type of analysis as a novice researcher. However, I persisted in applying Riessman’s approach to the analysis, interpretation and

presentation of my data based on my understanding of her assumptions of narrative research, recommendations and the way she conducted her analysis. Riessman (1990) suggested that it is important to pay close attention to talk, including the structure and the images it invokes, and its content. This means that both the content and structure of talk are important criteria in narrative analysis. Riessman (1990, p.116) analyses her text “by attending to longer stretches of talk, rather than to specific complaints ... to uncover how individuals give meaning to the events that have happened to them”. This means that the process of data analysis should be conducted by understanding the whole story rather than focusing on a certain part of the story. I acknowledge that for the purpose of this thesis, my focus was on decision-making experiences among women with breast cancer and their family members, but I still read and tried to understand the whole stories as an integral part of the analysis process. This is because the whole of the story is still relevant due to the fact that the participant has chosen to tell it in the way they have.

After completing the transcription process, the transcripts were read and re-read several times for the purpose of familiarisation and to gain a basic understanding of the participants’ stories as a whole. Any ideas and thoughts I had about the participants’ stories were written in a separate document, which would later help to inform my analysis. Then, I wrote a brief vignette of each participant.

Riessman (1993) recommended beginning the analysis with the structure of the narrative to avoid the tendency of reading a narrative simply for content. She also stated that individuals do not merely report events but put them together into a narrative sequence to gain understanding [ibid]. Therefore, as the first stage of data analysis, I began with the structure of each narrative. I endeavoured to examine the sequence of the events that had taken place. The purpose of the

structural analysis was to determine how a participant had made a connection from one event to another event and to then try to understand why the participant had structured their story in that way. After reading the transcripts, I realised that there were participants who had merely listed the events without any explanation and that I had missed asking them for further details on the matter during the interview. As such, there was limited knowledge in certain parts of the stories and I wrote about all of the limitations in my reflective memo. Next, I compiled the sequence of events in tabular form, which made it easier to refer back to later.

The second stage of data analysis is to consider the content of the narrative. Riessman (1990) stated that the content informs what each narrative is about. At this stage, I carefully considered the following aspects: What has the participant said? What is the participant's story when s/he talks about decision-making related to breast cancer? What is the decision? Who made the decision? What are the turning points, key features, people and events that influenced the decisions? These were all questions that I felt related to my research objectives and which I retained in my mind. I continually made notes as further ideas or answers came to my mind throughout the whole process. However, I acknowledge that this process was challenging as I sometimes struggled to understand what each participant was attempting to say, especially when he or she spoke in the local dialect. Therefore, referring to a Malaysian colleague who is fluent in the local dialect helped me to deal with this issue. As a way of organising, the example some part of the narrative table that I had previously created was expanded for each participant (see Table 4.2 below). The complete table was shown in Appendix 14 (p.340–351) which also represent a full analysis one of the participant in this study. Each of the participants was analysed based on MPTT, to give overall picture of participants' journey and to identify the

time line and contributing factors within the specific period of time (Appendix 15, p.352–365).

Table 4.2: The example part of the steps in an individual's narrative

Sequence	What are the decision	Who made the decision?	What are turning point, key features or event?	Accounts	Memo
Pain	Go to clinic	PT8	Pain	So, from the end of two thousand fifteen [2015], I felt, pain, at muscle areas under this armpit (/: ok). So, I thought because of menstrual or because of shaved. <u>So</u> , I went to the ordinary clinic taking a medication.	Is it pain not serious because she relate it with menstrual and shaving? What is association between pain under armpit with menstrual or shaving? <u>Not assume BC?</u>
Clinic	Go to hospital	Doctor referred & PT8 followed	Doctor unsure about PT8's condition	It seemed okay. Then it [pain] happened again. Three times it happened. So after it happened for a <u>third</u> time, the doctor asked me to go to, a hospital, referred to the hospital.	Standard procedure to refer patient to hospital if the doctor in the clinic unsure about the patient's condition.
Hospital	Undergo further investigation	Doctor suggested & PT8 followed	Doctor unsatisfied with the diagnostic result,	<u>So</u> when I went to the hospital, firstly the doctor did an ultrasound. The doctor also diagnosed the same thing, muscles aches, because at that time the ultrasound result was	How the doctor curiosity led the actual diagnosis although PT8 felt that the lump was

Finally, I came to the stage of interpretation. Although I list interpretation as the final process, I acknowledge that my interpretation began when I first listened to the audio recording, read the transcripts and started writing memos. At this stage, I looked at more specific aspects of narrative devices as Riessman (1990) emphasises the need to pay attention to language, causality, temporality and contextual aspects. Therefore, my interpretation was not only about "what the participant has told me", but also considered "how the participant tells the story". For example, how do women with breast cancer and their family members present themselves during the decision-making process? How do they present other people's characters in their story? How do they make connections between events from one period of time to another period within their stories.

Narrative devices such as the use of imagery, metaphors, idioms and the repetition of words or phrases within their stories provided clues for understanding how the women perceived their breast cancer experiences. The following example demonstrates how one participant employed the use of metaphor while speaking in this study.

PT7 said,

*“Nasi sudah jadi bubur”* (The rice has become porridge).

The rice has become porridge is a Malay language proverb that carries a similar meaning to the English proverb “there is no point crying over spilt milk”.

Additionally, Riessman (1990) stressed the aspect of language such as “word choices, pauses, expressive phonology” (p. 79) and the structural function of specific clauses that refer to the social understanding. Therefore, I did not ignore these linguistic elements that had a particular meaning, especially when they related to the Malaysian socio-cultural context. For example:

PT8 said,

*“Kita buat semua tu. So, bila kita pergi surgeri tu, kita dah tak ada rasa sangkut kat mana-mana. Kita rasa lega”*. (I did all that. So, when I underwent that surgery, I did not feel trapped at any point. I felt relieved.)

Meaning:

This phrase in Malaysian culture was interpreted as the participant explaining that she would like to fulfil or do the things that she wanted to do, meaning she would have no regrets if anything were to happen to her after the surgery.

This was understood by the researcher as a fellow member of the Malaysian culture.

PT9 said, “*Dah kita tahu kanser ni, kita ingat apa je kan. Kita tau apa akibatnya*” (Since I knew it was cancer, I could only think about that. I knew the consequences.)

Meaning:

In this context, the participant used the words “that” and “consequence” in reference to death. In Malaysian culture, people tend to speak indirectly about some subjects, such as death, as opposed to being explicit.

I also acknowledge that some sections of the participants’ narratives seemed irrelevant to the topic of the research questions, although the participants’ structuring of their narrative in this way may actually be an important narrative device. Narratives are told the way they are for a reason and they need to be analysed with this in mind, thus valuing these sections of narrative as being a mirror to the underpinning meaning of the narrative. For example, one of the participants often spoke about her friends and what had happened to them. At first, I found myself assuming that she was talking out of topic but, on later analysis, I was able to consider this issue from another perspective. She was actually attempting to make sense of her current condition and experiences as compared to other people.

By going back and forth between the transcript, listening to the audio recordings, field notes, memos and the process of data analysis, I was able to develop parts of the narrative based on my understanding and interpretation, as well as give a subtitle to each selected narrative by using the participants’ words. Initially, I believed this analysis process to

be straightforward. However, this was not necessarily the case, especially when seeking an answer for a reason and the meaning that underpinned the narrative. Sometimes, I tried to stand back from my ideas and held discussions with my Malaysian colleagues to make sure that my interpretation of a participant's story was accurate and within Malaysian people's perspectives and culture.

I acknowledge that some of the stories were quite straightforward and easily analysed, with the meanings quite clear in the examples given by the participants. Some of the stories had multiple interpretations based on my understanding from different perspectives. However, if I had difficulty understanding the stories, I would at times need to leave the participant's account for a while and return to it at a later time. Gubrium and Holstein (2009) suggested that the researcher is required to step out of the narrative text and to ask questions such as 'Who produces particular kinds of stories, where are they likely to be encountered, what are their purposes, and consequences, who are the listeners, under what circumstances are particular narratives more or less accountable, how do they gain acceptance, and how are they challenged?' (p.23).

After I had completed all of the individual analysis, a search for commonalities across narratives was undertaken to look for patterns across the experiences of the two groups of participants, women with breast cancer and their family members regarding their decision-making experiences. Since this study used the MPTT, the four concepts of interval (appraisal, help-seeking, diagnostic and pre-treatment) became the main themes. Next, the narrative themes within each interval were formulated by identifying the phrases or plot from the stories. Some of those narrative words and phrases are illustrated in Table 4.3 (p.107).

Table 4.3 Examples of participants' excerpt leading to narrative themes

Excerpt	Plot	Sub-themes	Narrative theme	
While taking a shower, I felt the lump ... Immediately, I told my husband. We went straightaway to see a doctor in a clinic. (PT11)	Symptom → told husband → see doctor	Women and family members who sought immediate medical opinion on finding breast changes	Appraisal	
My wife told me that she had found a lump when she took a shower. Immediately, I took her to see a doctor at the clinic (FM11)	Symptom → see doctor			
I was having a shower. I felt a small lump, but no pain at all. ... I only thought about breast cancer because my mother had it ... After that, I quickly told my husband, and he said, "Let's go to the clinic, see the doctor" (PT7)	Symptom (genetic) → told husband → see doctor			
When my wife told me that she had found a lump in her breast, I was worried, because her mother had previously had breast cancer. But I always prayed that she would not have the same disease. After that, I asked her to see a doctor immediately, to check (FM7)	Symptom → see doctor			
It happened again in two thousand sixteen. I felt the lump again ... I went to see the doctor near to our house (PT5)	Symptom (recurrent) → see doctor			
When I took a shower, I felt a hard lump ... I just observed to see how it would progress. After that, as the lump was getting bigger. I asked my daughter "What is	Symptom → decided to observe → symptom changes (getting bigger) → told daughter → see doctor	Women who informed family members of breast changes		

happening to me? She said, "We should go to the clinic." (PT3)		after the changes failed to resolve
I felt like, like my breast was firm ... but no lump. It was not painful. I thought it was normal, yeah maybe due to a menstrual cycle. After that, I observed, and it was still swollen ... After that I told my husband (PT6)	Symptom (menses)→decided to observe→ no changes → told husband → see doctor	
At first, PT8 had said that she felt pain under her armpit ... Every night, I massaged her, but she was still in pain ... After that, finally I said, "Uish, it is already a week, the pain is on and off." So, I told her, "I feel uneasy. We have to check." (FM8)	Symptom →massaging → no changes → see doctor	
I noticed a lump under my nipple ... I thought that it was a milk clot because I was breastfeeding ... After that, I tried squeezing it, it then disappeared. The second time, it appeared again. This time, it did not disappear ... after a while, I, I ignored it, thinking, assuming that it would dissolve by itself or whatever ... I told my husband... asked me to go to hospital (PT4)	Symptom→ squeeze→ disappeared → symptom (recurrent) → not disappeared→told husband → see doctor	
I touched my breast. I felt like a lump ... but sometimes I felt it, sometimes I did not. I kept feeling the lump ... The next morning, I told my husband (PT2).	Symptom (confused) →kept felt → told husband→ see doctor	

Narrative themes showed a plot of the story rather than simply presenting a short element of meaning. Therefore, some part of the narratives had lengthy extracts to illustrate how a narrative theme was identified. Reviewing the narrative themes also based on the MPTT, which relates to relevance of the themes in answering the research question. In establishing relevance theme, the judgement was made when the participant demonstrating a particular issue as important or when other participants made similar comment to that issue. Taking the example of social cultural template regarding symptom for breast cancer was a feature discussed in different ways by some women in the study, which, alongside other aspects of their story, led to development of narrative subtheme such as “women to tell family members of breast changes after the changes failed to resolve” that happened in “appraisal interval” theme.

## **4.10 Rigour**

The concept of rigour in qualitative research continues to be a challenge and a topic of ongoing debate among qualitative researchers (Cypress 2017). Davies and Dodd (2002) refer to rigour as the reliability and validity of qualitative research. However, several researchers have argued that reliability and validity cannot be applied to qualitative research because they were designed for quantitative research (Rolfe 2006). Thus, a new term, trustworthiness, was proposed from the work of Lincoln and Guba (1985) to replace the concept of reliability and validity. Trustworthiness in qualitative research means “methodological soundness and adequacy” (Holloway and Wheeler 2010, p.302). Trustworthiness consists of four concepts, namely credibility, transferability, dependability and confirmability.

The concept of credibility represents the confidence in the truth or validity of the research findings (Rebar et al. 2011). It means that the

findings at least represent plausible information from the participants' original data and are a correct interpretation in line with the perceptions of the people under study (Graneheim and Lundman 2004). One method of demonstrating credibility is member-checking (Tobin and Begley 2004). Member-checking means returning the research findings to the participants for them to evaluate the accuracy and credibility of the account (Creswell 2013). However, this seemed to contradict the idea of narrative research, the aim of which is to try and understand the meanings experienced by people rather than discover the truth of the stories (Polkinghorne 2007). Sandelowski (1991) claims that narratives are placed in a "hermeneutic circle of (re)interpretation" and can change from telling to telling. This means that the stories are fluid and the meaning of an experience might change over time. Riessman (1993) reported that "In the final analysis, the work is ours. We have to take responsibility for its truths" (p.67). Therefore, member-checking may not necessarily be considered as a hallmark against which to assess credibility in this study.

Moreover, Morse et al. (2002) stated that the researcher needs to make their analysis more descriptive and less interpretive to ensure the participants are able to clarify their perspective. In this study, the researcher is required to interpret beyond the original data and provide meaning that may be unrecognisable from the participant's perspective. Holloway and Wheeler (2010) reported some problems with member-checking, such as the perceptions of the participants may change over time and the researcher and participant may have different perspectives.

The concept of transferability considers whether the findings in one context will have the same meaning if they are transferred to similar circumstances (Leininger 1994). Bitsch (2005) suggested that thick description and purposeful sampling could be applied to show that the findings in qualitative research can be applicable to other contexts. A

detailed explanation of the methodology and methods used in this study has been presented in Chapters 3 and 4. The technique of thick description in a qualitative study can contribute to the trustworthiness of the study (Loh 2013).

The concept of dependability indicates that the findings of the study should be consistent, whereby the reader should be able to evaluate the adequacy of the analysis and the context of the research (Holloway and Wheeler 2010). Dependability can be achieved via an audit trail (Tobin and Begley 2004). An audit trail is a clear description of the research steps and decisions taken throughout the study (Carcary 2009). An audit trail was kept in this study because it was necessary to maintain a track of the steps and/or changes throughout the processes of data collection, analysis, interpretation and writing up of the findings. This audit trail was primarily recorded in the research diary together with the researcher's reflections on the research process, meeting with the participants, challenges, thoughts, feelings, assumptions and interpretations.

The concept of confirmability refers to a judgement on how the interpretation of the findings and conclusions were obtained from the data and were not based on the researcher's imagination (Tobin and Begley 2004). Cypress (2017) stated that the requirement for confirmability can be met through the use of an audit trail and reflexive journal. Reflexivity refers to an assessment of the effect of the researcher's background, perceptions, interest (Ruby 1980) and personal history (Krefting 1991) on the qualitative research process. In this study, I acknowledge my reflexivity and reflection in Chapter 8, (see section 8.5, pp.253–258).

Riessman (1993, p.68) suggested three strategies for determining the trustworthiness in her narrative research: a) describing how the

interpretations were produced; b) making visible what the researcher did, and c) making the primary data available to another researcher.

The interpretations of the findings in this study were based on the participants' interview transcripts and audio recordings, along with the reflective diary and field notes taken during the interview process. The research considers these to be credible when they present a description of how interpretations were made during the inquiry (Koch 1998). As a researcher, I tried to analyse and convey to the reader what the experiences of life were like for the participant in question, but I also brought my own set of intentions to the analysis. This acknowledges that my personal background may have had an influence on the interpretation process. Frequent discussions with Malay-speaking colleagues, especially about the meaning of sentences in the context of the language and Malaysian culture, improved the accuracy of interpretation. Moreover, the study benefitted from access to two experts in qualitative research, in the form of the supervisors, to review and discuss the identified themes and use of verbatim quotes as evidence to underpin the interpretation.

The research process, starting from the background of the study through to the interpretation process, is thus explained in detail in this thesis. Additional information is attached in the relevant appendices.

Since this is a PhD project, the researcher was obliged to abide by the ethical requirement to keep all of the primary data confidential. Only the supervisory team were able to access the data.

# Chapter 5: Introduction to the participants

## 5.1 Introduction

This introductory findings chapter provides an overview of the women and family members who participated in the study, outlining the emerging themes that will be discussed more fully in chapter 6.

## 5.2 Women with breast cancer and their family members

Fourteen women were interviewed from two hospitals in Malaysia. All of the women had already undergone their first treatment for breast cancer, such as surgery, chemotherapy or radiotherapy. However, those undergoing chemotherapy and radiotherapy had yet to complete their cycle. The same number of family members were interviewed after the women with breast cancer agreed for them to be included in this study. These individuals had a variety of familial relationships with the women with breast cancer, including husband, mother, daughter, son, sister and niece.

This section summarises the backgrounds of the women and their family members who participated in the study, focusing on their individual circumstances and the decisions that they made.

### PT1

PT1 is a forty-nine-year-old Malay woman who works at a sawmill. She lives with her daughter and two grandchildren. PT1 found a breast lump while taking a shower. Initially, she decided to observe her lump because it was painless but then went to a government-run clinic one to two weeks later to have it checked after having talked to her husband. She was subsequently referred to a hospital for further investigation,

after which she was diagnosed with stage one breast cancer. At this point, she refused surgery; instead, she attempted to control her diet by changing her eating habits as she believed that certain foods would affect her breast cancer. She had a mastectomy after initially having delayed this treatment by around three months. She has a family history of breast cancer, with her late sister having stage four breast cancer.

### FM1

FM1 is a forty-nine-year-old Malay man who works on a construction site and is the husband of PT1. He did not live with his wife because he worked in another state, but he usually returned home once a month. He knew about the breast lump when his wife told him about it and asked her to have it checked by a doctor. Since he worked in a different state, he communicated with his wife by phone regarding her health. Upon her being diagnosed with breast cancer, he was shocked and immediately returned home. He decided to encourage his wife to undergo treatment after having met the doctor when she refused the surgery. He did not force his wife to undergo treatment but rather provided emotional support. He was happy when she finally agreed to undergo surgery after a few months of encouragement.

### PT2

PT2 is a fifty-six-year-old Malay woman and retired teacher. She lives with her husband and daughter. PT2 found a lump in her breast while lying in bed. She attended a private clinic the next morning, but the doctor could not detect the lump. A year later, she went directly to the hospital when she realised that her breast was getting bigger. She underwent several investigations prior to being diagnosed with stage two breast cancer and undergoing a mastectomy. She has no family history of breast cancer.

## FM2

FM2 is a fifty-seven-year-old Malay man and retired teacher. He is PT2's husband. When his wife told him about her breast lump, he took her to the clinic, but the doctor said his wife was fine. A year later, his wife told him that her breast was getting bigger. They went directly to the hospital and his wife underwent several investigations prior to being diagnosed with breast cancer. He agreed with and supported his wife's decision to undergo surgery.

## PT3

PT3 is a sixty-two-year-old Malay housewife. She has lived with her daughter since her husband passed away two years ago. PT3 found a breast lump while taking a shower but did not tell anyone about it for two months. The lump was painless, but she attended a government-run clinic after telling her daughter about it. She told her daughter because she was worried when she realised the lump was getting bigger. On the same day, she was referred to a hospital for further investigation. She was subsequently diagnosed with stage three breast cancer, but she refused the suggested surgery. She had a mastectomy after delaying treatment for about three months. She has a family history of breast cancer, with her late younger sister having had stage four breast cancer.

## FM3

FM3 is a twenty-eight-year-old Malay woman who works as a clerk and is PT3's daughter. She came to know about the breast lump after her mother told about it. She did not know that her mother had already had the breast lump for almost two months. Thus, she felt and looked at her mother's breast. She was shocked to see the inverted nipple and immediately took her mother to the clinic. On the same day, they went to hospital after the doctor referred her mother for further investigation.

Her mother underwent several investigations to confirm the disease. When her mother was diagnosed with breast cancer and refused surgery, she was worried; however, she continued to support her mother until she felt ready for surgery.

#### PT4

PT4 is a forty-six-year-old Malay woman who works as a teacher. She lives with her father and a daughter. She had no family history of breast cancer but found a breast lump after having her baby, which she thought was clotted milk because she was breastfeeding. She did not tell anybody about the breast lump for around a year because the lump was painless and did not affect her breastfeeding process. She attended a private clinic after telling her husband about the breast lump and was later referred to hospital for further investigation. Subsequently, she was diagnosed with stage two breast cancer but refused the surgery suggested by a doctor. Instead, she bought supplements and tried traditional treatments, visiting five traditional healers. Nearly two years later, she suffered a severe cough and backache to the point where she was no longer able to cope with her symptoms, so she returned to the hospital and was diagnosed with stage four breast cancer with lung and liver metastasis. At that time, the doctor suggested chemotherapy to shrink the cancer, but she still refused and requested sick leave for a week. Finally, she agreed to start her chemotherapy as she promised with the doctor.

#### FM4

FM4 is a forty-eight-year-old Malay man who works for an oil company. He is PT4's husband. He returned home after three months spent working at an oil site and his wife told him about a breast lump she had had since last year. He took her to the clinic and she was later referred to hospital for further investigation. When the doctor said his wife had

breast cancer and she refused surgery, he went along with her decision and supported her attempts to find an alternative treatment. He bought a variety of supplements and took his wife to see traditional healers to treat her breast cancer. He agreed with and supported his wife's decision to undergo chemotherapy.

### PT5

PT5 is a fifty-three-year-old Malay housewife and lives with her husband. PT5 discovered a breast lump after rubbing her chest due to difficulty in breathing. She went to a private clinic the next day with her husband and was later referred to hospital for further investigation. She was diagnosed with a benign tumour and the doctor withdrew the fluid inside the tumour after she refused to have it removed. Two years later, the breast lump appeared again. She went to the hospital and underwent several investigations before being diagnosed with stage two breast cancer. She refused surgery, instead visiting three traditional healers to treat her breast cancer. Six months later, she again had difficulty breathing and felt unable to cope with her condition, so she decided to have a mastectomy. She has no family history of breast cancer.

### FM5

FM5 is a fifty-nine-old Malay man who is retired from a telecommunications company and is PT5's husband. When his wife told him about the breast lump, he took her to the clinic. His wife was subsequently referred to hospital and underwent several investigations. His wife was diagnosed with a tumour but refused to have it removed, and he went along with her decision. When the doctor withdrew fluid from inside the tumour, it disappeared, only to return two years later. They went straight to the hospital and his wife underwent several investigations. At that time, the doctor said that his wife had breast cancer and he felt shocked. When his wife refused the surgery

suggested by the doctor, he went along with her decision. Later, he supported his wife's attempts to try alternative treatments and they met with three traditional healers to treat the breast cancer. However, she experienced difficulty breathing and he immediately took her to hospital, where she decided to undergo surgery.

### PT6

PT6 is a thirty-five-year-old Chinese woman who works as a clerk. She lives with her husband and a daughter. PT6 felt her breast was firm and thought it was related to her menstrual cycle. She went to a government-run clinic three to four weeks later with her husband to check her breast and was referred to a hospital for further investigation. She was diagnosed with stage three breast cancer and started chemotherapy. She has no family history of breast cancer.

### FM6

FM6 is a thirty-eight-year-old Chinese man and self-employed. He is PT6's husband. His wife told him about her breast firmness and he took her to the clinic. His wife was referred to the hospital and underwent several investigations prior to being diagnosed with breast cancer. He supported her decision to undergo chemotherapy.

### PT7

PT7 is a twenty-eight-year-old Indian woman who works as a housekeeper and lives with her husband. PT7 found a breast lump while taking a shower. She told her husband and they went to a private clinic the next day. She was referred to hospital for further investigation. She was diagnosed with stage three breast cancer and started chemotherapy. She has a family history of breast cancer, with her late mother having had stage three breast cancer.

### FM7

FM7 is a thirty-year-old Indian businessman and PT7's husband. When his wife told him about her breast lump, he took her to the clinic. His wife was referred to the hospital and underwent several investigations. When she was diagnosed with breast cancer, he supported her decision to undergo chemotherapy as his mother-in-law had also had similar treatment.

### PT8

PT8 is a thirty-two-year-old Malay woman who works as a banker. She lives with her husband and two sons. PT8 had experienced intermittent pain under her armpit for about a week. She attended a private clinic with her husband three times in one month and was diagnosed with muscle ache. Later, when there was no abatement in her symptoms, she was referred to hospital for further investigation. After undergoing several investigations, she was diagnosed with stage three breast cancer with lung metastasis. Initially, she refused surgery as she needed more time to reflect on her diagnosis, during which time she made lifestyle changes, controlling her diet and becoming more physically active. She tried alternative treatments such as traditional treatment, Islamic treatment and dietary supplements in a bid to treat her breast cancer, but she had a mastectomy after about four months. She had no family history of breast cancer but had suffered from a fibroadenoma since university, thus predating the breast cancer. She also had a previous history of benign breast lump removal surgery, which she had undergone three times.

### FM8

FM8 is a thirty-seven-year-old Malay man who works as an executive. He is PT8's husband. One day, his wife complained of pain under her armpit, so he massaged her every night for a week, eventually taking her

to the clinic when the pain did not go away. At that time, his wife was diagnosed with muscle ache and experienced intermittent pain. They returned to the clinic and were subsequently referred to the hospital for further investigations. When his wife was diagnosed with breast cancer, she refused surgery and he went along with her decision. Then, they decided to try alternative treatments such as dietary supplements, Islamic and traditional treatment. He was also aware that his wife had had previous surgeries to remove benign breast lumps, but he had not expected the lump to be breast cancer. Finally, his wife underwent surgery after a four-month delay.

### PT9

PT9 is a thirty-four-year-old Malay woman who works as an administrative assistant. She lives with her husband and a daughter. PT9 found a breast lump while taking a shower. She went to a government-run clinic two days later with her husband to have her breast checked. She was referred to hospital for further investigation before being diagnosed with stage three breast cancer and commencing chemotherapy. She has a family history of breast cancer – her aunt.

### FM9

FM9 is a thirty-four-year-old Malay man who is self-employed and PT9's husband. He knew about the breast lump after his wife told him about it and he immediately took her to the clinic. Later, his wife was referred to the hospital for a further check-up and underwent several investigations to confirm the disease. When the doctor diagnosed his wife with breast cancer, he just followed and supported his wife's decision to undergo hospital treatment.

### PT10

PT10 is a fifty-two-year-old Indian woman who is a housewife. She lives with her husband. PT10 felt her breast was firm. She went to a government-run clinic the next day with her husband and the doctor said that it was a problem with her lymph nodes. Within four to five months, she went back to the same clinic when she realised that the breast was getting bigger. Then, she was referred to a hospital for further investigation, prior to being diagnosed with stage three breast cancer and beginning chemotherapy. She has a family history of breast cancer, with her aunt having passed away a few years ago.

### FM10

FM10 is a twenty-eight-year-old Indian man who works at a publishing company and is PT10's son. His mother told him about her breast cancer diagnosis, but he was not aware of the previous changes in her breast. He supported his mother's decision to undergo chemotherapy by looking for information about chemotherapy.

### PT11

PT11 is a fifty-seven-year-old Chinese woman who works as a rubber tapper. She lives with her husband. PT11 found a breast lump while taking a shower. She went to a government-run clinic the following day for the lump to be checked and was referred to hospital for further investigation. She was diagnosed with stage one breast cancer and underwent a mastectomy. She has no family history of breast cancer.

### FM11

FM11 is a fifty-nine-year-old Chinese man who works as a rubber tapper and is PT11's husband. When his wife told him about her breast lump, he took her to the clinic. His wife was then referred to hospital

and underwent several investigations. When the doctor diagnosed his wife with breast cancer, he supported her decision to have surgery.

### PT12

PT12 is a fifty-two-year-old Chinese woman and teacher. She is single and lives alone. PT12 felt her breast was firm, so she went to a government-run clinic three days later and the doctor said that it was normal. However, she had a bad feeling and went to the hospital three to four months later. Having undergone several investigations, she was finally diagnosed with stage two breast cancer, for which she had a mastectomy. She has no family history of breast cancer but she had a previous history of breast lump removal surgery twenty years ago.

### FM12

FM12 is a fifty-three-year-old Chinese housewife and is PT12's sister. Her younger sister told her about her breast cancer, but she was not aware of the previous changes in her breast. She supported her younger sister's decision to undergo surgery.

### PT13

PT13 is a sixty-year-old Malay woman who works as a seller of traditional Malaysian desserts. She lives with her husband. PT13 found a breast lump while taking a shower. She told her husband and he prepared some chanted water for her to drink by reciting verses from the Holy Quran. She went to a government-run clinic the next day to have her breast lump checked and was referred to a hospital for further investigation. She was diagnosed with stage three breast cancer and underwent an axillary clearance alone prior to radiotherapy. She has no family history of breast cancer.

### FM13

FM13 is a thirty-eight-year-old Malay woman who is a lecturer. She is PT13's niece. Her cousins told her about her aunt's breast lump and she accompanied her aunt to see the doctor when she received her diagnosis. She fully supported her aunt's decision to undergo hospital treatment.

### PT14

PT14 is a twenty-nine-year-old Malay woman who works as a dentist. She lives with her parents and three other siblings. PT14 noticed a small flat lump in her breast but ignored it for a year. When she realised that the lump was getting bigger, she went to a private hospital and the doctor informed her it was a cyst. The doctor offered to remove it, but she refused. After three months, the lump had doubled in size, so she went to the private hospital to have the breast lump removed. The doctor said the result was unconfirmed because there was a cancerous mass mixed with the cyst. After several months, she was diagnosed with stage two breast cancer and had chemotherapy. She has no family history of breast cancer.

### FM14

FM14 is a fifty-seven-year-old Malay housewife and PT14's mother. Her daughter told her about her breast lump and she accompanied her to the clinic. Previously, she did not know about the lump in her daughter's breast. Upon her daughter's breast cancer diagnosis, she went along with whatever decisions her daughter made.

## **5.3 Presentation of the findings**

Each participant's story in this thesis was a subjective presentation of their experience and a collection of stories, but commonalities were

observed within their narratives which led to the possibility of identifying narrative themes that were considered important in addressing an understanding of their experiences of breast cancer. The following findings chapter provides an understanding of the types of decisions these women and their family members made as they described their decision-making experiences related to breast cancer. Four themes were identified based on the MPTT concept of interval – appraisal, help-seeking, diagnostic and pre-treatment, that will be presented in detail. Each theme comprises a number of sub-themes that emerged from the interview transcripts.

The identified themes examine the way in which the participants expressed their decision through narrative and how they made sense of their decision. In terms of the form of narrative, some of the participants chose storying about specific events to invite me, as the listener at that time, to re-experience those events with them. Some of the participants narrated their accounts in a more general way over time to enable the listener to understand but not re-live. Some of them opted to share their stories as a series of events. There was a degree of overlap between some of the narratives, thus demonstrating the interconnections between and within the stories told by the participants. This also reminded me that the re-storying of experiences could be disorganised, but what was present was the content of each unique narrative. Exemplars from the interview transcripts are used to understand their experiences. Lengthy extracts from particular participants were used to represent how each narrative theme unfolded, while shorter narrative accounts from other participants were also presented to portray either an additional or different perspective on that narrative.

In addition to presenting the participants' accounts, I also interpreted the findings, which made it possible to gain a more in-depth

understanding of their decision-making experiences. I have tried to accurately represent their voice but am also aware of my own potential bias. I bring my own perspective to the interpretation of the data as a Malaysian woman with a nursing academic background and a middle-class socio-economic status; this is therefore the lens through which I view the decision-making among Malaysian women with breast cancer and their family members and so will have influenced how I represent them.

As a researcher, I had to decide how to represent the participants' voices in a narrative form that honoured their voices, feelings and experiences. This was challenging for me as a novice researcher using narrative research. I acknowledge that I was selective when presenting my findings due to pragmatic reasons. I decided to include all of the stories that contained different reasons within similar narrative themes. For example, in relation to decision delaying the conventional treatment, there were many reasons for the women to delay conventional treatments, including a fear of treatment, negative role model, social influences and others. All of these possible reasons were included in one theme. However, if there were many similar issues within the same theme, such as four participants claiming that a fear of treatment was the reason for delaying treatment, I selected a maximum of two excerpts to illustrate this. I tried to represent the participants' voice, but I also needed to remain aware of my own potential bias. The researcher tends to confront certain challenges to preserve the participants' meaning while also being aware of applying personal and professional meanings to the analysis (Daly 1992). My professional background and familiarity with the literature, albeit to a lesser extent, had an influence on the interpretation, but the findings and meaning were supported by the interview text. I also acknowledge that the meaning of the decision-making experiences for the participants in this study are complex, unique and overlapping.

# **Chapter 6: Findings**

## **6.1 Introduction**

This findings chapter describes the participants' characteristics and identifies narrative themes and sub-themes related to decision-making experiences about breast cancer among the Malaysian women and their family members. The four themes that based on the MPTT concept of interval will be presented in detail.

## **6.2 Participants' characteristics**

A total of 28 eligible participants were recruited for the study, half of whom were women with breast cancer and the other half were their family members. The highest proportion in terms of the participants' ethnic group was Malay ethnic, accounting for 64.3% (n=18) of the participants, followed by Chinese at 21.4% (n=6) and Indian at 14.3% (n=4). The age range of the women with breast cancer across the sample was 28 to 62 years, with a mean age of 46.1 years. While for family members, the age range was 28 to 59 years with a mean age of 43.9 years. Among the women with breast cancer, two (14.3%) were diagnosed with stage I, four (28.6%) with stage II, seven (50%) with stage III and one (7.1%) with stage IV cancer. Half of the women underwent surgery (n=7), 42.9% (n=6) had chemotherapy and 7.1% (n=1) underwent radiotherapy. The family members consisted of nine husbands and one each of daughter, son, sister, niece and mother. A demographic summary of all the participants is presented in Table 6.1 (see Appendix 16, pp.366-372).

A brief summary of the women with breast cancer is presented in Figure 6.1 (see p.127). The detail findings for each participants based on the MPTT were presented in Appendix 15 (see p.352-365).

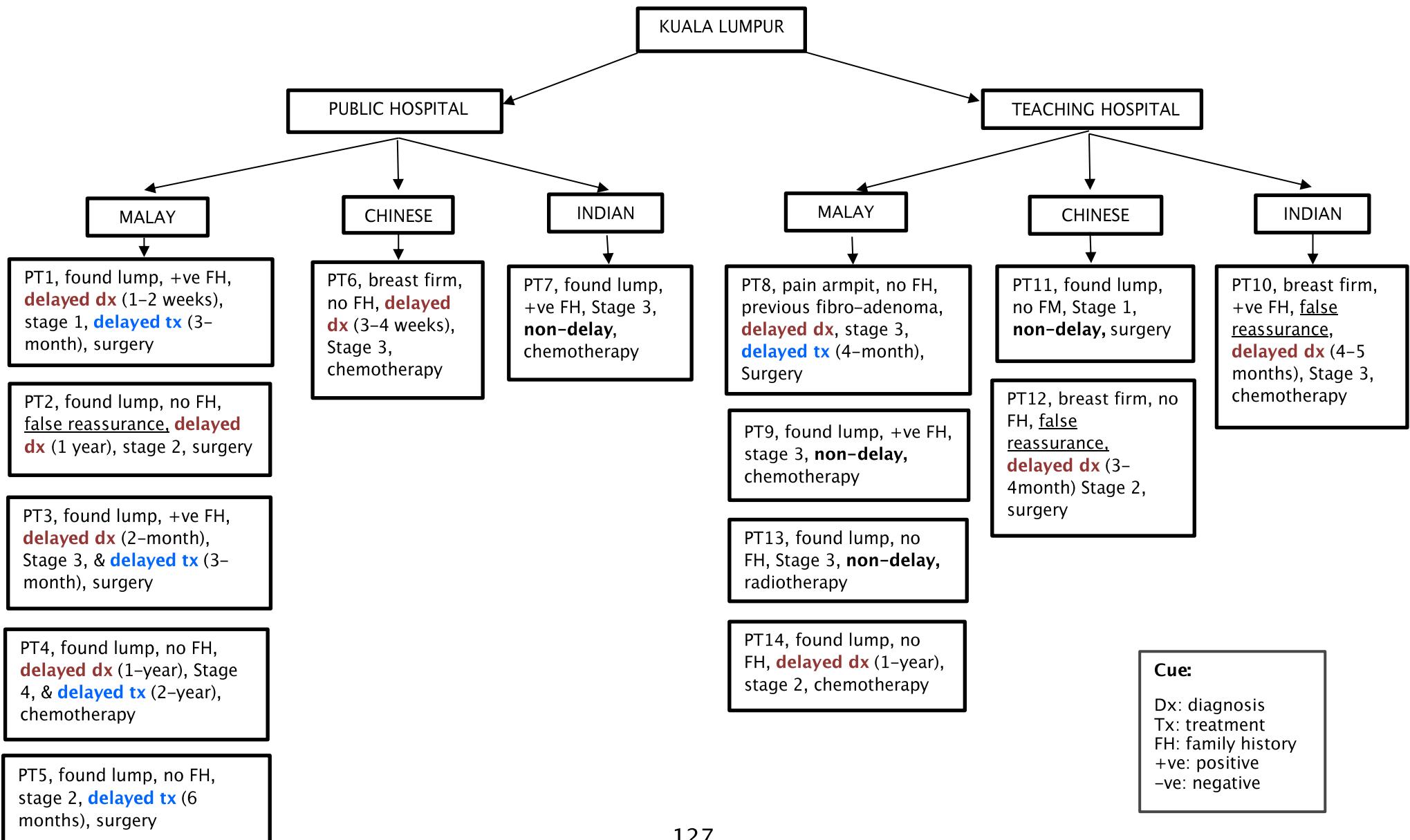


Figure 6.1: Brief summary of women with breast cancer who participate in this study

There were four non-delayed cases and ten delayed cases. Out of the ten delayed cases, five had a late diagnosis, including three cases categorised as having false reassurance, one had late treatment and four had both late diagnosis and treatment. A breast lump was the most common symptom noticed by the women before they were diagnosed with breast cancer. A family history of breast cancer, previous experience of a benign lump and communication with their husbands were the factors that made seven of the women seek immediate medical attention regarding their symptoms, but three of them were given false reassurance, being informed them that the symptom they were experiencing was either lymph nodes, normal or no lump. This false reassurance led to these three women having a late diagnosis of breast cancer. A potential factor among the four women who were categorised as non-delay cases could be the efficiency of the health care system, where they were detected and treated in a timely manner.

The women who were diagnosed late, with the exception of the three women who were given false reassurance, seemed to normalise their symptoms according to their social-cultural understanding, such as clotted milk due to breastfeeding, breast firmness due to their menstrual cycle or a painless lump unrelated to cancer. Thus, they did not consider their symptoms to pose a threat to their health, meaning they either merely observed them or chose to ignore them. For the group of women who chose to refuse or delay conventional treatment, they related their reasons to social-cultural belief regarding surgery, such as a fear of the wound not healing, that the cancer would spread to another breast if removed and the stigma that surgery is a dangerous procedure. Other factors, including needing some time and meeting with a negative role model, also contributed to the delay in treatment among these women.

For the family members, six of them knew immediately about the symptom when the women found it, two of them knew after the

diagnosis was confirmed and six of them knew within a certain period of time, from two weeks up to a year. This study revealed that the family members were supportive and let the women make their own decisions about their breast cancer. They also provided physical and emotional support after having learnt about the cancer

### **6.3 Appraisal interval**

The appraisal interval involves the period “from detection of a bodily change to perceiving a reason to discuss symptoms with a HCP” (Scott et al. 2013, p.51). In this study, some of the women discovered breast lumps by chance; for instance, while showering, dressing, breastfeeding or rubbing their chest due to shortness of breath. In contrast, some of the women had no noticeable lump, yet they experienced other symptoms, such as a change in the firmness of the breast and pain under the armpit. Their interpretation of these symptoms influenced how they decided to act.

#### **6.3.1 Women and family members who sought immediate medical opinion on finding breast changes**

In this study, telling their husband was one of the first decisions that some of the women made after having discovered their breast lump (PT/FM11; PT/FM7; PT/FM9; PT/FM5). Their husbands were influential in confirming the women’s concerns about the significance of the lump and in making the decision to seek immediate medical opinion. The husband’s narratives were more explicit about the potential threat posed by their wife’s symptoms.

PT11 immediately decided to share her discovery of a breast lump with her husband.

PT11 said:

While taking a shower, I felt the lump. It was small. This size [shows half of her little finger's nail]. There were two lumps. Immediately, I told my husband. We went straightaway to see a doctor in a clinic.

FM11 said:

My wife told me that she had found a lump when she took a shower. Immediately, I took her to see a doctor at the clinic.

Another couple, PT7 and FM7, spoke about the influence of genetics on the presence of breast cancer. Both of them recognised the vulnerability to get breast cancer due to PT7's family history. After discovering the lump, PT7 told her husband immediately.

PT7 said:

At that time, I was having a shower. I felt a small lump, but no pain at all. Left breast. At that time, I only thought about breast cancer because my mother had it. But she had already died a few years ago. After that, I quickly told my husband, and he said, "Let's go to the clinic, see the doctor." So, we went to a private clinic.

FM7 said:

When my wife told me that she had found a lump in her breast, I was worried, because her mother had previously had breast cancer. But I always prayed that she would not have the same disease. After that, I asked her to see a doctor immediately, to check.

Another participant in this study, PT9, initially felt uncertain and had questions regarding the presence of a lump in her breast. The lump was small and painless. Later, she told her husband:

PT9 said:

I started to feel a lump while taking a shower. It was in my right breast. I said, "What is this?" Then I told my husband. my husband said, "Go to the doctor, go to the doctor." So, we went to a clinic.

FM9 said:

One day, my wife told me that she had a lump in her breast. I felt her breast. I felt a lump, it was like a thumb size, like that. So, then we went to the clinic.

From the women's narratives that represented the husbands' voice, such as "Let's go to the clinic" (PT7) or "Go to the doctor" (PT9), both reflect on how dominant was the husband's role in the decision-making process to see the doctor. At this part of the interview, both women raised their voice in monotone, not in anger but in instructional decisions for them. In contrast, the word "we" in PT11's and FM9's excerpt possibly showed that joint decision to see the doctor were made with spouses as a consequence when these women shared about their breast problem.

The next example illustrates PT5, who had recurrent symptom of breast lump after two years. At this time, the lump was smaller as compared to her previous experience. She went to see the doctor with her husband. Moreover, the presence of healthcare facility closer to home provided easy access for PT5.

PT5 said:

It happened again in two thousand sixteen. I felt the lump again. I felt it, but it was not as big as before, about 5cm, rather than 7cm. Huh, I had the lump. I went to see the doctor near to our house.

FM5 said:

When she realised the presence of lump in her breast again, we went to the hospital immediately.

Similarly, one woman (PT12) still remembered her previous experience with a benign lump despite this having been almost two decades ago. PT12 is the only participant that met directly with the doctor without telling her family members.

PT12 said:

Like me, because I am single, my right breast felt slightly firm. I thought it was due to the menstrual cycle. And then, twenty years ago I had a benign lump removed from my breast. But that happened a long time ago. So, recently, maybe because of work stress, I was always tired, very tired. Then I felt that I would like to have a check, checking on my breast ... So, I went to a clinic and checked with the GP. So the GP would know.

These situations demonstrate how PT5 and PT12 made sense of their previous experience and might be the reason why they chose to consult the doctor directly.

### **6.3.2 Women who informed family members of breast changes after the changes failed to resolve**

For various reasons, the remaining women waited after noticing breast changes before seeking medical opinion. The interval between noticing symptoms and seeking medical advice ranged from two weeks to one year. Some women normalised the symptom in terms of their previous or contemporaneous experience (PT1; PT3; PT6; PT14; PT8; PT4). When these women's breast changes failed to resolve after a period of time, they began to doubt their explanations of cause and told a family member. Their family members advised seeking medical opinion as soon as they were told because they were uncertain about the symptom.

Family members also tried to reassure and comfort the women, to relieve pain and anxiety about the potential meaning of the symptom.

Two women (PT1, PT3) acted by continuing to observe their symptoms, recognising bodily changes, but no bodily disruption. They normalised the symptoms as nothing to worry about because they were not associated with pain or pain rarely happened. Thus, they waited before seeking medical help. However, when they told their relative, their concern was raised and they immediately sought medical opinion.

PT1 said:

I took a shower again that night, I felt it again ... Eh, this size [shows her little finger]. I felt this size, in the middle of my breast [points with her finger]. After that, I just left the lump alone. I decided to observe it ... because there was no pain, nothing. I just felt the lump. On that weekend, my husband came back. He works at KT (place). When he came back, I told him about the lump. Then, he felt it and he asked me to check in the clinic.

FM1 said:

When I came back, she said, "Dear, could you please feel this [breast]." I said, "What's the problem? Then, I felt it. A lump. Then, I said, "You should have it checked at the clinic. Have it checked."

PT3 said:

When I took a shower, I felt a hard lump. I felt it. Sometimes, I felt like a throbbing pain. But, the pain was rare. On this side [pointing to her breast]. Left side. It felt like a hard lump. It happened almost two months ago. I just observed to see how it would progress. After that, as the lump was getting bigger. I asked my daughter "What is happening to me? She said, "We should go to the clinic". That's why I went to the BB clinic (clinic's name).

For a couple of months, PT3 observed the lump until it changed its size. So, she told her daughter about the lump. Her daughter wanted to look at her mother's breast after she had told her about it. FM3's early interpretation of her mother's breast lump as "excess milk" may have drawn on her sociocultural context and this is an example of recognition of typical cultural belief about the lump for FM3.

FM3 said:

When my mother told me about that [lump], I felt it first. I thought it was excess milk. There were people that had had excess milk. When they were getting older, they started to have it. So, I thought it was nothing. But I was still not satisfied, I wanted to see it. Then I said, "Mum, I would like to see it." When I saw the nipple already inverted, then immediately I asked my mother to go to a clinic.

FM3 asked her mother to see a doctor straight away when she noticed the apparent changes in her breast. It appeared that the inverted nipple was enough to instil in her a sense that there was a serious problem as opposed to it merely being a matter of excess milk. At this point, it showed that the cultural belief about the symptom could be changed when the symptom had obvious changes that deviated from what people make sense about it.

Both PT1 and PT3 had a family history of breast cancer. Over time, they made a connection between this and their own breast cancer.

PT1 said:

... because there is breast cancer in my family too. My late sister, also in her left breast. But when she found out, it was already in stage four. She had cancer outside the breast, like meat.

PT3 said:

I have a family history of breast cancer, my late younger sister, she passed away more than a year ago. She was in stage four. But her breast cancer was outside the breast. Yeah, outside the breast. So, we could see the thing [breast cancer]. It looked like a cauliflower.

The above excerpts reveal that the participants were aware of breast cancer due to their previous experiences of dealing with family members who were already in the advanced stages of cancer when they first discovered it. However, they remained unaware of the early symptoms of breast cancer and endeavoured to make a comparison between their symptoms and those of their family members. They stated that their sisters' breast cancer looked like "meat" and "cauliflower", thus suggesting that they interpreted their symptoms as being somehow hidden or different. They may also have considered that their symptom was neither serious nor cancer due to the fact it appeared different from their sisters' breast cancer. It seemed that both of these participants constructed a meaningful interpretation for them at that time, which stated that the breast cancer should have clear features that were visible to the naked eye, and that this potentially prompted their decisions to merely observe their breast lump. In this respect, PT1 and PT3 demonstrated that they were unaware that a painless or presence of lump could be a warning sign of early breast cancer.

Similarly, one woman (PT6) did not have a noticeable lump. Instead, noticing changes in her breast mass, PT6 also decided to observe the symptoms.

PT6 said:

In July, I felt like, like my breast was firm. It was just firm, but no lump. It was not painful. I thought it was normal, yeah maybe due to a menstrual cycle. After that, I observed, and it was still swollen.

Later in her account, she talked about the menstrual process in light of her attempts to make sense of the changes in her breast. She may have felt that her breast firmness was “normal” due to menstrual processes.

PT6 said:

... during menstruation, our hormones are productive, right. I thought it was just normal swelling. So, I did not suspect anything.

PT6’s account exemplifies how a woman’s previous experience influences the interpretation of the symptom. It seemed that PT6 was unaware that breast cancer could present in different ways, not just through the presence of a lump. However, when she told her husband, he advised her to have the symptoms checked.

FM6 said:

On that day, my wife had told me that she felt her breast was firm. She had said that her breast was firm a few weeks ago. So, I asked her to check. So, we went to the clinic area BH (location). Yeah, it was better to check.

Another woman (PT14) decided to ignore her breast lump because of its abnormal shape. PT14 seemed uncertain about the unusual shape and was not suspicious of breast cancer symptoms. It is likely that the existence of breast cancer was not in her mind. However, when the lump started getting bigger, she met the doctor directly.

PT14 said:

I started to feel, when I wore the bra. It felt like a lump, but it was not a round lump, but it was like, like slightly flattened, nail size, two thousand, two thousand fifteen, in January, and in my left breast. It was also painless, so, I just ignored it ... because I never thought that thing [lump] could be cancer. But then, from January two thousand sixteen until April two

thousand sixteen, it doubled in size. So, I went to the hospital, to check.

Similarly, when she told her mother, she advised a medical opinion.

FM14 said:

One day, PT14 told me that she had a lump in her breast.  
Then, we went to hospital, to check.

Another participant (PT8) initially experienced pain under her armpit and she did not suspect anything serious about it. At the same time, she was aware of the presence of breast lump and related it to her previous experience.

PT8 said:

So, from the end of two thousand fifteen [2015], I felt, pain, at the muscle areas under this armpit (/: ok). So, I thought it was because of menstrual or because of shaved ...

I had a lump. But that lump was normal. Because, before this, I had already had lumps removed many times. Because it kept on growing, or I removed that lump, not because it was cancer, but because it had an infection, or it was painful. So, I removed it. It was cosmes- cosmetic surgery, because I felt uncomfortable with that lump, but, actually it was not cancer. It was just an ordinary lump, ordinary fibroadenoma. But I did not suspect at that time that it was cancer. I didn't feel any pain. I felt nothing. I didn't care. Before this, when I removed the lump, I felt pain. Because it had an infection or it was swelling.

PT8's narrative suggested that she normalised her lump in terms of her previous experience of fibroadenoma disease. Moreover, from her description that the lump was normal, painless and not related to cancer, she may have considered that the lump was not a serious

symptom at that time in comparison to her previous experiences. In making sense of her experience, PT8 said:

Because I had no family history. No friends had this disease. So, I don't know, I had nobody to guide, nobody to ask, yeah to ask. You are on your own.

At this point, there are four possible interpretations for how PT8 built her sense of self related to her decision. Firstly, PT8 seemed to present herself as someone who was trying not to blame herself for the delay because she did not know, had no family history, no experience and no source of reference to ask about breast cancer. Secondly, the way in which she understood her symptom, combined with her belief in the hereditary element, revealed that she might not have known about breast cancer. Thirdly, she presented herself as someone who was alone when referring to her breast cancer symptom, as shown by "You are on your own", because she did not know about breast cancer or know anyone with the same problem. Finally, she may have assumed that the lump was similar to what she had previously experienced since it continued growing and she had already undergone several previous lump removal procedures.

For her husband, FM8 tried to comfort his wife to reduce the pain by massaging her. At that time, he also did not suspect that the pain was a serious problem. The pain was intermittent for about a week.

FM8 said:

At first, PT8 had said that she felt pain under her armpit, under the armpit, which is, I think, just a common condition, so I told her that. Every night, I massaged her, but she was still in pain. I just kept massaging ... After that, finally I said, "Uish, it is already a week, the pain is on and off." So, I told her, "I feel uneasy. We have to check."

FM8 actually took his wife to see the doctor a week later when she could no longer cope with the pain. His wife's pain thus appeared to serve as a catalyst that led him to seek help from a doctor.

Another woman, PT4, located the beginning of her breast cancer journey with the event of giving birth. She believed that her breast lump was "normal" as she drew on the post-delivery narrative and her role as a nursing mother to her baby.

PT4 said:

I started to feel sick after I gave birth to, gave birth to my baby. At first, I noticed a lump under my nipple. At first, I thought that it was milk. I thought that it was a milk clot because I was breastfeeding. After that, after quite some time, after some time, I tried squeezing it, it then disappeared. The second time, it appeared again. This time, it did not disappear. It did not go away. Then, after a while, I, I ignored it, thinking, assuming that it would dissolve by itself or whatever.

This story illustrates how PT4's view of her postpartum experiences reshaped her ideas about why she had a breast lump. She spoke of accepting and normalising the symptom as part of her experience as a new breastfeeding mother. As such, the breast lump did not pose a serious health concern to her at that time.

Later, PT4 had flashbacks of her experiences during confinement, as detailed in the next extract. This reveals how PT4 gathered up the thread of events that enabled her to link her story and plot it coherently as a way of providing more information to me, as a listener at that time, regarding her condition. Here, PT4's account reflects what Hydén (1997) refers to as how the narrative links events into providing a whole that creates an illness narrative. It reveals that her postpartum experiences came to play the leading role in her interpretation of the breast lump.

PT4 said:

That's why I felt odd during my confinement, something was not right with my right breast. Although it was engorged, but I did not feel any pain. But my left breast was hurting. I did wonder why, but I did not expect anything bad since it was not hurting. I decided to ignore it since I did not feel any pain. I thought it was normal hardening of the breast. I thought it was overfilled with milk. It was a normal thing.

At this point, PT4 illustrates a situation where she was experiencing confusion between thinking something was wrong with her breast and normalising her symptom. It was all in her mind; as such, in order to make sense of her symptoms, she related them to her postpartum condition and accepted them as not being indicative of anything being physically wrong despite the fact that she felt strange about it. Her interpretation of the lump as clotted milk, it would dissolve by itself, and that this was part of the normal process of breast growth may have been based on her understanding regarding the sociocultural framework of breastfeeding.

When she told her husband about her concerns, he advised seeking a medical opinion.

FM4 said:

When I came back, my wife told me that she had a lump. She thought it was clotted milk, but till now, the lump was still there. So, I asked her to check and we went to the clinic, to check with a doctor.

Two women (PT13; PT2) waited while they assessed the seriousness of the symptom by keeping an eye on the symptoms. They described how they kept checking that lump until they had felt it was still present. Their husbands reacted by trying to reassure them, one by using chanted water and one by expressing "*InshaAllah*", meaning that he hoped

nothing serious was going to happen to his wife. In both cases, this reassurance was followed by a decision to seek medical help.

In PT13's case, she kept checking her breast for the lump while waiting for her husband to come back.

PT13 said:

While taking a shower, I felt a lump when I touched my breast. I touched it again. It felt lumpy and hard. Thumb size. At that time, I was alone at home. My husband had not come back from work yet. After I finished taking a shower and performed *Asr* prayer, I tried checking my breast again. There was a lump. I felt the lump. When my husband came back that evening, I told him. That night, he immediately made chanted water because of our religion. Sometimes, certain verses in the Holy Quran are used for healing. My husband, actually my husband previously learnt at DS (name of the organisation). He did it [made chanted water] by himself for me to drink. He recited some verses from the Holy Quran. Next morning, we still went to the clinic to check the lump.

PT13's story exemplifies how Muslim people believed that the Holy Quran possessed a healing power. Although her husband had faith in chanted water, they did not trust it wholeheartedly to be the answer to the lump because they still went to a clinic on the next day for a further check-up. It seemed that they incorporated both Islamic and seeking conventional methods to deal with the presence of breast lump. However, there was no information from family members within the appraisal interval because her niece knew about the presence of a lump when PT13 had already met the doctor.

Another woman, PT2, kept feeling for her lump after she first found it because she was unable to feel the lump all the time and was unsure whether it was something to worry about or not.

PT2 said:

While lying on the bed, I touched my breast. I felt like a lump ... When I found it, it was small and I can't remember in which month, last year. So, small, like a tip of the nail [shows her index finger's tip], but sometimes I felt it, sometimes I did not. I kept feeling the lump. Then I was asleep. The next morning, I told my husband.

When she told her husband, he took her to seek medical advice directly.

FM2 said:

Last year, my wife told me that she had a lump in her breast. I thought it was nothing. I told her, "*InshaAllah*, it's nothing." But we went to the clinic to check. I took her to the clinic because the doctor knows about this thing [lump].

Both women (PT13, PT2) seemed as though they wanted to confirm that the lump was real and present in their breast before telling their husband. At this point, they might have been fearful of the presence of breast lump or they might have been hoping that, despite the presence of the lump, nothing was wrong with them.

### Summary

This session has presented some women immediately understanding the potential meaning of their breast changes and seeking medical opinion, while others were waiting to keep an eye on symptoms or normalising them in terms of previous and current experiences. Some of the family members acted to comfort, reassure and advise medical opinion towards the women, demonstrating family members as a decision-maker to determine whether symptoms were serious enough for medical opinion and support. All of these decisions were made depending on the way they made sense of the presence of symptoms.

## 6.4 Help-seeking interval

Help-seeking interval involves the period between people “perceiving a reason to discuss symptoms with a HCP to the first consultation with a HCP about their symptom” (Scott et al. 2013, p.51). At that time, the body needed a check-up to identify the problem. Thus, these findings revealed the reasons to consult HCP.

In Malaysia, the clinics or hospitals accept walk-in patients for a check-up. Therefore, patients do not need to make an appointment to see the doctor. In this study, the decision to seek a doctor’s input in the first instance indicates that participants wanted a qualified person to examine the abnormal symptom in the breast. However, throughout the interview, women did not talk much about the decision-making process within the help-seeking interval. The possible explanations could be that the family members made a decision for the women where they should go or women felt that they have no voice there or they were just recipients of medical help. Therefore, this part only showed the family members’ narratives because the similar quotes from the women were already presented in the appraisal interval.

FM11 said:

My wife told me that she had found a lump when she took a shower. I immediately took her to see a doctor at the clinic. So, for me, I didn’t have any experience of dealing with this. So, I asked her to see the doctor first, because only the doctor could confirm it. For me, I didn’t know, I’m not sure. But, there was a lump. There was a lump.

FM2 said:

Last year, my wife told me that she had a lump in her breast. I thought it was nothing. I told her, “*InshaAllah*, it’s nothing.” But we went to the clinic to check. I took her to the clinic because the doctor knows about this thing [lump]. It was the doctor’s job.

These family members had taken the women to see the doctor as soon as they found out about the breast lump because they were uncertain or worried about the symptom. They may have regarded the symptoms as something that required action. This is closely related to their understanding and belief that only the doctor could examine the breast lump properly to make sense of what was happening to the women. Drawing upon the cultural narratives of illness, these husbands took their wives to consult the doctors possibly for an examination, diagnosis, advice or perhaps medication. With respect to the role of the doctor, it seems that they had high expectations of the doctor's knowledge when they stated, "The doctor knows about this thing [lump]. It was the doctor's job" and "only the doctor can confirm." Thus, they assumed that the doctor was an expert and gatekeeper to knowledge regarding health problems, perhaps drawing on a reasonable expectation or sociocultural view of the medical profession.

However, due to no accessibility to public clinics on account of public holiday, one woman (PT1) was unable to see the doctor straightaway after she told her husband.

PT1 said:

On that weekend, my husband came back. He works at KT (place). When he came back, I told him about the lump. Then, he felt it. He asked me to check in the clinic. On Monday, I went to the clinic K (clinic's name) because the clinic was closed at the weekend. I met with the doctor in that clinic.

### Summary

This session has presented that some family members realised the importance of women to check their symptom with a doctor, so that they could recognise the potential health problem. However, unable to access health facility straight away might be the potential limitation to check the symptom for one of the woman in this phase.

## **6.5 Diagnostic interval**

Diagnostic interval involves the period between “the first appointment with a HCP and the formal diagnosis being made” (Scott et al. 2013, p.51). During this interval, the women had met with the doctor and undergoing several investigations such as ultrasound, blood test, mammogram, biopsy or Magnetic Resonance Image (MRI) before they were diagnosed with breast cancer.

### **6.5.1 Investigation phase**

#### **6.5.1.1 Women and family members who had suspected having breast cancer**

In this study, the doctors play an important role because they are the first line of healthcare providers that patients consulted regarding their symptom. Their appraisal and action influences the participants’ interpretation and decision regarding the symptom. For example, PT6 was referred to the hospital after being checked with the doctor in the clinic.

PT6 said:

After that, I went to a government clinic. The doctor referred me to the hospital. I went to Hospital TH, checked with Dr T. Then, on the same day, he immediately asked me to have a mammogram and ultrasound. The next week, he asked me to do MRI. The following week, I did biopsis[biopsy].

Later in her story, PT6 linked the breast problem she had and the hurrying of the doctor doing tests and procedures as meaning something was serious happening to her. Her husband also had the same thought about it. This situation conveyed that the doctor’s actions became a catalogue of things going wrong and were signs of an impending negative outcome, which was being diagnosed as breast cancer.

PT6 said:

From the start, I could see that the doctor seemed like he was rushing to do the test. I felt like, like something was wrong. As usual practice, we tend to have late appointments, right, usually two to three weeks, but at that time, starting from the first day I met with the doctor, that doctor seemed to want to do many things. So, I expected something serious, like cancer.

FM6 said:

So, we went to the hospital every week. Many times, too. The doctor really hurried to do the things. I had a feeling that something was not right about my wife's condition.

Another couple, PT4 and FM4, reported that the doctor already suspected PT4's symptom as probably breast cancer during the investigation phase.

PT4 said:

During the ultrasound, the doctor said, "This is not good, not fine." The doctor said "You may have cancer. They said, "If this is cancer, you should not seek treatment at an inappropriate place." I understood what the doctor meant by inappropriate place. Like using traditional remedies, seeking a traditional practitioner here and there.

FM4 said:

The doctor checked, and informed that s/he suspected cancer based on PT4's condition. I was shocked at that time.

PT4's narrative illustrates how the doctor expressed his/her concern regarding the presence of other treatments for breast cancer that were commonly chosen by patients. This excerpt also conveys how the term "inappropriate place" was accorded the same understanding among the members of the communities, with no further explanation being required during the conversation.

### 6.5.1.2 Women and family members who experienced false reassurance

Some of the women in this study, who were initially aware of their breast symptoms, had a delayed diagnosis due to an incorrect initial judgement by their first doctors. According to Scott et al. (2013), during diagnostic interval, the HCP appraisal process can be subjected to error and biases that may lead to misdiagnosis, dismissal of symptoms or no diagnosis. The women's perception of their early signs was shaped by what they were told by their doctors.

PT2 said:

I said to that doctor, "I feel that I have a lump." She checked. She said, "It's nothing. No lump." But I thought that there was a lump present. It might be that it was small at the time. "Nothing", she said, "nothing"... When the doctor at the SS clinic told that she did not feel anything, for me, it was fine. I felt relieved after the appointment.

FM2 said:

Alhamdulillah, the doctor said that the breast was fine, nothing. After that, I thought everything was okay.

PT10 said:

The doctor said, "It's nothing. Lymph nodes only." S/he gave me medicine. S/he gave an antibiotic. I thought it was fine.

At this point, the outcome of their consultations with the doctor influenced the way the women felt about their symptoms. PT2 and PT10 felt positive and did not worry about their conditions. This provided them with an ongoing sense of security. Their narratives portrayed that those who have a reliance on the doctor's assessment regarding a health concern do not, therefore, see the need for any action on their own part. Consequently, they ignored the symptoms until they came to realise more noticeable changes in their breast several months later.

PT2 said:

Before that, there was nothing happening, so I just left the lump because it was not painful. I felt the lump, but it did not burst, no watery [discharge]. People said that breast cancer was painful and had watery discharge ... It felt lumpy, but there was no pain. So, I just ignored it. I did not know it was cancer. I thought there was nothing wrong with it because there was no pain. Moreover, I did not have any family members who had had this disease.

After that, when I went back to the clinic in July this year, I said, "Doctor, do you still remember me? I had my breast checked with you before. Look what's happened now?" At that time, I was very irritated. Then, yeah, when I got it, I don't know. It's like that.

PT10 said:

Four to five months later, I realised that the thing had got bigger. I had already told the doctor. I was mad at that doctor. It was already quite big, 8cm.

Referring to PT2, she may have been experiencing a sense of dissonance between what she was experiencing and what other people within her community had said about her symptom. Her extract illustrates the sociocultural elements and other influences that affected her decision. The main plot in PT2's narrative concerns her interpretation of the breast cancer symptoms that led to a delayed decision in seeking help and receiving a diagnosis. Her interpretation of the symptoms and presence of disease is associated with the sociocultural template. For example, the symptoms of breast cancer are associated with what is socioculturally considered as pain. Within this template, pain has a direct impact on an individual's health; therefore, the presence of a lump in the breast, but without pain, is socioculturally considered to be "normal" and does not alter the body. Thus, the lump is considered as something that is not serious and does not require immediate action. In order to make sense of her symptoms, PT2 compared what she was experiencing to what others in her community had mentioned about the

symptoms. Since she was not experiencing any pain, she decided to ignore the lump. In addition, PT2 seemed to believe that breast cancer was genetic; thus, family history became another influential factor in her understanding of breast cancer.

The above accounts also illustrate how both PT2 and PT10 tried not to blame themselves for the delay because it was not their fault as they had tried to obtain advice, but were given the wrong information. They also expressed their negative feelings and anger, which suggests a sense of being unsatisfied with their initial consultation with the doctors. When they stated, “I was so irritated” and “I was mad at that doctor”, they were angry and frustrated that the doctors were not able to identify their early symptom as something actually being wrong. These situations are considered examples of those women who participated in this study who were given false reassurance from the doctor about their condition and, therefore, experienced a delay in the opportunities for an early diagnosis of their breast cancer. Although they expressed their anger with the doctor when they made the comments, they did not talk much more about this issue. This type of situation might be synonymous with the Malaysian culture, whereby people attempt to preserve the face of others by avoiding criticism.

#### **6.5.1.3 Women and family members who experienced delayed referral**

In this study, one woman had delayed referral. For example, PT8 had sought medical consultation three times at the clinic regarding her pain, and it took nearly more than one month before she was referred to the hospital for further investigation. The doctor kept diagnosed her with muscle ache and gave painkiller to relieve the pain. Her husband’s narrative is more explicit about this situation.

PT8 said:

So, I went to the ordinary clinic taking a medication. It seemed okay. Then it [pain] happened again. Three times it happened. So, after it happened for a third time, the doctor asked me to go to a hospital, referred me to the hospital.

FM8 said:

We went to the clinic. The doctor gave Panadol, a painkiller. After two weeks, the pain was on and off again. We went back to the clinic. The doctor gave another painkiller. After that, every night the pain got more intense. She was uncomfortable, under her armpit. I massaged her back, but she still in pain. We went back to the clinic. Finally, the doctor referred my wife to the hospital.

#### **6.5.1.4 Women and family members who experienced unconfirmed investigations result**

Sometimes, the investigation result was delayed due to the human or technology error. In this study, for example, PT1 had to do the biopsy investigation two times because the first lab result was unable to identify the problem. Her husband did not talk about this event because he was not available due to work commitment in another state.

PT1 said:

Two, three days after that, I went to the hospital again. Checked, checked, checked, checked. The doctor took, what is that called (p), took our meat (tissue) inside. Biopsy. Huh, biopsy. Two times she did it. At first, with the small needle. Cannot, unable to identify. The doctor did it again, on the following week. S/he did again.

Another woman, PT14, had a unique case because her investigation result showed cyst mixed with cancer mass, yet, the doctor was unsure about her condition at that time. It took almost three months before she

was confirmed as having breast cancer even though she went to counter check with another hospital.

PT14 said:

I went back to that hospital, checked again. The doctor said it was a cyst. So, after they removed that (cyst), the doctor sent the specimen to the lab. They said it was CA (pronounced alphabetically), but CA mass mixed with cyst. So, they felt like it was unconfirmed, at that hospital GE, where I had it (removal of cyst). Then I came to hospital TH. Hospital TH did the same thing, sending the specimen to the lab many times, because they were also unconfirmed.

FM14 said:

When the result came out, the doctor said it was still unconfirmed because PT14's cancer was mixed. The doctor said this situation rarely happened. After that, PT14 said she would like to check in the TH hospital because there were many specialists in cancer. So, we went to that hospital, met the doctor. They took the tissue and sent it to the lab again. The result was still the same, unconfirmed cancer. We kept coming to this hospital. Eh! It was quite a long time we waited.

Both events (biopsy, pathology results) could be considered problems with processes and procedures, but these incidents already increase the time during diagnostic interval and lead to delayed diagnosis.

### **6.5.2 Formal diagnosis**

#### **6.5.2.1 Women and family members who accept the diagnosis immediately**

In this study, some women accepted their diagnosis of breast cancer after the doctor breaking the bad news. The participants arrived at their own justifications based on their understanding of the presence of breast cancer.

PT3 and PT7, in their narratives, suggested that the basis for their breast cancer was genetic and they believed that they were going to develop this disease. They recognised their own vulnerability related to their strong family history and were psychologically prepared for their illnesses. Both PT3 and PT7 were reflecting Hydén (1997)'s idea (1997) of how individuals with a chronic illness attempt to provide an explanation and a cause for their illness.

PT3 said:

When the doctor said that I had breast cancer, I didn't know what to say. But it was already fate, so there was nothing I can do. My younger sister had breast cancer. I said that I would also get it. People said it was because of heredity.

PT7 said:

I was sad, but I accepted the fact that I had a family history. So, the chances of me getting breast cancer were high. I knew that. Breast cancer is a really scary word. Yeah, I still remember how my mother, my mother fought her breast cancer. Although she suffered because of the side effects of chemotherapy, she acted like the treatment was no big deal. She was so calm and positive, and I learnt from her. So, I did not cry when the doctor said that I had breast cancer. The breast cancer was already there, so there was no point in regret. The rice has become porridge, but I am still alive. So, I just accept whatever treatment suits my breast cancer. I felt that my life had just begun. Now, I really appreciated what I had. My life, my work, my husband. Everything seemed important to me. I wanted to enjoy my life before I closed my eyes.

“The rice has become porridge” is a Malay language proverb with a similar meaning to the English proverb, “There is no use crying over spilt milk”.

Through the use of metaphor, PT7 managed to convey a sense of acknowledgement concerning the presence of her breast cancer;

specifically, that she already knew she had breast cancer and could do nothing to alter the fact. The cause of her breast cancer was irreversible; therefore, she needed to face it without being upset. The way PT7 told her story seemed to resemble a subtype of automythology of a quest narrative based on Frank's narrative (2013), in which she regarded her illness as fate or destiny and presented it through the use of metaphor. Another similar aspect of PT7's quest narrative is that it is representative of her memories of her mother. Her indirect quest narrative conveys the lessons she learnt; despite not yet having experienced restitution, she had become more appreciative of life even though she faced the challenge of breast cancer. Her illness led to a new insight into herself and the world in which she is living. In the Malaysian cultural context, the phrase "I close my eyes", referring to the phrase "passing away", shows how PT7 chose indirect expression rather than being explicit.

For the family members, FM3 acknowledged that her mother did not show any emotional distress after she knew about breast cancer as compared to her.

FM3 said:

Mother did not cry at all. She looked like as usual, as usual. She's very strong. If other people might be worried, right. I was hectic, but she was so relaxed.

Another family member (FM7) attempted to regulate his emotions and kept putting on a brave face in order to support his wife.

FM7 said:

After that, the result confirmed that my wife had breast cancer stage three. I already suspected it, it just needed confirmation. I was really worried because her mother had died from the same disease. If you want to say it was sad, it's really sad, but

what was I supposed to do? I have to give her support to face this entire thing. That's why every time she goes to the hospital, I'll make sure that I'm with her. I don't want her to go alone.

Other women, such as PT2 and PT11, accepted the diagnosis of breast cancer because they understood it to be a common disease in the community nowadays. In order to make sense of what was happening, some of the women needed to find plausible reasons for why they had breast cancer even if there was no family history of it. One way in which they did this was by accepting that they too could develop cancer, as other people had, because of the random nature of the disease. This could also be due to the higher prevalence of breast cancer in Malaysia.

PT2 said:

Because, nowadays, many people get cancer. Previously, cases were very rare, but nowadays many people get cancer. If you want to know, the hospital was full of cancer patients.

PT11 said:

Nowadays, many people get it [breast cancer]. It is common. Everybody can get it. It is just a matter of bad luck.

With regards to PT11, when she stated "It is just a matter of bad luck", she may have been portraying her identity as someone who is unfortunate, as she interpreted that breast cancer can happen to anybody by chance. Therefore, in order for PT11 to make sense of what was happening to her, it seems that she may have expected the disease but did not know when she would get it.

Husbands (FM2; FM11) related their wife's condition to God's will. Their story showed that they accepted the existence of breast cancer without any negative feeling and kept supporting their wives.

FM2 said:

I always advised her to be patient. This entire test came from God. Yeah, to give encouragement. It was not easy to face all these things.

FM 11 said:

It's normal. Like other illness. It's God's will. But I still supported her.

The following examples show how the participants make sense of what is happening to them in the context of religious belief and the power of God. PT12's and PT14's stories appeared to suggest their positivity accounted for how they cope with breast cancer, enabling maintenance of a sense of self-value. They believed that God owns everything because He created everything, including breast cancer.

PT12 said:

When it [breast cancer] was confirmed, I had to accept it. Just, just accept it. Whatever happened, I just accepted. It is from God. So, it seemed like you fell down in a drain. And inside the drain, there were leeches, mice, what should I do? I already felt down in the drain. So, I just accepted it. Because many people have this [breast cancer]. But you can't blame everything. You, you did not do anything wrong. I didn't take any other treatment or things like alcohol or smoking or whatever. But that understanding does not guarantee that nothing will happen to you. No matter how many good deeds you do, there is no guarantee that people who do good deeds will be safe. So, well, if you had a bus accident and you were inside the bus, what you can do? You want to clear whatever, but you must go to the hospital first. Then, when it is already destiny, it will still happen. So, you have to accept it. So, you consider you have bad luck, but don't blame anything. Don't feel guilty, like you did something bad or whatever. It's ok.

The story that PT12 told regarding her condition "... like you felt down in a drain. And inside the drain, there were leeches, mice, what should I do? I already felt down in the drain") has a similar meaning to the English idiom, "Beggars can't be choosers".

The excerpt presented above illustrates how PT12 came to perceive and view her breast cancer. The way in which PT12 explained her diagnosis of breast cancer, which included powerful imagery to amplify the message to me as the listener at that time, conveyed that she felt she had no choice and she needed to accept whatever God had given to her. She stated that she realised that God controls and has a place in her life. She also clarified that good people are not necessarily free of disease. Thus, the meaning PT12 constructed from her diagnosis of breast cancer helped her to deal with it.

For PT14, she went to the hospital alone on the day when the doctor revealed that she had breast cancer.

PT14 said:

I never question why I got this [breast cancer], yeah *Allah*, *Allah* [God's name] has got a better plan, so, for all this, I said that God loves me.

There is a quote that says, "God will never give you more than you can handle." So, I knew that I was able to deal with this cancer.

In this respect, PT14 believed that her breast cancer diagnosis happened for a reason and that God was preparing her for good things when she stated "*Allah* has got a better plan." Using the quote "God will never give you more than you can handle", PT14 portrayed herself as a strong woman with a strong faith in God. This quote is comforting because, as a faithful Muslim, PT14 believed that God guaranteed that she would be able to deal with her situation, which is part of a test for His servant.

The situation was different for PT9. She initially found it quite difficult to accept what was happening to her body. However, she described how she had accepted the diagnosis due to the role of the doctor. It seemed

that the doctor was able to provide a good explanation that ensured PT9 had a better understanding of her condition.

PT9 said:

At first, I could not accept it. I really could not accept the diagnosis at that moment, but the doctor seemed, the doctor was an experienced doctor. The doctor explained a lot to me about this disease.

... The doctor gave me hope that I was able to recover if I underwent the treatment. The doctor talked like that.

Another woman (PT6) talked about how her instinct during the investigation phase made her feel ready, as she articulated, “not too disappointed” during the breaking of the bad news.

PT6 said:

When the doctor informed me that I had [breast] cancer stage three, I felt like, did not feel too disappointed because early on I already saw the doctor seemed rushed. Crying, I'm crying but I already expected it from the early phase. So, I accepted it.

The husbands (PT6; PT9) expressed their love for their wives when they were unhappy at them being diagnosed with breast cancer. This emotional support may have brought their wives happiness.

FM6 said:

When she knew that she had that thing [breast cancer], I saw her cry. I felt so sad. I just told her, “I will always be with you no matter what happens”, I didn't want to see her cry.

From my experience, when dealing with someone who needs support, you must have positive energy when you're around that person. Because they often depend on our positive energy to be happy. So, I am always positive in front of her. And never say that you understand what they are going through because

you never will. As a husband, I have, actually I also felt the same things, but as a husband, I have to be strong because I have to help her.

FM9 said:

We went back to the hospital and the doctor verified that my wife had breast cancer. It felt (p) hard to say, it felt unbelievable, felt sad. Mixed feelings because this thing (breast cancer) is a chronic disease, right. Even if it is tough, I am always putting on a brave face to support her. She needs emotional support ... My love never changed.

The husbands realised that their behaviour and emotional reactions could have an impact on their wives. They tried to avoid facing their inner feelings and minimised their emotional reactions to the diagnosis of breast cancer because they did not want to make their wives feel sad. Thus, it can be seen that the husbands were also taking care to maintain some sort of personal coherence regarding themselves in order to remain strong for their wives. It appears that the husbands may have been feeling similar emotions to the women; as such, the husbands may find themselves in the difficult position of having to support their wives while also managing their own stress.

#### **6.5.2.2 Women and family members who accepted the diagnosis later**

Two women (PT8, PT1) showed that they needed some time to adjust emotionally to their diagnosis. Returning to an earlier point PT8 made regarding her current breast lump, there was an assumption that the lump would not progress to cancer because she had previously experienced it several times. It seems that she was trying to convince herself that there was nothing sinister about her breast lump.

PT8 said:

... I had a lump. But that lump was normal

... it was not cancer. It was just an ordinary lump, ordinary fibroadenoma.

Her previous experiences of being diagnosed with fibroadenoma over many years might have provided her with a false sense of security. She may have felt that her diagnosis would remain the same. That's why PT8's narrative later articulated a sense of hope shattered regarding her symptom.

PT8 said:

Yeah, it was hard to believe what had happened as I didn't expect it to be cancer. I thought the lump was okay

Over time, PT8 started to consider her previous experiences, which enabled her to seek a connection between events in order to make sense of her diagnosis. Later, she realised that her previous breast problem had actually served as a clue that it was possible for her to develop breast cancer.

PT8 said:

After some time, actually like I was already [diagnosed] because I had done it many times, three times I already underwent the breast surgery, one time in the right side, two times in the left side. So, like, either you wanted or not, I had expected something. Somehow rather I felt, like I felt, I knew that I had a problematic breast. So, it was not all of the sudden, you do not have any history, but suddenly you got it, it was shocking.

Subsequently, PT8 decided to accept her diagnosis of breast cancer. In order to understand her situation, PT8 gathered up the thread of events, which enabled her to revise the plot of her story. She had constructed a coherent account of her breast cancer, shifted her mindset, moving from a time of uncertainty or denial to a time of understanding and

acceptance. She had now accepted the strong possibility that her breast lump was linked to the occurrence of breast cancer. PT8's narrative was also akin to the concept of contingent narratives as set out by Bury (2001) in terms of how she related her situational event (problematic breast, undergoing breast surgery three times), which were then wrapped in her belief of the breast cancer diagnosis as being an outcome. When PT8 told me this story, she expressed it as a series of events to help me understand her situation.

Her husband's (FM8) immediate decision when he knew about the breast cancer was to put on a brave face and be strong for his wife. FM8 had to decide how he would react and what emotions he would convey to his afflicted wife.

FM8 said:

At that time, she knew that she was at stage two, end of stage two, going to be stage three. So, as her husband, it really breaks my heart, so sad, sad, but I can't show my sadness in front of her. I maintained positive thinking for her. I worried she would be more down. If she was down, she would be worse. Because I knew that my wife is a strong person. But I can't let her down. I feel sad, really sad because my children are still small. Only God knows me, groaning alone, so sad. But in front of her, I'm okay.

Another woman, PT1, talked about how she had emotional distress after she knew her diagnosis.

PT1 said:

I cried a lot. Two, three days I was crying. I was afraid of this thing (breast cancer) [tears in her eyes] (p). I can't (P). I felt like (P), I don't know how to say it, so (p), worried, loss of appetite. I felt like I'm going to die like that when I knew I had that thing (breast cancer). It's normal, right? Because I was afraid.

As a husband, FM1 talked using a different approach to convince PT1 of his way of thinking about her breast cancer. He used the inspirational story of the Prophet Ayyub as well as logical appeals to instil positive moral teachings and help her to avoid negative thinking.

FM1 said:

I felt sorry for my wife. I knew she was sad. She asked me, “Why did I get this disease? What is my sin?” I gave support to her. I told her a story about our prophets. “I gave her an example, the Prophet Ayyub. He was a beloved prophet of *Allah SWT*. He was given the privilege. Did he commit many sins before he got sick? No. “This disease”, I said, “Consider it as a test in life. Yes, a test for the sick and a test for me as your husband. If no one is sick, the doctor does not exist, the hospital does not exist. So, consider this disease as a test. And, as Muslims, we believe that if we accept, these diseases will eliminate our sins.” I just said to my wife, “*Allah* exists. *Allah* is close to those who are patient.”

It seemed that women diagnosed with breast cancer needed strong interpersonal support from their family. Moreover, the husbands in this study were always preparing themselves to assist and support their wives.

### Summary

This session has presented that the doctor played a significant role towards women’s decision-making process after the consultation. Some women realised their potential health problem and were being referred to the hospital, while some women experienced false reassurance or delayed referral by the doctor. After a breast cancer diagnosis, some women accepted it openly due to reasons such as their heredity, the high prevalence of the disease, as being a test from God, the doctor’s role or previous experience of benign lump while some women still needed more time to digest the information.

## 6.6 Pre-treatment interval

Pre-treatment interval started “between formal diagnosis and initiation of treatment” (Scott et al. 2013, p.51). This interval also depends on the availability and arrangement of the healthcare system and the patient’s input and decision. This interval will be ended if the patient decides not to accept the conventional treatment. However, since this pathway has a “forward and backward movement”, a patient who refused conventional treatment might, thus, consider alternative treatment or other things to do and reconsider conventional treatment if symptoms persist or change. Activities that the patients did before they started the treatment will prolong pre-treatment interval and indirectly delay early treatment. However, this interval was not only related to treatment, but other things that seemed important for the participants to share within their decision-making process.

### 6.6.1 Women and family members who were cautious about the food

Within this transition period, people may come to realise that they need to make changes to their lifestyles and environment. Some of the women in this study talked about their decisions to control their general wellbeing through diet. In Malaysian culture, certain foods are categorised as either “hot” or “cold”. In this study, some of the women talked about cold foods, because they believed that this type of food had effects on both their body and breast cancer. Therefore, they took precautions about the food they ate.

PT1 said:

I also took precautions about food. I didn’t eat meat. Cancer will grow very fast if you eat meat. Cold vegetables such as pumpkin, I didn’t eat. Nuts like groundnuts, I also avoided.

However, for FM1, he did not say anything about the food. This might be due to his situation, in which he was working away in another state due to job commitment and maybe he was also not aware about the food that his wife concerned and ate.

PT5 said:

When I went back home, I think a lot until I lost 10kg. Hurm, 10kg lost from 55kg. My weight turned to 45kg. I kept thinking. I rarely ate. I was worried. Abstained too. I didn't eat oily foods. I ate grilled fish. I avoided cold vegetables such as long bean, pumpkin, fern leaves. Fruits such as bananas, duku, *langsat*. All these foods can swell the nerves and make the lump get bigger. Moreover, if we take out the cancer, it will grow back on the other breast. It will get more and more. Because that thing was alive. It had a root. It can spread. That makes me feel afraid.

In this respect, both PT1 and PT5 had developed their own thoughts about certain types of food. Food is not only considered important for all living organisms, but it is also believed to have specific effects on ill bodies. According to PT1 and PT5, they believed that certain foods were associated with what is culturally considered as "hazardous". Using this cultural template, "these foods", such as meat, certain vegetables and fruits, tend to have a direct impact on breast cancer, promoting the growth of the cancer and swelling the nerves. This misconception made them afraid to eat those foods and they, thus, decided to change the pattern of nutritional intake in their diet. However, it is a fact that avoiding oily food is generally good for health. In this way, the women chose to take control of both their body and the progression of breast cancer through their food consumption.

In the narrative, the form of telling rather than the content also reflected a sense of meaning. In PT5's excerpt above, her stories seemed to resemble the chaos narrative based on Frank's illness narrative (2013).

Her speech was dominated by sentences that each jumped from one sub-topic to another, starting from when she went back home after her diagnosis to her loss of weight, loss of appetite, her emotions, food taboos and then back to her belief about the surgery and her emotions again. It is not difficult to understand PT5's speech, but some of her sentences did not make sense in terms of context. For example, when she said "I think a lot until I lost 10 kg." Although her overall sentences remained relatively intact, the concern is that some of the text does not flow well and this reflected the impact of the significant moments for PT5. The way she told her story revealed both her state of being overwhelmed and her anxiety concerning the effects the breast cancer were having on her, including her physical changes.

For PT5's husband, he showed his support by following whatever were his wife's preferences.

FM5 said:

Also, I have to be cautious about food. I cannot simply buy. Meat, I cannot eat at all. No sugar. Whatever my wife did not eat, I also did the same thing.

### **6.6.2 Women and family members who talked about their religious beliefs**

Religion is deeply embedded within Malaysian culture. Since part of our lives are beyond our control, people believe that God is required to intervene. People need to find an inner strength to cope with a disease such as cancer, which is considered to be a life-threatening condition. All of the participants in this study found tremendous solace in their religion.

During the pre-treatment period, the women with breast cancer and their family members acted by increasing their obligation to God

through their religious practices and opted to pray more. In their minds, they believed that God controls everything and was able to help them deal with the breast cancer, whether they were Muslim or non-Muslim. Thus, religion was a source of comfort and hope.

PT10 said:

I pray a lot. I said, “I have God. I believe in God. God only gave you upset. You can’t tell when you will die, I can’t tell ... I did my pray, pray, pray. Every day I pray. God is everything.”

FM10 said:

I pray to God. Pray a lot. My heart said, mmm my mum is still able to be cured.

PT5 said:

I prayed, *Hajat* prayer. Then, I recited du'a. I prayed, *Hajat* prayer. Then, I recited du'a. Every night I woke up for prayers with my husband.

FM5 said:

That thing [breast cancer] was related to death and life. She already had it. But I have to be patient. Have to be patient. Then, what should I do? Then, I prayed, *Hajat* prayer. Recited *du'a*. Requested from God. Because this thing happened from God. People said, “Test, test”. We have to be pleased. Be patient.

These narratives also reflect how the participants saw prayer as forming a close connection to God, and, through prayer, they saw God as controlling their health and recovery. The Muslim participants performed a specific prayer known as a request prayer or *Hajat* prayer, which is for a wish that they would like to see realised. By performing this prayer, they could request and bargain to God regarding the illness. They also believed that the breast cancer came from God and that only God was capable of curing it. God is the healer; accordingly, they asked God to cure their breast cancer. This provided them with a sense of security. By

having faith in God, they felt their battle with cancer was filled with hope instead of despair. By remembering God, they felt peace and gained the power to deal with breast cancer. This reflected the interconnection between what they perceived as the power of prayer and the sense of God's existence in their lives. Indirectly, these narratives seemed to represent another feature from Bury (2001) regarding contingent narratives, portraying how religious beliefs were able to shape the participants' accounts of how they coped and managed their illness.

### **6.6.3 Women and family members who were looking for information**

Accessing information on breast cancer was part of the personal responsibility of the participants. Some women and family members alike chose to find out more about breast cancer, ranging from the symptoms to treatment, after they had learnt of their breast cancer diagnosis. They used information from online resources such as the Internet and social media.

PT8 said:

Somehow, I also read the blog, Facebook, about what they wrote about this cancer, especially its treatment.

PT9 said:

I study from the Internet. I read all the necessary information. I have to read if I want to know about it.

However, the PT8's and PT9's husband did not mention anything about their searching information. The possible reasons might be they realised their wives had already read about it and shared with them or they actually did not look for the information about it because of the fear of knowing more about breast cancer. In contrast, within family members, only FM3 and FM10 shared their effort to look for information while the women did talk about this issue. This might be due to women

depending on their children to look for the information or they feared to know more about breast cancer.

FM3 said:

When the diagnosis was confirmed, I kept reading all the information about breast cancer.

FM10 said:

Then, my mom told me that the doctor suggested undergoing chemotherapy. Then, I searched everything for my mom. I searched for information through the Internet.

There were large amounts of relevant information available online. It seemed that the participants believed that the online information sources were to be trusted and could provide them with the information they needed. However, there was no certainty regarding the reliability and accuracy of the information since none of the participants talked about this in any detail.

#### **6.6.4 Women and family members who were concerned about work life**

In this study, some of the women interviewed had a strong commitment to their occupation. They decided to continue working as usual prior to undergoing treatment in hospital. None of the participants who participated in this study mentioned any financial difficulty in relation to their breast cancer.

PT8 and PT9 took only a few days' sick leave after they learnt about their breast cancer diagnosis.

PT8 said:

After that, next Monday, I went to the office as usual. I worked as usual. Nothing happened to me. I completed my work that was important first. The work that I can settle, I have settled it already.

PT9 said:

At that time, I was still working. At first, some friends realised that I was quiet. I did not want to talk much. I just did my work, because I did not talk too much, because I did not want to think. I did not want to remember.

In this respect, PT8 and PT9 continued to work with a normal routine and their stories reflect that their work life was not affected even though they had breast cancer. This situation enabled them to maintain a sense of control and supports what Bury (2001) refers to as the concept of normalisation. However, their decision to work might also have provided a distraction from thinking about their illness, as conveyed by statements such as "Nothing happened to me" and "I did not want to think." Thus, both of these participants demonstrated the use of some kind of coping mechanism by carrying on as normal and minimising their thoughts about breast cancer.

However, PT8's and PT9's husband did not say anything about their work. This might be because as FM9 is working as self-employed, he can have flexible time while FM8 might have felt that he had no problem in dealing with his work because he is one of the top authorities in the company.

#### **6.6.5 Women and family members who shared the news**

PT12 and PT9 decided to share the news with their family members soon after they had received their breast cancer diagnosis. This meant

they still had active contact with those family members; however, they also warned them not to disclose their diagnosis to other people.

PT12 said:

I still have a sister. I went to her house that night. I told her everything about what had happened. I also asked her to keep it secret from everybody. I don't want to worry them with my problem.

FM12 said:

When she told me that she was confirmed as having it [breast cancer], I was really shocked. Really shocked. I didn't know what I should say. I felt sad. I didn't know how she had it. Everybody was healthy. But when I looked at her, she just smiled. When she told the story, she was so calm. No crying. She said, "It's already happened, nothing I can do. Just undergo treatment." I didn't ask many questions, I was afraid she would be more sad.

In this respect, FM12 seemed to be a good listener who respected her sister's privacy and requests. She felt that she did not want to put more pressure on her younger sister and thus avoided asking for more clarification about her breast cancer. She portrays her younger sister as a strong woman.

Another couple, PT9 and FM9, reiterated that they just shared the news with close family members only.

PT9 said:

I didn't tell anybody, except my close family, like my mother, father, siblings. They knew about it (breast cancer), only close family members. I also reminded them, "Please don't tell anybody, I'm still not ready."

FM9 said:

When we knew this thing (breast cancer) happened, I met my siblings, parents, sharing the story with them. Everyone seemed shocked.

At later stages, however, PT8 and PT12 would have no choice. Their job requirements led them to tell their employers because they wanted to apply for sick leave.

PT9 said:

After some time, by hook or by crook, I had to tell my boss because of leave. So, I told my boss.

PT12 said:

I met my HOD (Head of Department). I did tell her my condition after I had met with the breast surgeon and the oncologist. I asked her to keep it confidential because I didn't want any attention. I told her that I would like to apply for sick leave due to the treatment.

However, one woman (PT14) felt more comfortable talking to her friend first after she received her breast cancer diagnosis, because she was concerned about upsetting her mother.

PT14 said:

Before I told my mother, I told my friend first because I didn't want my mother, mother shocked. I didn't want her worried about me. I told my friend. I shared everything with her.

PT14 took around a week to prepare herself because she did not feel ready to deal with her mother's response to her diagnosis. At the same time, PT14 decided not to tell everyone about her diagnosis because she still felt shocked and did not wish to deal with a wide range of feedback.

PT14 said:

At first, it was hard to say that I had cancer, but now I can tell people that I have cancer. One of the reasons was because I was also still in denial, and I couldn't anticipate their reaction. Some people will look at you and say, "I pity you, you're still young." Some people will be like "It's fine. It's fine. You can. Don't worry." I don't want to deal with all those mixed reactions. I do not like this feeling.

It seemed that PT14 was worried about how the people in her personal network would react when they knew about her condition. She believed they would look at her in either a sympathetic or insensitive manner, which might hurt her feelings.

Her mother (FM14) talked about her emotional distress and accepted the news as a destiny from God to her daughter.

FM14 said:

One day, PT14 came to my room. She said that she would like to tell me something. She said that she already met the doctor at TH hospital. Immediately I felt uneasy. When she informed me that thing (breast cancer) was confirmed, only God knew how I felt. Sad, confused, scared, chaotic, everything. I was crying until I was unable to control it. My eyes were swollen. Who would not be not sad? My daughter has cancer. I never imagined that she will get cancer ... I just accept it. I have to accept because illness is God's test. Allah has already stipulated that illness. It has its wisdom.

## **6.6.6 Conventional Treatment**

### **6.6.6.1 Women and family members who accepted conventional treatment immediately**

Conventional or hospital treatment such as surgery, chemotherapy or radiotherapy is widely recommended by most HCPs for treating cancer.

Thus, the HCP usually plays a substantial role within society to persuade and influence patients and their family members regarding conventional treatment. Thus, the interaction during the consultation phase is important for both parties.

One way that participants tended to make decisions was based on one person's knowledge or expertise in a particular area. Expertise is a form of power and the doctor is seen as an expert in treatment for breast cancer, at least in having the major say in how the decision was made. PT9 agreed with the doctor's explanation and recommendation with no hesitation. Her husband also recognised the doctor's credibility.

PT9 said:

During the meeting with the doctor, the doctor advised and explained clearly what I should do. So, the doctor recommended doing the chemotherapy first. Undergo chemotherapy to shrink the lump.

That's why the doctor said, if I did not undergo immediate treatment, it will, I'm afraid it will spread to another part of the body. So, I agreed. I started my chemotherapy.

The doctor gave me hope that I was able to recover if I underwent the treatment. The doctor put it like that. Huh! I followed the treatment.

FM9 said:

No other choice, we have to treat the cancer. I mean do the treatment. So, the doctor asked for chemo first to shrink the lump. So, we followed it, followed the suggestion, like that because the doctor is the expert.

The main plot in PT9's narrative is her conversation with the doctor, which reflected the cultural view of westernised medicine in terms of how to treat her breast cancer. This narrative seemed to resemble to what Frank refers to as restitution narrative (2013), in which PT9 told

the details of her illness from the perspective of treatment, namely what will be done soon. It is a story to portray that conventional treatment is the main preference to treat breast cancer. At this point, PT9 also demonstrated that the doctor had played a significant role in encouraging her to undergo conventional treatment and provided her with hope for the future. She believed in the ability of the doctor, who had already offered her good advice that was appropriate to her condition. Therefore, the relationship that evolved between PT9 and the doctor enabled her to rebuild her sense of self and the belief that she would survive. This is because PT9 actually felt threatened and associated breast cancer with death.

PT9 said:

Since I knew it was cancer, I could only think about that. I knew the consequences.

In the Malaysian cultural context, these sentences are interpreted as relating to death because of breast cancer, showing how Malaysian women deliver the message indirectly through their narrative. The above excerpt demonstrates the subjunctive element in the story, in which the participant visualises her possible future in her thoughts about breast cancer. Later, PT9 continued:

One more thing, I felt that there were so many things that I would like to do. So many things that I would like to try. I also thought that my daughter is still very young. Next year she will start school. I would like to send her to school. I would like to see her grow. What will happen to her if I'm not around?

... when I said that I want to get better, I will do whatever to get better.

At this point, there are two possible interpretations of how PT9 built her sense of self related to her decisions. Firstly, PT9 could be seen as

presenting herself as being optimistic about her condition. Despite knowing she had breast cancer, she felt motivated to do something in order to increase her chances of survival when she stated “I will do whatever to get better.” In contrast, the second interpretation might be that she is a pessimistic person. It seemed that she was not ready to face the possibility of death. She had many things that she would like to do and try. She also tended to have negative thoughts when she was worried about her daughter’s future. The above example illustrates that it was quite hard to form a definitive interpretation of the decision-making experiences in relation to the participants’ voice. These narratives, therefore, present the complexities involved. On the one hand, we can point to quite negative narratives in terms of the attitude, yet these are then countered, with a positive narrative on attitude. However, the interpretation was derived based on looking at many perspectives, such as the context of talk in Malaysian culture and the main point or message that she wanted to deliver to me, as the listener, at that time.

Further analysis of PT9’s story highlights that she also had certainty in her treatment decision. She felt that real-life experiences of successful treatment were more reliable than listening to what people said in general about treatment.

PT9 said:

I had an aunt that had breast cancer too. She has already recovered. So, many times I met her. She gave advice. She said “Don’t be scared to undergo chemotherapy. Just do it. I already recovered”, she said. Not fully recovered, but she already proved that chemotherapy might cause hair loss. She had demonstrated that her hair started growing back. She said. She said like that. She said that if she was able to recover, why wouldn’t I? I take it from that.

... Because I already had an experience. Like me, if that thing happened and I can see with my eyes, I trusted it.

... the real tip is we have to meet the real patients or survivors. Don't just talk to anybody and believe what they say.

PT9 believed that she would feel more confident if she had reassurance from a patient who had already undergone the same treatment. To ascertain whether a treatment is beneficial, one requires a comparison to the same treatment in another patient. As such, PT9 was more likely to accept the treatment because of her aunt, with whom she shared a similar cultural and social background and who had also had breast cancer and undergone chemotherapy. Thus, her aunt became a positive role model and this allowed her to trust chemotherapy as a treatment for her breast cancer. The positive feedback increased her confidence and provided her with a greater sense of control. Following the cultural practice of good example, her aunt's experiences motivated her to do the same thing as she viewed her aunt's survival as a positive sign for her own survival. Therefore, cultural norms and expectations play an important role in the decision-making process. This narrative conveys how PT9 drew together her experiences regarding her decision and changed her plot to present herself in relation to other people regarding her breast cancer decision-making.

Her husband, FM9 also talked about how their aunt always supported and assisted in the decision-making process.

FM9 said:

And even my wife's aunt also had breast cancer. So, we always visited her. She is the one who always gives advice, encouraging words. It was like her aunt became the source of reference for us.

Another example that showed family members experience with breast cancer is the influence on the decision-making process which could be seen in PT7's story. Even though her mother had already passed away,

she still remembers what her mother told her about the treatment for breast cancer. It seemed that PT7 tried to repeat the same decision based on what was beneficial from what she observed from her mother.

PT7 said:

Yeah, I still remember how my mother, my mother fought her breast cancer. Although she suffered because of the side effects of chemotherapy, she acted as though the treatment was no big deal. She was so calm and positive, I learnt from her ... My late mother told me that only chemotherapy could kill cancer. No other medicine.

In addition, she knew what to expect and realised that she could no longer take her life for granted if she did not get early treatment for her breast cancer. She felt that she did not want any suffering arising from the cancer being left untreated.

PT7 said:

I still want to do many things with my husband. And if I don't get the treatment, my cancer will get worse. And I don't want it happening to me.

Other than being influenced by other people, PT7's decision to have breast cancer treatment also resulted from a sense of desire to survive. Her positive attitude indirectly influenced her treatment decision.

PT7 said:

After I was diagnosed [with breast cancer], my main goal was to get healthy again ... I told myself, "The quicker I get better, the better it will be."

Another woman (PT14) was confident in the drug being used to treat the breast cancer, even though her meditation trainer had advised and convinced her to decline the conventional treatment.

PT14 said:

Because the chemotherapy is scientifically proved. Other things are based on people, people's responses.

My yoga instructor said, "Don't do [chemotherapy]" because she said, "Our body is like a miracle, it can heal inside", like that, she said it like that, so I trusted her.

Her mother (FM14) also supported her decision.

FM14 said:

When I knew she had cancer, I asked her, "What should you do?" She said, "The doctor said I have to have chemotherapy." I just followed whatever she wanted to do. Whatever happened after that, I did not regret it because that is what she wanted. We, as parents, try to do the best for our child.

While the above accounts relate to confidence, the following example relates to self-determination among one of the women with breast cancer.

PT6 said:

Of course, I want to cure my disease ... I have to undergo treatment if I want to get better.

At this point, PT6 decided to accept the suggested treatment because she wanted to get rid of her breast cancer. Therefore, her decision to pursue breast cancer treatment emanated from a sense of desire to live. Her narrative suggested that she regarded breast cancer as something that had to be dealt with in order to become healthy again.

Her husband, FM6 also supported her decision.

FM6 said:

I asked the doctor, what should we do? Doctor suggested chemo, so we agreed. That's all. So, when the time to have chemo, I sent her to the hospital.

Another family member (FM13) agreed that the advice and encouragement from a breast cancer survivor at the very least provided guidance, helping them to decide on hospital treatment.

FM13 said:

When we were inside the doctor's room, there were two other patients sat behind us. It was like a blessing in disguise because they were breast cancer survivors. So, they supported us. They said, "We already went through it. We've already had our treatment. *Alhamdulillah*", they said like that. So, they could indirectly have been good role models for us at that time.

Since FM13 and PT13 interviews were conducted together, PT13 seemed to agree by nodding their head when FM13 talked about this event.

#### **6.6.6.2 Women and family members who refused immediate conventional treatment, but later accepted it.**

Surgery represents one of the central components of breast cancer treatment, but some of the women immediately refused surgery during their consultation sessions. The following extracts illustrate how some of the women in this study made a connection with their fear of surgery as a reason for refusing treatment, even though the doctor tried to convince them to undergo surgery. This illustrates the inability of some of the women to rationalise the advice from the doctor and their decision to take responsibility for their own lives at that time. A diagnosis of breast cancer did not, therefore, necessarily lead to acceptance of the conventional treatment.

PT1 said:

I went to see the doctor. The doctor said, "Remove the whole [breast]." "Eh, I don't want that", I said. "I don't want to remove it.", I said. Then, the doctor said, "You cannot be like that, aunty, the doctor said. "You cannot be like that aunty. It is dangerous", the doctor said. "I'm afraid that it will spread." After that, "It is fine", I said. "Let it be, if it wants to spread or whatever", I said. I really did not want to have it removed.

I was afraid. Because of being afraid, I was thinking about my children, grandchildren, husband. What would happen if I died during the operation?

PT3 said:

I should be operated on early, but I said, "It's fine. I didn't want it." At that time, I couldn't think about anything ... I wanted to calm myself first. Afraid, I was really afraid about what would happen next.

In this respect, it seemed that these women made a connection between surgery and negative consequences because they were fearful of undergoing surgery. They may have considered the surgery to be a life-threatening procedure rather than a cure. These situations indicate that these women in this study believed they faced a greater likelihood of dying either during or after the surgery than as a result of having untreated breast cancer. These subjunctivising elements in the above accounts regarding the women's possible future outcomes had thus influenced their decisions. These findings also provide new meaning to the treatment and its consequences in a new world of social reality. People talk about treatment which creates a different dimension rather than talking about illness as a narrative, as suggested by Hydén (1997).

Other than fear, how the treatment was presented to the patient through the language used by health professionals might have influenced the patient's decision at that time. Referring back to PT1's narrative above,

the phrase “Remove the whole [breast]” may be considered to have been conflicting and fearful phrases for PT1 for the first time.

FM1 and FM3 also agreed when these women (PT1, PT3) decided to refuse treatment because they realised that they were not emotionally ready.

FM1 said:

But at that time, she said that she didn't want to have it removed. I knew she was sad. I just followed.

FM3 said:

Maybe because my mum was shocked when she heard that (breast cancer). When the doctor suggested to operate, if not the condition would get worse. I just let mum calm down first. Not force her.

During the interview with PT1, she often talked about her husband in her storyline. Her husband appears to have been an important person whom she continually relied on, starting from when she found the breast lump to undergoing a mastectomy. This is one example of how the plot in a narrative can be used to interpret the story, wherein it indicates to me that PT1 values her relationship with her husband.

PT1 said:

My husband kept persuading me. At first, I still refused. Because I was afraid. But, after some time, my heart melted. I agreed to do the surgery with the support from my husband.

At that time, I could see my husband's effort in trying to persuade me. He never gave up. Sometimes I felt like he begged me. That's him.

At this point, it seems that her husband's effort was not a one-time occurrence; thus, it happened over and over again, as seen in “kept

persuading" and "he never gave up". This repetitive action was able to change PT1's decision. When PT1 said "That's him", I interpreted it as her expression of her husband as a very loving and caring person. Her husband always supported her. This account suggests that the wife's decision to undergo treatment might have links to the way a woman feels, loves and cares about her husband.

For FM1, even though he supported his wife's decision to refuse the treatment, he did not stop there because he understood the importance of treatment after he met with the doctor who was treating his wife. He took an active role and did not give up on convincing his wife, although it took some time.

FM1 said:

I met the doctor at the hospital. The doctor said, "Her [breast] cancer can still be treated because it is still at the early stage, but we have to do it quickly. If we just let it be, I'm afraid of it getting worse. When the lump grows bigger, it is more difficult to treat. Then it will spread to other parts of the body. At that time, we cannot do anything."

At first, it was quite hard for me to persuade my wife. I knew she was sad. I just told her that surgery was the best treatment if she wanted to treat her breast cancer. Every day, I tried to persuade her to undergo the treatment. I asked her, "What will happen if you don't undergo the treatment, and just let it be like that?" At first, she refused, but I stressed to her, "If you don't undergo treatment, your condition will get worse. You must be strong to accept this entire test, think about your family and children." I told her like that. I told her about the effect if she did not remove her breast cancer. The doctor had already told me. I always advised her. Finally, she agreed to undergo treatment, which had taken nearly three months for her to agree. That made me really happy.

This story outlines how FM1 portrayed to me his identity in his role as a husband who was aware of and cared about his wife's health. He tried

finding ways to support his wife after she was diagnosed with breast cancer. He used a psychological approach to persuade her to seek treatment by talking about family and child-related matters. FM1 reflected on his experiences as a moment of success when he stated “That made me really happy”. His efforts to take control of the decision paid off when his wife agreed to undergo surgery. Gradually, FM1 changed his role from being a supporter to an influencer of his wife’s decision regarding the treatment for her breast cancer.

The decision to undergo treatment was also driven by the women’s positive attitude. Self-confidence in this study served as an inner motivation that influenced PT3’s decision to undergo hospital treatment. Referring back to an earlier point, PT3 delayed her conventional treatment due to fear. However, during her period of delay, the support she received from her children regarding the surgery was able to slightly build her confidence in her sense of self and the conventional treatment.

PT3 said:

But I thought that if other people can do it, then so can I. I said it was fine. Other people were fine. Nothing happened. Just operate. I thought like that.

FM3 said:

At that time, mum was okay. She was ready for operation.

With regard to PT3’s account, she portrayed her ability to confront the fear and think positively about the treatment. She made social comparison with other people in a way that conveyed equitable and positive outcomes of the treatment. PT3’s narrative represents the impact of temporality on the perception of conventional treatment and how this perception can be affected by time and context.

Another woman, PT5, also explained that she was afraid to undergo surgery. At first, she appeared concerned about her body rather than the treatment when she stated, "I did not want to lose my breast".

PT5 said:

Then, the doctor said, "Sister, we should remove it [breast cancer]. If not, it will get worse, spreading to other parts." At that time, I really didn't want to have my breast removed. I was afraid. I did not want to lose my breast. I said to the doctor, "I do not want to remove it yet."

However, further analysis of her interview revealed an unfolding story in which she also had her own thoughts about treatment for breast cancer. She believed that the breast cancer would recur and spread if she had it removed and that the surgery would not be effective in preventing this condition. This is an example of recognition of typical cultural belief about the treatment that was valid for her at that point in time.

PT5 said:

If we take out the cancer, it will grow back on the other breast. It will get more and more. Because that thing was alive. It had a root. It could spread. That made me feel afraid.

Her husband, FM5, felt that his wife had the right to make her own decision about her body and life. He aimed to support whatever choices she made.

FM5 said:

I asked her. I asked. I said, "So how? If you want to remove, remove it. It's up to you." Because this thing involved her. Only she felt that. I can't tell. I can't tell. If I forced her, I worried something else would happen. So, I didn't force. It depended on her. If she wanted to remove it or not, I just followed.

It seemed that FM5 exhibited mutual respect and trust regarding his wife's decision. However, I acknowledge that this is an example of how the details of the story were not asked about during the interview. I am now wondering what he meant when he said "I worried something else would happen"; was it negative behaviour or perceptions that he was worried about?

Not being able to imagine being diagnosed with breast cancer, PT8 chose to portray her condition within a story of trying to delay the treatment. PT8 said, "but I did not suspect at that time that it was cancer." Thus, she wanted a reasonable period of time in which to accept her diagnosis. She managed to convey a sense of it being a negotiation in order to make sense of what was happening to her.

PT8 said:

So, of course, the doctor wanted to operate by tomorrow. The doctor asked to do the surgery immediately. But of course I, I needed some time first, to think so many things through. It was not easy, I wanted to have the [operation], just like that, right. So, I just went travelling as usual, but I still had alternative treatments like homoeopathy, Islamic treatment, traditional treatment. I tried to take a supplement. I changed my lifestyle. I went to the gym. I changed my diet.

After PT8 had delayed her conventional treatment, she adopted a healthier lifestyle with the aim of bringing herself into balance. Her actions of taking exercise, improving her diet, taking a supplement and having a holiday all reflected her strong resolve to improve her physical or psychological wellbeing. It seems that PT8 chose to take control of her body by making great efforts to manage her condition despite the fact that she had delayed the conventional treatment. PT8's narrative suggests that she was not going to allow her breast cancer to impede her life or otherwise affect her activity. As the account progressed, she

described what she meant by saying that she needed some time when I prompted her for further clarity.

PT8 said:

I took time to calm my mind. After that, I had to settle my work. I had to apply for a long leave. I then settled matters with my children. After that I thought, I planned. “Okay during the sick leave period, what should I do?” I had to make sure that I was not bored. I had nothing to do. So, I had to plan because I knew myself, what I like to do, whatever.

At this point, there were four possible interpretations with regard to PT8 building her sense of self related to her decision. Firstly, she seemed to portray herself as someone who needed to feel in control. It appeared that PT8 was more concerned about other matters that seemed more important to her than about her breast surgery, and this situation demonstrated how she expressed her identity as someone who is in control of her life. Secondly, she portrays herself as a busy professional and mother who needed to get everything organised and planned ahead of time. This meant that she had to rearrange her activities according to her preferences. Thirdly, she is portraying herself as someone who did her best to try the remedies recommended to her. Finally, it is possible that she needed more time to adjust emotionally as well as practically with regard to her diagnosis of breast cancer.

PT8 later talked about how she already had a considerable amount of time to prepare herself for surgery and made her own decision to undergo surgery when she was satisfied with her own life.

PT8 said:

So, the most important thing before that surgery is to make sure you do anything you want to do, anywhere you want to go, you feel like you want to go for any kind of holiday

whatever, do it first. I did all that. So, when I underwent that surgery, I did not feel trapped at any point. I felt relief. I felt sincere. I felt ready to do it.

PT8 talked about doing her best to lead as full a life as possible, yet she also acknowledged there were times that she might have to face unexpected outcomes from her treatment. She could have been preparing herself for an unexpected future. When she stated, “I did not feel trapped at any point”, this can be interpreted in the Malaysian cultural context as having no regrets if anything were to happen to her after the surgery. In this context, it appeared that she was saying that she was prepared for any consequences after the surgery. Therefore, the turning point for PT8 in accepting the treatment was her preparation.

As a husband, FM8 supported his wife’s decision to refuse conventional treatment at that time in order to avoid tension.

FM8 said:

So, as a husband, I followed because I didn’t want her stressed. Because only she knew when she felt ready.

FM8 later talked about how he provided emotional support by demonstrating his empathy, concern, love and acceptance towards his wife. He believed that being healthy was more important than the loss of the breast. This situation conveyed to me that the husband did not care about the changes to his wife’s body, despite the fact that the breasts are regarded as a symbol of women’s identity.

FM8 said:

She asked me, “Is it okay, dear, if I’m not perfect as your wife?” I said, “It’s fine, I accept you as who you are.” I said to her, “Whatever you look like, that is you, you will be my wife forever.” That is what I told her. “It’s fine if you want to remove

[the breast].” I said “I don’t care as long as you are healthy. Our children, myself, we still need you.”

At this point, FM8 needed to reassure his wife that her physical changes had not altered their relationship. It seemed that his wife was worried and needed to know whether or not FM8 would still love her. In this respect, the husband needed to be sensitive to whatever concerns his wife had.

Other people were considered as another influential factor of the decision-making process in this study. Individuals interact with others, sharing experiences mainly when they suffering the same illness. FM4 reported that other patients with breast cancer influenced the ways her decisions was made. Early on in her account, while she was in the investigation phase, she decided to accept surgery if her lump was confirmed as being cancer. It appeared that she had positive responses in the first place regarding the treatment for her breast cancer.

PT4 said:

The doctor said during the ultrasound, “This is not good, not fine.” The doctor said, “You may have cancer”. The doctor said, “If this is cancer, you should not seek treatment at an inappropriate place.” I understood what the doctor meant by inappropriate place. Like using traditional remedies, seeking a traditional practitioner here and there. Indeed, at that moment I had also, when the doctor said that, I had already decided to myself that if it was confirmed to be cancer, I wanted to have the surgery immediately.

Later, however, PT4 recounted talking to another patient with breast cancer while waiting to meet the surgeon; consequently, that interaction changed her decision from one of agreement to her refusal of surgery. In this narrative, PT4 constructed a coherent story that connected to

others, drawing upon her personal story and the other people in her local community in order to make sense of her decision.

PT4 said:

I then met someone, at that hospital. She had cancer too. She had had the operation and had undergone chemo. She was telling me her stories (p), of her chemo (p). It was really *terrible, horrible* (p). While listening to her story [laughing], I felt a little afraid. When I went into Doctor H's room (p), I didn't know. I can still remember how many hours it was (p), I stayed in Doctor H's room for a long time. Of course, I can still remember that time. He persuaded. He elaborated. He also showed pictures, of how that cancer spread inside the body. That persuasion still did not affect me. Then I told Doctor H, "Doctor, let it be, I want to think about it first. I want to go home to think about it first."

Then, Doctor H did not force me nor did he do anything. Because he said, "Nobody can force you to have the surgery if you do not want it." He repeated, "Exactly, cannot be forced."

At this point, PT4 expressed that she was influenced by another patient who had had a bad experience, leading her to believe her story rather than the doctor. She also stressed the keywords "terrible, horrible" to represent the effect of conventional treatment as being really bad. She also remembered how she felt at the time when she stated "I felt a little afraid". PT4's account suggested how she reflected on the moment that had a significant impact on her decision. I profoundly felt this moment through those seconds of silence, "(p)", during her storytelling. The laughter seemed to represent not only her perception about the treatment, but also a sociocultural position as a moral basis for the story, which she later mentioned in her narrative. Although the doctor she consulted made an effort to convince her to undergo treatment, she was still unable to overcome her fears of cancer treatment. It appeared that the doctor's information was still not enough to influence her decision. Moreover, it was PT4's choice to decide whether or not to

undergo surgery. She was apparently faced with the opportunity to make an autonomous decision, and she chose to refuse the treatment.

Later in her narrative, PT4 also shared how bad stories about treatment for breast cancer were inbuilt within her social context. These awful social stories were then incorporated into her own breast cancer narrative and were attributed as another cause when she spoke about her treatment decision. The following extracts are taken from different parts of PT4's recounts, demonstrating that the story was not necessarily in chronological order and how memorable, influential and important these stories were for her.

PT4 said:

Because I really got scared, listening to other people's stories. Because they did not get better after being operated on. The wound then got pus. So, I was really scared actually.

... the story that I listened to before. Like when she got a wound, after the surgery, the wound did not heal. The doctor let it be, just like that. When I heard many people had had bad experiences, I was very scared ... And when you're scared, scared is always there when listening to the bad, bad case.

People asked me not to have the operation, they said it is dangerous, that it would not not get any better if it was touched with a knife.

She described how the sociocultural template of awful stories, which all portrayed the negative effects of surgery, led to PT4 believing them, thereby influencing her emotions and, subsequently, her decision. Surgery for breast cancer was primarily related to non-healing of the body; for example, surgery is associated with stigma within her culture, that any metal object has an effect on the healing process of breast cancer. Within this cultural template, the instrument to be used during

surgery was portrayed as “risky” and should thus be avoided. She felt afraid and worried that she would also experience the same conditions.

In this respect, it seemed that PT4 had constructed a new understanding of the hospital treatment for breast cancer in light of her attempts to make sense of her decision. Surgery would not only fail to cure the breast cancer, but its consequences would make the breast cancer worse. Her narrative presents how these events became interrelated when she appeared to make relational links between them. Meeting with a patient who had had a negative experience with breast cancer, listening to other people’s stories and the myth prevalent within her local society regarding the treatment meant that she believed in the veracity of these things and they, thus, came to influence her decision to refuse conventional treatment. These stories seemed to illustrate Bury’s idea of moral narratives (2001), in which an evaluative aspect is given through the linking of personal and social factors.

Later, PT4 expressed her reaction to her decision to delay the treatment, thus suggesting a sense of caution about what had happened to her. This excerpt also revealed the important lesson or moral of the story that I, as the listener, could learn from her experiences.

PT4 said:

... don’t listen to other people’s story, don’t believe what they told you, because I already experienced it.

Therefore, I would argue that these examples exemplify how acquaintances with negative stories and sociocultural beliefs have the ability to shape some women’s thinking about breast cancer treatment. This is not surprising given that Malaysian people tend to be society-oriented, have close relationships with other society members and easily believe their personal views or stories. The issue is that these stories

come to affect the women's treatment decisions, as has been recounted during the interview process. On the other hand, these narratives portray how women construct a sense of themselves, in relation to other people in their community.

PT4 reflected on her promise to the doctor who treated her and how she had decided to undergo chemotherapy because of her respect for that doctor.

PT4 said:

After that, I gave the result to Dr. S. I still did not want. Still did not want. Still did not want to undergo chemotherapy. I requested more leave for a week until Dr. S got irritated. "Do you know sister, your cancer has already spread to the liver and lung", she said. "You still do not want it", she said. "It is fine." But, under that situation, she still gave me, she still gave me an M.C. [medical certificate] for another week. Then, since I already made a promise to her [the doctor], the following week I was admitted to the ward. I got admitted. I was admitted to the ward and had the chemo.

However, further into her narrative, she spoke of how her symptoms had worsened over time and she felt unable to cope with the situation. This suggests she was willing to deal with the pain to the point at which she could no longer simply ignore her condition. She had suffered for nearly seven months and that had really made her feel very ill.

PT4 said:

Before that, I still remember when I was coughing. If I ate, I had to eat in a small amount; if not, I would choke. If I drank water, I had to drink slowly. I could not drink a lot. If I drank a lot, it made me cough. It would all come out, all coming out through the nose, through the mouth. Everything was really coming out. When I had that coughing, I really felt, I felt like I was nearly dying. I really couldn't sleep because of coughing. If there was a fan like this [pointing to ceiling fan], even in daylight, I could not lie down, not even just a bit.

My back was hurting, I didn't know how to explain. And with the coughing, I couldn't sleep at all at night. I was really not feeling well ... But I did not know why (p), presumably no other choice, perhaps due to the unbearable pain. I had been suffering from coughing for quite some time. The coughing never stopped.

However, PT4's husband explained that he rarely accompanied his wife to the hospital because he was working in another state. He only updated the information by phone or when he came back home.

Similarly, another woman (PT5) experienced a worsening of her symptoms.

PT5 said:

At that time, I didn't think. I couldn't do anything with the breathing difficulty. I was really in pain. I said, "Doctor, you can do whatever you want, I'll just follow. I can't cope any longer. I felt that I was going to die."

At this point, PT4 and PT5 were suffering incredible pain, feeling that they were in an unpleasant situation when they stated, "I felt like I was nearly dying" and "I am going to die". People tend to have negative thoughts when they are in extreme pain. I refer to these accounts as defining moments, as the women chose to illustrate to me how they had suffered from untreated breast cancer. They spoke of their symptom changes, of feeling differently about themselves and becoming empowered to take control of their condition and their lives. Indeed, the pain was considered as the trigger or turning point for PT4 and PT5 to undergo hospital treatment.

However, referring to PT4, while she was undergoing chemotherapy, her conversation with the doctor conveyed how she constructed a relationship between her illness, faith and medicine. She also echoed the idea of Frank's (2013) restitution narrative, which reflected her sense that she was healthy at present, although she knew she was not as healthy as she had been prior to her breast cancer.

PT4 said:

Doctor W told me, "When I saw you, I knew that you were healthy", he said. It means that he said that chemotherapy was appropriate for me. "That's right doctor, all these", I said, "It's already fated that chemotherapy is appropriate for me. Moreover, the supplements that I took previously might also have helped.", I said. "Moreover, it's not the time for me to die yet. Like this doctor, when the time comes, we still die. If not the time yet, we get healthy", I said. Then, Doctor W said, "Usually the patient has a loss of appetite. But I saw you are healthy." "Yeah. I feel that I am healthy", I said. Because my appetite was okay, I always eat. *Alhamdulillah*, till today. I didn't want to think about cancer that had already spread, I don't want to think about that. I said, "Let it be. If that is my fate, I accept it. I don't want to think, I don't want to get a headache, I don't want." If I think it [spreading cancer] is still there. I just want to undergo chemotherapy.

This study also revealed how some women talked about their illness experiences from two perspectives depending on their condition at the time of telling their story, their illness perspective and as a healthy person voice. According to Radley (1994), "it is one thing to talk about health when hale and hearty, another thing to give one's views when suffering a serious illness" (p. 37). Thus, it is possible that people will discern different perspectives of themselves because it depends on which voice they are speaking with and to whom they telling the story. Referring back to PT4's story, when she talked to me about how she suffered after refusing conventional treatment, she presented herself at that time from the perspective of illness, and on another telling, after

having undergone chemotherapy, she chose to present herself as a healthy person because she felt better. Therefore, as people tell their stories, they can choose how they present themselves; time is captured as an integral part of the narrative, as I could hear how PT4's presentation of herself shifted in her telling of her experiences.

### **6.6.7. Alternative treatment**

#### **6.6.7.1 Women and family members who used alternative treatment**

In this study, some of the women with breast cancer and their family members also talked about alternative treatments, such as the use of traditional treatments, Islamic treatments, dietary supplements and herbs to treat breast cancer. Many people still preferred to opt for alternative treatments first, thus delaying the time for conventional treatment. The use of alternative treatments could, thus, be considered as one of the causes of delayed treatment among the women with breast cancer. However, all of the women in this study who opted for alternative treatments were among those who had either delayed or refused conventional treatment in the first place. This situation illustrates how the participants in this study perceived the choice of treatment as being a single discrete area, situated between conventional or alternative treatment, as opposed to a combination of both.

##### **6.6.7.1.1 Traditional treatment**

Traditional treatment is popular within Malaysian culture as a form of treatment for many diseases including cancer, orthopaedic conditions, mental illness and so forth. The role of traditional healers is so embedded among the society members that, at times, they are the first ones to treat the disease. In this study, some of the women and family members decided to try traditional forms of treatment in a bid to heal their breast cancer. The following extracts relate to how some of the women made decisions to try traditional treatment.

PT8 said:

There were people who shared on Facebook or whatever about traditional treatment. Then about Islamic treatment. Huh, just like that. I just tried it. I just went there. For me there was nothing to lose if you would like to try anything else, but you cannot lean to one side only. You have to balance. You cannot say like "Ooo, this was good, this was not good." For me, I just tried it. Nothing to lose. So, I just followed. People said, "Go there", so I went there.

The traditional healers did not say anything bad about cancer. They said it still can be treatable and to continue the treatment. They gave advice about prohibited food like red meat, long bean. They gave water too.

PT4 said:

I did somehow use traditional remedies. I went for a spell. I went there. I would go if I heard that someone is able to heal, but it was not a ridiculous treatment, just chanted water. The traditional healer asked to find remedies like plants.

Usually I went there three times. Three times I went to each person (traditional healer). After three times, I stopped. I followed the old people's advice previously, in which it is enough to see them three times. After three times, the condition is okay, considered okay.

PT5 said:

When I went to the hospital, while waiting for the doctor, there was one person, and she asked, "Did you try any traditional treatment?" I said, "No, I can tell you, there is a traditional healer, just try it." So, that person asked me to go there. I went to the place where that person told me. That traditional healer told me that I had a lump. That was the traditional part. Then she made chanted water for me. She said, "Everything belongs to God. We just try. No harm."

One traditional healer gave me slaked lime. She prepared the slaked lime. She said that slaked lime is able to restrict the lump's growth. She asked me to recite *Three Quls, Ayatul-Kursi* and *Al-Fatiha* (Holy Quranic verses) before I applied the slaked lime to the lump. Like that. She also recited *d'u'a*

(invocation). She asked me to apply it to the lump by myself ... another traditional healer gave me oil. Cooking oil. She prepared the oil.

These women decided to try traditional treatment because they felt it would not harm their conditions. Plain water, plants, slaked lime and cooking oil were considered to be natural remedies, which they thought would not be harmful to their health. It is clear that they expressed a sense of reassurance and safety with regard to the usage of the traditional treatment. Additionally, the traditional healer related the effectiveness of the treatment as depending on God's will and recited verses from the Holy Quran as part of the preparation for the remedies. Indirectly, this practice enhanced the confidence of and encouraged the Muslim woman in this study to use traditional treatment. This demonstrates how religious belief and practice influenced the women's treatment decisions. However, none of the non-Muslim participants in this study had tried traditional treatment for their breast cancer.

PT4, PT5 and PT8 described how their sources of information for traditional treatments were social media and the people in their community, thus suggesting that these sources influenced the women's decision to try traditional treatment in this study. For PT5, specifically, she obtained information about traditional treatment through informal dialogue with someone she met in the hospital and this became the trigger for her to try alternative treatment. PT4 had met five traditional healers, PT5 met three and PT8 met four traditional healers prior to undergoing conventional treatment, thereby suggesting that they still recognised and believed the relevance of traditional treatment for their breast cancer. Moreover, specific to PT4, she believed that she had to complete traditional treatment three different times for the healing process based on her sociocultural belief. Therefore, traditional treatment could be considered as one of the reasons for delaying the

time for hospital treatment among the women with breast cancer in this study.

Family members also promote traditional treatments as an option for treating breast cancer. FM4, FM5 and FM8 actively sought traditional treatment for their wives.

FM4 said:

I bought her a supplement, tried traditional treatment, found the remedies that the traditional healer asked for ... We just tried it. *Allah Almighty* heal. For me, it's fine to try, who knows if it is suitable, she will recover. As long as it is not contrary to religion, I just tried it.

FM8 said:

We made a second option before undergoing mastectomy. We had a second alternative. We went to, followed whatever people said about the treatment. I had spent a lot of money at that time, but it was fine, for her. At least, when she looked at my effort, she got more enthusiastic ...We tried a lot of things. We met this Islamic practitioner, that traditional healer, we tried as an attempt to treat her disease.

PT5 said:

We met the traditional healer. Yeah, to treat her. She gave the remedy that she did by herself. She gave slaked lime. Then, a water. A lot of water. We met three traditional healers.

The above narratives portray how the husbands focused on their effort by attempting other treatment options that were available in the belief that trying various treatments would increase their wives' chances of recovering from breast cancer.

#### 6.6.7.1.2 Islamic treatment

In Malaysia, Islamic treatment is accepted as one of the methods for treating many illnesses, including breast cancer, among the Muslim population. Recommendations from family members influenced PT8 to seek an Islamic healer. She received chanted water and selected verses from the Holy Quran to read as the treatment.

PT8 said:

My family suggested seeking Islamic treatment because they said it might terminate the cancer.

That Islamic treatment, s/he also gave the water. So, s/he recited some Holy Quran verses to that water. Then s/he gave a note, you have to read certain verses, certain Surah, certain verses number. Huh, that's all s/he gave. So, just practice.

Similarly, PT5 talked about Islamic healing to treat her breast cancer.

The “ustaz” (Islamic healer) just gave a bottle of water and asked me to recite selawat (praise to Prophet Muhammad) and several Quranic verses before drinking it. Moreover, all disease came from Allah. So, it's acceptable to try. At least we tried.

In this study, the husbands were supportive of their wives trying Islamic treatment for their breast cancer. FM5 and FM8 believed that God had the ability to heal their wives' condition and delay the development of breast cancer.

FM5 said:

Then we met the Islamic treatment practitioner as an endeavour. All those diseases belong to God. Healing also belongs to God ... the Holy Quran itself has miracle as healing power.

FM8 said:

We met an Islamic treatment practitioner, we tried to do many

things, this treatment might slow down the progression of cancer. We put our trust in God.

#### **6.6.7.1.3 Dietary supplements and herbs**

Some of the women decided to take a specific product, in the form of a dietary supplement or herbs, to treat their breast cancer. They, thus, spent money on buying supplements and herbs.

PT4 said:

After that, I started buying a supplement. At first, I took K [brand name]. It was about *Ringgit Malaysia* (RM), six hundred per week ... Within two years, I felt that I had spent nearly thirty thousand RM on buying supplements.

... herbs like mushroom, tiger milk mushroom, I also got it. I blended it. I applied. People said it could cure cancer.

PT8 said:

There were people who talked about Sabah Snake Grass [*Clinanthus nutans*], so I tried it. I drank it ... somebody said that the effect was almost like chemo, and then, they said it would reduce the size, reduce the cancer size.

PT4 and PT8 seemed to trust the information given to them by their community regarding the effectiveness of herbs to treat their breast cancer, thus revealing that the social members in the community had influenced the women with breast cancer's decision regarding their intake of supplements and herbs.

#### **6.6.7.2 Women and family members who did not use alternative treatment**

Only three of the women in this study shared their decision to refuse alternative treatment. One of these participants (PT9) spoke at length

regarding her disagreeing with the use of traditional treatment for breast cancer.

PT9 said:

Some of them would like to bring certain people [traditional healer], using traditional treatment. I said, "Please, I am not ready", I said, "No." For me, if there was no proof that the patient recovered, I really didn't want to go there. Of course, people said, "Just try", but for me, I saw the doctor first, except the doctor could not do anything. There was then no other choice I could try. But it was not like me to seek traditional treatment first. Because I also said that there are many specialists nowadays. Many specialists, so why should I seek another thing. Why do I have to believe another thing?

With other people's suggestions about traditional treatment, I still did not know whether I was getting better. I said, "Just apply the remedy, but this lump is located deep inside the skin. Can it reach it?"

There were people who said "You apply for this medicine. You apply, you apply." Then when you see the doctor, the doctor says, "No need to operate." I said, "I cannot apply like that, that thing deep inside", I said. "I have to use the medicine that goes inside." If I follow this thing, I don't know what will happen to me now.

In this respect, PT9 explained her belief in the uselessness of traditional treatment for treating breast cancer. She questioned the effectiveness of a remedy. In addition, she portrayed herself as someone in control of her decision despite being faced with many people around her suggesting that she try alternative treatment. PT9's narrative is akin to Bury's concept of moral narratives (2001) that give an evaluative dimension by linking the personal with the social influence. Indirectly, PT9 also felt pleased with her current situation because she did not follow other people's suggestions about traditional treatment for breast cancer; as she stated, "If I follow this thing, I don't know what will

happen to me now." Her story illustrates that PT9 was talking about the past to make sense of what was happening in her present situation.

Two women presented a view of why they refused to take a dietary supplement. PT7 decided not to take dietary supplement after what she had witnessed from her own mother's experience, which had led her to question its effectiveness.

PT7 said:

I also didn't take a supplement, because I saw my mother take many supplements, but with no change. She took a supplement, tried to reduce the effects of chemotherapy, but there were no changes. So, I felt that buying a supplement would just be a waste of my money, and some of them are very expensive.

Another woman, PT12, also decided to refuse a dietary supplement. Her background as a teacher made her worried about the possible effects of unknown biochemical products on her breast cancer.

PT12 said:

I didn't take any supplements or whatever. I didn't. I just followed treatment. Just followed. And as a bio [biology] teacher and teaching a pre-year programme, I knew that I didn't know whatever clinical [product] you took. It might have a chemical reaction, which may affect each other or not. Then, what will happen if the supplement is not okay? Who are we supposed to blame?

However, none of the husbands talked about the alternative treatment, possibly because their wife did not use that.

## Summary

This section has presented the ways in which the women took control of their diet, continued to work actively and shared their diagnosis with their family members and employers. The family members always supported the women's decisions and provided them with physical and emotional support. They also looked for further information about breast cancer and enhanced their religious practices.

The narratives so far presented have highlighted a number of factors influencing those women who opted to undergo conventional treatment: personality, the role of the HCP, their husbands, breast cancer survivors and their worsening symptoms. This study also revealed that not every woman agreed with alternative treatment. Some of them refused such treatment because they did not believe it was effective to treat breast cancer. For the family members, the main factor that influenced their decision to support the women's conventional treatment was the readiness among the women with breast cancer themselves.

# Chapter 7: Discussion

## 7.1 Introduction

This study was motivated by the argument presented by Norsa'adah et al. (2011) stating that breast cancer morbidity in Malaysia is a consequence of delays in consultation and diagnosis. Malaysian women tend to take a longer time seeking their first medical consultation and being diagnosed compared to women in Thailand (Poum et al. 2014), which has led researcher to believe that Malaysian women are more likely present with advanced cancer at initial diagnosis. This suggests that women encounter delays at both the appraisal and diagnostic intervals. By examining the women's narratives that were constructed for this study using Scott's model pathway to treatment, it is possible to raise a debate about this explanation. Additionally, some of the findings have been discussed based on the Health Belief Model and the health locus of control, which consider belief about health determined the subsequent behaviour.

## 7.2 Model pathway to treatment (MPTT)

This study is informed by Scott's MPTT, which integrated the complex processes involved in making decisions starting from detection of bodily change(s) until start of treatment, which included the cognitive, emotional and behavioural factors. This model also recognised the dynamic nature of the structural processes and the contributing factors such as the patient, the disease and the available health care within each interval. The findings in this study revealed that all the women were aware of their bodily changes during the appraisal interval. However, their decision to seek an initial consultation with the HCPs was either immediate or later on depending on their interpretation of the presenting symptom. During the diagnostic interval, the women underwent several investigation procedures depending on their

symptoms and disease presentation, availability and arrangement of the health care system. After the women were diagnosed with breast cancer, they decided on the treatment for their illness. This study also showed that the socio-cultural reality of women's lives in Malaysia was highly relevant to how symptoms were interpreted and following diagnosis decisions on treatment choices. The narratives also present a contrasting role of their husbands to that presented in previous research during the decision-making process, in which the husbands became pro-active by encouraged the women to check their presenting symptom immediately and supported the decision to start the conventional treatment. Thus, the application of the model significantly challenges previous research in Malaysian studies that associate women's decision-making mainly in appraisal interval lead to diagnostic delay, and presented with advanced stage of breast cancer.

### **7.2.1 Appraisal interval**

The first event in this interval required the women to be aware of their bodily changes. In this study, the way that the women experienced and responded to their abnormal breast symptoms influenced their subsequent decisions. The presence of a lump, the hereditary factor, a past personal experience of benign lumps and the socio-cultural view are the contributing factors for the interpretation of their symptoms. These factors portray that the participants' initial response to their breast problems were varied and depended on how they made sense of the presenting symptoms.

Some of the women in this study recognised themselves and their risk of developing breast cancer according to their family experiences. These women appeared to identify a clinically significant family history with the presence of breast cancer. Thus, the hereditary component played a part in their narratives. Haber et al. (2012) reported that women with a family history of cancer have a higher risk perception levels compared to

those without. Due to the awareness of their personal risk, they had the logical interpretation that their breast lump might be breast cancer. As a consequence, they consulted with the doctor immediately as soon as they discovered the symptom. This finding is consistent with another study, in which the decision was made to seek HCP due to the presence of a family history of breast cancer (Jacobi et al. 2003). Therefore, those who sought prompt medical help appeared to be more likely to have recognised their symptoms as being indicative of something serious or as requiring a further check-up.

In this study, some of the women did not perceive their symptoms as abnormal due to a lack of knowledge about breast cancer. In line with other study findings in Malaysia (Taib et al. 2011; Norsa'adah et al. 2012) and the UK (Marlow et al. 2014; Jones et al. 2015), some women with no family history of breast cancer did not expect their symptoms to be cancer because they did not consider themselves to be at risk. This means that these women had constructed the knowledge that a potential breast cancer diagnosis might not happen to them. This led them to live with a sense of security that directly influenced how they defined themselves, even when they realised the presence of a lump in their breast.

Several narrative accounts have suggested that the breast cancer symptoms were seen by some of the women in the wider community as being “normal” and interpreting their narratives to rationalise such an opinion is based on a number of factors. This study is congruent with other studies in Malaysia (Norsa'adah et al. 2012). Three women in this study related their breast symptoms to a previous history of having had a benign lump, clotted milk due to breastfeeding or menses symptom due to the hormonal changes. According to Lam et al. (2008), women interpret their breast symptoms based on a comparison of the nature of the symptom with their pre-existing knowledge and experiences. These findings showed that these women made a causal attribution and that

they developed a logical interpretation about the presence of the symptom as a common condition for them at that time. Their narratives also presented the interconnection between societal norms and the meaning related to various breast symptoms. According to Macdonald et al. (2019), studies of symptom appraisal in cancer patients typically concluded that the failure to regard the sensations as serious or symptom misattribution results in lengthier help-seeking intervals.

This study also highlighted the narrators' account of their community view regarding the symptoms of breast cancer. Some of the women in this study had difficulty appraising their symptoms, particularly when they differed from what other people had reported or experienced concerning breast cancer. This was noted by White and Epston (1990) as a lack of fit between the cultural narrative and the actual lived experience of the people. The socio-cultural template regarding the symptoms, including that "breast cancer was painful and had watery discharge" and viewing the lump as "clotted milk", made the women interpret that they did not have breast cancer because they experienced only a painless lump. Their lived experience differed from the prevailing cultural narrative construction of breast cancer. Using this template as a reference point, their symptoms did not require urgent attention and could be temporarily ignored. According to Donkor et al. (2016), symptoms may be considered to be serious depending on the individual's preconceived ideas about the nature of breast cancer, which is that the presence of cancer in the breast should cause pain. Therefore, this study showed an interconnection between cultural beliefs and symptom interpretation related to breast cancer.

This study's findings answer the research question 1 regarding the women's narratives about their abnormal symptoms by addressing multiple interpretation of the presenting symptom. The narratives in this study have illustrated how the life events were different for each woman who had breast cancer and how these events shaped their responses to

their decisions and, through narration, how it generated different perspectives that is what the HCPs need to understand.

### **7.2.2 Help seeking interval**

This interval involved the participants' decision to consult HCPs regarding their symptoms. As outlined in Chapter 2, previous research has suggested that some Malaysian women reported that their husbands refused permission for the respondents to seek medical treatment (Norsa'adah et al. 2012) and that they decided that the women should try alternative treatment (Taib et al. 2011). As a consequence, there can almost be a sense of "blaming" the husbands for any worsening of the women's situation because of the husbands' decision. This study demonstrates a contrasting view of the negative images about the husband at the time. All of the husbands encouraged the women to check their symptoms immediately with a doctor the moment that they knew about it. Even though in some cases it seemed like the husbands led decisions, mainly during the appraisal interval, the consequence of that decision was beneficial for the women when it came to detecting their breast cancer early. At the same time, the husbands' narrative showed that they were more worried about the symptoms or that they took a more proactive approach than their wives. The possible underlying reason for this might be that the husbands were more sensitive to what the breast symptoms might indicate regarding their wives' health and this prompted an early consultation. In the previous study, the husbands believed that the lump was clotted milk (Taib et al. 2011) or a normal symptom (Yusof et al. 2013). Consequently, the husbands' responses to the symptoms discouraged the women from seeking a medical consultation. Possible explanations for the differences in findings between this study and previous ones may include differences in socio-economic status, education and respect for medical professionals. This study's findings answer the research question 2 regarding the family members' narratives when they knew about the

women abnormal symptom by addressing the proactive and supportive roles of the husbands to seek medical help.

### **7.2.3 Diagnostic interval**

Diagnostic intervals have focused on the role of HCPs to appraise and investigate the symptoms until a formal diagnosis was made. Even though some of the women sought an early medical consultation, this study shows that it still took 1 to 3 months of undergoing diagnostic procedures before the diagnosis of breast cancer was confirmed. However, this interval was shorter compared to countries such as Libya (Ermiah et al. 2012) and Brazil (Soares et al. 2012), but it was still longer when compared to Thailand (Poum et al. 2014). In Malaysia, this situation occurred possibly due to the waiting times and queues for appointments for both diagnostic tests and consultations in government hospitals. The long duration of the diagnostic procedure and treatment could be linked to the excessive demand for service in government hospitals. As previously mentioned in the Chapter 1, government hospitals have faced several issues, such as a shortage of professional experts, a lack of treatment facilities and doctors, overcrowding and long waiting lists. According to Rivera-Franco and Leon-Rodriguez (2018), developing countries have limited health care resources and infrastructures. Most of the people in those countries rely on the public health care system, which affects the diagnosis of breast cancer [ibid.]. This study demonstrates that the health system is under pressure and this may influence patient experience towards the services provided. Therefore, it is important to act quickly, so the diagnostic tests could be start without delay.

Some of the women in this study had experienced premature reassurance from the first medical doctor that they consulted, even though they met with that doctor within 1 to 3 days after realising the symptoms. They were diagnosed with minor illnesses at the time, such

as swollen lymph nodes, normal breast firmness or no presence of a lump. They felt like their concerns were dismissed during their visit, where breast cancer was not suspected; therefore, this situation gave the women a false reassurance at the time. As a consequence, the women took about 4 months to 1 year before they went back to see the doctor for the second time. This situation prolonged the interval to getting an early diagnosis. This duration was almost the same as in a previous study, in which Renzi et al. (2015) reported that false reassurance can persist for months and even years in relation to seeking help for subsequent cancer symptoms.

In this study, one woman sought a medical consultation three times at the clinic due to her armpit pain and it took more than a month before she was referred to the hospital for further investigation. The number of consultations is associated with an increased time from presentation to referral for cancer treatment (Lyratzopoulos et al. 2014). Patients with cancer who had a higher proportion of three or more pre-referral consultations typically also had longer median intervals (Lyratzopoulos et al. 2013). In the UK, the national audit data shows that the median time to referral is 34 days for patients having three consultations, 47 days for four consultations and 96 days for five or more consultations [ibid.]. Interventions aimed at reducing the duration of the diagnostic pathway are likely to be very different for the different cancers and what works for one may well not work for another (Neal 2009). Lyratzopoulos et al. (2014) argued that prolonged diagnostic intervals reflect the limitations in the scientific knowledge of the HCP and in the delivery of healthcare. Therefore, poorly differentiated symptoms among the primary doctor might explain the reason why this situation happened even though a generalisation cannot be made from one participant's account in this study.

Being diagnosed with breast cancer was challenging for the women and their family members. This phase was usually filled with emotional

turmoil, including feelings of fear, anxiety, anger, disbelief and a high sense of mortality (Karbani et al. 2011; Scanlon 2004; Thomas et al. 2005; Halkett et al. 2007). “Breast cancer is really scary word” (PT7) is a statement that underlines the devastating consequences following the diagnosis and the increase stress of coming to terms with a future that was not certain. This period of time not only revealed complex relational factors of the self, society and culture but it also illustrated the strength of the women and their family members when it came to facing the challenges of their breast cancer diagnosis. Their stories also revealed how the decision-making process took place within their new life with breast cancer.

The presence of family history not only influenced the women’s decision to seek help immediately but it also helped the women to cope with their diagnosis (Blinder et al. 2012) because they were aware that they were at a high risk of developing cancer (Cohn et al. 2008; Maheu 2009). A previous history of fibroadenoma also helped one woman in this study to accept her diagnosis of breast cancer. Fibroadenoma is a benign breast tumour that is usually diagnosed among young women and that is related to a slight increase in the risk of breast cancer (Dupont et al. 1994).

In this study, none of the Chinese participants blamed God for their breast cancer. Some of the women spoke in contrast to what had been presented in the previous literature in Malaysia, in which Vivien et al. (2013) reported that Chinese women saw cancer as a punishment for wrongdoing. This finding presented a contrasting view of this specific ethnicity socio-culture belief, in which two Chinese participants mentioned that they were unlucky to get breast cancer and that it did not relate it to their behaviour. They accepted that, like other people, they could get breast cancer due to the randomness of the disease since there were many patients with breast cancer living in their community. These women may attempt to normalise what is happening to them and

they seek to accept their diagnosis by finding a logical reason, particularly if there is no family history of breast cancer, which seemed to be a unique finding in this study.

Moreover, some women believed their breast cancer to be some form of fate from God. This finding is consistent with other research conducted in Malaysia (Yusoff et al. 2011), Iran (Taleghani et al. 2008), Oman (Al-Azri et al. 2014) and Brazil (Santos et al. 2017), where the participants reported that one of the most important and effective approaches during the diagnosis stage of breast cancer was their religious beliefs. The women believed that God holds the power to create and cure everything, including their breast cancer. Terry and Cornblat (2002) reported that women with breast cancer felt that they needed to trust and rely on a higher power, God, because they knew that their life, including their breast cancer, was beyond their own control. People did not blame God for giving them cancer but instead they came to realise a deeper relationship with God because of their cancer (Murphy 2012). Goldblatt et al. (2013) found that both Muslims and Christians believed in God and their beliefs were a source of their coping. They believed that it had an impact on their destiny. Therefore, in this study, religious belief in God appeared to be a relatively stable resource for the women in terms of helping them to understand and approach their diagnosis of breast cancer. In contrast, Flórez et al. (2009) and (De Jesus and Miller 2015) reported that some women in their study denied that God had caused their breast cancer, instead believing the cause to be related to food, their lifestyle and the environment. Therefore, the arguments concerning the relationship between God and the presence of breast cancer depended on the people's beliefs and knowledge in the area.

The doctor's role was another contributing factor that influenced one woman in this study to accept her condition. According to Van Manen (1998), people may accept that they are ill when others have told them

that they have a disease and they may believe that the person who informed them about their illness will take responsibility for their care (Sartre 1969). A previous literature reported that many patients with breast cancer admitted that their doctor's attitude was important to them during the diagnosis stage (Roberts et al. 1994). Currently, doctors prefer to share detailed information about the disease with patients, such as the spread of the tumour, the course of the disease, the treatment options and the effects of the treatment on the body (Dhage and Wilkinson 2017). This may have been the case in Malaysia when some of the participants shared their experiences with their doctor during the consultation. When a patient understands the information given by the doctor, there is a tendency for them to accept their condition.

From the husbands' narratives, they were sad about their wives' breast cancer diagnoses but they refrained from revealing their emotions to avoid adding to their wives' distress. This finding might be related to the social-culture view in which men are usually portrayed as strong and unemotional when confronting challenging situations. Similarly, Coyne et al. (2012), in their study, found that some of the husbands hid their true feelings from the women with cancer to avoid causing them distress. Therefore, the husbands in this research were aware of the emotional needs of women with breast cancer and they often had to fight with their emotions, which they did not share openly with their wives. The husbands made a great effort to be sensitive towards their wives while working hard to remain positive about their wives' condition (Zahlis and Lewis 2010). One of the family members also showed respect for her sister's wish and decided to keep her promise to withholding her diagnosis from other people.

Emotional support is important for most cancer patients during their illnesses, including being able to talk to someone about their concerns, fears and even about the treatment options (Snyder and Pearse 2010). In this study, the family members listened to the women's expressions of

their feelings about themselves and their concerns associated with their illnesses. Ardahan and Yeşilbalkan (2010), found that families were supportive towards patients in everything, including giving them confidence and listening to their complaints. Encouragement and support from family members, such as from the husband or son, made the women feel strong when it came to facing the challenge of breast cancer and fight the disease (Naz et al. 2016). At the same time, one of the husbands in this study appeared to know part of the history of the Prophet Ayyub, who had suffered from a different kind of disease and which he shared with his wife to help her to cope with the diagnosis of breast cancer. This portrays how the power of Prophet Ayyub's story can be used as one way of helping patients cope with the disease, especially among Muslim people.

#### **7.2.4 Pre-treatment interval**

This interval involved the participants' decision regarding the treatment of their breast cancer. Even though MPTT focused on the treatment decision, this study extends the knowledge that other decisions are also important to be discussed as a part of the decision-making process such as diet, religious practice, looking for information, work and informing others. This study's findings answer the research questions 1 and 2 regarding the women's and family members' narratives about the treatment by addressing various decisions within this pre-treatment period.

##### **a) Conventional treatment**

The decision-making process about conventional treatment was complex, unique and interrelated. The contributing factors could change from person to person and from the context of the decision to the actual decision to be made. In this study, the decision-making process to pursue or delay conventional treatment could be affected by individuals, their personal experiences, their emotions, the social and

contextual factors. For some of the participants, these contributing factors were not taken to be a single cause. However, for the purpose of this discussion, each of the contributing factors will be presented separately and answering research question 3 regarding the key features, events, people and decision points in these narratives that prompted the Malaysian women and their family members to pursue conventional treatment.

#### ➤ **Doctor**

Clearly, how the treatment of breast cancer was presented by the physicians to the patients influenced their decisions (Tariman et al. 2014). This study found that communication between the participants and doctors tended to result in both positive and negative responses. Some of the women accepted conventional treatment while some of them chose to delay it after communicating with the doctor during the consultation. Moreover, this finding is consistent with a systematic review of older adults that showed that the decision to accept or decline the recommended cancer treatment was influenced by the physician's recommendation, their trust in the physician, communication with the physician, expectations about side effects and the treatment experiences of their significant others (Puts et al. 2015).

Sheppard et al. (2011) reported that communication is important because the doctor is considered to be the primary source of information concerning treatment. This finding was congruent with a previous study stating that trust in the abilities and experience of the HCPs and maximising their chances of survival influenced their treatment decision (Swainston et al. 2012). This confidence was enhanced when the woman (PT9) narrated about the presence of several breast cancer specialists in the hospital where she underwent her treatment.

In contrast, some patients might have misunderstandings and not be ready to absorb the information when the doctor talked to them about their treatment options. For example, referring to the excerpts from PT1, the patient may have been shocked when the doctor mentioned “remove the whole breast”. The doctor seemed to communicate matters related to the treatment rather than the psychology of the patient. At that time, she might experience mixed emotions in which the fear about the future was put into suspension. Most of participants in this study did not discuss support from HCPs in their narrative, yet only one participant mentioned this issue but with limited information. Claramita et al. (2011) reported that doctors in South East Asia are more likely to emphasise the medical elements rather than the socio-emotional dimension of the patients.

#### ➤ **Other patients with breast cancer**

In this study, other patients with breast cancer were constructed as having either a positive or a negative role in terms of influencing the decision-making process among the participants. The precise role may have been dependent on the personal experiences of the patients with breast cancer themselves. This finding was consistent with the previous study by Pieters et al. (2012), in which they found that obtaining information from patients with breast cancer influenced some of the women to accept treatment for their breast cancer, while others refused.

In some narrative accounts, this was a positive case when some of the women described how their experiences with patients with breast cancer who had been successfully treated gave them confidence in their decision. This finding was consistent with a previous study in Malaysia (Shariff et al. 2008). As a consequence, these participants reported that their connection increased their sense of control and that it provided them with valuable information about the treatment. The importance that women and family placed on their interactions with other patients

with breast cancer can be understood in relation to the concept of being with others (Heidegger 1962). This concept explains that people gain an understanding about who they are and what to think about their situation from their interactions with other people in the world. In this study, these participants seemed to trust the patients with breast cancer whom they met to provide them with new interpretations of breast cancer. They also admitted that having a connection with past patients with breast cancer was important and that it had influenced their decision to accept treatment.

In contrast, not every woman of breast cancer had good story when it came to sharing her experiences. Indeed, one of the participants in this study chose to refuse conventional treatment based on the poor outcome story of another patient with breast cancer, which may thus have served to provide a clear indication that conventional treatment is futile. It seemed that she made her treatment decision informed by the lived experience of another patient with breast cancer who became a negative role model for her at that time. Sharing bad experiences led to the woman being fearful and thinking that she might have the same experience. Similar findings were found among the patients with breast cancer in Malaysia (Taib et al. 2011; Norsa'adah et al. 2012) and Germany (Singer et al. 2015), whereby listening to the bad experiences related to cancer treatment was found to be highly related to a fear of treatment.

#### ➤ **Family members**

In this study, the husbands played a significant role in influencing some of the women to undergo conventional treatment, which is consistent with a study by Hobbs et al. (2015) and Schonberg et al. (2012). However, this finding is in contrast to the work of Norsa'adah et al. (2012) and Taib et al. (2011) in Malaysia. Unlike their study, all women in this study were being supported by their family members, especially

their husbands, in reference to undergoing conventional treatment. FM1's story represents how he cared about his wife after she was diagnosed with breast cancer. He tried to convince and persuade his wife to accept conventional treatment. A similar image and character was portrayed about FM1 when conducting an interview with his wife, PT1, separately. These findings presented a counter-narrative in the form of a positive image regarding the husbands' role, which has not been examined in the previous research from their perspective. Therefore the socio-cultural context of the husbands tending to present them as being responsible for the delayed diagnosis and treatment for women with breast cancer seemed to be incorrect in this study.

Another finding contrasted with the socio-cultural view regarding the husbands' roles in terms of controlling the wives' decisions and actions. Therefore, the traditional patriarchy system in Malaysia, whereby males dominated the decision-making (Norsa'adah et al. 2012), seemed incorrect because this study found a different result. This study revealed that the husbands supported and respected their wife's decision. This impression could be seen from the discussion between some of the couples which led to an action that was mutually agreed.

The treatment decision-making process can lead to an emotional response in the women with breast cancer. In this study, one family member talked about his wife's concerns regarding her body image and her role as a wife, as the mastectomy would involve removing the whole breast and she needed her husband's approval prior to undergoing the treatment. The body is considered to be the medium in which the sense of self might be formed. This reveals that the woman expressed concerns about her body image because breasts are associated with a strong symbol of femininity and sexuality (Spencer 1996). In reference to this case involving women with breast cancer, Charmaz, as cited by Bury (1991), stated that chronic illness leads to the disruption of the physical body, which challenges an individual's sense of identity and

threatens their self-worth. A mastectomy can thus pose a significant threat to a woman's body image and identity, meaning that the woman referred to in this study might have felt that they could no longer function in the same way as before due to the treatment. Her husband therefore had to reassure her that any change to her body would not alter their current relationship. This is consistent with studies showing that married men perceived that their wives' body image after mastectomy did not affect their relationship (Diji et al. 2015).

#### ➤ **Positive thinking and attitude**

Having positive thinking, including being hopeful and having confidence that they were going to survive, was rarely considered to be an important factor that influenced treatment decision-making in Malaysia. But in this study, this manner and thinking was consistent with the study by Hajian et al. (2017), which reported that an optimistic outlook, such as being hopeful, positive and having cognitive acceptance, was considered to play an important role among the women in helping them cope with the challenges that they faced related to breast cancer. Hawley et al. (2009) found that a patient's attitude influenced their breast cancer treatment decision-making, whereas Saita et al. (2015) reported that the women who appraised the breast cancer as a challenge or a threat mobilised their assertiveness.

Some women focused on reliving their lives by lifting themselves out of any sense of negative thinking about their breast cancer. These women felt that they needed to battle the disease because they wanted to survive and fulfil their dreams. They kept a focus on the goals that they wanted to achieve, such as seeing their daughters grow up and doing activities with their husbands. Therefore, they wished to undergo conventional treatment to ensure that they had the greatest possible chance of surviving breast cancer. Skott (2002) reported that some people perceive a need to fight their cancer. The women's sense of control was enhanced when they felt confident in their decisions. This

showed that the women controlled their decisions, thus demonstrating their right and authority to make decisions about their breast cancer.

➤ **Symptom changes prompting action**

Some of the participants in this study decided to undergo conventional treatment after a delay due to worsening conditions or due to them not being able to cope with the pain. In other words, conventional treatment was positioned as a choice related to the exhaustion of alternative treatment. As the disease progresses, it can prompt a change in women's attitude, from initially refusing to accept the conventional treatment to doing anything to survive when their symptoms worsen. Burgess et al. (2001) stated that at any point in the decision-making process, a change in symptoms could be the trigger for women with breast cancer to seek medical advice. This study also revealed that women with breast cancer would tend to eventually come to agree with whatever was the suitable treatment at that time, even if this treatment had not been their first choice initially. Moodley et al. (2016) reported that most of the women in South Africa in their study reported that an increase in the size of the lump, pain or skin changes were the triggers to seeking medical care.

➤ **Time**

One woman in this study stated that she delayed conventional treatment because she needed some time for herself, time to accept her diagnosis, time to rebuild her sense of self and time to look for more information about breast cancer. Citrin et al. (2012) found that the women in their study needed time to absorb the shock of their breast cancer diagnosis and to educate themselves about the treatment options. Although the doctors they consulted had suggested immediate surgery, the women felt that they needed time to make the decisions themselves about their own lives. Ramfelt and Lützén (2005) reported that patients with cancer may need more time to make decisions about treatment and that they

felt isolated when a treatment decision was rushed by the physician. Such rapid decision-making led to some of the women opting to delay their treatment. Additionally, they appeared to place greater priority on their family and children than on their own health. Similar reasons have also been reported among women in Jordan (Taha et al. 2012).

After she had had enough time and was satisfied with the things that she had done, this finally lead her to decide to undergo conventional treatment. She felt happy after trying a variety of alternative treatments, changing her lifestyle and fulfilling her wishes. In the case of prostate cancer, White and Verhoef (2003) reported in their study that some men had established their own specific time frame, such as six months, in which they tried alternative treatments and prepared themselves before undergoing conventional treatment.

### **b) Alternative treatment**

Globally, alternative treatments have become increasingly popular among cancer patients because of the hope of being able to find a cure for their illness and making them feel better (Puataweepong et al. 2012). Breast cancer is considered to be a highly treatable disease but some women may choose to reject conventional treatment in favour of alternative treatment, which may end up contributing to poor health outcomes (Citrin et al. 2012). In this study, some of the women with breast cancer refused or delayed conventional treatment but instead tried a variety of alternative treatments, such as the use of herbs, dietary supplements, traditional treatment or Islamic treatment to treat their breast cancer. With the presence of many alternative treatments in Malaysia, some women tend to choose this method rather than conventional treatment even though Han et al. (2011) reported that using alternative therapies as the primary form of treatment for breast cancer had an effect on the progression of the disease and an associated increased risk of recurrence and death.

Multiple factors might contribute to the higher prevalence of alternative treatment use in Asian countries, such as traditional culture, religious beliefs or the cost of conventional treatment (Puataweepong et al. 2012). This study also showed that family members were supported the women in their use of alternative treatment by accompanying them to the traditional treatment, buying supplements and looking out for remedies in the hope that the women would recover from their breast cancer. Latte-Naor et al. (2018) found that family members supported the use of alternative medicine accompanied by the expectations of a cure and improved survival among the cancer patients.

However, some of the women in this study had refused to try traditional treatment and supplements because they believed such treatments to be ineffective in treating their breast cancer. This illustrates that they believed that the conventional treatment was appropriate for them. Tautz et al. (2012) reported that 34% of their participants refused alternative treatment because they felt that the conventional treatment was sufficient enough to treat their breast cancer. Moreover, work background, previous experiences with family member who have used alternative treatment and self-awareness may influence the way that these women made the decisions about alternative treatment in this study.

#### ➤ **Traditional treatment**

Many countries have their own traditional or indigenous forms of healing that are based on their culture and history (WHO 2013). The mainstream health care system in Malaysia is based on conventional treatment, but it is estimated that 80% of Malaysian people seek out traditional practitioners at some point in their life regarding health-related issues (Razali and Yassin 2008). This demonstrates the popularity of traditional treatment and this could be considered a constituent part of the culture and tradition in this country. Tovey et al.

(2005) reported that 80% of the world's population continue to utilise traditional treatment, although conventional treatment is also still in demand.

Although only three Malay women with breast cancer in this study sought traditional treatment, the problem is that they had met three to five traditional healers, thus demonstrating that these participants turned to traditional healers as their choice of treatment for their breast cancer. As a consequence, this situation will prolong the time for the participants to observe the effects of the traditional treatment and shifting from one traditional healer to another healer. They usually followed the suggested treatments such as drinking water that had been chanted over and applying plants, slaked lime and cooking oil to their breast, in which they viewed this form of therapy as a viable and safer option to treat breast cancer. None of them were aware of a study suggesting that traditional treatments leads to time wastage and that it was associated with poor outcomes, in which having more advanced disease states is common (Khan et al. 2015b).

#### ➤ **Islamic treatment**

Islamic treatment is interwoven with religion and culture. In Malaysia, Islamic treatment is frequently sought as a preferred method among Muslim cancer patients (Suhami et al. 2014) and this is consistent with the finding in this study. However, this type of treatment is also practised in both developed and developing countries such as Indonesia, Lebanon, Iran, South Africa, the USA, the Netherlands and Pakistan (Suhami et al. 2016). In this study, the husbands typically supported their wives in trying Islamic treatment because they believed that God had the ability to heal their wives' breast cancer. As stated in the Holy Quran (chapter 26, verse 80) regarding the healing context: "And when I am ill, it is *Allah* who cures me". In America, based on a God-centred Islamic framework, Muslim citizens believe that God causes disease or

that it is part of His will, with such a belief leading them back to Islam in order to find a way of healing the disease (Padela and Curlin 2013).

Another important criterion in Islamic treatment is the use of verses from the Holy Quran, which are believed to be *Baraka* or a divine blessing when recited (Suhami et al. 2014). As stated in the Holy Quran (chapter 17, verse 82) regarding healing verses: “And we sent down in the Quran such things that have healing and mercy for the believers”. Moreover, the participants believe that Islamic treatments are harmless as they are made from plain water while reciting the Holy Quran.

#### ➤ **Dietary supplement and herbs**

There are numerous nutritional supplements and herbal products available in Malaysian markets (Farooqui et al. 2016). One of the women in this study was willing to pay a huge amount of money for a supplement to treat her breast cancer. She took the products for almost two years. This long term use of dietary supplements and herbs indicates that some women prefer these products that offer new options rather than conventional treatment. This issue needs to be raised by the HCPs. Some studies have reported patients with cancer using herbal products to slow down the progression of the disease and to relieve their symptoms (Afifi et al. 2010; Ali-Shtayeh et al. 2011). Even though the participants did not narrate about the effectiveness of the dietary supplement and herbs, it is important for HCPs to give health education regarding the effects and safety of the products because the participants might be unaware of the side effects.

#### **c) Diet management**

An area which has not been developed in the literature, but that was a significant issue discovered in my study, was the inter-relationship between socio-culture beliefs and food and in particular how food was believed to affect the progression of breast cancer. This research has been the first in Malaysia to make an associated link between cultural

issues and the intake of food in relation to Malaysian women with breast cancer. The socio-cultural template concerning food included “cancer will grow very fast if you eat meat” and “all these foods can swell the nerves and make the lump get bigger”. This made the women believe that certain types of food have a direct effect on the progression of their breast cancer. Using this template, women avoided specific foods including meat, certain fruits and certain vegetables and these changes in nutritional intake should be noted among the HCPs. Even though Yusof et al. (2013) recognised in how Malaysian women with breast cancer had changed their dietary patterns, they did not explore why. This research has delved further, drawing out the interconnection between cultural belief and dietary intake.

This study showed that women with breast cancer considered taking control of their condition by learning about ways to manage it. Women may feel that dietary changes would establish their sense of embodiment and thus help them to control the disease. For example, they changed their diet and practised healthy eating, not eating meat and eating only certain types of “cold” vegetables and certain fruits because they believed that these types of food had an effect on their breast cancer. This finding is consistent with the research by Maskarinec et al. (2001), in which they reported that patients with breast cancer avoided meat because it affected their cancer due to hormonal changes and high cholesterol level. People are more likely to make healthy dietary changes when they believe that a certain diet is linked to cancer (Patterson et al. 1996). Other foods that the women with breast cancer reduced was animal fat, sugar and red meat (Salminen et al. 2000). Although having a red meat intake may not be solely responsible for a higher cancer risk (Genkinger and Koushik 2007), many of the cancer patients still believed this to be the case and therefore tried to avoid it. In contrast, a few of the women with breast cancer in a study in the USA did not consider there to be an association between food and the presence of their breast cancer (Ashing-Giwa et al. 2004).

#### **d) Religious practice**

Some of the narratives in this study highlight the power of God and the way in which this shapes how the women viewed their breast cancer. Regardless of religion or ethnicity, being diagnosed with breast cancer led the participants to seek guidance from God regarding their condition. Understanding the relationship between religious practice and breast cancer was important for emotional, spiritual and treatment decision-making among the woman in this study. They had faith in God as the main source of healing power and as the creator of diseases. A strong faith in God was noted from the time of diagnosis through to the treatment decision and it had a positive influence on the patients' lives and decisions. Through their faith, women with breast cancer can worship God and ask Him to give divine protection to them (de Sousa Barros et al. 2018). Terry and Cornblat (2002), in their study, found that a relationship with God served a variety of functions for women with breast cancer, such as encouraging greater inner strength or faith in the self, guidance in terms of life decisions, helping their emotional control and crisis and the development of a positive attitude of acceptance and hope with regard to their treatment and life. The importance of faith as an influencer of people's health has led to certain medical schools in the United States introducing a curriculum based on the relationship between spirituality and health (Brooks and Koenig 2002), with a similar situation also being seen in Malaysia.

Existing evidence suggests that prayer helps patients with breast cancer to cope with their diagnoses and with the treatment of their illness (Fina 2009). Prayer is considered to be one of the efforts involved in cleansing the soul based on the belief that every disease is created by God and thus only God has the cure (Tohar et al. 2011). Parker, a professor of theology and religion at Elmhurst College, Chicago, added that every religion, including Judaism, Christianity, Islam and Buddhism, believes in the power of prayer for healing (Stein 2006). In a study in Oman, the majority of the participants strongly believed that an attachment to

*Allah* could serve as a cure for cancer, whereby the stronger their faith in *Allah*, the more likely that there was going to be a cure for their cancer (Al-Azri et al. 2014). In contrast, Powell, an epidemiologist at Rush University Medical Center, Chicago, felt that faith did not significantly slow cancer growth or improve the recovery from acute illness but it did provide comfort in times of illness (Kalb 2003).

### e) Looking for information

Traditionally, the knowledge provided by medical professionals has been considered necessary and sufficient to support patient treatment decision-making (Polacek et al. 2007). However, some participants in this study began searching for more information when they knew about the diagnosis. They became more active in seeking out information about their breast cancer symptoms and treatment. Due to advances in technology, many people now prefer to seek knowledge about breast cancer through the Internet. This is consistent with a study by Asiedu et al. (2014) in the USA, where it was found that cancer patients and their family members actively sought information from the Internet to understand the diagnosis and available treatments. They used the Internet as their main source of information. According to the Malaysian Communications and Multimedia Commission report, 77.2% of Internet users in Malaysia search for health-related information online and 82.7% trusted the health-related information they found regardless of its source. People with health problems often turn to the Internet to seek out relevant health information as it is easily accessible (Kim et al. 2012).

The Malaysian Communications and Multimedia Commission (2017) reported that 26.9% of the Malaysian people in their survey stated they had no access to the Internet and that 23.7% did not have any devices on which to access the Internet. It thus seems that many Malaysian people have limited access to the Internet. In the same report, 35.1% of

non-users of the Internet were in the 50-64 age group, while the highest level of Internet use was found among the 20-34 age group (53.6%). This supports the finding in this study in which half of the women with breast cancer were aged 50 years and above and those women who searched for information online were in the 28-34 age group.

#### **f) Work**

Being diagnosed with breast cancer is considered to be an important issue in relation to employers and the workplace (Schultz et al. 2002). In Malaysia, people with certain chronic diseases, for instance breast cancer, who work in the private sector are entitled to paid medical sick leave of no more than 60 days per calendar year, while those working in the public or governmental sectors can take up to one to two years paid leave (Tan et al. 2012). However, in this study, some of the women preferred to continue with their jobs as usual. They took medical sick leave for just a few days after finding out about their diagnosis. It seems that having breast cancer did not interfere with their work.

Additionally, they might feel that their job provided a distraction from thinking about their illness. This finding is consistent with the research by Blinder et al. (2012), where some of the women felt that maintaining normal lives at work prevented them from thinking about their breast cancer problems, helped them to regain control of their lives and helped them to feel empowered to cope with the breast cancer diagnosis. Other than as a distraction from illness, Kennedy et al. (2007) also found that several women with breast cancer enjoyed the social network of work and felt emotionally better whilst they were at work.

### **g) Informing others**

Some of the women in this study felt comfortable informing their close family members of their disease soon after they received their breast cancer diagnosis, but they did not want everyone to know about it. In line with other study findings, Hilton et al. (2009) reported that some of the patients with cancer informed their family members, close friends and close work colleagues of their diagnosis, although they did not necessarily wish for it to become common knowledge among other people.

In this study, one participant felt that she was not ready to tell her mother about her diagnosis. She therefore delayed telling her mother because she did not want to upset her. It thus seems that a disclosure of the diagnosis to family members is hardest due to a feeling of needing to protect the emotional well-being of their loved ones. This finding was consistent with a previous study by Morgan et al. (2004), who found that the women in their research had difficulty disclosing their diagnosis to their family members. At the same time, she also worried about other people's views toward her disease when they knew about it. This finding was supported by the study conducted by Taleghani et al. (2006) in which they found that some of the women did not like talking about their breast cancer because they felt uncomfortable when other people displayed inappropriate reactions. Elobaid et al. (2016) found that women preferred to remain quiet and to not share their breast cancer diagnosis with anybody because they did not know how the people around them would react when presented with the information.

In this study, some of the women with breast cancer mentioned that they had to tell their employer as a part of the procedure for taking medical leave. It seemed that they were unable to conceal their diagnosis from their employer. This finding was consistent with a study by Maunsell et al. (1999) who found that most of the patients in their

study found it difficult to keep their cancer diagnosis a secret at work because they were obliged to inform their employer. According to Kennedy et al. (2007), the patients told their employers about their cancer because they needed time off for treatment.

#### **h) Culture**

Another unique finding that extended the current knowledge base was the interrelationship between cultural beliefs and the decisions related to treatment for breast cancer. This finding is the first to identify the present socio-cultural template highlighting some of the different perspectives on culture which have not been developed in the Malaysian literature before. The socio-cultural template, such as the statement that the breast cancer will be spread to another part of the body through surgery and the belief in the self-healing capabilities of the body, was behind some of the reasons why some participants in this study refused conventional treatment in the first place. Using this template as reference point, conventional treatment was viewed as a risky procedure that could disrupt their lives and future. Moreover, their respective community perceived the conventional treatment differently and they could possibly imagine what the women would experience if they underwent the treatment, such as dying during the surgery, the wound not getting better and the presence of pus after surgery. These scenarios exemplify how entrenched cultural beliefs can affect women's health behaviour related to the treatment for breast cancer, and that this needs to be understood by HCPs.

Another cultural belief, which led to one of the women in this study delaying treatment, is that breast cancer will not get better if it is touched by a knife, with a similar reason having also been reported in a previous study in Malaysia (Farooqui et al. 2011). This shows that the myths surrounding breast cancer treatment indicate that such myths are indeed prevalent in Malaysian culture and that they may greatly

influence the study participants' beliefs. Indeed, they had a direct influence on the treatment decision-making process of some of the women in this study. These findings thus demonstrate the importance of considering socio-cultural beliefs in terms of understanding the reasons behind a decision.

Additionally, this study highlights the significant influence of social networking with regard to talking about conventional treatment for breast cancer, which, as a culturally embedded process, had the ability to lead to a delay in conventional treatment among some of the participants. Some of the participants in this study tended to listen to negative stories of conventional treatment based on what other people said about it. They tended to share information via informal conversations about breast cancer and its treatment. This illustrates that they rely on unofficial information obtained from the people surrounding them. Tohar et al. (2011) reported that Malay people tend to rely on word of mouth or verbal communication from the people surrounding them as opposed to any factual evidence that they discover on their own. Their decision-making process could be relevant to the collectivist tradition in Malaysia, in which people appreciate their relationship with society. They interact, interpret and act in ways that are understood to be socially and culturally acceptable. A possible reason for the participants accepting the response from their social groups may thus have been to maintain harmony and to reinforce a sense of belonging to the group (Olafsdottir 2013). Understanding these diverse experiences reflects the significance of the social ability to influence decisions, which is important to be understood by HCPs.

The Malay, Chinese and Indian communities have a shared geographical location but as a community, they hold differing cultural orientations, norms and values according to their ethnicity (Bakar and Mohamad 2017). This study has recognised the nature of the dissimilarity in their narratives about how their respective communities talk about breast cancer. Some Malay women perceived their communities as being more

open but they tended to focus on the negative image regarding the decision related to conventional treatment. One Indian highlighted that her community perceived breast cancer as a death sentence while one Chinese woman narrated that her community was less likely to talk about breast cancer. Additionally, it was observed that none of the Chinese participants directly used the term ‘breast cancer’ during the interview, referring to it instead as “that disease” or “it”. This may be related to the existence of Chinese taboos in terms of language among this ethnicity group. Chinese patients do not like mentioning words that concern disease, with a particular avoidance of the word ‘cancer’ (Lei 2016). Recognising these differences regarding the views about breast cancer is important to plan effective health strategies in order to better inform these communities about breast cancer.

### **7.3 Health Belief model (HBM)**

The HBM was used as the underpinning theoretical framework to provide a broader conceptual understanding of the decision-making process among Malaysian women with breast cancer. The HBM has six components; 1) perceived susceptibility; 2) perceived seriousness; 3) perceived benefits; 4) perceived barriers; 5) cue to action; and 6) modifying variables. The HBM considers beliefs about certain behaviours to be essential indicators for said behaviours. This study revealed that all six components were useful in terms of explaining the decision-making process among the participants in this study. However, I acknowledge that some discussion in this section might be overlapped with the discussion based on Scott’s MPTT above.

HBM postulates that people will take actions to prevent, detect or control the conditions of illness if they believe that they are personally susceptible to develop a particular disease or health outcome (Burke 2013). In this study, the family history of breast cancer influences some women to consult the doctor immediately regarding their symptom while others believed that their symptom was not cancer due to absence

of this factor. This is consistent with the findings in other studies (Katapodi et al. 2010) where family history and breast cancer worry were considered to be significant predictors of personal risk judgments for women. Therefore, those who sought prompt medical help appeared to be more likely to have recognised their symptoms as being indicative of breast cancer that requiring a further check-up.

Some women did not perceive themselves to be susceptible to getting the disease even though they realised the presence of bodily changes. This situation could be explained through perceived severity in HBM, which is the belief about how serious a disease is and its effects on an individual's health or life (Burke 2013). Since these women experienced a painless lump, they did not consider the symptom to be a threat to their health at that time. Moreover, the presence of the socio-cultural template regarding symptoms such as "breast cancer is painful" and the lump is like "clotted milk" influenced the women to interpret their breast symptoms as a non-serious condition at that time.

Another important concept in HBM that influences the decision-making process is the cue to action, which is the trigger for taking the action. The findings in this study revealed that symptom changes (lump getting bigger or an inverted nipple) and the disclosing of the symptom to family members increases the likelihood of women seeing a medical doctor. Lim et al. (2015) reported that family members played a positive role in encouraging and facilitating the immediate seeking of medical advice. In this study, the family members immediately brought the women to the clinic after they knew about the symptoms. Additionally, modifying variables such as the level of education and the current condition such as breast feeding influenced how the women made sense of their symptoms at that time.

Perceived benefit in HBM refers to the positive benefit of taking action to offset a perceived threat (Burke 2013). At this stage, the participants believed in the ability and credibility of their HCP to check and explain the symptoms. People tended to seek medical advice if they expected a doctor to be able to help with the symptoms (De Nooijer et al. 2001). Moreover, the participants' decision could be related to overcoming negative aspects such as the physical and psychological barriers (Burke 2013), which is another component of HBM. In this study, the family members accompanied most of the women to the clinic and to the hospital. Thus, they did not experience the physical barrier to seeking medical help regarding their symptoms as reported in the previous study, in which women found there to be difficulties in terms of cost, transportation and the time taken to check their breast symptoms (Norsa'adah et al. 2012). It seemed that this perceived benefit had a greater influence on the decision than the perceived barrier.

The HBM could also explain the participants' decision about the conventional treatment. Some of the women believed that they would have to undergo conventional treatment for their survival and recovery. In this case, they trust the doctors' ability due to the presence of many breast cancer specialists and the effectiveness of conventional treatment based on scientific research. Additionally, they have personal experience with the family member who had breast cancer previous and they received support from these family members as they motivated them to accept the conventional treatment. At the same time, a positive attitude and thinking becomes another variable that influences their decision.

However, the decision to refuse or delay conventional treatment because of a fear of surgery could be integrated with the perceived barrier in HBM. In this case, the women had the negative expectation that they would suffer or that their life would be worse if they chose to undergo surgery, thus becoming a barrier to them undergoing conventional treatment. It seemed that this perceived barrier had a greater influence

on the decision than any belief in the ability of the treatment to either treat or cure the disease. Moreover, the socio-cultural view of the negative image of conventional treatment influenced the women's decisions. Therefore, some of the women in this study preferred to delay or refuse conventional treatment since they were unable to move beyond their fear of the consequences of conventional treatment.

## **7.4 Health Locus of Control (HLOC)**

The final theoretical framework that was incorporated in this study was HLOC. HLOC consists of three components; internal, external and chance. This theory describes the belief that people's health is dependent on these three components. This study portrayed that these three components were useful to understanding the decision-making process among the participants in this study.

Internal HLOC refers to the belief that health is dependent upon self-behaviour. This study revealed that being optimistic and having the desire to survive as the internal HLOC made the women decide to undergo conventional treatment. This internal power meant that the women tended to have a stronger sense of well-being and want to control their body. Individuals with increased perceptions of control over their lives are more likely to take active steps towards reducing or avoiding negative circumstances. Another example in this study that could be linked with internal HLOC is the decision related to dietary changes. Dietary changes were made because the women considered that this type of action could improve their health and help to control their breast cancer. Therefore, this finding suggests that people feel like they are able to control or change their actions in order to determine the consequences of health outcomes.

External HLOC refers to the belief that health is dependent upon other people behaviours. This study portrayed that some participants made their decisions when influenced by other people's opinions. For example, the doctor as they perceived them to be the gatekeeper to the knowledge about breast cancer while their family members with breast cancer become the role model for accepting conventional treatment.

Chance locus of control (CHLC) refers to the belief that chance factors determine health outcomes. An example of people with a chance HLOC in this study was those who believed their breast cancer to be some form of fate from God. This belief helped some of the women in this study to confront and accept their diagnosis. The participants also believe that God had the power to heal illness and that the Holy Quran has a certain healing power. Therefore, they prayed a lot in order to get God's blessing for their condition.

## **7.5 Integration of theoretical framework in decision-making**

The integration of the HBM and HLOC (see Figure 7.1, p.236) in the context of decision-making regarding breast cancer could be considered a new contribution to the current knowledge in Malaysia, since it has not been discussed in any of the previous studies. This model was developed based on the findings in this study, supported by the previous literature. This model added several variables as the influential factors in the HBM component. The concept of HLOC and the socio-cultural factor appeared to be intertwined with the HBM during the decision-making process about breast cancer.

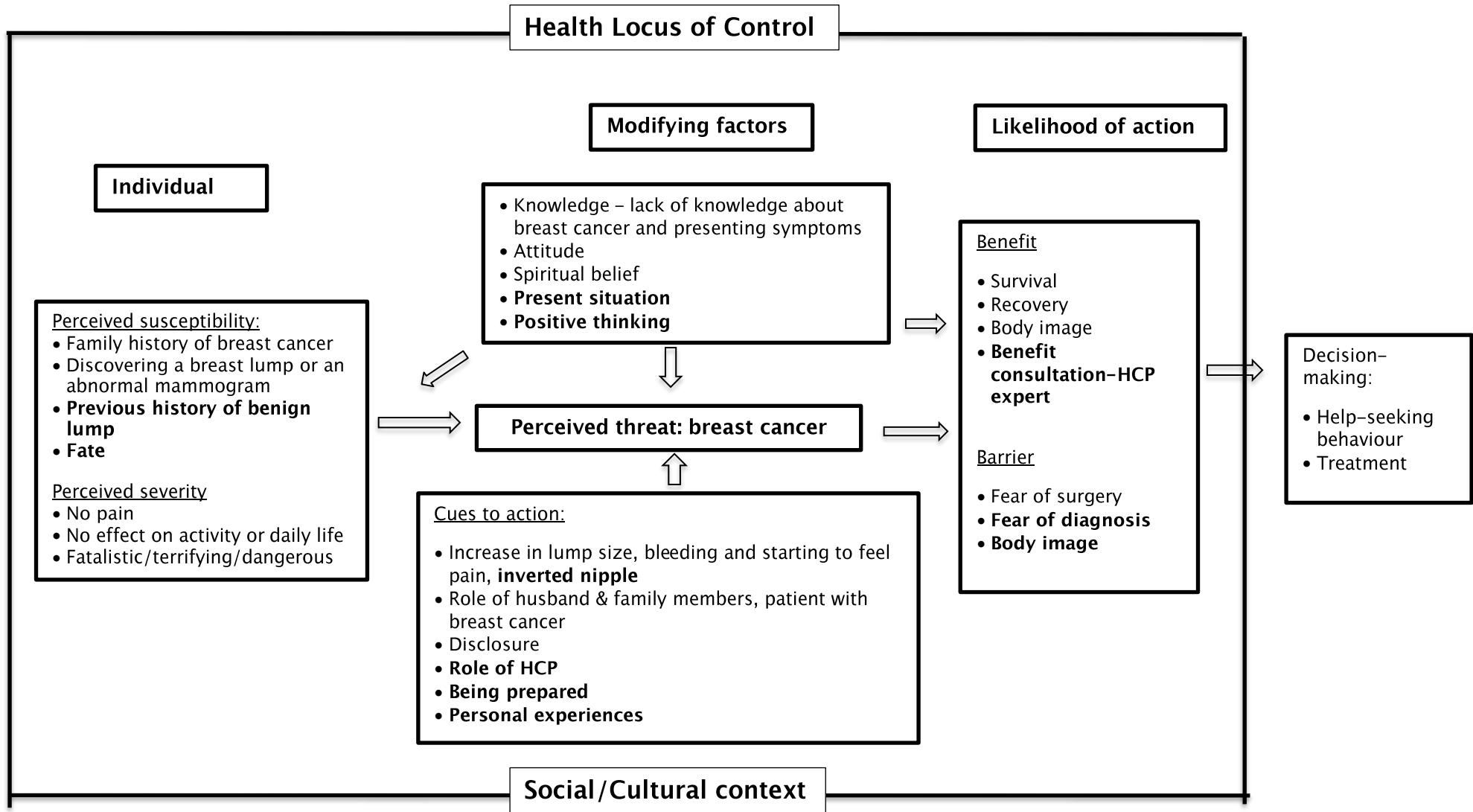


Figure 7.1: Adapted HBM and HLOC towards decision-making among Malaysian women with breast cancer based on the present study

This study shows how the HBM could be used to understand decision-making with regard to seeking help about the presenting symptoms and about the potential treatment after receiving a breast cancer diagnosis, while not necessarily focusing on screening programmes. The use of HBM increases our understanding of the meanings of the concepts related to how decision-making takes place among women with breast cancer and the factors that can be influential when making decisions. This HBM could be integrated within Malaysian populations but the social and cultural values that influence the decision must also be considered. The concept of HLOC is significantly linked with the HBM and it is useful for gaining more of an understanding of the decision-making process.

This study has proposed an integration of HBM and HLOC was beneficial to explain Malaysian women's help-seeking behaviour and treatment decision-making. Malaysian women are surrounded by many influencing factors concerning their current situation, knowledge, social environment, cultural belief and religion, which all present advantages and disadvantages in terms of the decision-making process. This model demonstrates that a complex array of personal and other factors influences how women make decisions relating to their breast cancer. It is clear that the breast cancer decision-making process is not straightforward. Understanding the socio-cultural dimensions underlying a patient's health values, beliefs and behaviours is critical to a successful outcome of a clinical encounter (Ariff and Beng 2006).

### **Chapter summary:**

This chapter discussed the study findings in the context of the existing supporting literature and in relation to the theoretical frameworks of MPTT, HBM and HLOC. These findings suggest that decision-making regarding breast cancer is an ongoing experience with many changes along the way and that the decision-making is not necessarily a

sequential process. Some decisions have minor effects while others have many consequences. The present study shows that decisions may change over time in line with the influence of many factors. The meanings that people construct from their chronic illness can also change over time (Charmaz, 1991). The complexity of the women's decision-making experiences was influenced by their knowledge of breast cancer, the role played by their family, HCPs, other patients with breast cancer, community members, cancer treatment, attitudes and the availability of alternative treatments. Therefore, the MPTT and an integration of HBM, HLOC and socio-culture components provides a useful framework to understand participants' decisions as both takes into account the complex nature of the decision-making process. These frameworks also could identify the factors that influencing the key events and this provide opportunities for targeted interventions in order to encourage early detection, presentation and treatment.

In this study, the participants constructed coherent narratives in connection to themselves, their family members, HCPs and other people to show how they had played a part in their decision-making experiences. This study also exemplifies the ways that the participants make sense of their decisions from the people and culture that surrounded them. When people become more familiar with an event such as breast cancer, the cultural resonance tends to be higher and it is more likely that these people will be able to participate in the participants' narrative in order to support and share the opinions within, depending on the story. Additionally, culture provides a medium with a different perspective for the individual to understand breast cancer, such as how it arises and how to treat it. Using a narrative approach provided opportunities to identify different perspectives on culture, some of which are reflected positively while others provide a negative perception towards the decision-making process.

The narratives revealed how culture transcended a number of areas, such as symptom interpretation, food and treatment. It also highlighted different perspectives of known socio-culture challenges towards health care. By narrating these stories, it appeared that some women wanted to address the misconceptions present within their respective communities, as well as the socio-cultural template about several issues related to breast cancer. Understanding how Malaysian women with breast cancer think is fundamentally important for HCPs to begin to support and understand the reasons for their actions.

The experience of making decisions related to breast cancer led the women and family members to acquire new knowledge, to make appropriate changes to deal with their new situations, developed an inner strength to deal with the disease and made a variety of decisions following their diagnosis. They did not think only about themselves but also took their family, work and future hopes into consideration. Therefore, plotting the personal narratives of breast cancer experiences onto their life stories showed how the participants integrated their decisions with their personal experience, their relationships with other people and their socio-cultural beliefs. Their decisions surrounding breast cancer issues need to be accorded certain significance in order to understand the decisions.

# **Chapter 8: Conclusion, implications and limitations**

## **8.1 Introduction**

This chapter concludes the overall findings in this study and highlights its unique contribution in terms of new knowledge. It also offers recommendations for health care staff and future research about breast cancer decision-making. The strengths and limitations, together with the reflexivity and reflection of the study, are also acknowledged.

## **8.2 Contribution to knowledge**

This is the first qualitative study carried out in Malaysia that recruited women diagnosed across all of the stages of breast cancer (together with their family members). This study utilised women's narratives, and that of family members, to understand decisions and actions from discovery of their symptoms and the first conventional treatment undertaken. This study describes the range of decisions and the complexity of the process of making decisions among the participants. Importantly, this study challenges previous Malaysian studies, which attributes women's decision-making in the appraisal period to be a key cause of diagnostic delay, and consequent high rates of advanced cancer at diagnosis. This study provides a new understanding in which most women take seriously their symptoms and are supported by their family to seek medical help. Moreover, the narratives demonstrate socio-cultural explanations for their symptoms and to their attitudes to seeking medical help and conventional treatment.

Several of the narrative accounts verified that the socio-reality of women lives in Malaysia influenced their appraisal of the symptoms and how they decided to seek medical help. Additionally, their beliefs influenced

decisions about treatment, for some resulting in refusal of the conventional treatment offered for breast cancer. They believed that conventional treatment produced a worse net result than curing the breast cancer. Therefore, it is important that health promotion takes account of women's socio-cultural beliefs and how these are used in decision-making. This requires sensitive and non-judgemental attention by HCPs. Therefore, by being aware of the existing socio-culture beliefs in the local context, Malaysian HCPs have the opportunity to dispel the myths and guide the patients in their decision making process.

The study also challenges the role of husbands in decision-making especially in the traditional patriarchy system, where the husbands were more dominant. In contrast, this study showed that husbands were supportive towards their wives in seeking treatment. None of the husbands was against conventional treatment. They became pro-active when they knew about the symptom and they were supportive of their wives' decisions in any situation.

Using the narrative approach enabled the participants to describe their experiences, providing rich data within a given context, which in this case is about breast cancer decision-making. This approach enabled the researcher to listen not only to the individuals' stories but also to how those stories interconnected. The participant's stories became more valuable in their ability to be more informative and the interconnections between each story gave richness to the value of this research. In essence, this narrative approach provided an opportunity to explore how the process of decision-making disrupts and reshapes the participants' thinking about the past, present and future. Their narrative presented a complex interconnectedness between personal, socio-culture, gender and education, which affected their decision-making process.

The application of a theoretical framework such as MPTT, HBM and HLOC with the integration of the socio-culture factors provides an informative explanation in terms of understanding the participants' decisions in this study. These frameworks could help to identify the contributing factors that influence the decisions such as the patient, the disease and the available health care. This enables the HCPs to plan appropriate interventions in order to tackle early detection, presentation and the treatment of breast cancer.

Overall, the findings in this research contribute to a greater understanding of the decision-making experiences related to breast cancer among women and their family members in Malaysia. This study suggests that decision-making in relation to breast cancer should not be considered as an isolated matter, with some of the participants having experienced difficulty in their decision-making process. Their stories indicate that breast cancer decision-making is an ongoing experience with many challenges and that it is an interactive and complex process since each individual with breast cancer is unique. The process of understanding decision-making in the case of breast cancer is not linear but rather, it resembles a multifaceted circle with dynamic movement in which decisions can change due to knowledge, social-cultural, family issues, personal experiences, the health care staff and religious beliefs.

## **8.3 Research implications**

### **8.3.1 Recommendations for health care practice**

The findings in this study highlight a number of practical improvements for the Malaysian women with breast cancer and their family members that need to be addressed. Most of the women in this study reported that they found their breast lump by accident, such as while showering or dressing. Therefore, women should be educated by HCPs about

breast self-examination (BSE) and they should be encouraged to check their breasts regularly as BSE has still not reached optimum practice levels in Malaysia (Institute Public Health 2008). Although many studies have found BSE to be ineffective at reducing breast cancer mortality in the general population, it is nevertheless recommended for raising awareness among women in Malaysia (Ministry of Health Malaysia 2010).

The better targeting of information should be conducted. Improved information can challenge misconceptions, myths and negative beliefs and feelings by providing guidance and education to the Malaysian communities regarding the symptoms, risk factors and treatment, which affects them in terms of early detection, diagnosis and treatment. This can be achieved by increasing awareness among the public regarding breast cancer through health promotion. HCPs working with women from different communities and cultures should be sensitive to their interpretation of breast cancer as well. According to Loh et al. (2017), several breast cancer campaigns are conducted in Malaysia, notably in October since this is the month that is focused on breast cancer. However, there are also issues with such campaigns, including the fact that they tend to be sporadic, short in duration, are usually held in big cities, are not targeted programmes and they contain no outcome measure on the effectiveness of the programme [ibid.]. Therefore, in future programmes, HCPs should be consistently involved in addition to targeting specific objectives and populations.

Furthermore, HCPs must also stress the specific benefits of early detection and seeking help early for a timely diagnosis. They should encourage women and their family members to get an expert opinion as soon as they realise that something is wrong with their breasts and not to wait until the symptoms worsen. They should be informed about the available government-provided screening subsidises and facilities for detecting breast cancer, in addition to the non-governmental funding

incentives available. Women should also be encouraged to seek a second opinion if they feel unsatisfied with the doctor's examination or explanation or if their symptoms persist. Opportunistic screening by the Malaysian MOH may need to be revised to consider a younger age presentation of breast cancer.

The diagnostic investigation is often conducted in a sequential process and the presence of limited resources in terms of either staff or facilities might explain the waiting time and long system delay found in this study. Therefore, the government and policy makers must recognise and find the initiative to overcome any and all barriers in the system itself in order to improve the accessibility to screening, diagnosis and treatment. According to Shyyan et al. (2006), simplicity in the diagnostic process is critical in limited-resource settings and they suggested that a combination of the many diagnostic tests available allows for the establishment of pathology diagnosis in one visit.

The HCP's role is considered to be one of main factors that influenced the decision-making process among the participants in this study. Therefore, effort is required to minimise the potential risk of falsely reassuring patients. This can be accomplished by informing the patients about any uncertainty in the findings, explaining the symptom changes that need special attention, advising immediate help seeking behaviour if necessary and explaining the potential progress of the illness over time (Renzi et al. 2015). Additionally, Goodson and Moore (2002) suggested that doctors need to be more educated regarding the different types of breast cancer symptoms and their management. Knowledge about breast cancer and patient assessment appears to be crucial for effective early detection at the primary care level.

Regardless of when a decision to undergo conventional treatment is made, the doctor needs to support their patients by ensuring that they

are aware that delaying treatment tends to reduce their overall chance of survival. According to the American Cancer Society (2015b), it is important to make sure that those who refuse cancer treatment have a full understanding regarding their decision. HCPs should assess their patients' culture and beliefs prior to a consultation. Improvement in communication, especially a deeper understanding of their value system and cultural conations and how these affect the decisions-making process, enhances the HCPs awareness and skills in terms of identifying and working with the patient and their family members.

None of the participants in this study mentioned specifically about the role of nurse, except after the treatment already started. This demonstrates that the nurse's involvement in decision-making process before the treatment might be lacking in these two institutions. The possible explanation for this situation might be the doctor's autonomy is more dominant rather than the nurses or might be lack of guideline to support the nurse's role in decision-making process before the treatment. Previous study showed that nurses could contribute to improvement of decision-making process among patient with breast cancer (Eicher et al. 2006). Therefore, the government might consider the seven specific roles of nurses during the cancer treatment decision-making, which have practiced in Western countries (Tariman and Szubski 2015) to be implement in Malaysia oncology setting.

If the HCP has a better understanding of the decision-making process among women with breast cancer and their family members, they can provide support that is appropriate to their needs. Women experience their illness in many different contexts and each of them has personal individual differences. Therefore, the complexity of decision-making must be taken into consideration whenever health care interventions related to breast cancer are planned or developed. Ethnic and cultural

considerations should be integrated further into the health delivery system to improve care and health outcomes.

### **8.3.2 Recommendations for further research**

This study has contributed to the gap in the literature by focusing on the decision-making experiences of women with breast cancer and their family members in the Malaysian context. No one factor appeared dominant in this research as many of them were interrelated in terms of their respective influence on the process of making decisions about breast cancer. However, this study has raised some concerns that require further exploration, including concerns surrounding women and family members' responses with regard to their decisions. This study provides a starting point for further research that may benefit from using other research paradigms and research methods to further understand the whole decision-making process.

This study was conducted in an urban area of Malaysia, so further research should be conducted among women with breast cancer from rural areas. Malaysia is a very diverse nation. According to Abdullah et al. (2013), women from the east coast of Peninsular Malaysia and East Malaysia may have different beliefs and be more passive in their role within the decision-making process. Different decision experiences may also be obtained from women and family members from other cultures or who live in different geographical locations and contexts.

This study provides a basis for future research to gain other people's perspectives that are directly or indirectly involved in the process of decision-making about breast cancer; for example, to gain further understanding of the contribution of HCPs such as doctors and nurses, traditional healers and Islamic practitioners in breast cancer decision-making experiences. Information captured from a variety of such

sources could work synergistically to improve the quality of life of women with breast cancer.

Some of the participants displayed positivity, optimism, strength and courage when diagnosed with breast cancer and when undergoing treatment, which merits further exploration. This is because breast cancer has a tendency to incite a fear of death and provoke great suffering among patients (Fonseca et al. 2014). Thus, it appears to be worth examining how these women determined their path and made decisions throughout the course of their disease to enable us to understand their adaptation to breast cancer.

The myths and beliefs surrounding breast cancer and its treatment should be further explored, as these combine to make up one of the challenges in the decision-making process. This knowledge might contribute to the development of a culturally appropriate approach that helps to break down taboos and stigma, raise awareness and promote timely help-seeking and treatment decision-making for breast cancer among women.

#### **8.4 Study strengths and limitations**

It is important to discuss the strengths and potential limitations of this study. The selected research participants were an important factor capable of shaping the research findings. In this study, the participants displayed a breadth of characteristics, including variety in their stages of breast cancer, ethnicity, treatment, age and family member relationships. The participants also had diverse experiences in terms of their decision-making, thereby enhancing and expanding our knowledge about decision-making from various perspectives. However, the small number of Chinese and Indian participants might serve to limit

the knowledge with regard to socio-cultural beliefs within these ethnic groups.

A strength of this study was that the interviews began with the same introduction phase for every participant. From there, the participants began to recount their experiences depending on their understanding and preferences because it is important to let the participants tell their own stories. By according them this sense of freedom, I was hoping to hear what was important to them and for them to speak about this in the manner in which they wanted to tell me. I wanted their stories, and I acknowledged what they wanted to tell me. Hence, the voice of the participants was both central and heard. However, since this study did not contain any follow-up interviews, some of the accounts were lacking in detailed explanations for some of the issues talked about.

The narrative analysis was also limited by the role of the researcher to construct and interpret the participants' stories. The researcher decided what should be included in the analysis, what should be excluded and interpreted the meanings of the transcripts. Consequently, the researcher decided what was significant about the narratives. It is thus possible that certain important issues may have been overlooked or not included in the findings. However, I tried to the best of my ability to construct my interpretation based on the participants' stories. This was achieved by being reflexive, referring back to the transcripts, field notes and reflective diaries and listening again to the audio recordings.

## **8.5 Reflexivity and reflection**

According to Finlay (2003, p.108), reflexivity refers to “the process of continually reflecting upon our interpretations of both our experience and the phenomena being studied so as to move beyond the partiality of our previous understandings and our investment in particular research

outcomes". Reflexivity is a hallmark of excellent qualitative research because of the researcher's ability and willingness to acknowledge and consider the many ways in which they influence the research findings and for these to be accepted as knowledge (Sandelowski and Barroso 2002), including to reflect upon oneself as an inquirer, the cultural, historical, linguistic, political and social interaction between the researcher and participant, and other factors that shape everything in respect of the inquiry (Alvesson and Skoldberg 2000). Hence, reflexivity is a critical element as I brought my own identity and biases during the interaction with the participants, and this also had to be considered during the interpretation of the narrative data. This demonstrates that the written report for which I am accountable is a narrative that was created by me and was generated from the narratives of the participants. At the time of writing, I was a 36-year-old Malay woman who was born in Malaysia, raised in an average middle-class home in a rural area and had experiences both as a nurse and as a health academic. Thus, I shared some of the culture, values and norms with the participants in this study. Thus, it would not be difficult to share and understand the stories.

Finlay (2003) stated that reflexivity could be considered a potentially valuable tool with which to examine the impact of the researcher's position and perspective. Regular supervisory discussion was important for me, especially when my supervisors probed for more critical interpretation. Their suggestions helped me to review back and to think in different ways. Thus, it might be possible for there to be more than one interpretation for the same quotation from different perspectives. Talking to Malaysian colleagues who had experience in qualitative research was beneficial in obtaining their views regarding my interpretation.

According to Goldblatt and Band-Winterstein (2016), reflection is defined as “thinking about something after the event” (p.101). Reflection is crucial for qualitative research because it allows the researcher, myself in this context, to think critically about previous experiences so as to improve knowledge and research skills for conducting qualitative research projects in the future (Jasper 2003). Initially, I had mixed feelings about conducting this study. I was excited because it is my first qualitative study yet I also felt overwhelmed because I was worried about conducting the research in an unfamiliar environment, wherein I was an outsider who knew little about breast cancer and had no personal contact network there.

After obtaining ethical approval from both the University of Southampton, UK, and Malaysia, I began to visit both hospitals for recruitment of the participants. I had two local supervisors, with one person in each hospital. After holding a discussion on the study with my local supervisor from the teaching hospital, she oriented me towards the clinic and ward, introduced me to the other staff and asked me to join a medical case review, wherein all of the oncology, radiology and surgery teams discuss cancer case by case. However, in the public hospital, I had to approach the staff and identify the recruitment locations by myself, as the local supervisor was very busy at that time. I felt thankful because all of the staff were very helpful and accepted me as one of the researchers there.

During the recruitment, I positioned myself as a graduate student and talked about the value of the participants’ experiences in my learning about the decision-making processes related to breast cancer. On the day of the interviews, I dressed informally and interacted with their family members when they were present. Malaysian people are kind and friendly by nature. From my experience of conducting research, it is necessary to be considerate, polite, respectful and patient, with such a

manner providing the ability to gain rapport and collaboration. I initiated a casual conversation related to their health, family and activity to increase their comfort. Then, I emphasised the importance of understanding the participants' experiences and provided insight into explanations of their decisions.

Reflecting back on my experience during the interviews, I chose to speak in the local dialect so that they would be able to understand and speak fluently. The women with breast cancer and their family members seemed to have no problem with sharing their experiences. Since most of the interviews were conducted in the participants' homes, the presence of other family members who were not involved in this study at times seemed to disrupt the interview and may have influenced the stories that the participants told me during the interviews. The presence of children shouting and talking to the participants tended to distract them from the interview process. Thus, I would suggest conducting the interviews on weekdays if possible for those who have small children, when the children are in school and other people are at work.

As a researcher, I was conscious regarding my research objective and which area I would like to explore. However, during the interviews, the participants led the conversations in terms of how they responded to the interview script and in what they said. Each participant chose their own way to begin and selected what they talked about in relation to their experiences.

I experienced a variety of anticipated feelings as the participants' stories unfolded. I felt pity when they described how they made sense of their symptoms, how they had false reassurance from medical doctors, believed what other people said and suffered due to untreated breast cancer. The way in which the participants shared their stories occasionally led to me re-experiencing events with them. I could

sometimes see tears flowing but they kept talking. The participants also spoke about how their decisions had changed over time due to many influential factors. I began to gain a greater understanding of the complexity of the women and family members' lives and the challenges they faced due to breast cancer.

At times, I felt shocked when the participants spoke about their beliefs regarding breast cancer issues. What I perceived to be normal I also assumed was a shared norm, even beyond my cultural context. I had never encountered a situation such as where breast cancer did not seem to be serious for some of the women. What I realise now is that different contexts will raise different meanings and interpretations. Even though the participants and I may have had certain things in common, such as our language, tradition and culture, these are not necessarily interpreted via the same understanding. Although I experienced mixed emotional feelings, I tried to maintain a neutral attitude because I recognised my role as a researcher.

After listening to the audio recordings, I realised that my interviews were not perfect. There was some information given for which I did not request a more detailed explanation, especially from those participants who were being interviewed at an earlier stage of the data collection process. It is important to listen to your interview soon after the process and capture all of the field notes. Therefore, for future research, I would suggest conducting a follow-up interview with the purpose of clarifying any uncertainties from the first interview. This could also further enhance our understanding of the participants' experiences.

I found transcribing the interviews to be the most time-consuming part of the research process, but it was also the most important part of the information gathering and assisted me in making sense of my data. I could have repeated, amended and added some information that I had

not concentrated on or noted during the data collection. It took me several months to complete this process but it also assisted me in spending less time on the data analysis because I understood and remembered most of the data after continuing to listen to the recordings many times.

Data analysis is the most challenging aspect. Even some analytical approaches have been discussed within the literature, narrative analysis is considered challenging and difficult because “clear accounts of how to analyse the data … are rare” (Squire et al. 2008, p.1). Therefore, lack of prescriptive steps including in Riessman’s analysis tend to be daunting. The first challenge is where should I started the analysis even though this is not all the case in my study. This refers to a situation where the participants did not simply shared their experiences in chronological order, but their stories were scattered all over the interview. At times, talking about one issue would trigger memories of other experiences that the participants considered important to include in the stories they were sharing. I also acknowledge that some sections of the participants’ narratives seemed irrelevant to the topic of the research questions. However, I could not ignore this narrative because it had been told for a reason and they need to be analysed with this in mind, which is quite challenging. Sometimes, the plot of the stories could be change at any time during the conversation and possibly have multiple interpretations that I have to be aware if I looked from different perspectives.

Qualitative data analysis requires time and effort to analyse and reanalyse until there is no remaining doubt as to the findings. As a researcher, I have to be concerned about the quality of the analysed data, as well as the ethics of presenting a participant’s quotation. Translating selected quotations is also time-consuming. I asked my Malay colleagues who were also studying in the UK to check the translations. Selecting participants’ quotations sometimes caused me

further personal dilemmas. Some of the quotations led me to think that I did not want to embarrass my country, such as noting inaccurate knowledge and unreasonable socio-cultural beliefs. However, if I did not write this as it was said, how would we be able to improve and take appropriate action in respect of it? Therefore, I decided to write the quotations and ensure that all of the anonymities were fully implemented.

Throughout the whole process of the interviews, including the transcription, translation, analysis and interpretation, the knowledge reported may not have been complete. Whilst I was aware that the representation of the participants' experiences in decision-making may have been incomplete or partial, I remained strongly committed to doing what I could to best represent their voices and experiences.

## **8.6 Conclusion**

The findings of this study answer the research questions on exploring the decision-making experiences among women and their family members regarding the issues surrounding breast cancer. This study contributes to the understanding of the process of decision-making, types of decisions and decision points that the participants made within the specified time frame, namely from the discovery of an abnormality to the point at which the women underwent conventional treatment for their breast cancer.

This study provides qualitative evidence from the women and family members' perspectives on decision-making in Malaysia. This will inform and guide HCPs about what women with breast cancer and their family members consider when making a decision, to enable them to support patients and their families, which is an area that has so far been neglected in the research. HCPs may be able to use this in-depth

understanding to interact more effectively, improve their relationships and assist women's and their family members' decision-making about breast cancer. The quality of support and care provided by HCPs is dependent, at least in part, on their understanding of patients' experiences of making decisions concerning their treatment and ongoing care (Halkett et al. 2007). This information will also assist HCPs in their interaction with patients and help them to extend the care that they provide [ibid.]. It is also anticipated that the findings of this research will enable HCPs to use the knowledge to inform their own practice and manage patient care to suit their patients' situations and improve their quality of life.

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## Appendix 1: Search strategy used to identify articles that relate to breast cancer

Table 2.1: Search strategy used to identify articles that relate to breast cancer in Malaysia

Keyword /database	MEDLINE	CINAHL	PsylINFO	EMBASE	AMED	Web of Science	SCOPUS	*Google Scholar
"Breast cancer" OR "breast carcinoma" OR "breast neoplasm" AND Malaysia* or Asia* OR South East Asia*	150	6	30	227	12	32	9	
"Breast cancer" OR "breast carcinoma" OR "breast neoplasm" AND Malaysia* or Asia* OR South East Asia*	50	0	11	47	2	9	2	
"Breast cancer" OR "breast carcinoma" OR "breast neoplasm" AND Malaysia* or Asia* OR South East Asia*	8	0	2	1	0	0	0	

AND Health seeking OR help seeking								
“Breast cancer” OR “breast carcinoma” OR “breast neoplasm” AND Malaysia* or Asia* OR South East Asia* AND Perception* OR view* OR opinion*	14	1	1	9	0	0	1	
“Breast cancer” OR “breast carcinoma” OR “breast neoplasm” AND Malaysia* or Asia* OR South East Asia* AND Understanding* OR awareness*	29	0	9	9	2	0	2	
“Breast cancer” OR “breast carcinoma” OR “breast neoplasm” AND Malaysia* or Asia* OR South East Asia* AND Attitude* OR behavio?	16	0	15	21	0	1	1	

“Breast cancer” OR “breast carcinoma” OR “breast neoplasm” AND Malaysia* or Asia* OR South East Asia* AND Screening OR mammogram OR mammography	40	2	15	39	1	8	0	
“Breast cancer” OR “breast carcinoma” OR “breast neoplasm” AND Malaysia* or Asia* OR South East Asia* AND Delay treatment*	8	0	3	0	0	1	0	
“Breast cancer” OR “breast carcinoma” OR “breast neoplasm” AND Malaysia* or Asia* OR South East Asia* AND Barrier* OR hindrance* OR factor*	90	3	19	79	3	5	7	
“Breast cancer” OR “breast carcinoma” OR “breast neoplasm”								

AND Malaysia* or Asia* OR South East Asia* AND Alternative* OR traditional OR complementary	9	0	9	11	3	7	1	
“Breast cancer” OR “breast carcinoma” OR “breast neoplasm” AND Malaysia* or Asia* OR South East Asia* AND treatment option* treatment*	54	0	8	70	4	10	6	
“Breast cancer” OR “breast carcinoma” OR “breast neoplasm” AND Malaysia* or Asia* OR South East Asia* AND End of life OR dying OR palliative OR terminal	2	0	9	12	0	0	0	
“Breast cancer” OR “breast carcinoma” OR “breast neoplasm” AND	9	0	1	11	1	1	0	

Malaysia* or Asia* OR South East Asia* AND Decision-making OR decision* OR choice*								
“Breast cancer” OR “breast carcinoma” OR “breast neoplasm” AND Malaysia* or Asia* OR South East Asia* AND Experience* OR involvement*	26	0	6	27	0	5	0	
“Breast cancer” OR “breast carcinoma” OR “breast neoplasm” AND Malaysia* or Asia* OR South East Asia* AND Famil* OR relative* OR husband* OR spouse* OR partner* OR sibling* OR parent* mother* OR father* OR son* OR daughter* OR next of kin	43	1	4	68	5	5	0	

“Breast cancer” OR “breast carcinoma” OR “breast neoplasm” AND Malaysia* or Asia* OR South East Asia* AND Culture* OR belief* OR religious OR spiritual belief* OR spirituality OR faith OR value*	27	2	10	24	5	6	2	
“Breast cancer” OR “breast carcinoma” OR “breast neoplasm” AND Malaysia* or Asia* OR South East Asia* AND Nurse* OR oncology nurse* OR breast care nurse*	4	0	2	1	0	1	1	200
Limiter	2005–2015, adults, English							
Date of search: 3 <sup>rd</sup> & 4 <sup>th</sup> Oct 2015	Malaysia	Asia	Subject : Asians, South East Asia	Embase , human, male, female		Research domain: Social Science, Art &	Research domain: Health Science & Social	

			cultural groups			Humanities ; Malaysia	Science; Malaysia	
<b>TOTAL</b>	<b>579</b>	<b>15</b>	<b>154</b>	<b>656</b>	<b>38</b>	<b>91</b>	<b>32</b>	<b>200</b>

\*Google Scholar was added later to search purposely for role of nurse only. Haddaway et al. (2015) recommended to focus on the first 200 to 300 results for retrieved article through google Scholar.

## Appendix 2: Inclusion and exclusion criteria with rationale of article rejection and selection

Table 2.2: Inclusion and exclusion criteria with rationale of article rejection and selection

No	Inclusion	Exclusion	Rationale
1	Study related to women with breast cancer and their families' members (husband, parents, and siblings).	<ul style="list-style-type: none"> <li>i. Studies that are not exclusively about breast cancer but include other types of cancers.</li> <li>ii. Non-target population (healthy women, pregnant women, and friends).</li> </ul>	The experience and impact of breast cancer women and families may differ to another type of cancer and non-target population.
2	Study related to decision-making or related issues such as delay, health/help seeking, experience, treatment, screening, cultures, religious, spiritual and beliefs.	<ul style="list-style-type: none"> <li>i. If the studies report about general breast cancer information, epidemiology, survival, and risk factors.</li> <li>ii. Not relevant topic such post operation pain, a side effect of chemotherapy and software.</li> <li>iii. Studies on laboratory method such as pathology, radiology, pharmaceutical, biopsy and histopathology.</li> </ul>	This study focuses on decision-making and other issues that relevant to it.
3	About involvement of nurses to deal with breast cancer women and their families.	Other healthcare staff (physician, dietitian, physiotherapy, counsellor, radiotherapy, and pharmacist).	This study focuses only nurses as opposed to other healthcare staffs.

4	Malaysia	Studies that are not exclusively conducted in Malaysia but include other countries.	To find the gaps from existing literature within Malaysia context.
5	Year 2005–2015 and in English or Malay language	Not available in Malay or English language	There was no resource to translate articles. Maximum time-frame of ten years accepted as the evidence.

## Appendix 3: Descriptive summary of selected articles in Malaysia

Table 2.3: Descriptive summary of selected articles in Malaysia

No	Authors (Year)	Study design	Participant characteristics	Analysis	Finding related to decision-making
1	Abdullah et al. (2013)	Qualitative	Sample size:8 Age range:41–64 years Breast cancer stage: stage I & II Inclusion criteria: aware of the diagnosis, not undergone surgery, chemotherapy or radiotherapy.	Thematic analysis	4 phases in decision-making process:  1. Discovery phase 2. Confirmation phase 3. Deliberation phase 4. Decision phase
2	Yusof et al. (2013)	Phenomenology	Sample size: 20 Age range: 34–59 years Breast cancer stage: Stage I to IV Inclusion criteria: Phase 1 (first week after women received breast cancer diagnosis) and follow up in phase 2 (six-month following diagnosis of breast cancer)	Thematic analysis	1. Lack of knowledge about breast cancer and presenting symptoms 2. After receiving the diagnosis, women in dilemma about treatment 3. Fatalistic view of breast cancer

3	Norsa'adah et al. (2012)	Qualitative	Sample size: 12 Age range: 27–67 years Breast cancer stage: stage II to IV Inclusion criteria: women showed delay in consultation, diagnosis or treatment	Thematic analysis	Delay in seeking help:  1. Lack of knowledge about breast cancer and presenting symptoms 2. Fear of cancer consequences 3. Sanction by husband, family members, neighbour 4. Other priorities 5. Denial 6. Attitude of wait and see 7. Weakness of health care provider and system
4	Taib et al. (2014)	Qualitative	Sample size:19 Age range:35–82 years Breast cancer stage: stage IIA to IV Inclusion criteria: women with advanced breast cancer or delaying presentation or treatment beyond six months and diagnosed within 2-year	Constructivist Grounded Theory	1. Total breast cancer delay (TBCD) model 2. Breast cancer delay explanatory model

5	Shariff et al. (2008)	Qualitative	Sample size:36 Age range: 36 –65 years Breast cancer stage: stage I to III Inclusion criteria: breast cancer patient and survivors	Thematic analysis	Person involved in decision-making:  1. Women themselves 2. Family members 3. Physician
6	Yusoff et al. (2011)	Qualitative	Sample size: 16 husbands, 10 breast cancer women  Age range: 37–70 years (husband), 37–71 years (women)  Breast cancer stage: not stated  Inclusion criteria: delay case either patient's delay or hospital's delay	Thematic analysis	Delay in getting treatment:  1. Seek traditional healer 2. Lack of knowledge about breast cancer and presenting symptoms 3. Weakness of healthcare services and/or staff 4. Following someone such as friends or relatives 5. Fear of breast removal, time constraint due to job
7	Taib et al. (2011)	Qualitative	Sample size:19  Age range:35–82 years  Breast cancer stage: stage IIA to IV  Inclusion criteria: women with advanced breast cancer	Thematic analysis	Reasons presenting with advanced breast cancer:  1. Lack of knowledge about breast cancer and presenting symptoms

			or delaying presentation or treatment beyond 6 months and diagnosed within 2-year		2. Fatalistic view of breast cancer 3. Denial 4. Role of significant others
8	Muhamad et al. (2012)	Qualitative	Sample size: 11  Age range: 34–75 years  Breast cancer stage: not stated  Inclusion criteria: women who had access to western medical system and traditional healer	Thematic analysis	Reasons seeking traditional healers:  1. Recommendation by family and friends 2. Sanction from family 3. Perceived benefit and compatibility 4. Healer credibility 5. Reservation with western practice and system delay
9	Teh et al. (2014)	Quantitative	Sample size: 184  Age range: <40 to >60 year  Breast cancer stage: stage I & II  Inclusion criteria: had undergone surgery and completed adjuvant treatment	Descriptive and Chi-square	Malay women considered the opinion of their partners (84.8%) and family members (72.1%) very important compared to Chinese and this finding statistically significant.

10	Leong et al. (2009)	Quantitative	<p>Sample size: 186</p> <p>Age range: common age 40–49 years, mean age 51 years</p> <p>Breast cancer stage: stage 0–IV</p> <p>Inclusion criteria: a two-year prospective study of all newly-diagnosed breast cancer or any referral cases from other institution to Queen Elizabeth Hospital.</p>	Descriptive and Chi-square	<p>69.4% had a mastectomy, 12.3% had breast conserving surgery, 18.3% had no surgery, 0% had breast reconstruction.</p> <p>Fear of surgery and culture belief as jeopardized the role as mother or wife reasons for refused treatment.</p>
11	Shameen et al. (2008)	Quantitative	<p>Sample size: 136 (23 patient undergone immediate breast reconstruction, 113 not reconstructed)</p> <p>Age range: mean age reconstructed 41.6 years, not reconstructed 51.7 years</p> <p>Breast cancer stage: stage 0–III</p> <p>Inclusion criteria: post-mastectomy who had and had not undergone immediate breast reconstruction.</p>	Descriptive and Chi-square	<p>Twenty-three out of 136 had undergone breast reconstruction. The main reason was to feel complete again, to regain femininity, to feel more balanced and no clothing limitation. The main reasons for not having reconstruction were fear of additional surgery, fear of complications of surgery, and not essential for physical and emotional well-being</p>

12	Mohamed NA and Muhamad M (2013)	Quantitative	Sample size:69 Age range: > 60 year Breast cancer stage: stage I to IV Inclusion criteria: older breast cancer survivors	Descriptive statistics	Decision-making on treatment: 55.1% women themselves 8.7% family members 7.2% physician
13	Shaharudin et al. (2011)	Quantitative	Sample size: 116 Age range: 21–67 years Breast cancer stage: stage I to IV Inclusion criteria: 2-year post-diagnosis and currently undergoing follow-up at Hospital Kuala Lumpur and University Kebangsaan Malaysia Medical Centre	Descriptive and Chi-square	Reasons for using CAM 57.6% assist in healing the body's inner strength 41.1% cure cancer 27.4% family encouragement
14	Muhamad et al. (2011)	Quantitative	Sample size: 400 Age range: not stated Breast cancer stage: Inclusion criteria: breast cancer survivors	Descriptive statistics	Supports for making treatment decision: 52% from spouse 25% from children 16% from parents 26.3% from siblings 14% from relatives

15	Norsa'adah et al. (2011)	Quantitative	Sample size: 328 Age range: mean age 47.9 years Breast cancer stage: stage I to IV Inclusion criteria: diagnosed with primary breast cancer with 2-year from 5 selected hospitals.	Multiple logistic regression	Factors associated with diagnosis delay and significant: use of alternative therapy, breast ulcer, palpable axillary nodes, false-negative diagnostic test, non-cancer interpretation and negative attitude towards treatment
16	Taib et al. (2007)	Quantitative and qualitative	Sample size: 27 Age range: 30–74 years Breast cancer stage: stage III and IV Inclusion criteria: presented with locally advanced and/or metastatic disease	Descriptive	Reason refused treatment is fatalistic view from role model and used of CAM
17	Yu et al. (2015)	Meta-synthesis	Sample size: 9 studies in Malaysia	Synthesizing and transforming the description	Barriers to health seeking: 1. Lack of knowledge 2. Psychological burden 3. Socio-cultural effect 4. Health system issues

18	Maskor et al. (2013)	Qualitative	Sample size: 17 Age range: 28–56 years Inclusion criteria: had post-basic course in oncology or working experience as a cancer care nurse	Constant-comparative method	The important of communication between nurses, patients and family members. The nurses combine both verbal and non-verbal communication in their work.
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## Appendix 4: PRISMA flow chart of the data selection process

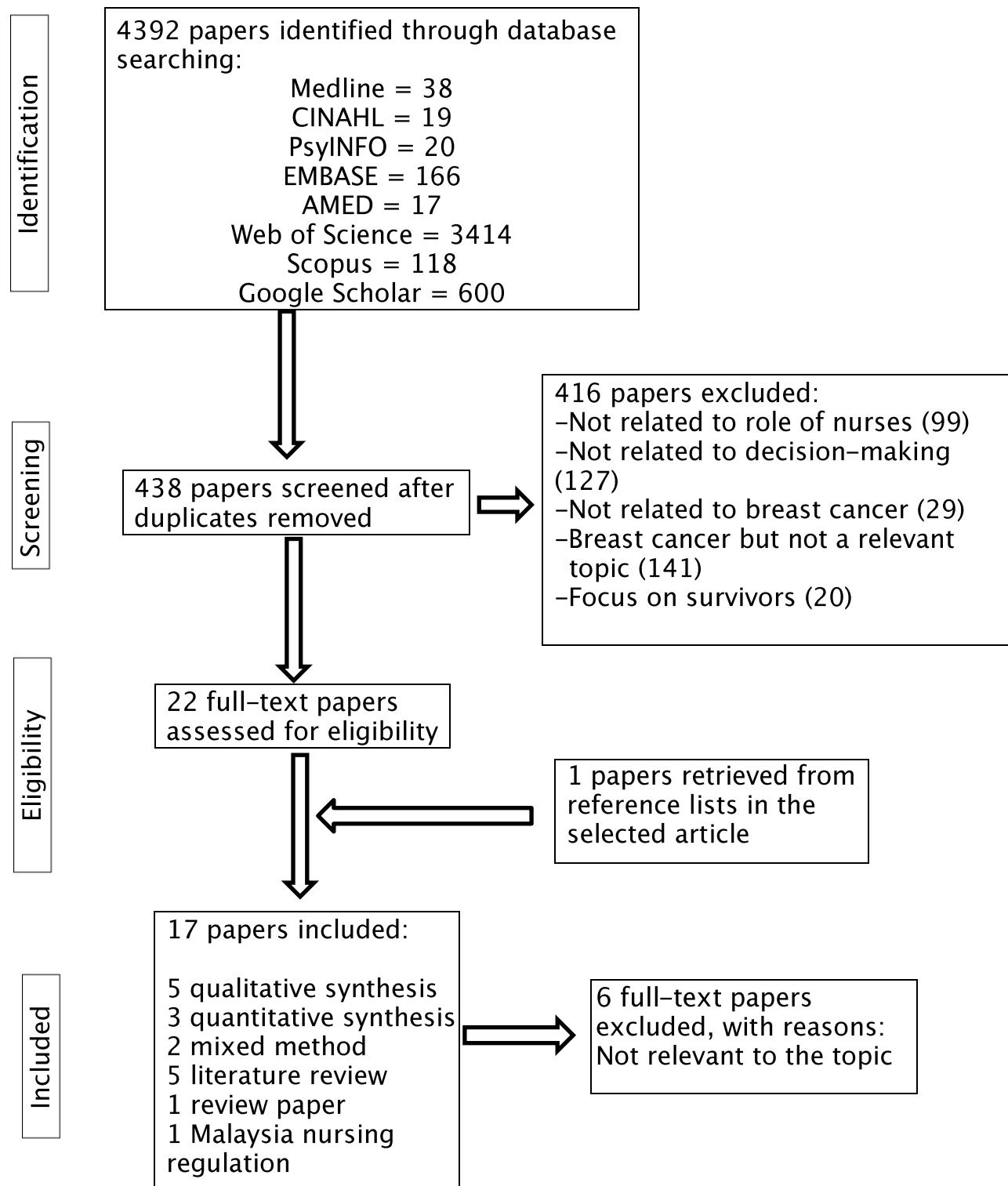


Figure 2.2: PRISMA flow chart of the data selection process for the policy and roles of oncology nurses other than in Malaysia

## Appendix 5: Search strategy used to identify articles that relate to role of nurses

Table 2.4: Search strategy used to identify articles that relate to role of nurses

Keyword /database	MEDLINE	CINAHL	PsyINFO	EMBASE	AMED	Web of Science	SCOPUS	Google Scholar
<p>“Breast cancer” OR “breast carcinoma” OR “breast neoplasm”</p> <p>AND</p> <p>Nurse* OR oncology nurse* OR breast care nurse*</p> <p>AND</p> <p>Role* OR function* OR job*</p>	22	14	13	99	14	1738	65	200
<p>“Breast cancer” OR “breast carcinoma” OR “breast neoplasm”</p> <p>AND</p> <p>Nurse* OR oncology nurse* OR breast care nurse*</p> <p>AND</p> <p>Role* OR function* OR job*</p>	11	4	2	32	1	651	26	200

Decision-making OR decision* OR choice*								
“Breast cancer” OR “breast carcinoma” OR “breast neoplasm”  AND  Nurse* OR oncology nurse* OR breast care nurse*  AND  Policy* OR law* OR legislation* OR regulation*	5	1	5	35	2	1025	27	200
Limiter	2005–2019, adults, English							
Date of search: 30 <sup>th</sup> & 31 <sup>th</sup> Mar 2019	Subject major: Nurse’ roles	Subject major: Nursing role	Subject: nurses	Embase cancer nursing		Research domain: Social Science, Art & Humanities ; Nursing, open access	Research domain: Health Science & Social Science;	Haddaway et al. (2015) suggests searches of article titles focus on the first 200 to 300 results through Google Scholar
<b>TOTAL</b>	<b>38</b>	<b>19</b>	<b>20</b>	<b>166</b>	<b>17</b>	<b>3414</b>	<b>118</b>	<b>600</b>

## Appendix 6: Descriptive summary regarding the policy and role of nurse

Table 2.5: Descriptive summary of selected articles regarding the policy and roles of nurse

No	Authors (Year)	Study design	Participant characteristics	Analysis	Finding related to roles of nurses
1	Halkett et al. (2006)	Qualitative	Sample size:18 Age range:39–77 years Status: Patient	Thematic analysis	1. Give information, emotional and practical support 2. Give advice and reassurance
2	Pongthavornkamol et al. (2018)	Qualitative	Sample size: 16 Age range: 23–59 years Status: Nurse	Content analysis	1. Support & allow patient to make decision 2. Provide adequate information 3. Potential conflict when patient made decision against the treatment recommendation
3	Barthow et al. (2009)	Qualitative	Sample size: 13 Status: Nurse	Content analysis	Factor influencing nurses' involvement in treatment decision support 1. Knowledge 2. Experience 3. Structural 4. Belief & attitude
4	Admi et al. (2011)	Qualitative	Sample size: 3 interview & 125 thank you letter Status: Patient	Content analysis	1. Emotional aspect 2. Cognitive aspect 3. Instrumental aspect

5	Tariman et al. (2016)	Qualitative	Sample size:30 Age range: 40 –59 years Status: Nurse	Content analysis	1. Patient education role 2. Advocacy role 3. Information or data gathering role 4. Symptom and side effects management role 5. Information sharing role 6. Psychological support role 7. Complex role
6	Kadmon et al. (2015)	Quantitative	Sample size: 321 Age range: 28 –84 years Status: Patient	Descriptive statistics	1. Give information, psychological and practical support 2. Coordination and navigation of care
7	Luck et al. (2016)	Quantitative	Sample size: 100 Age range: 29 –67 years Status: Nurse	Descriptive and non-parametric statistics	1. Patient advocate 2. Patient educator 3. Care coordination 4. Clinical expert
8	Makabe et al. (2018)	Quantitative	Sample size: 3829 Age range: 33 ±10 years Status: Nurse	ANOVA and Chi-square	The background of the countries, culture, education, health services and internal problems lead to different nurses' quality of life across Asian countries.
9	Jones et al. (2010)	Mixed-method	Sample size: Study 1:11 nurses & 7 other HCPs	Thematic analysis & descriptive statistics	1. Direct patient care at different stages of the journey including diagnosis, treatment and post-treatment.

			Study 2: 27 nurses & 21 HCPs		<ol style="list-style-type: none"> <li>2. Provide support or care including informational, psychosocial, educational, physical, and attending consultation with other HCPs</li> <li>3. Coordinating patient care</li> </ol>
10	Eley et al. (2008)	Mixed-method	Sample size: 51 Age range: 40 –79 years Status: Patient	Thematic analysis & descriptive statistics	<ol style="list-style-type: none"> <li>1. Give information, emotional and practical support</li> </ol>
11	Ahern and Gardner (2015)	Literature review	Sample size: 9 studies in Australia	Synthesizing and transforming the description	<ol style="list-style-type: none"> <li>1. Provision of support including emotional, informative and practical</li> <li>2. Provision of treatment information</li> <li>3. Provision of ongoing support, advice and information at different stages of the cancer journey</li> <li>4. Educate, encourage and support patients to self-manage different aspects of their disease</li> <li>5. Referral to other services as needed</li> <li>6. Attend MDT meetings and be present as patient advocate</li> </ol>

12	Eicher et al. (2006)	Systematic review	Sample size: 10 studies	Synthesizing and transforming the description	Outcomes of specialised nurse interventions 1. Improvement of physical impairment 2. Improvement of psychosocial problems 3. Improvement of decision-making processes 4. Improvement of collaboration in MPT 5. Improvement of costs
13	Vaartio-Rajalin and Leino-Kilpi (2011)	Literature review	Sample size: 10 studies	Deductive analysis	Nurses as patient advocacy
14	Tariman and Szubski (2015)	Literature review	Sample size: 33 studies	Synthesizing and transforming the description	1. Patient education 2. Advocacy role 3. Outcome evaluation role 4. Assessment, monitoring and treatment of side effects 5. Information giving role 6. Psychological support role 7. Complex role
15	Koutsopoulou et al. (2011)	Critical review	Sample size: 46 studies	Synthesizing and transforming the description	Nurses as information provider
16	Quinn (2008)	Review paper			in Asian countries, there are lack of clarity regarding the role of

					oncology nurses and they mainly function in a caregiver role, focusing on treatment delivery, education and symptom management. Specialization is rarely seen
17	Nursing Board Malaysia (2015)	Code of Professional Conduct for Nurses			<ol style="list-style-type: none"> <li>1. Respect for patient</li> <li>2. Standard of care</li> <li>3. Accountability</li> <li>4. Advocacy</li> <li>5. Teamwork</li> </ol>

## **Appendix 7(a): Letter of invitation (English version)**

Date:

Dear Sir/Madam

### **Letter of Invitation: Interview**

I am conducting interviews as part of a research study, in which the main focus is to gain information about the decision-making experiences in relation to seeking and undertaking conventional treatment in the hospital among women with breast cancer and their family members in Malaysia. As a [patient or family members,] you are considered to have experiences in this matter.

Therefore, I would like to invite you to take part in this study. I will ask your personal story about making decisions for breast cancer. The interview will take approximately one hour to complete and is informal. Please read the information sheet and consent form enclosed with this letter. This will help you to decide whether you would like to take part or not. You are expected to complete the consent form prior to the interview. Please do not hesitate to contact me if further information needed through the given contact details below.

I hope that you will find this study interesting and thank you very much in advance for your cooperation.

Sincerely,

Wan Hasliza Wan Mamat

PhD student

Faculty of Health Sciences

University of Southampton

Southampton SO17 1BJ

Tel: +447752417235(UK)/+60139375709(MYS)

Email: [whwm1c14@soton.ac.uk](mailto:whwm1c14@soton.ac.uk)

## **Appendix 7(b): Letter of invitation (Malay version)**

Tarikh:

Kepada Tuan/Puan

### **Surat Jemputan: Temubual**

Saya sedang menjalankan temubual yang merupakan sebahagian daripada kajian penyelidikan, yang mana fokus utama adalah untuk mendapatkan maklumat berkaitan dengan pengalaman dalam mencari dan membuat keputusan tentang rawatan konvensional di hospital dalam kalangan pesakit wanita yang menghidapi kanser payudara dan ahli keluarga mereka di Malaysia. Sebagai [pesakit atau ahli keluarga], anda dianggap berpengalaman dalam perkara ini.

Oleh itu, saya ingin menjemput anda untuk menyertai kajian ini. Saya akan meminta anda bercerita tentang pengalaman dalam membuat keputusan bagi kanser payudara. Temubual ini akan mengambil masa kira-kira satu jam. Sila baca lembaran maklumat dan borang persetujuan yang dilampirkan bersama surat ini. Maklumat ini akan membantu anda untuk membuat keputusan sama ada anda ingin mengambil bahagian atau sebaliknya. Anda dikehendaki melengkapkan borang persetujuan sebelum temubual dijalankan. Sila hubungi saya melalui butiran peribadi di bawah.

Saya berharap anda akan mendapati kajian ini menarik dan terima kasih terlebih dahulu di atas kerjasama anda.

Yang benar,

Wan Hasliza Wan Mamat

Pelajar PhD

Faculty of Health Sciences

University of Southampton

Southampton SO17 1BJ

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Email: [whwm1c14@soton.ac.uk](mailto:whwm1c14@soton.ac.uk)

# **Appendix 8(a): Participant (patient) information sheet (English version)**

## **Participant (Patient) Information Sheet (English version)**

**Study Title:** Malaysian women's and family members' narratives of their breast cancer decision-making experiences

**Researcher:** Wan Hasliza Wan Mamat      **UoS Ethics number:** 22983

**Please read this information carefully before deciding to take part in this research. If you are happy to participate, you will be asked to sign a consent form.**

### **What is the research about?**

This study is about understanding your experiences as women with breast cancer in relation to decision-making regarding seeking and undertaking conventional treatment in the hospital. Thus, this study will explore your stories from the time you discovered symptoms in the breast until you have undergone the first conventional treatment in the hospital

### **Why have I been chosen?**

You have been invited to take part in this study because you have been identified by your hospital staff as a patient who has already undergone first treatment for your breast cancer.

### **What will happen to me if I take part?**

Taking part in this study will involve an interview. In the interview, I will ask your personal story about decision-making for breast cancer such as how you made the decisions, what type of decisions you made and what are the factors that influence your decisions. I also will be taking notes along with the audio recording of the interview. Later, I will be checking with you using the timescale that I had creating during the interview. The interview will take approximately one hour to complete. The time and location for an interview will be determined by you at your convenience. The audio recording will be requested before starting an interview.

### **What will I have to do?**

If you are interested to take part in this study, you can contact the researcher directly by phone or email to address provided below.

### **Are there any benefits in my taking part?**

There is no personal benefit from your participation in the study. However, the information gained from this study may guide health care professionals about what women with breast cancer consider in making decisions and enable them to support patients. Additionally, this information also enables health care professionals to interact more effectively, improve their relationships and adapt patient care to suit a patient's situation.

### **Are there any risks involved?**

While we do not foresee any risk or harm to you by taking part in this study, we do understand that you may be distressed talking about your condition. However, this interview is not intended to be upsetting, but it

may raise issues for you. If you feel you would like some additional help during or after the interview, I will be able to advise you whom to contact, for example, telephone contact of the hospital or counsellor services. Moreover, you are free to stop or withdraw at any time without giving any reason.

### **Will my participation be confidential?**

Yes. No names will be used in any documentation except the consent form. However, these entire documents will be stored in a locked cabinet in the researcher's home. The voice recording of the interview will be transferred and kept in the researcher's laptop with the security password. All the recording will be anonymised (unidentifiable) and treated with sensitivity. Your personal details such as home address will be destroyed after taking part in the interview. However, if you disclosed information that might indicate serious risk or concern such as harm to yourself or another, the researcher will have to disclose this information to the appropriate authorities. Personal data such home address, phone number or email address will be destroyed after the interview finished. The researcher will keep all research data in accordance with the University of Southampton research data management policy which requires that all significant research data be kept for ten years after the study finished. All the research and personal data will be destroyed after the time period.

### **What happens if I change my mind?**

You have the right to withdraw from this study at any time without giving any reason. However, the researcher will retain data collected up to that point if it relevant with the study.

### **What happens if something goes wrong?**

If you have a concern or a complaint about this study you should contact the Research Governance Office (Address: University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 5058; Email: [rgoinfo@soton.ac.uk](mailto:rgoinfo@soton.ac.uk)). If you remain unhappy and wish to complain formally, the Research Governance Office can provide you with details of the University of Southampton Complaints Procedure.”

**Thank you for taking the time to read this information sheet. This information sheet is for you to keep.**

**For further information, please feel free to contact the researcher**

#### **Researcher:**

Wan Hasliza Wan Mamat,  
PhD student,  
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# **Appendix 8(b): Participant (patient) information sheet (Malay version)**

## **Participant (Patient) Information Sheet (Malay version)**

**Tajuk Kajian:** Naratif wanita Malaysia dan ahli keluarganya berkaitan dengan pengalaman membuat keputusan tentang kanser payudara.

**Penyelidik:** Wan Hasliza Wan Mamat      **No. Etika UoS:** 22983

**Sila baca maklumat ini dengan teliti sebelum membuat keputusan untuk mengambil bahagian dalam kajian ini. sekiranya anda berpuas hati untuk menyertai, anda akan diminta untuk menandatangani borang persetujuan.**

### **Kajian ini berkaitan dengan apa?**

Kajian ini berkaitan dengan memahami pengalaman anda sebagai wanita yang menghidapi kanser payudara dalam membuat keputusan untuk mencari dan menjalani rawatan konvensional di hospital. Maka, kajian ini akan meneroka cerita wanita bermula dari anda mendapati tanda gejala pada payudara sehingga mereka menjalani rawatan konvensional pertama di hospital.

### **Mengapa anda dipilih?**

Anda telah dijemput untuk mengambil bahagian dalam kajian ini kerana anda telah dikenalpasti oleh kakitangan hospital sebagai pesakit yang telah menjalani rawatan pertama untuk kanser payudara.

### **Apa yang akan berlaku sekiranya anda menyertai kajian ini?**

Kajian ini akan melibatkan temubual. Semasa temubual, saya akan bertanyakan cerita peribadi anda tentang membuat keputusan untuk kanser payudara seperti bagaimana anda membuat keputusan, apakah jenis-jenis keputusan yang anda buat dan apakah faktor-faktor yang mempengaruhi keputusan anda. Saya juga akan mengambil nota bersama-sama dengan rakaman audio temubual. Kemudian, saya akan memeriksa dengan anda menggunakan skala masa yang saya tulis semasa temu bual. Temubual ini akan mengambil masa kira-kira satu jam. Masa dan lokasi untuk temubual akan ditentukan oleh anda mengikut kesesuaian anda. Rakaman audio akan diminta sebelum memulakan temu bual

### **Apa yang perlu saya lakukan?**

Sekiranya anda berminat untuk menyertai kajian ini, anda perlu membaca dan melengkapkan borang persetujuan yang dilampirkan. Anda boleh menghubungi penyelidik secara langsung melalui telefon atau e-mel ke alamat yang diberikan di bawah.

### **Adakah terdapat apa-apa faedah melalui penyertaan kajian ini?**

Tiada faedah peribadi daripada penyertaan anda dalam kajian ini. Walau bagaimanapun, maklumat yang diperolehi daripada kajian ini akan membantu ahli profesional penjagaan kesihatan tentang perkara yang dipertimbangkan oleh wanita yang menghidapi kanser payudara dalam membuat keputusan dan membolehkan mereka memberi sokongan kepada pesakit. Selain itu, maklumat ini juga membolehkan ahli profesional penjagaan kesihatan untuk berinteraksi dengan lebih efektif, meningkatkan hubungan antara mereka dan menguruskan penjagaan pesakit yang bersesuaian dengan keadaan pesakit.

### **Adakah terdapat apa-apa risiko yang terlibat?**

Kami tidak menjangkakan sebarang risiko atau bahaya kepada anda dengan mengambil bahagian dalam kajian ini, namun kami faham kemungkinan anda berasa sedih untuk bercakap mengenai keadaan anda. Walau bagaimanapun, temubual ini tidak bertujuan untuk membuat anda bersedih, tetapi kemungkinan perkara ini menjadi isu untuk anda. Sekiranya anda memerlukan bantuan tambahan semasa atau selepas temubual, saya boleh menasihati anda tentang siapa untuk dihubungi, contohnya, nombor telefon hospital atau perkhidmatan kaunselor. Tambahan lagi, anda boleh berhenti atau menarik diri pada bila-bila masa tanpa memberikan sebarang alasan.

### **Adakah penyertaan saya rahsia?**

Ya. Tiada nama akan digunakan dalam apa-apa dokumen kecuali borang persetujuan. Walau bagaimanapun, semua dokumen akan disimpan di dalam almari berkunci di rumah penyelidik. Rakaman suara temubual akan dipindahkan dan diletakkan dalam komputer penyelidik dengan kata laluan keselamatan. Semua rakaman akan disimpan tanpa nama (tidak dapat dikenal pasti) dan dikendalikan dengan sensitif. Maklumat peribadi anda seperti alamat rumah akan dimusnahkan selepas anda mengambil bahagian dalam temubual itu. Walau bagaimanapun, sekiranya anda memberi maklumat yang berkemungkinan menunjukkan risiko atau kebimbangan yang serius seperti kecederaan kepada diri sendiri atau pihak yang lain, penyelidik akan mendedahkan maklumat ini kepada pihak yang berkenaan. Data peribadi seperti alamat rumah, nombor telefon atau alamat e-mel akan dimusnahkan selepas temubual selesai. Penyelidik akan menyimpan semua data kajian selaras dengan polisi pengurusan data kajian University of Southampton yang menyatakan bahawa semua data penyelidikan penting disimpan selama sepuluh tahun selepas kajian selesai. Semua data kajian dan data peribadi akan dimusnahkan selepas tempoh masa tersebut.

**Apakah yang akan berlaku sekiranya saya mengubah fikiran?**

Anda berhak untuk menarik diri daripada kajian ini pada bila-bila masa tanpa memberi sebarang alasan. Walau bagaimanapun, penyelidik akan mengekalkan data yang dikumpul sekiranya ia berkaitan dengan kajian.

**Apa yang berlaku sekiranya terdapat masalah?**

Sekiranya anda mempunyai kebimbangan atau aduan mengenai kajian ini, anda perlu menghubungi Pejabat Tadbir Penyelidikan (Alamat: University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ; Tel: +44 (0) 23 8059 5058; E-mel: [rgoinfo @ soton.ac.uk](mailto:rgoinfo@soton.ac.uk)). Sekiranya anda masih tidak berpuas hati dan ingin membuat aduan secara rasmi, Pejabat Tadbir Penyelidikan dapat menyediakan butiran aduan tatacara Universiti Southampton.

**Terima kasih kerana meluangkan masa untuk membaca lembaran maklumat ini. Lembaran maklumat ini untuk disimpan oleh anda.**

**Untuk maklumat lanjut, sila hubungi penyelidik**

**Penyelidik:** Wan Hasliza Wan Mamat,

Pelajar PhD,

Faculty of Health Sciences,

University of Southampton,

Southampton, SO17 1BJ.

Tel: +447752417235(UK)/+60139375709 (MYS)

Email: [whwm1c14@soton.ac.uk](mailto:whwm1c14@soton.ac.uk)

**Penyelia:**

Dr. Nikki Jarrett, Timbalan Program MPhil/PhD, Pensyarah di Health Sciences, Faculty of Health Sciences, University of Southampton, Southampton, SO17 1BJ.

Tel: +44(0)2380597954

Email: nj1@soton.ac.uk

Dr. Susi Lund, Felo Penyelidik Jemputan, Faculty of Health Sciences, University of Southampton, Southampton, SO17 1BJ.

Tel: +44(0)2380598250

Email: s.lund@soton.ac.uk

# Appendix 9(a): Consent form (English version)

## CONSENT FORM

**Study Title:** Malaysian women's and family members' narratives of their breast cancer decision-making experiences

**Researcher name:** Wan Hasliza Wan Mamat

**Study reference:**

**UoS Ethics reference:** 22983

*Please initial the box(es) if you agree with the statement(s):*

I have read and understood the information sheet (insert date /version no. of participant information sheet) and have had the opportunity to ask questions about the study.

I agree to take part in this research project and agree for my data to be used for the purpose of this study

I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected

### ***Data Protection***

*I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.*

Name of participant (print name).....

Signature of participant.....

Date.....

## Appendix 9(b): Consent form (Malay version)

### BORANG PERSETUJUAN

**Tajuk Kajian:** Kisah wanita Malaysia dan ahli keluarganya berkaitan dengan pengalaman membuat keputusan tentang kanser payudara.

**Nama penyelidik:** Wan Hasliza Wan Mamat

**Rujukan kajian:**

**No. etika UoS:** [tangguh]

*Sila tandatangan ringkas sekiranya anda bersetuju dengan pernyataan:*

Saya telah membaca dan memahami lembaran maklumat (tarikh/no. versi lembaran maklumat peserta) dan telah berpeluang untuk bertanyakan soalan mengenai kajian ini.

Saya bersetuju untuk mengambil bahagian dalam projek penyelidikan ini dan bersetuju bahawa data saya akan digunakan untuk tujuan kajian ini

Saya faham penyertaan saya adalah secara sukarela dan saya boleh menarik diri pada bila-bila masa tanpa menjelaskan hak undang-undang saya.

**Perlindungan data**

*Saya faham bahawa maklumat yang dikumpul mengenai saya semasa penyertaan saya dalam kajian ini akan disimpan dalam komputer yang dilindungi kata laluan dan maklumat ini hanya akan digunakan untuk tujuan kajian ini. Semua fail yang mengandungi data peribadi akan dibuat tanpa nama.*

Nama peserta (cetak nama).....

Tandatangan peserta.....

Tarikh.....

# **Appendix 10(a): Participant (family member) information sheet (English version)**

## **Participant (Family member) Information Sheet (English version)**

**Study Title:** Malaysian women's and family members' narratives of their breast cancer decision-making experiences

**Researcher:** Wan Hasliza Wan Mamat **UoS Ethics Number:** 22983

**Please read this information carefully before deciding to take part in this research. If you are happy to participate, you will be asked to sign a consent form.**

### **What is the research about?**

This study is about understanding your experiences as family members' in relation to decision-making regarding seeking and undertaking conventional treatment in the hospital. Thus, this study will explore your stories after you knew your [wife/daughter/sister/younger sister] had something wrong with her breast until she had undergone the first conventional treatment in the hospital.

### **Why have I been chosen?**

You have been invited to take part in this study because you have been identified by your [wife/daughter/sister/younger sister] as an important and supportive person during her decision-making.

### **What will happen to me if I take part?**

Taking part in this study will involve an interview. In the interview, I will ask your personal story about your involvement in making decisions for your [wife/daughter/sister/younger sister] that have breast cancer. For example, how you made the decisions, what type of decisions you made and what are the factors that influence your decisions. I also will be taking notes along with the audio recording of the interview. Later, I will be checking with you using the timescale that I had creating during the interview. The interview will take approximately one hour to complete. The time and location for an interview will be determined by you at your convenience. The audio recording will be requested before starting an interview.

### **What will I have to do?**

If you are interested to take part in this study, you can contact the researcher directly by phone or email to address provided below.

### **Are there any benefits in my taking part?**

There is no personal benefit from your participation in the study. However, the information gained from this study may guide health care professionals about what family members consider in making decisions and enables them to interact more effectively and improve their relationships

### **Are there any risks involved?**

While we do not foresee any risk or harm to you by taking part in this study, we do understand that you may be distressed talking about your [wife/daughter/sister/younger sister] condition. However, this interview is not intended to be upsetting, but it may raise issues for you. If you

feel you would like some additional help during or after the interview, I will be able to advise you whom to contact, for example, telephone contact of the hospital or counsellor services. Moreover, you are free to stop or withdraw at any time without giving any reason.

### **Will my participation be confidential?**

Yes. No names will be used in any documentation except the consent form. However, these entire documents will be stored in a locked cabinet in the researcher's home. The voice recording of the interview will be transferred and kept in the researcher's laptop with the security password. All the recording will be anonymised (unidentifiable) and treated with sensitivity. Your personal details such as home address will be destroyed after taking part in the interview. However, if you disclosed information that might indicate serious risk or concern such as harm to yourself or another, the researcher will have to disclose this information to the appropriate authorities. Personal data such home address, phone number or email address will be destroyed after the interview finished. The researcher will keep all research data in accordance with the University of Southampton research data management policy which requires that all significant research data be kept for ten years after the study finished. All the research and personal data will be destroyed after the time period.

### **What happens if I change my mind?**

You have the right to withdraw from this study at any time without giving any reason. However, the researcher will retain data collected up to that point if it is relevant with the study.

## **What happens if something goes wrong?**

If you have a concern or a complaint about this study you should contact the Research Governance Office (Address: University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 5058; Email: [rgoinfo@soton.ac.uk](mailto:rgoinfo@soton.ac.uk)). If you remain unhappy and wish to complain formally, the Research Governance Office can provide you with details of the University of Southampton Complaints Procedure.”

**Thank you for taking the time to read this information sheet. This information sheet is for you to keep.**

**For further information, please feel free to contact the researcher**

**Researcher:** Wan Hasliza Wan Mamat, PhD student, Faculty of Health Sciences, University of Southampton, Southampton, SO17 1BJ.

Tel: +447752417235(UK)/+60139375709 (MYS)

Email: [whwm1c14@soton.ac.uk](mailto:whwm1c14@soton.ac.uk)

## **Supervisors:**

Dr. Nikki Jarrett, Deputy Programme Lead MPhil/PhD, Lecturer in Health Sciences, Faculty of Health Sciences, University of Southampton, Southampton, SO17 1BJ.

Tel: +44(0)2380597954 Email: [nj1@soton.ac.uk](mailto:nj1@soton.ac.uk)

Dr. Susi Lund, Visiting Research Fellow, Faculty of Health Sciences, University of Southampton, Southampton, SO17 1BJ.

Tel: +44(0)2380598250 Email: [s.lund@soton.ac.uk](mailto:s.lund@soton.ac.uk)

# **Appendix 10(b): Participant (family member) information sheet (Malay version)**

## **Participant (Family member) Information Sheet (Malay version)**

**Tajuk Kajian:** Kisah wanita Malaysia dan ahli keluarganya berkaitan dengan pengalaman membuat keputusan tentang kanser payudara.

**Penyelidik:** Wan Hasliza Wan Mamat      **No. Etika UoS:** 22983

**Sila baca maklumat ini dengan teliti sebelum membuat keputusan untuk mengambil bahagian dalam kajian ini. sekiranya anda berpuas hati untuk menyertai, anda akan diminta untuk menandatangani borang persetujuan.**

### **Kajian ini berkaitan dengan apa?**

Kajian ini berkaitan dengan pengalaman anda sebagai ahli keluarga mereka dalam membuat keputusan untuk mencari dan menjalani rawatan konvensional di hospital. Maka, kajian ini akan meneroka cerita ahli keluarga setelah anda tahu [isteri/anak/kakak/adik] mengalami kelainan pada payudara sehingga dia menjalani rawatan konvensional pertama di hospital.

### **Mengapa anda dipilih?**

Anda telah dijemput untuk mengambil bahagian dalam kajian ini kerana anda telah dikenalpasti oleh [isteri/anak/kakak/adik] sebagai orang yang penting dan menyokong semasa beliau membuat keputusan.

### **Apa yang akan berlaku sekiranya anda menyertai kajian ini?**

Kajian ini akan melibatkan temubual. Semasa temubual, saya akan bertanyakan cerita peribadi tentang penglibatan anda dalam membuat keputusan untuk [isteri/anak/kakak/adik] anda yang mempunyai kanser payudara. Contohnya, bagaimana anda membuat keputusan, apakah jenis-jenis keputusan yang anda buat dan apakah faktor-faktor yang mempengaruhi keputusan anda. Saya juga akan mengambil nota bersama-sama dengan rakaman audio temubual. Kemudian, saya akan memeriksa dengan anda menggunakan skala masa yang saya tulis semasa temu bual. Temubual ini akan mengambil masa kira-kira satu jam. Masa dan lokasi untuk temubual akan ditentukan oleh anda mengikut kesesuaian anda. Rakaman audio akan diminta sebelum memulakan temu bual

### **Apa yang perlu saya lakukan?**

Sekiranya anda berminat untuk menyertai kajian ini, anda perlu membaca dan melengkapkan borang persetujuan yang dilampirkan. Anda boleh menghubungi penyelidik secara langsung melalui telefon atau e-mel ke alamat yang diberikan di bawah.

### **Adakah terdapat apa-apa faedah melalui penyertaan kajian ini?**

Tiada faedah peribadi daripada penyertaan anda dalam kajian ini. Walau bagaimanapun, maklumat yang diperolehi daripada kajian ini akan membantu ahli profesional penjagaan kesihatan tentang perkara yang dipertimbangkan oleh ahli keluarga dalam membuat keputusan dan membolehkan mereka berinteraksi dengan lebih efektif dan meningkatkan hubungan antara mereka.

### **Adakah terdapat apa-apa risiko yang terlibat?**

Kami tidak menjangkakan sebarang risiko atau bahaya kepada anda dengan mengambil bahagian dalam kajian ini, namun kami faham kemungkinan anda berasa tertekan untuk bercakap mengenai keadaan anda. Walau bagaimanapun, temubual ini tidak bertujuan untuk membuat anda bersedih, tetapi kemungkinan perkara ini menjadi isu untuk anda. Sekiranya anda memerlukan bantuan tambahan semasa atau selepas temubual, saya boleh menasihati anda tentang siapa untuk dihubungi, contohnya, nombor telefon hospital atau perkhidmatan kaunselor. Tambahan lagi, anda boleh berhenti atau menarik diri pada bila-bila masa tanpa memberikan sebarang alasan.

### **Adakah penyertaan saya adalah rahsia?**

Ya. Tiada nama akan digunakan dalam apa-apa dokumen kecuali borang persetujuan. Walau bagaimanapun, semua dokumen akan disimpan di dalam almari berkunci di rumah penyelidik. Rakaman suara temubual akan dipindahkan dan diletakkan dalam komputer penyelidik dengan kata laluan keselamatan. Semua rakaman akan disimpan tanpa nama (tidak dapat dikenal pasti) dan dikendalikan dengan sensitif. Maklumat peribadi anda seperti alamat rumah akan dimusnahkan selepas anda mengambil bahagian dalam temubual itu. Walau bagaimanapun, sekiranya anda memberi maklumat yang berkemungkinan menunjukkan risiko atau kebimbangan yang serius seperti kecederaan kepada diri sendiri atau pihak yang lain, penyelidik akan mendedahkan maklumat ini kepada pihak yang berkenaan. Data peribadi seperti alamat rumah, nombor telefon atau alamat e-mel akan dimusnahkan selepas temubual selesai. Penyelidik akan menyimpan semua data kajian selaras dengan polisi pengurusan data kajian University of Southampton yang menyatakan bahawa semua data penyelidikan penting disimpan selama sepuluh tahun selepas kajian selesai. Semua data kajian dan data peribadi akan dimusnahkan selepas tempoh masa tersebut.

**Apakah yang akan berlaku sekiranya saya mengubah fikiran?**

Anda berhak untuk menarik diri daripada kajian ini pada bila-bila masa tanpa memberi sebarang alasan. Walau bagaimanapun, penyelidik akan mengekalkan data yang dikumpul sekiranya ia berkaitan dengan kajian.

**Apa yang berlaku sekiranya terdapat masalah?**

Sekiranya anda mempunyai kebimbangan atau aduan mengenai kajian ini, anda perlu menghubungi Pejabat Tadbir Penyelidikan (Alamat: University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ; Tel: +44 (0) 23 8059 5058; E-mel: [rgoinfo @ soton.ac.uk](mailto:rgoinfo@soton.ac.uk)). Sekiranya anda masih tidak berpuas hati dan ingin membuat aduan secara rasmi, Pejabat Tadbir Penyelidikan dapat menyediakan butiran aduan tatacara Universiti Southampton.

**Terima kasih kerana meluangkan masa untuk membaca lembaran maklumat ini. Lembaran maklumat ini untuk disimpan oleh kamu.**

**Untuk maklumat lanjut, sila hubungi penyelidik**

**Penyelidik:** Wan Hasliza Wan Mamat, Pelajar PhD, Faculty of Health Sciences, University of Southampton, Southampton, SO17 1BJ.

Tel: +447752417235(UK)/+60139375709 (MYS)

Email: [whwm1c14@soton.ac.uk](mailto:whwm1c14@soton.ac.uk)

**Penyelia:**

Dr. Nikki Jarrett, Timbalan Program MPhil/PhD, Pensyarah di Health Sciences, Faculty of Health Sciences, University of Southampton, Southampton, SO17 1BJ.

Tel: +44(0)2380597954

Email: nj1@soton.ac.uk

Dr. Susi Lund, Felo Penyelidik Jemputan, Faculty of Health Sciences,  
University of Southampton, Southampton, SO17 1BJ.

Tel: +44(0)2380598250

Email: s.lund@soton.ac.uk

## Appendix 11: Narrative script

Hello. My name is Wan Hasliza. I am PhD student at the University of Southampton. Thank you for your support and your spending time with me today. I'm collecting life histories about decision-making for breast cancer for my project and please could you tell me yours? I will listen first. I will not interrupt, and I may take a couple of notes that I will ask you questions later. Please take the time that you need and as I said I will not interrupt you. So,

### Woman

may I ask you to share with me your story since you first thought that you may have a problem with your breast?”.

### Family member

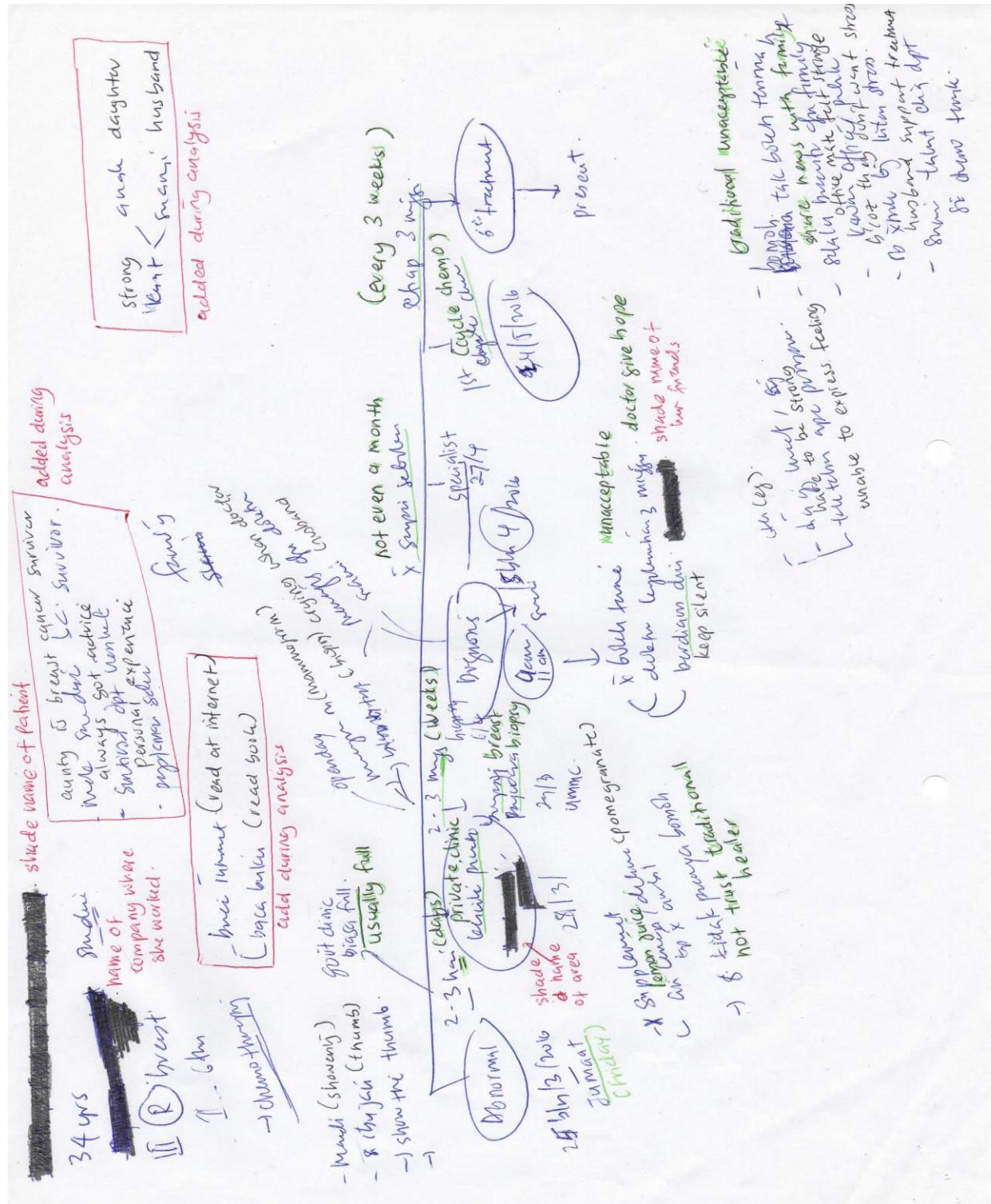
may I ask you to share with me your story when your [wife/daughter/sister] told you that she had something wrong with her breast?”.

The researcher continues to:

- Probe
- Rephrase/reframe
- Clarify
- Explore meaning in the conversation

## Appendix 12: An example of the timeline during the interview

Figure 4.3: An example of the timeline during the interview



# Appendix 13: Approval letter from Malaysia Medical Research and Ethics Committee



## JAWATANKUASA ETIKA & PENYELIDIKAN PERUBATAN (Medical Research & Ethics Committee)



Tel.: 03-2287 4032/2282 0491/2282 9085  
03-2282 9082/2282 1402/2282 1449  
Faks: 03-2282 0015

Tarikh : 26 Ogos 2016

WAN HASLIZA BINTI WAN MAMAT  
UNIVERSITY OF SOUTHAMPTON

Tuan/Puan,

Malaysian women's and family members' narratives of their breast cancer decision-making experiences

Lokasi Kajian:

Dengan hormatnya perkara di atas adalah dirujuk.

2. Jawatankuasa Etika & Penyelidikan Perubatan (JEPP), Kementerian Kesihatan Malaysia (KKM) tiada halangan, dari segi etika, ke atas pelaksanaan kajian tersebut. JEPP mengambil maklum bahawa kajian tersebut hanya melibatkan pengumpulan data menggunakan kaedah:

i) **Temuramah**

3. Segala rekod dan data subjek adalah **SULIT** dan hanya digunakan untuk tujuan kajian ini dan semua isu serta prosedur mengenai *data confidentiality* mesti dipatuhi.

4. Kebenaran daripada Pegawai Kesihatan Daerah/Pengarah Hospital dan Ketua-Ketua Jabatan atau pegawai yang bertanggungjawab disetiap lokasi kajian di mana kajian akan dijalankan mesti diperolehi sebelum kajian dijalankan. Tuan/Puan perlu akur dan mematuhi keputusan tersebut. Sila rujuk kepada garis panduan Institut Kesihatan Negara mengenai penyelidikan di Institusi dan fasiliti Kementerian Kesihatan Malaysia (Pindaan 01/2015) serta lampiran **Appendix 5** untuk templet surat memohon kebenaran tersebut.

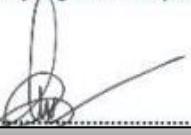
5. Adalah dimaklumkan bahawa kelulusan ini adalah sah sehingga **tamat kajian ini**. Sekiranya terdapat sebarang pindaan atau perubahan dalam dokumen kajian yang mungkin meningkatkan tahap risiko secara signifikan kepada subjek/pesakit/responden, sila maklumkan kepada pihak JEPP dengan kadar segera melalui email ke [mrecir@nih.gov.my](mailto:mrecir@nih.gov.my). Tuan/Puan juga perlu menghantar **Study Final Report** ke JEPP pada penghujung kajian. Borang tersebut boleh dimuat turun daripada laman web MREC (<http://www.nih.gov.my/mrec>).

6. Sila ambil maklum bahawa sebarang urusan surat-menyurat berkaitan dengan penyelidikan ini haruslah dinyatakan nombor rujukan surat ini untuk melicinkan urusan yang berkaitan.

Sekian terima kasih.

**"BERKHIDMAT UNTUK NEGARA"**

Saya yang menurut perintah,

  
Pengerusi  
Jawatankuasa Etika & Penyelidikan Perubatan  
Kementerian Kesihatan Malaysia

**MAKLUMBALAS PERMOHONAN KEBENARAN PENGGUNAAN UNTUK MENJALANKAN PENYELIDIKAN**

Tajuk Penyelidikan : *Malaysian women's and family members' narratives of their breast cancer decision-making experiences*

Nama dan Jabatan Ketua Penyelidik : Wan Hasliza Wan Mamat, University of Southampton, UK

Pihak hospital/institusi dengan ini membuat keputusan seperti berikut :-

Membenarkan projek penyelidikan dijalankan  
 Tidak membenarkan projek penyelidikan dijalankan

**“BERKHIDMAT UNTUK NEGARA”**

Saya yang menurut perintah

S.K.

<Ketua CRC hospital

<Nama penyelidik bersama (co- investigators) di fasiliti berkaitan (jika berkaitan)

Ketua Jabatan & Pakar Onkologi  
Jabatan Radioterapi & Onkologi

TIMBALAN PENGARAH (PERUBATAN) 1

## Appendix 14: Sample analysis

### Sample analysis – PT8

PT8 is a thirty-two-year-old Malay woman who works as a banker. She lives with her husband and two sons, 7 and 5 years old. She had been diagnosed with stage three breast cancer. She underwent mastectomy on her left breast. She has no family history of breast cancer but she had fibro-adenoma since her studying in the university and had undergone three times surgery to remove the lump.

I first met PT8 in the clinic, while she was waiting for her follow-up appointment with her husband. We had little conversation after the staff introduce me when she initially interested to participate in this study. She always smiling and easy to build rapport although in the first meeting. She invited me to come to her house for the interview. After set up the date and time, I drove to her house.

This interview was conducted in the morning, around 10am on Saturday. So, her husband and kids were present. They live in the apartment, level 4 and fully furnished. When I arrived, her husband greet me. Her husband made a cup of tea and serving some biscuits while waiting for his wife to join us. We just having little chat about my study and about living in UK. When the time for interview, the husband said that I can started interview with his wife first as he will take care with the kids.

Generally, the PT8 seemed healthy, and she wore a long pant with t-shirt and black cardigan. The interview was conducted in the living room, we sat on the sofa. She sat beside me, and both of us try to

maintained eye contact. The television was on. The cartoon show. She reduced the volume but not switched off because her kids would like to watch it. Sometimes, her son coming and telling something to his mummy.

I started the interview, as I did using Malay language based on the interview scripts that I had already memorised. During the interview, she look very calm. She speak confidently and smoothly without many interruption from the interviewer. She seemed understand what I telling her about the study. Overall, she constructed her narrative that temporally organised, started when she felt pain, go to clinic and go to hospital. After confirmed the diagnosis, she refused the treatment. She continue her story with activities that she did within the delayed period such as change lifestyle, try alternative treatment and travelling. Finally, when she felt satisfied with her activities, she underwent surgery. I had prompt for clarification when she did not talk in details for certain issues. Sometimes, she organised her talk in episodic, a series of events. However, I acknowledge that some of the information given was limited because I missed to ask for clarification.

Table 4.4: Sample analysis – PT8

Sequence	What are the decision	Who made the decision?	What are turning point, key features or event?	Accounts	Memo
Pain	Go to clinic	PT8	Pain	So, from the end of two thousand fifteen [2015], I felt, pain, at muscle areas under this armpit (/: ok). So, I thought because of menstrual or because of shaved. So, I went to the ordinary clinic taking a medication.	Is it pain not serious because she relate it with menstrual and shaving?  What is association between pain under armpit with menstrual or shaving?  Not assume BC (breast cancer)?  Lack of knowledge?
Clinic	Go to hospital	Doctor referred & PT8 followed	Doctor unsure about PT8's condition	It seemed okay. Then it [pain] happened again. Three times it happened. So after it happened for a third time, the doctor asked me to go to, a hospital, referred to the hospital.	Standard procedure to refer patient to hospital if the doctor in the clinic unsure about the patient's condition.

Hospital	Undergo further investigation	Doctor suggested & PT8 followed	Doctor unsatisfied with the diagnostic result, found a lump in the breast & query with the armpit pain	<p>So when I went to the hospital, firstly the doctor did an ultrasound. The doctor also diagnosed the same thing, muscles aches, because at that time the ultrasound result was okay (<i>I: hmm</i>). So the doctor did not suspect anything at that time. Then, the doctor asked me to do mammogram and blood test straight away. After that, after two weeks, I took the medicine that doctor gave, the pain was gone, mus-muscle aches. Then, I came back for an appointment. The doctor said the mammogram result was okay, blood test result also okay. But s/he still not satisfied because s/he, s/he found a lump in the breast. That lump actually already there in the breast. That lump was normal (<i>I: ok</i>), but s/he wanted to do a further investigation because the pain was not at the lump. The pain was near bottom here [point to her left armpit] (<i>I: ok</i>) at the gland (<i>I: hmm</i>). So, after that, the doctor told me to do a biopsy to get confirmation. So, I had a biopsy in February.</p>	<p>How the doctor curiosity led the actual diagnosis although PT8 felt that the lump was normal. She assumed the lump was ordinary lump because she had previous history of breast lump.</p> <p>This portray that the doctor did his/her job well by continue to investigate the problem.</p> <p>She seemed denial any problem related to the lump, but she still follow the doctor's suggestion.</p>
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				<p>*** <i>Later I prompt for further clarification is it she did not know the presence of breast lump at that time?</i></p>	
Diagnosis	Refuse immediate treatment	PT8	Need some time	<p>After that, [biopsy] result ruled out it was confirmed cancer. So, the doctor diagnoses stage two at that time because the doctor based on lump size. That was roughly how s/he made the staging at that time. So, of course the doctor would like to operate by tomorrow. The doctor asked to do the surgery immediately. But of course I, I needed some time first, to think so many things through. It was not easy I wanted to do [operation], just like that, right.</p> <p>*** <i>Later I prompt for further clarification what she mean by 'need some time'</i></p>	<p>She cannot do immediate decision at that time. This is because she felt not ready when she said she needed some time.</p> <p>How PT8 construct her justification to make the listener agreed of what she did (delay treatment?). She persuade the listener that she had to consider many things as this is not simple decision when she stated 'it was not easy'. She use the word 'right' suggesting that she seek that the listener will agreed on what she said.</p>

After delay treatment	Do other things	PT8		<p>So, I just went for travel as usual, but I still did alternative treatment like homeopathy, Islamic treatment, traditional treatment. I tried to take a supplement. I changed my lifestyle. I went to the gym. I changed my diet.</p> <p>*** <i>She just listed what she did in her early talk &amp; later I prompt for further clarification</i></p>	<p>She adopted healthy life-style, holiday, and tried alternative treatment to improve/balance physical, psycho well-being &amp; treat BC.</p> <p>She use the word 'but' to tell the listener that although she travelling &amp; refuse conventional treatment, she still try to treat her BC at the same times using other methods. She did not ignore her BC.</p>
Treatment	Undergo surgery	PT8	Self-satisfaction, ready	<p>So after few months, had been diagnosed in February, in that June I felt like okay, I felt satisfied trying all sorts of things, I felt like ready for surgery whatsoever. So in that July, I met with the doctor to make appointment whatsoever. So the doctor had arranged, twenty eight of July I underwent the operation.</p> <p>... So the most important thing before that surgery make sure you</p>	<p>Felt ready &amp; satisfied with her preparation</p> <p>It seemed that she try to give message to the listener also known as moral of the story – fulfil our needs and wishes before had big decision that affect life, so that no regret if anything happened later.</p>

				do anything you want to do, anywhere you want to go, you feel like you want to go for holiday whatsoever, settle it first. I did all that. So when I underwent that surgery, I did not feel trapped at any point. I felt relief. I felt sincere. I felt ready to do that.	
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Researcher prompt for further clarification

Current breast lump	Ignore	PT8	Lump 'normal', assume benign lump, painless lump	I.: At the beginning when you felt armpit pain, did you know the presence of breast lump?  PT8: I had a lump. But that lump was normal. Because before this I already removed the lump many times. Because it kept on growing, or I removed that lump not because it was cancer. Because it had an infection, or it was painful. So I removed it. It was cosmes-cosmetic surgery, because I felt uncomfortable with that lump, but actually, it was not cancer. It was just an ordinary lump, ordinary fibro-adenoma. But I didn't expect at this time it was cancer. I didn't feel any pain. I felt nothing. I didn't	She assume the lump is benign as she had experienced before.  She had lack of knowledge about BC when she said 'But I didn't expect at this time it was cancer'. She did not know that benign breast lump had possibility to be cancer when she said 'it was not cancer. It was just an ordinary lump'. She seemed confident based on her previous experience had benign lump that lead her to has
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				<p>care. Before this, I removed the lump, I felt pain. Because it had an infection or it was swelling.</p>	<p>false sense of security. That made she seemed denial the presence of BC.</p> <p>She tried to compare the present symptom with her previous experience regarding the lump – pain, no size changes. When it painless, she might think that the lump was okay.</p>
Needing time	Calm mind, settle work, children matter, plan for treatment	PT8		<p>I.: When you said you take time, what do you mean?</p> <p>PT8: I took time to calm my mind (I: ok). After that, I had to settle my work. I had to apply for long leave (I: ok). Then settled matters with my children. After that I thought, I planned. 'Okay during that sick leave period, what should I did?' I have to make sure that I was not bored. I had nothing to do. So, I had to plan because I knew myself, what I like to do whatsoever.</p>	<p>*** <i>link to why she refuse immediate treatment</i> ***</p> <p>She need time to adjust emotionally when she stated 'to calm my mind'.</p> <p>She portray identity as someone who control her life. She knew what she needed to do. She had to settle other matters that seemed</p>

					important for her rather than her breast cancer at that time. It may be related to herself, as busy professional, role as a mother and her character as an organised person.  She might to try all the possible treatment to treat BC.
Breaking bad news	Accept	PT8	See connection between previous experience of benign lump with current BC	I.: When the doctor inform the diagnosis, how do you feel? What is happening?  PT8: After some time, actually like I was ready [diagnosis] because I had done many times, three times already underwent the breast surgery, one time in right side, two times in the left side. So like, either you wanted or not, I had expected something. Somehow rather I felt, like I felt, I knew that I had problematic breast. So it not all the sudden, you do not have any history, suddenly you got, it was	She had lack of knowledge as she said 'I had no family history' as she try to relate the BC with genetic factor.  She not blaming herself although she knew the presence of breast lump, but she did not know about BC, did not know anyone had BC before & she was alone (identity?) because no source of reference when she

Work	To continue working	<p>shocking. But I can deal. But somehow I still sad. Because I had no family history. No friends had this disease. So I don't know, nobody to guide, nobody to ask, yeah to ask. You are on your own. Yeah, it's hard to believe what had happened as I didn't expect it was cancer. I thought the lump was okay. Since I knew the result on Wednesday, met the doctor that discussed the result. So only that Wednesday and Thursday, two days crying and that's it. Already move on. Had nothing to think. Never think myself sick. Never treat myself as a patient or whatsoever. Nothing. Just act as usual. Live as usual. After that, next Monday, I went to the office as usual. I worked as usual. Nothing happened to me. I settled my work which was important first. The work that I can settle, I settled it already.</p>	<p>stated 'You are on your own'.</p> <p>Lack of knowledge as she not expected her benign lump could be BC, gave false sense of security. She seemed denial/disappointed when she said 'Yeah, it's hard to believe what had happened as I didn't expect it was cancer'.</p> <p>Denial or coping? When she said 'Had nothing to think Never think myself sick. Never treat myself as a patient'</p> <p>Then she link with her work because the said 'live as usual'. Means that going to work is normal routine for her.</p> <p>Possible that working as method of coping when she said 'nothing'</p>
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					happened to me'. She might portray she is strong and able to deal with her diagnosis.
Reveal diagnosis	Informed family & employer	PT8	Sharing diagnosis with family & apply sick leave with employer	Immediately after I got the result, I told my parents. After that I call the office. Telling them that I want to take leave. I also call my boss. Telling him about this matter. Yeah after this I will take leave. Of course I have to hand over the workload.	SOP to apply sick leave as employee.
Alternative treatment	Try traditional, Islamic, supplement	PT8 influence by others	Just try and nothing to lose	I.: You had said about alternative treatment. Could you please tell in details about it?  PT8: There were people shared on Facebook or whatsoever about traditional treatment. Then about Islamic treatment. Huh, just like that. I just tried it. I just went there. For me nothing to lose if you would like to try anything else, but you cannot pro to one side only. You have to balance. You cannot say like 'Ooo this was good, this was not good'. For me, I just tried it.	Her decision to try alternative treatment was influence via her reading through media social and family.  Traditional healer gave advise and water—not harm to her health, so its fine to try.  Islamic treatment based on Holy Quran—it is well known among Muslim that Holy Quran as power of healing.

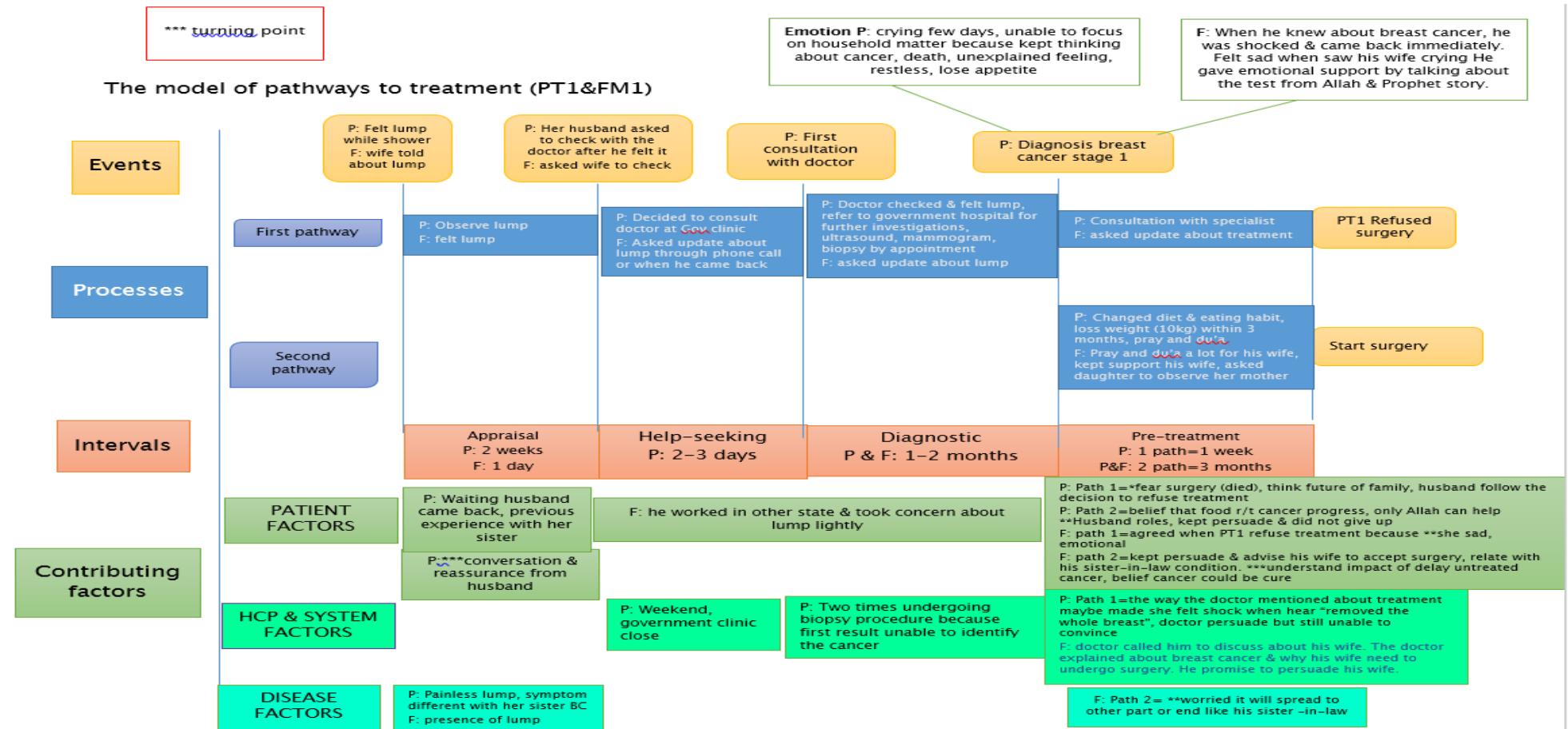
			<p>Nothing to lose. So I just followed. People said, 'Go there', I went there.</p> <p>The traditional healers did not say anything bad about cancer. They said it still can be treatable and continue the treatment. They gave advice about prohibited food like red meat, long bean. They gave water too.</p> <p>I.: Islamic treatment?</p> <p>PT8: My family suggested seeking Islamic treatment because they said it might terminate the cancer.</p> <p>That Islamic treatment, s/he also gave the water. So s/he was recited some Holy Quran verses to that water. Then s/he gave note, you have to read certain verses, certain Surah, certain verses number. Huh, that's all s/he gave. So just practice.</p> <p>I.: How about the supplement?</p>	Supplement-follow other patient
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				PT8: Supplement 4life and then for that daily diet soursop juice. Many people [patient] take it at this time. There were people who talked about Sabah Snake Grass, so I tried it. I drank it ... somebody said that the effect was almost like chemo, and then, they said it would reduce the size, reduce the cancer size.	
Travel	Holiday	PT8 and her husband	After being confirm the diagnosis	I really want to go for holiday before but there is no right time. Yeah, we are working. Husband also working. Children go to school. But when it happened like this, I really informed my husband I want to go for holiday. When I discussed with him, he suggested go to AA [oversea]. So I agreed. So we went there.	She is busy woman Fulfill dream
Treatment	Undergo conventional treatment	PT8	Read info through internet, change character??	I.: Who made the decision for surgery?  PT8: Myself. Make a decision after 'Eid because it close to my birthday. So supposedly to be a new person on my birthday. Somehow, I also read at the blog, Facebook about	I missed to ask what did she mean when she said 'to be a new person'.  She dominant and control her decision.

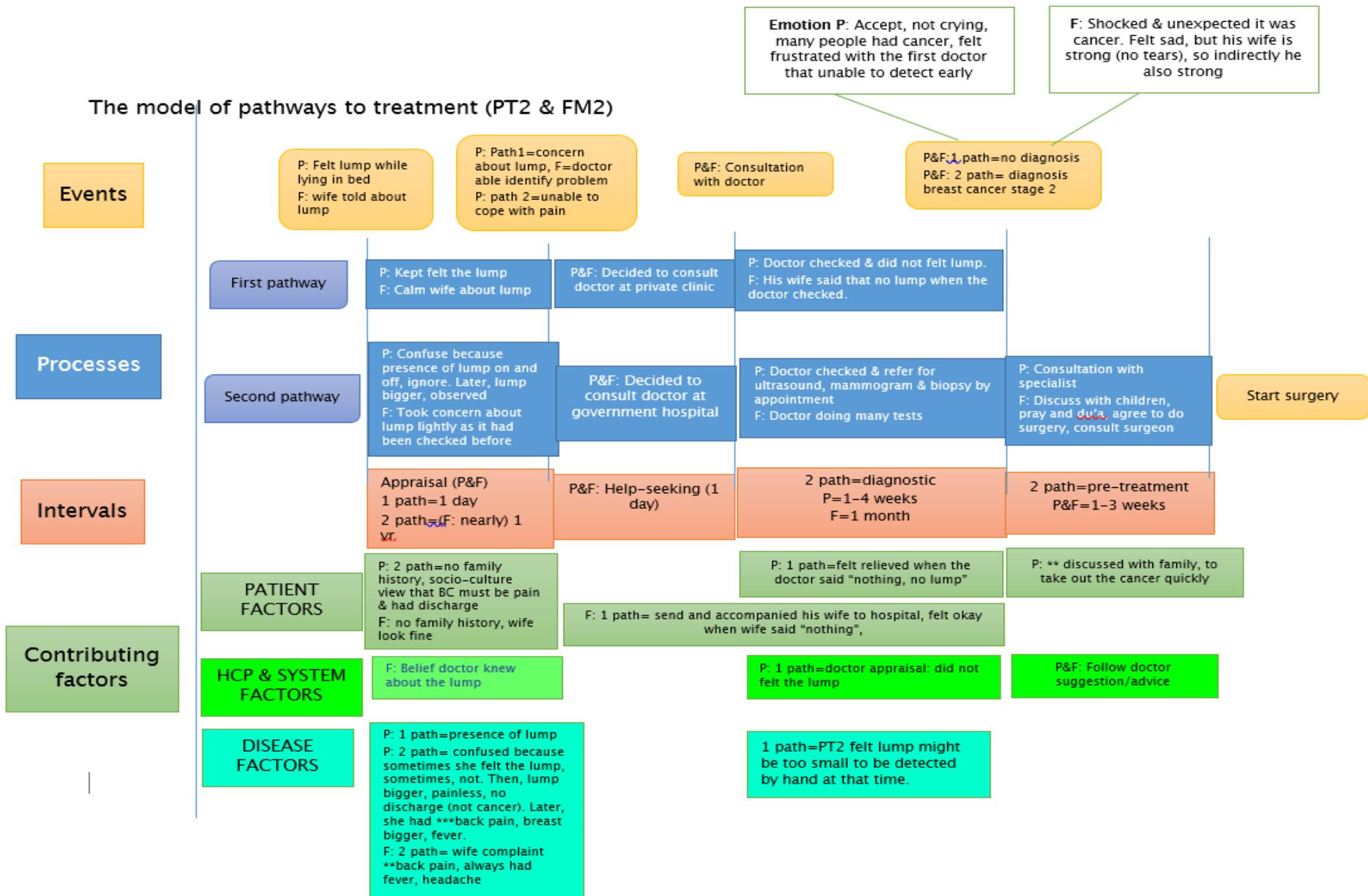
				what they wrote about this cancer especially its treatment.	
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# Appendix 15: Participant's description based on the MPTT

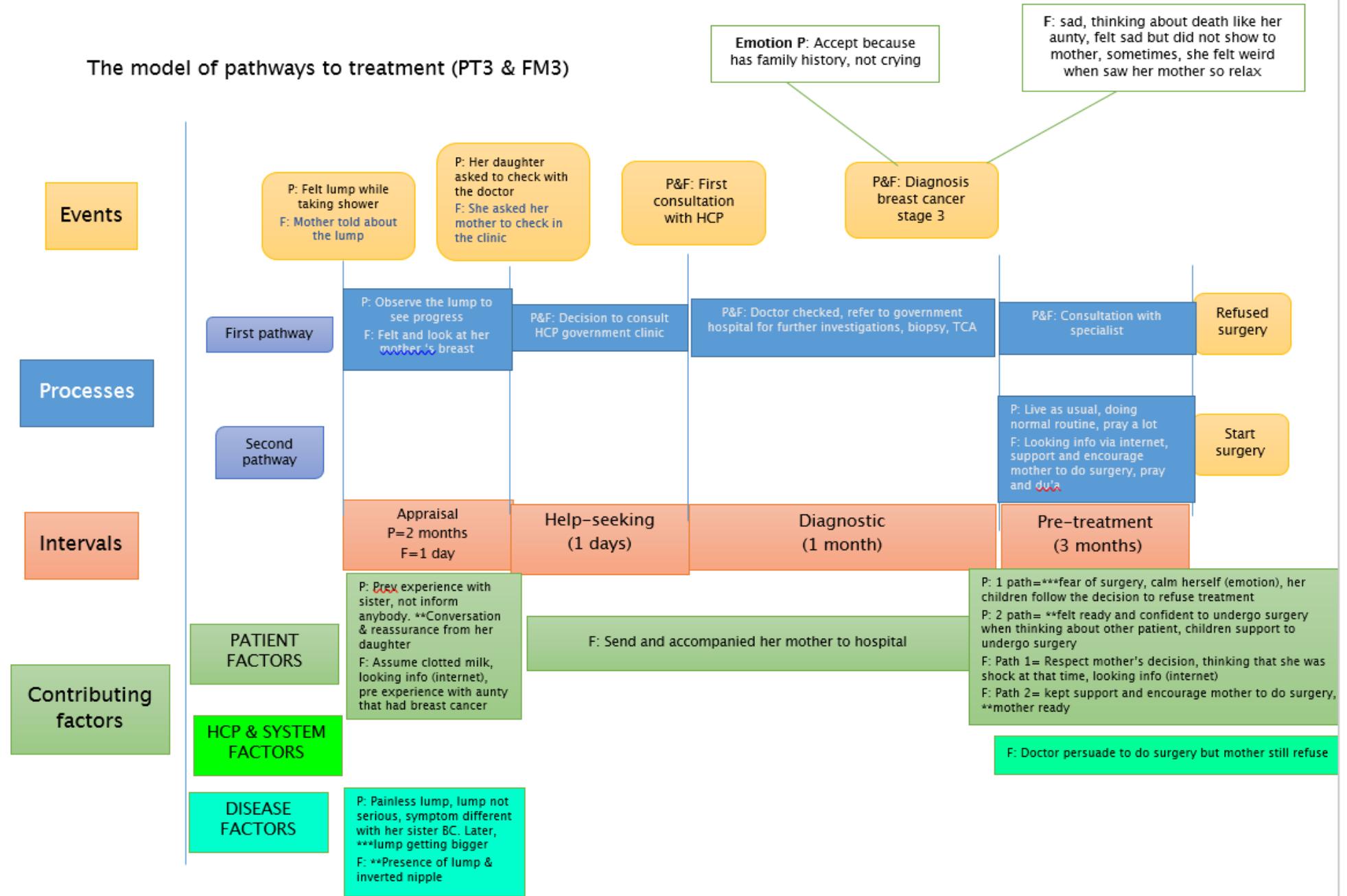
Figure 6.2: Participant's description based on the MPTT



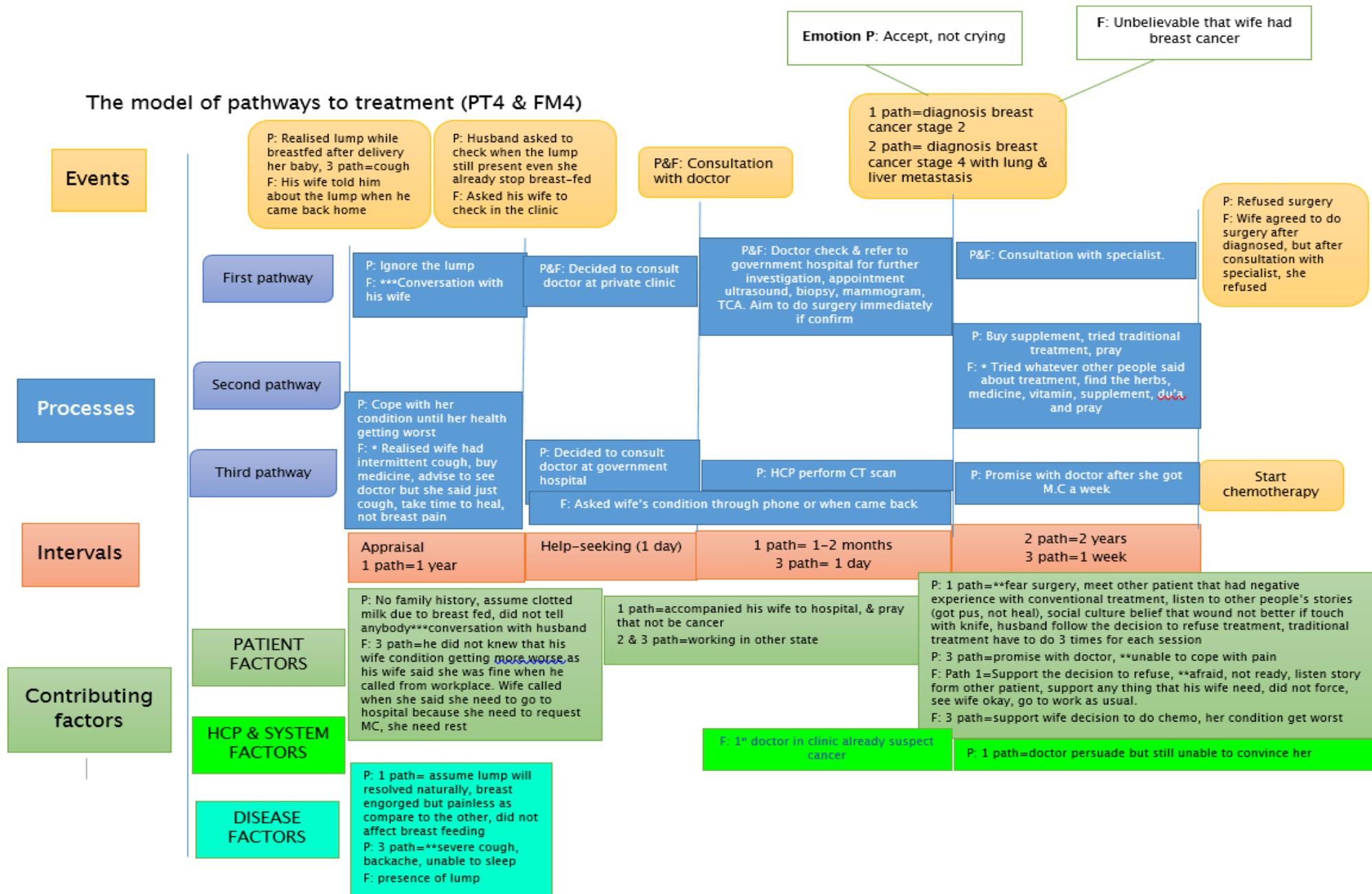
## The model of pathways to treatment (PT2 & FM2)



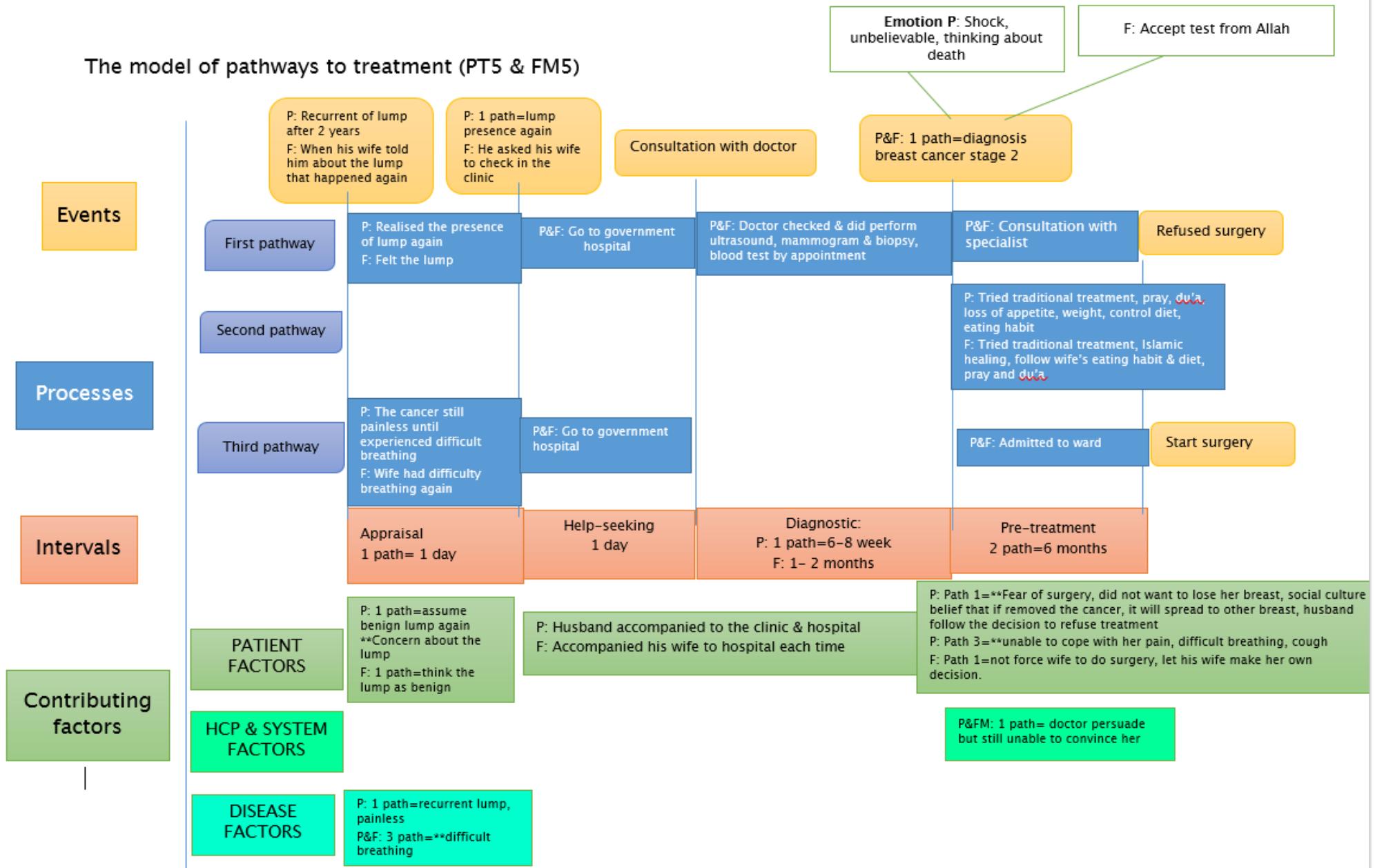
## The model of pathways to treatment (PT3 & FM3)



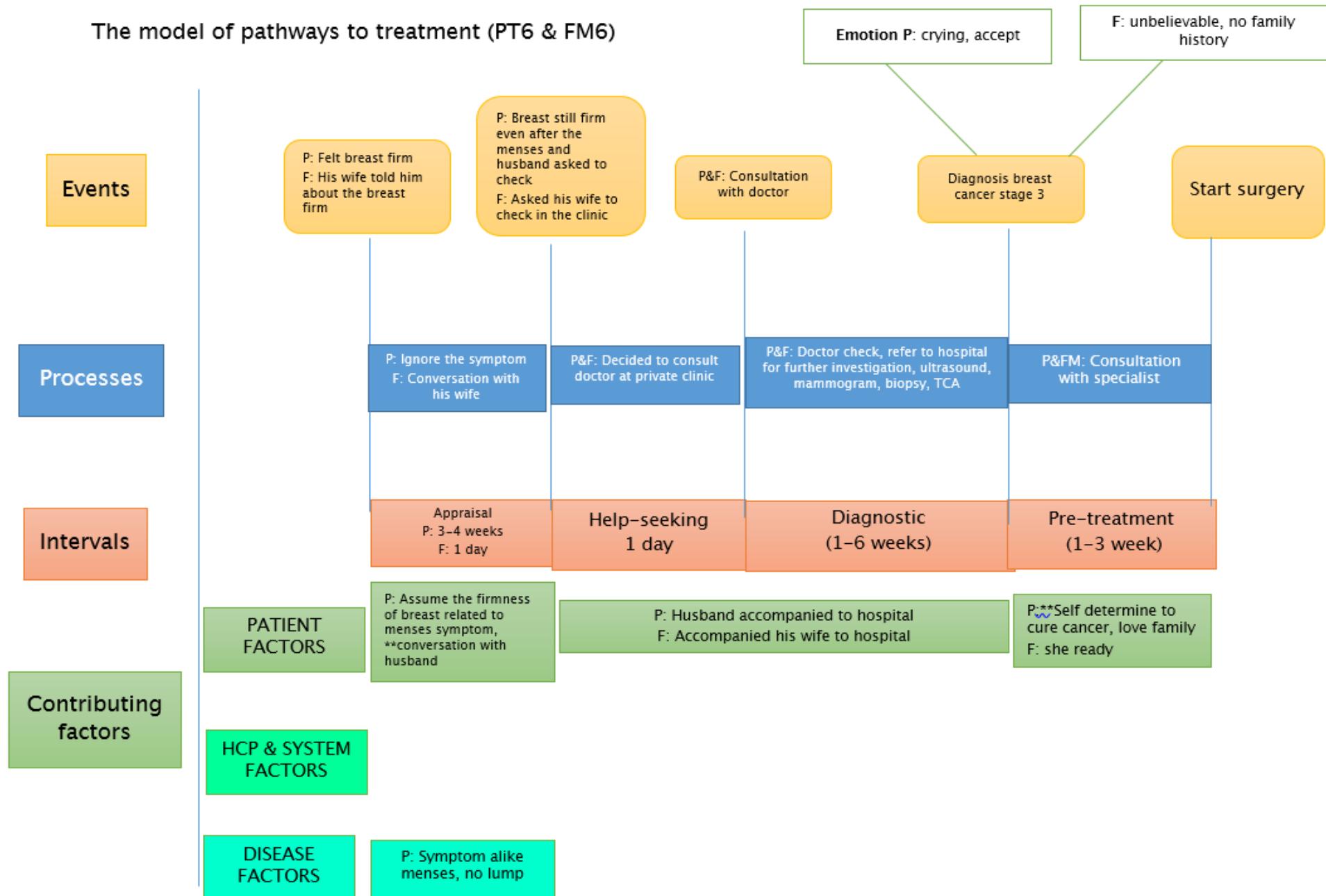
## The model of pathways to treatment (PT4 & FM4)



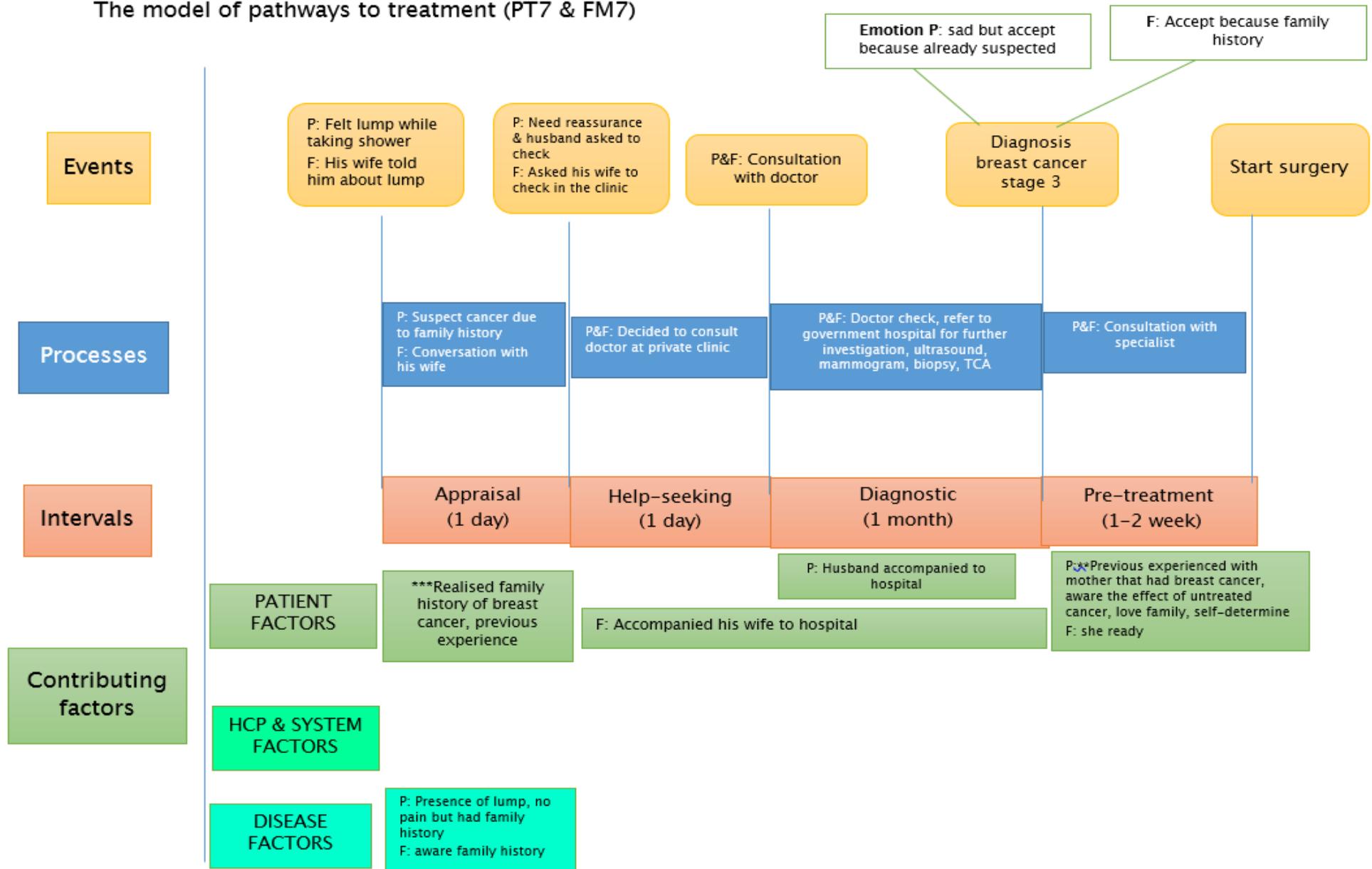
## The model of pathways to treatment (PT5 & FM5)



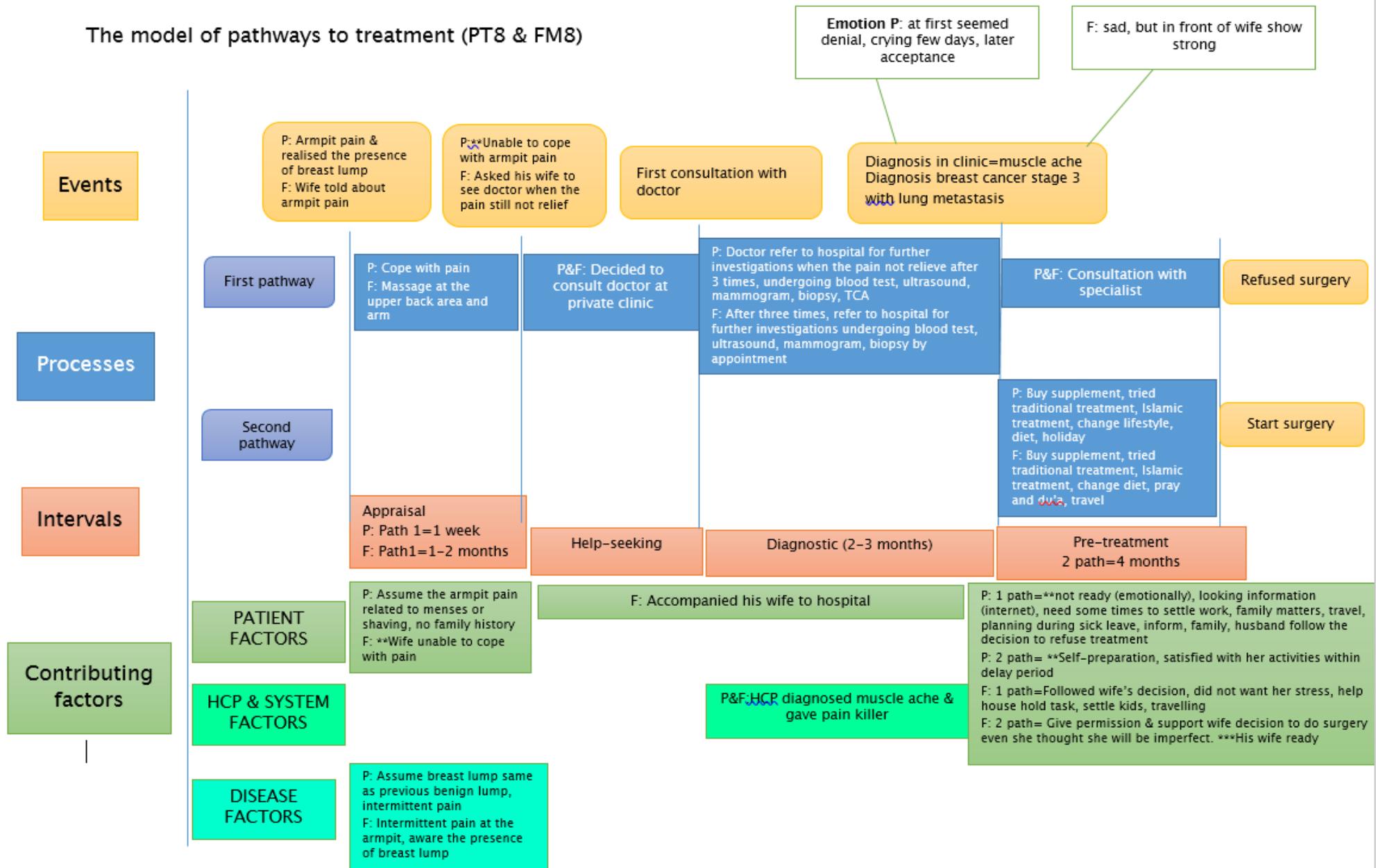
## The model of pathways to treatment (PT6 & FM6)



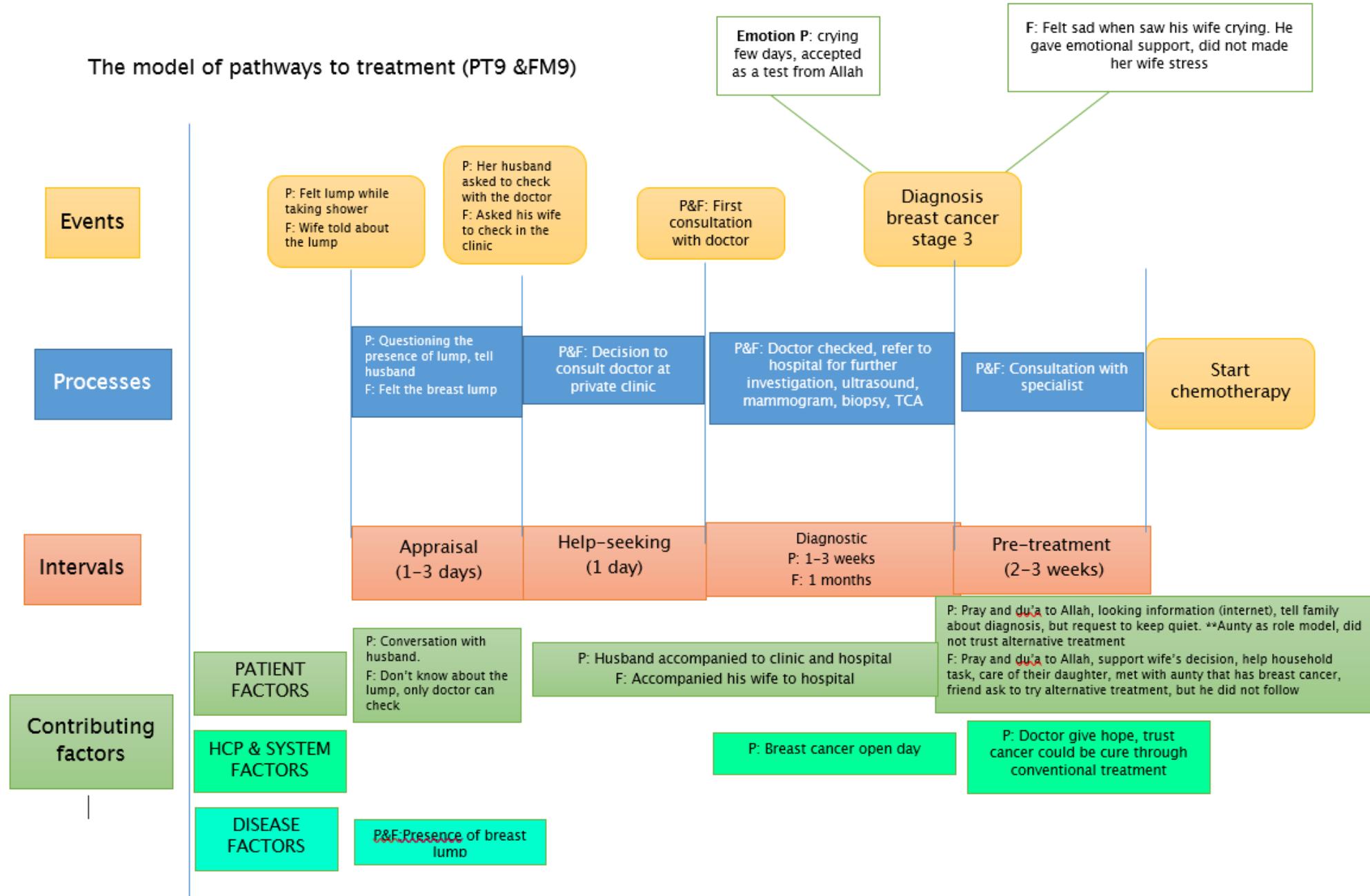
## The model of pathways to treatment (PT7 & FM7)



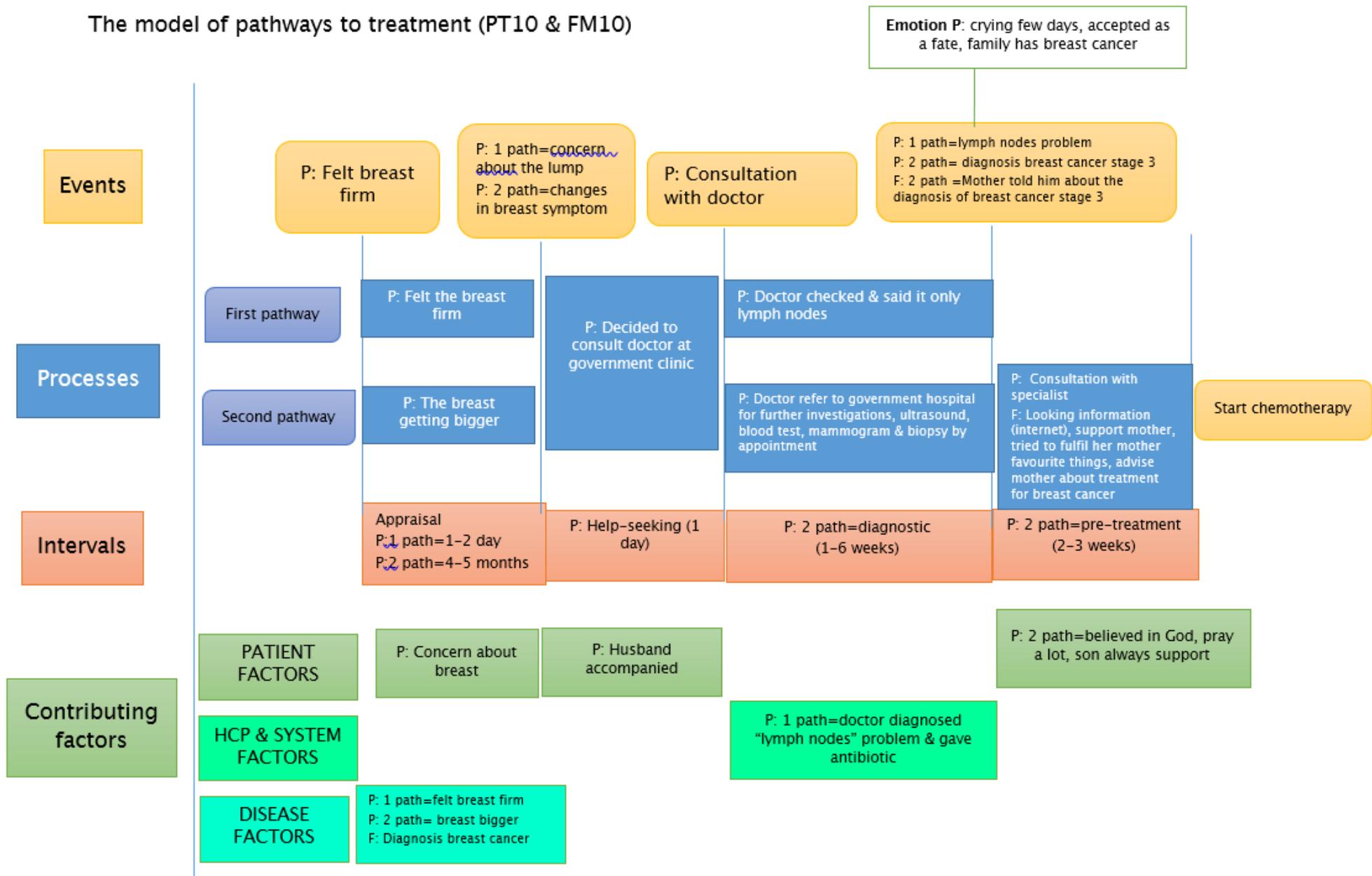
## The model of pathways to treatment (PT8 & FM8)



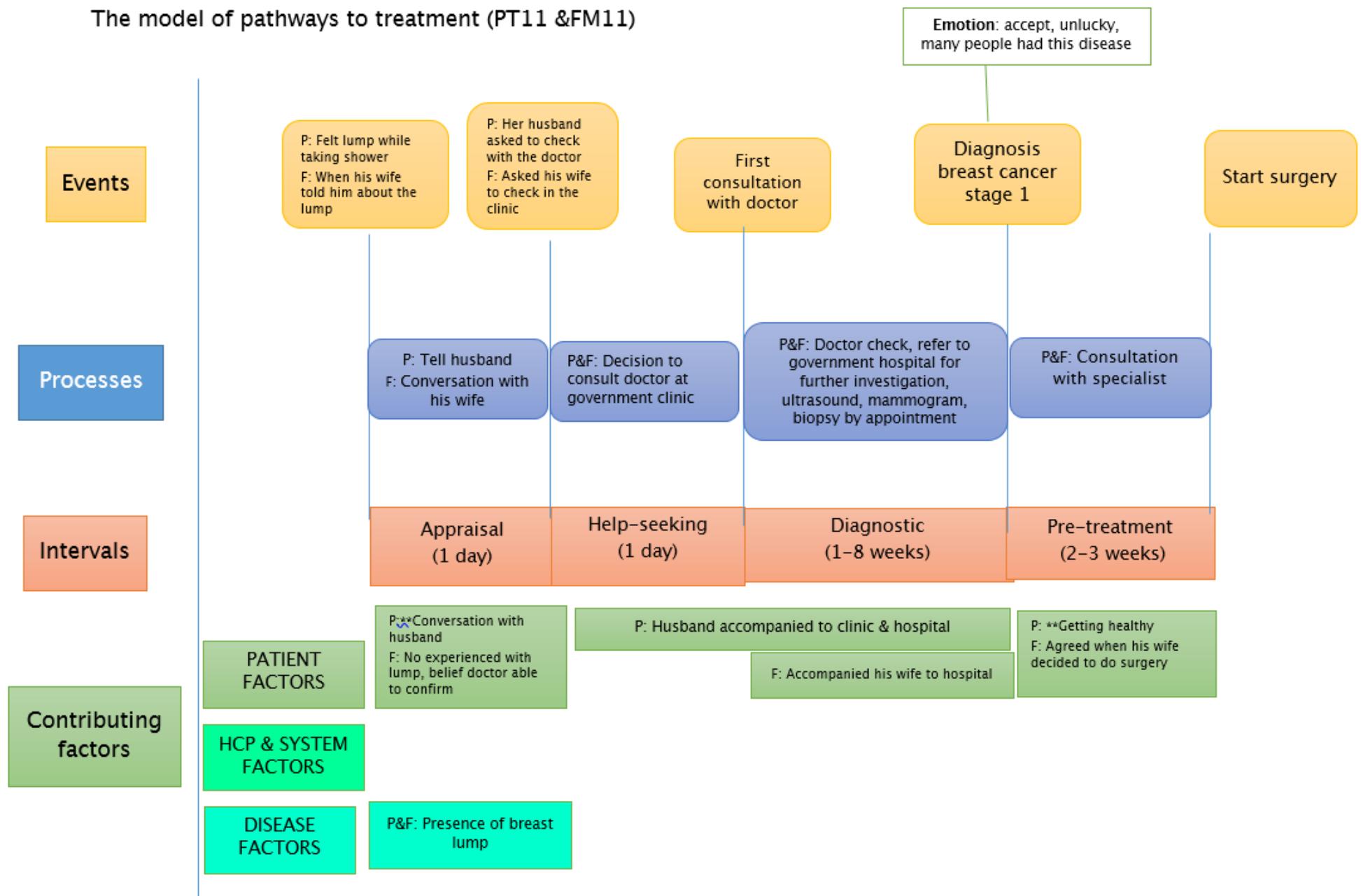
## The model of pathways to treatment (PT9 &FM9)



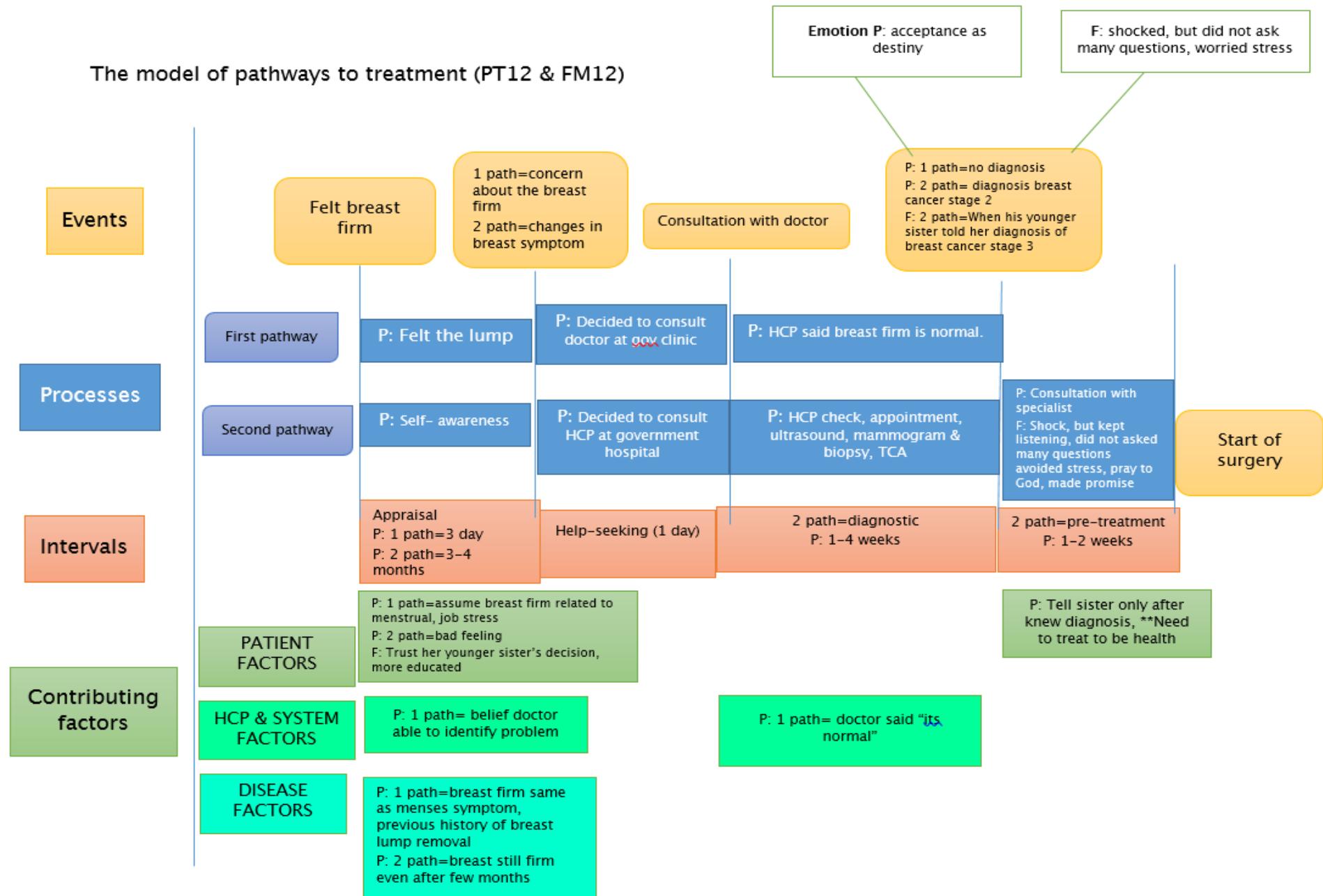
## The model of pathways to treatment (PT10 & FM10)



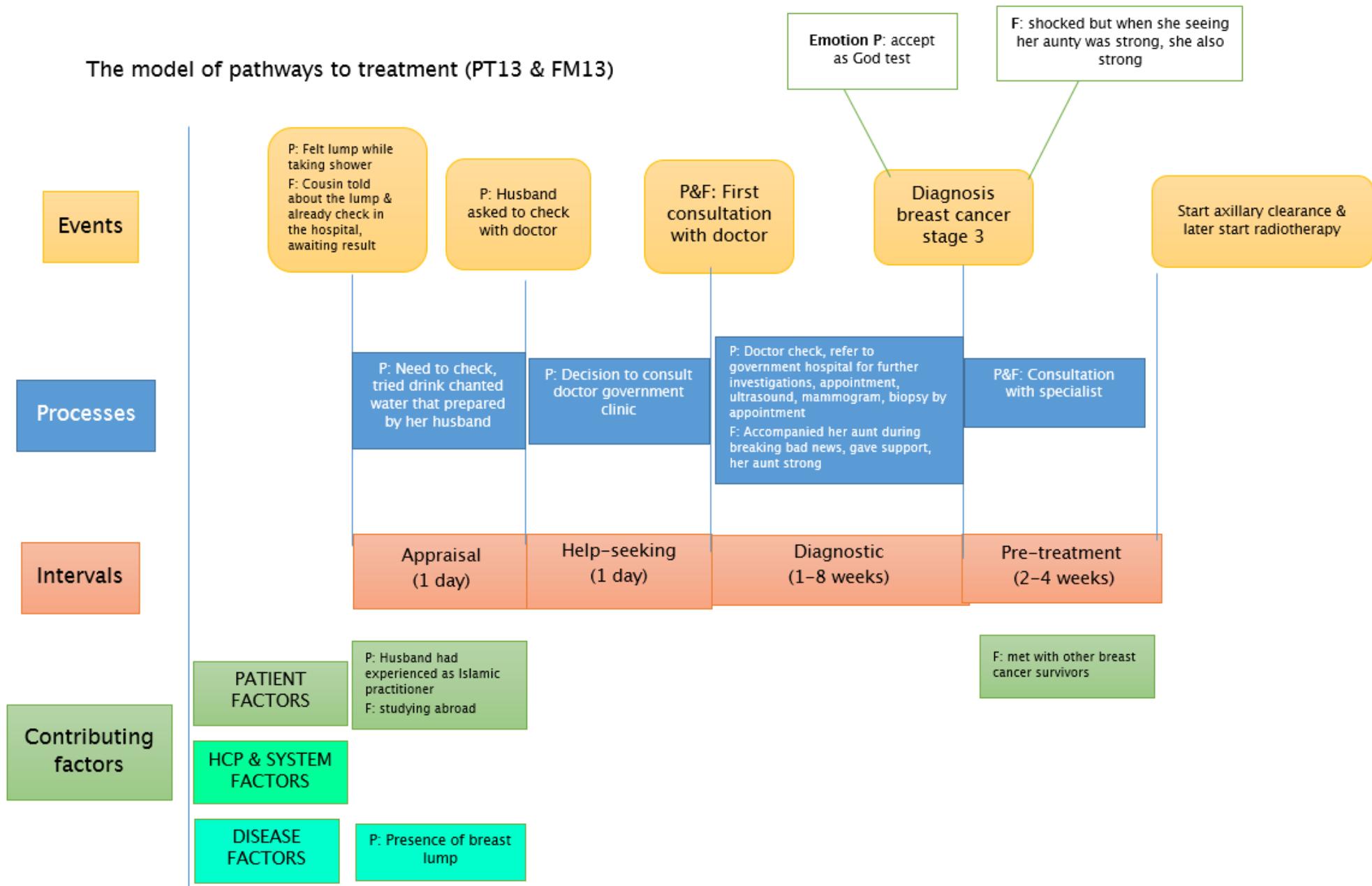
## The model of pathways to treatment (PT11 &FM11)

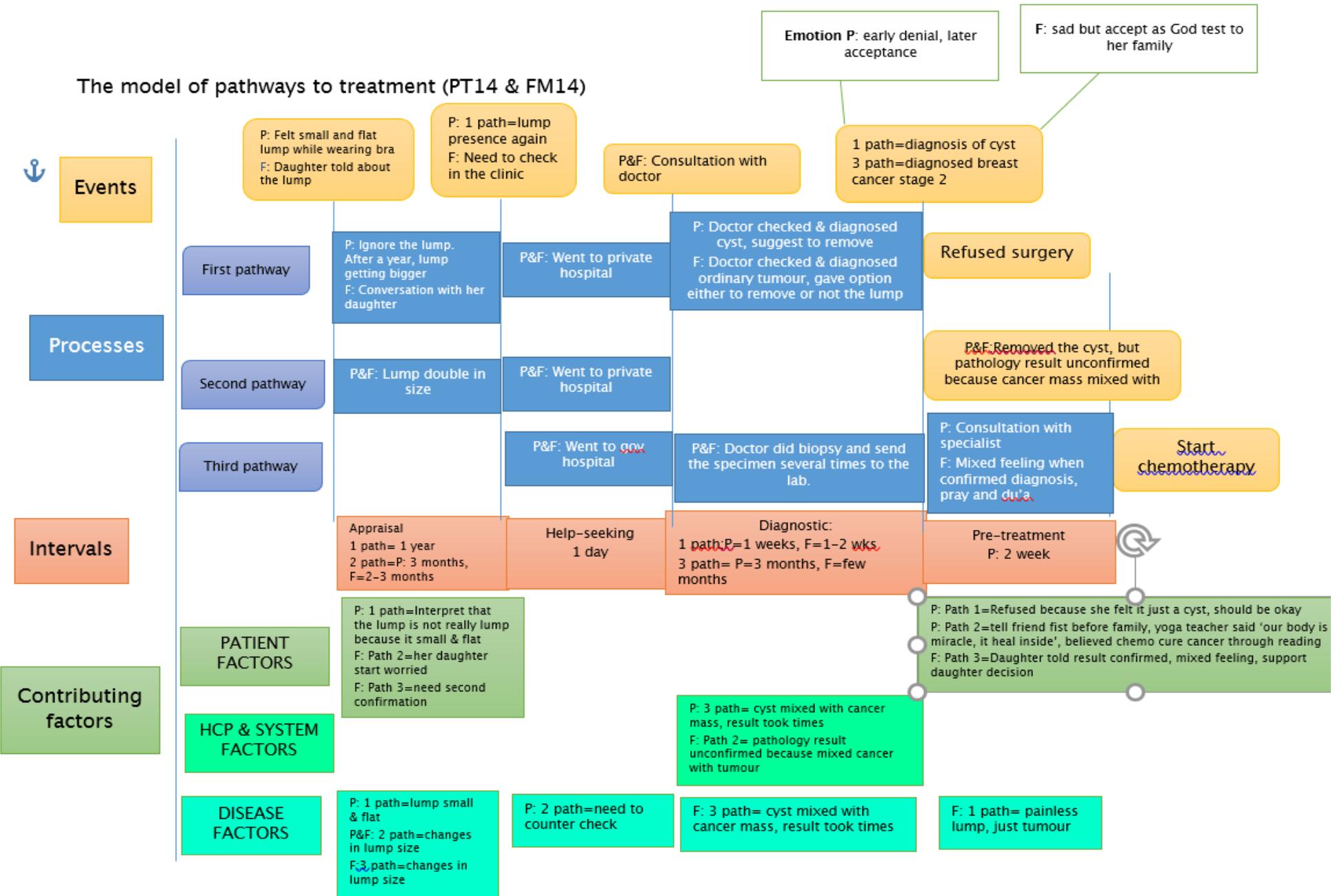


## The model of pathways to treatment (PT12 & FM12)



## The model of pathways to treatment (PT13 & FM13)





## Appendix 16: Summary of participants

Table 6.1: Summary of women with breast cancer and family members

No.	Name	Age	Relation	Race/ Religion	Occupation	Stage/ Location	Year diagnose	Notes
1	PT1	49	Wife	Malay (M)/ Muslim (M)	Sawmill worker	I/Right	2016	<ul style="list-style-type: none"> <li>- decided to observe the lump.</li> <li>- refused surgery because fear.</li> <li>- finally agreed after being persuade by her husband</li> </ul>
2	FM1	49	Husband	M/M	Construction worker			<ul style="list-style-type: none"> <li>- Respect wife's early decision to refuse treatment but later influence his wife to accept surgery</li> </ul>
3	PT2	56	Wife	M/M	Retired teacher	II/ Right	2016	<ul style="list-style-type: none"> <li>- In 2015, the GP unable to detect the lump.</li> <li>- went back to hospital after the symptom had obvious changes and agreed for surgery straight away</li> </ul>
4	FM2	57	Husband	M/M	Retired teacher			<ul style="list-style-type: none"> <li>- took his wife to clinic when his wife complain of breast lump.</li> <li>- Support his wife decision to undergo surgery</li> </ul>

5	PT3	62	Mother	M/M	Housewife	III / Left	2016	<ul style="list-style-type: none"> <li>- decided to observe the lump</li> <li>- told her daughter when the lump getting bigger</li> <li>- refused surgery because to calm her mind</li> <li>- finally agreed after she felt ready</li> </ul>
6	FM3	28	Daughter	M/M	Clerk			<ul style="list-style-type: none"> <li>- took her mother to clinic when she realised the inverted nipple</li> <li>- respect her mother decision to refuse treatment, but kept gave support</li> <li>- looking for information about breast cancer</li> </ul>
7	PT4	46	Wife	M/M	Teacher	IV/Right	2014	<ul style="list-style-type: none"> <li>- decided to ignore the lump.</li> <li>- decided to undergo surgery, but later she refused after accidentally met with other patient in the hospital &amp; listening to her experiences about conventional treatment</li> <li>- tried alternative treatment.</li> <li>- finally agreed to undergo chemotherapy after her symptom getting worse</li> </ul>

8	FM4	48	Husband	M/M	Work at oil company			<ul style="list-style-type: none"> <li>- took his wife to clinic when he knew about the presence of lump</li> <li>- respected his wife decision to refuse surgery</li> <li>- took his wife to meet traditional healer &amp; bought supplement</li> <li>- Support his wife decision to undergo chemotherapy</li> </ul>
9	PT5	53	Wife	M/M	House wife	II/Left	2015	<ul style="list-style-type: none"> <li>- refused to surgery</li> <li>- tried alternative treatment</li> <li>- finally agreed to undergo surgery after her symptom getting worse</li> </ul>
10	FM5	59	Husband	M/M	Retired tele-communication staff			<ul style="list-style-type: none"> <li>- took his wife to clinic when he knew about the presence of lump</li> <li>- respect his wife decision to refuse surgery</li> <li>- took his wife to meet traditional healer</li> <li>- Support his wife decision to undergo surgery</li> </ul>
11	PT6	35	Wife	Chinese (C) /Buddha (B)	Clerk	III/right	2016	<ul style="list-style-type: none"> <li>- Decided to observe the firmness of breast</li> </ul>

								<ul style="list-style-type: none"> <li>- went back to hospital after observed no changes and agreed for chemotherapy straight away</li> </ul>
12	FM6	38	Husband	C/B	Self-employer			<ul style="list-style-type: none"> <li>- took his wife to clinic when his wife complain of breast firmness.</li> <li>- Support his wife decision to undergo chemotherapy</li> </ul>
13	PT7	28	Wife	Indian (I) / Hindu (H)	Housekeeper	III/left	2016	<ul style="list-style-type: none"> <li>- Immediate seek the medical attention when found the lump because of family history</li> <li>- undergo chemotherapy</li> </ul>
14	FM7	30	Husband	I/H	Businessman			<ul style="list-style-type: none"> <li>- took his wife to clinic when his wife complain of breast lump</li> <li>- Support his wife decision to undergo chemotherapy</li> </ul>
15	PT8	32	Wife	M/M	Banker	III/Left	2016	<ul style="list-style-type: none"> <li>- ignore the lump because of previous experience of benign lump</li> <li>- refused surgery because need some time</li> <li>- finally agreed after she felt ready</li> </ul>
16	FM8	37	Husband	M/M	Executive			<ul style="list-style-type: none"> <li>- took his wife to clinic when he his wife complaint of armpit pain</li> </ul>

								<ul style="list-style-type: none"> <li>- respect his wife decision to refuse surgery</li> <li>- took his wife to meet traditional healer</li> <li>- Support his wife decision to undergo surgery</li> </ul>
17	PT9	34	Wife	M/M	Admin assistant	III/right	2016	<ul style="list-style-type: none"> <li>- Went to clinic after found the lump</li> <li>- undergo chemotherapy</li> </ul>
18	FM9	34	Husband	M/M	Self-employed			<ul style="list-style-type: none"> <li>- took his wife to clinic when his wife complain of breast lump</li> <li>- Support his wife decision to undergo chemotherapy</li> </ul>
19	PT10	52	Mother	I/H	Housewife	III/left	2016	<ul style="list-style-type: none"> <li>- notice her breast was firm, but the GP said lymph nodes problem.</li> <li>- went back to hospital after the breast getting bigger and agreed to undergo chemotherapy straight away</li> </ul>
20	FM10	28	Son	I/H	Publication company			<ul style="list-style-type: none"> <li>- knew after her mother already diagnosed with breast cancer</li> <li>- supported her mother to do chemotherapy</li> </ul>

								- looking for information about chemotherapy
21	PT11	57	Wife	C/B	Rubber tapper	I/left	2016	- found the lump and agreed undergo surgery
22	FM11	59	Husband	C/B	Rubber tapper			- took his wife to clinic when his wife complain of breast lump - Support his wife decision to undergo surgery
23	PT12	52	Sister	C/B	Teacher	II/left	2016	- notice her breast was firm, but the GP said its normal. - Few months later, checked the symptom with another GP in hospital and agreed to undergo surgery after it confirmed.
24	FM12	53	Elder sister	C/B	Housewife			- Knew after her sister already diagnosed with breast cancer - Support her sister's decision to undergo surgery
25	PT13	60	Aunt	M/M	Local business	III/left	2016	- Tried Islamic treatment before when to see GP about the lump - undergo radiotherapy

26	FM13	38	Niece	M/M	Lecturer			- Support her aunt's decision to undergo surgery
27	PT14	29	Daughter	M/M	Dentist	III/left	2016	<ul style="list-style-type: none"> <li>- notice a lump, but she decided to ignore because unusual shape of the lump.</li> <li>- went back to hospital when the lump getting bigger</li> <li>- agreed to do chemotherapy because she realised chemotherapy is scientifically proven although her yoga's instructor suggested her to refuse chemotherapy</li> </ul>
28	FM14	57	Mother	M/M	Housewife			- Support her daughter's decision to undergo chemotherapy