

Table 4.21 Staging and histopathological features of the study participants

		N=19	%
Stage	IIA	1	5.3
	IIIA	4	21.1
	IIIB	6	31.6
	IV	8	42.1
Histology	Infiltrating ductal carcinoma	15	78.9
	Infiltrating lobular carcinoma	3	15.8
	Malignant phylloides	1	5.3
Tumour size		Mean: 12.0 cm (SD 7.5) Median: 8cm (4.0-31.0 cm)	

Most of the women were in Stage III, followed by Stage IV. One participant was in Stage IIA, she presented with a large lump of 8 cm and delayed for more than 6 months when she was recruited for the study before the histopathology report gave a definitive result for her tumour size which was 4 cm, which down staged her to Stage IIA The median tumour size was 8cm, and ranged from 4 to 31 cm.

Table 4.22 Types of treatment done

First-line treatment modality	Chemotherapy	4
	Surgery	8
	Hormonal therapy	9
Surgical treatment	No surgical treatment	5
	Breast conserving surgery and axillary clearance	1
	Mastectomy and axillary clearance	13
Ever had chemotherapy		15
Currently undergoing chemotherapy		6

Table 4.22 shows that four had undergone chemotherapy, eight had undergone primary surgery and nine had undergone hormonal therapy as their first line of treatment.

Thirteen had mastectomy and axillary clearance, one had breast conserving surgery after neoadjuvant chemotherapy and five eventually did not undergo surgery. Fifteen women had experienced chemotherapy and six were still on it.

4.3.2 Voices of women with advanced breast cancer

4.3.2.1 The phenomenon of late presentation

These women presented with advanced breast cancer. This was regardless of ethnicity and socio-demographic background. The meaning of this phenomenon is aptly evidenced by these following quotations:

Pain was one of the features of advanced presentation. Her initial symptom was a painless lump. It is ignored until progression that could either be locally in the breast or systemically spreading to other organs like the lungs and brain.

I knew since 5 years ago, I didn't care so much. I didn't want to think it was cancer. I continued being busy with work until I could not stand it anymore. When it became too painful and large, I went to see a doctor. (P18)

Later on I started coughing, it was during the festive season and I was making cookies. I was coughing with a lot of phlegm. And then they told me I had water in the chest. Then I had the worst headache. Until, I was bent over with pain. The oncologist told me it affected my sense of balance. She showed me the cancer was at the back of my head. (P2)

Besides the woman herself, significant others also suffered.

I started having severe pain when my son was going for exams. It was bad, until I could not sleep. It was piercing at the breast. Later on, after the massage, the skin became red. It became big and I walked leaning to one side. In the end my husband allowed me to go to hospital as he couldn't take it anymore. We were suffering. From being fat to really thin, both of us lost so much weight. He was worried. At night, I couldn't sleep. I keep waking up due to the pain. It was so bad, really bad. I try not to remember it. (P3)

I had to sit on a sofa to sleep in a sitting position. Because the minute I moved, I sensed the pain. It was quite severe. Until I couldn't take it. My pastor came, they have been coming to my house because they knew what I was going through. Then he said, "Uncle, you have to send auntie to the hospital. She has to go for a thorough check up." Because till that day we didn't know it was "c". (P10)

The disease in the breast or axilla can be quite distressing especially when it starts to ooze.

One day my armpit had pus and was oozing. That's when I became worried. I thought "What the heck is this, man?" (P19)

Again, it took awhile before cancer became apparent.

I think there are people who get breast lumps when they are pregnant. When the same thing happened to me, I didn't tell anyone, until I delivered it remained the same size, it didn't grow at all. After I delivered, I got pregnant again. Even then, it stayed the same size after I delivered. One year after I got that baby, it started to become aggressive. (P11)

I had this arm swelling only in the past 1 month. Before that I could do everything. (P1)

P15 had an excision biopsy but delayed definitive treatment, she experienced local recurrence very quickly in the same breast in the scar.

I just had the operation scar, that was in September. The doctor called again, but I still could not accept. In October I felt a small lump in the scar the doctor did say that it will get bigger. He was right, it did get bigger. From small to large. (P15)

Some thought that the lump would go away, until they had severe symptoms that drove them to seek help from a hospital. Women suffered the symptoms of advanced cancer, usually after a period of six months to two years. Initial symptoms were usually not very obvious, and they were fairly asymptomatic except for a breast lump. This phenomenon of poor symptom recognition will be displayed in Section 4.6.1.1.

The impact on relationships with their spouse and children were also seen . Husbands provided the participants support and became closer to their wives. Sexual difficulties were expressed and closer relationship was formed with soon to be husbands.

*He [husband] is doing so much for me. Now, praise God I am happy. I can still move about but yet he wants to help. He wants to make my juice for me, he wants to do *laughs* everything. He can even wash plates for me which I used to do. He never used to do anything. I don't want him to feel a sense of guilt. But I know inwardly, he feels bad. But I don't harbor any hurt towards him. I know he was in denial and he didn't want to go through that. But eventually he had to. Uhuh. That's my honest feeling, you know. (P10)*

My relationship with my husband is closer since I have stopped working, but the chemo makes [sex] different, it has become dry, quite difficult [to have sex]. Is it like that? (P3)

The doctor did ask about putting in silicon. I asked my boyfriend. Then he said, does it mean you need another operation. There is no need, it's painful isn't it. And the doctor asked him if he wants me to get pregnant later on. He said, let's see what happens, we do what is necessary first. He said to me, you mustn't get pregnant, he saw me in pain. For the second operation, I was in so much pain. I asked him, can he accept, he said , yes. (P15- had discussed this even before she was married)

The impact on children of young mothers with advanced breast cancer was tremendous, also to the young mothers whose instinct is to protect their young from hurt.

I believed he [my husband] cried also. But he dared not cry in front of me. He did not say anything. He comforted me, but I dared not speak to him, I dared not look at the baby. Inside my heart, if I look, I will cry, I dared not look at the baby. Because I felt that I could not look after him. I had "heartache", I do not know if I could live long enough to look after him, build a relationship with him. (P8- after induction of labour after delivering her first child after a diagnosis of cancer)

My eldest is eight years old. My, kids, are very strong. You know because mama is sick. At such a young age, they say it's ok mama, don't worry, you will get better. Sometimes, they cannot accept. Mama, I don't want you to die. Then I will say to her: if we die we can go to heaven, then she will say, I would like to go to heaven too. I wanted her to know that my dying should not destroy her life, making her not want to live anymore. I wanted her to know that dying

is where someone goes to a great place. To the extent my children will ask, "Mama, do they have play station 2 there?" [laughs]. I told her you can have whatever you want in heaven. If it's like that I want to go there too, she said. Then she said, in heaven you can find my little sibling who died. (P11)

The participants found it difficult to help their children understand about the disease.

My husband will say to the children "Do you think mom's illness is like just having fever?'. They don't really understand what cancer is. If I get back from the hospital, my second son will ask, "Have you had the operation mom?" He sees me go to hospital; he thinks it's so simple. He doesn't know about operation or anything. (P3)

I have two children, one in Form 4 and the other in Standard three. My children don't understand. "Mom is well,so why do you need an operation?". I told them "Mama has a lump in the breast. I need to remove it since its dangerous". They are kids, they don't understand about cancer. Just knowing about a lump is good enough. (P6)

At times, communicating with loved ones becomes a problem. Everyone is devastated by the cancer, but have difficulty consoling each other.

I had a lot of turmoil. At night, I was sad, I cried. My children also were sad. But we didn't talk about it much, because we were all so sad. (P5)

4.3.3 Section summary

Therefore, this chapter introduces the participants in this study and justifies why an exploratory study on why women present with advanced breast cancer is needed.

It illustrates the great impact of the disease on women with untreated cancer by the evident progression of symptoms of the disease from a minor to a major complaint and life may be shortened but most importantly the quality of life was impaired.

The next sections will look at the meaning of health care utilisation for women with advanced breast cancer, where the delay is in the journey of breast cancer patients and the next chapter will be an exploratory account of why women present with advanced breast cancer.

4.4 Meaning of health care to participants: utilisation of health care in women with advanced breast cancer

4.4.1 Health pluralism

4.4.1.1 Utilising a pluralistic health system

In Malaysia, multiple pathways of care can be seen. The patient makes a choice of undergoing conventional or alternative medicine. The type of treatment ranged from prayer to use of “scientific’ products from multilevel marketing companies. The choice relates to the belief that conventional treatment gives very poor quality of life. The alternative therapies also lends them support and also meets their need for psychological and emotional support.

For some women, treatment decision delay (refer to section of Stages of delay) happened, due to worsening of symptoms after using alternative therapy, after which these women presented to the hospital .

What for, want to see the doctor I said. No need to waste the money. When it became big, then I went to see a doctor(P18)

4.4.1.2. Alternative medicine

Alternative therapy was used at any stage of the breast cancer journey, namely at recognition of symptoms, after seeing a health provider, after a diagnosis, even after completion of treatment.

Before diagnosis, some women have preconceived ideas that they have cancer and readily sought alternative therapy. They had fatalistic view of the cancer and needed hope.

All who had no hope went there. I was the only one who had not been diagnosed. No diagnosis, but went there. I was the only young one. (P11)

The homeopathy doctor told me there is a seed growth, he said it was not cancer but a growth. He said God willing it can be treated. At that time the lump was small, I thought, maybe it can disappear. (P12)

The women could not accept the diagnosis and was not ready to accept mainstream modern medicine.

No [I didn't take anything else besides homeopathy]. I think I took homeopathy about six months before seeking any diagnosis. (P10)

Some participants with encouragement from their family members used alternative therapy.

I accepted to have chemotherapy and surgery after delivering my baby. Everything was arranged (the chemo and surgery). They (the parents) then took me to see the Chinese physician. (P8)

Some women sought alternative treatment after completing hospital treatment.

I didn't see any other doctors except the Chinese physician in TS hospital. This was later after completing chemotherapy, radiotherapy and operation. It was in the Chinese medicine department. (P13)

Some women did not get a sense of hope from conventional medicine, they obtained it from alternative practitioners.

For my condition [after completing all treatment], he [hospital doctor] said no other medicine to take. No medicine to take? So, I looked for other medicines to take. That type of Chinese physician [I went to earlier] I dare not go now. We went to the more 'authentic' ones, the 'real' one. The one that I went to had no "license". Now, I go to TS hospital. That hospital is government-approved. Approved by Ministry of Health. (P8)

4.4.1.3. Types of alternative medicine

Using a questionnaire, 10 out of the 19 reported the use of alternative treatment. Four used Chinese herbs. 3 used direct selling products, herbal pastes, 2 used qigong, traditional massage, blessed water and one used spiritual surgery. Two women reported that they did not pay anything for the alternative treatment, 4 spent more than RM 8000.00, 4 spent between RM 1000 to 1200.00. The median cost was RM 1200 (range from 0 to RM 30 000.00). One participant used four types of alternative therapies, three used 3 types, three used 2 types and 3 only had one type of alternative therapy.

The homeopathy tablets cost more than RM 1000 [~USD330] for a month's supply. (P3)

Types of therapy corroborated with the survey. However finer details, such as detailed description of the alternative therapy was better in the qualitative interviews.

Homeopathy was used by Malay and Indian women. The practice of homeopathy varied from oral, applications to the use of ice cold water. Some women doubted the alternative practitioners.

One white tablet daily and then apply the oil. He used a computer, he looked at it and said, this is a "lump" he said. In my heart I told myself, how can a hard lump just be a "lump" (meaning not cancer). Then he asked his wife to palpate. The wife felt and said yes, she felt a "lump" They used keminyan [incense]. I didn't believe what I saw, is he for real? I met the wife jogging nearby, she said it was not "it" [cancer]. (P2)

Each time was RM 80 [~USD 25] for the [homeopathy] medication. The medicine lasted very long about one month. There were five types of medicines, we have to finish it one by one. (P2)

My husband just went you know. I didn't go see the brother (homeopathy therapist). My husband said, "Okay. I will give you this homeopathy" and give you all the tablet and all that. He said, "You try. You take this. It will dissolve." (P10)

The homeopathy therapist checked my hand, after that he gave the medicines. He asked me to dip my feet in ice water. I couldn't take the ice water. It was so painful, it was more painful than the pain in the breast. (P3)

But it was interesting that some alternative practitioners reassures women, that small lumps are just a growth not cancer.

If it was small, like the homeopathy doctor said. It's a growth, he didn't say it was cancer, he just said a growth. But in the hospital, big or small, the lump would be removed. Right? (P12)

It was seen some practitioners had their wives examine the patient, and some examined on their own. In one participant, the therapists used blood tests as adjuncts and were wrong in their interpretation of those tests.

He said this is a growth not a cancer. I see that it didn't get smaller, in fact it became larger. The homeopathy therapist just felt with his hand and then made a diagnosis. It was his way. He said it's not getting bigger, he said it's the same size. But he asked me to take blood at a private lab G, and it was normal. So he said it's not cancer. But when I went to private hospital am, they said, cancer cannot be detected from a blood test.(P12)

Direct selling products were seen to feature prominently. And used by all three races.

They too indiscriminately used blood tests to support their claims.

Women found information from the television.

Just before I became unconscious I watched Astro 106[cable tv], Halal Bio[television programme], it was about vitaminB-17. And I was really impressed, but at that time I didn't have the energy. After that they brought me to hospital. In the hospital I was really scared about radiotherapy and chemotherapy. (P11)

I saw on Malaysia Hari Ini, a tv programme about the apricot treatment. (P3)

Direct selling products came in many forms.

I tried the direct selling products, sometime tablets, sometimes water. (P18)

At times, women used what they saw being sold in pharmacies.

I just took "gamat healin" [sea cucumber] but it got bigger. I bought it from a pharmacy. I just wanted to try since I have asthma and all. Nobody told me to

try it. Just wanted to buy it. I saw it at the pharmacy. It was quite expensive. (P16)

It was common to see the terms such as “berubat kampong” or village treatment used by the Malay women in this study. This varies from water blessed with Quranic verses to the use of home remedies, spiritual surgery and specific diets.

“Kampong”[village] medicine I did try. I just applied and drank water blessed with Quranic verses. (P12)

I am doing “kampong”[village] treatment. Alhamdulillah, I don’t feel pain anymore. This one I did it myself, I asked my friend to go. I went there just after my first hospitalisation. I followed the practitioners way, do surgery his way. So that it doesn’t spread. After that, we have to put in the effort ourselves. We brought rice flour, which we applied around the tumour to kill off the germs. After that at home at night, I use leaves, roots, like galangal, dried malabar tamarind [asam keping]. This is for inner cleansing. Boil it from two glasses to make it into one. Drink it. That was what he taught me. (P9)

This was not restricted to Malay women in this study, Chinese woman also used home remedies. Furthermore, these remedies failed to control the cancer.

I went to the road side to pluck them [plants], people told me it was good. After eating (the herbal plant), I got better. After about one year, my stomach started bloating’. (P7)

I tried chicken with Chinese herbs and ginger like the type we eat during confinement. We put in some wine. It’s supposed to make us strong. I was very weak. I tried it for a year. I used village bred chickens. But the lump became bigger and bigger (P18)

The use of massage was seen prominently in the Malay women. Massages were performed by traditional midwives and also by immigrants from Indonesia.

I went for a massage for the fingers and toes. At Taman Kosas Ampang. I go there often, initially for three days, but when I was in pain I would go. We only give sedekah (charity) as payment. It was an Indonesian man. (P3)

I did breast massage in Pandan Jaya. An Indonesian lady, she claims she had cured someone, but I never met that person. It was painful when she massaged I couldn't touch it after that. Don't know what was wrong, maybe she didn't give pain killers. On the second day, it was okay. The breast lump inside was painful like being pierced. (P3)

At times, these masseuse would advise for the participants to go to hospitals.

Whilst massaging, then the midwife said you have a lump. You actually need to go to the hospital. The midwife told me to go.(P9)

Religious revival and mainstreaming of religion in the media have brought about awareness and commercialisation of religious practices in the community.

I watched TV3, there was a treatment based on the sunnah [lifestyle of the Prophet Muhammad]. So I went for it. The treatment was based on tahajud [voluntary night] prayers. I believe this was not "bomoh" or shaman type of medicine, where water was blessed and we drink it. This is about asking directly from Allah [God]. You wake up at 3 am, you make "doa" [supplication] and ask for whatever that you want. You get closer to Allah. The first time I was there the ustazah [religious teacher] asked, are you coming for treatment or preparing to die? I was like both, I thought. Because tahajud prayers, zam-zam water [holy spring water from Mecca] and all the medications mentioned in the Quran like honey, habatul sauda [black cumin] were proven. Because I met a patient that said she was cured completely of cancer. All the people I met there had terminal cancer, no more hope. All had surgery. Majority were breast cancer. All with no hope went there. I was the only one who had not been diagnosed. I was the only young one. (P11)

The use of prayer in making decisions was seen. A total submission to the will of God was used by the participants.

I was confident with my choice. Because every time, I want to make a decision, I made the istikharah prayer (divine guidance prayer). I totally submitted to Allah's will. Because I don't know which is the best way? If anyone conned me, I asked for his guidance. Don't allow anyone to con me. If it's for me then let me feel that I want it. The treatment must interest my instincts. If I was conned, I left it to him. If it happened to me, I accept. Because I want His help. If it happened, it is a test for me. I was like that.. After 19 days[on apricot B-17 treatment] I felt confident. (P11)

The istikharah (divine guidance) prayer is used by Muslims to make difficult decisions, and may be interpreted in many ways, for P11 she described getting direction through intuition.

For me I don't get this messages from dreams [what is believed about istikharah prayers] I believe that Allah will open my heart towards the decision and what is good for me will interest me. Like coming to this hospital, if Allah willed it that the hospital will cure me, let me have interest for it. Like yesterday when I called the doctor yesterday, I asked about radiotherapy and I asked Prof A. I wanted the lightest one. I wanted radiotherapy first. Because chemo is too hard for me. Hard to think and hard to accept. After I made istikharah, "oh Allah, if it is good for me, even if I am scared, please reduce the fear for me. And if it is good for me, please show me. If it is bad for me, keep it away from me with whatever way. I will avoid it. So I accept, if I had to do it because I have submitted myself. Like suddenly yesterday with Prof X, I felt strongly against chemo. After that I prayed and called Dr.Y. Then I felt, maybe that could be my treatment. It's like if this is for me, Allah wills that the interest comes by itself. At the beginning when I made the istikharah prayers, I didn't believe, how do I know which one is the right message? We make doa to Allah so that what we feel is the right thing. After that we must truly believe. Because we have asked from him, if we don't believe, and do not ask wholeheartedly, no one would give it. That is my story on istikharah (divine guidance) prayer, everytime even for simple things. (P11)

Even for daily activities, this participant would ask for guidance from God.

Should I go to the market today? Or I'm too tired? Even for things like that I do istikharah prayers, because I don't know. I might get tired if I go. Would it be worth it? Minor things like that I would ask, because we don't know. So I was dependent on that. And if anything [bad] happened, I remained with my beliefs. When you ask someone's opinion, you believe it, and if they con you, I have to accept. (P11)

At times, religious teachers were directing women towards conventional treatment.

So I went to see the ustaz (religious teacher), he read verses from the Quran and gave blessed water. That's all. After that he told me to pray istikharah (divine guidance prayer), he said maybe it's a test for you from Allah. The ustaz said you need to remove it. You can no longer run from it. I accept what the ustaz said. (P15)

The bomoh or shaman is the medicine man for cultures in the Asia pacific region, where herbs and prayers were used as treatment. Women, used other's experience to justify using alternative medicine.

My aunt's daughter said that a friend had breast cancer and she is well now. That was why I tried. It was a shaman. (P3)

With recent revival of Islamic understanding that bomohs are not congruent to Islamic beliefs, many women expressed their justifications of seeing traditional therapists who are not bomohs.

There are Malay shamans. But no, I don't go to them. It is shiriyq (polytheism). It is a major sin. You know, why should we do it. "batin"[magic] treatment, I don't believe, I believe in Allah. (P1)

Chinese medicine also varied from those who are accredited and practicing in a hospital setting with oncologists and those without accreditation practicing in the community.

Those who have no license, if he [the Chinese sinseh] treats you successfully, he gets the good name, if no good [treatment failed]. Then...we ourselves have to accept (the responsibility) right? We, the sick people have to accept (the wrong treatment. So I went to TS (hospital) they said it is more 'authentic', can guarantee. It is not like a "couldn't care less" type of "Chinese medicine". Because the Chinese hospital has an oncologist. (P8)

I told the Chinese physician [in the hospital] I have breast cancer. It's for making my body and mind 'right'. (P13)

Qigong: one of the women used qigong to improve their breathing techniques.

At first I was a bit skeptical. I said how can oxygen cells fight cancer cells. I was also into the internet. I went on reading in the internet and they all said oxygen, oxygen, oxygen. John Hopkins also came up with a few articles on taking in a lot of oxygen and it can kill the cancer cells. I said ok, I got nothing to lose. It's free of charge. Oxygen is free. (P19)

Dietary adjustment was the other way participants tried to improve their odds. Being vegetarian sometimes did not help when they had to undergo chemotherapy.

My body was so toxic, they were scolding me because I switched my diet from non-veg to veg. So when you are a vegetarian and if you want to go through chemo. It's not easy. You become very weak. (P19)

At times it may be detrimental to their health like admission for hyponatremia from malnutrition as seen in P9, which will be discussed further in the section for failure of alternative treatment below in section 4.6.1.6.

4.4.1.4. Triggering factors to use alternative treatment

Many factors triggered the use of alternative therapy in these women. Namely; strong recommendations from significant others. Women needed direction in their choice of treatment. Some participants describe this as a directive that may cause friction in relationships. Husbands and parents played an important role.

Everything was arranged. But, they [the parents] then took me to see the Chinese physician. I did not think of going. But they [parents] kept on scolding me... my mother and my elder sister also scolded my husband. "Why you must listen to what your husband said". I was very sad, do you know that? My husband was very upset, the way they scolded him. My husband also had no other choice. So, in order not to let my husband suffer, I went. (P8)

My mother, she said, no need to have surgery. We can try "kampong" (village) treatment and other things. So I did kampong treatment. Before I went to see the doctor again, the doctor called me up to have the surgery. I told the doctor I cannot accept. I am trying other things. He asked "Are you trying "kampong" treatment?" I told him the truth, I am doing kampong medicine because my mother told me to do so. He said, never mind, please come back in two weeks. When I saw him, I postponed the date again. (P15)

I just used homeopathy. Because my brother-in-law recommended that. He meant well. And then I did not pay anything. It's not because it was cheap. He didn't charge me anything. He didn't. Nothing. He just said, "You take this." I know he meant well. But it so happen I went through what I did. (P10)

And there were times when I took it [homeopathy] the pain was so severe, there were times, I told my husband, I just wished I could die. (P10)

Some women made their own choices, and remained with it, despite being advised against it, for P11 she felt it was fated that her family brought her to hospital.

I was not angry at those people who brought me there, although when I was conscious I was adamant that I did not want to go. But when they brought me, it was fate, Allah willed it. In the end I went to hospital. And after the surgery, I became well and healthy. (P11)

Some women, went for therapy to relief themselves of physical pain

I went for a massage, I go there often, initially for three days, more often when I was in pain. (P3)

Women received information from multiple sources, from other patients, from television, from cable television and the internet. These medicines were sold by self-proclaimed “doctors” and “professors”, using scientific language at times.

I was impressed by the direct testimonial from my neighbouring patient in the hospital. After that I called him from the hospital, Prof SP, I don't know where he got the title of Prof. I asked him, “Can I be cured 100%? He said “I'm talking about cure”. (P11)

It was a Malay doctor. But I never got to see him. The shop was like a beauty salon with beauty products and other products too. They said the doctor was not in and had gone abroad. The doctor used the title Dr and it was written in the salon. I don't remember his name. I have thrown away his card. (P3)

The participants could not help but be convinced by this façade of scientific evidence; they could not differentiate this evidence with those from conventional treatment as the alternative practitioners used the argument that conventional medicine does not support them, because they have invested a lot into development of chemotherapy drugs.

It was convincing. He said hospital doctors will not agree with this kind of medicine because they have spent a lot for chemotherapy. (P11)

4.4.1.5. Value of alternativemedicine

Several themes emerged when looking into the value of alternative medicine to the participants :-

4.4.1.5.1. Psychological support

The need to treat emotional effects of cancer was seen prominently in the participants. Psychological support was needed to reduce anxiety of waiting for treatment in a public hospital as well as fear from the spread of cancer.

The Chinese physician prescribed some medicine, Chinese medicine for some treatment. Taking it will help mentally. I stopped going when I felt slightly better. Because that time I still have pressure, because at that time the (breast) tumour was not removed yet. That time.....every cell in my body was 'jumping with worries'. Still has a kind of pressure there. After surgery, tumour was removed, but I still had pressure. Don't know, I was very scared. Scared that it will spread, will recur. (P8)

Everybody was scolding me. What are you doing? Still not done your operation yet. Look at us. We have finished everything. I said I don't know I leave it to God[laughing]. Public hospital is slow. What am I to do? I had my chemo first. Then I waited one month for the operation. Then another month for the radio. Whereas in private hospital they don't wait you know. They go straight away. They do chemo and radio at the same time. How on earth they do it I don't know. So they were all feeling very sorry for me you know. My support group. They said aiyo...they said how are you going to survive this man. Nine months. Still no treatment yet. I think qigong helped me. (P19)

4.4.1.5.2. Alternative medicine provided spiritual support

Strength and hope from the use of spiritual treatment allowed one to cope with the disabling effects of fear. P11 needed spiritual support, which she obtained from her religious beliefs.

Although the tumour became larger. I was confident; Allah can cure me, since he can fold the mountains at "kiamat" [doomsday]. All can be ordained by Allah if he wills it. What more with this minor painful disease like mine. If Allah wants to cure, he can. All the treatment mentioned in the Quran, I believe would work. At that time the belief was very strong. And I liked it, because I had no fear, I no longer felt paralysed and unable to get out of bed like when I heard about the death of the former first lady of Malaysia when she

died. I was so weak thinking of my fate. But after starting prayers with the ustazah [female religious teacher] I was no longer like that. (P11)

I went through the whole procedure but at the same time, I got into this religious thing. I started praying, praying for a miracle. I said look I'm going through this treatment. It's not going to be easy. My hair has all dropped. I look like a real horrible hag when I look at the mirror. You [God] have to help me. You [God] decide whether I'm going to be ok. To pull through this treatment or I should just give up. (P19)

Spiritual support induced peace in P11. Spiritual support was seen as preparation for a fatal outcome. In a hopeless situation only divine intervention and a miracle could save her.

Having undergone treatment there I felt peace. I am a very spiritual person. I feel I can accept faith, I am sick, and everyone would die one day. Having an illness is a test. Any illness, if it was fated that you die, you would die. Therefore, we must strive hard. Illness can be cured by "tahajud" (voluntary night prayers) prayers, the food that Allah taught in the Quran, making doa (supplication). This is the longest treatment that I used. And I was satisfied that I tried the prayers until the tumour became so large. (P11)

Confidence that divine intervention was at work, directed her towards the treatments that she could accept.

Another reason was that I believed that all the treatments I took were willed by Allah who showed me the way. (P11)

The use of religion in treatment was endorsement for the efficacy of that treatment. Who can deny the truth of the Quran in a Muslim society? The careful justification was the participants clarifying that the practitioners were not "bomohs" that would be

wrong in Islam. “Bomohs” (Malay shaman) are known to use djin’s (supernatural creatures) powers and therefore not trusting in God’s powers to heal.

He is not a “bomoh” [shaman], it would be shiriq [polytheism, equating others to the power of Allah] if we say so. A lot of people go to him for cancer treatment. Alhamdulillah[praise to God], someone told me and brought me there. (P9)

I felt she wasn’t like a “bomoh tiup” (shaman). She told us to do it ourselves; we pray and make doa on our own to Allah, asking for what we want. For me, we drink zam-zam water[spring water from Mecca]. Allah says it is an antidote, like habatul sauda [black cumin], which is an antidote for all sickness except death. So I kept steadfast in my beliefs. Until when I went into a coma, my family had brought me to hospital. I accepted it, if I died, I will always ask from Allah, show me the way that is best for me, that does not pain me. After that I truly believe what Allah placed in my heart [instincts to choose] , and that is what I want to follow. This is a sign for me from Allah, only Allah knows best in terms of curing me. (P11)

Consciously or unconsciously I was thankful, I don’t blame the ustazah (female religious teacher) whom some people said I was obsessed with. The say zam-zam water treatment alone cannot cure, that’s wrong because Allah said in the quran that it can cure. You mustn’t blame the ustazah., To me I don’t blame her although the disease was not cured but my inner strength became strong. She contributed to that. If my disease cannot be cured, I “redha”[accept]. (P11)

An elderly grandmother expressed her disbelief in bomohs and this was displayed earlier.

4.4.1.5.3. Explanation for the breast cancer

Confidence in alternative treatment was also due to the perception of understanding the disease that they have. Logical explanation related to the patient’s own journey,

brought about a feeling of trust and confidence in the therapist. Participants liked to be able to explain what is happening within them.

After that he asked me to think logically: “Has there been a pregnant women dying of cancer? Actually the source of cancer is from the pancreas, because they don’t release trypsin. Our pancreas releases trypsin. Trypsin fights the cancer, and once you have problems with the pancreas the trypsin cannot be released. I was pregnant twice, when I had the “thing” and it didn’t grow bigger, so I was really convinced that this was exactly what I experienced. ecause the baby’s pancreas helped the mother to produce trypsin. So the cancer became stagnant, fought by my baby. Logically that time I had my baby inside, the thing did not grow. So I took the B-17 vitamins for 19 days. (p11)

The psychological strength and the understanding of how to control it provided by alternative medicine allowed the participants to have confidence in conquering the cancer.

But then I became friends with the cancer cells now [laughing]. I’ve come to terms with them.ok, you fellows are in my body, so what do I do. I give you oxygen and you just go to sleep. I may not be able to cure myself of it.But I know I can put you to sleep.So I talked to them sometimes when I’m doing my qigong[Chinese exercises]. I have to. I cannot run away from it right? To my cancer cells, if you want, you can be in my body I couldn’t care less which part of the body you are in, but you sleep. You don’t disturb me. So, it took a while to have courage to face. It took one year of Qigong to finally accept.that means after surgery, chemo, radiotherapy. Even at that time I wasn’t confident. Even after radio I wasn’t confident. But the exercise gave me the confidence. (P19)

4.4.1.5.4. Accessibility of the practitioners.

These practitioners were accessible to the participants and their loved ones.

My husband just went you know to see his brother. I didn’t go see the brother but he just said, “Okay. I will give you this homeopathy” and give you the tablets and all that. He said, “You try. You take this. It will dissolve.”(p10)

So I went to see “Prof SP”, who had a clinic in Bangi. But he also meets people behind private hospital AP in town [in a restaurant]. He said, if you want to see me in the Bangi clinic it will take too long. He has another clinic in Raub in another state. I went to see him, I gave him my results. He took two days to contact me again. He prepared the B-17 procedure.(P11)

Using scientific terms and logical thinking, using blood tests and giving more explanations about what controls the cancer made the women confident with the treatment by the alternative practitioners.

He said “I’m talking about cure”. When you leave the hospital bring your medical reports and come and see me, we can analyse. So I waited for my medical report, which took some time to get out. He told me, better get your report yourself. I will list all the whole body test needed, and the tumour marker test for breast, ovarian, lung and pancreas cancer. Then I went to the private lab. I spent RM 300 for the whole test. My tumour marker, I could read it myself since it has a reference in the report, Where-ever it was abnormal they would bold the letters. Surprisingly my breast was within the normal people range, but for pancreas it was very high. It means cancerous. He prepared the B-17 procedure. He gave a schedule of what I can and cannot eat. And within 19 days, I have to avoid handphones. Because of the radiation will affect the cancer cells, it will become active. This is what he explained, it was quite convincing[laughs]. After that stay away from tv at least 15 feet due to the radiation. Do not use cosmetics, cannot wear lipstick and anything. Then “pantang”[restrictions] or stay away from meat, chicken, especially chicken which have been injected with vaccine, meaning the normal chicken. But “kampong”[village bred] chicken is ok. That one is very dangerous. And within 19 days, you have to be a vegetarian. And so I became vegetarian, at that time my cholesterol was high, so I used olive oil, I didn’t take prawns and all that. I became a vegan, it was good. He asked me to eat what cancer cells don’t like. Like mushroom, broccoli, cauliflower and papaya and pineapple juices. Do everything yourself. The pineapple you have to drink every hour. But in the packages, there was pineapple, apricot, bitter apricot extracts and flaxseed. The cancer cells hate these. Then he said, do you know in this world there are three places with zero % cancer. Firstly, the Himalayas because they take apricots. The Eskimos and another place. After all that the B-17 was all about nutrition. (P11)

4.4.1.5.5 Sincerity of the practitioners

The fees were collected from the participants as a contribution and not payment. The perception of the participants is that the practitioners were sincere in their effort to cure them.

When I went to see the therapist I brought just flour. We only pay with what we can give in sincerity. For the first visit, he did the “operation”, he can check the blood then he would know what to do. He himself doesn’t know how much he will charge, his mouth would tell by itself. For me, my fidyah [compensation] was RM 1113 [~USD350]. I forget. He just speaks without knowing. He is a man from Terengganu. Even in hospital Terengganu the doctors there call him. My friend introduced me. I call him Din. We just try, who knows [it can be cured] God willing. (P9)

Alternative medicine provided many advantages namely psychological support, provided spiritual support, confidence in explanation of disease, accessibility of the practitioners who were sincere in their quest to cure and the value of having a choice. Alternative treatment remains as an underground concept. Participants took responsibility for their choices as it was not mainstream health care.

4.4.1.5.6 Alternative remains an underground healthcare concept especially after failure of alternative treatment

Although, realising alternative therapy was not very effective, some were very thankful for the benefits in calming, and other beneficial effects like lowering cholesterol level etc.

I am not angry at people [alternative therapists]. Because I feel like, at least, some contribution has been done to my body. At least, my cholesterol levels improved, and the tumour marker test too. At least part of what I imagine as my illness although not completely cured, part of it, was cured. It was proven by the blood test. He wasn’t talking nonsense. And he didn’t do the blood test. I went there independently. (P11)

Women, blamed themselves for the failure, took full responsibility for their mistakes in choosing the therapies. Some were more accepting of it. Some had even blamed themselves for the failure as they could not stick to the restrictions and instructions.

After seeing the Chinese physician. We[the patients] are surely very weak. If you hear of anything good[about the treatment], thinking [the cancer] can be cured, surely one will be happy. Why not I go and try? So then I tried. What the Chinese physician did [medical records revealed she had joss stick burns on both breasts]. It's not "convenient" for me to say. No need to say so much. I did the Chinese treatment for 2 months, half way through, he [the Chinese physician] said " It's not possible [to continue], he was not able to treat. At that time, it was more serious [wound had broke down]. You know...a person had a lot of hope in the beginning....then he [Chinese physician] said he can no longer treat. (P8)

I think I felt it was suitable for me. The one in Bukit Antarabangsa, a lot of people have used it. I met an older woman. After her surgery she had a recurrence in the spine. So she tried the treatment there. And she followed the food restrictions strictly. Alhamdulillah[thanks to Allah] it worked. For me, it was my mistake, I went against the restrictions. I believe I did it on to myself. Because initially it became dry, it wasn't weeping anymore. But after two days I tasted the chicken gravy. I felt the sting first and then it started weeping. I haven't gone back there in a while, since I was admitted to hospital. But I plan to go again this week, I want to do it again. Wash it with hot water. Pour over it and blot it. It was not painful. That was the mistake, it was dry before this. After eating the restricted food, it stung and wept. The dry spot became waterlogged. It was so difficult, sometime it was scary to look at the tumour. Sometimes, I was angry at myself, I was so stupid, as if I never had chicken before. As if I was so hungry. Serves me right, I was so sad. Maybe if I took great care, it would have healed to like normal. Most people became well. Whoever did the treatment, it would dry up. All was well and shrunk up..(P9-during her admission for hyponatremic coma and fits due to poor nutrition)

Some women were unhappy with the outcomes and expressed themselves accordingly. They felt cheated.

Of course, I thought it could be cancer. I thought I could use an alternative way. The homeopathy therapist gave good explanation; he gave us a feeling of hope towards his treatment that it could be cured. That's what he said, this

thing can be cured. I do feel angry, my husband too. Next time, if I had anymore problems, I will never go there again. (P12)

I told my sister, I was “played out” by the Chinese healer. (P8)

The Chinese healer who has no license but treats you successfully, gets a good name. If the treatment failed, then we the patients have to accept the responsibility, right? We, the sick people have to accept the wrong treatment. If his treatment is not good; you have no choice. (P8)

Some blamed their significant others for directing them towards those therapies but in the end took responsibility for it.

He couldn’t accept the fact that his wife had to go through that. I think that time he couldn’t but when I was diagnosed, he was broken. He feels very bad about it now. He should have sent me to the hospital earlier. The homeopathy couldn’t do [the job], alternative medicine could and cannot do anything. (P10)

Because the way they look at cancer, they don’t seem to understand it. They don’t seem to say “you must see the western doctor”, or provide mental support, or try and understand what cancer is all about. Whatever they provided were all the opposite things. They all used all those ‘weird’ things. It is not that I want to say bad things about my parents. Maybe I was not strong enough. If I was strong, maybe my cancer will not reach third stage because at that time, all my appointments with the doctors in the hospital were done up. I actually wanted to accept “western’ medicine. But my parents wanted me to see the Chinese healer. Maybe my parents don’t understand much about ‘western’ medicine. So, I went to see the Chinese healer. (P8)

Failing to obtain a cure through traditional treatment, participants were weary of going back to conventional hospitals due to fear of being scolded and ridiculed. The attitudes of doctors were a deterrent for seeking care.

I was seen by DrX. She became very angry, “your cancer has become more advanced, why did you come back?” I asked my husband before that, would the doctors be angry? He said just tolerate it, put on a deaf ear. We just ignored her, but when you are in pain you become very sensitive. (P3)

If you are well, you don’t know how it feels like. This doctor was angry.”So backward, didn’t go to hospital” she said. “How surprising, that educated people can be fooled by B-17” she said. I don’t think I was conned. At least on my part, the pain disappeared. When I came to hospital they scolded me. I am so sensitive, I felt slighted. People don’t understand unless they are sick too. I didn’t ask to be ill, if she wants to understand, she has to be ill first. If not, she won’t understand. I’m not asking that she gets sick. She thinks she is right. But I believe in God. God will show me, like now, I am here due to His will. I have tried all the other treatments. I have sought them and tried them. I didn’t choose hospital first due to individual reasons.(P11)

Alternative therapy can bring about side effects; in this study a strict vegetarian diet caused coma and fits due to low sodium intake in P9, the medical case notes revealed there were no other cause for the fits like brain metastases.

This is because I was too strict with my food. I didn’t eat chicken to the extent I didn’t have salt in my body. Even my brain didn’t get enough salt. (P9)

Besides side effects, alternative therapy may also be quite challenging for the participants.

He asked me to dip my feet in ice water. I couldn’t take the ice water. It was so painful, it was more painful than the pain in the breast.(P3)

I went there for cancer treatment. I bought the medications. It cost more than RM 1000. But I couldn’t eat it. It just wouldn’t go in. Then you have to take the juice, papaya and pineapple. He showed me how to take it. I only did it for a day. I couldn’t take it. My husband was angry. But I couldn’t take it, it was bitter. (P3)

There were doubts on authenticity of the practitioners. It appears the women questioned themselves, and felt other people were also questioning their choices.

Then I went to see him, I waited for him for an hour. Maybe longer, many were seeing him personally, but it wasn't in a room, it was just behind a petrol station behind the private hospital AP. He sat there. People were seeing him. It was at a mamak's shop (a foodstall). While having a drink. The way he sold his medication was like a con man, many people said that he was a con man. (P11)

This section highlighted the value of alternative treatment to the participants, namely psychological, spiritual, a clear and reasonable explanation of the disease provided by accessible and impressive practitioners. Significant others also trusted these therapies, but when resulting in negative effects, these women take full responsibility. Knowing the values placed by these participants, practitioners caring for them will need to provide the support shown by these alternative therapists. Conventional treatment leaves little support for women undergoing the rigours of cancer treatment.

4.4.1.5.7 Advise from women with advanced cancer

Some women in this study were regretful of their choice of treatment and delaying diagnosis or treatment. They gave advice to provide women with new breast symptoms the understanding of what they have experienced.

A 58 year-old homeschool teacher advised people recently diagnosed with cancer:

Learn from my mistakes. Uhuh. Mine is over, you know. So if it's someone else, I don't want them to go through what I have been through. (P10)

A 54 year-old housewife who delayed coming to hospital due to fear also gave similar advice:

As for me at this stage if I have anymore problems, I will just go to the hospital. Don't use "kampong" (village) treatment or homeopathy even if it seems like it is so great... don't go. That is my experience. If anyone asks me, I will help them, I will say go straight to hospital. I don't want them to become like me. (P12)

A young 35 year-old journalist advised:

Whenever I meet anyone with cancer, I will tell them to accept western treatment, do not go to those so-called Chinese physicians, who say they can cure you. They are all out to cheat people. (P8)

A lady who presented to the hospital with hyponatremic fits due to overzealous diet control said:

Just see the doctor. (P9)

A young 24 year old, advises people with lumps:

My advice would be to quickly see a doctor. Scary, but cancer is very dangerous. Like me, I may have come too late.(P15)

A lady living alone with a bachelor son, talks about why she has now decided to have treatment.

The doctor said to have chemo, I will follow what they say. In the past, I was scared, so scared. That was the problem, now I am in this condition [admitted for hyponatremic fits]. I just have to give in, surrender to the doctors.(P9)

4.4.1.5.8 The path to acceptance of hospital therapy

Having young children motivated one of the participants to have treatment although the prognosis was not good.

Then I said never mind. Let me carry on. Even though the prognosis was not good. Even though they said you came at the late stage. I said never mind I'll do whatever I can. So I went through the western treatment. Like I was instructed to do. Chemo, operation and radio. Moreover, I married late so my son is still very young. That chap was also a motivating factor for me. If I die who's going to take care of him and my husband also without me I don't think he can go forward. You know we are a closely knit family, just the three of us. So it's like we're dependent on each other. So he said you have to fight it. You have to fight it. Why not. I said ok. Whatever I have I'll fight it. So I went into this pray thing. I literally went into meditation, everyday praying and I had a very good friend who'll help me through the prayers. (P19)

As mentioned before despite rejecting hospital treatment at first doctors accepted the patients when they came back in trouble

After that, I went back to public hospital A. It was good that Prof X still accepted me back. (P8)

Pain that's all. Later....Prof X was very good, she found out that I did not go for follow up, she asked, " Why did you come so late? She did not scold me she asked, " Why wait until so serious then only come?"My stomach was bloated with 'water".(P7)

As mentioned previously, it was not easy for women to return, at times, the reception from treating doctors was not very welcoming.

4.4.2 Conventional health care barriers

In this section the physical and psychosocial barriers of conventional health care will be displayed. Making decisions on having alternative therapy or having conventional treatment depends very much to existing barriers in health care services. Main themes that emerged were:

Physical barriers

- Financial
 - Access
 - Timeliness

Barriers towards building a therapeutic relationship

- Patient provider communication to build rapport
- Trust
- Collaboration
- Clarity

4.4.2.1 Physical barriers

4.4.2.1.1 Financial barriers

A prominent barrier noted in the survey as well as the in-depth interviews of women with breast cancer, was the financial need. Financial issue emerged strongly in the interviews, displaying that the cost of treatment was expensive and were out of pocket expenses especially for the uninsured poor. The perception of needing treatment in private hospitals was seen in a middle aged single Chinese woman P4.

After the lump appeared, I thought, why did it hurt? And it was quite big; almost like the size of a small chicken egg. That's how I began to feel 'a bit' scared. I was thinking, that's the reason why I dared not go for surgery. Because private fees are very expensive. I was worried, people like me, not much savings, need to spend more for surgery. When old, unable to work, then problem with living expenses. Because of this, I did not think of surgery. (P4)

Competing use of funds, made them think of cost-effective measures. Rather than having a chance for cure, they want a guaranteed cure for effective use of their money, and this for P4 would mean by getting treated in a private facility.

If treated in a private hospital, if it can be cured, then it's alright. If not, then all money spent would go to waste. When I am old and can't work anymore, I still have family commitments. By then, no one will employ me. That's why I thought, no need to treat, save the money and let the family have a better life. (P4)

Having to burden family members became a big worry to this lady.

My medication very expensive for 28 tablets, does not last even for a month. Every month, the social welfare gave me a discount, but I still need to pay RM498.00 [about USD 150]. This RM 498.00 will increase their [siblings] burden. They are still paying for their house instalments; currently the cost of living has gone up. If they have to pay for my medications, I am afraid, it will become a problem. That's why I am worried, I am not worried about other things, I only worry about the money. (P4)

The financial impact of financing breast cancer treatment was massive especially in young women with young families with a sole breadwinner in the family.

He asked the doctor about the price. The doctor said the first 3 chemotherapy will be cheap and the next 3 chemotherapy will be expensive. It will cost about RM2000 ~USD800. My husband is the only one working, with no extra income, he asked the doctor whether the price can be reduced. The doctor said, let us do the first 3 chemotherapy and then we will see how. Three of my children are still studying. I have one baby too. We have to manage everything with one person's salary. We have no one to support us. My parents are old already. They cannot support me. (P14)

And in women with no social support, as seen in P9 who was separated from her husband, and was only supported by a young bachelor son.

Actually it's not difficult to see doctors, it's whether you want to or not. And of course it's worse when there is no money. (P9)

The women were also aware that government hospitals may provide cheaper medications and treatment.

The doctor said, “ Go to the government hospital.”I thought it should not be too expensive, better to go and see. (P8)

UMMC being a public hospital caters to government servants. Being a government pensioner was good in that the drugs were all paid for. However not all medications are covered by the government, and may incur out-of pocket expenses.

No.. I’m very lucky in the sense I’m a government servant... So it’s everything taken care of in the sense that I don’t have to pay like whatI see others are doing. I feel so sad for them.I’m very fortunate in that sense.(P17)

My husband is a retiree, but this medicine we still have to pay, [GCSF or immunity boosting medication]. We worry about the money as it wasn’t available on the weekend in this hospital, we had to go out and buy it. It was so expensive, it costRM 300(~USD 100). My husband’s pension is RM 300, if the medicine is in the hundreds, what are we going to eat. But he said he can manage, but it will take some time. He used to work as a driver with the local council. (P16)

Sometimes, good samaritans helped ease the financial burden.

About financial matters, the professor helps me a lot. There is a Dr. T, he is good. He helped me, I must not mention, but he helped me.(P7)

4.4.2.1.2. Access

The participants used multiple means of getting their loved ones to be seen by specialists. Through word of mouth, through phone calls and email too.

My daughter tried her very best to contact the professor through the internet where she got her email address. It was very nice of her to reply the e-mail. The professor allowed my daughter to bring me here, that's how I came to see her on Wednesday.(P17)

One woman P11 had already contact with the breast care nurse, and could access the hospital quickly when she needed help.

Once my son finished his exam in the morning, I said to my husband, I cannot take it anymore. I called the nurse. I took her number when she gave it to me when I was diagnosed last time. She told me, please call me if you run into any problems. So I called her and met her on the sixth floor.(P3)

Professor treats us very well. She is concerned about patients. She did say, " if anything important happens, can call me on the phone" she asked me to get admitted immediately. Earlier on, Prof X had told my daughter, if anything happens, we can get immediate admission.(P7)

4.4.2.1.3. Timeliness

Everything after that went on smoothly for me. There was no hitch and anything that I did my chemo then after that my op then after that now I'm doing my radiotherapy and things like that.(P17)

Access was easy, after the diagnosis for a woman who presented late due to lack of symptom recognition.

Once I knew it was cancer, the operation date was given. Within two weeks. It was closeby. It was easy. I had to wait two weeks, since I came late anyway. (P1)

With facilities that required these women to wait, receiving bad news were amplified.

Some patients mentioned the callousness of the interaction with a male doctor.

I waited so long, there wasn't enough doctors. We waited so long. He said, they didn't have enough doctors. We understand, but doctors also have to understand, we are cancer patients, it's not an easy thing for us to accept. He was a male doctor, even before I sat down, he said we are not sure what this is, we need to operate. He told me straight away. That's it, psychologically, everything went blank. (P3- her initial results was suspicious, and she required an open biopsy to confirm it))

At times, doctors in government hospitals recommended patients to get services from private hospitals to shorten the waiting time.

Will the cancer spread? He never say anything about it. He only asked me to take the medicine. He asked me to do an x-ray and take chemotherapy. But they will only do the chemotherapy in July. We asked them to do it early. But they said, if you go private, they can do it early. But it will be very expensive. (P14)

I am really grateful to professor, thanks to her. Then, professor said it was third stage. Then she said to try chemo. And after chemo, we can do surgery. The facilities in public hospital like the CT scan had a long appointment because there were so many patients. So, I went to a private hospital to have it done, because their facilities were complete. It was quite good to have the CT scan there. No headache.(P8)

Perception of being cared for was important to patients. They appreciated the effort when the doctor asked more beyond the routine questions. Participants were aware of time constraints that the doctors have and tried to help by not asking too many questions, to the detriment of being unsettled with some issues.

I feel that some doctors, I am afraid to ask them. I may 'trouble' them. Some doctors are very good, they will explain to you, but some doctors, we dare not ask because I can see they hardly speak. So.. I dare not ask. I feel that they may think we are troublesome people.(P4)

I don't have much opinion on this except that the doctors here are very caring, very good. But at times, not sure if it was because I was afraid to ask too much because when doctors treat patients, there should be a certain distance. Because I was afraid if I asked too much, the doctors would not like it. I was afraid many patients were waiting. If I asked too many questions, I would hold up the doctors' time. Yes, that's how I felt. So, I dared not ask too much. Usually after asking about the illness, when I took the written prescription, I then would not ask anymore. Once, Dr C spoke to me 'a bit' more. The rest seldom do that, they only asked how my illness was. I also did not ask if my illness had spread, when I was there, I also did not ask, also did not think of finding out. (P4)

Perception of doctor's time constraints and heavy workload impeded communication.

The doctors, they don't have much time. Next to each room, is full of patients. Sometimes they see two patients at a time. Just have a short consultation. What can I ask, I don't really understand it anyway. The doctor checks and says you are okay. That day I asked, about this pain I have around my axilla. The young Chinese doctor told me, aunty, the other day, during the operation they scrap, scrapped that area. Scrapped? I feel scared when I get the pain, but it's okay, it is healing. (P5)

4.4.2.2. Barriers to building a therapeutic relationship

4.4.2.2.1. Provider-patient communication

Health care providers were seen not to be able to communicate effectively with some patients. Three themes emerged: 1) Rapport: the mannerisms of the doctors were commented upon as rough in breaking bad news. The women also felt when they came late they were being laughed at and ridiculed behind their backs. 2) Trust: the confidence in their treating doctors diminished because of this. 3) Collaboration: at times, they described their doctors as their adversary rather than their ally in their fight

against cancer and lastly 4) Clarity: the women described contradicting information and recommendations from different health care providers resulted in more confusion.

4.4.2.2.2. Nature of results disclosure

The effect of results disclosure method, had ramifications where, women were usually disclosed the diagnosis and treatment options at the same sitting. Some women, were shocked and some accepting, the quality of disclosure was seen to affect treatment adherence. As mentioned before in the section on timeliness as a physical barrier, waiting for their results was described as a torture. Most diagnosis was disclosed within one week of biopsy. Open biopsies were longer taking 2 to 3 weeks.

At times, a hospital staff would contact them for some preparation for bad news.

Later the nurse in the surgery side, she spoke Cantonese or Mandarin, she called me and said, " can you please come over?" Afterwards, I came on with my nephew. At that time, I already thought that it must be 'bad news". I thought it must be bad news. But I still came. When I arrived, the report said it was cancer. The cancer was second stage. Already second stage in December 2007. (P8)

Some results were unexpected, and in young women, the doctors preferred to disclose the news to their parents as seen in P15.

Yes, it really didn't occur to me, it was three weeks. They called to tell me to bring my mother and father. I asked them why, he said there was some problem. I asked again, why? He said, nevermind, I will discuss this with your mother. My father had passed away. (P15)

Waiting for the results was torture and because the results clinic was on Friday, P5 jumped to conclusions quickly. Clinic staff also inadvertently added on to more stress. It also didn't help that they have to wait for so long.

Initially I didn't want to think about it. They told me to come again. I thought I would just make do. Then they gave me a Friday date. Then the nurses there said Friday appointments would mean it's a cancer case. I overheard, I thought to myself if my appointment is on Friday then will just have to wait to be diagnosed. And on Friday, my friends keep texting me, I didn't answer. I waited till it was 4 pm before I saw the doctor. (P5)

4.4.2.2.3 Culturally appropriate health care

One patient was very sensitive to the different ethnicities of the treating doctors, and noted the callous manner that they communicated with her.

But the second time I went, it was a different doctor, a Chinese one, then an Indian one. The Indian doctor scolded me, he said I did not take care of my health. He said I breastfed for too long until my breast became red, I felt very pressured. That's why I ran away. (P2)

One of the participants observed the medical students getting a history and noticed how they communicated to her, the medical students may not be aware, that culturally sensitive ways of approaching the patients may yield more results.

Yesterday I met some medical students. First the lecturer came to introduce the two students, one was a Malay the other an Indian. I told them not to ask any sensitive questions. The Indian one just kept quiet. But the Malay one was good, he told me to remember God, and that, what is happening now is ordained by Him. This is borrowed time before the permanent hereafter. The Malay one could dig out our family secrets, even my husband's. The Indian one didn't know what to say, because he didn't know how to ask. (P2)

Language barrier was a major problem, the commoner race inflicted by cancer were the Chinese, but health providers in a government hospital were of a different race and not able to converse in Chinese.

In the beginning, most of them [hospital personnel] spoke to me in English. Later on, they knew I did not know how to speak English. That's why I want my younger sister to accompany me. When I meet with Malay or Indian doctors, "the sister" would help me interpret Bahasa Malaysia. I can speak a little Malay and understand a little English. But I cannot speak fluently. Like the common words, I can understand. (P4)

Explanation by doctors was at time graphic and not acceptable to the patient.

Furthermore the patient could not ask about what worried her the most.

The doctor told me, I was shocked by the way he said it. The doctor explained how he will remove the breast. Of course doctors have treated thousands of women with breast cancer. But I was shocked. He showed how it was done with his handphone. I was thinking, "Oh, no! How can this happen to me?" He showed how he made the incision. He showed how it was done to his other patients. I asked what if, we don't remove it. He said, no that cannot be done. It would spread to the skin. So I kept quiet, I couldn't understand why other people didn't need to remove all. In the end I understood. But at that time I tried to think about it by myself. I asked my friends, they kept telling me to be safe, it's best to remove. (P5)

4.4.3. Some women do not use alternative treatment

Although there is evidence of health pluralism in this study, eight participants did not use alternative medicine due to an abhorrent due to personal experiences, trust and heavy reliance on conventional treatment, religious beliefs and lack of finances.

There are Malay shamans. But no, I don't go to them. It is shiriy (polytheism). It is a major sin. You know, why should we do it. "batin" [magic] treatment, I don't believe, I believe in Allah. (P1)

No, I didn't think of seeking treatment elsewhere. Because they told me Professor X is (a breast specialist). Whatever she said, I just followed. (P13)

No, I did not see any Chinese physician. Nothing at all (no other treatment)...I only went to the hospital. (P7)

My children did ask, mom don't you want to try other treatments? They have friends offering to pay for it. I said no thank you. I didn't want to travel to Johor. It was too far. They offered "kampong" (village) treatment. (P1)

Some were alarmed with the fatal outcomes due to alternative therapy. Three women candidly revealed these points. A grandmother, teacher and a nurse, but they came late due to poor symptom recognition and due to the aggressive biology of the tumour.

For me, things like this if it is good, we listen, but in the end we have to endure the pain ourselves. No way I will do it [alternative medicine]. If you die then it is of no use. Many people use alternative treatment. Just yesterday I met a cousin at a wedding. Her lady boss from one of the major banks in town lost her voice and was so sick. She took alternative treatment and the disease [cancer] became bad. It was too late. (P5)

No I didn't do any other treatment. I did everything quickly, ultrasound, operation within 3 weeks. I didn't delay, since we know it's beneficial. I removed the breast, had chemotherapy and radiotherapy, hoping to kill all of it. God willing, we will

live long. I had a friend whose relative had cancer. The lady was a nurse, I haven't seen her in a long time. I heard she died of breast cancer. I asked my friend why? She said she didn't go to the hospital, she chose traditional treatment and she "went" very quickly. (P6)

One of my friends had "Malay treatment" she had passed away. Young lady, she went to Kedah, Kelantan. My nephew tells me he wants to bring me. I said no, I had my treatment. Better not go. (P1)

4.4.4. Section summary

- Ten women in the study used other forms of treatment besides conventional treatment. The types of therapies used include homeopathy, direct selling nutritional products, kampong (village) medicine, massage, prayers, and herbal Chinese medicine and other types of Chinese treatment.
- Alternative therapy was found to be used at any stage of the breast cancer journey, namely at recognition of symptoms, after seeing a health provider, after a diagnosis, even after completion of treatment.
- Factors that triggered the use of alternative therapy in these women were strong recommendations from significant others where participants describe this as a directive that may cause friction in relationships if they did not follow the recommendations. Husbands, sisters and parents were seen as the significant others. Autonomous decisions were also made.
- The use of alternative medicine was triggered by need to relief physical, spiritual and emotional pain as well as loss aversion.

- Some women did not use alternative medicine due to past experiences of fatal outcomes associated with its use, trust in conventional treatment, their religious beliefs and lack of finances.
- Barriers to conventional health care include financial factors, poor development of the therapeutic relationship and culturally insensitive provision of care.

4.5 The stages of delay in UMMC

4.5.1 Conceptualising the meaning of delay in presentation

The finding in this study describes not only the phenomenon of advanced presentation of the disease, but the reasons why they present at late stages. The themes that emerged can be seen in two perspectives: the trajectory or chronology of the events and the explanation for the delay. This section will classify delay according to the stages of the breast cancer journey.

4.5.2 Stages of delay

Analysis of the interviews in this study and reviewing the case notes revealed eight important stages of when women delay (Fig. 6.1 page 316). The definitions of each stage will be displayed at each of the sections below.

- i. Appraisal delay
- ii. Disclosure delay
- iii. Illness delay
- iv. Behavioural/ Referral delay
- v. Scheduling delay
- vi. Diagnostic delay
- vii. Treatment decision delay
- viii. Treatment delay

The stakeholders involved in affecting delays in an individual's breast cancer journey are the patient and the health system. In this case we would term these as patient delay and system delay.

Patient delay was found at each stage of the breast cancer journey. System delays influenced appraisal delay, illness delay, diagnostic delay, treatment decision delay and treatment delay. For instance, public health services like health education influenced appraisal delay. Primary care and first line health care providers influenced

illness delay, hospital systems affected diagnostic delays, treatment decision delays and treatment delays.

The evidence will be displayed according to the stages of delay. Due to the complexity of human behaviour, there are overlaps in each of the women. For example patient 18 and 19 had poor symptom recognition but also delayed seeking a diagnosis, in contrast some women only delayed at one stage ie. Patient 2 and 3 did not delay seeking a diagnosis but delayed having treatment.

4.5.2.1 Appraisal delay

4.5.2.1.1 Definition

Appraisal delay occurs when there is a failure to recognise a bodily sensation and labeling it as a serious condition. Eleven patients (P1,3,6,7,8,9,13,14,16, 18 and 19) were seen to be involved in appraisal delay.

Themes that emerged with regards to labeling a breast symptom as an illness were displayed in [Section 4.6](#) which explains the reason why they delayed at the appraisal delay stage. The themes were: a) poor symptom knowledge (Chapter 4.6.1.1.); b) poor knowledge of the disease and its outcomes (Chapter 4.6.1.2 and .3); c) role of coping mechanisms (Chapter 4.6.4.1.) And lastly d) role of significant others in appraising a breast symptom (Chapter 4.6.5.1.1.). This process is governed by knowledge of the disease and its outcomes and the need to disclose and obtain social support and sanctioning or validating the presence of the breast symptom. These factors are governed by the social, cultural and affective context. Coping of the affective responses

when she discovers the bodily sensation influences her coping after she labels the symptom as threatening or not.

4.5.2.2 Disclosure delay

4.5.2.2.1. Definition

Disclosure delay occurred due to poor recognition of symptoms. Disclosure delay also occurred when there is a failure to disclose their symptoms when there was a suspicion of cancer. Lastly it occurred when there was social isolation.

Disclosure was seen as an important conduit to receiving support, we have shown the role in symptom appraisal, but disclosure itself is important in obtaining help.

Table 4.23 Percent distribution in first person symptoms disclosed

First person disclosed	N	%
Spouse	11	57.9
Mother	1	5.3
Sister	2	10.5
Daughter	1	5.3
General practitioner	1	5.3
No one	3	15.8

Eleven women chose to tell their spouses. Four told family members that were female.

One had gone to her doctor's (Table 4.23).

I told my husband. He asked me to go for check-up. Day by day, I delayed, one day dragged on to the next.(P13)

Some women were silently hiding their symptoms from others. Four women (P1, P4, P9 and P17) hid symptoms until it became too obvious to hide. In the survey, only three reported not disclosing to others. It shows the superiority of in-depth interviews to tease out these issues.

4.5.2.2.2. Poor symptom recognition

Some had opportunities to confide, but didn't because they did not recognize the symptoms. Some had good social support, but because they did not tell, they were not able to utilize the support.

It can be seen, my breast on this side. I didn't tell my grandchildren. But they saw it, they forced me to come to hospital. I didn't think it was cancer. My granddaughter accidentally brushed against it, she asked why is your breast hard? It cannot be left like that..(P1)

4.5.2.2.3. Stigma

Non-disclosure was sometimes done to protect loved ones from the stigma of breast cancer that would impair receiving marriage proposals. As a single parent P17 felt responsible on ensuring the happiness of her children.

So I just kept quiet, not telling anyone, I carried on with life, doing all the house work. The reason was that I didn't want them to know. I would be hospitalized and would not gather marriage proposal that comes for my daughters. I will be the one who will be keeping them back. They will just put me first and then they will not go through with the marriage proposals. If I don't tell them, then that will let them go on with their life. I'm afraid that someone would leak it out. I just kept it to myself. Two of my sisters-in-laws were going through this. The recent one is a nurse, she had a lump and I visited her in another hospital but I didn't tell her what I had. At that time I did have this but I didn't tell her. It was small (the lump). I was able to rub and it would subside by itself. Everyone was talking about cancer but I just kept quiet and listened to what they were saying. Yes... It is frightening to know the truth in fact.(P17)

4.5.2.2.4. Non-disclosure and social isolation.

The need to have another person insisting one to seek diagnosis was also seen in the data. Lack of disclosure occurred and many had symptoms discovered when they were

truly symptomatic with a bleeding tumour. Reasons for not disclosing include no social support, and the impact on significant others.

No one knew about the lump, my husband did not know, we slept apart. When we separated, this thing grew little by little. When I was happy there was no lump but when the pressure came on, it begun. You know what my husband did to me. I believe in hospital treatment, but I didn't come early because no one could send me. No one, my children are married and stay on their own. I am staying with my son, just the two of us. But I didn't ask him. I was scared to go to hospital, I don't know how to say it but I was scared. Now that it has progressed, I just give in. At that time I didn't go because I had no one to count on. (P9)

Being single and poor, and having poor financial resources brought a woman to isolate herself so that she does not impact on her family members' lives.

At that time, I thought of not going to hospital. Later, I told my colleagues, they all advised me to seek treatment. I told one or two of my colleagues. But I waited till 19th Nov 2007, the lump became worse. When I showered, it would bleed...big drops of blood would flow. I told my sister's children who then took me to the doctor immediately. My younger sister's son, was the first in the family to know. (P4)

Disclosure is an important factor of obtaining support. With this experience p17 advised to disclose to those who love and care for them.

I'm the wrong person to ask me about what one should do with a lump. My children told me "you are fond of hiding things". I should tell the truth right from the beginning, don't hide anything. That was the biggest mistake I made, I regretted doing that. (P17)

My grandchildren said, if you went earlier grandma, it would be easier. So I kept quiet, I know I was wrong. I don't like to fight and confront my family, we never fight. (P1)

4.5.2.2.5. Role of significant others- sanctioning

When a woman had gained enough confidence to seek help, an important ingredient is to have support in doing so. The role of significant others are very important at this stage. Sanctioning and providing instrumental support was important in ensuring that participants seek help to navigate to a diagnostic centre. Sanctioning was the validation of the symptoms that they have and at times is permission by significant others ie.

Husbands, parents to seek medical help.

Till that it came to that stage and still he says, "No. You'll be okay. You'll be okay." On one side, I want to obey my husband. My sister said, "Don't tell him. Just go to the hospital and do it quietly." "Are you afraid of money?" I said, "no." They were all concerned for me including my church members, some were very close friends. Go quietly and do it. I know my husband means well for me, but still I didn't want to disobey him. It came to a stage where I couldn't sleep.(P10)

Despite other family members trying to advise women to go for treatment, the role as a subservient wife who does not go against her husband's word prevailed.

My younger sister used to scold me, "Why are you doing this?! You have to go and see the doctor." After that they stopped asking me because they know without my husband's permission, i would not go. It's not that my husband is dominating or controlling. No. He's not. But it's just if I do it, I may hurt him. I didn't want to hurt him. (P10)

In contrast, P13 who delayed the visit to the doctors blamed her husband for not being more forceful and lending her confidence to act, this is displayed in the self-efficacy section 4.6.4.1.4.

4.5.2.3. Illness delay

4.5.2.3.1. Definition

Illness delay occurred when the participant failed to make an appointment with a diagnostic centre due to poor symptom recognition, sanctioning by significant others and having competing interests like work. Illness delay also occurred due to the failure of the primary care health provider to recognize symptoms and signs of cancer.

4.5.2.3.2. Competing interests

Competing interests of work also played a role in impeding seeking medical help.

I was also very busy with work and coupled with not being so brave to see the doctor. That's how it kept on delaying. (P13)

I continued being busy with work until I could not stand anymore when it was so painful. I went to see a doctor. When it was big only then I saw a doctor. It was black in colour. (P18)

Some were busy with their lives and also the stigma of cancer may affect one's source of income.

I have a business selling noodles, it's out in the internet and also the newspaper. If people know I have cancer nobody will come and eat. I was afraid of that. (P18)

4.5.2.3.3. Fear of diagnosis and the lure of alternative treatment

One of the triggering factors to seek alternative treatment occurs in the pre-diagnostic period. I have discussed this in [Section 4.4.1.2.](#)

4.5.2.3.4. Navigation of health system

Some women, went to see a primary care doctor, whether a general practitioner, or other primary health care professionals eg. midwives and primary health care medical officers involved in antenatal care

Well, see a doctor of course. (P15)

Then I went to our company's clinic to check. He [the doctor] felt it (the breast lump) and told me it must be something not good. He also could not ascertain whether it was 'that type' or cancer. He wrote a referral and asked me to go to UMMC for check-up. (P13)

And I just went to a GP and she told me to go and have a checkup. (P10)

P3 went straight away to a diagnostic cancer facility in Kuala Lumpur managed by radiologists.

Since Monday was a holiday, I immediately went to the National Cancer Society radiology facility in Kuala Lumpur the next day[when I discovered the lump]. (P3)

4.5.2.4. Referral delay

Referral systems were seen to be in place with health centres referring to surgical outpatient services, primary care physicians within the same hospital as well as cross hospital referrals.

I went to the primary care clinic first in UMMC, they told me to go to the surgical clinic for an appointment. (P16)

4.5.2.4.1. Poor recognition of signs of breast cancer by health provider

Pitfalls of general practice and first liners lack of awareness of breast cancer sign and symptoms. at times doctors and midwives were quick to diagnose normalcy in young and pregnant women.

The doctor in the private clinic told me the lump was normal, nothing to worry about. (P15)

Breast lumps were not adequately assessed during pregnancy and in breastfeeding mothers. A 24 year old woman in this study had presented early to a private clinic for a breast lump, but was erroneously told to it was a sign of normal breast changes.

Women do not get opportunities to have clinical breast examination because it is not routinely practiced, even in pregnancy.

After I delivered, the obstetrician never checked my breasts, since I already have so many children. Only when we are pregnant with the eldest, they will check in case we have problems with breast feeding. I lost one pregnancy, but quickly after that, I got pregnant again within two months. (P11)

Nurses who perform post-delivery care also missed the opportunity to refer P14 to a diagnostic facility.

I found an 'abscess' in my breast when I was 7 months pregnant. When I was about to deliver, my breast started to swell. I thought it might be because of milk. After delivery, the nurse came to the house, she also said it was because of the milk. (P14)

General practitioners also missed the opportunity.

I delivered my baby I went to one of the clinics in Sentosa, Klang. They didn't say that it was cancer. They also said it was caused by milk accumulation and gave me antibiotic for that. After taking the antibiotic, it remained the same. Then I went to Clinic X in Sungai Way. Immediately after he saw my breast, he put in needle to aspirate abscess but he can't do that because my breast was very hard. Straight away he referred me to this hospital. (P14)

Doctors in general practice found it uncomfortable to examine women with breast problems.

The breast was black and painful. I went to see the doctor that night itself when it became painful. The doctor did not want to touch it. (P17)

Some GPs also provide initial investigations for the patients.

I saw a doctor in Clinic R. The doctor said to do “ultra sound” the next day. I said it was of no use (to do the US). The next day was Tuesday. (P8)

In terms of seeking definitive diagnosis for their breast complaint, P4,P11,P13,P15 and 16 had an overlap of illness delay and referral delay.

4.5.2.4.2. Self-imposed referral delay

P10 had a pure self-imposed referral delay. Although she was referred for further diagnostic work-up, but she did not go.

Somewhere in June, I felt a lump there and the same thoughts came back “No, we are not going to be affected. Everything is fine with you. It’s just a normal cyst. And I just went to a GP and she told me to go for a check-up. (P10)

4.5.2.5. Scheduling delay

4.5.2.5.1. Definition:

Scheduling delay occurred due to failure to obtain an appointment in the diagnostic centres within the conventional health system. Scheduling of clinic appointments

ranged from immediate, a week, two weeks and sometimes a month. Some diagnostic centres provided walk in services.

In a public health system, women with symptoms are seen in health clinics then referred to surgical outpatient clinics or breast clinics for a diagnosis.

Ability to know where to seek help was important, navigating and knowing what facilities were available was imperative.

First, I went to the health centre. I had to wait one month for a date. (P2)

Sometimes, even getting referred, P13 had to wait for her employers to approve the referral.

The doctor gave me the referral letter. But I was not referred to UMMC. I didn't know where to go, so I came to UMMC. It's much nearer to my home. When we get the letter, we need to wait for the company to approve, then only we can come to UMMC. (P13)

There was information that private general practitioners had arrangements with private surgical clinics when a woman needs to be referred due to a breast complaint.

I asked the doctor to write me a referral letter to come here. He said it was difficult, he did not want to refer to UMMC. He wanted to refer to a private hospital. I said that I didn't want that. My sister works in UMMC, I showed him my sister's card. The private hospital, I have to pay money, he didn't tell me which one. I said I don't know how to speak in Malay or English, I bluffed the Sikh doctor. (P17)

4.5.2.4.2. Navigation to a diagnostic facility

Navigating to a diagnostic centre in these interviews showed the varying approaches that women take. Navigators included family members, friends and GPs who know which clinics to direct them to.

4.5.2.4.2.1. Personal contact via family member or close friend

The heavy reliance on personal communication and word of mouth to get to a diagnostic centre showed a lack in information available to the public to safely get to a surgical or breast clinic in a timely manner.

Family members again helped navigate participants to diagnostic services.

My younger sister called from her office and told me to see the professor. She drove me to the clinic at 5pm. Prof X asked some questions and examined me. She officially said it was 3rd stage breast cancer; she said it was serious. She wrote her telephone number and wrote "urgent" on the envelope and the appointment card. She said if I was unable to find her, call her on her phone.(P8)

Again, through personal contact a referral was made.

Now my husband feels bad. Finally he said to go to hospital, my ex-student who now works in the ministry of health. She wrote me a referral letter. she said, you just go to UH. She said. "They have the best doctors there. She said, no need to go to private hospitals. The professor is there. So she gave me a letter and that's how I came to this hospital. University Hospital is very good. Because they are very thorough you know. The minute you come in, they check you, come to diagnose, to do your biopsy. It's immediate you know. (P10)

Women preferred to go where they had a family member in the hospital. They seem to perceive they need to have someone navigate them in those hospitals.

My sister told my mother, that I need to go for surgery. It was getting to a dangerous stage. In the end, my mother agreed to let me go, my mother was quite insistent, in the end I accepted it. I prayed and I accepted this test from God. My sister admitted me to Hospital T in another state.. My sister brought me to see a specialist, CTscan and biopsy was done, he told me it needs to come out. My sister works as a nurse there.(P15)

My sister will take me to see the professor. My sister helped me the whole day. It was quite easy. Help cut the queue.(P17)

4.5.2.4.2.2. Health care providers as navigators

Knowledge of the panel doctor of reputable doctors in public hospitals helped P2 to gain confidence in the public hospital.

So I came here. My panel doctor said, go see the professor. She is a very good doctor. His wife said. So I did, and I said I wanted to be under her care. She quickly did the biopsy and in four days I got the results. It was confirmed.(P2)

Logistics played a role on where women decided to seek a diagnosis. And GPs are good navigators if they know the details of where are the breast clinics.

I said, I would like a letter to go to UMMC. My house is close by. My GP told me the clinic is only on Wednesdays. (P3)

Unlike P3, whose GP knew the breast clinic's walk-in policy. Waiting for an appointment can be long in a public hospital when appointments were made at the counter system.

I needed to get an appointment, I waited two weeks. Then only I managed to go to the surgical clinic.(P16)

Referrals from obstetricians and coordination to a diagnostic centre were important to obtain a timely diagnosis. At this stage, women still counted on their significant others to sanction the visit. This is not just seen in diagnostic delay but illness delay and symptom appraisal delay.

I was about 7 months pregnant, it was 4 months since I found the lump. I told the doctor, the doctor measured the lump. At that time I still did not know what it was, he only helped measure it. He then wrote a letter and asked to go and see another doctor. I discussed with my elder sister, then I was almost 9 months pregnant, whether to go for check-up. The doctor there said it could be cancer. He asked me to go to the surgical clinic. They 'aspirated' the lump and I got the report a week later.(P8)

4.5.2.6. Diagnostic delay

4.5.2.6.1. Definition

Diagnostic delay occurred when the diagnostic process in a diagnostic centre was delayed either by patients or the health system. In contrast, illness delay occurred even before entering a diagnostic facility.

The diagnostic process includes:- i-visiting the diagnostic centre, ii- adhering to diagnostic investigations, iii- scheduling and undergoing investigations.

Some women sought diagnostic services directly without consulting any primary care health provider. Some women went straight to a specialist clinic, this is also through a sister who had seen the specialist for a breast symptom in the past.

No. I did not go and see (other doctor) during that 6 months. When it became bigger, then I became quite anxious, so I went to clinic to see the doctor. I was very scared. Very scared. For once, very scared. It was quite big actually. The professor said it was about 6cm big. That's why she said must 'do' chemo immediately. She did not say much, and immediately made arrangements. She said, "do not delay anymore." (P13)

At times, the triple assessment was not performed, possibly because of the unexpectedness of cancer in a young 24 year old. In public health clinics with no facilities for operations, patients have to be referred to another hospital. P15 had to go to two clinics: a GP and a health centre before getting a definitive diagnostic procedure.

After I went to the private clinic, I went to a government clinic. They told me I needed an operation. I felt that I could not believe it. But the doctor reassured me that it was nothing, they didn't suspect it was cancer. They didn't do the biopsy. They sent me to another district hospital for the operation. (P15)

4.5.2.6.2. Timeliness in diagnostic services in public hospitals

Although, in some women there was no delay in diagnosis, some women experienced delay in appointments for imaging.

In hospital X, they said it was urgent, but I got the ultrasound appointment in 2 weeks. (P2)

In the case of P15 she found out about her biopsy results after two months.

When I did an Xray, they told there was nothing there, so there was nothing. After a month it got bigger as large as a 20 sen coin. I went again to the hospital, they told me I had a breast swelling in the breast. They said, they have to operate because it was getting bigger. After that it grew larger, then I had an operation in a government hospital in another state. I had the operation in June and in August it was confirmed I had breast cancer. (P15)

The perception is that public hospitals did not produce good service, and that one needed to go to private hospitals to be guaranteed a cure. This was displayed in chapter 4, section 4.4.2.1 on physical barriers towards conventional treatment).

Some were surprised public hospitals were quite orderly despite the long waiting hours.

I feel that the service here is not bad. Not as bad as I used to think. Many people also said, going to UMMC? Then you have to wait, all said that. Because they know, we have to wait, must wait when taking medicine, must wait when seeing doctor, even paying money, we have to wait. That's what people said. But coming here, it did not feel like what I used to think. Still quite good, it's quite orderly. (P13)

Patient delay occurred at this stage when they defaulted to follow-through in the diagnostic process. P12 did not understand why the doctor told her that a mastectomy was needed only after a mammogram and ultrasound. The fear of surgery and chemotherapy drove her away to alternative medicine. But she later came back for a biopsy.

I went to see a specialist clinic in Hospital X. I did that first even before the homeopathy. He told me many things, need to do biopsy, chemotherapy. So I became scared. The he said must remove all [breast]. At that time I only had a mammogram and an ultrasound done. That's when I went away and did homeopathy. But before I came here, I went again to hospital X [after finding out homeopathy did not work]. That's when they did the biopsy. (P12)

In contrast, public hospitals can provide timely diagnosis as seen in this interview. P13 talked about public perception of getting a diagnosis in a public hospital and how surprised she was when she was proven wrong.

I have known of many cases where you go to a hospital and they prolong and delay it. The professor here was very good in the sense, she gave me her hand phone number, she said, "you can call me and find out." (P13)

4.5.2.6.3. One stop clinic in a public hospital

In a public hospital, providing urgent care for breast complaints can be daunting, with patients waiting the whole day for investigations. As P5 observes, she was exhausted as well as the radiologist. The triple assessment was done quickly and diagnosis disclosed promptly.

All except one participant did not have a needle biopsy. Two had an open biopsy to come to a diagnosis.

From the family clinic, I was sent to the breast clinic, I was there at 7 am, and spent the whole day there, I only got the mammogram at 2 pm. The ultrasound was close to 5 pm. This was because they asked for urgent investigations. The poor Sikh lady doctor, she had to do it many times. I was second last. At 5 pm I was still there. The poor doctor. At that time, I couldn't think, I also didn't ask. When they asked me how long I had it, I couldn't answer, since I only noticed it because of the pain. (P5)

I came to UMMC for check-up. I had two types, a mammogram and an ultrasound. After doing that, we confirmed what the type of cancer was. The doctor put in a needle and aspirated. (P13)

Disclosing the news was done in a busy clinic.

Doctor here told me that it is cancer. They took some tissues from the swollen part and send it for a test. Yes. They used something like an injection needle. They asked me to come back after one week. They asked me to come to check the biopsy results. At first they said that they haven't got the report. My husband asked them to check. They checked in computer and the doctor confirmed that it was cancer. (P14)

4.5.2.6.4. Patients' experiences in obtaining a diagnosis

4.5.2.6.4.1. Patient's discomfort

The patients complained of pain after the biopsy, and was not given pain killers after the biopsy. Biopsy of the breast is considered a minor procedure and rarely pain killers are given. It is possible that these women have tumours that are large and already causing pain, which was further increased after the biopsy.

The biopsy was a very painful process. That whole night I couldn't sleep and two days later when I called, they said yes, you have [cancer]. It was quite big, not sure but about 9 or 13 cm. They were thorough. Immediately they put me on chemotherapy and radiation. Now I am here. That's how it all happened. (P10)

P16 also attributed her back pain to the biopsy, this could further perpetuate the myth of biopsies within the community and the fear of having them.

After the biopsy there was pain. He did not inject first [local anesthetic]. He just poked at it. After that my daughter bought Celebrex. I ate two capsules. Later on the chemotherapy doctors told me, asthmatics can't take Celebrex? But it was so painful, the doctor did not provide any painkillers. I lost two kilos due to the severe pain. I just lay at home in pain. But the one they did here [in UMMC] was not painful, because they gave the injection first [local anesthetic]. But I was depressed, I couldn't get out of bed. Severe back pain, it was all over. (P16)

Yes, they aspirated something out. Oh god! It was scary. I cried. It was done in the ward. They poked about five times. Even with local anesthetic it was

painful. Oh god! I cannot describe it. The doctor told me it was cancer. He asked to do the operation where I need to remove one side.(P9)

P16 had a tumour that was hard or schirrous and cells could not be aspirated. Other forms of biopsy like an incisional biopsy was done, but the results took longer.

My daughter took me to see the surgeon. The surgeon said, “It cannot be operated, need to inject chemo first!”. They were not able to sample [the affected breast]. The needle could not ‘suck’ any ‘juice’ from the breast cancer. In the end, they cut my skin for testing. I waited for the results in about two weeks.(P16)

I came here straight away [I didn’t seek second opinion]. (P14)

4.5.2.6.4.2. Patient-provider communication

Issues of communication have been alluded earlier in [Section 4.4.2.1](#). P3 defaulted having surgery after she reported an inconclusive biopsy and when medical records were traced she actually had ductal carcinoma in-situ and was offered breast conserving surgery. However she was told that it was not cancer and she needed an operation- lack of clarity in the information undermined the patient’s trust in the health system.

4.5.2.6.5. Emergency presentations

At times, women did not electively go to diagnostic services, they were admitted in an emergency

I lived alone, maybe would be different if I had a friend, a husband. When you are alone there is no one to help. I just did the massage, but in the end it broke through. I was carrying a kettle when it just broke through and bled, the blood just dripped, but I continued to lift the kettle and pour, blood spurted out and I fainted, thank goodness my son just got home from work. He brought me straight to hospital. He didn’t know, nobody knew. Only the one who massaged me knew. (P9)

Even though we are educated and sometimes we make the biggest mistake in life for not telling.. Earlier. So.. One day when I was watching tv and just... It happened and my blood suddenly felt sticking to my skin so I looked down and I saw, blood on my breast and I slowly went in and did my own dressing. For about a week, I just kept quiet and then. My daughter discovered me out of breath, she cornered me and asked me actually what is wrong with you? I said nothing then she said you tell me the truth. She started screaming [when she saw the tumour]. They all took it very badly. They immediately took me to a hospital nearby to do a test. The main reason is because I wanted them to settle down [get married] ... but I don't want to trouble them ... be a burden to anybody... hoping some miracle will happen that I'll be cured or something will happen that... it won't be known to others . Just like that I will go off [die] or when it burst it will just slowly dry up. I mean I just didn't know, that it'll be later [slowly progressing] if I didn't tell... I'm fortunate I was caught by my [daughter] if she didn't catch me at that period of time, I wouldn't have told her. I would have just carried on I think. (P 17)

Family member caught her with severe signs of a bleeding tumour and she was brought to medical attention almost immediately.

So when this was second, the youngest one came in, to see what's wrong and she saw and they all took it very badly. They immediately took me to a hospital that is in Seremban to do a test. Immediately. In about half an hour. Once they knew that I had this, they didn't wait. They just took me straight to Columbia hospital to do biopsy and there the doctor diagnosed it. He did the biopsy and immediately x-ray and he told me... So I have cancer. (P17)

I did not think of surgery. Waited till later, the lump became worse. When I showered, it would bleed...big drops of blood would flow. I told my sister's children who then took me to the doctor immediately.(P4)

At times, in advanced breast cancer, biopsy results were not necessary to start treatment.

He confirmed that I'm having cancer. He said that he can't do anything for the moment. He said that the swelling is very big. Then, one lady doctor came. She said that I'm still young and asked them to send me here. She is the one who made all the preparation for me to come here in oncology. After came here, they asked me to take chemotherapy on the next week itself. Since I'm young, they don't want to wait and asked me to do chemo immediately. (P14)

4.5.2.7. Treatment decision delay (TDD)

4.5.2.7.1. Definition

TDD occurred when treatment recommendations were not adhered to.

Patient delay played a large role, but health systems influenced responses of the participants, thus making it a factor towards TDD.

4.5.2.7.2. Delayed decisions

Seven women in this study delayed at the treatment decision stage (P2,3,8,9,11,12 and 15). P2 delayed having surgery after neoadjuvant chemotherapy.

I came when it was big. I did a biopsy and had chemotherapy. It was around 5 cm. After chemotherapy it was good, the lump became smaller. But after that I didn't go for the surgery, it swelled up again. When I was going to sign the consent form, I asked the doctor if I could partially remove the breast. (P2)

Symptoms that bring them back towards receiving conventional treatment were usually severe signs of distress. Pain was an important sign that triggered women to seek help.

Then I had the worst headache. Until I was bent over with pain. The oncologist told me it made me not able to balance, she showed me it was at the back of my head. (P2)

I started having severe pain when my son was going for exams. It was bad, until I could not sleep. It was piercing at the breast. Later on after the massage, the skin became red. It became big and I walked leaning to one side. In the end my husband allowed me to go to hospital as he couldn't take it. We were suffering. From being fat to really thin, both of us lost so much weight. He was worried. At night was so difficult as I couldn't sleep. I keep waking up due to the pain. It was so bad, really bad. I try not to remember it. (P3)

After delivery of her baby, P8 was influenced by her parents to have alternative treatment instead of chemotherapy.

I accepted to have chemotherapy and surgery after delivering my baby. Everything was arranged (the chemo and surgery). They (the parents) then took me to see the Chinese physician. (P8)

P9 had no social support from her family and also tried alternative treatment from her few friends that supported her. P9 was admitted the second time for hyponatremic seizures, the first admission was for bleeding tumour, for which she did not follow through with the doctor's recommendations.

If I didn't faint, maybe someone will still bring me. But because I was alone, nobody can bring me to hospital. I was also afraid, the fear was still there. But I have no regrets. But this time I have to listen to the doctor, whilst doing village medicine, I must take the doctor's medicine. It's becoming dangerous.(P9)

For P9, she had no choice in that she did not have any social support at all.

I am a fearful person. I didn't know who to ask for help. There was no one. Just on my own, so alone, everyone left me all alone.(P9)

P11 defaulted further chemotherapy and radiotherapy after an emergency mastectomy of a 10kg tumour.

I asked about radiotherapy and I asked Prof A. I wanted the lightest one. I wanted radiotherapy first. Because chemo is too hard for me. Hard to think and hard to accept.(P11)

The reason was so she could spend quality time with her children, this was not recorded as it was a phone conversation with the researcher. She was also trying out other forms of treatment like vitamin B-17 as displayed in Section 4.4.1.5.).

P12 did not complete the diagnostic work-up and sought alternative treatment. With a probable diagnosis of cancer, some women sought other forms of treatment even without a tissue diagnosis. They presented again to hospital when they had other disturbing symptoms. One could argue that this is a diagnostic delay, but because

women sought treatment although in non-conventional types, they have made a decision to pursue alternative treatment as a replacement of conventional treatment.

It was a year, and it was not painful, I ate the homeopathic medicines since it was not painful I was not worried moreover I was on treatment. But when my fever did not improve, then I went to see the doctor at the private hospital. I also felt the breast lump to be enlarging. It didn't become smaller, so I asked my husband I wanted to go to the hospital and remove it. And he saw me having fever, so he allowed it, he just followed suit.(P12)

And P 15 was influenced by her mother not to have conventional treatment and delayed having surgery. She did it only when the tumour gave local problems. The participant had time to accept.

I saw two doctors, both said I needed to remove the breast. After that I could accept, I said. Never mind doctor, I accept. Because the swelling had become the size of a thumb, and fluid started to discharge wetting my clothes, the swelling and discharge was where the operation site was. After that they told me they will refer to Prof X in public hospital X.(P15)

Factors that contribute towards decision making, can also be seen by the quality of interaction between health provider and patient as displayed in section 4.4.2.2.1. In that section P3 had a bad experience during results disclosure; there was lack of rapport and trust with the doctor that broke the news; furthermore there was no collaboration in recommending surgery to her. She was also not clear about the diagnosis, from the medical records, the histopathology reported ductal carcinoma in-situ, for which she reiterated that the doctors didn't know what it was. Hence the quality of that interaction may have contributed towards her choosing alternative therapy. However, it could be more complex in that she was in a state of shock after the result disclosure and may be using maladaptive coping mechanisms like avoidance.

This section provides evidence that treatment decision delays occur and is very much dependent on patient factors as in system factors. Treatment decisions were made by

women, sometimes precipitously, but some women had a period of indecisiveness, or decisiveness not to have conventional treatment. The pluralistic effect of Malaysian healthcare systems, bring about choices to use alternative treatment, as seen in the previous section on health utilization of women with advanced breast cancer.

The adoption of conventional medicine and alternative medicine was displayed in the previous 4.3 section. Barriers to care especially poor patient provider communication and culturally appropriate care would greatly impede adherence to treatment recommendations.

To explain treatment decision delay, the explanatory model will be discussed in Section 4.6.

4.5.2.8. Treatment delay (TD)

4.5.2.8.1. Definition

Treatment delay occurs when health systems failed to provide timely treatment.

This delay stage is important to illuminate the processes of providing treatment in a hospital setting. Treatment delay differs from TDD in that TD is mainly a systems failure of health services failing to provide treatment services in a timely and effective manner.

The reasons for this could be medical contraindications to having treatment. This is not a health systems failure but a valid medical reason. Losing patients to follow-up and not recommending alternate effective treatments are health system failures.

P7 is an example of TD. This patient had a competing illness, where she had a foot ulcer. In the patient's notes it was due to stepping on a nail. Due to that she faithfully went for check-ups and dressings at the wound clinic.

She was first seen in breast clinic in October 2007 and was referred to the oncology clinic for chemotherapy and orthopaedic clinic for her foot ulcer. She was seen in the orthopaedic clinic from December 2007 to January 2008.

It was a small wound. The doctor wrote me a letter (referral), asked me to go for surgery because the leg wound was infected. I had a debridement where the skin and "rotten meat" was cut away. It was on the sole of the foot. In UMMC, Prof X's assistant wrote me a letter for admission (to the ward). After that, I was back to normal. My leg wound healed after about a year. I have not gone back to UMMC to see (the doctor). This Chinese new year I went to see (the doctor), in 2008. I also went to see 'a little' (visit the doctor once or twice). (P7)

She was seen in the oncology clinic in January 2008 and had one cycle of chemotherapy. The chemotherapy was postponed due to the ulcer.

I always have problem with my leg ulcer. Then another doctor said, "You have wound in the legs, so you cannot have chemo. Because the wound can easily get infected." So I had one cycle (chemo), then no more. After that, when I got better, after 2 months, the wound came back. On the sole of the feet. I could not stand the chemotherapy....so I stopped. I took some herbal remedy at home. (P7)

The patient defaulted her oncological follow-up due to her wishes to stop chemotherapy because she felt she could not stand it. She also tried other home remedies and she was not contacted by healthcare providers. She reappeared a year later with ascites (fluid in the abdomen due to progressive disease) to the primary care clinic in February 2009.

After that in 2009, my stomach started to get bloated up, filled with 'water'. (P7)

She was started on palliative chemotherapy in April 2009.

In the end I started chemotherapy. I had the first cycle, then I could not. (P7)

She was then called up by Prof X and was seen in the breast clinic. She was started on Tamoxifen since she was ER and PR positive. This treatment would have been effective if it was started a year ago, when she could not tolerate the chemotherapy.

Prof X was very good, she found out that I did not go for follow up, she asked, " why did you come so late? " she did not scold me but she said, " why...why wait until it is so serious, then only come?" (P7)

The important role of health systems in navigating patients is seen in P7, where due to competing illness, ie. a foot ulcer, the patient did not attend to her cancer. She was not called back despite her having other options of treatment besides chemotherapy.

In contrast to P7, many other participants revealed that treatment was commenced in a timely fashion. This was also displayed in section 4.4.2.4.

And within a week, I have appointment for surgery, have to do mastectomy. (P16)

4.5.3. Section summary

This chapter states the chronology of events and possible stages where delay could come about in patients who present with advanced breast cancer. Figure 6.1 illustrates the stages of delay. Further discussions about the stages of delay found in this study in relation to models described by other authors will be discussed in chapter 6.2.

4.6 Explanatory account of why women present with advanced breast cancer

Six women in this study delayed seeking a diagnosis (P4, 10, 11, 13, 15, and 16). P4 had financial reasons, P10 needed her husband's permission to seek a diagnosis, P11 did not get a diagnosis, but sought alternative treatment as she suspected it was cancer. P13 had to care for a daughter who just delivered and also cared for her husband in ICU. P15's GP erroneously told her it was a benign lump and the referral systems in government hospitals where having clinics and operation services were in different hospitals and also waiting for biopsy result delayed the diagnosis.

There is a complexity in human behaviour. It is not just a cognitive process rather it's a mix of cognitive and emotional response towards an event. Knowledge of the disease and its' outcomes, perhaps forms one of the many basis of the responses that women have towards a diagnosis, or even when faced with a possibility of breast cancer. Breast cancer is a disease that invokes fear as it is perceived to be fatal. Themes that emerged in the interviews that could explain reasons why women present with advanced breast cancer were displayed in this chapter. Convergence of these themes into constructs, eventually allowed the researcher to build an explanatory model at the end of this chapter.

4.6.1 The disease and its' outcomes

Knowledge on breast cancer was found to be lacking.

4.6.1.1 Symptom knowledge

A process of symptom appraisal occurs when a patient detects an abnormal bodily sensation and infers or labels it as 'serious'. Of the 19 women, 16 had infiltrating

ductal carcinoma, 1 had malignant phylloides, 2 had infiltrating lobular cancer which is well known for producing vague non-lump symptoms.

4.6.1.1.1 Painless breast lumps

Pain was only seen in 5 out of 17 patients presenting initially with a breast lump, the other two women presented with axillary lumps, none of the women in this study had vague initial symptoms like nipple inversion or just thickening. In this study, non-recognition of both lump and non-lump symptoms were found. Five women in this study did not recognize the symptom of a breast lump as something potentially dangerous. The women associated painless lumps as being harmless.

I couldn't really feel it, just saw my armpit becoming swollen. There was a lump. But I left it, I thought it was nothing. It did not occur to me that it was cancer. It was painless. After checking with the doctor, I cried. (P 16)

Very small one [at first]. Then I keep quiet and nothing [happened]no painno nothing. (P18)

Some women lacked confidence in the breast changes; they had to be sure there was something there, so they waited for some time.

It was a very small lump when I felt it [for the first time]. I could not be certain. I waited 6 months. (P 13)

At times they did not notice the lump until it was very large, it is not something a women keeps looking out for. Accidental discovery was mentioned by some participants

I didn't notice it because of the stress. I don't really do breast self-examination, when I was washing clothes I felt it, I told myself it couldn't have grown so big? (P 3)

Overnight the hard lump appeared. I pressed and felt pain. Earlier on, I pressed when I showered, it was not hard. I did not pay attention. Overnight it became like that. After the lump appeared, I thought, why did it hurt? And it was quite big; almost like the size of a small chicken egg.(P4)

4.6.1.1.2. Presence of family history

There was a strong belief that family history should be present for someone to be at risk for cancer.

"I noticed when it was already large. It didn't occur to us. I had no family history. (P 1)

I have been having pain for 2 years on my left side. I thought, "Oh, I don't have cancer... there is no cancer in my family. (P 19)

4.6.1.1.3. Prior experience

The participants used prior experience to interpret the symptoms; optimistic bias towards a less serious condition was seen. Knowledge of cancer was limited, even a registered nurse interpreted her signs to be benign, and expecting cancer to present as a rapidly enlarging mass with skin and nipple changes. Her previous exposure at work and nursing school had been with women with advanced disease.

Even in my breast this was actually the third blood clot. First two I went and checked they said 'Its benign so I assumed this was also benign.(P 19)

Every month I checked after my periods. But the thing became bigger and bigger. At that time I thought it was a fibroadenoma. Because it was mobile. There were no skin changes on the skin, no nipple discharge or retraction. So I was confident. But when I asked the doctor, she said you better check. Only a biopsy will tell if it is cancer. I thought to myself: if this is cancer, it will be fast growing, there will be skin changes, the nipple will not be symmetrical, it would be pulled in, then there would be nipple discharge. One breast would be smaller than the other. I have seen breast cancer myself, but they were all late presentations. All were quite bad, ulcerating, cauliflower types, with nipple retraction. During my nursing course, that was what was shown to us. All were late staged. Not the early ones. The early type is just a lump right? Maybe a

fibro or a cancer. Could this be cancer? But the lump was mobile, cancer would be strongly fixed and not movable. That was my thinking at that time. (P6)

Two participants were pregnant when the lump was discovered. Many were misled by breast changes due to pregnancy. Including their significant others and more importantly this included doctors and nurses who examined these women (also refer to Illness Delay in Section 4.5.2.3, page 231).

I told many people about it. When I went for check-up, i did tell them that I have something like milk abscess and i felt pain. But no one said anything about cancer. Everyone [doctors and nurses during checkups] said that it might be milk abscess because I was pregnant. If any one of them said that it might be cancer, I definitely would have come earlier. My husband also has never seen cancer before and he also doesn't know anything about cancer. Both of us thought the swelling was because of the milk. (P 14)

There are people who get breast lumps when they are pregnant. I felt a lump but I didn't tell anyone, until I delivered it remained the same size. After I delivered I got pregnant again. After that it stayed the same size. One year after I got that baby, it became aggressive. (P11)

Women who had experienced pregnancy and childbirth were elected to be significant reference persons by these women.

My husband also doesn't know what it was. Then I asked elder sister. She is much older, besides she has children. I asked her, then she said it was "bloated with milk". (P 8)

4.6.1.1.4. Young age

Being young, also influenced the woman's perception and her significant others of her risk of breast cancer.

The doctor did say that it will get bigger. He was right, it did get bigger. From small to large. But it was not so fast, I didn't even feel scared because you can't really see it. I am young that was why I didn't believe it, unless if I was an older woman. (P15)

My husband also says that you are too young for cancer. So, I began my treatment, but, not with the doctors.(P11)

4.6.1.1.5. The need for triggering symptoms besides a breast lump

Some believed that cancer is a hard discrete breast lump portrayed by the media. Thus other types of breast changes were not attended to.

The newspaper mentioned that if there is a hard lump, we must immediately go for check-up. Knowing that it is (a hard lump) that is not good. Sometimes I cannot feel [the lump], but most of the times [I] can feel [but] at times, it is as if [I] cannot feel [the lump]. (P 13)

Women get information from people around them,. If they did, the information was not detailed to include pictures.

Maybe because people around me, my relatives and friends do not have this cancer. Only heard about it, not seen it. Newspapers also did not print pictures of breast cancer. (P 8)

They do not read newspapers

Nobody said... I never heard anything about it. I don't read newspapers. I am busy. (P 18)

Women felt cheated that they did not know the symptoms of early cancer, to act upon it.

We have to tell them, even if the swelling is small, you must come to know what it is. Do not wait too long, do not do traditional treatment. We must do it like that, if not they go for traditional treatment and the cancer in the end, will spread. That would be more complicated. Should tell people clearly and early in the course of disease. (P6)

You can't see it, when we detect it, it must be big already or red, then only we know this is cancer. (P12)

Table 4.24 shows the responses of the 19 women with regards to their initial breast symptom. Majority of the women(17) had breast lumps, the other two had axillary lumps. Of those with breast lump, 5 were painful. Majority were painless. Median duration to consulting doctor was 6 months. Range from 1 day to 10 years. P3 sought medical help one day after she discovered her symptom, but defaulted further recommendations to have surgery after an inconclusive biopsy.

Table 4.24 Type of initial presentation in the 19 women with advanced breast cancer

		N	%
Clinical presentation	Breast lump	16	84.2
	Axillary lump	3	15.8
	Mastalgia	6	31.6
	Nipple discharge	3	15.8
	Ulcer	1	5.3
Breast lump (n=17)	Painless	12	
	Painful	5	
Non-breast lump symptom (n=2)	Axillary swelling	2	
Duration of first symptom to consulting doctor	Median 6 months(1 day- 10 years)		

Some women, went for a check-up at clinics once they detected a lump,

Once I felt the lump, I went to check at the clinic. (P2)

When I felt the lump, I went to see the homeopathy doctor.(P12).

Some waited until there was pain or other symptoms like pain and fever.

I don't know if I came late, only that when you feel the pain you would go for a check-up. I didn't have any other treatment. (P5)

It was quite big, but wasn't painful. What I couldn't stand was the fever. It came off and on. My body felt hot. (P12)

4.6.1.2. Causes of breast cancer

Information on what causes breast cancer was variable. Some attributed it to stagnant milk or blood clots. Many were ignorant of the causes. In the interviews, it was noted that women wanted to know what caused the cancer.

Maybe it's milk that causes the cancer. It was painful when I breastfed my child who is now 11 years old. I thought it was just a normal swelling. Maybe after that, a long time after that, the pain went away and just recently it came back again. It was just a lump. Initially I didn't feel anything but sometimes it smarts, then one day I felt a lump. (P 16)

Heck it's just a lump. You see I'm prone to blood clots. Ever since I was young I will get blood clots here, blood clots there. Even in my breast this was actually the third blood clot. (P19)

4.6.1.3 Breast cancer outcomes

4.6.1.3.1 Natural history of breast cancer

Due to the misconception of the disease, many thought progression would be immediate death, not realizing the slow protracted course of the disease and impact on their quality of life. When they experienced the severity of the disease, many regretted not attending to it earlier

I didn't want treatment, just let it [breast cancer] progress naturally. When the time comes to die, just let it be. I don't care, that's how I was thinking. (P4)

Scared to know the reality I should say. At the same time thinking of the family and thinking that it would means I may go off suddenly. (P17)

Some were not aware of cancer and the seriousness of the diagnosis in relation to the metastatic potential.

I didn't know the cancer could run. I think only the breast would be involved. Just a little bit. I think that was how cancer behaves. I thought it's very easy, operation was enough. I didn't know that cancer can go to other places. (P18)

4.6.1.3.2 Concept of cure and control of disease

There was an omnipresent misconception of outcomes of breast cancer in the participants and their social contacts. Fatalistic views of cancer were pervasive in the community.

I know I don't have much time to live anymore. (P11 when she first discovered a breast lump)

Everyone says it's fatal. My neighbours came to comfort me, but no one knew anyone with cancer. I cried when they told me. (P16)

This pervasiveness was from the contact they have with breast cancer patients, usually within their neighbourhood. This was substantiated by their significant others who felt the same way.

Many of my neighbours were affected, had so many types of chemo but still they died. Two in my neighbourhood died. (P12)

I would have just left it like that because you know when you hear you have cancer, you just feel well, that's it. You just wait for the time to come. Because everybody tells you that ooo....cancer, that's it. Sorry. Pray hard that you'll go in peace. There were a few who came and blessed me and said just pray hard that you'll go in peace. (P19)

P11 responded acutely to the death of the past prime minister's wife.

When I found the lump, I could not accept, that was in 2004, Datin Seri Endon (the late former first lady of Malaysia) passed away, when she died, I imagined myself dying. (P11)

P11 was preparing herself for the afterlife.

I had a lump, my child died, that was when I knew life challenges had begun. I have gone through so much, it is no longer easy to live in this world, God-willing Allah will provide me an easy life in heaven.(P11)

I found that fatalism resulted in two responses, one was that women who believed in the afterlife felt they had nothing to lose in this world, hence chose treatment that were not toxic and congruent with their values of good quality of life, but still tried their best to find treatments that cured but was not toxic. The other was that one had given up with living and just waited to die, these women were not in denial but was conscious of not doing anything about it. They later found out that, cancer was a protracted problem and that needed medical attention due to worsening symptoms as seen in P4 and P17.

4.6.1.3.2 Social impact

Being ill is a stigma in itself. Many in this study chose to shy away from the public eye especially when they were on chemotherapy due to the hair loss, the experiences of these women, would help illuminate the issues that the public is exposed to ie. Bringing about a sense of stigma to the disease as well as being ill. Stigma was seen very much

in the community, stigma of being ill and other connotations to visiting health care facilities.

A staff at school(someone with breast cancer). I never met her, because she too did not want to meet people. Someone asked to visit, but even to visit her she did not want because of that , I never knew.(P3)

My neighbours knew, but I rarely went out. Just to buy vegetables, I can be head strong, I love to buy vegetables. After chemo they say we can't go near other people. Afraid that we can get fever. But I always go out without my mask. Too embarrassed to wear one. Then people would know you are sick. (P16)

Losing hair was a big deal for these women.

The most important thing is my hair. You know I wear a wig when I come to KL. Nobody bothers. But in Seremban, everybody looks at you like a freak. Yes, because we go out with hair like this. They just look at the head and then they will be wondering what's wrong with you. At the shop where I used to go and buy groceries. They always asked my children. Where is your mother? They lie because I have told them don't tell them anything and they just keep quiet. So they just kept on asking why I wear a wig. So when you wear a wig it's a lot of difference. You know that hair does not match. Once a week I used to go out to town. When they go, I just followed them and sit in the car. (P17)

They didn't want sympathy from others. They wanted genuine friends not those who felt pity for them.

Yes, at the beginning,when my hair started to drop Ii didn't want to mix. I mean relatives or anybody. Just leave me alone, let me cope with the day to day in my life. That is just one of those things that I want. I don't want them to sympathize.(P17)

I don't want to let people know I am sick, like purposely wanting them to accompany me. It's like holding up their time. I feel that it is not good. I also don't wish to be like that because I have this illness I am 'special', others sympathise or need to help me or take care of me. Being friends should be something natural. (P4)

Visiting a gynaecology clinic also is a stigma, especially in a young woman, where people talk about a concealed pregnancy.

People think of me in a bad light, but it's ok, I can accept. Because I went to a gynaecological clinic to check the breast lump. Then all the aunties in the neighbourhood said I was pregnant. Someone saw me there. They asked why, I said I came to check my breasts. After that I heard all kind of stories. After my surgery, then only they knew I had breast cancer. (P15)

The experiences of these women are real, although this section describes their experience, it would be a valid indicator of the social impact the disease has on them. Hence, it would be understandable why; people would avoid this disease at all costs.

4.6.2 Treatment and its' outcomes

Women had past experiences that help shape their perception on their disease and decisions for having treatment.

4.6.2.1. Past health practices

This study also looked into the health behavior of women with regards to their prior experience with health care and breast cancer. A survey of these 19 women, showed that many women had experienced breast cancer before their own diagnosis, three had experienced it amongst their own family members and nine had it in non-family members. Women worry and get information from people around them, and garnered

confidence or no confidence from other peoples' experiences. This issue is displayed further in the "role" section below.

From the qualitative interview, the participants felt they did not know much about the disease because of lack of exposure from relatives and friends which is where they obtain most information from.

I don't know anyone with cancer, no friends, or family members with cancer. (P16)

Surprisingly they also practiced preventive medicine, especially with regards to blood pressure checks, most likely due to antenatal check-ups. Six had history of pap smears and seven had diabetes blood tests. Ten had prior surgical treatment, two had breast lump excisions, five had caesarian sections, 1 thyroid operation. 1 had appendicectomy and 1 had a spine operation. Hence, having prior experience with medical conditions did not stop them from delaying early treatment for their condition and for presenting with advanced cancer.

4.6.2.2. Fears of outcomes of treatment

Obtaining a diagnosis also appeared to be fear generating, as seen in the young lecturer P11 who never sought a diagnosis until she was brought in comatose by family members.

I know one has to go for a biopsy; I looked for information about what treatment and what doctors would do. I read about mammogram, it will crush your (breasts). That's painful, that one I knew. After that they do a biopsy, they take cells from there and test it. That's painful too. My friend told me, she didn't know I had a similar problem. If she has a problem she likes to talk to people. And from her stories i felt really frightened. (P11)

4.6.2.2.1. Fear of surgery

Fear of having surgery was still prevalent, women were worried of being disabled and even dying from the surgery. They formed these beliefs from people around them. The stress from their significant others transmitted to them, to add on their burden on making decisions. P8, a young woman had a double burden of her own fears and her mother's fears.

I was thinking all kinds of things. I was scared to do the operation. I asked the doctor, can I move or walk after the operation. Because someone in my neighbourhood could not move her arms and could not get up. She died she had breast cancer too. After that my mom was thinking all kinds of things, after that mom said, we pray and accept and see what happens, maybe after removing (the breast) everything could be okay. My mom was worried, worried that I won't be able to get up after the surgery. So I asked the specialist later, the doctor told me why won't be able to get up? Of course you will be able to. Have you ever met someone like that. I told her yes, and I thought it could be that the woman was old, and her body was weak. The specialist said, you are young, and your "antibodies" are strong. And it turned out to be ok, just a little bit of pain after the operation. (P15)

Educational programmes on television may serve to educate the public. From the women, it may seem to be doing the opposite, women and their family members were afraid of images of surgery, putting them at an awkward position when they themselves need to undergo the operation. They also did not believe the positive outcomes that was shown on television, and they were sceptical.

I always watched Medic TV (a medical themed television programme in Malay), at that time I frequently watched, as I was healthy then. My husband did not dare to watch it. So I watched, then after that I was the one operated on, I thought that's it. After seeing it, I got more frightened, with the metal equipment and the wanton tearing of tissues... Although the women looked well after the surgery, I didn't believe it, surely they must have been in pain, because my Chinese neighbour, had metal put into her arm, before surgery there was pain, after the operation she still had pain, but less. The feeling of being scared is in everyone. (P3)

Some felt loss of confidence because significant others had negative perception on the success of surgery. There seem to fear in the public with respect to the success of surgery. It was a life and death situation.

At that time, I have confidence in myself, and feel that I will not die just because of one surgery. I believed medical knowledge is very advanced; death will probably happen after surgery when the disease progresses or something like that. The surgery will not give much trouble. My older sister from Singapore was also very worried. She came all the way from Singapore to visit me, she was very concerned. When she called (from Singapore) to talk to me, she cried (over the phone). I had not had surgery that time. She came from Singapore to visit me because she knew I was going for the surgery. I said to her, "I am not even afraid, why should you be afraid? There is nothing to fear, medical knowledge is so advanced now" she thought that I would die after the surgery. I never thought about such question (about death). I told her to wait after surgery to see the situation. Then on the following day, I had my surgery. (P4)

My neighbour said, people always say, older folk say that when we operate we will die. I didn't want to entertain them. They say, look at that person, after operation.. After two days she is dead. I closed my front door to a neighbour, but she keeps on knocking. She also has a lump and doing traditional treatment. She's scared of operations. Sometimes I entertain her, as it is not nice to close the door on her. She said, don't have mastectomy, look at so and so.. She died! (P7)

4.6.2.2.2. Fatal outcomes despite treatment as a normative belief

Close neighbours died from the disease, perpetuated the fatalistic outcomes even with having chemotherapy and surgery.

Many of my neighbours were affected, had so many types of chemo but continued to die. Two in my neighbourhood died. SoLi tried homeopathy. But I don't know what stage they were in, they don't talk about it. They had operated, but still died. But if they came in earlier stages may be different? But I found quite a large lump.... (P12)

Knowing figureheads who succumbed to the breast cancer after having the best treatments also did not help.

I was not peaceful. When I heard Datin Seri Endon's death. I was thinking, this is the first lady of Malaysia, she had first class treatment, in the US. Even with that, she died. How about me, I don't even have class to be treated that way. I said, I better find another alternative. So that I could control myself to accept this illness. (P11)

Treatment outcomes seem to be prevalently negative in these participants for chemotherapy as well as surgery.

4.6.2.2.3. Fear of disfigurement

The worry of disfigurement was seen in the data as a cause of not having surgery, however she found that the breasts gave so much trouble after the cancer had progressed and wished she had it removed.

Wonder how it would be like without a breast, can I accept it, I was so undecided. I kind of regret not removing it then. My friends who knew I didn't remove the breast were angry at me, especially those who had a mastectomy before. I didn't know what to tell them. I was worried that when I opened my eyes, the breast is gone, that I am disfigured. I don't care about the wound, it's just that the breast is not there. I feel burdened now that I did not remove it, why didn't I do it earlier? Now it's become an illness and has spread here and there. "itulah"(reprimanding self).(P2)

Worry about losing husbands was evident in one of the women (P2).

She (another patient) was young, she listened to the doctor. She didn't have a husband, thus it's ok. But for us married women ... if I didn't have a husband, I would just remove the breast, no problems. You know.. Men, if we remove it he would feel different. (P2)

Single women who felt that they would no longer find marriage, P15 a young participant also described how the doctor had expressed that concern, for which he was proven wrong.

If we have removed it[breast] it would be difficult to get married, I feel like that. But I could accept. The doctor in a district hospital did “curse” me. But when I went back to get some results, I met him. I told him..”Doctor I’m getting married”.. The doctor was so shocked.(P15)

4.6.2.2.4. Fear of chemotherapy

Response towards chemotherapy was variable, some women sailed through it, but some were aware of the side effects and found later that their fears were unfounded.

Like arranging for me to undergo chemo, it was divided into 3 treatments: chemo, operation and radiotherapy. It is all the same. She said that operation after chemo, or chemo then operation, it is all the same. Because at that time, was quite big [the lump], so chemo first, let it ‘shrink’, then only operation. Better like this. I completed the chemotherapy with no incidents, except the last 2 chemo were much more ‘difficult’. The earlier chemo was ok, not so difficult like what the others said. They [others who had chemo] said, “some will vomit immediately”. I did not have that. Did not vomit at all. All my hair dropped but I did not vomit from first chemo to the 6th chemo.(P13)

I always hear people saying its hot when you go for chemotherapy, no appetite and all that. It was scary to hear that, but when i did it, it was okay, i could stand it. (P15)

However, some women did have side effects from the chemo, feeling hot, vomiting and dizziness were main complaints.

I didn’t feel anything during chemo. But each time I had chemo, I had an allergic reaction. They had to give something and Piriton. Because I would have rashes. After the injection it would be ok. I just felt dizzy and vomited. Whatever it is, we have to be strong, we must drink and we must eat. That was my principle. Eat fruits, drink coconut water, so I bought coconut water. Every

other day I would take it, and barley water in between. To cool the body. The body really felt hot. (P6)

When I had chemotherapy, FEC, I felt hot inside. It was so bad, my hair all dropped, it dropped. But then the breast lump shrunk. (P2)

First chemo was ok.second chemo, third chemo, by the time I came to the fourth chemo..... I just wanted to give up.....because it was so toxic (P19)

I got my spirits back after completing my chemo. I could not stand it, no appetite, incessant vomiting for about a week before getting better. My blood pressure was low, for the fourth cycle they gave the chemo despite the low blood pressure. At home I was so dizzy. (P3)

After I got home, the temperature was 37.4. The next day the fever was less but when I had an injection in nuclear medicine, the fever became worse. I couldn't cover my head, it was painful. I felt a burning and smarting sensation on the skin. I wasn't scared of chemo. Then my white cells became less. That was scary. (P16)

A retired teacher described her experience with surgery, chemotherapy and radiotherapy. She mentioned that a great deal of mental strength and physical strength was required for her to complete her treatment.

I didn't know anything about chemo. So they had to inject here. The nurse did say about the side effects, dizziness and vomiting, killing the cells and all that. I also took blood. Six times. The operation was quite fast. The chemo had quite a lot of side effects, no hair, baldness. After the first chemo, my hair started dropping. Then my veins became damaged. Others had the same problem, there was a dark discolouration, like a tattoo. At least mine was just minor. It was difficult to face, the heat. A lot of people said they have to undress. But I don't think it should come to that. The heat that made me lie down for a week. There was a lot of stories from others, same as me. When I get home, I eat something, then I lie down for a while. Then I have my bath. After that I will vomit, but I could still do my prayers. We have to be strong you cannot be too emotional, you do feel sad and cannot take it. Other people would not know what it's like. Then came frequent urination, at night I get up so many times. I drink a lot to remove all the dirty tumour. After I had radiotherapy, fifteen times of it. But that wasn't so bad. But maybe the effect was bad, who knows.

But it was quick to do, but the waiting was so long. The radiotherapy was just a few minutes "nyeet" then it's time to go home. If you look at my chest there is some discolouration. (P5)

Besides chemotherapy, hormonal therapy also gave side effects to women, although it is taken orally, they still had side effects.

Now I visit the doctor every 3 months. Just like that, I continue to take medications (aromatase inhibitors), sometimes I get side effects when taking these medications. I felt very hot sometimes, the legs get painful. Because the doctor had said before "for those with breast cancer, they will get pain at night".(P4)

Experiences that these women share with others about having treatment even at an advanced stage, would perpetuate the fear of others to having chemotherapy. The suffering described by the women, would make chemotherapy a very fearsome treatment, and to have these women not respond to treatment and succumb to it, would perpetuate the fears in the community further.

4.6.3 Sources of information

Lack of information was evident in this interview:

I wanted to know more about what will happen if you removed the breast, I wanted to ask. Nobody told me at all. Would it be okay after removing it, no one mentioned anything about it. Also during chemo, no one explained, did anyone survive after chemotherapy? But people would tell me, how would the doctor know? But the people kept asking me, am I okay, have I been cured. I would tell them I do not know. Just wait and see, I said. It's different when one goes in for a caesarian section, after delivering the baby, there is no more sickness. For me, I still had pains after the operation. Does it mean I am still not well? I am not sure until today. (P5)

The survey of finding out where women obtain their information about cancer after a diagnosis was done, and it shows that majority obtained it from doctors and family

members, books on breast cancer as well as fellow patients. Very few sought information from complementary or alternative therapist. Only 2 participants still sought information from these people (Table 4.25). The survey also asked them to respond if the item was not applicable to them, ie, not just of no importance but where it is not applicable to them (this could be from various reasons such as resources) and we found a large proportion and this was also supported by a larger survey that internet, VCD/DVDs were not applicable to most women, nine women also reported that getting information from alternative/complementary therapists were not applicable to them (Table 4.26).

Table 4.25 Percent distribution of sources of information after diagnosis of cancer

	N	%
Doctor	13	68.4
Family members	10	52.6
Books on breast cancer	9	47.4
Women with breast cancer	8	42.1
Newspaper	8	42.1
Survivor support group	7	36.8
Nurse	7	36.8
Friends	7	36.8
Women magazines	6	31.6
Television	6	31.6
Internet	4	21.1
Food supplement salesperson	3	15.8
Vcd/dvd on breast cancer	3	15.8
Alternative /complementary therapist	2	10.5
Movies	1	5.3

Table 4.26 Source of information that were not applicable in the women

	N	%
Internet	12	63.2
Movies	12	63.2
Food supplement salesperson	10	52.6
Vcd/dvd on breast cancer	11	57.9
Alternative /complementary therapist	9	47.4
Survivor support group	7	36.8
Women with breast cancer	4	21.1
Women magazines	3	15.8
Books on breast cancer	3	15.8
Friends	2	10.5
Doctor	2	10.5
Newspaper	1	5.3
Nurse	1	5.3
Television	1	5.3
Family members	0	0

In the in-depth interviews, internet was not used very much, only 2 patients used it. One was a young lecturer and the other a retired editor. Due to the fear of meeting doctors, a young Malay lecturer used the internet to get information.

So, it's only two months, I recognize that thing, so I considered this maybe part of milk. But, I was scared of going to the doctors, in case that is not part of breastfeeding, it may be cancer. After that, I just let it be, but, I tried to search the internet, tried to find out. Because I'm not so strong to go straight away to the doctor. So, I searched the internet on my own.(P11)

The editor used sites which were of high credibility such as the John Hopkins patient information site.

At first I was a bit skeptical. I said how can oxygen cells fight cancer cells. I was also into the internet. John Hopkins also came up with a few articles on taking in a lot of oxygen and it can kill the cancer cells. I said ok, I got nothing to lose. It's free of charge. Oxygen is free. (P19)

The participants needed information not just during treatment but after completing treatment. Information still need to be channeled to women to improve their quality of life.

I think, with my basic nursing knowledge, I can understand a little if not a lot. But for some, with no medical background, you need to give clear information and follow-up. It could be done in the resource centre where, three months once, have a sharing session, so they can ask about their problems. Sometimes, patients feel pressured. Especially with no breasts, and they have less capacity. They need clear information. After treatment, they will need to know how to get back to normal, how to handle the treatment side effects. What exercises to do, what are the effects of the drugs they are taking. I have a friend from Kedah, I taught her how to eat and what to do during the treatment. Every week, I told her to make juice from fruits, carrots, the fresh stuff we must drink. I just taught her what I did. It should be a small group of four women. So that their opinions can be heard. If there are too many, it would be difficult. That's my point of view. (P6)

4.6.4. Resources

The ability to be resilient against the disease and the treatment would mean they needed to unearth resources required to successfully have treatment.

4.6.4.1 Emotional distress and coping mechanisms

Upon finding a lump, the reactions of women were varied, and it had to do with disease outcome expectations. In one of the women, the 80 year old grandmother was very casual about finding it.

I felt nothing, I was not distressed at all. (P1)

However, some were devastated and spoke of the coping mechanisms that they used will be elaborated in this section.

The emotional distress that women had when describing on how they felt when they received the news of a cancer diagnosis, was acceptance to sadness to disbelief.

Most of these advanced breast cancer patients had time to accept their illness. The progression of the disease made them suspect it was cancer even before the biopsy result was disclosed.

I did not feel anything, I was not afraid [when the doctor told me the results]. Because I knew it was breast cancer then, and I have accepted it. What should I be afraid of? I was not afraid. I was a bit more cheerful. My children were with me. (P7)

We were both in the doctor's room, my husband and myself. The doctor explained to both of us. The cancer is in the right breast. I accepted it bravely. (P6)

Disbelief was one of the responses that showed the lack of breast cancer awareness amongst some of the participants. They felt that by not being Chinese it may confer some protection against the disease.

At home and in my neighbourhood, I never heard of cancer. When I got the diagnosis, I cried. It didn't occur to me. The Chinese usually get cancer, I cried, it was so sad, (P16)

The doctor never warned me at all, until I came back one week later, he then told me. I was shocked, but I didn't cry in front of the doctor my friends told me that some women hugged the doctor or fainted when they heard the news. I wasn't that bad to that extent. We just need to accept "redha". But it's impossible to say that I wasn't sad. When I got home, I cried at times loudly until I had surgery. It's one of our organs. I could not describe the feelings. Even now when someone asks, I have difficulty talking about it. (P15)

The doctor told me I had cancer. It didn't occur to me. He told me straight in the face. I saw them one week after the biopsy. I cried every day, so did my husband, it was totally unexpected. I've never heard about it. With time, I got used to it. (P16)

P8 had the double burden of having a cancer diagnosis and being a new mother on the same day.

I came with my niece as my husband was working on that day. She is in secondary school. Because at that time I was coming in for delivery. We came by taxi. I was admitted for delivery. I cried all the time during the delivery. Everyday I cried, luckily I could still sleep. During that admission, I could really sleep. I only cried from morning till night. After crying, I went off to sleep. (P8)

P14, a young mother was thinking about not only her fate, but her dependents as well.

I felt very sad. All my children are still young and I'm worried about them. Earlier I was very sad. I liked to be alone inside the room, and think about my children. What's going to happen to me and who is going to take care of my children? (P14)

The need for psychological support continues even after surgery and even after chemotherapy as seen in P8.

After the operation, I was suffering, I felt faint, the breathing was not comfortable. I went to the hospital, there was an oncologist, also a Professor from China. And I let him treat. He also looked at our reports and prescribed Chinese medicine. Taking it will help mentally. I stopped going when I felt slightly better. (P8)

4.6.4.1.1 Denial

Denial was seen in many women, who readily admitted that they were not ready to accept an expectant diagnosis of cancer. Because cancer was perceived by the patients as being fatal, it was easier to deny the truth, than to be faced by a life-threatening disease. Fear is an emotion described by many women, the fear was on outcomes of treatment related to the cancer and about the fatal outcome of cancer itself. They were insightful of this fear and used denial to avoid the truth.

It took a while, to make sure it really was cancer, about two to three months, I didn't really want to accept the truth. (P2)

But it was not so fast, I didn't even feel scared because you can't really see it. I am young that was why I didn't believe it, unless if I was an older woman. (P15)

Actually I should say it was a small lump and sometimes it was mobile and it just goes off. It disappears when I rubbed it, it subsides. So I didn't take it that seriously at the beginning but I was a bit scared, I mean in my sub-conscious mind I was maybe thinking that I may have cancer but I didn't want to face reality. I didn't want to know about it or I was afraid of knowing the truth. I was not scared of the treatment or anything. Scared to know the reality I should say. (P18)

When they first discovered breast cancer on the right, I was fifty seven. And when I was given this news I was shattered. I didn't know what to do. So, one of my friends suggested I go and see the Professor and get her opinion. But I was very reluctant because you know fear sets in. When fear sets in, denial also sets in. It cannot be me. (P19)

When unable to cope with the distress, denial is a way of coping that the women used.

P2, 11, 15, 18 and 19 used this coping style. In order to assist women to cope with their distress, techniques and counseling may be useful, but may not be readily available to women in the community.

4.6.4.1.2 Religious coping

Spiritual support and the use of religious connotations in therapy suggest need of spiritual support. Health providers need to be sensitive to the spiritual needs of their

patients to be successful allies in their fight against the cancer. Muslim and Hindu women used spiritual coping much more than other races as seen in the survey conducted on all breast cancer patients attending the outpatient clinic (refer to section 4.2.5.1, page 175). In the in-depth interviews, the Muslim, Hindu and Christian women spoke of how much spiritual support is needed for them to cope with the illness.

If Allah wants to cure, he can. All the treatment mentioned in the Quran, I believe would work. At that time the belief was very strong. And I liked it because I had no fear, I no longer felt paralysed and unable to get up like when I heard about the death of the former first lady of Malaysia when she died. I could not get out of bed. I was so weak thinking of my fate. But after starting prayers with the ustazah (female religious teacher) I was no longer like that. (P11)

I leave it to fate... God will decide my fate.. Ask from Him to protect me...God willing.(P7)

I was just putting it off. Until I looked at the mirror one day and said what the heck am I doing. I better face the consequences. There was a fear but I told you I was in denial. I said it cannot be. I went on a pilgrimage to India. I just had this feeling that it's cancer and nothing else. Even in India it was oozing. I knew it was cancer....and I better attend to it otherwise they were like a sign to me. If you don't attend to it now then.. We...cannot help you. (P19)

But God was with me all throughout. That sort of pulled me through. It was okay. (P10)

Using religion and being a member to a religious organization like a church in P17 or a surau (minor mosque) in P9, helped women not just in spiritual support, but in instrumental and physical support, this was further elaborated in Section 4.6.4.3, page 286.

Other coping mechanisms that were found, included avoidance as seen in P9, a lady separated from her husband with very scarce family support.

When I am seeking treatment, I mustn't think it's cancer. Just treat it like a normal illness. I try not to think about it. I don't think of cancer. I just want to get treated. I ate vitamins; I get my energy from that. I didn't think it was cancer. My friend told me don't think of cancer, if you think about it, you get worried, worried then the thing will spread. (P9)

Venting was also found to be a method to coping.

Like this, I bring out my past and share it with people, talk, talk, talk to let people know. And then, one day, I will slowly get back to normal. (P8)

Therefore, helping women cope with the distresses which are mainly psychological and lack of information to help them deal with their disease and treatment, would assist them in making good decisions. Acceptance of their diagnosis as described by the women, is the right step before they can take action towards dealing with it and accepting treatment for the cancer.

4.6.4.1.3 Acceptance

In the survey of women using outpatient services in UMMC, acceptance was the commonest coping mechanisms for these women during the period of diagnosis (Figure 4.8). The path to acceptance was mentioned by the advanced breast cancer participants, they had the insight on when things settled down, and that they were more at peace with the diagnosis and could move on to have treatment. Some merely needed time to accept.

I just had an operation scar in September. The doctor called again, but I still could not accept. In October, I felt a small lump. (P15)

When the Prof saw, she said you must remove the breast. She asked me can I accept that. I told her I could. Never mind it is a test I told her. She gave me a date but I postponed it to another 2 weeks. After I prayed, it was clear that I need to remove it. I telephoned the professor to tell her I have agreed. After that I removed my breast.(P15)

Many women, were accepting of hospital treatment, these were women, who were not aware of the gravity of the symptom that they had. Once diagnosed they quickly wanted to do something about it.

When the doctor told me about the treatment. I took it easy and accepted it.(P10)

Time was a great salve to many women, and learning to handle their emotional turmoil made them stronger.

My feelings of acceptance came during treatment; I can better accept the diagnosis. At first, it was not so. The feelings now are not like how I felt when I initially knew about the illness. During treatment, I said to myself I want to fight [the illness] till the end. They all said, the most important thing is to relax mentally. Then only, we can carry on, we must let go of all emotions. (P8)

If you had tried to interview me in 2007, I wouldn't have cooperated. I found it very hard to talk about it. Because every time you start talking about it, you start tearing. You get emotional. You get depressed. I said, I don't want to think about it. Don't want to think about it. I can talk about it now, because it's now already two years. (P19)

Acceptance is easily attained with strong support from family members evident by what P6 said.

For the operation, I don't feel so sad, I could accept it. My husband also knew, the doctor told both of us together. My husband also agreed to it, when I went home I told my family, my sisters and brothers. They said to go for it, since it's a good thing. They all agreed. My friends and my siblings all gave emotional support, because of that my morale was strong. (P6)

4.6.4.1.4 Self-efficacy- a component to act

In the study, it was found that many participants had low self-esteem after a mastectomy. It could be a reason for the fear of losing a breast. The idea that mastectomy caused physical disability and also a psychological one, needs to be addressed.

*Can you imagine, after I had my mastectomy, one of the psychologists came to my hospital bed and said, "Do you mind if I ask, you don't have a breast right?". She said it just like that! It was in front of my husband. Actually I had very low self-esteem, I am now a lesser person. Just don't mention it, you know*crying*. So I just kept quiet.(P11)*

Especially with no breasts, and they [women with breast cancer] have less capacity. They need clear information. After treatment, they will need to know how to get back to normal, how to handle the treatment side effects. What exercises to do, what are the effects of the drugs they are taking.(P6)

Few challenges in life may bring about complacency in life, when, life's challenge presents itself, it is difficult for women to withstand it. The concept of fragility, in them, may reduce their self-confidence in facing the cancer and its treatment. Hence, self-efficacy is found to be lacking.

At times, I feel, if Allah gave me a choice, who would be ill in my family, my children or husband or myself. I would definitely choose to be the ill one. I don't know if I could care for sick people. It is ok that I am the sick one. If my children were sick, I wouldn't be able to handle that, it's better that I am the sick one. I wondered if my husband was ill. My husband cleans me after passing motion and did all that, if he were sick, would I be able to do the same? I feel squirmish thinking about it. But for him, he just gets used to it.(P11)

A participant P3 described how horrible it was for her to take alternative medicine, using the apricot treatment and homeopathy where she had to immerse her feet in ice. She was not able to complete it; this was similar to chemotherapy, the same patient talks about her view that she would be disabled after chemotherapy, further proves this point. There was a great reliance on husband's response in this participant's responses (see Section 4.6.5.1, page 310). It may be cautiously interpreted as being dependent and lacking in self-confidence.

My husband was angry. But I couldn't take it, it was bitter. It wouldn't go in. Then you have to take the papaya and pineapple juice. I only did it for a day. I gave away the apricot b-17 medicines to other people for charity. (P3)

The homeopathy therapist checked my hand, after that he gave the medicines. He asked me to dip my feet in ice water. I couldn't take the ice water. It was so painful, it was more painful than the pain in the breast.(P3)

But I really had no appetite. I don't know which chemo caused my veins to become shorter (thrombophlebitis). My husband said, in the future, it will make you become disabled, he said[laughing]. (P3)

Many participants reported that they cannot withstand chemotherapy side effects (see Section 4.6.2.2 on treatment outcomes, page 277) and rather not try it. Having to deal with side effects of treatment is an expected thing with cancer treatment; hence it would be difficult for a patient to undergo treatment without clear education and support.

Women may have beliefs of their fragility that are unshakable and hence feel they are not able to withstand and therefore unwilling to undergo hardship. Accordingly, support of women's symptoms related to side effects of treatment and disease progression need to be validated and managed well for them to adhere to these treatments.

The lack of self-efficacy was seen in P13 too, where she blamed her husband for her advanced presentation but knew that she was the problem with her fear of the cancer. Not taking responsibility for her own actions also showed lack of self-confidence and there was dependence on her husband to direct her to get a diagnosis.

In my heart, I am still blaming my husband a little for not trying to drag me to see the doctor earlier. But I also know it is my own problem. Because he did ask me to go, only I did not. I was afraid, knowing that it could be breast cancer. (P13)

As for P10, her own set of beliefs about her place in a marriage does put herself in a compromising situation. It was not the husband imposing it on her, it was her own set of values. This again disempowers women from seeking treatment with confidence.

I should have been bold enough to face my husband and say, "No. I want to go." I should have, I tell myself, I won't talk, I won't fight back. So I should have told him, I want to go. But I don't want to hurt him. I respect him. I didn't want to hurt him. But it all turned out for the better. (P10)

P8 had a self-realization that it was not other people's fault that she came late, she could have been stronger to resist the directives from her parents to use alternative treatment. If she had the self-confidence, she could have followed the doctor's recommendations.

I felt I was not strong enough. I cannot blame my parents. If I was a bit stronger initially and did not go for the Chinese sinseh treatment, the cancer will not have progressed to the third stage. Now, I cannot blame anybody. (P8)

The need of empowerment and self-efficacy was evident in the stories of these women for seeking diagnosis and treatment.

4.6.4.2. Physical support

Having instrumental support or physical support was seen in the survey of women using outpatient services (see section 4.2.1.), use of physical support like financial and social support were important in successfully undergoing treatment. Moderate or high financial need was found to be important in eight of 19 women interviewed in the survey using the SCNS SF-34. The evidence for the need of physical support is presented in physical barriers to health care in Section 4.4.2 page 226.

4.6.4.3. Social support

In this study, it was evident that social support was needed at each step of the stages of delay. The role of significant others would be discussed in more detail in this section as a factor in treatment decision making. Asian tendencies especially among women of deferring to their elders' opinion and that of husbands were evident in this research.

In the group with advanced breast cancer, spousal support remains the most important form of support among married women. This finding corroborated with the survey of breast cancer patients in Section 4.2.2.6 page 150, where husbands provided good support for most women. Strong family support was seen in these participants.

As for single women and separated women, children and nephews were their main support. It is still evident that although single women stay with their extended families, they do not feel fully supported by them and rather not impose on them.

4.6.4.3.1. Spousal support

My husband is considered very good. He loves me very much. He always asks about me. When he come back from work he will ask, "How are you?" My father, mother, younger brother and daughter. They all love me. Also, my daughter, nowadays she bathes me, helps me when I pass motion, pass urine. She will take me to the toilet. All of them are very good, they love me very much. If I am sick , they get very panicky.(P7)

I had family support, in the sense my husband was there. My son was there, my sister-in-law was there, my mother-in-law was there. So, all these helped. Without family support, it's not possible to go through a treatment of this nature. Especially, after each chemo. The first to third chemo was ok, by the time I came to the fourth chemo, I just wanted to give up, because it was so toxic. (P19)

Husbands provide physical, emotional support and at times spiritual support.

I wasn't scared of surgery. My husband read "selawat" (salutations to the prophet). That's the medicine to all illnesses. (P1)

My husband took care of me, he bought food. I don't have a helper at home, so we just packed the food. When I said I had no appetite, my husband would be angry. Just eat a little. (P3)

My husband is okay, he pities me. Sometimes I pity him too. We haven't had sex in a while, he pities me. At times he tells me don't think of the negatives, the disability [of losing the breast]. Don't think of all that, if not you will feel sad, it's okay, at least you're alive. (P5)

Husbands especially need to take care of us, give advice and strong support. Family members too. Without them, it would be very difficult. (P6)

He always said, although I told him that I had stitches behind my back [from a flap surgical procedure] he said even with a hundred stitches it's ok. He is very supportive, he is very good. He can take care of me, wash me after I passed motion when I was ill. I don't think I could do the same for him if he was sick. I think for those who are sick, Allah would give them a good spouse vice versa. (P11)

My husband of course and my mother and my family, but on his side of the family, he was the only one that was supportive.(P11)

My husband accompanied me each time.(P13)

My husband took care of me very well. He said, don't worry about anything. We will see what we can do. (P14)

During that time, my husband took care of me. Feeding me, he looked after me completely. When I became mentally better, had recovered, I did some housework at home, like cleaning.. With the baby, I have no choice, I definitely cannot look after [the baby] myself. (P8).

P15 was very young when she was diagnosed, she was only 24 years old, she was in a relationship which was strong and she got married eventually.

I got married after I removed my breast. I had surgery in December, and got married in February. The doctor asked me to do chemo in January, I asked if I could delay. He said, you have the delaying look, why do you want to delay. I told him I'm getting married. He didn't believe me, so I showed him my wedding invitation card. So three days after the wedding I had my chemo. I knew my husband for more than 7 years. It's so long already. He knows everything, I tell him everything. I have very strong support from my husband, it strengthens my spirit. (P15)

Except for two husbands, most husbands were supportive, P18 did not get any support from her husband and P9 was separated from her husband.

He[husband] was angry and did not want to send me to hospital. I had to go by myself. He said, the clinic is so near, you have legs and arms, don't tell me you cannot go by yourself. (P18)

I can't fight cancer anymore, because I am weak. The fear is still there. I am scared. After this, the professor says to do chemo. I am too weak to do the operation. I feel scared. If I can avoid operation, I would. My children and husband followed what the doctor said. My husband told my children, if the doctor wants to operate, do it, you don't need to ask your mother. He said that! They just simply said that. But when I fainted, they brought me here.(P9)

Despite being separated, P9 still expected some degree of support from her husband, but was disappointed at the end.

I don't care anymore, with or without my husband's support, my tears have dried up. (P9)

My husband did not come to visit me in hospital, the nurses keep asking him to come. I have suffered for five years. After he left, I babysat children, to find a source of income. Now I don't do it anymore, I just asked my children to help. I have five children, all grown up. Only two in school, I also have three grandchildren. I stay with my son who is single. He is the one taking care of me. He comes here to hospital every night, if at night I have severe pain, he will give me a massage. He is everything [cries]. The night I fainted, he brought me here, he borrowed a car from his friends and brought me to hospital. He is my main source of help, but my husband was nowhere to be seen. (P9)

4.6.4.3.2. Children

Children were also prominently giving support to the mothers, especially in broken marriages or in P17 the widower's case.

I didn't tell them. Even till now they told me, why didn't I tell about the lump. They keep asking me that question. I didn't tell them but I did it for their sake. Now they have gone all out, they took half pay leave. They make sure that every time when I come to hospital, one of them is with me. They do that. I'm very lucky. I'm very fortunate for everything that God has given me. It's not that he has let me down in any way. Even with this sickness I am very fortunate. (P17)

My children support me. My eldest girl is in UK. She is working. She's a lawyer and she went to do her Masters. There is nothing much she could do because she is doing her Masters there. (P10)

This daughter, she gives me support. (P12)

My daughter always scolds me. “Don’t be sad, I don’t see you smiling”. I said I am like that. She said must smile, so I have to smile. When eating rice, I also have to eat a little. I vomit after food. I cannot drink plain water. I cannot. Not even a little. (P7)

4.6.4.3.3. Parents

Mothers were a source of support, at times financial support and instrumental support in caring for their young families. At times, mother-in-laws did not support very much.

My mom also supports me. (P15)

Financially, my mother helped us because my family is very young. I have two children. The elder one is still schooling. (P13)

I leave my child to my mother. I told her it is just a milk abscess. But sometimes she did ask why am I going so often for the treatment. She also did ask whether I am lying to her. (P14)

Me and my husband, we stay with my mother-in-law. I dare not tell my mother-in-law because my mother-in-law has a heart problem. She is also in her 80s. I was afraid the old lady cannot stand the pressure. She does not know. But when I had chemo, she knew, so I let her know. She was also upset. My father-in-law had died a long time ago. (P8)

The participants have been main carers for children, especially those with young families, those who had loss of their abilities, and their battle with cancer brings about hardship and the need for very strong family support. P14 is a young Indian lady who just delivered a baby, and needed help.

I sent my baby to my mother when I come for treatment. A lady takes care of another 2 children. My husband will go and pick them up. I don’t have people to take care of my children. My mother in law won’t look after my children. She also doesn’t know that I am sick. When I told her about the abscess in my breast she doesn’t bother about it. She went to her daughter’s house two weeks before my delivery and never come back until now. I did all the work on my own without any help. I feel very sad because my mother-in-law doesn’t want to help me. (P14)

At times, the role of carer, is not just as carer to small children but to elderly parents too.

As for my mother-in-law, we asked her to stay with her daughter. Because my mother-in-law smokes, and kept on smoking non-stop. Smoking is not too good, so there was no choice but to send her away. (P8)

Sisters were also a source of support. As seen in the survey of breast cancer patients, attending the outpatient clinic, female relatives were the main support for women after the diagnosis.

My other older sister from Singapore was also very worried. She came all the way from Singapore to visit me, she was very concerned. (P4)

It was very easy; my sister helped me the whole day. Cut the queue, the professor helped me the whole day. She was actually on leave. I was at home, when we heard she was on leave. Then my sister saw her in the lift. She asked my sister to get me back to the hospital. The whole day she helped me. It was good that I brought money to pay for my mammogram. (P18)

My eldest sister is the best, she also has a breast lump, but the size remains the same, she is on follow-up in another public hospital. (P2)

Fathers were mentioned by one participant.

My father and sister-in-law know about my problem. I always inform my father first, if I have any problems. Furthermore, my mother has a block in her heart and she is going for an operation next month. Therefore my husband doesn't want me to tell anything about my sickness to my mother because she will be sad. I'm the only daughter. Yesterday I told my father about my problem. He did cry for me. (P14)

For one of the women, the parents support was unwelcome as they had different ideas about treatment and was not able to help her psychologically cope with the diagnosis.

Only that...the caring aspect from my family was really not enough...may be because whatever I need, they cannot give it to me. At least they must provide some comforting words, 'mental comfort' but they don't know how to comfort (me) (P8)

They were very directive in their support of Chinese medicine.

Parents support? I do not know. Because I felt that they found it difficult to face me, they did not understand much or could not help me much. Like they prefer to use Chinese medicine. (P8)

Because of this conflict, relationships break down, adding more to the pressures of the participant.

Currently my relationship with my family members is at its worst. Because whatever they [family members] said, has no logic. I would surely argue with them. After arguing, they would become unhappy. Then, I too become unhappy. That's why I seldom go visit them. So there is less trouble, less contact, so I be a little happier. (P8)

The understanding of the disease itself may create conflict as seen in this Chinese woman P8. especially in food taboos creates unhappiness and conflict.

My husband's relatives and my friends are more logical. My own relatives will listen to what others said, and come home and tell me "no" to everything, nothing is allowed. We the sick people, for example, cannot eat this and that. There is no fun at all [laughs]. They are listening to others all the time and after that they will tell me. As if I cannot do it by myself. Isn't it better for me to find out myself? I can always interact with doctors and those who are more accurate. They will listen to the 'pasar'[market] talk. Every person in the market says different things. I feel that there is no proof at all. They asked me not to eat lotus stem. (P8)

At times, women being the main carer always put others' well-being before theirs, and may have felt guilt in not being able to care for them.

Nobody took care of them when I was ill, they [husband and children] took care of themselves, they ate whatever was at home. My husband brought me to hospital, even though he was having pain. With a walking stick he came twice. (P 16)

Neighbours also played a role, in providing support for the women,

I have very good support from my neighbours. We have Indonesians, Indians, all of them are very good and very nice. When they see me, they will come over and ask to see how I am. All of them will come by to visit me. (P7)

At times neighbours also brought about fears in women due to negative perception of cancer as mentioned by P7 and 12 in Section 4.6.2.2 page 277 in fear of treatment outcomes.

4.6.4.3.4. Friends and work colleagues

Friends also lent support.

I also had friends, two of them had breast lumps, they told don't care what people say[when her villagers accused her of being pregnant when she saw the gynae]. We just accept and move on. (P15)

So in December I went to see a very close friend of mine who's also a practising doctor. She examined me and she said you better go to the hospital. This is not something you can play the fool with. So, I got a recommendation from her and she referred me to the National Cancer Centre and told me to go and see Dr.S.(P19)

The network of colleagues and friends from their workplace, gave them a lot of support.

When I see the children face, you know, there is always joy and some one child, you know, they are all different children. One child will joke and then the beautiful part, the home school is such a beautiful thing you know. Even the parents, they bought essence of chicken...that is also a support group you know. Because you touch the children and then the parents, they heard it, they come and visit you. They want to do things for you. They buy fruits for you.

These are things that is not that we don't have, but the love that they show, you can conquer the hardship. It helped a lot. (P10)

I told them I have cancer, but they didn't believe me, they thought I was joking. They said, please don't joke. But how do I tell them, I shouldn't be crying right? They kept asking me, is this for real? Yes I told them, it's true. The teachers in my school told me to go to the hospital, one of them had a sister with breast cancer and is well until now. (P3)

At that time, I was taking some medicine, my colleagues said, " Why don't you take leave, go home and rest?" I said, "I don't want to, if I take leave to rest for one or two days, I won't be tired, but when I go back to work, I get tired again. Not so good in terms of work. "That's why I said don't want to take leave". When I was going home that night, I told my colleague that I was not sure why I felt very giddy. My colleague asked, " Are you able to walk because you still need to go to the bus stop to catch a bus." I said that I was still fine. (P4)

I met my doctor at work, she gave me advice. And she said you must follow the doctor's treatment, do not miss. God willing, it would be okay. I usually go to her for advice, I would tell her all my problems. (P6)

I told my colleague about the bad news. I asked my colleague to inform my supervisor. I could not repeat the sad news, because if repeat, I would be very stressed. After that, all my work colleagues came to know about it. They all came over to comfort me in the house. At that time, I have not gone to the hospital. They telephoned me, because they have to work and it is not convenient. They encouraged me a lot. (P8)

4.6.4.3.5. Membership to community organisations

Membership to a religious establishment, gave women physical and emotional support that were unexpected.

And I thank god I have a good support group, my church was also there. My church is big but we have small, small support group. We have cell group we call that, you know. So we get together once a week or twice in a month we get together and then we prayed for each other and sharing and all that. Like someone is sick, we will cook food and take and... nobody ask you to do that, but the heart is so caring, they want to do it for you. I had wonderful care from my support group and I do not want to dwell on pity party and on sympathy. No way. (P10)

Because I am a Buddhist, I want to tell all my buddhist friends. It is like we can all use our Buddhist prayers for mental support. That night before admission day, I still go for prayers. I will go once or twice a week to pray. They telephoned me, provided me with mental support. (P8)

I have a friend, she helped me. She knows I don't take meat, so she would cook for me a dish with pulses and nuts. And give me a whole tubful. She said, eat this with rice. She helps me so much, she stays near my house, a bit far but we share the same 'surau' (minor mosque). We go to the same religious classes, she is very religious. (P9)

Some women lacked extended family, and church members became their family members. Community assistance to provide finances and supporting the daily needs of the whole family during chemotherapy was seen with church groups in the case of P10, Buddhist groups in the case of P8 as well as Islamic "surau" (minor mosque) groups in P9.

4.6.4.3.6. Health care personnel

Doctors also gave support by being accessible and approachable.

I let her [breast surgeon] examine me, she said, "okay". Okay means okay to me. She said, "if anything important happens, then come and see me." (P7)

Healers and alternative and complementary practitioners also provided avenue to support women.

My Qigong teacher said that "everything can be eaten. There is no such thing as poison". This is in line with our medical knowledge, we must not eat big portions and do not purposely keep on eating. Healthy eating is the right thing. (P8)

4.6.4.3.7. Fellow patients

Peer support from fellow patients also provided comfort to the women.

And that time, I was sharing with my neighbour in the ward and now, unfortunately she has passed away. She had liver cancer. I had a good time with her. (P10)

Fellow patients in the hospital setting became buddies. Groups like Qigong also helped.

I met other patients with similar illness. We all 'chit chatted' and laughed together. There were 4 or 5 of us. We joked and laughed, quite happily, it was as if we did not have any illness, unlike sick people, more like at home. Quite happy, not feeling any kind of pressure. I also learned "Qigong". My husband was very good. I went out, learned 'Qigong'. We were all like friends, we were all having some form of sickness so all of us got together and were very happy. It makes the mood a bit better. Otherwise, if I seldom go out, and keep to myself in the house, I will keep thinking about it, then I want to cry again. (P8)

Social support is important in the whole journey of the breast cancer patient. Be it, during decision making of women choosing their options of seeking help, getting a diagnosis, treatment and even after treatment. Hence, the lack of social support would be an important theme to explain reasons for delay.

4.6.5. Roles

4.6.5.1. Significant others in directing treatment

It was found that women needed direction towards having treatment, Asian perspectives on patient autonomy may differ from western perspectives. As seen above women required or expected not just social support but sanctioning to be able to move on to the next step. The participants needed some direction, such as from God, parents and spouses to decide treatments. Voices from these women give insight that some Malaysian women need directive instruction rather than making up their own minds. In this section, the roles of significant others were discussed according to the stages of delay that the participants experienced.

4.6.5.1.1. Role of significant others in symptom appraisal

The role of significant others in symptom appraisal are two fold, as a source of information as well as to validate the presence of a serious symptom (sanctioning).

Somewhere in June, I just felt, there was a lump there and the same thoughts came back. So, my husband was in sort, sort of a denial, you know, "God won't allow this thing to happen to us." His brother is a pharmacist and he said, "There is alternative medicine you know." And he put me on homeopathy. (P 10)

I asked around my family members. They said nah...forget it. Nobody in the family has it, how can you have it. . I said but you see the papers are saying the number one killer is breast cancer you know. Don't even think about it, they said, think positive. I said ok, think positive that's what I'll do. (P 19)

The need for being sanctioned sick or ill was an important trigger to labeling symptoms as serious. Therefore when significant others were not informed of signs of cancer, the symptoms were left unattended.

He [my husband] only knew there was a boil with pus. He asked me what was it. I said it was a boil. We just left it like that. It didn't occur to him that it could be cancer. Nothing, because I was a normal person. I had no symptoms nothing. (P 19)

Lack of disclosure was seen to impair this need for sanctioning.

4.6.5.1.2. Role of significant others in seeking help for a breast symptom.

My daughter said go get it checked at the hospital. Don't go when it's too late... I told her to wait awhile. It wasn't painful. I was also scared. (P 16)

4.6.5.1.3. Role of significant others in adhering to treatment recommendations.

Significant others directed the participants to have alternative treatment and not to have conventional treatment.

They (the parents) then took me to see the Chinese physician. I did not think of going. But they (parents) kept on scolding me. (P8)

Some women, were too overwhelmed to make decisions, leaving others to direct them.

Significant others included God, parents, husbands and other family members. The inability to cope with decision making may bring about this phenomenon. By using proxy decision making with use of prayer and just following orders, may have strangely given them the ability to feel being in control of the situation.

After I made Istikharah prayer [guidance prayer] "oh Allah, if it is good for me, even if I am scared, please reduce the fear for me. And if it is good for me, please show me". If it is bad for me, keep it away from me with whatever way. I will avoid it. So I accept, if I had to do it because I have submitted myself. If it comes to interest me, like suddenly yesterday with prof b, I felt strongly against chemo, so I didn't want. (P11)

I tell them, to have western treatment, do not go to sinseh, even if brought by family members, you must not be influenced, because we the patients will find it hard to resist. Because if patients have hope, we will find it hard to resist. (P8)

Sometime, significant others tried hard to direct the participant towards conventional treatment, but to no avail.

Some family members were angry because I was obsessed with the ustazah. Actually I wanted to be obsessed, because of that my confidence grew. For me, she wasn't like a "bomoh tiup" shaman that chants and blows. (P11)

P1 did not take long to decide, she after all did not know that her symptoms were sinister, she accepted and followed the doctor's recommendations.

I didn't take long to decide. I just went into the tunnel [CTscan]. After that I had chemotherapy and radiotherapy. I had 23 times of radiotherapy. I didn't have any side effects. The doctor also said, aunty, you look so healthy, and the nurse said, you can really move quickly when you walk. (P1)

Some women, took time to decide and depended on significant others for information.

I asked my sister who is a nurse, she knows more about cancers. The doctor did say that it will get bigger. He was right, it did get bigger. From small to large. (P15)

Husbands at times prevented their wives from seeking treatment, the women not wanting to be disrespectful, at times suffered in silence.

Immediately after my sons exams, I begged my husband, I said.. "I cannot bear it anymore, I want to go to the hospital. I asked frequently, every day I asked but my husband said no. (P3)

He couldn't accept the fact that his wife had to go through that. I think that time he couldn't but when I was diagnosed, he was broken. He feels very bad about it now. He should have sent me to the hospital earlier. The homeopathy couldn't do [the job], alternative medicine could and cannot do anything. (P10)

Significant others played a major role in the treatment uptake of the participants, and therefore would be a main construct in reasons why women present late.

4.6.5.2. Needing autonomy

Women in this study, showed a need to have a choice in deliberating what is most suitable for them.

It's my weakness that I cannot accept reality. In hospital its definite, if they say the results is like that, then there is no way out. It would be fatal that you get cancer, the procedure is fixed, we cannot have a choice. Seldom that the doctor will let you choose. If you have to, you have to. Even though they are experts, they never been exposed to alternatives. Thus I cannot accept, because I can no longer be in control. (P11)

The professor asked me if I wanted chemo injection?. I said, " I don't want it" because I was very scared. Chemo injection means 'hardship', I cannot stand it. Later, I asked her if I can take oral medicines to control the cancer. Because I am a patient, she gave me freedom the freedom of choosing. She said," ok ". So she gave me the oral medicine to try. NowI am taking it.(P7)

I am a noodle hawker. Customers sell me alternative treatment for cancer. Then I tried it. I cannot remember. I ate so many types for so many years. Sometimes for three months, sometimes for six months. If it doesn't work, I changed to another type. One bottle is RM 160[~USD50]. One for each month. I don't know how much I spent, it has been so many years already. Finally I stopped,I didn't want to try it anymore. I spent thousands; I wanted to see if it could disappear. No need to see doctor, no need operation.(P18)

A need for control of their situation to avoid further losses and hardship was evident.

I wanted to treat myself so that I wasn't going to get worse. I heard a lot about chemotherapy, I still have phobias,I saw them suffering, vomiting. I didn't want that if possible, ifI have a choice I don't want to suffer, even to get better,I am already sick, to get better must I suffer? So I looked for alternatives, where I could be cured without having to suffer like that. Like when I ate b-17, it was nothing. Just like normal, I knew it was just apricots; it wouldn't poison me, right? (P11)

P11 further iterated her views on how directive hospital personnel can be and how she likes to have choices in the type of treatment.

In hospital, it is like being forced. Whatever the doctor says, you must follow, if not you get scolded, just like how I was scolded when I returned. What she said was, this is what happens when one does not listen. Didn't learn from the last time did you? If I wanted the easy way out, I would come to hospital, it's free for me. I wouldn't spend all my insurance money, I would keep it for my children. If I didn't try and look for treatment on my own, what I need, what I like. I would have kept all that money. I tried harder than other people to stay alive, but I was the one who got scolding. Even though, I am the sick one. She doesn't know how I feel. I felt dejected after that. (P11)

Some felt pressured by their doctors who kept calling, but P15 was not ready to have treatment.

It was very stressful, they kept on calling, to the extent I didn't take the calls. You don't try to avoid, they said. I knew I had to remove. In the end I told them, please give me a chance, I haven't accepted it yet. (P15)

Although women had a choice, they were overwhelmed in making decisions, leaving others to direct them. Significant others included God, parents, husbands and other family members. The inability to cope with decision making may bring about this phenomenon. By using proxy decision making with use of prayer and just following orders, gives them the ability to control the situation as mentioned above in the Religious Coping in Section 4.6.4.1.2, page 272.

4.6.6 An explanatory model to explain the reasons for advanced presentation of breast cancer.

Besides aggressive biology of cancer, that can make the duration of symptoms very short due to the rapid progression of the disease. Eleven patients (P1,3,6,7,8,9,13,14,16,

18 and 19) were seen to be involved in appraisal delay. Four women delayed disclosure (P1, P4, P9 and P17). Some women did not present to a primary care facility, P9 and P11 presented as emergencies to hospital without a diagnosis. P3 and p19 presented at a private mammography centre without seeing a general practitioner. The rest of the participants were seen by a public health care clinic, GP or other secondary care eg. Obstetrics clinic before referral to the breast clinic. Six women in this study delayed seeking a diagnosis (P4,10,11,13,15,16). Seven women in this study delayed at the treatment decision stage (P2,3,8,9,11,12 and 15) and treatment delay which is health system related was seen in P7.

To explain the phenomenon at each stages of delay (refer to section 4.5), a model to explain the behavior at that point emerged from themes that emerged from the interviews. These themes had been displayed in this section.

Themes that emerged after listening to the stories of these women, emerge four main themes in helping women to act (Figure 4.12).

Firstly, knowing the emergent danger either puts them in action, or not, depending on how they respond to this threat. Hence assessing the severity of the situation is important. Themes that converged with them understanding what they are dealing with by understanding the disease and its presenting symptoms would aid women to present earlier. There was an overwhelming evidence of low breast health literacy amongst the participants, and also health care providers. Knowing about the disease symptoms, natural history and controllability in terms of cure was important to understand the severity of the disease.

BCDE Model: Decisions to disclose/ seek help/diagnosis/treatment

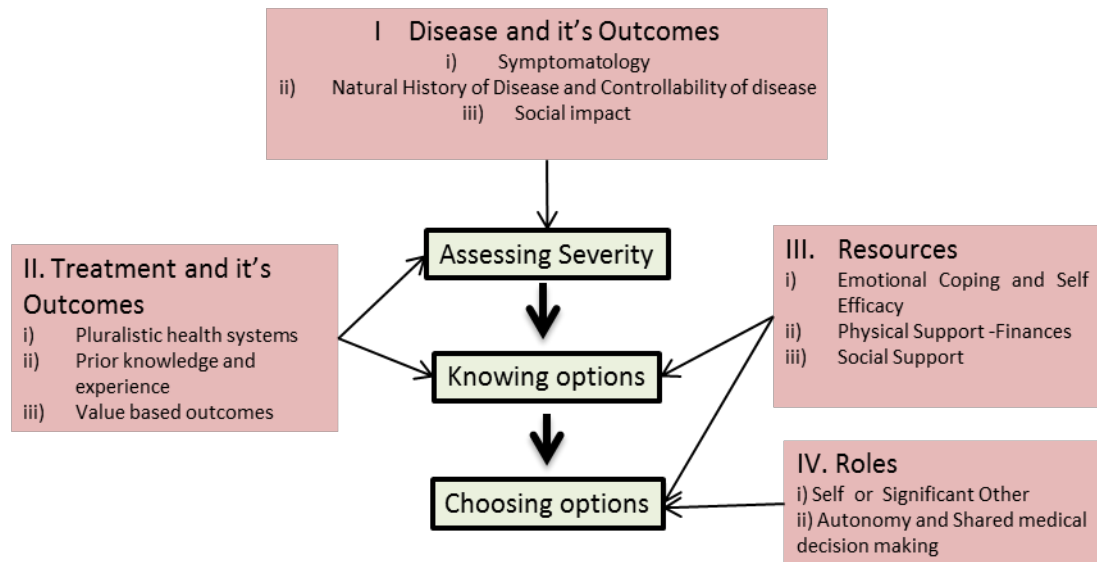


Figure 4.12 The breast cancer explanatory (BCDE) model

Secondly, options that were available to them; the treatment and outcomes were mainly from women comparing other experiences of their own and people close to them and with a background of a pluralistic health system. Misconceptions of surgery, chemotherapy outcomes were some reasons why women delayed their presentation. Also the value placed on outcomes may not necessarily be life gained but more of quality of life.

Thirdly, resources: which are emotional reserves and coping, physical reserves in terms of perceived ability to withstand treatment (assume strength, not fragility- resilience and self-efficacy) and having the finances and social support to go for diagnosis or treatment.

Fourthly, role played by the women, mostly needed significant others to direct and or sanction their actions. Only one woman, mentioned autonomy, however she was reliant on God to help her make decisions.

Hence, choosing an option would entail that the patient must know what options are available and having the resources to act, her decision is influenced by the role she plays.

Hence there were three main stages of making a decision were assessing the severity of the condition, knowing the options of treatment that is available and finally making a decision. This is a process that was seen operationalised in the decision making in each of the stages of delay that had been elaborated earlier. Figure 4.20 illustrates the 4 main constructs to explain the reasons why women present with advanced breast cancer.

Constructs that were derived were disease and outcomes, treatment and outcomes and resources available. Finally, women chose the treatment based on the role they played, and the role of significant others in directing and sanctioning their decisions was especially seen in P8 and P15.

The resilience of these women and their perception of weakness and inability to withstand treatment even alternative treatment was seen in P3 (lack of self-efficacy), however some women wanted control in their choices in P11, values that were important like quality of life and perception of control was important to them. But in some women, ignorance of the disease and its outcomes caused a delay in their coming to the hospital as in P1 and P18. This explanatory model is able to explain the stages of delay after symptom recognition, as the fear of a self-diagnosed breast cancer that was seen in P11, she was already assessing the severity of disease, looking out for options and finally choosing one, in her case that of alternative treatment. Some of the women

lacked disclosure like P1, P4, P9 and P17. P1 had poor symptom knowledge, P4 had issues with finances and social support. P9 had poor family support and P17 had issues with social impact of the disease ie. stigma. Managing emotions rather than the disease and a question about self-confidence and resilience was seen in P11.

Referring back to the section on alternative treatment, choice of having them, were based on “scientific merit” but more important areas were valued eg. spiritual, psychological and having no side effects. In many ways, perhaps quality of life is main issue and not length of life. Although reasons for delayed presentation of breast cancer are very complex, and different in different individuals, there may have multiple reasons why they delay presenting for a diagnosis and later treatment. The stages of delay chapter helps to clarify this time related events in the patient’s journey, and this section tries to sum up the reasons why they present late.

Using the exploratory model, I would like to illustrate P10 and P11 as a case study.

P10 is a retired homeschool teacher; the dualistic nature of the health system was evident in that she attempted homeopathy medicine recommended by her brother in-law and husband. Although suspecting cancer, she and her husband was in denial to cope with the fear of having cancer. She played the role of a subservient wife to her husband. She needed sanctioning from her husband to get medical attention and this support was provided by her church friends who advised her husband. She presented to hospital due to intractable pain that she could not lie down to sleep.

P11 , a young professional, lecturer in a university was admitted in a state of unconsciousness with a 10kg tumour . She assessed severity of breast cancer in a very

exaggerated fashion even before obtaining a diagnosis, the disease was fatal in her eyes even when it was a small lump.

I knew, so I would do as I please, because I know I don't have much time to live anymore. So don't force me [to do chemotherapy]. Allow me to satisfy myself [with what I want to do] but I'm not sure how it will be when I die. (P 11 when she first discovered a breast lump)

Treatment outcomes were linked to the first lady's unsuccessful treatment, when choosing an option, she had a lot of issues on the emotional resources required. There were issues of self- confidence and low esteem that she had when she talked about her sheltered childhood and her reaction after the mastectomy (section), she needed to make herself strong enough to withstand the disease as well as treatments. She explored all treatment options in the conventional as well as alternative areas, and finally chose what she felt strengthened her spiritually

We become stronger (by using alternative treatment). Because of the strength, I could last for four years. Many were shocked I could last four years with cancer without proper treatment like some people said. (P11)

And using other “pseudoscientific” treatment like vitamin B-17 was congruent with her values of having a life of dignity with breasts intact and having better quality of life, less physical pain and emotional pain. She also valued not being controlled by doctors as seen above. She was one that was acting on her own without any direction from family or friends. She made treatment as well as daily activity decisions based on her role as a servant to God which would show her the way by making her “want” to have certain types of treatment.

The implication of this model is that it lays a complex framework on future research, to look at associations and significance of each component. Furthermore it lays a

framework for intervention that can be done at the community level, at the primary care level and at the hospital level. Designing educational programmes with this exhaustive model, would help health educators to focus more on issues that matter to the public and also to provide a framework for first line doctors managing people with breast symptoms, be it in the primary care or diagnostic or treatment setting. In hospitals, psycho-educational programmes and training communication skills to doctors on how to communicate bad news and also to recommend treatment can be done.

Theoretical sensitivity on existing explanatory theories as discussed in the literature review chapter section 2.2 revealed that most were concentrated on symptom appraisal, to explain the behaviour of women in the context of disclosure, seeking help, diagnosis and adopting treatment can be explained through the meaning what breast cancer and having treatment are to these women, and their roles in making decisions. In the Asian, context there was a significant contribution of significant others to the options chosen by participants. However, there were still autonomous decisions made by participants without any influence from significant others.

The explanatory model will be discussed further in relation to available explanatory models that had been discussed in the literature review in Chapter 6.

4.6.7 Chapter Conclusions

This section attempts to explain the reasons that brought about delayed presentation to hospital. Important constructs were:-

Women make decisions based on :-

1. Severity of the situation which was assessed by:-
 - Knowledge about the disease and its outcomes

- Poor breast health literacy
 - Fatalistic views of breast cancer prevails
2. Knowledge about treatment options
- Knowledge about conventional as well as alternative treatments and their outcomes and the values they place on these treatments.
 - Choosing based on their values
 - Knowledge is obtained mainly from doctors and family members
3. Women needed resources to act :-
- Physical
 - Emotional
 - Social support
 - Self-efficacy
4. Women needed directives from someone or a divine being to act.

This section was important as it lays the ground work for intervention in explicitly laying out constructs that affect each decision from symptom recognition and to having treatment. The implication of this model will be discussed further in Chapter 6.

Chapter 4 in essence had displayed the results. An introduction to the chapter was shown in Section 4.1, the quantitative survey results in Section 4.2; the qualitative analysis in Section 4.3 with regards to displaying the phenomenon of late presentation and describing the study participant characteristics; Section 4.4 displayed the utilization of a pluralistic health system; Section 4.5 the chronological and health systems context and finally Section 4.6 an explanatory account of the emerging themes. Chapter 5 will then discuss the emerging constructs and models built. Chapter 6 will then be a critical account of the limitations of the study. Chapter 7 will then present the contribution and implications of the models.

Chapter 5 Discussion

5.1 Explaining why women present with advanced breast cancer

The findings on the phenomenon of late presentation had been discussed extensively in chapter 4.5 and 4.6. Themes that emerged to explain the phenomenon were seen to revolve around 4 main constructs: i) knowledge in disease and outcomes, ii) treatment and its outcomes, iii) resources- namely emotional support and finances, social support and resilience and self-efficacy and iv) role played in decision making ie. self vs significant others. However placing a chronological, roles of patient and health systems to the explanation was important and this was attempted by the Stage of Breast Cancer Delay (SBCD) model where pluralistic health systems, conventional health systems as well as patient and health system delays were included the model.

This chapter begins with discussing the SBCD (Fig 5.1) and the BCDE (Fig 4.19) models and the next subchapters discuss each conclusion found in this study (Fig5.2).

5.2 The Stages of Breast Cancer Delay (SBCD) and the Breast Cancer Delay Explanatory(BCDE) model

5.2.1 Clarity in the process and reasons for advanced presentation of breast cancer

This thesis is generative in putting the phenomenon into the context of chronological events and explanatory in that it suggests reasons for late presentations in breast cancer at each time points. Refining existent theories, adding on to what is known and to see its applicability in the context of an urban Malaysian practices. These two approaches lay a framework of opportunities to act upon the problem at hand, which is women presenting with advanced breast cancer.

Four contextual concepts were introduced in the SBCD model and 4 major constructs were displayed in the BCDE model. Both conceptual models explicitly attempt to clarify the phenomenon. Putting both models together, would lead to confusion as a theoretical framework and each model should be concise, change clinical practice and should be testable(Peterson, 2009).

In the SBCD model, the four contextual concepts were:-

- i- The role of patient or health systems in delay
- ii- The chronology of events that occur in the breast cancer journey- the points of delay
- iii- The pluralistic health systems
- iv- Patient decision making at each stage of delay

Patients, health systems or both were seen to play a role in delayed presentation in this account. An overlap can be seen and it was important to clearly define their roles at each stage of delay.

The chronology of events uncovered the importance of stages of delay very much in line with the total patient delay from Andersen's seminal work (Fig.2.17) (Andersen & Cacioppo, 1995). It is important to stratify the stages of delay, to be able to plan interventions later on. In this population of patients, unique to an urban Malaysian practice, total patient delay extends not only in the pre-diagnostic phases, but very much involves the post-diagnostic phase. Patients play a major role in delay in the pre and post-diagnostic phases. Community, health systems and significant others also play a major role in delay. The modified stages of delay in this study, showed the importance of patient factors in treatment decision delay. The composite of these women's stories that builds this chronological model notes down each time points, which may or may not occur in each individual chronology of breast cancer. It is

important to note the trajectory of progress and speed of disease is very much individualized to the biological aggressiveness of the breast cancer.

The other important issue addressed by the stages of delay model is the presence of a dualistic health system which is the conventional modern medical system and the alternative system that indeed reflects the multiplicity in range of treatments available to the Malaysian public.

The fourth concept is the importance of patient decision making at each stage of delay.

Fig. 5.1. shows the modified stages of delay, modified from the Andersen model. A more detailed chronology was captured from the data from interviews and review of the case notes as well as a reflective exercise of a breast surgeon. Section 4.4. laid down the evidence for building this model and [Section 3.6.10.](#) showed the development of the model during analysis. We found eight stages of delay in the SBCD model and were displayed in [Section 4.4.](#)

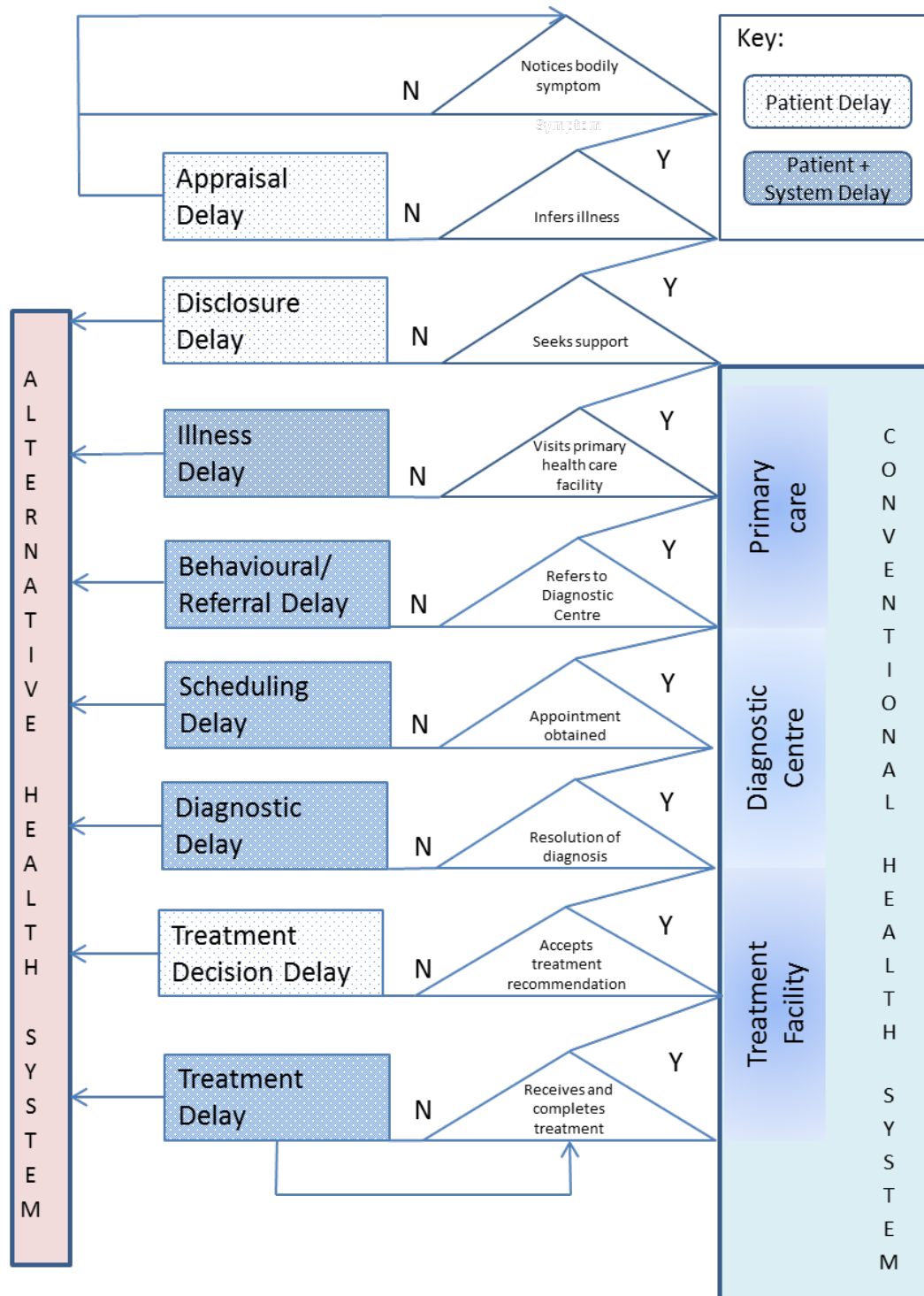


Figure 5.1 The stages of breast cancer delay (SBCD) model a chronological, pluralistic health systems and patient and system delay model

5.2.1.1.Role in Breast Cancer Delay

Patient delay in this study includes the socioeconomic and cultural context of the patient. System delay in this study involve healthcare provider delays. The model is not explicit in which patient or system delay resides as seen in many models as discussed in Chapter 2. In this study the researcher found that both patient and system delay overlap in many time points. The Andersen model describes it as total patient delay and stops at treatment recommendation. However, to be able to utilise such a model, there should be identification of which party influences each time points and the need to recognise that both patient and system delays can occur as evidenced by the data presented in Chapter 4. Hence, to summarise patient delay involves all the stages of delay and system delays which occur at illness delay, referral delay, scheduling delay, diagnostic delay and treatment delay., This is clearly demarcated in Fig. 5.1.

In comparison to the Andersen model where total patient delay was described in the perspective of a patient, the SBCD model in this study encompasses both patient as well as system delays. Other studies have shown that delay is not within the domain of the patient but the systems as well, especially in developing countries where health systems are not accessible to all patients (Rebentisch, Rebentisch, Thomas, Karat, & Jadhav, 1995; Unger-Saldaña & Infante-Castañeda, 2011).

The first difference with the Andersen model in 1995 was an addition to a stage of patient delay in this study which was disclosure delay that was not in the Andersen model. This is likely because the Andersen model is a model based on western perspectives, women were autonomous and empowered, hence sanctioning as well as

support would be less needed for women to come forward when she has a breast symptom.

In another model by Bish in 2005 discussed in chapter 2, disclosure falls within the explanatory context rather than the chronological and socio-economic cultural and health utilisation contexts. The researcher found in this study that disclosure for some women was an important step in resolution of a symptom as well as adherence to treatment. This was discussed in more detail in Section 5.4.

Illness delay in my perspective was similar to Andersen's model. The researcher used the word illness to denote an undefined health issue that patient and significant other may perceive to be cancer or otherwise that makes either patient and/ or significant other seek treatment by non-conventional means. It is similar to illness delay in Andersen's model where after deciding to seek medical attention they did not follow-through; the difference is that in the case of stages of breast cancer delay (SBCD) model, not seeking medical help may bring about seeking alternative care as seen in Fig 5.1. This was grounded in the data from P10.

The third difference between the SBCD model and the total patient delay is the referral delay in this study where as in the Andersen model it is stated as only behavioural delay. Behavioural in this means that the patient delay where a clear referral was made or after inferring an illness fails to seek help at a diagnostic centre. The referral delay was also found caused by system delays in this study where primary health or primary medical care doctors did not recognise the symptom to refer to a diagnostic centre. Scheduling delay was retained in the researcher's model; however it addresses both patient and system delays. Diagnostic delay was also retained but included adding a

path to alternative health system after decision to seek diagnosis at a conventional centre or an alternative centre.

Delays can occur in both systems or using one and then proceeding to the next one if the first one does not work, for example when a patient delayed in seeking diagnosis in a conventional medical centre by first using alternative treatment to attempt to remove the breast lump .

Treatment decision delay occurs after a diagnosis of cancer. , Women delay adhering to treatment recommendations or absolutely reject it. This was not discussed in Andersen's model. As discussed in Chapter 2, other models (Andersen, et al., 2009; Bish, et al., 2005; Safer, et al., 1979) were mainly concentrating on symptom recognition and diagnostic delays rather than post diagnosis delay. Treatment delay is when system delays or patient delays due to competing interests of other medical therapies. System delays that were discussed in Chapter 2 were on diagnostic and treatment provision. In this study a distinction between the two is also made.

5.2.1.2 Dualistic health systems

It is important to note that in the SBCD model, there is a bias in the definitions where it is weighted more towards conventional treatment which is proven to be superior to alternative forms of cancer. The pluralistic health system seen in Malaysia needs to be explicitly addressed in this model as alternative health systems play a direct role in all delays from disclosure delay to treatment delay.

In the survey, the use of alternative medicine was seen not significantly different among different income groups, age groups, cancer status. It was mainly used by Malay

and Chinese women and the least used among Indian women. Further discussion on this phenomenon is discussed in Section 5.5.1. Where a valued but unaccountable alternative health system co-exists with a hostile conventional health system.

Among all the delay models presented in Chapter 2, alternative medicine as a cause of delay was only found in the Unger grounded delay model where “informal health services” were included in the delay model(Unger-Saldaña & Infante-Castañeda, 2011).

5.2.1.3. The explanatory model

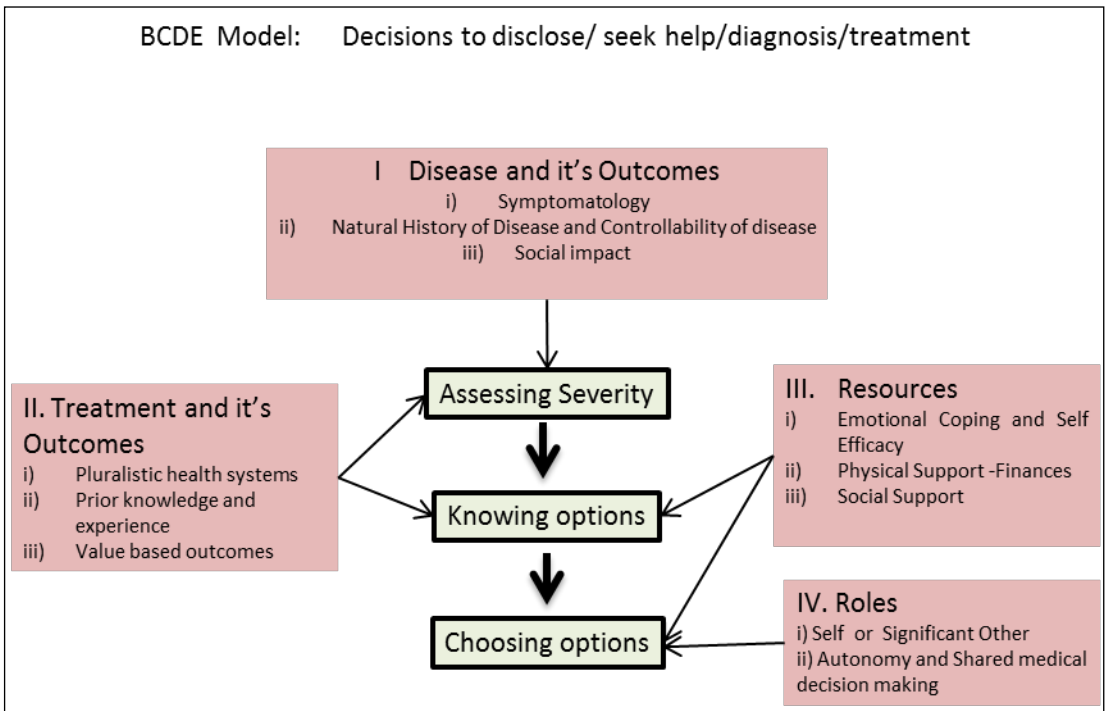


Figure 4.12 The breast cancer delay explanatory (BCDE) model

The analysis of emergent themes was shown in Section 4.5.6. The iterative process of building the explanatory model was presented in Section 3.7.9. At each time point of the SBCD model, decision making process was key. Important constructs for decision

making was presented in Figure 4.12, and shown again here. In Chapter 2, existent explanatory models were discussed and decision making theories presented. The explanations for the reasons for delayed presentation are indeed complex. By having the end in mind, the model should be a simple framework for interventions, hence splitting it into two models. Theories presented in Chapter 2 try to explain help seeking behaviour of women with breast symptoms. The crisis decision theory put forth by Sweeney (2008) explains these processes. However, the role of the participants was assumed as one of autonomy. In contrast, in this study we found the roles played by the participants in decision making toward treatment was active or passive i.e. whether relying or not relying on significant others. Hence, an additional construct- role was added to this model. The crisis decision theory was proposed as a grand theory that can be applied to different scenarios when someone is confronted with a crisis i.e. taking examinations or facing a life crisis like diagnosed to have a cancer. It states that there was a hierarchy in the process of determining a decision (refer Chapter 2.2.3). The three steps were presented as assessing severity of the event, determining the response options and evaluating response options before a choice can be made.

In this study the decision making occurred at each time point:- 1- symptom recognition or inferring illness at the first time point of SBCD model, 2- seeking for support as in the second time point, failure of that leads to disclosure delay, 3- visiting a primary health care provider, 4- referral or visit to a diagnostic centre, 5- scheduling an appointment at the diagnostic centre, 6- receiving a diagnosis of breast cancer, 7- accepting and adhering to treatment recommendations, 8- receiving the treatment. Making appointments and receiving treatment was not solely the decision of the woman and therefore the explanatory model does not apply at these time points.

The BCDE model adapts the crisis decision theory by adapting the three constructs in the process of decision making 1-assessing severity of event, 2-knowing and evaluating options and 3- finally choosing options. By knowing, one is already evaluating options. The three constructs in the process are more intuitive for the average health practitioner. The themes that came out to what led to decision making of women, were similar in that themes those converged towards the construct assessing severity were disease and its' outcomes and treatment and its' outcomes, it was difficult to separate the disease from the treatment, both were feared by the women who participated as displayed in Chapter 4. This was similar to the grand theory where information about causes and consequences was placed as the factors to assessing severity.

The next important construct that predicted the assessment of severity and knowing and evaluating options were treatment and its' outcomes. This included not only conventional but alternative medicines. The BCDE model not being a grand theory is more specific towards decision making in breast cancer. In assessing severity of the symptoms, women also assessed severity treatments, and values placed on these treatments and their' outcomes came out strongly as a theme in the data. In the Malaysian context, there was a heavy reliance on the roles participants adopt in making a decision- some are autonomous and some reliant on others. The overlaps of constructs in the process of decision making was seen also in knowing and choosing options where resources available that were found in the data were emotional coping and self-efficacy, financial support, instrumental and social support. Lastly choosing options were affected by resources as well as roles the women play in the decision making process. These four major constructs affect decision making in women at the time points mentioned earlier. Bearing in mind that decision making is not a logical stepwise exercise, and a great deal of irrational responses based on heuristics and short

cuts do occur (see Chapter 2). It was important that 'resources' was within the model; especially the themes related to emotional coping and support. As these themes suggest a more complex approach towards decision making, the model illustrates that women make decisions also based on these intangible factors.

There are similarities between the BCDE model and the Unger grounded theory (Unger-Saldaña & Infante-Castañeda, 2011). She found traditional delay models too simplistic, she had built a grounded model based on 4 dimensions she found emerging from the IDI i- the context: social, economic, cultural, family-related and health system; ii- symptom interpretation and decision making processes; iii- social network's influences; iv- health service utilisation. I found similar constructs in this thesis, but I had broken the models into two models, one addressing four important constructs: being time based and contextual in the "delay time points"; the pluralistic health systems and identifying the roles of patient and system delays and the importance of patient decision making. The second model addresses the complexities of making decisions that can occur in all the "stages of delay" introducing not just the context of economics and social, it also addresses the psychological impact of the disease. The models that have been built were to improve the clarity of the situation and to be able to offer insights towards possible interventions.

Attitudes and factors affecting help seeking in health may differ in the populations and societies studied. The Unger model has helped improve the clarity of the phenomenon, and validates the findings of this study. Similar issues like economical and social and cultural context can be seen in the study in Mexico and in Malaysia, as both are developing countries. Previous models have been built in the developed world and in mainly Caucasian women.

Unger's grounded model may provide four basic constructs that can be used to plan further research and interventions. However its complexities would have been made more clear by breaking the process or the trajectory as Unger had suggested into a stages of delay model. This would ensure a stepwise clarity for understanding the phenomenon as well as for health policy makers to plan interventions. These models (Fig. 5.1 and 4.19) would serve as a theoretical model for designing confirmatory studies, a practice tool and for designing interventions. Fig 5.2 summarises the reasons for why women present with advanced breast cancer derived from the BCDE model and the next section discusses these constructs.

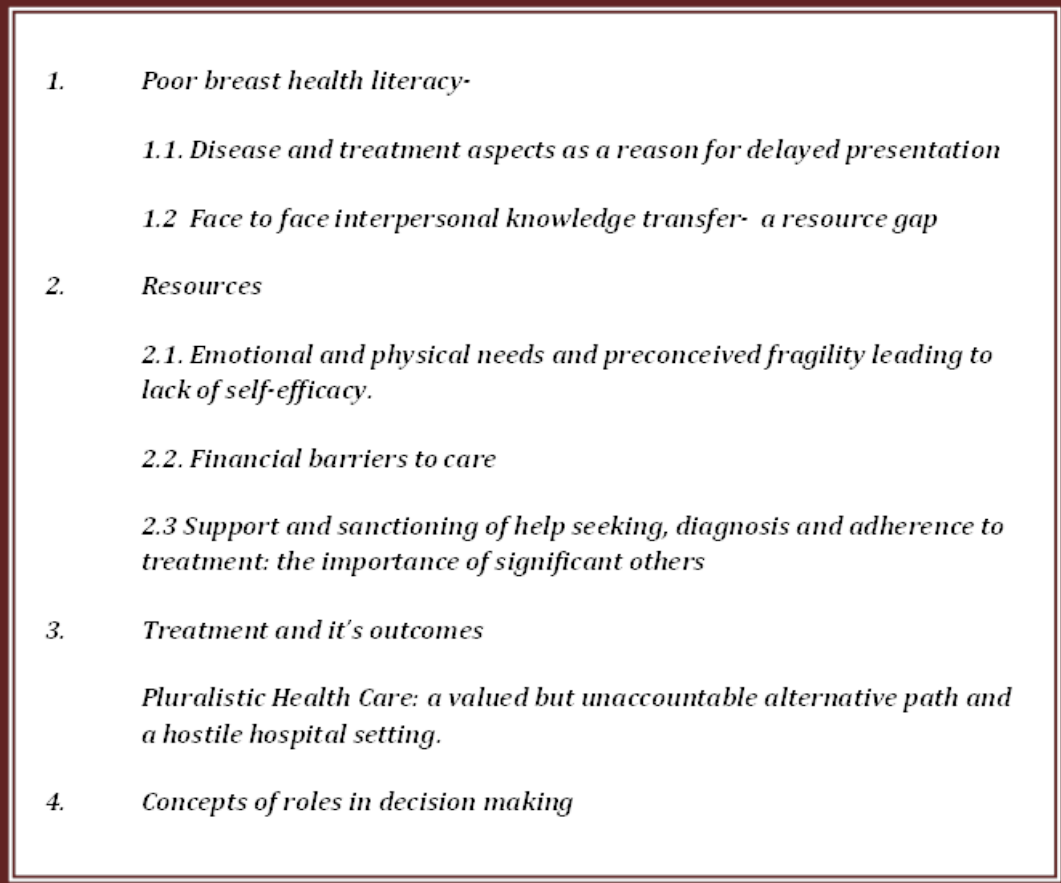
- 
1. *Poor breast health literacy-*
 - 1.1. *Disease and treatment aspects as a reason for delayed presentation*
 - 1.2. *Face to face interpersonal knowledge transfer- a resource gap*
 2. *Resources*
 - 2.1. *Emotional and physical needs and preconceived fragility leading to lack of self-efficacy.*
 - 2.2. *Financial barriers to care*
 - 2.3 *Support and sanctioning of help seeking, diagnosis and adherence to treatment: the importance of significant others*
 3. *Treatment and it's outcomes*
 - Pluralistic Health Care: a valued but unaccountable alternative path and a hostile hospital setting.*
 4. *Concepts of roles in decision making*

Figure 5.2 Summary of the findings of why women present with advanced breast cancer

5.3 Poor breast health literacy- disease and treatment aspects as a reason for delayed presentation

5.3.1 Knowledge of disease and outcomes

5.3.1.1 Participant's representations when labelling a symptom

It is very important to note that women in this study had various reasons for presenting with locally advanced breast cancer. Two of the women had biologically aggressive cancers which progressed within weeks. Many delayed seeking a diagnosis; five did not know the symptom was that of cancer, nine knew there was a breast lump but due to worry that it was cancer, delayed seeking a diagnosis. Four did not disclose their symptoms to anyone and three presented as an “emergency because of massive bleeding from the breast.

This study also highlights the importance of symptom appraisal as seen in other studies as well (C. Burgess, et al., 2001), (Nosarti, et al., 2000; Rauscher, et al., 2010). The analysis indicates that symptom interpretation were weak, with not only non-lump symptoms as seen in studies (Bish, et al., 2005; C. Burgess, et al., 2001) but unique to this study, in that those with symptom of a lump were also delayed, especially if it was painless. In contrast, for some women, expecting classical breast cancer symptoms such as a hard discrete lump and signs of advanced disease also led to missing the diagnosis at an early stage, similar with other studies (C. Burgess, et al., 2001). In this study, three women, one Malay, one Chinese and one Indian participant presented as an emergency when they had massively bleeding tumours. These strong sensory signals such as pain and bleeding also lead to shorter appraisal delay in other studies (Safer, et al., 1979). Studies show that misconception of symptoms was more in ethnic minorities and women of lower socioeconomic status (Rauscher, et al., 2010). This study saw a

mixture of participants from a housewife grandmother to a young university lecturer. Also there were three distinct ethnic groups who presented with advanced cancer. A larger study will be needed to identify who are at risk of presenting with advanced disease.

Other factors that contribute to symptom recognition delay were perceived less personal risk (Bish, et al., 2005) as seen in this study where participants erroneously expect a strong family history to be associated with breast cancer. Negative beliefs about breast cancer and its treatment were also seen to play a role in this study and others (Bish, et al., 2005). Poorer knowledge of symptoms and risks among older women may help to explain the strong association between older age and delay in help-seeking (Cordova, Studts, Hann, Jacobsen, & Andrykowski, 2000; Grunfeld, et al., 2002). In this study, most women were younger in their 40s and 50s. They were not knowledgeable in breast cancer symptoms. An elderly lady of 82 years also did not know that the hardening of her breast was due to a cancer. In addition, young women like P15, didn't think it was cancer because she was young. It appears poor breast literacy was seen across all age groups. Larger quantitative studies will be needed to confirm this.

The literature has consistently placed past experience as a central theme in appraising symptoms (B. L. Andersen & Cacioppo, 1995). Relying on past experience of others, the individual will form ideas on the causes of the breast symptom. As seen in this study, previous history of benign lumps brought about a false sense of security.

5.3.1.2 Healthcare provider lacked knowledge in breast cancer

Symptom appraisal by the patient may not be the only source of delay, misdiagnosis by health providers is also well known. Attributing a malignant lump to a benign lump was seen where a constant annual false negative rate of 4-5% was seen in the assessment of breast lumps in a referral centre (Goodson & Moore, 2002a). Thus, symptom appraisal by physicians and other health professionals is important to diagnose symptomatic women early in the course of the disease especially in young “low risk” women (Eberts, 1934; Greenough, 1935; McCarthy, 1948). Although there have been numerous campaigns by the government and non-governmental organisations on early detection of breast cancer, the messages have been mixed and confusing or perhaps academic detailing of breast cancer symptoms have not reached the masses. More urgently health care providers providing first line services for women with a breast symptom may not be equipped. Studies have shown attributing to a benign diagnosis of a breast lump without a biopsy causes system delays/physician delays (Goodson & Moore, 2002a). Currently, there is no general practitioner focused education on cancer prevention in Malaysia, and this could be reflected by the missed diagnosis in the young and pregnant women in this study.

Information on early signs of cancers is not provided to first line doctors, and neither are there pathways to accessing care. Lack of women seeking preventive care has also increased the barrier.

5.3.2 Sources of information

5.3.2.1 Face to face interpersonal knowledge transfer- a resource gap

Studies have shown varied ways of providing medical information, and varied requirements based on ethnic groups (Kakai, Maskarinec, Shumay, Tatsumura, & Tasaki, 2003) and literacy levels. Although we did not study this in detail, the quantitative survey in this study found surgeons, oncologists, and nurses to be important sources of information, followed by books on breast cancer (refer Chapter 4.2). About a third of the women found that survivor groups were not a main source of information. There was also an unmet need for written information.

A study in Hawaii found that there was a difference in health information use amongst different ethnicities, the Caucasians preferred objective, scientific and updated information from medical journals, whereas Japanese ethnic group relied on media and commercial sources, like television, newspapers, books, magazines and CAM providers. Non-Japanese and Pacific islanders used information sources involving person to person communication with physicians, social groups and other cancer patients. Patients with higher education level related to more scientific knowledge, whereas patients with lower education level needed more interpersonal communicated information. It was important to note that patient's receptiveness to accurate health education depended on a culturally developed world view. Hence, health information should be provided in a culturally sensitive way (Kakai, et al., 2003).

Findings from the in-depth interviews revealed there were gaps in the provision of information. The participants found that doctors were too busy and they were aware that they were in a public system (see Section 4.4) which lacked resources as described in Chapter 2. The quantitative survey measuring the supportive care needs of the participants found that they needed to address their fears of the cancer returning. Hence, with the limited resource that is available in UMMC and most parts of

Malaysia, there is a need to close this gap by providing an interpersonal conduit of information transfer. Specialised nurses may play a major role in this as reported in the UK (refer Chapter 2 from the literature review).

5.3.2.2 Making sense of cancer

The congruence and the understanding of cancer seem to be an important theme, where explanations for cancer helped demystify it and give hope that it can be controlled and cured. “Scientific logic” was used by practitioners to convince the participants in this study. In 2005, the Malaysian government launched the national biotechnology policy, which is the core of the government in promoting biotechnology as a source of wealth for the country. One of its objectives were to improve the scientific literacy in the community (Malaysia, 2005). Although the community accepts the relevance of science, many are easily misled due to a poor foundation in the sciences. A study in Malaysia have shown the need for information from hospitals (S. Y. Loh, et al., 2007). These needs may be different from other countries thus would need to be modified (Gopal, et al., 2005). It was noted that P11 valued that the alternative practitioner explained to her in scientific terms what was happening to her in a much individualised form. There was an unmet need for health information and explanations on tests and treatments provided. However, information alone is not adequate. A form of coaching which provides interpersonal effect and health professional sensitization on value based decision making need to be put in place.

5.3.2.3 Internet as a source of information

Although we found from the study that 61.6% had found the internet to be a non-relevant source of information, this could be partly due to the socio-demographic pattern of the women in this study who are mainly in the low socio-economic group. Internet usage in Malaysia has tripled over the last 5 years (see Chapter 2). The internet usage for Malaysia in 2007 was quite high with 14.3 per 100 inhabitants (Abu Hassan & Omar, 2010). In 2012, a greater number would have access to the internet. The importance of significant others especially the younger generation ie. children of women who have no access to the internet may influence the uptake of these therapies. Also the use of internet as an important source of information for women of this generation that may be affected with cancer in the next decade. A pluralistic approach towards treating illnesses was apparent on the internet. An internet search engine search on 5th February 2011 resulted in 26 700 hits for “rawatan alternatif kanser payudara” (Malay language for breast cancer alternative treatment in). This may represent the accepted norms of the society in accepting alternative treatment as a valid form of treatment. Significant contribution of significant others also influence decision making of cancer patients who have no access to internet. Further studies on the effects of the internet on adoption of cancer therapies are needed. The uptake of direct selling by word of mouth and advertisement may also be perceived as endorsement by the community on the validity of these treatments against cancer. They may well contribute to the dominance of alternative treatments in certain communities in Malaysia. In the qualitative interviews, we found that women used alternative treatment from word of mouth, from internet and also on recommendations of their significant others.

5.4 Resources

5.4.1 Emotional and physical needs and preconceived fragility leading to lack of self-efficacy.

5.4.1.1 Cancer normative beliefs and perceptions as a source of distress

Interpreting the symptom would lead women to label whether they think the symptom is benign or malignant. What that means to them influenced their behaviour to seek help or to avoid confirmation of diagnosis. Avoiding would be due to maladapted coping mechanisms to reduce anxiety. In this study, it was seen that many women could not verbalise why they didn't seek a diagnosis. The fear of having cancer was too much for them to bear, thus they avoided knowing the truth. Avoiding could also mean that they feel that the outcomes of treatment of breast cancer is fatalistic and therefore try to choose pathways that they have not seen before. The relatively low incidence of cancer in Malaysia, which is half the incidence seen in the developed world (Yip, et al., 2006) would make a personal encounter with breast cancer quite rare within the community. Due to the poor outcomes of breast cancer which are stage related and ethnic specific where women of Malay ethnicity survive poorly compared to the Chinese and Indian women (Boo Pathy, et al., 2010; Mohd Taib, et al., 2008), this brings about a social norm of doom. The poor outcome of women with advanced disease is a clear reminder to women with a new breast symptom that it is futile to treat by conventional means. Fatalism has been studied in other cancers (Johnston, 1953)(Davis, Thompson, Gutierrez, Boateng, & Jandorf, 2002; Powe, Ross, Wilkerson, Brooks, & Cooper, 2007) and exists in many communities in blacks in USA (Powe, 1994) and in Caucasians and Mexican-Americans(Joiner, Perez, Wagner, Berenson, & Marquina, 2001) and ethnicities(Prior, 2009). Studies show that fatalistic belief was different in Asians where cancer was seen to be pre-ordained or fated (Straughan & Seow, 1998), while in African Americans, it was a sign of helplessness and hopelessness (Powe & Finnie, 2003). These studies however were focused on well women and their intention and reasons for performing screening mammogram.

In this study, the theme of fatalism emerged strongly and gave some women a sense of hopelessness. Whereas, in some women it did not trigger helplessness or powerlessness but more importantly, it triggered fear and response and rendered ineffective coping, like avoidance of getting a diagnosis. In some women, it triggered the use of alternative treatment (Chapter 4.3.1.2.) as they see conventional treatment not being effective or not compatible with their needs.

Knowing the effect of fatalism in our community, may give some background towards interventions. Faith based interventions have been studied and show a positive effect in the Black American society (Morgan, Tyler, & Fogel, 2008). The concept of cancer fatalism and activism is an important concept towards the behaviour of women (Morgan, et al., 2008).

5.4.1.2 Coping mechanisms and expediting acceptance.

Distress was found not to be dependent on stage of disease (Gilbar, 2005), hence understanding that distress occurs despite an early diagnosis of cancer, would entail a need to provide support to all women. The stages of grief/ the distress can be looked upon in many different frameworks namely the Kubler Ross stages of grief as described in Section 2. Emotional reactions to decision making have been found to be a barrier towards decision making (Luce, 2005).

The most often used coping mechanism that was found in the survey amongst women in the study was acceptance. However this is limited by recall bias as well as a bias of an experienced breast cancer survivor, but we can conclude that it is important to understand the power of reaching acceptance hence promoting adherence to treatment.

In China, women used coping strategies like planning, positive reframing and self-distraction as main coping mechanisms (Li & Lambert, 2007).

In the in-depth interviews the researcher found that women used coping mechanisms like denial, avoidance, self-distraction and acceptance. When the patient is stuck in a non-productive stage of coping, delay occurs. Hence, it is plausible that to intervene crippling coping mechanisms was to expedite acceptance. The case study of P1 an elderly grandmother accepted her condition very quickly after she was told that she has cancer despite her lack of knowledge that her hardened painless breast was a cancer, the use of religion was seen here as a mediator towards acceptance. In most of the

Muslim women, the word “redha” or acceptance was used several times in the interviews when there was a resolution to have treatment or when they had reached a more progressive advanced stage of disease. The same phenomenon was seen in Hindu women and Christian women. Besides use of religious coping, sanctioning and support by significant others also is a factor towards acceptance of the situation.

The non-productive coping mechanisms found in this study were found in other studies of women with breast cancer delay e.g. denial(Phelan, et al., 1992; Wool, 1986).

5.4.1.3 Self-efficacy

Interpersonal resources that promote positive coping and adaptation were found to be; resilience, hopefulness, optimism, self-efficacy, emotional intelligence and spirituality (Andykowski 2008).

Self-efficacy as we saw in Chapter 2 was an important construct in the health behaviour change models, such as, Bandura’s social cognitive theory. In this study, it was found

that some women put a heavy reliance on significant others for support in seeking help, in obtaining a diagnosis and in supporting them for treatment. This may be due to a lack of self confidence and the need for direction.

A western perspective of autonomy and the need for support may contrast with the needs of Asian women. But in this study, autonomy was seen in some women providing a clue that both mechanisms are present but in comparison with the western patients, those needing directives from others may be at a higher proportion. This was also found in other studies related to help-seeking behaviour, obtaining diagnosis and adhering to treatment recommendations in Iran (Taleghani, Yekta, & Nasrabadi, 2006) and in Singapore (Straughan & Seow, 2000).

Self-efficacy was seen to operationalise in patient communication with health care provider too. Improved self-efficacy in interacting with healthcare providers was found to reduce diagnostic delays (Maly et al., 2011). Others had shown that, health self-efficacy determined positive or negative emotional wellbeing by promoting exchange of treatment information on an online discussion group (Namkoong et al., 2010).

Resilience is competence in the face of adversity, where positive adaptation occurs; it is not about invulnerable or invincible qualities but normal adaptation systems (Bonanno, Galea, Bucciarelli, & Vlahov, 2007). Hence, pre-conceived ideas may dampen the ability to act in some women in facing the realities of cancer. Educating women on how to obtain resilience and that it can be obtained by anyone and that the fallacy that inner strength is an innate quality must be debunked to empower them.

Factors that affect resilience are namely relationships with caring others, good problem solving skills and good intellectual functioning (Masten et al., 2004). It was found that

women in this study needed support from family members, friends and also the treating health professional domain.

5.4.1.4. Financial barriers to care

5.4.1.4.1 Financial resources

Financial issues were brought up by one single Chinese lady. Although she stayed with her extended family; she did not disclose to them, neither did she attend to her symptoms until her tumour bled. She was very distrustful of public hospitals that she perceived to be inferior, hence not worth her money to spend, and private care was beyond her reach. Thus, she chose to only seek treatment when she had serious problems, in this case when it progressed to a bleeding tumour. Women made decisions based on their perception of the resources that was present. Only when she had received satisfactory care in a public hospital did she realise how misguided was her notion that care is always unsatisfactory at a public hospital due to the lower cost. This will be further elaborated on below. This misconception proved to be non-productive for this participant.

5.4.1.4.2. Financial impact and cancer outcomes

The cost of treatment had increased over time (Galy, et al., 2010). Women from low income who had self-detected abnormalities were more likely to cause delay than possible delays caused by system detected abnormalities (Maly, et al., 2011). In chapter 2, low socioeconomic groups have been shown to be marginalised in terms of early detection, and treatment. Low socioeconomic groups were associated with poor breast health literacy, poor health care access, poor communication and self-efficacy.

Improvement in survival have been found in early detection programs in low income communities in the USA, and it was not attributed to regular mammogram screening alone and was postulated to access and navigation to care (Howard, et al., 2010).

Racial disparity in survival of breast cancer has been studied in our hospital population patients and in other communities (Boo Pathy, et al., 2010; Tian, Goovaerts, Zhan, & Wilson, 2010). Low socioeconomic status has been implicated and the fact remains that racial minorities are often within the category of lower socioeconomic status.

In this study, we saw both extremes where women who were financially capable of paying for conventional care still chose not to have conventional treatment but spent a large amount of money on alternative therapies. In the other extreme, there were women who were financially challenged but still decided to pay for more expensive conventional care rather than opt for relatively cheaper alternative therapy.

Perception of care in private and public hospitals also emerged in the interviews.

Hence, pluralism in Malaysian health care also relates to the variable cost of treatment in private, public hospitals. The common misconception that the more expensive treatment would be better seems to have brought about a paucity in resource for some, where they perceived they had no resources to pursue curative treatment and hence gave up on the possibility of receiving any form of care.

5.4.1.4.3. Financial cost of pluralistic health care system

The pluralistic nature of health care in Malaysia would bring about the financial burden of paying not only for conventional health care but for alternative medicines too.

In Malaysia, sales of traditional and complementary/alternative medicines are estimated to be 1000 million Malaysian ringgit annually, compared with a market of 900 million Malaysian Ringgit for allopathic pharmaceuticals(WHO, 2001). Neither national healthcare insurance nor private insurance covers alternative medicine in Malaysia. The commercialisation and widespread use of new age medicine especially from other countries was seen in this study, like apricot B-17 from Mexico, transfer factor and Erexel from the USA. A variation of cost of the surgical treatment may reflect not just pluralism in different types of treatment, but different types of allopathic health systems i.e. private or public. Further quantitative research in cost and cost effectiveness analyses are needed to measure the impact of not only allopathic but alternative medicine.

5.4.2. Support and sanctioning of help seeking, diagnosis and adherence to treatment: the importance of significant others

Aside from personal attempts of coping, social support was seen to attenuate and reduce distress(Low, Stanton, Bower, & Gyllenhammer, 2010) and provide resilience.

Facing illness is a highly social event (Charmaz 1995), and it involves the whole outlook of the daily activities of someone when they are diagnosed or perceive a diagnosis of cancer. Appraisal is a decision making process. Andersen (2009) studied process of appraisal and theorised that bodily sensations are also governed by the social and cultural situation experienced by the individual (R. Andersen, et al., 2009).

Reflecting their past bodily experiences, background expectancies and perceived risk based on public information of symptoms of cancer and family history. Furthermore,

women used past experiences of others to validate their symptoms. Women needed to validate these symptoms to seek and obtain help.

5.4.2.1 Disclosure to gain support

Self-blame and shame occurred because cancer is often perceived as a disease caused by self-indulgence and lack of discipline, namely a lifestyle related disease and also due to lack of preventive care that is common a norm in the community. Hence, women may avoid disclosure of their condition due to a sense of shame as a diagnosis of cancer would negatively affect their social status and lead to role transformation. Disclosure and diagnosis would alter social relations, obligations and self-image. They actively held on to their normal duties to reduce future marginalization and social exclusion. This was seen in P11 in her working life, P17 in her social life as a single parent to two eligible brides, P4 who did not want to burden her family members, P9 as she had no social support at all. Lack of disclosure was seen in P1 due to ignorance of not knowing the symptoms and signs of cancer. As a result, these women were not able to garner the support to seek medical treatment at an earlier stage.

5.4.2.2 Sanctioning

In this study, it was found that since at times, symptoms were too mild to be important enough to disclose, it was important to have significant others to provide validation to label their breast symptom as serious. This is called sanctioning and was seen in another study (Smith, et al., 2005).

Non-disclosure in this study was due to social isolation or a personal choice. Seeking help was seen to be dependent on social support with daughters or sons rushing mothers off to emergency departments for a bleeding breast tumour. Sanctioning was important for women at all stages of delay as was discussed in Chapter 2.

5.5 Treatment and outcomes

5.5.1 Pluralistic health care: a valued but unaccountable alternative path and a hostile hospital setting.

Malaysia has a rich pluralistic health seeking culture, the dichotomy of conventional and alternative therapies are evident in the interviews, where women choose one over the other, and both seem to be of equal standing. This phenomenon was also evident in other Asian countries as well as western countries (Tseng, 2001).

Complementary treatment or alternative medicine (CAM), is defined as a broad domain of healing resources that encompasses all health systems, modalities and practices and their accompanying theories and beliefs other than those intrinsic in to the politically dominant health system of a particular society or culture in a given historical period (Zollman & Vickers, 1999). Different health systems need to coexist with each other. The argument made by practitioners is that positivistic trained physicians are not open to complementary medicine. Whether or not the use of complementary i.e. the use in adjunct to biomedicines are accepted by the alternative practitioners and vice versa, remains to be seen. Some studies suggest it may work in Malaysia (Talib, 2006).

The therapeutic relationship and trust that patients experience with their health care giver in either realm evidenced in this study provides some understanding of the values patients place in their health seeking and health utilisation practices.

5.5.1.1 Alternative treatment

In this study, alternative therapy was used by the participants. It appears to be both alternative and complementary in nature. It was seen that traditional healers like shamans or “bomoh” were not used by this urban sample of women, in fact it was seen as against their Islamic beliefs. But traditional treatment like massage and home remedies are still being used. New age medicines seem to feature prominently in this study with homeopathy and direct selling products being used by the women. This was supported by another study of the immigrant Korean community in Australia. Not only folk or ethnomedicine were practiced but there was a trend towards new age medicine due to changing social conditions (Han & Ballis, 2007). Additionally, another study in Malaysia found that the population use herb-based therapies for both health issues and health maintenance (Siti et al., 2009). Nevertheless, studies have shown use of alternative and complementary treatment delayed seeking medical attention in Pakistan (Malik & Gopalan, 2002) and Taiwan (Tseng, 2001).

The participants’ significant others and social support like husbands, parents and extended family remain the main source of information on alternative therapies for most of the participants. Therefore health literacy needs to reach the masses in order to allow women more option and information not only on folk remedies and alternative treatment, but conventional treatments that have been proven to be efficacious for cancer treatment.

5.5.1.1.1 The value of alternative treatment

The value of alternative medicine remained important to the participants, despite the obvious progression of the disease. The attitude seen was a balance of the positive and negative. Value was placed on the good psychological and spiritual support properties,

which gave them strength. The negative attitude was the anger when the treatments did not work, or when it caused great discomfort. It was very interesting that many blamed themselves for the poor outcomes and took responsibility for their treatment choices.

5.5.1.1.2 Emotional and spiritual salve

The effect of the cancer diagnosis on the affective response is well known (Link, et al., 2005) and was evident in our study. There is lack of psychological support in cancer care in the biomedicine model health system in Malaysia (S. Y. Loh, et al., 2007). The pluralistic nature of Malaysian health systems brings about many choices. Patients try to reap benefits from all quarters. Spiritual support is also needed by cancer patients (Taylor, 2003). It is not readily available in Malaysian hospitals (S. Y. Loh, et al., 2007) as compared to the west (Frenkel & Cohen, 2008; Ott & Lynch, 2002). Although spiritual coping has sometime been seen as a barrier to health seeking behavior (Hamilton, Powe, Pollard, Lee, & Felton, 2007}, Harandy et al., 2010), it cannot be ignored as a need of the patient as evident in our study. In Norway, younger women felt the need for pastoral services to be provided in hospitals (Risberg, Wist, Kaasa, Lund, & Norum, 1996). In Taiwan, specialist nurses are trained to provide spiritual support to elderly cancer patients (Shih et al., 2009). The sensitive issues of religious conversion in Malaysian society do not allow religion to be discussed openly in institutions like hospitals. However, in the last 30 years in the US, spiritual care programme has matured in cancer centres, and they have become an integral member in the multidisciplinary cancer team, and a multi-faith approach has been used (Sinclair, Mysak, & Hagen, 2009).

The misunderstanding and cultural dissonance between patients and health providers are important to address. Culturally competent health care is recognized world wide, due to the heterogenous cultural backgrounds of many communities (Barlow-Stewart et al., 2006)(Ka'opua, 2008; Prior, 2009)(LZ, 2010)(Malaysia, 2005).

5.5.1.1.3 Non-accountable treatment

However from this study, not using metal at all is a total departure from what is practiced in modern medicine, where a biopsy with a needle is mandatory to obtain a diagnosis. In our study, conventional medical ethics were not a feature in alternative therapy medicine. Many used lab- based scientific research, commercialising it without clinical trials. Using lab tests without knowledge of the traps of its interpretation was seen in this study. Female chaperone in examination of a female patient by a practitioner is also questionable, some used their wives, but are there regulations and ethics to regulate practice? Burning the breasts with joss sticks as seen in this study was dangerous. Traditional Chinese medicine is self-regulatory in Malaysia, with the unit of traditional Chinese medicine that had been established at the Primary Health Care Section, Family Health Development Division, Ministry Of Health (WHO, 2001).

The stigma of looking silly for choosing this path may also be responsible. In the interviews, the word *con man* did surface. It is very unlikely that women would complain to regulatory bodies against these alternative practitioners, as the participants blamed themselves for choosing these therapies. Therefore, regulatory bodies would not be able to take action against errant practitioners.

From this study, we can see that norms of the society are changing in that women are aware of failed attempts at curing their cancer after using alternative medicine for cancer. However, in this study there seems to be a lack of awareness amongst participants and their significant others in the accreditation and regulation of alternative practitioners. Registration of traditional and complimentary products had been legislated in 1992. The Ministry Of Health Traditional And Complementary Medicine Division was created in 2004 to regulate the practice of alternative practitioners. This has brought about integrative medicine in eight government ministry of health hospitals in 2006 (Traditional and Complementary Medicine Division of Ministry of Health of Malaysia). However, further data on registered practitioners are not readily available to the public and in the interviews only one patient was aware of this accreditation. Furthermore, since the practice is not mainstream, women felt powerless to report against them. Therefore information on regulation in the community is required to protect women from unethical practices. For example, the use of an unlicensed Chinese healer by a participant in this study who was traumatised by the event and not able to disclose what happened to her in the interviews, as corroboration with medical notes revealed that her breasts had multiple burnt marks with joss sticks which must have been painful for the patient. Unhealthy nutritional practices where patients were advised not to take proteins from meat source, was unethical when education on a proper vegetarian diet was not given.. The effects were seen in one of the participants who presented with hyponatremic fits and coma. Adverse side effects of complementary alternative medicine have been reported in the literature, but due to non- structural reporting systems in most countries, little is known about it (Jose, Rao, Kamath, & Jimmy, 2009). There was a difference in the values based on what was important. There are laws on production and sale of traditional medicines since

1992(WHO, 2001), however nutritional supplements and practices may escape this regulation.

Direct selling medicine, in addition to other alternative medicines were utilized by these urban women. Women need direction in adopting treatment, therefore engagement of significant others is crucial to ensure women make good decisions. Using scientific arguments, religious revival and premature commercialization of lab research have added on to the success of alternative treatment in the Malaysian market. Education of the public on evidence based medicine and regulation of alternative practitioners and public awareness of this accreditation exercise are urgently needed.

In this study, it was seen that some alternative practitioners used titles like ‘Professor’ and ‘Doctor’ indiscriminately to lend justification on the efficacy of the alternative treatment. Some of these alternative therapies were sold in beauty salons and in restaurants lending some scepticism to scientific communities but may be acceptable to lay people. The use of ‘Professor’ and ‘Doctor’ titles in websites of alternative therapists are wide spread, with no justification of where those titles come from. As these titles refer to a reputable and knowledgeable person, the products recommended were felt to be endorsed by knowledgeable and reputable members of the society. The medical act in 1971 clearly states that those impersonating a qualified doctor can be charged (WHO, 2001).

The local media report cancer cure therapies based on preclinical research data, which are mainly seen in animal and cell lines studies and the call for industry to commercialise these products were reported in the local newspapers (R. Lim, 2011; Unknown, 1998). Unsuspecting members of the public with no knowledge of clinical trials and the need to prove safety and efficacy in human subjects will be easily duped

into using these products for treatment of cancer. Furthermore with the pressure to self-fund, public universities are keen to commercialise their research products quickly (Moynihan & Sweet, 2000) without the rigours of clinical trials.

Access and lack of regulation of medical tests that can be done in private labs have made its use readily available to anyone who can pay for these services. These tests are plagued by variable sensitivity and specificity and without trained medical personnel to interpret the results correctly bring about a false sense of security. This is seen in one of the participants who were upset to learn that cancer cannot be diagnosed by a blood test as claimed by a homeopathic practitioner.

The use of religion as therapy has brought about commercialisation of businesses in relation to health products such as black cumin, Zamzam water and water blessed with verses from the Quran, and health programmes such as sunnah treatment mentioned by the participants. Although spiritual support for patients may be lacking in UMMC and other Malaysian hospitals, its exclusive use may lead to undertreatment of cancer patients. Advertisements are seen on national television as seen in this study. Thus, education of the public on evidence based medicine and regulation of alternative practitioners and public awareness of this accreditation exercise is urgently needed.

There was value attributed to alternative medicine in the participants studied. It fills a void in the biomedical model in cancer health care in Malaysia. A new direction in healthcare in Malaysia must take into account the biopsychosocio-spiritual model. Adoption of this paradigm is urgently needed in cancer care today.

5.5.1.2 Conventional treatment

5.5.1.2.1 Knowledge on treatment outcomes

5.5.1.2.1.1 Fear of mastectomy and chemotherapy (Section 4.6.2.2.)

In this study, it was fear of surgery and not just mastectomy as was seen in P15 and fear of death from surgery by significant others in P7 and P12, fear of pain in P3. Other western studies also showed similarity in the issues with mastectomy that was expressed by three women (Weinmann et al., 2005).

In P11 it was described that mastectomy led her to have low self-esteem, P5 felt she was disfigured, P2 describes mastectomy may cause losing husbands and not being able to marry in P15.

A case control study of 2600 patients in a multi-centre study in the USA found that patient diagnostic delays in women with suspicious symptoms was seen in older women 75 years and above, and other who have six or more children, low use of mammogram, high use of clinical breast examination and missed appointments. Some recorded reasons were avoidance-denial-fatalism, fear of diagnostic tests, fear of surgery or disfigurement(Weinmann, et al., 2005)

A qualitative study in Malaysia on all types of cancer had shown a similar aspect towards fear of surgery, but this was not a study specific to breast cancer. In this study, fear of chemotherapy was also seen(Farooqui et al., 2011).

Fear of chemotherapy surfaced in many of the participants, not being able to stand the side effects (Section 4.6.2.2.4). However from this study many reported that they did not suffer very bad side effects contrary to what they anticipated.

5.5.1.3 Health systems and access

Placing systems to downstage cancer have been shown in Sarawak, where by educating health care providers in the primary health care setting successfully downstaged multiple cancers over a period of 4 years (Devi, Tang, & Corbex, 2007). Studies on experience and needs of women illuminated needs of women in accessing doctors and information (Loh, et al., 2007).

Studies on outcomes of treatment in Malaysian hospitals have been scarce with reports from individual hospitals rather than national figures (Mohd Taib, et al., 2008; Ong & Yip, 2003; Taib, et al., 2007).

Health system predictors of timely diagnostic resolution that have been identified were self-identified abnormalities and health provider detected abnormalities. Which refers to detection in the radiology or surgery department and these predictors were found to be different in different hospitals. Thus, interventions need to be tailored to a hospital's unique culture (Mojica, Bastani, Boscardin, & Ponce, 2007). This is very revealing in that one intervention may not be suitable for another hospital, as each individual hospital may have a distinct health care provision culture.

5.5.1.4 Patient provider communication

Providing instruction and teaching communication skills to health care providers caring for cancer patients is now a priority in the UK (Eggly et al., 2009). A study of two county hospitals in the USA with a predominant Latina presence showed that patient factors that predict delay were patient-provider communication. It was found that diagnostic resolution was achieved when there was satisfaction on how physicians explain breast abnormalities (Mojica, et al., 2007). In Chinese women in Hong Kong,

decision making was made in the absence of information. Most used intuitive and emotionally driven decision-making and they were coping with cancer by gambling their lives. There was a need to provide emotional support when there is overwhelming uncertainty (Lam, et al., 2005). In Brazil, Primo & Garrafa (2010) found that culturally inappropriate language was used by health care providers and there was a lack of consideration for patient autonomy. There was an absence of a mechanism that provide decision making power to patients, 73% considered negative quality of information received on diagnosis and treatment. 40% had experienced poor physician-patient communication. Age and extent of disease did not influence patients' degree of understanding (Primo & Garrafa, 2010).

Further, in a study of black and white Americans, satisfaction in patient-provider relationships was an important predictor to earlier diagnosis. The narratives of the women revealed that many lacked knowledge about their diagnoses and treatment regimens. Those patients who demonstrated a better understanding of their disease and treatments also seemed to adhere to recommendations for adjuvant therapy (Sheppard, Adams, Lamdan, & Taylor, 2010). Although there was similarity in these findings with this study, the study design was too dissimilar to make direct comparisons. A narrative of a Malaysian breast cancer survivor published in the *Lancet* in 2005 reiterated the importance of patient-provider communication not only in the aspects of information provision but also on being sensitive to the social needs of women (Kaur, 2005).

As we saw in the previous section on the values of alternative treatment, women needed psychological, spiritual support and treatment that fitted their values. In this study, there is an obvious gap; likewise this has been reported in African Americans in the USA (Davey, Kissil, Nino, & Tubbs, 2010).

5.5.1.5 Culturally appropriate health service

5.5.1.5.1 Cultural sensitivity

Interpretation of disease and health is very much in the social and cultural context. A study of Malay Muslim women had shown the need for culturally appropriate health provision which involves understanding what is important to women of different cultures and religion (Ahmad, et al., 2010). There is a call for health care professionals to be aware that their values are culturally and socially constructed (Dein, 2004). There are obvious challenges in catering to three major ethnic groups in Malaysia where the use of differing language and cultural context in healthcare and the diversity of the ethnic groups of health care providers somewhat caused a mismatch in providing culturally sensitive healthcare.

The misunderstanding and cultural dissonance between patients and health providers are important issues to address. Culturally competent health care is recognized worldwide, due to the heterogeneous cultural backgrounds of many communities in a globalized world (Barlow-Stewart, et al., 2006), (Ka'opua, 2008; Prior, 2009). Malaysia is a multiethnic, multicultural and multi-religious society, therefore health providers have to be equipped to understand their patients, in order to gain their confidence in instituting therapies that are wrought with side effects. Hence, healthcare providers like surgeons, oncologists and nurses trained in the biomedical model, will need to have a holistic view of the patient, ie. not just treat the disease or bodily effects of disease but also treat the illness or the symptoms experienced by the patients. The diversity of the beliefs that are intertwined with their treatment choice was seen in this study. Without cultural competence, it is very likely that women may be misunderstood.

There seems to be a lack of clinical practitioners like social workers, counsellors and psychologists who may support the psychological and spiritual needs of patients in Malaysian hospitals. This was attributed to poor career development in public hospitals (LZ, 2010). Hence, the incorporation of the biopsychosocio-spiritual model need to be addressed by doctors and nurses directly involved in the care of cancer patients especially general surgeons and oncologists and the staff nurses managing these patients. It appears that, many women will still need to use alternative treatment to cope with their anxieties and fears as it is not addressed in conventional biomedical model hospitals.

The explanatory model in this study will help to narrow the gap by providing a framework to health care providers to understand and provide for the information needs of patients. A more culturally sensitive workforce is needed and this has to be provided in medical and nursing schools. The model of course cannot replace training in communication skills, but awareness of the needs of patients including coping resources would improve communication of treatment recommendations.

5.5.1.6 Integrative medicine

Conventional and alternative medicine may co-exist together, and a new model in health care delivery is called integrative medicine. Where integrative medicine reaffirms the therapeutic relationship, with a focus on the whole person and lifestyle and not just physical body, willingness to use all appropriate therapeutic approaches whether they originate in conventional or alternative medicine (Maizes, et al., 2009). Although Malaysia has eight integrative hospitals in the country, most cancer services do not include integrative health care. There is a disparity in the acceptance of

alternative treatment use in a complementary fashion amongst health care providers. Medical school of origin may have a distinct effect on exposure and acceptance of complementary medicines(Nabilla, et al., 2002).

5.5.1.7 Navigating conventional health systems

Word of mouth, GP network and contacts emerged from the data, again suggesting an informal network is present in Malaysia. A less resourceful person may not be able to access care. Disparities in cancer outcomes in the USA between the two major ethnic groups ie. Black Americans and White Americans were attributed to poor access to care. Hence, interventions such as navigation projects have been studied in this community as well as the Asian community there (Carroll et al., 2009; T.-U. N. Nguyen & Kagawa-Singer, 2008).

5.5.1.8 Regulation of cancer services

Auditing conventional health systems and alternative health systems may be necessary to provide the public information to make good choices on therapy. This will be further discussed in the section on the impact of the explanatory model in breast cancer.

5.6 Concepts of roles in decision making

5.6.1 Significant others

In Section 5.4 it was evident that in the support and sanctioning of help seeking, diagnosis and adherence to treatment, the importance of significant others cannot be further emphasized. This subchapter takes into account the role women play in their health-related decision making: 1) from the perspective of the client- i.e. do women make decisions on their own or are they directed towards it, 2) the other is the perspective of the health care provider i.e. does the health care system in UMMC provide directive or shared decision making

Triggering factors to utilisation with directives from significant others gives insight that a women is not a sole decision maker in deciding her treatment. There are types of influence - significant others influence decision making namely persuasion, assistance with understanding, indirect influence and negative influence. The first two led to higher surgical uptakes and reduced decisional conflict in a study (Dancyger, Smith, Jacobs, Wallace, & Michie, 2010).

The social capital is missing in the context of self-efficacy construct. A study on Latina and Filipino women in the US found that women rely on the quality and quantity of social capital to make health related decisions (Burke et al., 2009).

5.6.2 Patterns of health related decision making: role of the health care provider

In this study, themes emerged to show the importance of decision making made by women along the trajectory of the cancer experience. Although in this study, the transaction between patient and health care provider was not studied explicitly, the

importance of these transactions is important in encouraging adherence to health care recommendations.

There are varying amounts of responsibility that women may be comfortable taking in making treatment decisions, so sensitivity of the health provider towards individual variations is important to ensure a comfortable compromise can be made (Errico & Rowden, 2006). As illustrated in this study, each individual women had their own reason for not following recommendations based on their interaction with the health care provider. Furthermore, in this study, the values they placed on acceptable side effects of treatment shown a need for health practitioners to respect this need. There is a move to include values of patients into the decision making process (Karel, 2000; O'Connor, Drake, et al., 1999). Shared decision making is where two parties discuss and make a collective decision. The responsibility of decision making falls on both parties with a heavy consideration towards the patients' preferences (Charles, et al., 1997; Charles, et al., 1999; Frosch & Kaplan, 1999).

However, the sense of feeling through a consultation is important because for some patients, a more directive approach is needed. A study in the USA showed that people with cancer had a higher need for health professionals to select cancer treatment options and in contrast the general public wanted to select their own treatment. In addition, they wanted their family members to share responsibility towards decision making when they are too ill to participate in it (Degner & Sloan, 1992). This again highlights the importance of significant others in their decision making.

Assumption of decision making capacity of patients has been studied and that healthcare providers make judgments based on ten myths, especially the myth that

women who go against medical advice are considered lacking decision making capacity (Ganzini, Volicer, Nelson, Fox, & Derse, 2004).

5.6.3 Autonomy

Individualised preference towards decision making is an important concept. In the USA, females, with higher educational attainment, better self-rated health and fewer prescription medications predicted active involvement in discussing and selecting treatment, while older women preferred to be given treatment options (Flynn, Smith, & Vanness, 2006). No studies have been done in this area in Malaysia.

Chapter 6 Limitations of study design and execution

This chapter is a discussion on the strength of the study design and analysis and the limitations encountered in this study.

6.1. Mixed method study design

The time for this MD programme was limited to a two year study leave- for data collection, learning research methods- hence a pragmatic view of data collection was used. There are other types of mixed methods design; the sequential design and triangulation design(Creswell & Plano Clark, 2007). These designs would require a longer period of study. It was important that in the period of the two years, not only information regarding the reasons for late presentation were studied, but a need to understand the population that further research and intervention would be applied on was required.

Although the embedded design, is usually used for experimental designs where a large interventional quantitative study is supplemented by smaller qualitative study (Creswell 2007). The embedded design clearly states that it answers multiple research questions concurrently and the aim is not to triangulate but to complement the research(Creswell & Plano Clark, 2007). Consequently, that was why this study design was selected.

6.2. Qualitative design

6.2.1 The tensions between purist or objectivist and constructivist epistemology

Reflexive aspect of a breast surgeon interviewing the patients would limit the interpretation to a more constructive grounded theory rather than the original objectivist Glaser grounded theory which required complete independence of the researcher. This would produce some tension between purist researchers and constructivist researchers

(Whittemore et al., 2001). The constructivist acknowledges the researcher's background, beliefs, knowledge and values; it is unrealistic that a researcher can be truly agnostic about the phenomenon being studied. It also means by acknowledging the presence of the researcher's background, a more objective view of the phenomenon is taken into account. Being a breast surgeon examining a topic that has affected my practice for several years, may place the researcher with pre-conceived ideas. It was refreshing to have the awareness of reflexivity. The researcher is able to understand the value of alternative therapy that the participants spoke about, and the equal weight that alternative medicine is placed in our society. A psychologist or social scientist may not see this as an important aspect of the data, but this is valuable information for a surgeon with an implication towards changing one's practice to accommodate alternative medicine as complementary form of medicine.

There were tensions of using quantitative typology for qualitative designs as there are limits the choice of words. In this account, the researcher used validity to mean the authenticity of the study, reliability as a measure to be able to replicate the methods. An audit trail was done to ensure the reliability of the results.

6.2.2 Validity/truthfulness of the study

Validity of a qualitative study can be divided to primary and secondary criteria (Whittemore, et al., 2001).

Primary criteria; include the authenticity and credibility where one must remain true to the phenomenon studied. The stance on constructivist grounded theory, clearly declares the role of the researcher. Thick description and the differences between participants were displayed in Chapter 4. There are issues of participants portraying themselves in

the best light as well as delivering what they expect the interviewer wants. Participants shared many sensitive accounts as well as their bad experiences in the hospital despite knowing that the researcher was a surgeon. This proves that although it was disclosed, the trust gained in sharing their accounts showed that this issue was kept to the minimal. Also included in the primary criteria were criticality and integrity. For instance, the ability to critically appraise one's work, hence the limitations of the study are presented in this chapter.

The secondary criteria include explicitness of the study. This is done through vivid descriptions of the data. In Chapter 4, there was creativity in delivering the results in a clear and simple way and was backed up by data. The phenomenon of delayed and advanced presentation was displayed in Chapter 4.3; the meaning of health care utilization in Chapter 4.4, the stages of delay in Chapter 4.5. and lastly an explanatory account as to why women present with advanced breast cancer in Chapter 4.6. The discussion in chapter 5 ties up these major themes and constructs. Presenting the case studies based on the models was also done in Chapter 4.6.

6.2.3 Design considerations:

6.2.3.1. Sampling decisions

Due to the time constraints, triangulating data from other sources such as sampling other stakeholders like breast surgeons, oncologists, and policy makers was not done due to the time limitations. Including negative cases or, women who presented early was important to further find reasons why they come early, hence giving evidence for enabling women to present early in the course of disease (Garro, 1998; Andersen, et al., 2010). This was not performed due to time constraints.

6.2.4. Analysis

6.2.4.1 Lost in translation

The data was coded in English from the transcripts' original form in Bahasa Melayu (Malay language)(12 participants) and English (3 participants), since the researcher is conversant in Bahasa Melayu and English. In the non-Malay or non-English interviews (4 participants) some meaning and nuances may have been lost in translation. Four Indian women were interviewed; three in English by the researcher herself and one was in Tamil. The four Mandarin interviews and one Tamil interview were translated by a research assistant and by the research nurses (RN) conducting the interviews. In addition to the transcripts and translation, field notes were annotated by the research nurse to convey the non-verbal cues that she picked up during the interview since the researcher was not present. At the end of the transcript the RN also provided other observations like the place of the interview and other activities occurring at that time ie. if the interview was done at home, what type of additional information about the significant others or non-participants in the interview was noted.

In four of the Mandarin and in the only Tamil speaking participant, member checks were performed after translation and transcription. The coding was then performed by the researcher in English, and this was shown to the RNs to corroborate the meaning to ensure accuracy.

5.2.4.2 Internal checks

There would be credibility in the findings since the researcher had two supervisors, one clinical and one from outside the clinical field, a clinical psychologist who is sensitive to the methodology of qualitative interview. Listening to the audiotapes to check on the researcher's interviewing skills. This was important at the beginning, and furthermore doing codes for earlier transcripts allowed some form of quality control.

Internal checks, namely member checks should be done at the transcribing and after coding and analysis. In this study, member checks were done only at the transcribing stage. The women who had presented with advanced cancer were quite ill and were dying from the disease, hence some were not able to be re-questioned. Member checks after interpretation were not done as the time for analysis and completion of the thesis far exceeded the lifespan of some of these participants. This somewhat limited the validity of the study.

Triangulating with other sources of data ie. sampling other stakeholders- doctors, nurses, policy makers was not done due to the time limitations.

Participation of non-participant observers in the in-depth interviews like spouses, family members present during the interviews allowed check and balance on what really happened. Also observation of family interaction occurred, and at times may lead to bias in reporting due to the presence of these persons (Andersen, et al., 2010). The focus of the study was on the individual women and not the carers, hence, little was done to incorporate this into the analysis.

6.2.4.3 Cultural differences

More cultural differences may exist but was not studied specifically in this study. Thus a sampling of more Chinese and Indian women may help unearth some important differentiating cultural issues to aid designing culturally appropriate educational programmes to the public, although care was taken by communicating with the research nurses interviewing women in Mandarin and Tamil. The limitation of not being able to interview all women due to the language barrier faced by the researcher and losing the nuances not provided by translated transcripts also reduced accuracy of the findings of this study.

6.2.4.4 Recall bias and effect of the cancer trajectory

Illuminating reasons for delay is the main objective of this thesis. A more accurate study would be to study the illness episodes prospectively. A study by Garro (1998), women were interviewed as they made their decisions after experiencing breast symptoms (Garro, 1998). In contrast, this was a retrospective study. Recall of past events with a foresight of experience may unwittingly make the stories of these women biased and inaccurate in explaining their journey. Especially so, because they personally experienced progressive disease, hence their perspectives and interpretation of what happened to them, earlier would be altered. The adaptation to the emotional turmoil and progressing towards more effective coping mechanisms like acceptance may have altered their perceptions and narrative of their experiences.

6.2.5. Generalisability

This study has limitations inherent to its inductive and exploratory nature.

Confirmatory studies would need to be done to confirm these findings to generalize it to the population (Ritchie & Lewis, 2003). Although a limitation of this study, the nuances and in depth study of the phenomenon would be impossible to capture in a quantitative survey. This study was carried out in an urban tertiary practice, hence a practice in secondary care and in rural areas may reveal a different pattern all together. On the whole, the in-depth interviews and constructivist grounded theory analysis would contribute much to the research field in highlighting the medical, psychological, social, and spiritual issues faced by such women in their “real” world.

Although generalisability can be executed in quantitative research, Firestone (1993) had described generalization for qualitative research. Generalisation in qualitative research can be divided into three types as listed below (Ritchie & Lewis, 2003).

(1) Representational generalisation (empirical generalisation) where applications to other groups within same population. But as mentioned, transferability of findings may be difficult, since this is an urban practice, with patients mainly from the outskirts of the Klang Valley. However, we did have patients who were from other states like P15. Some of the participants experienced the diagnostic process outside UMMC (P2, P15). This is especially true in the northern states of Malaysia where issue of delayed presentation is prevalent. This study will not be able to explain the phenomenon there completely as the patients there may have other issues that are unique in that population that need further research.

(2) Inferential generalisation (also called naturalistic generalisation): Transferability to a different cancer may be possible. However, this study is mainly on women and specific to the breast cancer, hence cannot be generalized to other cancer populations.

It is however plausible that the four constructs in the explanatory model of knowledge of the disease and its outcomes, knowledge on treatment and its outcomes and resources the patients have and the roles that they play may be of the same constructs to explain why people would present late in other types of cancers.

(3) Theoretical generalisation: The model that was generated would be a middle range theory which would explain the problem in a specific group of people. However, with this finding, the crisis decision theory by Sweeney (2008) has proven to be universal in its application at least to breast cancer patients in an urban practice in Malaysia.

6.2.6 Reliability

Soundness of the study design is dependent that research can be replicated elsewhere. This is possible when using the steps in the study, such as using the topic guide, interviewing and coding as described in Chapter 3.

6.2.6.1 Audit trail

The trustworthiness of the project can be traced back with the audit trail left by the researcher. Audit trail of the study was all the recordings in the N Vivo program and memos written in Word program. Other types of data that was used to triangulate the findings were from patients' hospital folders and a written memo on the patients' progress.

The interviews were transcribed verbatim by research assistants, which meant each sound made by the participant was recorded. The transcripts were personally checked by the researcher by listening to the audio-recordings for accuracy. Member checks

were done where these transcripts were also shown to participants to ascertain the accuracy.

6.3 Quantitative discussion

Descriptive analysis was done with most of the data. The instruments that used continuous variables were explored for normality and when was not normal in distribution, non-parametric tests were done. All categorical data were analysed using non-parametric tests.

6.3.1 Quantitative design

6.3.1.1 Sample size and representation

The sample size calculated was to obtain a number that could be generalized to breast cancer patients in Malaysia. The calculation was presented in Chapter 3.

Consecutive patients were asked to participate; the types of patients that attended the oncology clinic were a mixed group of patients. There may be a bias towards breast cancer patients who have recurred as well as women with metastatic breast cancer.

Besides the oncology clinic, breast cancer follow-up is also done in the surgical outpatient clinic. The women followed up there are more likely to be in remission.

Logistically, it would be more difficult to accrue women from the surgical breast clinic as it was a casemix of with well women coming in for screening and for other breast related symptoms.

The statistical model for generalization is built upon random sampling. Results with human subject rarely involve random sampling, as cooperation and logistics issues

rarely can be solved (Ritchie, 2003). Sampling that was done was not random sampling, although a violation in statistical analysis, most medical evidence are based on consecutive purposeful sampling, rather than random sampling.

For the validation exercise, the 19 women included in the qualitative study also answered the questionnaires at least 2 weeks after the in-depth interviews. Validation using factor analysis does not need rigorous sampling methods (Field, 2009). Thirty seven women repeated the questionnaire for reliability testing.

6.3.1.2 Missing data

A total of 266 patients were interviewed, 5 were excluded due to missing socio-demographic data. Some data was missing in the instruments. The research nurses went back to re-question but some questions were deemed too sensitive to disclose and participants refused to answer them.

6.3.2 Instrument development and adaptation

Limitation of time did not allow instrument to be developed after an exploratory study. The descriptive instruments were validated for content and face validity. No psychometric testing was needed.

6.3.2.1 Validation of instruments

Psychometric property testing was done for the SCNS SF34 instrument (refer Appendix A). Exploratory factor analysis was done to see whether the items mapped to the same categories for the instrument that was used in an Australian population (Bonevski et al.,

2000). The SCNS SF 34 was found to be a valid instrument in English version. The numbers were not adequate for testing the Malay and Chinese version.

The Brief Cope had been validated for the Malaysian population, hence no validation was done for the instrument (Yusoff et al., 2010). Furthermore, to be able to psychometrically test, each construct would need at least 3 items, for which the Brief Cope only had 2.

6.3.2.2 Criterion validity

The researcher did not provide another questionnaire to perform criterion validity since there was no recognised gold standard questionnaire that could measure needs of women. On hindsight, the needs questionnaire would have been better developed from qualitative methods, to ascertain unique needs of Malaysian patients attending cancer services. There was a lack of time to conduct this study within this MD programme. However, the findings of having unmet needs in health systems and information as well as psychological needs can be addressed in this population.

6.3.3 Administering the instruments

6.3.3.1 Face to face interview

Although the SCNS was designed to be self-administered, a decision to use face to face interview was used to standardise how the survey was administered. Issues of non-response and a biased disclosure due to the research nurse were taken into account before a decision to administer using face to face method of interview.

6.3.3.2. Recall bias

The data collected was to represent at their period of diagnosis. However the time from diagnosis varied among the participants. Hence, may place recall bias on the findings where the instruments measured during the period of diagnosis, like the Brief Cope. With time constraints in data collection it may take more than a year to collect data from incident cases(newly diagnosed women) as opposed to just over 6 months as was in this study.

The needs questionnaire measure their needs in the last one month, hence has less recall bias and would be a good representation on current needs of the patients in our hospital.

6.3.4 Analysing the data

Generalising the quantitative survey results to a larger population of cancer patients may be limited due to the fact that the sample was not random sampling of the population as mentioned. There are controversies about whether a Likert scale is interval or ordinal (Newman 1994). In this study the Likert scale was used as an ordinal scale in the SCNS SF34 and interval for the Brief Cope. As these scales have been found to communicate interval properties to the respondent, and therefore produce data that can be assumed to be intervally scaled (Madsen 1989; Schertzer & Kernan 1985). It was important that the RNs were briefed about how to question the participants.

6.4 Chapter summary

This chapter discussed the limitation of both the qualitative and quantitative study design and execution. The following chapter will progress into the implications of the research findings.

Chapter 7 Contribution and implication for policy, practice and future research

7.1 Introduction

The thesis objective was to clarify and inform the issues related to late presentation of breast cancer with the use of thick descriptions and high order analysis. In brief, two models were built to explain this phenomenon, and to sum the importance of these models, the implication of the models are discussed in this chapter.

7.2 The SBCD model

7.2.1 Identifying gaps in knowledge using SBCD chronological model

The Stages of Breast Cancer Delay model illuminates the needs to understand where exactly is the problem. By explicitly placing the trajectory of the breast cancer journey in a simple measurable form, designing studies on delays can be made clearer. Having a chronological and interval perspective as having the context such as stakeholder's role, a pluralistic health perspective and decision making at each stage allow careful design of studies.

There are gaps in knowledge in the local scene, this have been partly presented in Chapter 2. Only one local study has looked at the profile of women who delayed in presentation (Norsa'adah, Rampal, Rahmah, Naing, & Biswal, 2011). The study included 328 patients seen in a few centres in Malaysia, 5.2% were in stage I, 38.7% in stage II, 44.8% in stage III and 11.3% in stage IV. The median time to consultation was 2 months and the median time to diagnosis was 5.5 months. The frequency of diagnosis delay of more than 3 months was 72.6% and more than 6 months occurred in

45.5% of the cases. The factors associated with diagnosis delay included the use of alternative therapy, false-negative diagnostic test, non-cancer interpretation and negative attitude towards treatment (Norsaadah b et al 2011). This study was a good account of the pre-diagnostic stage. From the SBCD model the post-diagnostic stage, where treatment decision delay and treatment delay clearly states that the post-diagnostic stage must also be taken into account.

The chronological account of the SBCD model, show the importance of health seeking from the perspectives of those with breast symptoms. Cancer rates in symptomatic women have been reported in the hospital settings but not in the community (Taib, et al., 2007; Yip, Alhady, & Jayaram, 1995). Studies on reasons for not coming forward for diagnosis and treatment are still lacking. Understanding the behavioural aspects of a women with breast symptoms would have to be done first to be able to design interventions. Likewise, only one study by Gorin (2006) has been done in the western world (see Chapter 2). Only studies on attitudes and behavior towards early detection for asymptomatic women using screening mammogram have been carried out, showing only 13.6% of women ever had a mammogram (Parsa & Kandiah; Rosmawati).

7.2.2 Measuring performance of cancer diagnostic and treatment facilities

This study illuminates the stages of delay and at present there are no indicators in place to audit performances of centres. Lack in audit information on timely diagnostic facilities does not help elucidate whether the issue of late presentation is confined to patient delay alone or health systems delay. Application of the SBCD model, would assist public health policy makers to audit and ensure each delay stages is measured as

a performance indicator in centres providing diagnostic and treatment services to the public.

The recent Clinical Practice Guidelines published in 2010 (Ministry of Health & Academy of Medicine of Malaysia, 2010) provide a greater emphasis on treatment based indicators, rather than diagnostic indicators. A single proposed performance indicator in timely treatment within 2 months of presentation into a diagnostic facility was included (Fig. 7.1). There was no emphasis on timely diagnosis.

In Northern Ireland, reorganisation of cancer services took place in 1996 with the Campbell report in response to the Calman-Hine report in the UK and this came about due to pressure from patient advocacy groups who lobbied for better cancer services. By reducing the number of hospitals performing dedicated cancer services, an improvement of their performance indices in 2001 was seen compared to 1996. By being compliant towards the basic guidelines on timely cancer services, UK hospitals were successful in reducing the stage at diagnosis (Monaghan et al., 2005).

Interventional education of primary health care providers in the rural interiors of Sarawak, East Malaysia had also seen a reduction in stage at presentation in Sarawak (Devi, et al., 2007). Thus, it is important to identify the delay time points as an audit indicator to justify resources to be diverted and to adopt strategies and guidelines to guide practice.

PROPOSED CLINICAL AUDIT INDICATORS FOR QUALITY MANAGEMENT

$$\text{Percentage of newly diagnosed breast cancer patients receiving initial treatment within two months of presentation} = \frac{\text{Newly diagnosed breast cancer patients receiving initial treatment within two months of presentation}}{\text{All compliant newly diagnosed breast cancer patients}} \times 100\%$$

$$\text{Percentage of eligible breast cancer patients post-surgery commencing chemotherapy within two months} = \frac{\text{Eligible breast cancer patients post-surgery commencing chemotherapy within two months}}{\text{All breast cancer patients post-surgery requiring chemotherapy}} \times 100\%$$

$$\text{Percentage of local recurrence of breast cancer within two years} = \frac{\text{All patients with local recurrence of breast cancer within two years}}{\text{All patients with surgery for breast cancer}} \times 100\%$$

Figure 7.1 Proposed clinical audit indicators for quality management from the Clinical Practice Guidelines Malaysia 2010

Source: Reprinted from “Management of Breast Cancer Clinical Practice Guidelines Malaysia ”by Ministry of Health and Academy of Medicine of Malaysia, 2010.Permission not required..

7.2.3 Navigating the health system

Navigating through the breast cancer journey is challenging if there are no clear cut pathways as well as dedicated services. Educating the public about symptom recognition, diagnostic resolution and treatment adherence are important. In this study, significant others as source of information as well as to sanction health seeking behavior as well as the main support to having a diagnosis to completing treatment was found. Hence, educating the public would include husbands, fathers, mothers and daughters.

Navigation towards a diagnostic centre and treatment facility is an important task that has been practiced in identified areas of disparity in the USA, for Asian Americans and Pacific Islanders where culturally appropriate community based programmes are implemented (Nguyen & Kagawa-Singer, 2008). Studies have shown it works in uncoordinated health care systems and not only do they provide instrumental support but also emotional as well as information needs, logistics and problem solving assistance (Carroll, et al., 2009).

Aside from community navigation, primary health care providers play a role in referring to diagnostic facilities. Besides knowing when to refer, knowing pathways and networking to other secondary providers provide confidence and smoothen the journey of the patient. A study in Egypt also found that delays occurred when women with symptoms attended non-dedicated diagnostic clinics managed by general surgeons, primary care physicians and gynaecologists as compared to those run by surgical oncologists (Mousa et al., 2011). Educating primary health care givers in navigating a non-structured health care system in Malaysia is challenging, and the needs of health care providers have not been studied. Treatment of cancer is

multidisciplinary in nature and maybe fragmented, where some centres may not be able to provide care in all areas of oncology. In UMMC, although all treatments are available in-house, the needs survey revealed high needs in areas of hospital systems and information. Hence there are needs in information provision.

7.2.4 Addressing a pluralistic health care system

The pluralistic nature of health care in Malaysia has been discussed extensively in Chapter 4.4, thus its existence cannot be denied. Providing women with adequate information on both aspects of treatment may allow women make informed decisions. Alternative treatment provides for the unmet needs of a hostile conventional medicine environment. By providing services of value to the patient, ie. psychosocial support, adequate amelioration of symptoms related to cancer and its treatments are important strategies that have been practiced in USA (Maizes, et al., 2009). By validating the presence of alternative health care in Malaysia, physicians would be better at providing information to patients.

7.3 The BCDE model

7.3.1 Normative beliefs and attitudes towards breast cancer

The in-depth interviews revealed a prevalent fatalistic feel towards the diagnosis and treatment of breast cancer. A vicious cycle of women presenting late, having palliative treatment and succumbing to the disease can be seen influencing women not to seek medical attention early in the course of the disease that may be potentially curable. Fatalism that was seen in usually ethnic minorities like African and Latin Americans

(Powe & Finnie, 2003) Asians and Pacific Islanders (Nguyen & Kagawa-Singer, 2008) and aboriginal Australians (Prior, 2009) and similarly in Caucasians. Many believed the futility of treatment and made culturally based decisions rather than biomedical reasoning with regards to the treatment of breast cancer (Prior, 2009). Although patient value based breast cancer outcomes in Malaysia is unknown, ie. is quality of life valued more than length of life. There are several gaps on knowledge in the biomedical outcomes of breast cancer in Malaysia. Whether treatment outcomes are similar to those reported abroad, are important indicators to provide confidence to the Malaysian public. There have been institutional reports on breast cancer outcomes, but not for the whole country. The studies in UMMC (Mohd Taib, et al., 2008; Ong & Yip, 2003; Yip, et al., 2006), another public tertiary medical centre (UKMMC) (Suthahar et al., 2009) and in a single hospital in Sabah (Leong et al., 2009; Leong, Chuah, Kumar, & Yip, 2007) have reported outcomes. The study findings show the relevance of stage of presentation is to the breast cancer outcomes.

The fatalistic views as well as the misconception of cancer and its outcomes seen in this study calls for more information and exposure to long term survivors. Survivors' stories have been found to indicate fatalistic perception of the disease. Changing norms and beliefs within the community is challenging, there is a need to have positive role models to reflect the true prognosis of breast cancer. Civil societies have been providing such roles. Cancer survivor organisations now have high profile events that are widely publicized with a theme towards early detection. Locally, the Breast Cancer Welfare Association or BCWA is actively providing not just information but navigation towards diagnostic centres and support for women newly diagnosed with breast cancer through The Mobile Unit Reaching out Nationwide or MURNI program.

Relevant interventions that incorporate spirituality in African Americans (Powe & Finnie, 2003), and other culturally competent methods described have been proposed in the Asian American communities (Nguyen & Kagawa-Singer, 2008). Hence, innovative ways to provide information to the Malaysian public is required. Addition of social capital construct in self-efficacy has been discussed in Chapter 5, indicating the need of modulating the beliefs of significant others too. Besides that, primary care providers also play a role in preventing fatalistic beliefs in breast cancer outcomes (Peek, Sayad, & Markwardt, 2008; Prior, 2009). As seen in this study, breast health literacy amongst primary care practitioners was found to be lacking.

7.3.2 Health education for the public

In this study, we found a poor level of breast health literacy. Symptomatology is the understanding of breast cancer symptoms. This study challenges views on Malaysian community breast health literacy with the evidence of ignorance not only towards non-lump but towards breast lump symptoms. Parsons sick role theory of candidacy may explain why when there is a painless lump, it is difficult for the women to accept a sick role (Mackenzie et al., 2011). What more to undergo treatment that is riddled with side effects. In Australia by providing targeted intervention of providing guidelines for women with new breast symptom, an improvement in concordant management was seen (Cockburn, Pit, Zorbas, & Redman, 2001).

This study informs the need for urgent interventions in the primary health care and primary care settings for general practitioners, obstetricians, midwives or other health providers, when providing for women who seek help for breast changes. Education on breast changes and signs must be detailed and taught to women, and in view that they

may play a passive role in decision making, the education of their significant others and doctors and other health care providers would be imperative. Lack of knowledge on usual symptoms of breast cancer as seen in this study calls for more detailed information that may have to be disseminated in innovative ways. In the USA, academic detailing of primary care physicians in urban underserved areas was effective in improving breast screening practices (Gorin, et al. 2006).

Natural history of breast cancer was not well understood by the participants and there were myths that were discussed in Chapter 4.6. Hence, educating about disease natural progression and outcomes was important as women may erroneously think the cancer has been successfully controlled whilst they are on alternative forms of treatment but in actual fact they remain asymptomatic except for the lump which is the natural history of the breast cancer.

Novel areas of providing meaningful information to women on breast cancer have been studied. Sanctioning of symptoms and validating their condition through videos about women sharing their experiences was found to be more powerful than didactic education in African American women (McQueen & Kreuter, 2010). Educational programs based on the explanatory model, with its four main constructs, may offer insights to policy makers and non-governmental organisations to plan education based on these findings. The MURNI educational materials based on disease outcomes, detailed symptom recognition and value of screening are designed based on these findings. In the quantitative portion of this study, breast cancer survivor organisations were deemed irrelevant in providing information in a third of the breast cancer patients surveyed. However, women with breast cancer were important source of information.

This contradiction can be further reduced by providing a structured education and support by survivors of women with breast cancer in the hospital setting.

Public education can be improved by providing adequate information to patients and their significant others. There have been studies on patients' values and needs in relation to treatment (Farooqui, et al., 2011; S. Y. Loh, et al., 2007). Information needs of Malaysian women differed from those in the UK, in that they needed more sexual information as women in Malaysia were younger (Gopal, et al., 2005). By providing relevant information to breast cancer patients and their significant others on treatment and disease outcomes, a cohort effect can be expected within the community. The provision of this would need to be addressed within the hospital context, as women found doctors and nurses as their main sources of information. The lack of utilising family physicians as source of information and in the support of women with breast cancer was seen in the quantitative portion of this study negates the beneficial role that can be played by GPs. However, educating women and their GPs about cancer follow-up may be a cost-effective management strategy for ever increasing burden of cancer care in Malaysian hospitals.

7.3.3 Culturally sensitive health care: effective communication, provision of psychosocial, spiritual and instrumental support

Effective communication is important in providing cancer services (Eggly, et al., 2009). There are however, no studies looking at the barriers that health care providers face in providing diagnostic and treatment services for breast cancer patients in Malaysia. Providing health care in Malaysia is a challenge due to the multi-ethnic, multi-linguistic community, the effectiveness or lack of it emerged from the data.

Hence, provision of providers who communicate effectively would improve adherence to recommendations, be it a diagnostic procedure or treatment. Training for effective communication would be a must for all health care providers providing services not only to breast cancer patients but to all patients, training a culturally competent health care provider would entail not just the generic communication skills in medical school, but provides insights and sensitivity towards the meaning of disease to individuals. Studies on survival disparities in many communities have recommended the cultural competence approach (Polacek, et al., 2007);(Nguyen, Belgrave, & Sholley, 2010; Prior, 2009).

The BCDE model may provide an avenue to sensitise the health care provider. The four main constructs discussed previously can be used to provide information not only on the health care recommendation within the biomedical sense but sensitised towards the psychosocial and economic reality that the patient is embedded within. Assisting patients to find their source of support as well as recognising the role they play in decision making, would ensure early engagement of those who makes the decision eventually.

7.3.4 Diagnostic and treatment decision support using the BCDE explanatory model. Using value based counselling for decision making of procedural and treatment recommendations

Health care professionals play a major role in medical decision making of their patients (Aberegg & Terry, 2004; Charles, et al., 1997, 1999).Communicating cancer related material is highly complex, and by being sensitised to the individual patient needs using the BCDE model, the physician, surgeon, nurse or counsellor would be able to

carry out this task in a more effective manner. From this study and other studies, one can see the complexities of decision making. To assist decision making in women with newly diagnosed breast cancer, would be to intervene with not just information giving but also needed to be coupled with the ability to coach the patient towards making better choices.

Decision aid tools have been found to improve knowledge, promote active participation in decision making, reduces decisional conflicts and promote better satisfaction in their decisions (Neuman, Charlson, & Temple, 2007). From the survey presented in Chapter 4.2, women, perceived receiving information from a doctor, and other health professionals as very important sources of information. Hence, this approach can be further strengthened using specific decision coaching aids, this may reduce decisional conflict and may provide respite for women who are coerced into decision making by their significant others as seen in this study.

As evidenced in this study, there are gaps in providing culturally sensitive and patient centred care, guidelines for this have been produced in the west favouring patient centred care e.g.. NHS patient centred care(de Gelder et al., 2009) that recommends: minimising delay, providing clear information, effective communication and providing for psychosocial and practical support. Diagnostic services aside, another important delay time point seen in this study: the treatment decision delay where decisions to adhere to treatment recommendations deserves the same attention. The BCDE model provides a quick reference for practising surgeons and oncologists as well as breast care nurses and other health care professionals providing supportive care to patients on important areas that should be covered to assist patients in their decision making.

There are very few Asian patients reported outcomes and value based studies on decision making support (Durand, Stiel, Boivin, & Elwyn, 2008; O'Connor, Drake, et al., 1999; Schapira, Meade, & Nattinger, 1997; Weinfurt, 2003). The BCDE model may provide a good platform to build one to suit the needs of local patients.

7.3.5 Garnering support as a prerequisite to recommending medical advice

The biomedical model has been used to provide sound medical advice, but adherence not only depends on information but the patient's social and economic situation. Hence, this can be communicated to health care professionals by using the BCDE model.

Resources make up the third construct. Besides emotional coping, financial and social support came up strongly in the interviews. Financial issues came up in the in depth interviews as well as the survey. UMMC being a semi-government Ministry of Health hospital does not enjoy the same benefits as a Ministry of Health hospital, patients are only subsidised on the first line therapies, hence second and third line chemotherapy and targeted therapies are out of pocket expenses for the patients.

7.4 Section summary

In summary, Chapter 7 discussed the models and implications derived from it. In Chapter 5, the discussion on the results of this mixed method study was done. Below are the conclusions from this mixed methods study again:-

1. Poor breast health literacy a reason for poor informed decision making and hence delayed presentation. Poor breast health literacy- disease and treatment aspects as a reason for delayed presentation. Poor knowledge in women and first line health care providers and fatalistic beliefs resulted in poorly informed decision making. Breast health included knowledge on the disease and its outcomes and treatment and its outcomes.

2. Face to face interpersonal knowledge transfer- a resource gap

The quantitative survey revealed the need for interpersonal information giving. A resource gap was found in-depth interviews with regards to low consultation time in a public hospital.

3. Emotional and physical needs and preconceived fragility leading to lack of self-efficacy.

There was a perception of low self-efficacy amongst the women interviewed on coping with the emotional and physical impact of breast cancer and its treatments. Decision making as seen in this study was based not on rational biomedical issues but emotional and practical logistics issues.

4. The importance of significant others in providing support and sanctioning of help seeking, diagnosis and adherence to treatment. The role of significant others were important at all stages of the breast cancer journey from symptom recognition, seeking a diagnosis to adherence of treatment recommendations. There was a detriment of secrecy, shame and changed social identity after breast cancer. There was a lack of individualistic and autonomous decision making by playing the role of a dutiful wife or daughter

5. Financial barriers to care.

Financial issues were prominent in both the qualitative and the quantitative study.

6. Pluralistic health care: a valued but unaccountable alternative path and a hostile hospital setting. The effect of pluralistic health systems in Malaysia showed that women had multiple options and therefore made deliberate choices based on their values on the disease and treatment outcomes. Alternative medicine filled a void in spiritual, emotional care in the biomedical model in cancer health care in Malaysia. It was more in line with patient values.

7. Concepts of roles played by participants in decision making. The perspectives of autonomy or directed by others in health care decisions were discussed.

8. The SBCD model and the BCDE explanatory model can be utilized as frameworks for further research and practice. Contextual understanding of eight stages of delay and four contexts of: i- The role of patient or health systems in delay, ii- The chronology of events that occur in the breast cancer journey- the points of delay, iii-

The pluralistic health systems and iv-Patient decision making at each stage of delay UMMC were illustrated in this model.

The BCDE model provides a theoretical drive for educating the public and health professionals. Utilising this model can assist communicating diagnosis and treatment recommendations. Both models have clarified the reasons for why women present with advanced breast cancer. In summary, cancer control strategies need to be supported by research (Harford et al., 2011). The models presented in this research may serve as a framework towards further research in delay as well as decision-making. Practice based research have been shown to bring about improved services (Rust & Cooper, 2007). With the SBCD model and the BCDE model, a model or theory driven practice can be advocated to UMMC health practitioners, not only in the education and support services but to assist all health professionals caring for patients with breast cancer. The models presented here are specific to this population of breast cancer patients; generalisation of theory towards other populations and other cancers needs further study.

Chapter 8 Conclusions

8.1 Introduction

The main objective of this thesis was to clarify the process of delay and to offer an explanation to why women present with advanced disease which was obtained through a qualitative inquiry. A quantitative survey was carried out to understand the socio-demographics, needs and coping mechanisms that women in UMMC employed.

By answering different research questions with a pursuit towards planning interventions, two models were built grounded from the data using the constructivist grounded theory approach.

With these models, the researcher hopes that the community researchers, policy makers and the health care professionals alike may understand women who present with advanced disease and a provision for future theory driven research and implementation. Interventions to promote early diagnosis, commencement and completion of efficacious treatment may improve survival of women.

8.2 Why women present with advanced breast cancer

Women may delay in one or several delay stages seen in the SBCD model, identified as appraisal delay, disclosure delay, illness delay, behavioural/referral delay, scheduling delay, diagnostic delay, treatment decision delay and treatment delay. The phenomenon can be explained by four main constructs in the BCDE model.

The first two being the disease and treatment and its outcomes, where there is evidence of poor breast health literacy. A pluralistic health care system compounded matters further. Women sought treatment in a perceived caring but non-accountable alternative therapies and there were barriers towards seeking a diagnosis and treatment in a hostile

hospital environment. Thirdly, resources were required to make decisions, they had inadequate emotional resources to cope with the trauma of the diagnosis and accepting the diagnosis was crucial in making decisions. They had inadequate financial resources and in addition poor social support. Finally there was reliance on significant others to sanction and direct their actions. Moreover, there needs to be a variable responsibility towards decision making, where health professionals needed to be sensitive to those who have and do not have self-efficacy in making decisions to having treatment. It was important to note that biological aggressive cancer also contributed to advanced presentation where women present with advanced disease in a short duration after a breast symptom is discovered.

8.3 Understanding the population of breast cancer patients attending the oncology services, would help tailor interventions later.

Women with breast cancer attending oncology services in UMMC had high needs in financial and hospital systems and information and very low needs in sexuality issues. Women with breast cancer in UMMC used acceptance followed by religion as common methods of coping. Women found that surgeons, oncologists, nurses were perceived to provide good support to women. Family doctors were found to be an irrelevant source of support for the majority of the women. The important sources of information after their diagnosis were from doctors, books on breast cancer, women with breast cancer, family members, nurses and newspapers. Survivor support group was found to be an irrelevant source of information in a third of the women. Understanding important sources of information of women with breast cancer in UMMC allows future intervention as well as required exposure of patients towards relevant resources that can be used by women with breast cancer.

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Appendix A: Ethical Clearance

 JAWATANKUASA ETIKA PERUBATAN PUSAT PERUBATAN UNIVERSITI MALAYA ALAMAT: LEMBAH PANTAI, 59100 KUALA LUMPUR, MALAYSIA TELEFON: 03-79494422 FAKSIMILI: 03-79545682	
NAME OF ETHICS COMMITTEE/IRB: Medical Ethics Committee, University Malaya Medical Centre ADDRESS: LEMBAH PANTAI 59100 KUALA LUMPUR	ETHICS COMMITTEE/IRB REFERENCE NUMBER: 655.7
PROTOCOL NO: TITLE: Why Woman Present With Advanced Breast Cancer? A Qualitative	
PRINCIPAL INVESTIGATOR: Dr. Nur Aishah Binti Mohd Taib TELEPHONE: KOMTEL:	SPONSOR:

The following item ☒ have been received and reviewed in connection with the above study to be conducted by the above investigator.

<input checked="" type="checkbox"/> Borang Permohonan Penyelidikan	Ver date: 9 May 08
<input checked="" type="checkbox"/> Study Protocol	Ver date:
<input type="checkbox"/> Investigator Brochure	Ver date:
<input checked="" type="checkbox"/> Patient Information Sheet	Ver date:
<input checked="" type="checkbox"/> Consent Form	Ver date:
<input type="checkbox"/> Questionnaire	Ver date:
<input checked="" type="checkbox"/> Investigator(s) CV's (Dr. Nur Aishah Binti Mohd Taib)	

and have been ☒

☒ Approved
☐ Conditionally approved (identify item and specify modification below or in accompanying letter)
☐ Rejected (identify item and specify reasons below or in accompanying letter)

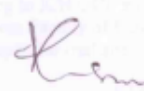
Comments:

i. Investigator is required to follow instructions, guidelines and requirements of the Medical Ethics Committee.
 ii. Investigator is required to report any protocol deviations/violations through the Clinical Investigation Centre and provide annual/closure reports to the Medical Ethics Committee

Date of approval: 28th May 2008

s.k Ketua
 Jabatan Surgeri
 Timbalan Dekan (Penyelidikan)
 Fakulti Perubatan, Universiti Malaya

Setiausaha
 Jawatankuasa Penyelidikan Pusat Perubatan
 Fakulti Perubatan, Universiti Malaya


PROF. LOOI LAI MENG
 Chairman
 Medical Ethics Committee

Appendix B: Qualitative Topic Guide

Introduction (5 min)

Introduce yourself as a field researcher; explain that as a researcher you are genuinely interested in knowing the main reasons on why some patients do not come at an earlier stage to hospital for diagnosis and treatment. We would like to improve services and their honest opinion would help us a lot. There could be many reasons and many could be personal. This interview aims to discover the actual feelings and issues that the patient experience. This discussion will take two hours and would be grateful to switch off all hand phones and lock the door for no interruptions.

Please fill up the forms given.

Stress that:-

- Interested in personal views and opinions
 - No right or wrong answer
 - It's alright to disagree with others
 - Views are kept confidential. Identity only identified by race, age and occupation. All members present in the room have the responsibility that they should leave the room later without propagating what have been discussed. Only share information if they feel comfortable doing so.
 - Explain that audio taping is necessary to do the research analysis and documentation
 - Take verbal and written consent for the interview and the audio taping from each participant by name
 - Any questions before we start?
1. Can you tell me what breast cancer means to you? The disease presentation, what causes it, it's progression, curative treatment and cure rates
Bolehkah puan nyatakan apakah maksud kanser payudara, tentang tanda-tandanya (simtom), penyebabnya, proses penularannya, penyembuhnya dan kadar sembuhnya.
 2. Can you describe your experience on how you discovered your initial symptom of breast cancer i.e breast lump, pain etc. ? What was your initial reaction? What did you do upon discovering that symptom? How long did you take before seeing a doctor? Why did you take a long time?
Bolehkan anda ceritakan apakah yang telah anda alami apabila mendapat tahu tanda-tanda(simtom) pertama kanser payudara seperti ketulan ataupun sakit dan sebagainya? Berapa lamakah masa yang telah diambil untuk berjumpa doktor? Mengapa anda mengambil masa yang panjang?
 3. Who did you confide in when you first discovered your breast cancer symptom? Why did you confide in this particular person?
Apabila anda mengalami tanda-tanda pertama itu, siapakah orang pertama yang menjadi tempat anda mengadu. Mengapa anda memilih orang itu, dan bukan orang lain?

4. Can you describe what you went through to arrive at the diagnosis? Probe about clinic visits, the biopsy experience, doctor hopping ie. how many doctors were consulted and why.
Apa yang telah anda lalui untuk mendapat kepastian/diagnosis kanser payudara? Selami tentang lawatan ke klinik, pengalaman sewaktu biopsi dibuat, bilangan doktor yang dirujuk serta mengapa begitu.
5. How was the diagnosis communicated to you? What was your reaction(s) when the doctor told you the diagnosis? Was there anyone who accompanied you when your diagnosis was told to you?
*Bagaimanakah doktor memberitahu anda tentang diagnosis itu?
Bagaimanakah perasaan dan reaksi anda apabila mendapat berita tersebut?
Adakah sesiapa yang menemani anda sewaktu itu?*
6. Who did you first confide in about the diagnosis? Why did you choose to disclose to this person. If you didn't tell anyone, why didn't you?
*Siapakah orang pertama yang anda beritahu tentang diagnosis tersebut.
Mengapakah anda memilih orang itu? Sekiranya anda tidak memberitahu sesiapaupun, mengapakah anda berbuat demikian.*
7. How did your life change after the diagnosis (at home, at work and socially)? How did it affect your marital (communication, sexual) relationship, work and social life?
Bagaimanakah perubahan kepada kehidupan seharian puan (di rumah, di tempat kerja dan pergaulan dengan masyarakat)? Bagaimana ia mengubah alam perkahwinan (komunikasi/ hubungan kelamin atau seksual) , pekerjaan dan pergaulan dengan masyarakat?
8. Please elaborate and tell us all the different types of treatment that you have had so far for breast cancer (modern medicine, alternative medicine and other types of treatment). Did they work for you? If it worked, how? If it didn't, why didn't it work?
Sila berikan penjelasan tentang jenis-jenis rawatan yang telah anda lalui untuk kanser payudara (perubatan moden, alternatif dan rawatan lain). Adakah ia berkesan dan mengapakah begitu? Jika tidak berkesan, mengapa ia terjadi begitu?
9. How did you make the decision to have whichever treatment first? Who and what helped you make that decision? Looking back, could you have made a better decision?
Bagaimanakah anda membuat keputusan pada awalnya untuk menjalani rawatan yang pertama (tidak kira rawatan apa) ? Siapakah atau faktor yang telah memberi dorongan anda membuat keputusan tersebut. Bila melihat ke belakang mungkinkah anda dapat membuat keputusan yang lebih baik?
10. As time went by, how did the cancer progress? What were the symptoms? How did you cope at home, at work and when socialising? Did you face any problems (include emotions, ability to work, financial (was treatment expensive?) and social relationships)?

Apabila masa berlalu, bagaimanakah kanser itu berubah, apakah tanda-tandanya/simtomnya dan bagaimana anda menghadapinya di rumah, di tempat kerja dan bila bergaul dengan masyarakat. Adakah anda menghadapi kesukaran (termasuklah masalah emosi, kurang keupayaan untuk bekerja, masalah kewangan (adakah rawatan terlalu mahal?) dan masalah pergaulan dengan masyarakat)?

11. What are the factors that prevent you from coming early to the hospital or refuse hospital treatment? There is no right or wrong answer. Most people might not really know why, but it is okay to share your thoughts. We would really like your honest opinion on this issue.

Apakah sebab-sebab mengapa anda tidak datang ke hospital pada peringkat yang lebih awal ataupun mengapa anda menolak rawatan hospital? Tiada jawapan yang betul atau salah. Ramai orang tidak tahu mengapa tetapi elok untuk berkongsi pendapat. Kami benar-benar ingin mengetahui pendapat anda.

12. What are your needs in terms of the health care system (delivery of services eg. clinic, doctors, nurses , information etc) , financial support, social support and family support. Were the needs met? How can these needs be met.

Apakah keperluan anda dari segi perkhidmatan kesihatan yang disediakan (penyampaian perkhidmatan kesihatan seperti klinik, ward, doktor, jururawat , informasi/pengetahuan dan sebagainya), sokongan kewangan ,sokongan sosial dan sokongan daripada keluarga. Adakah keperluan-keperluan dicapai? Bagaimana untuk mendapat keperluan-keperluan ini?

13. On hind sight, would you now have come for treatment earlier? Why would you?

Bila melihat ke belakang, mungkinkah kini anda akan mendapatkan rawatan dengan lebih awal? Mengapa begitu?

14. What would enable/make you have hospital treatment earlier? Probe for financial support, psychological support, social support, more information and health care delivery.

Apakah yang membolehkan anda mendapat rawatan dari hospital di peringkat awal. Tanya tentang sokongan kewangan, sokongan psikologi, sokongan sosial, informasi(pengetahuan) dan penyampaian perkhidmatan kesihatan.

15. Are there any regrets or disappointment for what you have been through?

Adakah anda kesal atau sedih dengan keadaan yang telah anda lalui setakat ini?

16. In case I have missed out anything, is there anything else that you would like to share with me regarding your illness?

Sekiranya saya ada tertinggal sesuatu. Adakah apa-apa perkara yang ingin anda bangkitkan kepada saya tentang penyakit ini?

Appendix C : The Quantitative Instruments and Validation

1.0 The Supportive Care Needs Survey (SCNS)

1.1. Introduction

Three methodologies have been applied to the study of the morbidity outcome for cancer patients: quality of life, patient satisfaction and needs assessment. Needs assessment spans both quality of life and patient satisfaction issues when the impact of disease on patients' needs is assessed (Bonevski et al., 2000). The Supportive Care Needs Survey-Long Form (SCNS LF)-59 was developed by the Cancer Council of New South Wales. It was first published after adaptation from the Cancer Needs Questionnaire CNQ (Bonevski, et al., 2000). The SCNS was a 59 item questionnaire that has been found to have very good psychometric properties in Australia (Bonevski, et al., 2000). The SCNS was shortened to a short form with 34 items, and was found to be a valid tool with good correlation with the original instrument (Boyes, Girgis, & Lecathelinais, 2009). The SCNS LF-59 and F-34 are open access questionnaires. Nevertheless, permission was obtained and the manual was purchased from Cancer Council Victoria.

The instrument consists of 5 domains which are Psychological (PSY), Health Systems and Information (HSI), Physical and daily living (PDL), Patient care and support (PCS) and Sexuality (SEX). There were four additional questions including talking to other people about cancer, changes in other people's attitudes and behaviour, concerns about financial problems and concerns about getting to and from the hospital. Responses were in Likert scale of 1 to 5 coded as: no needs: 1 for not applicable and 2 for satisfied. Some needs are categorised from 3 to 5, based on low, moderate and high needs.

The validation of the questionnaire was conducted in Australia in a heterogeneous group of cancer patients (Bonevski, et al., 2000; Boyes, et al., 2009). The SCNS-SF34 has been validated in Japanese (Okuyama et al., 2009).

The SCNS-SF34 has been used in studies concerning patients with advanced breast cancer (Gibson, Ma, & Shaw, 2007), brain cancer (M. Janda et al., 2008) and multiple myeloma (Theurillat et al., 2007) and prostate cancer (Steginga et al., 2001). Newly diagnosed cancer patients' needs are measured with the adapted SCNS SF-31. The SCNS has been used as a measurement tool for supportive care needs in intervention studies (Aranda et al., 2006). It has also been used to measure longitudinal needs of patients, and a strong predictor of unmet need is unmet needs at baseline and longer duration from diagnosis (McDowell, Occhipinti, Ferguson, Dunn, & Chambers, 2009).

The SCNS-SF34 was designed to be self-administered, measuring needs within the past one month. The use of computer systems for patient to rapidly report their needs in clinical practice has been explored; a similar screen and paper forms are recommended

(Boyes, Newell, & Girgis, 2002). It has been modified into a telephone survey(Sutherland, Hill, Morand, Pruden, & McLachlan, 2009).

It has also been found to correlate well with EORTC-QLQ-30 and found to be more patient- centred assessment for health related quality of life (HRQOL)(Snyder et al., 2007).

The SCNS has also been used to measure carers' supportive care needs as well (Monika Janda et al., 2008).

1.2. Justification

The implications of assessing needs are to indicate needed resources. The Supportive Care Needs Survey-Short Form 34 (SCNS-SF34) can also measure the magnitude of this need, thus allowing prioritisation of services and identifying subgroups that have higher levels of needs. Patient reported outcomes are important in clinical practice and needs assessment tool can be an important tool to provide this assessment rapidly to clinicians. Hence, the SCNS SF-34 was chosen to provide a patient reported outcome measure for this study.

2.0The Brief Cope

The Cope instrument was published in 1989 by Carver et al using two theoretical models: the Lazarus model of stress(Lazarus, 1985) and a model of self- regulation by the authors themselves(M. L. Perou, Fielding, & Nelson, 1958). Stress consists of three processes: primary appraisal where stress is perceived; secondary appraisal is the potential response to the threat and thirdly, coping which is the process of executing that response (Lazarus, 1985).

A qualitative study on cancer patients using the Lazarus model in 2005 (Link, Robbins, Mancuso, & Charlson, 2005) built a 5 stage model to coping (Fig 2.23). The authors found that forming options of coping involves personal goals, emotions and perception of disease. The coping acts are also modified by internal and external modifying factors.

Thus, an instrument was used to measure the styles of coping. The full Cope instrument was shortened to reduce the overall time burden, and was shown to have good psychometric properties(Carver, 1997)(Cuzick, Sestak, Cella, & Fallowfield, 2008).

Psychometric properties showed the validity of its constructs (C. M. Perou et al., 2000).The Brief Cope measures constructs with regards to 14 styles of coping, using two items for each construct. This 28 item instrument measures: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support,

behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion and self-blame.

The Brief Cope has been validated in English in Malaysia (Yusoff, Low, & Yip, 2010). Hence, further validation using psychometric properties is not done in this study.

3.0 Permissions

Permission to use the open access instrument SCNS was obtained via personal communication with the developers at Centre of Health Research and Psycho-oncology (CHERP), the cancer council New South Wales Australia through Dr Afaf Girgis and Allison Boyce. Open source scales were obtained from the CHERP website and the SCNS user's guide which was purchased. Translation of the SCNS was done with permission from CHERP.

The brief cope is an open source instrument that does not require permission to use or translate. The instrument was obtained from an open source website: <http://www.psy.miami.edu/faculty/ccarver/ccscales.html>.

4.0 Translation and Adaptation of the Instruments

All the instruments were translated using the method described below.

The translation method was according to a method from the MAPI research institute recommendation (www.mapi-research-inst.com).

The forward translation step was done by employing two independent translators to translate the original scale in English into the target language. Back translation was done by another two independent translators. Finally, one Malay, Mandarin and Tamil translator each adjudicated with the researcher on the translated versions to ensure concepts and meanings were not lost. The translators were bilingual being native speakers of the target language and fluent in the source language, and this ensured cultural and linguistic adaptation of the original scale.

Cognitive debriefing was done with breast cancer survivors on English, Mandarin, Malay and Tamil versions to assess the clarity, appropriateness, wording and acceptability of scales. Proof reading of the instruments was provided by research nurses doing the pilot test, as well as the pilot test participants.

5. Validation of SCNSF-34

The sample size was calculated based on the number of items, having 5-10 respondents for each item (Field, 2009), and a given range of 150 to 340 participants. Thirty were needed for test-retest reliability. Retested participants answered the questionnaire within 2 to 3 weeks after completing the first questionnaire, since the survey focused on their needs within one month.

5.1 Respondents included in validation of questionnaire

The Supportive Care Needs Survey was carried out in 322 patients, (266 patients from oncology services, 19 advanced breast cancer patients (involved in the qualitative study) and 37 retested participants), of which 307 had complete answers. Those who refused to answer some items were excluded from the analysis. 152 of the respondents used the English version, 85 used the Mandarin version and 77 used the Malay version.

5.2 Content validity

Content validity was performed by ascertaining clinical coherence by an expert panel comprising a consultant breast surgeon, a clinical psychologist and the researcher.

5.2.1 Face validity of the SCNS SF-34 English, Malay and Mandarin versions.

Cognitive debriefing was done with 3 breast cancer survivors on the Malay version, 3 in the Mandarin and 3 in the Tamil version and 3 in the English version to assess clarity, appropriateness, wording and acceptability of scales. Proof reading of the instruments was provided by 3 research nurses doing the pilot test, as well as the pilot test participants. A total of 7 Malay, 3 English and 2 Mandarin educated and 3 Tamil educated survivors piloted the questionnaires.

The terms used in the SCNS SF34 that was least understood was item 4 “working around the home” in the Malay, Indian and Mandarin versions, as there was some misunderstanding with the word “work” as some people do work at home for a living. Rephrasing it to make it understood was important. Otherwise all the items of the original version of the SCNS were found to be well understood.

The Likert scale response was also a challenge to the pilot respondents, especially the “no need category” categorised into 1= not applicable and 2 = satisfied. The “some need” category categorised into low, moderate and high need was easier to understand”. Hence, there was the need to use this instrument using a face- to- face interview, it was difficult for the participants to understand, and the research nurse had to ask the question in 3 steps; i- whether they had needs or no needs, ii- if they had no needs, were they satisfied or because it was not applicable to them and iii- if they had needs, was it low, moderate or high needs.

5.3 Reliability

5.3.1. Internal consistency

Internal reliability was measured using the Alpha Crohnbach test, with a cutoff value of 0.7 to denote good internal reliability (Field 2009).

5.3.2. Stability

Thirty seven participants were invited to answer the same survey within three weeks after the first one was administered. Test retest reliability was done using the interclass coefficient (ICC) (Laschinger, 1992).

5.4 Construct validity-The Psychometric properties of the Supportive Care Needs Survey SF- 34 (SCNS SF-34)

Psychometric properties were measured using exploratory factor analysis by analysing the KMO values, Eigenvalues more than 1 and the screen plot. The sample size for factor analysis was calculated based on having 5-10 respondents for each item (Field, 2009). The SCNS-SF34 has 34 items, giving a range of 150 to 340 participants. The psychometric properties which were tested have been elaborated further in section 3.0 below. Each language was analysed separately except for the Tamil version, which was only used to collect data from 3 participants.

5.4.1. The SCNS SF34 English Version

The English version of the SCNS-SF34 was complete for all 34 items in 149 participants. Principal component analysis was conducted with orthogonal rotation (Varimax).

The Kaiser-Meyer-Olkin measure was 0.94 and individual items were above 0.73 (Range 0.73-0.95). Bartlett's test of sphericity was significant, $\chi^2(561) = 5103.11$, $p < 0.001$. Five factors were extracted using Eigenvalues over 1. Items for PDL, PSY factorised were very similar to the original SCNS-SF34. Three items were consistently factorised into the SEX domain. Only item 18, which was originally in domain PCS was factored into HSI (Table 1). This in combination explains 73.21 % of the variance (Table 2). The scree plot was slightly ambiguous and showed inflections that would justify retaining components 1 to 5 (Fig. A-1)

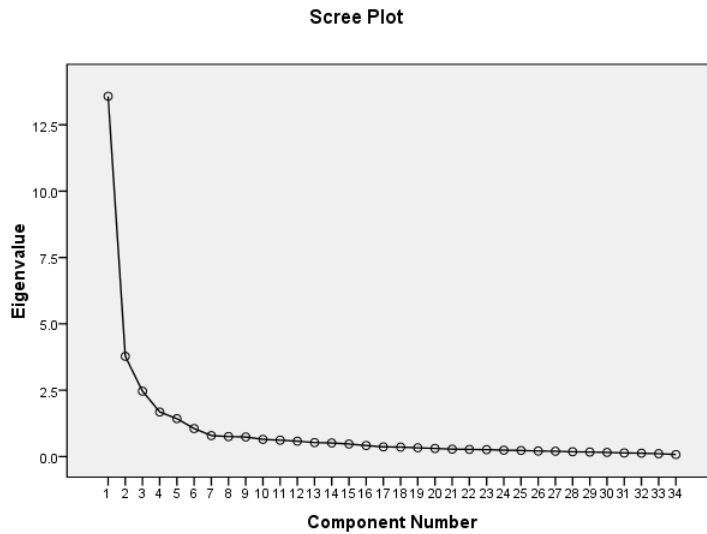


Fig. A-1 Scree Plot after Factor Extraction for the English SCNS SF-34

Table A-1 shows the internal consistency of the SCNS SF-34. The results show very good internal consistencies with all domains exceeding 0.8 shown. The Chronbach Alpha was similar to the referenced values. Cronbach Alpha coefficients for internal consistency for Psychological domain was 0.94; Health Systems and Information was 0.96; Patient Care and Support was 0.913; Sexuality was 0.90 and Physical and Daily Living was 0.85.

The stability of the instrument was conducted on 37 participants. The ICC was excellent with the lowest value of 0.81 for all five domains (Table A-2).

Table A-1: Summary of exploratory factor analysis rotated factor loadings of the English version of the SCNS SF-34

	Item	PDL	PCS	PSY	HSI	SEX
1.	Pain	0.58	-	-	-	-
2.	Lack of energy/tiredness	0.80	-	-	-	-
3.	Feeling unwell a lot of the time	0.79	-	-	-	-
4.	Work around the home	0.73	-	-	-	-
5.	Not being able to do the things you used to do	0.78	-	-	-	-
6.	Anxiety	-	-	0.79	-	-
7.	Felling down or depressed	-	-	0.81	-	-
8.	Feeling of sadness	-	-	0.85	-	-
9.	Fears about cancer spreading	-	-	0.65	-	-
10.	Worry that the results of treatment are beyond your control	-	-	0.70	-	-
11.	Uncertainty about the future	-	-	0.83	-	-
12.	Learning to feel in contrl of your situation	-	-	0.76	-	-
13.	Keeping a positive outlook	-	-	0.72	-	-
14.	Feelings about death and dying	-	-	0.74	-	-
15.	Changes in sexual feelings	-	-	-	-	0.92
16.	Changes in sexual relationship	-	-	-	-	0.93
17.	Concerns about the worries of those close to you	-	-	0.45	-	-
18.	More choice about which cancer specialists you see	-	-	-	0.56	-
19.	More choice about which hospital you attend	-	0.75	-	-	-

Table A-1, continued

20.	Reassurance by medical staff that the way you feel is normal	-	0.59	-	-	-
21.	Hospital staff attending promptly to your physical needs	-	0.73	-	-	-
22.	Hospital staff acknowledging ,and showing sensitivity to, your feelings and emotional needs	-	0.61	-	-	-
23.	Being given written information about the important aspects of your care	-	-	-	0.73	-
24.	Being given information(written, diagrams,drawings) about aspects of managing your illness and side-effect at home	-	-	-	0.76	-
25.	Being given explanations of those tests for which you would like explanations	-	-	-	0.82	-
26.	Being adequately informed about benefits and side-effects of treatments before you choose to have them	-	-	-	0.83	-
27.	Being informed about your test results as soon as feasible	-	-	-	0.82	-
28.	Being informed about cancer which is under control or diminishing (that is, remission)	-	-	-	0.82	-
29.	Being informed about things you can do to help yourself to get well	-	-	-	0.83	-
30.	Having access to professional counselling(eg. psychologist,social worker,counsellor, nurse specialist) if you, family or friends need it	-	-	-	0.68	-
31.	To be given information about sexual relationships	-	-	-		0.73
32.	Being treated like a person not just another case	-	-	-	0.63	-
33.	Being treated in a hospital or clinic that is as physically pleasant as possible	-	-	-	0.68	-
34.	Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	-	-	-	0.82	-
	Eigenvalues	2.34	1.84	3.91	15.63	1.16
	% of variance	6.89	5.42	11.51	45.97	3.42
	Chronbach α	0.85	0.91	0.94	0.96	0.88

*Factor loadings of below 0.4 were not recordedTable A-2. Test-retest reliability using intraclass correlation (ICC)

Domains	Mean	95%CI	P value
Physical and daily living	0.81	0.73-0.87	<0.01
Patient care and support	0.88	0.83-0.92	<0.01
Psychology	0.92	0.89-0.94	<0.01
Hospital Systems and Information	0.94	0.92-0.96	<0.01
Sexuality	0.90	0.84-0.93	<0.01

*Using average measures in the two way random effects model

5.4.2. The Malay Version of the SCNS SF34

A principal component analysis was conducted on 34 items with orthogonal rotation (Varimax). The Kaiser-Meyer-Olkin measure verified the sampling adequacy for the analysis, KMO = 0.747 and all the KMO values for individual items were >0.583 (Range .583-.887), which is well above the acceptable level of 0.5 (Field 2009). Bartlett's test of sphericity $\chi^2(561)=2015.192$, $p<0.001$, indicated that correlations between items were sufficiently large for PCA. An initial analysis was run to obtain eigenvalues over Kaiser's criterion of 1 and in combination explained 75.91 % of the variance. The scree plot (Fig. A-2) was slightly ambiguous and showed inflections that would justify retaining components 1 to 8. The 8 factors could be manually re-categorised and fitted into the original SCNS SF-34 domains. However we found that there was an overlap of the items in the psychological and health systems and information needs in the Malay version of the SCNS SF-34. The items did not discriminate into two different factors. Furthermore the variance due to this factor was large accounting for 34.2% of the variance (refer to Table A-3 below). However when internal validity was tested with Alpha Crohnbach, the original categorisation proved to be high. Therefore, psychometrically although the psychological need and HSI needs were not distinguished separately, the high validity would allow us to use the SCNS SF-34 Malay version as in the original scoring method.

Test retest was not performed in the Malay version.

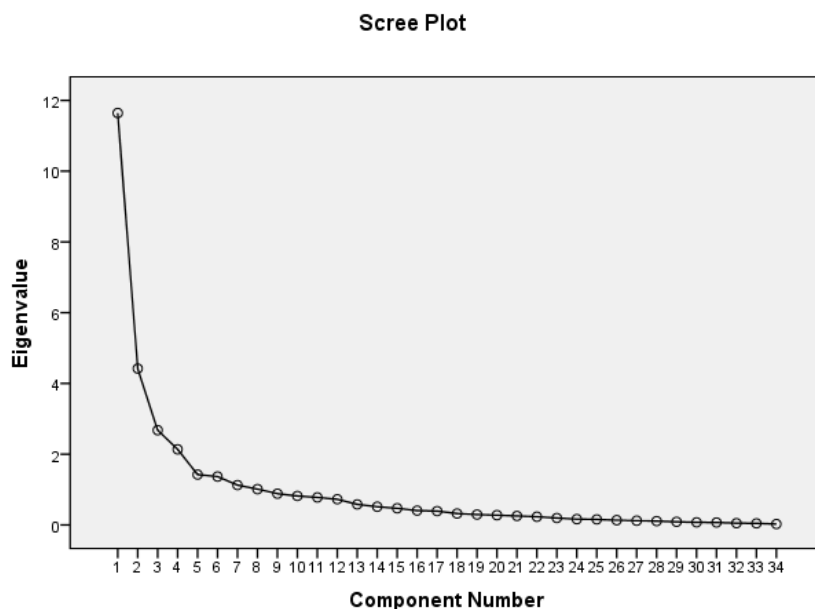


Fig.A-2 Scree Plot after Factor Extraction for the Malay SCNS SF-34