A PHENOMENOLOGICAL STUDY:
THE LIVED EXPERIENCE OF WOMEN WITH BREAST CANCER WHO ARE RECEIVING ADJUVANT THERAPY

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A PHENOMENOLOGICAL STUDY: THE LIVED EXPERIENCE OF WOMEN WITH BREAST CANCER WHO ARE RECEIVING ADJUVANT THERAPY

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Abstract

Understanding women's experiences with breast cancer and adjuvant therapy is important for nurses in order to help these women deal with a number of important issues that are related to their condition and treatment. There is a growing literature on women's breast cancer experiences, but most of these studies have been done from the perspective of women living in western societies and the findings may not be appropriate to women living in Malaysia. The purpose of this study was to obtain a deeper understanding of the experience of women who are living with breast cancer and who have undergone adjuvant therapy, focusing particularly on changes in the life perspective of these women in Malaya. Using Giorgi's phenomenological method six Malaysian women who had survived breast cancer and had received adjuvant therapy were interviewed in-depth. Through data analysis seven themes were identified. These themes were: 1) *Not knowing what to do;* 2) *The meaning of a diagnosis of breast cancer*; 3) *Suffering through the treatment*; 4) *The changing body*; 5) *Trying to protect others*; 6) *Finding strength and making changes*; and 7) *The importance of support.* The findings are similar to other research that has been done in this area, but suggests the concern these breast cancer survivors have for others, especially close family members, may prevent them from seeking earlier diagnosis and treatment. The findings also indicate the importance of cultural beliefs on women's experiences with breast cancer. The research has implications for how nursing practice and education is carried out in Malaysia. A number of areas are recommended for further research.

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CHAPTER 1

INTRODUCTION

The use of adjuvant therapy for women with breast cancer has enhanced the survival of these women and is thought to slow down a recurrence of this disease and perhaps add to their overall quality of life (Adjuvant Therapy for Breast Cancer, 2000). Adjuvant therapy, i.e., therapy given to "eradicate microscopic foci of metastatic disease after local control with surgery" (Otto, 2001, p. 1001), is therefore very frequently used for breast cancer. Usually adjuvant treatment is given in addition to surgery, and includes systematic treatments such as chemotherapy or hormone therapy, or localized treatment such as radiotherapy. Some women may have a combination of adjuvant therapies and some may have radiation or chemotherapy alone. While overall, adjuvant therapy has had a positive impact on survival among many women with breast cancer, both the diagnosis of cancer and side effects of treatment have had profound effects on women's lives as quality of life studies have demonstrated (Ganz et al., 2002; Ganz, Rowland, Meyerowitz, & Desmond, 1998). The purpose of this study is through a phenomenological approach to examine women's experiences with breast cancer and adjuvant therapy, to understand these experiences from the women's perspectives, and to do so in the context of women living in Malaysia, where relatively little of this type of work has been done.

Background

Among women worldwide breast cancer is more common than any other type of cancer (Parkin, Bray, Ferlay, & Pisani, 2005). The incidence is higher in developed countries than developing ones, however mortality is higher in developing countries. In the United States alone, in 2005, over 58,000 new cases of breast cancer will be diagnosed (Jemal et.al., 2005). It is now estimated by the American Cancer Society that every three minutes a woman is diagnosed with breast cancer. Since 1960 the lifetime risk of women developing breast cancer has increased from one in twenty to the current projection of one in seven (American Cancer Society, 2005). Within the United States the incidence and mortality rates vary by racial and ethnic groups. Of the five groups in North America that the National Cancer Institute reviewed for the period 1997-2001, white women had the highest incidence at 141.7 per 100,000, followed by African American at 119.9, Asian American women at 96.8, Hispanic/Latino at 89.6, and American Indian the lowest at 54.2 (American Cancer Society). Mortality rates are highest for the African American women at 35.4 per 100,000 and lowest for Asian American women at 12.6 (American Cancer Society).

As recently as 2001 evidence suggested that if Caucasian and African-American women, with comparable breast cancers, were treated with systematic adjuvant therapy, they tended to have similar benefits as measured by mortality (Dignam, 2001). More recent research suggested that ethnic variation and breast cancer is more complicated than previously thought. There is variation of incidence and survival by age, within and between different ethnic groups (Joslyn, Foote, Nasseri, Coughlin, & Howe, 2005). While mortality rates for breast cancer are decreasing worldwide, the incidence of this disease has increased and this pattern is expected to persist in 2005 (Jemal et al., 2005). Although historically, industrialized or developed countries have had the highest breast cancer rates, there has been an increase in these rates in developing countries in more recent years (Parkin, et al., 2005). The positive news about breast cancer is that survivorship is increasing. Breast cancer survivors constitute one of the largest groups of survivors among the various cancers, while the quality of life of these survivors varies a great deal (Helgeson & Tomich, 2005).

Malaysia is one of the developing countries facing an increase in the number of cases of breast cancer (Hisham & Yip, 2004). In Malaysia, one out of nineteen women will eventually develop breast cancer (National Cancer Society of Malaysia, 2003). The Ministry of Health in Malaysia has classified cancer as Malaysia's second most frequent cause of death after road accidents. In response to this frequency of cancer as a cause of death, a number of initiatives have been designed for earlier diagnosis and more effective treatment of all cancers. The increased incidence is not surprising as statistics also confirm that there are 95 new cases of cancer diagnosed each day in Malaysia (Lim, 2002). Unlike some of the developing countries, late diagnosis of breast cancer is more prominent in Malaysia, and more needs to be done around earlier diagnosis and treatment of cancer in this country (Hisham & Yip, 2003). Just as in the United States, ethnicity is also a factor that affects breast cancer incidence and treatment in Malaysia.

In the year 2002 breast cancer was the most common form of cancer among Malaysian women and this was true for all ethnic groups in the country (National Cancer Registry of Malaysia, 2003). Breast cancer made up almost 30% of all newly diagnosed cancers among Malaysian women in 2002. There were some ethnic differences noted. For Chinese Malaysians the risk is highest at one in 14 chances. The Indian Malaysians are not far behind; the risk is one in 15. Among the local Malays, the risk is one in 24. The Age Standardized Rate (ASR) of female breast cancer in Malaysia is 52.8 per 100,000. For Chinese Malaysians, the ASR is 70.1 per 100,000. Indian Malaysians have an ASR of 61.7 per 100,000. Malays have the lowest ASR of 41.9 per 100,000. The ASR of female breast cancer in Malaysia is higher than that in Singapore, Hong Kong, and Shanghai, but it is lower than that of Australia and the United Kingdom. Of the 4,337 new cases of female breast cancer reported to the National Cancer Registry of Malaysia in 2002, 52.3% were for women less than 50 years old. Compared with the other two ethnic groups in Malaysia, i.e., Chinese and Indian, Malay women also have a shorter recurrence-free survival (Ong & Yip, 2003).

Early detection and treatment are crucial to survival. In cases where breast cancers are at stage 0, defined as restricted to the breast, the five-year survival rate is 100% and for stage 1 it is still 98% (Breast Cancer: Statistics on Incidence, Survival and Screening, 2004). Not only does early detection and treatment contribute to improved survival rates, but also these activities improve the overall quality of life for these women. Early diagnosis usually means less invasive treatments and, therefore, these women have fewer side effects associated with their treatments. They would also experience fewer disruptions to their work and family life. However, too many women are still being diagnosed with breast cancer at a later stage and will require adjuvant therapy, and as a consequence experience greater side effects, and more physical, mental, and social consequences that accompany this treatment.

Rationale for the Study

In November 2000 a panel of national and international experts at the National Institutes of Health (NIH) Consensus Development Conference on Adjuvant Therapy for Breast Cancer made a list of recommendations about treatment for breast cancer for all women (Adjuvant Therapy for Breast Cancer, 2000). These recommendations included chemotherapy for most pre-menopausal and post-menopausal women with localized breast cancer, hormone therapy (most commonly with "tamoxifen") for most women whose breast tumors contained estrogens receptors, and radiation therapy after surgery for all patients with a lumpectomy and for some who had a mastectomy and had large tumors, or if four or more lymph nodes were found to be cancerous. The panel reported that in addition to surgery, most breast cancer patients should receive chemotherapy, hormonal therapy, or radiation therapy to improve their chances of surviving breast cancer.

Although the NIH panel recommended adjuvant breast cancer therapies, the experts noted that many of these adjuvant therapies could have serious short-term or long-term side effects for some women (Adjuvant Therapy for Breast Cancer, 2000). These side effects include premature menopause, weight gain, mild memory loss, and fatigue. Therefore, the panel recommended further research to investigate the quality of life associated with adjuvant breast cancer therapies. The experts also concluded that long-term follow up is extremely important to understand the full impact of breast cancer treatments.

There are numerous studies on various aspects of breast cancer. Most of these studies have focused on women living in developed countries such as the United States, Australia, and England, while very few studies were done in Malaysia. Nursing research in particular in Malaysia is at an early developmental stage as much of the research into breast cancer has been medical, and either epidemiological or at the molecular or genetic level (Lim, 2002). Nursing care given to patients with breast cancer in Malaysia is based on research findings done abroad. This may not be appropriate within the Malaysian healthcare environment, as Malaysian women's breast cancer needs have been shown to differ from women in western countries (Gopal, Beaver, Barnett, & Ismail, 2005). Knowledge, education, socio-cultural background, traditional customs, and traditional habits greatly influence the patterns of thinking and behaviour of women (Makabe & Hull, 2000) and this would be expected to be the case for women with breast cancer. Therefore, understanding and valuing cultural diversity is vital to develop more effective and individualized nursing care that is consistent with patients' and families' desires and comfort.

Women in Malaysia also tend to be diagnosed with breast cancer at a later stage than women in other countries even when compared with women in the region, e.g., Singapore (Yip & Ng, 1996). In addition many of the studies of experience with breast cancer have been on early stage breast cancer (Knobf, 2002; Simes, & Coates, 2001) and these findings may differ from those of women diagnosed at a later stage. Therefore, women's experience with the disease and treatment in Malaysia may differ from women in other countries where most of the research has been carried out. Cancer and improvements in women's health continue to be a major concern around women's health issues in countries such as Malaysia, Hong Kong, and Singapore (Choi, 2004). The National Cancer Control Program in Malaysia supports improving the quality of life of those individuals who are affected by cancer. This research has the potential to contribute to that mandate.

Purpose of the Study

Although there are increasing research efforts into a variety of aspects associated with breast cancer, there is a continued need for research to increase the nurses' understanding of how women experience living with breast cancer and adjuvant treatment, especially within the Malaysian context. Therefore, there is a need to conduct a study from these women's perspective. The aim of this study is to obtain a deeper understanding of the experience of women who are living with breast cancer and who have undergone adjuvant therapy, focusing particularly on changes in the life perspective of these women in Malaya.

CHAPTER 2

REVIEW OF LITERATURE

In the review of the literature for this study I used the bibliographic databases of CINAHL, MEDLINE, and OVID that contain numerous research articles on various aspects of breast cancer. I also searched the World Wide Web for articles, reports, and information and this search has contributed to my literature review. The focus of my search was to obtain research on the experiences of women living with breast cancer. I was particularly interested in those studies that focused on non-western women, in particular those living in developing or low-income countries, where less research of this nature has been done.

Based on the results from these search strategies, I collected literature that addressed either the overall phenomenon of living with breast cancer or particular phenomenon within that experience, e.g., survivorship, waiting. Given the nature of my study, articles that focused on women receiving adjuvant therapy were an important part of the search strategy. However, while it was one of my inclusion criteria for the literature review, I did not limit inclusion to those articles. Also important to the review were articles that informed of the Malaysian woman's experience with breast cancer. One of the strengths of this review is that I have tried to cover as fully as possible the literature pertaining to breast cancer in Malaysia and other non-western countries. The review is not meant to be exhaustive of the research that has been done on living with breast cancer, rather it is meant to inform and situate my particular research.

Living With Breast Cancer

Women with breast cancer may encounter a variety of physical, emotional, and social problems (Ganz et al., 1996). Psychological stress relating to the diagnosis of breast cancer is one problem that many of these women face (Golden-Kreutz et al., 2005). This stress is related to having a potentially life-threatening illness, but it is also associated with aspects of treatment and the many side effects experienced as a result of the treatment (Dow & Lafferty, 2000; Ganz et al., 1998; Schreier & Williams, 2004). Women also experience a number of physical problems, especially related to their treatment. In most cases cancer survivors face irreversible physical changes relating to the adjuvant treatment they receive (Casso, Buist, & Taplin, 2004). One of the changes that posed a number of problems, especially for younger women, is treatment-induced menopause (Ganz, Greendale, Petersen, Kahn, & Bower, 2003). Even though for some, menopause itself is not a significant problem, it is what it represents that may be problematic. For some it is a reminder of the many losses that they have had because of their disease and marks the end of their childbearing opportunities. For others it is the symptoms related to menopause that cause the most distress.

There is also a suggestion that treatment for breast cancer with chemotherapy adversely affects a woman's sexual functioning (Avis, Crawford, & Manuel, 2005: Berglund, Nystedt, Bolund, Sjoden, & Rutquist, 2001). In fact, breast cancer affects many aspects of women's sexuality including changes in physical functioning and her perception of "femaleness" (Wilmoth & Ross, 1997). Physical problems other than those related to menopause and sexual functioning have been investigated and these problems, such as numbness and lymphadema, seem to have long term consequences. Some physical changes attributed to adjuvant therapy may also have long term implications (Kornblith et al., 2003).

While many women find different ways to improve their lives and to cope with the consequences of breast cancer, it is important that nurses try and find out the various ways women's lives are affected. This will assist nurses in identifying strategies to improve the women's ability to cope and thus achieve a good quality of life. There have been numerous studies that have explored how women live with breast cancer. Most if not all of the studies located are qualitative. Many of these qualitative studies have used various phenomenological methodologies or alternatively have employed grounded theory. A few researchers have used quantitative methods. Most of these studies have been conducted with women living in the western world, with some of these focused on minority groups or various ethnic groups living in western society. A few studies have been conducted in Asia. The following sections contain a review of the research literature on women's experiences with breast cancer.

North American Women's Experiences

United States. Much of the research located documented the experiences of white or Caucasian American women and this section is an overview of these studies. The section also includes women of ethnic minorities living in the United States. Moch (1990) studied the phenomenon of health within the breast cancer experience. She interviewed 22 American women using Newman's (1986) "health as expanding consciousness" framework to analyze her data. Findings related to having cancer included themes that addressed information gathering to make choices, dealing with physical aspects of the disease, and means of dealing with lack of control and threat of future cancer, and retaining hope for the future. The three other themes identified related to the women's expanded consciousness and were experienced through how they changed their relatedness to others, the meanings they could attach to their experiences, and how they could develop new perspectives about their lives.

Since age at time of diagnosis has an impact on women diagnosed with breast cancer (Avis et al., 2005), the question that Loveys and Klaich (1991) asked in their qualitative study, with 79 white women living in the United States recently diagnosed with breast cancer, was what impact this condition had on younger women. Younger women were defined as those who were still able to have children. These researchers found that a number of areas of the women's lives were affected by the diagnosis and they characterized their findings as "demands of illness." These demands ranged from facing the fact that they had breast cancer to dealing with financial and work-related challenges. Treatment concerns and some of the bodily changes they had, also put demands on these women to work through the effects of cancer. The authors illustrated how many aspects of a woman's life are affected by a diagnosis of breast cancer.

Nelson (1996) focused on the phenomenon of uncertainty among nine breast cancer survivors living in the United States. She combined the research methods of hermeneutic phenomenology and photographic hermeneutics within her study. She identified five themes related to uncertainty. Uncertainty because of changing emotional feelings such as fear of dying and anxiety, who to rely on for supportive relationships, transitions in their lives around losses and waiting, how to deal with the death of other women with breast cancer, and how to gain a perspective of their lives given their condition were just some of the ways that uncertainty was experienced by these women. The author called the unifying theme of all these uncertainties "struggling to gain meaning." Breast cancer survivors frequently try to find meaning in what has happened to them throughout the course of their disease.

The phenomenon of surviving or being a survivor of breast cancer was the issue that Thibodeau and MacRae (1997) studied. They included 45 white American women who were three years post diagnosis with early breast cancer, in order to examine the experience of being a breast cancer survivor. They found that many of the concerns related to survivorship of these women were similar to those identified by Loveys and Klaich (1991). However, there were also some differences in that the women in the Thibodeau and MacRae study also identified positive aspects of their experience and identified how they developed their spiritual side as a consequence of their cancer diagnosis and experience.

The issue of survivorship is important to anyone diagnosed with a life-threatening disease. Pelusi (1997) also studied survivorship among eight women living in the United States. She used a phenomenological approach to her study. To these women the essence of survivorship had to do with how they responded to the multiple losses they had experienced as a result of having breast cancer and the uncertainty associated with the disease. Financial concerns were also an important part of their experience. Along the negative aspects of the disease, survivorship entailed growth and finding support along the way. The experience was characterized as a "journey"; a descriptor not infrequently used with an experience of cancer.

A third study also focused on survivorship. This study examined how the meaning of cancer had evolved for eight older American women who were long-term breast cancer survivors (Utley, 1999). In this study three meanings of cancer were identified for these women. Cancer was seen as "sickness and death," an "obstacle," and also as "transformative." These three themes illustrate the changing nature of the disease over time and how breast cancer survivors were able to move forward. Because the focus was on older women, the author did indicate that the meanings could be different for younger women. The transformative nature of experiencing breast cancer is an important theme in other qualitative studies (Coward & Kahn, 2005; Moch, 1990).

The experience of breast cancer would be expected to differ if women had adjuvant therapy versus not undergoing this treatment, given some of the side effects women may experience with adjuvant therapies (Adjuvant Therapy for Breast Cancer, 2000). Young-McCaughan (1996) specifically examined how the use of adjuvant therapy affected the sexual functioning of 67 women with breast cancer living in the United States. The author found that women receiving chemotherapy were more likely than their controls receiving endocrine therapy, to have moderate to severe problems with sexual functioning. Vaginal dryness, decreased sexual desire, and difficulties with intercourse were more frequent problems for the women who had adjuvant therapy. Similar findings of persistent sexual dysfunction and related symptoms have been noted with long-term survivors, e.g., up to seven years post-treatment, for American women with breast cancer who have received adjuvant therapy (Broeckel, Thors, Jacobsen, Small, & Cox, 2002). These researchers studied the outcomes for 58 women.

In another study that focused on adjuvant therapy, Knobf (2002) used a grounded theory approach to understand the social psychological processes of women with therapy-induced early menopause among breast cancer survivors. For the 27 women in this study "vulnerability" was identified as the main problem. The basic process that was used to theorize how these women dealt with this vulnerability was "carrying on." To deal with their challenges and to enable them to carry on, women learned how to become focused on immediate problems, face the uncertainty in their lives, become menopausal - in that they learned to accept this change, and balance the challenges. The substantive theory developed from this research helps to understand the problematic experience of early menopause in breast cancer survivors and some of the issues nurses and other health care professionals need to understand.

Women's outcome or adaptation is influenced by various factors. Samarel and co-researchers (1998) studied women's adaptation to the different aspects of breast cancer that survivors face. They examined this adaptation using Roy's Adaptation Model and within the context of support groups. Most of the 70 American women they interviewed in this quantitative study reported they needed to made adaptations in the four adaptive modes identified in Roy's model, i.e., physiological, self-concept, role functions, and interdependence. The finding would be in keeping with the known effects of breast cancer and treatment on the body, women's views of themselves, relational issues, and need for support. They also reported positive aspects of their experience similar to those noted above in Thibodeau and MacRae's (1997) study.

Sammarco (2001) used a quantitative approach as well to investigate how social support and uncertainty affected the quality of life of 101 younger women living in the United States, who had survived breast cancer. This researcher found that the women who felt they had greater social support had a better quality of life than those with less social support. However, those with greater uncertainty had a lower score on quality of life measures than those reporting less uncertainty. While the two variables, social support and uncertainty, explained much of the variance in quality of life scores, a large amount of the variance was unexplained, suggesting there are other important influences on quality of life for these women.

How women use decisional support aids for diagnosis and treatment was the focus of a phenomenological study by Lacey (2002). She interviewed 12 women who had been treated for breast cancer. The amount of stress that women experienced when faced with a diagnosis and coupled with the pressure to make a decision as quickly as possible, were some of the factors that made the early period of their breast cancer experience overwhelming. The women relied heavily on the advice they received from physicians, but their main support came from family and friends. The women felt nursing care was lacking during this important time. The research illustrates how important help and support is in making decisions for breast cancer treatment.

How breast cancer survivors are able to resolve issues like their fear of dying and feelings of being alone were the focus of an investigation by Coward and Kahn (2004).

The researchers were interested in how women were able to transcend these issues. Support from others, as well as spiritual connections, helped these women develop hope, find meaning in their experiences, and achieve a greater connectedness on different levels. In another phenomenological study by the same authors (Coward & Kahn, 2005) with 14 women who were breast cancer survivors, the authors found that the bonding that occurred among these survivors was an important type of connectedness that gave them a degree of comfort and appreciation. This phenomenon, i.e., the importance of connectedness among breast cancer survivors, has also been found by Solberg, Curran, and Church (2003) whose Canadian participants described it as an empathy that comes from really knowing what it is like to have breast cancer.

The last study located on white women living in the United States, by Boehmke (2004), attempted to measure symptom distress in breast cancer survivors receiving adjuvant therapy. She focused on 120 younger women living in that country and used quantitative measures in her study. Although symptom distress scores were generally low, symptoms attributed to chemotherapy, such as fatigue and lack of concentration, were sources of distress. Physical appearance was also a source of distress as the women experienced changes in their bodies. The researcher did not examine menopausal symptoms, and given the age group, did acknowledge that this factor might have increased distress scores.

Other researchers in the United States, rather than focusing on white or Caucasian women, looked at minority groups or other ethnicities. Most of these researchers studied the experiences of African American women. African women generally have poorer outcomes when it comes to mortality rates (American Cancer Society, 2005). Seven studies located focused on this particular group. Moore (2001) studied breast cancer solely among African American women. She used a narrative approach for her study of 47 breast cancer survivors. One of the main findings to come from this research was the belief that breast cancer was a disease of white women, thus leading to a feeling of alienation among black women with the condition. A second finding was the belief that stress associated with relational difficulties in the family, racism, and loss was a major etiological factor in the disease.

Lackey, Gates, and Brown (2001) wanted to explore how African American women responded to the diagnosis of breast cancer and early treatment. They conducted a study with 13 women using Colaizzi's phenomenological research method. In their study they explored the women's progress through diagnosis and treatment. They particularly wanted to know how threats to their femininity, because of loss of their breast and effects of adjuvant therapy, were balanced by their spirituality and dependence on God to get them through the progress of their disease and treatment. These same researchers (Gates, Lackey, & Brown, 2001) also examined the type of care African American women recently diagnosed with breast cancer needed and why they did not seek care earlier than they did. This study included 13 women and used ethnography. One of the main themes identified was how to care for others and thus ensure earlier care for other women. The women in the study talked about the importance of a positive response on the part of health care workers that would encourage women to seek earlier care and proceed with treatment.

Using focus groups, Wilmoth and Sanders (2001) studied the concerns of 16 African American women diagnosed with breast cancer. Although they had a different methodology and a different ethnic group than Loveys and Klaich (1991) or Thibodeau and MacRae (1997), many of the concerns identified by all researchers were similar. The women in Wilmoth's and Sanders' study identified their concerns with menopause related to their treatments. They also felt it was important to be more active in promoting breast health. Culturally appropriate care was important to these women.

Henderson, Gore, Davis, and Condon (2003) also conducted a study with African American women. They used a semi-structured interview to collect data on how these women coped with breast cancer. One of the main coping strategies these 66 women reported using was praying. Other ways of coping included staying away from people who expressed negativity, trying to develop a positive attitude, and relying on the support from family and friends. The women also believed that it was important to provide support groups that were sensitive to their cultural needs. They also expressed the need for culturally sensitive social support for women like themselves.

López, Eng, Randall-David, and Robinson (2005) combined the methods of photovoice, participatory action, and grounded theory to find out some of the concerns of African American women in a rural area in the United States. Thirteen women took part in the study; 12 breast cancer survivors and the mother of a woman who did not survive breast cancer. These authors examined quality of life concerns of these women. Some of the main concerns were finding a safe source of support for needs, making plans for the future, and serving as role models to others in their community with breast cancer. Two of the factors they had to deal with were negative beliefs about cancer and living up to the expectations of them as African American women. Main coping strategies of these women were to put their trust in God and their religious faith. This was one of the few qualitative studies that had quality of life as an identified phenomenon of interest.

The last study reviewed on African American women (Bradley, 2005) was done to explore why these women delay seeking treatment for breast cancer and what were some of the women's worries at this particular time. This was a quantitative study with 60 women. Contrary to the belief that this particular ethnic group of women delays seeking treatment, the researcher found little evidence of delay among her study participants. Thus she could not examine the influence of worry. She did report though, that her sample's socio-demographic characteristics, apart from ethnicity, were similar to white American women; a factor that could influence her findings.

Since most of the research on women, other than white or Caucasian women, has been conducted with African American women, less is known about other ethnic minorities living in the United States. However, one study on the breast cancer experience of Asian American women was located (Tam Ashing, Padilla, Tjero, & Kagawa-Singer, 2003). In their study 10 Korean, 11 Chinese, and 13 breast cancer survivors of other Asian descent were included. This group identified the importance of their spiritual beliefs and concerns about their families. One of the concerns they expressed was to what extent they were a burden on their families. They also voiced a need for care that was sensitive to their various cultures.

The final study included in this section compared various groups of women (Ashing-Giwa et al., 2004). These researchers compared the experiences of African American, Asian, Latina, and Caucasian women who were breast cancer survivors and living in the U.S. While they found differences in treatment the women received or were offered, some concerns crossed all ethnic groups. African American women were less likely to be offered the same treatment that their white counterparts were offered. Commonalities among the groups they studied were a fear of recurrence, worries about their children, and concern about medical expenses. Similar to Henderson et al. (2003), spirituality as a means of coping was common among the ethnic minorities and all reinforced the need for cultural sensitivity when dealing with women with breast cancer.

Canada. Canada and the United States are both part of North America and as such breast cancer survivors may share some similarities. However health care differs markedly between these two countries and this factor may affect some aspects of women's experience, therefore I have included the Canadian studies that I was able to locate as a separate category. A limited number of Canadian studies on living with breast cancer were found. None were located on aboriginal Canadian women's experiences or with women who could be considered ethnic minorities.

Richer and Ezer (2002) studied what meaning women with breast cancer gave to receiving chemotherapy. They used grounded theory in their study of 10 women. Three main dimensions of the experience were identified. The women illustrated how they lived through the experience of chemotherapy, lived with effects of the treatment, and then were able to move on after the treatment was completed. The period of receiving chemotherapy is known to be a period of distress for women with breast cancer. The study illustrated the different dimensions to this common treatment and how women experienced chemotherapy. Their study supported the importance of nurses in creating a caring environment for women with breast cancer so that they may discuss issues related to themselves and their disease.

With the exception of Nelson (1996), not much research has been done on the phenomenon of waiting, yet women who survive the initial treatment of breast cancer spend a great deal of time waiting. They wait for investigations, treatments, and then a period of survival. Gaudine, Sturge-Jacobs, and Kennedy (2003) studied this phenomenon among Canadian breast cancer survivors and the effects this phenomenon had on these women's lives. The women reported that their lives were changed as a result of their experience. They acknowledged that support groups gave them a feeling of belonging but also recognized how uncertain things were for them in the time that they spent waiting. They expressed a need to have a better knowledge of what may happen to them in the future.

Solberg et al. (2003) used grounded theory to try and understand the social-psychological processes by which breast cancer survivors living in rural Canada receive social support through audio teleconferencing. Women identified how they received support both at the local site when other women with breast cancer were present and through the use of the network by connecting with other survivors. While some women liked the medium of teleconferencing for support because it let them have some distance with other survivors, others did not like it as well as face-to-face support groups.

The type of treatment may have a profound effect on how women experience breast cancer, or at least how they understand this treatment. Thomas-MacLean (2004a; 2004b) studied how treatment influenced women's experiences in this context. She used both focus group discussions and individual interviews with Canadian breast cancer survivors to collect data, and then used Frank's approach to narratives to understand the problem of embodiment for these women. Her findings suggested that although women did not feel comfortable with the medical system and treatment given through this system, they were also not comfortable if they did not partake in this treatment, because of fear and the suffering they endured. Five areas of concern were identified. The women were concerned with how much control they had over their treatment, the amount of suffering involved, their interactions with the medical system, the loss of a breast, and the end of their treatment for cancer.

A pilot study on a special group of breast cancer survivors was done with Canadian women who take part in dragon boat racing (Unruh & Elvin, 2004). The authors looked at the meaning of this activity for three women through qualitative interviews and analysis. The racing helped these women in terms of social support, connecting with other survivors, and helping them build their confidence once again. The spirit of competition associated with the races helped them build confidence. They also felt an important aspect of taking part in the races was the public awareness for breast cancer that the activity fostered.

European Women's Experiences

United Kingdom. Other studies located on women's experiences with breast cancer were done in the United Kingdom. While this is a western society, there may be cultural and health care differences from North America, that makes women's experiences with breast cancer different. Burgess, Hunter, and Ramirez (2001) studied what factors might be associated with delay in seeking treatment among women in England who had been diagnosed with breast cancer. They conducted qualitative interviews with 185 women. Knowledge was an important factor, separating women who promptly sought care for symptoms versus those who delayed seeking treatment. If women recognized the importance of seeking help, they were more likely to do so. However a lack of understanding of the importance of early treatment or having other priorities in their lives resulted in delay in seeking treatment.

Whether women are in early or late stages of cancer also affect their experiences with breast cancer. Davies and Sque (2002) included in their study 10 women who had advanced cancer and were receiving hospice care in England. These women's experiences were predominated by feelings of isolation and fear because of the nature of their disease. These findings are in keeping with the seriousness of their condition and suggested that women at these times, i.e., later in the disease, have different needs. Not many studies deal with women's experiences in the later stage of breast cancer or of those women in hospice settings.

A third study, carried out as part of a larger study in the United Kingdom examined the overall phenomenon of women living with breast cancer (Lindop &

Cannon, 2001). These researchers selected 12 women living in England who had breast cancer and used a clinical pathway approach as a conceptual guide to examine the women's experiences. The pathway included feelings prior to diagnosis, how they reacted to diagnosis and treatment, and their feelings after treatment. Body image concerns and femininity were important reactions to the diagnosis and early treatment, while social support and informational needs were important throughout the experience. The study highlights some of the varying needs that occur along this pathway and some of the challenges these women faced.

Risk assessment and management strategies during adjuvant therapy for breast cancer was the specific phenomenon that Cowley, Heyman, Stanton, and Milner (2000) focused on in their qualitative study with 12 breast cancer survivors living in England. Prior to entering treatment these women found communication from health professionals was not always clear around what these women could expect during treatment. The women felt they always needed to assess their own risks vis-a-vis treatment. During the actual treatment phase they tried to live as normal a life as possible while trying to deal with the ups and downs that were part of the chemotherapy. The latter was described as a "rollercoaster effect."

Hare (2000) limited her phenomenological investigation to the phenomenon of breast-related lymphoedema. Lymphoedema is a common side effect after surgery for breast cancer. She included in her study 20 women living in England who had this condition. While the women had challenges related to their condition, they felt that accessing information on the condition helped them. They also were thankful for their survival and believed more could be done for women in similar situations. Women who have lymphoedema can have significant problems with functioning that involve the upper body (Hayes, Battistutta, Parker, Hirst, & Newman, 2005).

Scandinavia. Other research on women's experiences with breast cancer has been done in the Scandinavian countries. A limitation of accessing these studies is that they are not always published in the English language, therefore, the studies in this review underestimate the work in those countries. Jensen, Bäck-Pettersson, and Segesten (2000) studied 10 Danish women to understand the lived experiences of these women with breast cancer. These researchers used Giorgi's phenomenological method. One of the key themes related to the women's experiences was their active participation in treatment and fighting against the disease that was termed "not giving in." Women sought support from a variety of sources, from drawing on inner strength to seeking assistance from health care workers.

Landmark, Strandmark, and Wahl (2001) used a grounded theory approach to study the experiences of 10 Norwegian women who had recently received a diagnosis of breast cancer and had received adjuvant therapy. The core category identified among these survivors was "the will to live." Some of the social-psychological processes related to this core category identified, were looking at life values, thinking about the future, and thinking about what to expect from life. The processes identified could be of assistance to other women with a diagnosis of breast cancer and who are trying to make decisions. In another article two of these researchers (Landmark & Wahl, 2002) expanded on these women's experiences. They further explored the women's struggles in their will to live, but in addition discussed some of the emotional and physical changes these women experienced. An emotional change the women identified included fear related to their diagnosis, while physical changes included the women's loss of their breast and side effects of treatment.

In the study just cited social support, particularly from family was important to the women's progress. Landmark, Strandmark, and Wahl (2002) furthered explored the theme of social support in a third article. Different dimensions of social support, such as relational or emotional, informational, and instrumental, were all important to these women. Informal sources of support, i.e., family and friends, helped these women as did formal sources, i.e., health care professionals. The study does illustrate the many challenges these women may experience early in their treatment after a diagnosis of breast cancer and that coping strategies aimed at these women might usefully focus on this will to live.

Australian Women's Experiences

A number of studies with Australian women, who have been diagnosed with breast cancer and focused on these women's experiences with this disease or aspects of this disease, were located. The first study is that of 10 women with non-invasive cancer of the breast (Webb & Koch, 1997). The findings are presented in relation to women discovering that they have the disease, how they reacted to the diagnosis, and the type of information they felt was important to women who have this diagnosis. Perhaps because of the early nature of their disease, the women expressed optimism about their health and the diagnosis. They were, however, not well informed about the condition.

In contrast to the study above, Stegina, Occhipinti, Wilson, and Dunn (1998) used a quantitative approach and a large sample to study Australian women's experiences with primary breast cancer. Some of the main findings among these 245 women were fear, especially of recurrence and the effects of chemotherapy, uncertainty as to the best treatment, and threats to their self-image. Similar to Webb and Koch's (1997) findings, the women also had a number of informational needs.

Wilkes, White, and Beale (2002) focused on support for breast cancer survivors in Australia. They interviewed six women in order to understand the women's experiences with support, and in particular, to find out what they needed at different times, and whom they felt were their main sources of support. Emotional support was particularly important, especially after the diagnosis, because of the impact this diagnosis had on the women and their psychological health. Their family and friends were the main source of their support. They reported that nurses did not do much to help with the emotional aspect of their diseases. In fact, physicians were rated as a better source of support among the formal caregivers.

Most of the studies located were conducted in large urban areas, however Rogers-Clark (2002) reported on how living in a rural area in Australia influenced breast cancer survivors' lives. Nine women living in a rural area were interviewed and most felt that the nature of rural communities contributed to a positive experience. They also acknowledged that there were negative aspects to living in a rural area. Traveling long distances to access treatment and lack of breast cancer support groups are some of the factors that are particular to women living in rural areas.

Thewes, Butow, Girgis and Pendlebury (2004) examined the effect of age on survivorship among breast cancer survivors. They focused on the psychosocial needs of 18 younger and older women in Australia. Their findings supported previous work that age is an important variable especially related to menopausal effects of treatment. Nevertheless, both groups of women shared a number of important support needs, e.g, information and emotional, when it came to all dimensions of support, suggesting perhaps more commonalities than differences among survivors of breast cancer, in the area of support.

Only one study was located that studied indigenous Australian women's experiences with breast cancer (McMichael, Kirk, Manderson, Hoban, & Potts, 2000). These authors used a variety of methods, focus groups, individual interviews, and case studies, to collect data. There are a number of challenges these women face in getting a diagnosis and obtaining treatment. One of the challenges related to women's understanding of the importance of screening and receiving early treatment. Other challenges were a lack of social and financial support. Past relationships with the health care system also had an influence on the women's screening and treatment behaviours. Although not addressed, culturally appropriate care may be a factor that had an impact on these indigenous women's behaviours.

Asian Women's Experiences

Hong Kong Chinese. Given the purpose of this study it was important to locate any research that was done with women living in Asian countries. Few studies were located, but the number has been increasing in recent years. Again, language may have been a barrier to finding more studies. The first Asian study was from Hong Kong in which Lam and Fielding (2003) used phenomenology to explore 17 Hong Kong Chinese women's experiences with breast cancer. Many of these experiences are similar to women living in western societies in that fear of diagnosis and uncertainty about treatment were important themes. Themes that differed from previous studies with western women were dealing with the superstition related to breast cancer and the women's struggle to counteract this superstition by appearing normal and trying to conceal the fact they had breast cancer.

A second study by Lam, Fielding, and Ho (2005) was a quantitative study on the psychological consequences of breast surgery for early-stage cancer. This study was based on the experiences of 405 Hong Kong Chinese women one-week post surgery. At that time over 40% of the women had moderate to severe psychological distress and this outcome measure had decreased slightly by the one-month follow-up. Side effects of chemotherapy contributed to higher scores on psychological distress, as did their difficulties around decisions relating to treatment.

The third study with 22 Hong Kong Chinese women focused on decision-making and breast cancer treatment (Lam, Fielding, Chan, Chow, & Or, 2005). The metaphor of "gambling" was used to characterize this process and "*Gambling with your life*" was the core variable in this grounded theory study. The women relied on a number of self-related factors, from intuition to emotions, in their decision-making and felt that often they did not have as much information as they needed. They also felt that they did not get the guidance that they needed from the medical staff. Fear of death and uncertainty as to the outcome of their decisions were other factors that had an impact on making treatment decisions.

Viet Nam. One quantitative study was located that examined the beliefs of breast cancer survivors from Viet Nam (Baumann, Youngshook, & Love, 1997). The study was part of a larger study of women's attitudes toward breast cancer. In this study the researchers examined how the women viewed breast cancer, seeking care, and health practices. Women in the study first noticed a lump in their breasts as how the cancer was manifested, had no idea what caused their cancer, were optimistic about a cure, and yet realized that breast cancer was a serious disease. Their greatest fear about cancer was the threat of death. Most of them were not taught how to do a breast self-examination, and for those who did the most frequent source of information was the newspaper. They had some problems with transportation as a barrier to treatment but cost and childcare were not big barriers.

Malaysia. There was one nursing study by Gopal et al. (2005) that compared the informational needs of women in Malaysia with those of women in the United Kingdom who were mainly white women. This was a quantitative study, and while it did not focus on living with breast cancer as the other studies in this review have, it was the only study to have a sample of Malaysian women. The Malaysian sample included women of Indian, Chinese, and Malay ethnic origin. Women in the United Kingdom and Malaysia both rated information about a cure for their breast cancer as the most important informational need. However, information on sexual attractiveness was rated second by the Malaysian women and ninth by the British women. Within the Malaysian groups, Malay women rated information on sexual attractiveness slightly higher than the other two ethnic groups.

Other studies were located that are important to understanding breast cancer in Malaysian women. Yip and Ng (1996) compared the staging of breast cancer at diagnosis between women living in Singapore and those in Malaysia. They found that when women in Malaysia came to a clinic for treatment they were at a later stage of the disease than the women in Singapore. Ethnic variation has been found within the country as well. An epidemiological survey of women attending a breast clinic in Kuala Lumpur demonstrated ethic variation in seeking treatment for breast cancer. Chinese-Malay women were more likely than other groups of women to seek earlier treatment (Yip, Alhady, & Jayaram, 1995). Chan (1999) examined the number of women who performed breast self-exams and found that very few women in Malaysia engage in this practice. This might be a factor in later diagnosis. He also found that the majority of women surveyed had never been taught to do this examination.

Further epidemiological studies explored breast cancer among Malaysian women and confirm earlier findings. Hisham and Yip (2003) suggested some of the factors that result in delay in seeking diagnosis of breast cancer are related to ethnicity and living in rural areas of the country. They confirmed that Malay women delay seeking treatment until they are at a more advanced stage of cancer. In a second study they explored the delay and identified such factors as using traditional medicine as a first line of treatment, stigma associated with the disease, being poor, having lower educational levels, and the fear associated with the disease (Hisham & Yip, 2004). Other researchers have found that not only do Malay women have more advanced cancer on first diagnosis, but also have shorter time recurrence free. Lifestyle issues have also been correlated breast cancer among Chinese Malaysian women in one geographic area (Hejar, Chong, Rosnan, & Zailina, 2004).

There are a number of findings from this group of studies, which contributes to a greater understanding of the problems relating to breast cancer in Malaysia. First, Malaysian women delay seeking treatment for breast cancer, and therefore have more advanced cancer, and this may be particularly so for Malay women. Second, some of the reasons that Malay women delay seeking medical help are greater adherence to traditional medicine than biomedical approaches, fear and misunderstanding of the disease, and geographic isolation where messages of early detection do not reach. Third, there is ethnic variation in breast health practices in that Chinese Malaysian women are more proactive when it comes to breast screening than Malay women. Fourth, the majority of Malaysian women have not been taught how to do breast self-examination.

Qualitative Metasynthesis

There was one metasynthesis of studies on women's experience with breast cancer. This metasynthesis included studies on women living in countries in the western world; mainly Scandanavia, the United Kingdom, and the United States. Fourteen qualitative studies, all using a phenomenological approach, were used in this metasynthesis to look at the phenomenon of "hidden suffering" in breast cancer survivors (Arman & Rehnsfeldt, 2003). This synthesis examined how suffering was described or represented in these studies and how the women were able to deal with this suffering.

Suffering was found to be present throughout the women's experiences, during diagnosis and treatment, and also changed over time depending on how women incorporated suffering into their lives. The authors felt that frequently nurses and other health care workers underestimate the type and the strength of these women's suffering.

Summary

There have been a number of research studies on women's experiences with breast cancer and most of this research has been conducted with women living in western society. However, particularly in the United States there have been a number of attempts to include women who are not Caucasian or to include ethnic minorities. This effort has led to a number of studies on African American women. Less frequent research has been conducted on Asian or Hispanic American women, yet statistics on morbidity and mortality among these women differ (Joslyn et al., 2005). No Canadian, British, or Scandinavian studies were located that examined ethnic minorities or aboriginal women. One Australian study included indigenous women. Few studies on Asian women were located, but the research on women living in Malaysia suggested these women differed from women in other countries. However, there are differences among women of different ethnic groups within that country.

Breast cancer survivors shared a number of similarities and also some differences. Some of the similarities related to concerns or problems the women had as a result of having breast cancer. In those studies that included the use of adjuvant therapy, there were also some similarities noted in that women reported some of the same physical side effects and had the same fears. Women with breast cancer were concerned with the threat of a recurrence, choice of the best treatment, and changes to their bodies because of surgery or treatment. Studies focused on decision-making around diagnosis and treatment and suggested women need a great deal of informational and emotional support at this time. Many studies reported survivors' concerns about the effects on their families or on the type of information they felt they needed. Some of the differences noted were related to coping strategies, in that African American women frequently reported drawing on their spirituality while other women did not. At least among the women living in Chinese Hong Kong societal reactions and fear of cancer seemed to be a factor in how they coped with their diagnosis and treatment. Malay women delayed seeking treatment for breast cancer and as a consequence were treated at a later stage than those who sought treatment earlier.

There are some limitations to the literature review as well as to the research located. In terms of the former, I was limited to the research that was written in English or Malaysian and as a result may not have a good coverage of the research that deals with various ethnic groups. In terms of the latter, some of the research may not have identified the ethnic background of the women, so some ethic minorities may have been included in the research. Another limitation is that factors other than ethnicity, e.g., religion, socioeconomic status, may be important to the experience and were not identified. Additionally, because some of the research was focused on particular phenomenon, findings may reflect the focus studied rather than what might have been important to a particular group of women. For example, studies that did not enquire about the experience with adjuvant therapy may miss important findings related to that phenomenon.

What seems to be important in examining the experience of breast cancer from a cross-cultural perspective is that women identified the importance of cultural sensitivity when being provided with care. An important question then is what constitutes culturally sensitive care for a particular group? It is only by focusing on a particular cultural group that we can more fully understand their experiences. It is hoped that the findings from my study on Malay women, living in Malaysia, will contribute to this growing literature on breast cancer survivors in other countries. In particular it will help document some of the special concerns that Malay women have with breast cancer and adjuvant therapy.

CHAPTER 3

METHODOLOGY

This study used a phenomenological research method. A phenomenological method is appropriate as I attempt to understand the lived experience of women with breast cancer and to answer my research question "What is the lived experience of women diagnosed with breast cancer and who are undergoing adjuvant therapy? This chapter contains a description of the selected methodology and the methods I used in working with Malay women in Malaysia in order to understand their everyday life experiences, since they began treatment for their breast cancer.

Giorgi's Phenomenological Method

While all phenomenological research methods share some similarities in that the purpose is to identify the structure or the essence of a particular experience as lived, there are some differences in the methodological procedures and interpretations (Omery, 1983; Speziale & Carpenter, 2003). Phenomenology is a science that has as the overall purpose to describe a selected phenomenon as the participants live this phenomenon in their everyday lives. Phenomenology permits the researcher to seek, then uncover, and translate these experiences into words that get as close as possible to these experiences. It allows the researcher to examine what can be found in the participant's consciousness about the phenomenon of interest. In a phenomenological study the researcher would work closely with participants who have had the experience or "lived" this experience and thus can work with the researcher to access these experiences. Numerous aspects of these experiences are obtained, such as memories, feelings, moods, thoughts, personal events, and mental constructions. The main objective is to obtain and understand this experience.

In particular I selected Giorgi's (1985) phenomenological method for my study. Giorgi's method consists of five essential or core steps. The first step consists of data collection and the remaining steps, data analysis. These five steps are described as (1) obtaining a description of the phenomenon; (2) grasping a sense of the whole experience; (3) identifying "Meaning Units" related to the experience; (4) transforming the meaning units into insights to understand the experience; and (5) presenting a situated or general structure of what the experience means (Giorgi, 1986; Omery, 1983).

In the first step, the researcher collects the data or the account of the experience. This is sometimes described as a "naive description" (Omery, 1983). What this means is that the researcher allows the participant to recount their experience in whatever manner they feel comfortable. The researcher begins with an open-ended question or statement, such as "Tell me what it was like for you?" In my case the experience was having breast cancer and receiving adjuvant therapy. The intent here is that the researcher does not lead the participant in a particular direction. The researcher is then less likely to focus on what he or she feels is important but rather focus on what the participant has experienced. For my study it was to let the woman's experience unfold in her recounting of that experience in our conversations. In this way she could tell me what she wanted to say about her breast cancer and treatment and to use her own words to describe the events.

In the second step data analysis begins. The researcher takes the descriptions of the experience and listens to the audiotapes and reads the transcripts to try and get a sense of the overall or total experience. While Giorgi (1985) describes this as a "simple reading" (p. 10), it is far from that. Many of the phenomena that researchers try and understand are quite difficult. The phenomenon in this study, breast cancer and adjuvant therapy, is a complex experience and I found several readings of the women's accounts were needed.

The third step, or identifying meaning units, is the beginning of finding out what is essential or important to the overall experience. In this step the researcher reads the interview line by line and tries to separate out changes in meaning in the interview. Here the researcher, coming from her or his particular disciplinary perspective, attempts to delineate different aspects of the experience. For example, in my reading I was sensitive to when my participants talked out relational issues with their illness versus bodily sensations with the disease or treatment. It is in this step that the researcher tries to discern as Giorgi (1985) describes; " to make genuine discoveries concerning what is important" (p. 13).

In the fourth step, the researcher takes the meaning units described above and puts these in the language of the science of the researcher. It is in this transformation that the experience takes on a particular meaning. It is in this step that we make thematic sense of what a participant is telling us about her or his experiences. In the fifth and final step, the researcher does a synthesis of the various thematic interpretations of each participant and this step permits the researcher to understand an experience or the phenomenon studied. This is the step that gives an insight into the experience and results in a "general" experience. Here the researcher completes the move from the specific to the general.

The final description of the experience now takes on a shape that will be presented in the findings section.

Analysis using Giorgi's (1986) phenomenological method was appropriate to my study as it allowed me to conceptualize and analyze my phenomenon of interest from a nursing as well as a phenomenological perspective. This well organized methodological approach helped me as a novice researcher to deal with my data in a systematic way. The amount of textual data in a phenomenological study, even with a limited number of participants, can be somewhat overwhelming.

Methods of Study

Recruitment of Participants

My selection of participants for the study was based on finding individuals who had a particular knowledge of the phenomenon. The particular knowledge I was looking for was the knowledge of what it was like to have breast cancer and receive adjuvant therapy. In order to get the type of participant that I needed, I used the following eligibility criteria for recruitment:

(1) diagnosed with breast cancer and had undergone adjuvant therapy;

(2) were at least three months post adjuvant therapy;

(3) could be interviewed in English or Malay;

(4) willing to share their experiences in an unstructured interview; and

(5) willing and able to give a written informed consent for the study.

Recruitment of participants was done through the Clinical Oncology Unit of the University of Malaya Medical Center (UMMC) in Kuala Lumpur. Medical and nursing staff within that unit approached potential participants and gave them information to contact me if they were interested and willing to take part in my research.

Context and Setting

The context for this research was the Clinical Oncology Unit of UMMC where participants received treatment. The following is a brief description of this unit. The Oncology Clinical unit was started at the University of Malaya Medical Center (UMMC) in 1997. The unit is open five days a week from 8 a.m. until 5 p.m. The staff includes two oncologists, two medical officers, a nurse manager with six registered nurses, two assistant nurses, six radiographers, four hospital attendants and four clerical staffs. The Oncology Unit is divided into four divisions: Out Patient Clinic (OPC), Day Care for Chemotherapy and Radiotherapy, and the Counseling and Health Education Division.

The OPC receives confirmed cases of cancer based on histology results or a CT scan, referred from other departments from UMMC, or from neighbouring clinics and hospitals. It is a very busy unit. The number of cases is on average 50 patients per session. There are two sessions per day; one from 8 a.m. to 1 p.m. and the second from 2 p.m. to 5 p.m. In addition there are also special weekly sessions such as each Tuesday afternoon from 2- 5 p.m. for specific patients who have breast cancer. Only those newly diagnosed with breast cancer are seen on this day and a treatment decision is made for the patient by the attending oncologist and breast cancer surgeon together with the oncology nurse, patient, and their relatives. There are also weekly sessions for others newly diagnosed with cancer, follow up cases, nasopharyngeal cancer session, and review of cases for those receiving chemotherapy and radiotherapy.

The chemotherapy day care unit also opens everyday, five days a week from 8 a.m. to 5 p.m. Patients are required to visit the unit to have their blood tests a day or two before their chemotherapy sessions. If the blood results are abnormal, such as the white blood count being too low, the respective patient will have to have his or her treatment postponed. The nurse in-charge will give the patient a new date to have a repeat blood test in one week. Oncology-trained nurses give the chemotherapy drug based on a prescription written by an oncologist. About eight to ten patients receive chemotherapy simultaneously via eight sofa chairs, side by side, located in the day care. Here, patients can see each other. Two special beds with curtains are used for patients who are too weak or are using a chemotherapy port and are required to expose their chests during the therapy. Four oncology-trained nurses are on duty everyday. The number of patients for chemotherapy per day averages between 20 and 30. For those with breast cancer requiring chemotherapy, FEC (5-Fluorouracil, epirubicin, cyclophosphamide,) is the first line of drugs given. This is a free drug in this government hospital. Patients have to come for six cycles of chemotherapy. It is a three-week cycle, however the patient is required to have an acceptable white blood count prior to proceeding with a cycle.

The radiotherapy area is located in the same unit, at the back of the OPC and day care. There is another entrance that can be used by patients to go through the radiotherapy unit without passing through OPC or day care. Radiotherapy consists of four rooms, one for simulation (planning for radiation), two for accelerated external radiotherapy, and one mini theatre for internal therapy such as brachytherapy. There are four radiographers on duty in this area. The duration of each radiotherapy treatment is about 5 to 10 minutes. Appointments are scheduled every 15 minutes. Patients with breast cancer come for 15 to 25 treatments. The clinic operates every day for five days a week. Patients are given an option of choosing a time at their convenience to come for treatment.

The counseling room is located near the entrance of the OPC. After the oncologist has seen the patient, and decided on treatment, the patient will be sent for counseling sessions. Here, the nurse in-charge will explain about the treatments and the side effects. In these sessions, many concerns of the patients are addressed. The nurse will help patients and relatives to understand the condition and treatment regime, and will also assess each of the patients psychologically, financially, and socially. These are important interventions and most of the patients and relatives really appreciate the counseling sessions. Patients and relatives are also allowed to drop by to see the nurse in-charge at any time they feel they need to seek advice or require any help. Health education is given in a group session every Friday afternoon. Patients and family are encouraged to attend these sessions to fully understand the disease and treatment.

The women I interviewed would have these services available to them. My interviews were conducted mainly in the participants' homes, except for one participant who preferred a private setting close to her home. She chose not to be interviewed in her home setting, thus we selected the alternate setting. I wanted all my participants to feel comfortable with where the interview was conducted as well as to have privacy and a quiet environment. None of the women selected the clinic as a setting for the interview.

Data Collection

Data were collected through open-ended individual interviews with the women who contacted me to take part in the study. I began the interviews using an "ice-breaking" technique where I introduced myself and described the goals and objectives of the research. I went through the consent forms with the women emphasizing their rights, e.g., to withdraw at any point in the research if they were not comfortable with the interview session or if they did not wish to continue for any reason. They were also told they did not have to answer any question they did not wish to answer. I assured them that their care would not be affected in any way if they chose not to participate. Participants were encouraged to say anything they wanted to say about themselves and ask any questions before I proceeded with the questions for the interview.

I began my data collection by asking the participant to share her experience of being diagnosed with breast cancer and receiving adjuvant therapy. This was an open-ended unstructured approach that allowed the woman to begin where she felt comfortable and to tell me what her experience was like. Further questions had been drafted and used when needed to explore as fully as possible the phenomenon of interest or to clarify any point the woman made. I conducted the interviews using the following areas to guide our dialogue: 1) experiences living with breast cancer; 2) reactions to their diagnosis; 3) daily living patterns; 4) resources used throughout their treatment; 5) past experiences that influenced current reactions; and 6) views on their future life situation. I had allocated approximately one hour for each interview and adjusted the time frame to meet each woman's individual requirements. These interviews were audio taped with the participant's consent. Interviews ranged in length from 45 to 60 minutes. For some of the participants it was easier than for others, to express their feelings and experiences, so I let them proceed at their own pace. The interviews took place in the language of preference for the participant, either English or Malay, as those were the languages that I was comfortable with using for the research. All the women recruited could speak English, however during the interview sessions they kept switching their conversations between the Malay and English language. The first and fifth participant spoke almost 80-90% of the time in English, while the rest spoke a mixture of these two languages. In actual fact, none of the interviews were conducted in a single language.

A second interview was held with the participants to clarify any information from the first interview and to ensure a full description of their experiences. Most of the information was collected during the first interview and little was added in the second, but I spent around the same time with the participants as in the first interviews. Again the language used in the second interview was a combination of Malay and English.

Data Analysis

Data were analyzed using the procedural steps as outline by Giorgi (1985) and described in the beginning section of this chapter. Each interview conducted with a participant was transcribed verbatim and transformed into a textual account of the experience. These translations were time consuming in that I needed to translate words, phrases and sentences from Malay to English. A few words were left in the Malay language as there was no direct translation. My thesis supervisor has a beginning understanding of the Malay language, so would understand these words. These textual accounts were then read as a whole, a number of times, to get a sense of the overall experiences of these women as they encountered breast cancer and treatment in their daily lives. When I felt that I had a "grasp of the experience as a whole" as suggested by Giorgi (1986), I began to search for "meaning units."

For me the "meaning units" were participants' descriptions of different parts of their experience with breast cancer and treatment. To identify these meaning units I read through the textual accounts and highlighted what I felt was important to the participants' experiences. This part of data analyses allowed me to break my data down into a manageable size and sort out information regarding different meanings these experience had for the women. For example, when women talked about their reaction to their diagnosis and then moved on to talk about what happened during treatment, this was a shift in the meaning.

Once a series of highlighted phrases were identified as meaning units from the six initial interviews and follow-up, I took these statements and developed insights into the women's experiences. These insights allowed me to understand what the women were telling me and to describe what was important about the meaning units from the perspective of a nurse-researcher. It permitted me to develop a series of themes.

Finally in the fourth step of the analysis I took these themes, integrated them, and developed the themes into statements that best expressed the general experience of this group of Malay women with breast cancer who had undergone adjuvant therapy. These thematic statements for me were illustrative of what was essential about living with breast cancer and receiving adjuvant therapy. This is what Giorgi (1985) described as the "structure of the experience" (p. 10).

Trustworthiness

To ensure the trustworthiness of my data, I asked the participants to evaluate the quality of the data that I collected before I performed data analysis. The women were asked to read the transcripts of the interviews and make any additions or corrections they wanted to make. As a final step I sent the reports of my initial data analysis to the study participants for their review and to obtain feedback. My participants were very positive about my report and seemed happy and satisfied with my data analysis. I had also written memos following the interview process to guide me in my analysis. These memos consisted of thoughts and reflections on the interview.

Finally, I worked closely with my thesis supervisor who has both conducted and published qualitative research with survivors of breast cancer. My thesis supervisor has also worked with Muslim women in Southeast Asia and understands some of these women's responses in illness situations and challenges conducting research with this particular group. She has a beginning understanding of the Malay language and in particular some of the idiomatic phases in this language that express great feeling, but are not always easy to translate into English. A supervisory member who has also conducted qualitative research with breast cancer survivors had access to my interview data and read and commented on my thesis. This supervisory member also had experience with women in Southeast Asia through work in Viet Nam. It was in working with my thesis supervisory committee that I refined the data analysis technique that I used and decided on the final structure of these women's experiences.

Ethical Considerations

Prior to data collection I first received approval first from the UMMC Medical Ethics Committee (see Appendix A) where I hoped to conduct my study and recruit participants. This committee supported my research. After the UMMC ethical approval I submitted an application to the Human Investigation Committee (HIC) of Memorial University of Newfoundland where I was enrolled as a graduate student in nursing. This committee also approved my research (see Appendix B). All steps were taken to ensure that my research complied with the Tri-Council Policy Statement regarding research on human subjects.

Consent from each participant was obtained prior to an interview (see Appendix C). The participants were given a detailed explanation about the purpose of the study, the type of data to be collected, the approximate time required from them, and their right to withdraw from the study at anytime or to not answer a particular question. The participants were also informed about the risk for emotional upset due to the sensitive nature of the interview. They were assured that I would keep all data collected confidential. The transcribed interview had all identifying information removed. During the study, data collected was kept locked in the researcher's study room drawer and no one was present during the time the data was analyzed. It will remain securely archived for five years after publication.

CHAPTER 4

FINDINGS

This chapter is a description of the experiences of women living in Malaysia who are living with breast cancer and receiving adjuvant therapy. It is an attempt to understand as fully as possible what was essential about that experience. This chapter is divided into two sections. Section one is a brief overview of the six women who took part in my research. The second section, which is the main section, outlines the findings related to these women's experiences. From my interviews I found these women were still unsure about various aspects of their breast cancer treatments even though for most of them, the treatments were completed almost a year ago. It was very difficult for them to put some of the thoughts of treatment out of their minds no matter how hard they tried. The lived experience of these treatments was quite vivid, thus contributing to a good quality of data. Furthermore, throughout the interviews I felt the participants' feelings about their breast cancer and treatment had surfaced once more through their recollections and in many ways I believe the interviews helped them to make sense of these experiences. Some of the incidents they recounted were very poignant.

Participants

The participants were six women who had completed adjuvant therapy and were recruited from the Clinical Oncology Unit of UMMC described in the previous chapter. They all had surgery, which consisted of a total mastectomy of the affected breast. All had received chemotherapy and radiotherapy. They had six cycles of chemotherapy (FEC) and 15 radiotherapy treatments. All of the participants are still in their first year after the completion of their therapy. Three of them are still on hormone therapy, i.e., Tamoxifen. The length of time that had elapsed from the time of completion of therapy and the interview varied from three to nine months. The stage of their disease varied from stage 1 to stage 3, but none of the participants had distant metastases. These women represent a wide age range (~30 to 60 years) and are at different stages of their illness. Five of the six women were married and currently living with their spouse. Four women had children and these children's ages ranged from four to eighteen years of age. Four of the women are currently employed outside the home. All the women were Malay, which is one of the three main ethnic groups in Malaysia.

Themes

My interview data indicated that there were a number of feelings and issues associated with the phenomenon I studied. Breast cancer affected so many aspects of these women's lives that it was difficult to categorize these into themes. However, using Giorgi's (1986) method and working with the data I identified seven essential interrelated themes that together help understand these women's experiences. These themes relate to the women's diagnosis, receiving adjuvant therapy, and having breast cancer. These themes were: 1) *Not knowing what to do,* 2) *The meaning of a diagnosis of breast cancer*, 3) *Suffering through the treatment*, 4) *The changing body*, 5) *Trying to protect others*, 6) *Finding strength and making changes*, and 7) *The importance of support*. The following is a description of these themes.

Theme 1: Not knowing what to do

The diagnosis of breast cancer was preceded by a feeling of being indecisive about what the symptoms meant or what to do about them. The women spoke about a period of "not knowing what to do" when they discovered an abnormality. However, this not knowing what to do also characterized approaches to early treatment, and for some a projection into the future should they be faced with a recurrence. One of the challenges at the time of diagnosis was who to consult about the problem they had noticed with their breast and then what approach to take. Often the first person consulted was a family member. When they first became aware that something was "wrong" with their breast some of the women consulted with other women, such as mothers and sisters, or a colleague at work, while others confided in their husbands. Some would check out the symptom with a family member, because they did not know what to make of the changes that they had noticed in their breasts.

> *When I was having a shower I was palpating my breast and I felt a lump. I told my husband and then we went to the general practitioner's clinic. When the doctor checked it, he said that he thought it was an ordinary lump . . an ordinary lump. "Yes" he said "nothing to worry about, most women have that." I asked the doctor "do I have to remove it?"*

Upon noticing a breast change, they all spent some time trying to process the fact that they had detected a problem with their breast and wondered what that information might indicate. The amount of time before the women did something varied among the participants. Some did think about cancer when they noticed a sign and others were dismissive that it could be possible that they had this condition. Some thought because of their younger age and no family history of cancer, it probably meant they did not have cancer, but realized this was not so.

> *In my family. . they only have diabetes . . hypertension, . .*
> *no cancer. I'm the one to open this record.*

However, in many instances the symptoms they reported were strongly suggestive that they needed to seek medical attention and not to delay going to their doctor. Some of the symptoms experienced were discharge from a nipple to the extent the woman's dress was stained, a palpable lump, or noticeable nipple retraction. These are all symptoms indicative of seeking immediate help, but these women were not sure what to make of them or the best approach to take. In one example, involving nipple discharge, while the participant herself was unsure what to do, at least the colleague she confided in with her problem was able to help her.

> *There was a discharge from my nipple. First, I didn't notice it. At home I usually don't wear a bra, so it was staining on my dress and I suspected it was from my breast. I pressed my nipple, but there is no discharge, nothing. And after a few weeks later, again the discharge came out, and I pressed again and can see it is from my nipple. I'm quite worried so I talked with my lady boss and say "I'm having discharge from my nipple, what's wrong?" and she brought me to the cancer detection clinic.*

Getting medical help or being advised to seek medical help did not always happen very quickly, in that sometimes the person consulted did not really know the best response to help these women. One of the other participants who noticed a retracted nipple, first consulted friends, including nurses and her sister, about what she described as a "hardness" in her breast and then pain, and later confided in her mother. She had waited for a period of time to see if the hardness would go away following her menstrual period, despite realizing that this particular time her breast felt different than it had at other times around her period.

> *My nipple had gone inside already. It's like that already* [demonstrates by pressing her fingers on her skin*], so I'm frightened, you know. I go and show my mother and she said you do like this* [demonstrated by rubbing on her other breast] *and it will come out, so then I do that. I didn't think I had cancer* [laughing], *you know.*

Going through clinical investigations at the cancer clinic was also characterized by a feeling of not knowing what to do. Some of the participants had to go through the uncertainty of a number of tests giving them different information about whether they had breast cancer or not. Some of the participants described their attempts to get a diagnosis and how they experienced the course of events. More than one woman had a series of tests, including a biopsy, and when the results came back, found she had cancer. The emotional impact of this diagnosis, often described as fear, shock, or disbelief, often left the woman and her husband wondering what to do or how to proceed.

> *Then the doctor called me back after 4 days or 3 days, and the doctor said I have to remove the lymph nodes. He said "it's not only the lymph nodes that need to be removed, but the whole breast." And during that time I just didn't know what to say, I was shocked. They had to remove the whole breast. We didn't decide on that day.*

Most of the women talked about a strong emotional reaction to the diagnosis and also felt they needed to get a second medical opinion. One woman described the moment she heard about the possibility of having breast cancer as like a "*volcano going off in her* *head.*" The second opinion might give a different diagnosis or different treatment options. They also weighed the options of treatment offered and wondered if it was better or worse to lose a breast or still have some cancer cells left in that area. The question of whether or not to have a mastectomy was difficult. Some women even entertained the thought of pursuing traditional treatment rather than oncology treatment.

For some of the participants the quandary over not knowing what to do was helped by talking with another breast cancer survivor at the clinic who had been through diagnosis and treatment and could offer advice based on experience. One woman talked about sitting in the clinic with her husband after she was told she had breast cancer. She and her husband could not decide what to do, but there she had an encounter with another patient in the clinic.

> *We sat outside the room and then they introduced me to an old lady. She is a Malay woman who had just undergone the operation [mastectomy]. She gave me encouragement. She said to me "Sister, just remove it [breast]. It is already diseased, do not keep it."*

Theme 2: The meaning of the diagnosis

Some of the women readily admitted that the reason they did not know what to do was because they just could not accept that they had breast cancer, because of the fear of that diagnosis in their society. While they had realized it was possible, given the symptoms they had and what they knew about the disease, it did not seem possible that it could happen to them. There was a sense of denial among many of the women. As one women explained to me when she had received the actual diagnosis:

> *When I first found the lump, I prayed to God "Please, it is not that [cancer], not that." When the doctor told me it is cancer, I really cannot accept, really cannot accept . . . I feel that for two or three months I still was in denial. It's really hard. During the time the doctor was informing me, I cannot even listen. I don't believe it.*

Accepting a diagnosis of breast cancer was one of the more difficult things the women were faced with during this early part of the experience, because of the meaning of having this disease. There was a great deal of information for the women to process and to understand at this time, information about treatment, and effects of treatment and what all of this could mean for the participants. There was also the emotional impact of accepting such a difficult diagnosis because of the fear of breast cancer and what it means. In a society where fear of cancer is commonplace, fear is also a predominant response on the part of the woman just diagnosed.

> *When I first knew I had cancer, I was so afraid, you know. I was afraid. . My thoughts were coming and going very fast. Honestly, I thought "cancer," I never had a hope that I will live or I will continue . . . I began planning very quickly for everything. I quickly settled everything . . . I quickly, quickly arrange everything in case . . . you know.*

The difficulty with a diagnosis of breast cancer was in part because it was so incongruent to how the women saw themselves and how they felt they had led their lives. They believed their lifestyles were healthy. This led them to question the diagnosis and why it had happened to them. As one of my participants, who found her diagnosis particularly difficult and who kept coming back to that idea, said to me early in the interview after she described how she had detected an abnormality and underwent a series of medical investigations:

> *. . . but it's really hard to accept during that time [a clinic visit when she received her diagnosis] . . because I feel I always keep myself fit . . I really follow a healthy lifestyle. It's really hard to believe something like this . . but I did not cry. I was shocked but I was really strong.*

Given the stage of when the women were seeking treatment for their breast cancer, mastectomy was most often recommended as the first approach. The thought of a mastectomy was hard to accept because of associations of femininity with the female breast. Their breast was so much a part of being a woman and of being feminine that they needed some time to think about all the implications of losing a breast. One participant talked about her sexual desires being affected by the diagnosis. She no longer felt like a "sexual being," e.g., that she would be desirable to her spouse.

The women were concerned about the meaning of their diagnosis and treatment because they felt it was going to have a big effect not only on them, but also on their family members. They had observed what had happened to other women with breast cancer and their families. Some even told me about neighbours who had died. For some the possibility of a negative effect on a family member was the most difficult thing about their diagnosis. They did not want to cause family and friends additional work because of their illness and thus felt the need to make plans fairly quickly. Part of that motivation was so that no one would have any bother if the woman died, as one woman explained "*in the future the person* [family member] *won't have trouble.*" Others thought about the emotional difficulties the diagnosis would place on husbands, children, and parents, or how that family member would be able to manage without them.

> *Actually, I pity my husband. I always think of my husband. What will happen to him if anything goes wrong with me?*

A further meaning of having, or of getting, breast cancer was what did it say about how they had led their lives. Was it a punishment from God for something they had done, was it a test from God to see if they were strong enough to survive other challenges in their lives? These were just some of the questions the women raised. A participant told me about a time she had been exploring this issue with a friend, i.e., what did a diagnosis of breast cancer say about her. The participant felt she led a good life and was kind to other people so she asked the friend "why me?"

> *My friend said "no, maybe in the last generation you have done some very bad . . stuff." Maybe bad karma.* [And both started to laugh].

Theme 3: Suffering through treatment

Going through the experiences of chemotherapy and radiation were not without many challenges for these breast cancer survivors. The women talked a lot about what this treatment was like. They also related how they reacted physically and emotionally to the treatments. Even though hospital staff counseled them about the side effects of chemotherapy and radiation, it was still a difficult time. Many of the participants did feel there was a great deal of information about what to expect with chemotherapy and what they needed to do. As a participant recounted:

> *I was given counseling about all the side effects from chemotherapy . . . like hair dropping out, vomiting. The* [nurse] *told me that I will get very weak. I can easily get infection and they told me how I must take care of myself during this treatment.*

However, what they had was information about the treatment, not what it would feel like. Despite having the counseling about chemotherapy, nothing could really prepare them for the experiential aspect of this part of their illness. What would it feel like when the chemotherapy, the "pink" liquid, was flowing through your body? How would your body feel afterwards when you were nauseated and vomiting, or feeling very weak? The women did admit this part of their experience was "terrible" and many described in some detail what it was like. The first few cycles of the chemotherapy may not be so bad, but sooner or later you felt the effects. It was a time of physical incapacitation and trying to get through the treatments. Women graphically recalled the effects on their bodies and how they felt.

> *When the Chemo drugs entered my body, I felt it in so many ways, I feel it is a very bitter memory, . . bitter memory I cannot forget. During chemo I am always dizzy, I vomit continuously, I cannot eat at all. Sometimes I feel like I wanted to die.*

They had a number of physical symptoms associated with chemotherapy, such as nausea and fatigue. With the nausea they were unable to eat and some even had to be hospitalized for this symptom. The fatigue greatly affected what they could do, and not do, especially at home when they were expected to take care of the housework and family. One participant described how she sent her husband's shirts out to the laundry and did not tell him she did this. She just did not have the energy to do this task. When they were receiving their cycles of chemotherapy, they had to try and conserve their energy for the things they felt they really needed to do. The chemotherapy left most of the women with vivid memories of what it was like to experience these unpleasant symptoms. One woman could not even look at syrups that looked like the drug, she felt so adverse to her "chemo." It was even hard for some to go back to the unit in the hospital where they received the treatment because it made them relive some of these memories.

> *Even now I do not want to look at daycare* [where she received chemotherapy] *even after I had completed my chemo . . . I cannot pass by daycare. To go to Radiotherapy I took an alternate route as I do not want to see that place. Even the smell of the place. . the air-conditioning . . I cannot take it.*

For most but not all, radiation therapy was not as bad as chemotherapy, although some expected it would be, because again they did not know what to expect or how they would feel. Frequency of treatment and feeling fatigue rather than other side effects were two of the more difficult aspects, because they had to go every day and did not have the energy for this schedule. One participant was surprised she did not have burns on her body, because when she thought about the treatment she had imagined "*that my skin will turn black on one side.*" When they were describing the effects of radiation therapy, it was often in contrast with how badly they felt after chemotherapy.

> *My radiotherapy was so much better. I did not experience any major side effects. But the only thing is you have to travel every day to the hospital and it is really tiring.*

Theme 4: The changing body

Their mastectomy and treatment with chemotherapy not only created symptoms such as pain, fatigue and nausea, but also brought about visible changes to their body. These bodily changes created a wide array of feelings among the women. Loss of hair was one of the bodily changes that participants recalled experiencing. The loss of all body hair was harder on some women than it was for others. It depended to some extent on the value they attached to "femininity" and their hair as a reminder of this femininity, or even how "beautiful" they thought their hair was. The loss of hair made some feel "shy" to face the world or even friends, spouses, and children. By losing their hair to treatment they were embarrassed over how they looked, or that they would be branded as "*baldy*" in the community. This made some reluctant to take part in outdoor activities. It was an isolating experience.

Many of the women could remember the events surrounding the loss of their hair, how it made others feel, and how they felt about it all. For a participant who lost her hair when she was dining with her mother, it was particularly poignant as she described this day and her mother's reaction.

> *My hair fell out and it fell from under my scarf – the root is no longer there, right? All fell . . like being bald. It falls and falls while we are eating. I am very sad seeing my mother picking up my hair while she is eating.* [And the woman reassures her mother] *"It's o.k. mom, this is because of the medication. It's just the medication."*

Another woman talked about how she loved her hair and always felt it was so beautiful. When her hair fell out following chemotherapy, she was very sad and could not even look at herself in the mirror. She did not want to be reminded of the loss, even though it was difficult not to think about it. It was her husband who really tried to help her at this stage in her illness.

> *Whenever I saw myself in the mirror, I felt so sad. It's really sad my looks have changed. But my husband convinced me "you are always beautiful, before or now, you are still beautiful."*

The women used a number of strategies to deal with hair loss. Some cut their hair short and others used wigs. For others the fact that they usually wore a scarf outside the home, as is the custom for Muslim women, helped cover the loss. Underneath the scarf though they felt the absence of their hair. The scarf may hide the fact they had lost their hair, but it did not make the women forget this loss had occurred. One woman resorted to humor in dealing with the problem. When she was going out she would say to her children "*Please bring me my helmet* [her wig]." The irony in this was not lost because a helmet is also a protective device.

While hair loss was the predominant body change, it was not the only one that the women experienced or told me about. Loss of a breast was more permanent but the women did not discuss this as much in the interviews. Fear of remaining cancer cells if the breast was not removed seemed a greater fear than losing the breast. Some did talk about the use of a prosthesis or the use of a small sponge inside their dresses "*to look okay*." How a husband reacted to this body change was a helping factor and a few of the husbands did reassure their wives that their lives were more important than keeping a breast. Some women did wonder though, how the loss of a breast would affect their femininity.

Another bodily change that was noted was a premature aging. For a younger woman this was due to premature menopause because of her adjuvant therapy. She talked about the symptoms she had with her menopause and how it affected her body and her mood. She had lost any sexual desire that she had and compared herself to someone who has aged.

> *I don't want to be touched. There is no desire. I heard people who go through menopause, well after menopause, age is like that.*

Theme 5: Trying to protect others

Throughout the interviews what was particularly noticeable was the way the women talked about a need to protect family and friends, but also the wider society from their diagnosis, and what they experienced as a result of undergoing treatment. At a time when they were in need of so much care and support, they thought about family members, and often put the family members' needs and feelings above their own. One woman who was planning a trip to Mecca with her husband worried that if she scheduled her surgery before the trip, it would put too much physical strain on her husband.

> *My husband has a heart problem and he cannot carry heavy things. If I decided to go for surgery, then both of us would have difficulty to carry our bags and things around. We decided that I would not go for further treatment then.*

The women also seemed to weigh the effect of disclosure about their breast cancer to family members against what they felt the effect of this disclosure be on these family members. It was particularly hard for most of the women to tell a parent or a child. If a parent was older or had health problems, the women wondered what would happen to the parent when they found out that a daughter had breast cancer. As a participant remarked, the natural order of life had been upset, in that she should care for an older parent and not the other way around. When she was having treatment her aging mother came and took care of her. Women with young children were very protective of the children and sometimes had to be coaxed to let the child know. Husbands would sometimes encourage their wives to tell the children.

> *My husband advised me to inform our children. He said the children won't know that their mother is sick and you will be going in and out of the hospital. My eldest boy, well*

> *he is a bit of a "soft" boy.* [When told] *he went up to his room and didn't come down until nighttime. He is very sad.*

A participant's husband also tried to convince her to tell her mother about the breast cancer diagnosis, but she could not bring herself to do so. It was finally her brother who called and informed the mother of the daughter's diagnosis and that she was receiving treatment. She still remembers vividly when her mother telephoned her when she was in treatment. It was not that she did not want to tell her mother, she wanted to protect her mother and that became the deciding factor in whether or not to disclose this diagnosis.

> *My mother called me and that is a moment I cannot forget. My mother is crying . . crying . . . crying on the telephone. I do not know how to tell her, how to say it. We cannot even talk. My mother is disappointed I did not tell her earlier. It is not that I did not want to tell her, but I was worried about her* [health] *condition.*

The women talked about how when they interacted with other breast cancer survivors, there was still a sense of protecting others. Even though they supported each other, they did not always talk to each other about how ill they felt. One woman told me about an older woman in her support group at the hospital whom she had come to know quite well and they became friends. She felt really upset when this woman's condition deteriorated, and even though she was emotionally upset, could understand the friend's motives.

> *Recently one of my friends was ill. I was so depressed, but she is quite old and as I said . . .she - but even when I met her she didn't reveal anything to us. When we asked her, her stage – she never revealed. We protect each other.*

The sense of protecting others was so strong that the women understood when a close family member could not give the support they so badly needed. One woman who talked about the need for more support from her husband understood when he refused to discuss her breast cancer with her. She tried to understand his reasons for not wanting to talk about her situation and even offered a protective stance towards the husband's position:

> *He* [husband] *doesn't like to talk about breast cancer. Maybe because he has gone through a lot. His sister also died of breast cancer. I know his sister suffered.*

It was the wish to protect others that was a motivation for women to volunteer for the research. If through telling about their experiences they could help other women not go through the same difficulties with breast cancer, then that was sufficient reason to volunteer to be interviewed.

Theme 6: Finding strength and making changes

Despite the difficulty dealing with having breast cancer and the feeling of shock with the initial diagnosis, all the women talked about finding strength to deal with their illness and make changes in their lives. Some felt they had achieved this strength while others were still searching. For most of the participants this strength came from God. As this women explained:

> *Daily I pray and ask God to help me, save me. "It is all in your hands God." I just take whatever problems come and carry on. "Please guard me and save me." I pray like that . . . so I have some confidence.*

In fact some of the women interpreted their diagnosis as a test from God and they were determined to demonstrate that they could measure up to this test. It was sometimes their belief in God and "*putting their lives in God's hands*" that helped them get through the diagnosis and treatment. Prayer, meditation, and reading the Qu'ran were all methods the women found to help. Others felt the prayers of friends gave them strength and they welcomed this kind of support when offered.

For other women the strength came from their husbands or children, or at least was motivated by their concern over their children. This concern led them to feel that they needed to be strong to support their children. A participant who felt that she could not really accept her diagnosis and had a lot of trouble with this aspect of her condition described her main source of strength:

> *But the strength . . . children. My children, my children treating me very well. My children's future is very important so I have to be strong for my children* [Participant crying]. *My children are still studying and they are independent, so now I don't think so much* [about herself]. *I just concentrate on my family.*

Part of the experience of breast cancer was the women's wanting to do all they could to improve their chances of recovery and survival. It was how they fought against what was happening to their bodies and their lives. Since they felt cancer had threatened their existence, they were determined to make positive changes in their lives. For some women this was making big changes in their lifestyle, particularly in what they ate. This change might mean additional expenses, but they felt it was worthwhile. As a participant explained:

> *Now, I'm taking in more vegetables, compared with before* [breast cancer]. *Sometimes we buy hydroponic vegetables but it's so expensive. But I only eat healthy food and I'm also taking vitamins.*

Women also talked about the importance of remaining positive and having a good outlook on life. Some admitted that this was their usual manner of dealing with problems and they drew upon this strength. Others had to work to see positive things in life. One woman talked about the sight of people in the cancer clinic with other types of cancer, cancers worse than hers, or those she felt suffered more than she did. The sight of these others served to reinforce that maybe she was not so badly off.

Other positive changes that women made were to try and use their time well and not to think about their condition. They would read, travel, or do things that they had wanted to do. One participant refused to let the treatment affect her too much and would make an effort to meet with friends after her treatments. It gave her a chance to create a positive event out of a negative circumstance. Another talked about using her time well.

> *I want to utilize my time, when I have things to do I don't think about this. I use my time to do work or other beneficial things, so I don't have time to think about this.*

Other positive changes they made were taking better care of their health and paying attention to bodily symptoms. They made sure that they kept their clinic appointments and adhered to the advice they were given. This advice could be staying well hydrated when they received treatment or trying to remain positive about their condition.

This sense of finding strength and making changes was tempered by a sense of fate related to having breast cancer. While the women did talk about remaining positive and doing things that would enhance their survival, they had a number of fears related to the fact that they had cancer and that many of the things related to this disease was beyond their control. Some even talked about the fear of recurrence and worried that if this happened they did not really know if they would have the strength to go through another bout of chemotherapy given how terrible it was the first time around. In this respect a participant pushed the use of a metaphor of breast cancer as a journey when she told me:

> *But to be frank with you, if let's say I have a relapse I don't want to go for treatment. Even though I'm having positive thoughts with the first time . . . a second one I don't want to go through. I would say "let me pack and go because my visa cannot be extended* [laughing]." *Two years I had a visa but from there I'll leave it to God. If he wants to extend my visa I'll stay on, if not I will pack and go. It's not like the first time.*

Theme 7: The importance of support

Support from family, friends, and heath care professionals was very important to the women and made a big difference to how the women felt and their ability to deal with the breast cancer. All of the participants addressed just how important this part of the experience was. The support came in many forms and from different sources. One of the participants talked about how caring her young son became towards her, when he found out she had breast cancer and how touched she was by his response, despite being afraid at first to tell him.

> *My husband told my son when I was not around. It was very hard for him to accept and he started to be extra caring towards me and took care of me as though I were a baby.*

Others talked about the support they received from other family members and friends. They talked about the many occasions when a mother or a sister went to the clinic with them while they were receiving chemotherapy or came and stayed with them in their homes to help care for them and the households. Friends also came to visit and brought food or took them out for a social event. Being cared for and cared about were very important aspects of the support, especially for women who did not know what the reaction of family members would be to their illness. When the support surfaced in the family, it was a pleasant surprise for the women and the women could even see a positive aspect. In a traditional society where the woman is expected to manage the home, getting help in that setting is particularly important. They also saw their children and husbands gaining more independence, thus allowing the woman to recover from the effects of treatment.

> *It brought my family together. Before this I had to take care of all the house matters, but during my treatment, it's really my husband who has taken over. Thank God, there are good things behind it. My husband learned to manage everything and I can rest all the time.*

The women also talked about the support they received at the clinic and how much that meant to them. A caring nurse who explained what to expect from treatment, or explained how to deal with side effects of treatment, was a valued health professional. They talked about the nurse's smile or the doctor's words of encouragement and how that made them feel.

For others support came from being a member of the breast cancer support group and being with other women who had gone through the same experiences. It was here that they could make friends, ask questions that only another woman with breast cancer may be able to answer, or just "*share things together.*" One of the participants summed up the function of a breast cancer support group and why it is an effective means of both receiving and giving support:

> *The support group is also very helpful because you listen to other patients. You can compare your problems . . . and even some of them have survived for many, many years - 10 years and even more than that. I also talk with other patients who have been just diagnosed with breast cancer. You are really happy then because you can share with them.*

The participants could describe how support that they received from women and men differed. They found that the women in their lives, whether it was a mother, sister, or friend, could identify more with the emotional aspects that they were experiencing. It was in these female relatives and friends that they could confide the fears that they had. The men in their lives were more "problem" focused and offered support in helping them get a second opinion or in the case of a brother to tell a parent about the breast cancer.

However, it was really through the participants who did not get the support they felt they needed or from the sources that they felt were important, that the importance of support was demonstrated. These women also helped demonstrate what a difference support could make. There was one participant in particular who felt her husband was not supportive. Whenever she tried to talk to him about her cancer and how she felt, he would tell her that he did not want to talk about it and felt because her active treatment had ended that she was "cured." To deal with this situation her response is:

> *So I have to make myself as normal as possible. I feel it is so difficult. I will try my best to make everything as normal, as usual, as possible. I act as if though there is nothing wrong, but it is really difficult. I need someone to talk to. Sometimes I feel fear.*

Her reaction was echoed by the other participants, who told me they did not know what they would do if their husbands were not supportive. These women really felt it was the husband's strength at the time, and the fact they could depend on that strength, that helped them get through. However, it was not just within the family and circle of close friends that a lack of understanding or recognition of their condition could have negative effects. Neighbours were also important and women talked about how they felt when neighbours avoided them. The women did understand though that some people in Malaysia are afraid of cancer and it is not something that is talked about among all people. Yet they still feel that a failure to acknowledge breast cancer as a common problem causes unnecessary distress when it occurs.

CHAPTER 5

DISCUSSION

The findings from this study make a contribution to the literature of what it is like for a woman to have breast cancer and in particular contribute to the literature on women with this condition living in Malaysia. This chapter is a summary of that contribution and a comparison of my findings with the other literature on women's experiences with breast cancer. These two aspects of the discussion will be integrated. And as will be presented in a later chapter, the discussion gives some indications of the improvements needed in the lives of these women and directions for further research.

Concern for Others

One of the striking findings in this study is how concerned women are with the effect that breast cancer will have on others, especially those in their family. There was strong evidence that even when the women's very "self" both physical and existential was threatened, they were still able to think predominantly about others. They not only thought about others, but also acted on these thoughts by being protective towards the others they felt would be most affected by their diagnosis. Many times it was being protective of an older parent who may have had health problems. How pervasive this "other-focused" orientation is and what role it plays in preventing the woman from seeking earlier treatment or getting the emotional support that is important to surviving breast cancer needs further exploration.

In the literature on breast cancer, this "otherness" or "other-focused" did not seem to be as predominant a finding. While concern for others was a theme in some of the research, that concern did not seem to translate into putting others' needs above their own needs. The participants in my study looked at how they could actually protect others from the possible effects of their own condition. Many times it was protecting the others emotionally, but there was a concern that it could adversely affect the family member's health. In this study as well, it is not known how being a woman in a traditional family and society has placed the woman in the position of having to care and be concerned about others. My findings in this respect are in contrast with those of Gopal et al. (2005), who found that informational needs of Malay women on "Impact on Family" were rated least important out of nine needs investigated. These authors did question these findings because of the importance of family in Malaysian society. They felt that their findings reflected how the participants interpreted the question, rather than the women's concerns with their immediate family.

Social Support

Most of the previous research literature that addressed the importance of "others" for breast cancer survivors, has been from the position of breast cancer survivor's need for connectedness with other breast cancer survivors or from the need for various types of support or size of networks of support (Sammarco, 2001; Solberg et al., 2003). The women in this study also attested to the need for support in their lives. As in other studies, families, especially husbands, were the main source of support (Wilkes et al., 2002). In fact most of the women identified their husbands as being their main source of emotional and psychological support, particularly in restoring self-confidence in their changed appearance, i.e., after a mastectomy or when having a loss of their hair after adjuvant therapy.

Particularly interesting was the way some of the women described how their husband's style of support differed from that of females, such as mothers, sisters, and friends, who were supportive towards them throughout their cancer experience. The women who gave support tended to react with more empathy and understanding towards the breast cancer survivor, whereas the husbands and other men tended to take on the role of "problem solver." The participants indicated that their husbands attempted to find solutions to their concerns, presumably to put an end to their wives' dissatisfaction. Or perhaps the husbands' reactions were a way to bring a subject that the husbands had trouble identifying with or maybe even had trouble accepting, to a close. The husbands would suggest prostheses and other ways to "mask" the problem, or refuse to talk about some topics relating to breast cancer, as a means of avoiding certain issues and concerns of the women with breast cancer. This response on the part of the husband is not that unusual in that there are a variety of ways that spouses of these women choose to deal with their wives' breast cancer (Northouse, 2005). However, most often, all these women wanted was an acknowledgement of their feelings, or a reassurance that their "womanhood" as they perceived it, was not compromised, and that they were still regarded as feminine despite the loss of a breast or the loss of all their hair. Other researchers have found that some husbands do not use what could be identified as "emotion-focused" coping and less reliance on this means of coping actually results in better quality of life among these men (Wagner, Bigatti, & Storniolo, 2005). In addition some family members expect that once the woman has had treatment, she will return to how she was before the diagnosis (Lethborg, Kissane, & Burns, 2003). They do not realize the long-term impacts that a breast cancer diagnosis can have. Little cross-cultural research in this area was found, however one study demonstrated that approaching the disease together, helped African American couples cope with the women's breast cancer (Morgan et al., 2005).

My study also affirms the importance of different types of support for women with breast cancer and facing a long-term illness. The wider social support is thought to play an important role with the potential to contribute much towards the affected person's moral support (Hirschman & Bourjolly, 2005; Manning-Walsh, 2005). The wider circle of support includes children, friends, and health professionals. Breast cancer support groups also offered support of various kinds to these women and that theme is well represented in the literature (Michalec, 2005).

Cultural Beliefs

In other studies the importance of wider beliefs about breast cancer and how this affects women's lives has not received much emphasis. A couple of exceptions to this were found. One was a study conducted in Hong Kong by Lam and Fielding (2003) where the ethnic Chinese women in that country felt stigmatized by the superstitions held around cancer. These women, just as some of the women in my study, hid their breast cancer as best they could when out in public. Likewise, López and co-researchers (2005) found that the African American women they included in their study identified cultural beliefs about cancer as contributing to the "stigmatizing beliefs about cancer" that existed in their rural communities.

Hisham and Yip (2003) suggested "negative socio-cultural perception" of breast cancer is a factor in Malaysia and I believe my findings give support to their suggestion. Additionally, they believed that use of traditional medicine could also prevent seeking medical care (Hisham & Yip, 2004). While none of the women talked about the use of traditional medicine, one woman did consider that as a treatment for her breast cancer. The women I interviewed felt that societal beliefs, especially around survivorship and fear of cancer, were powerful effects on how the women themselves acted. In many ways breast cancer is a hidden problem in Malaysian society, despite the Department of Health trying to address this issue. Early diagnosis and treatment, keys to improved morbidity and mortality rates, are to some extent predicated on changing these attitudes and there have been campaigns to that effect. The need to empower women to seek help and care for themselves is just as evident in my study as in the comparative study of women in Canada, Hong Kong, Malaysia, Philippines, Singapore, and Thailand by Choi (2004).

Uncertainty

The theme of "not knowing what to do" that permeated the women's experiences throughout their first year of dealing with breast cancer found in this study is consistent with the theme of uncertainty that is prominent in the literature on women's experiences with breast cancer (Lam, Fielding, & Ho, 2005; Nelson, 1996). My participants demonstrated that even after treatment for breast cancer is completed, there is still a high degree of uncertainty in their minds. In addition, this theme may explain some of the delay that is noted among Malaysian women in seeking treatment for breast cancer. Burgess and co-researchers (2001) found that women who felt their symptoms were more serious or clearer indicators of breast cancer sought medical attention more quickly. While I did not focus on delay per se, there was some suggestion that not knowing how to interpret symptoms did lead to a longer period before the women in my study sought treatment. However, a similarity between the women in my study and those of Burgess et al. was the fact that other factors or events were given priority over help-seeking behaviours in the presence of an abnormality.

Suffering

My study also contributes to the growing body of literature on suffering within the breast cancer experience (Arman & Rehnsfeldt, 2003). For the women I interviewed memories of suffering remained vivid and powerful. In fact, through asking them to recall their treatment experiences I felt I had evoked strong emotions. The quality of life of these survivors was negatively affected by their memories of the adjuvant therapies. A number of studies have looked at the impact of adjuvant therapy on quality of life and noted that adjuvant therapies may explain lower scores on quality of life indicators (Casso et al., 2004). Other studies have focused on the distress caused by treatment for breast cancer, but some of these have been limited to surgical effects (Steginga et al., 1998), and not with the use of adjuvant therapy. For the women in my study, unpleasant or negative side effects from adjuvant therapy outweighed those from surgery, and chemotherapy was felt to have greater and more unpleasant effects than radiation therapy.

This is in keeping with studies that have included adjuvant therapy and that radiation may impact lives of breast cancer survivors in the longer term (Dow & Lafferty, 2000; Kornblith et al., 2003). However, some other studies report that in terms of premenopausal symptoms this may not be the case, in that in the longer term women adjust to these changes (Joly, Espie, Marty, Heron, & Henry-Amar, 2002).

Need for Information

Although not identified as a single theme in this study, but rather occurring throughout the interviews, was a need for greater information. The participants identified a number of areas where they expressed the need for information. This lack of information may have contributed to the feeling of not knowing what to do when they discovered signs and symptoms of breast cancer or when they were faced with treatment decisions. Information on how to recognize when to seek a medical diagnosis and treatment for breast anomalies would have been advantageous to these women. In addition, they may have been helped if they had information on what services may have been available to family members to deal with the diagnosis.

There is a large amount of research literature on the need for information by women with diagnosed breast cancer (Luker, Beaver, Leinster, & Owens, 1996; Ravidin, Siminoff, & Harvey, 1998; Vivar & McQueen, 2005) and the informational needs that the women in my study had were similar to those identified in other research. One of the needs that women in my study talked about was the need for what chemotherapy and radiation would feel like from an experiential point of view. In particular, the participants in my study wished that they had known earlier the side-effects of the adjuvant therapies they were exposed to, so they could have been better prepared in advance both mentally and physically for these effects. In this respect professional support in providing this information would have been particularly valuable when women commenced treatment. Participants stated that even *after* the breast cancer treatments had been completed, they still had some questions and uncertainty about the treatments and care provided to them. Thus follow-up professional support after treatment was also identified as important.

Coping With Breast Cancer

The women in my study approached coping in similar ways to those found in other studies, especially one that focused on African American women (Henderson et al, 2003). The women changed their lifestyles to reflect healthier practices as well as drew upon their spiritual resources. These strategies allowed them to learn to better appreciate what they had. Some had learned to transform the "tragedy" of their illness into an appreciation of life. Other researchers who have studied breast cancer survivors have noted the transformational aspects of breast cancer, thus the findings from my studies in this respect mirror some of these (see Coward & Kahn, 2005; Landmark et al., 2002).

What was different in my study however, was the extent that the women felt "fate" was a factor. Many of the women in study, while they actively prayed for a good outcome or to be spared, also expressed somewhat of a resignation. How much this might influence their emotional health is not really known. They did look for strength in a number of places and were also motivated by their children and husbands to survive. There was somewhat an undercurrent of fear and a feeling that should they have a recurrence, because of the negative effects of chemotherapy they felt they would not undergo this treatment a second time.

Summary

The findings of this study build on the broader research literature that provides an understanding of what it is like for women to have breast cancer and receive adjuvant therapy. Women, regardless of country of origin or cultural background, are concerned about having breast cancer and what that diagnosis might mean to their future. They live with a great deal of uncertainty and suffering as they try and deal with this diagnosis and the effects of treatment.

Two factors that are important to breast cancer survivors are social support and having their informational and emotional needs met. The main sources of support are spouses or partners. In fact when this support is not present in the spousal relationship, the woman experiences a great deal of distress.

The findings from my research may help to understand some of the delay in seeking a diagnosis that has been noted in Malay women. These women are very concerned how this diagnosis may affect other family members, such as children, parents, or their husbands. This degree of being other-focused or trying to protect others has not been noted in the literature and needs further explorations.

CHAPTER 6

LIMITATIONS, NURSING IMPLICATIONS AND CONCLUSION

This study has a number of important implications for nursing and nursing science in Malaysia. In this chapter I will highlight those implications. However, because I believe that there are also some limitations to be considered when looking at those implications I will address those as well. The last part of the chapter will address some conclusions that can be drawn from this research.

Limitations

There are some limitations to this study that need to be acknowledged. One of these was the fact that the interviews were done in Malay and English and while every effort was made to translate the Malay words into English, it was difficult. Therefore, some of the nuances of what the women were expressing as part of their experience may have been lost. It was important to allow the women to express themselves in the language in which they felt comfortable.

A second limitation is that as a novice researcher, it was difficult to follow-up on all the aspects of living with breast cancer that the women mentioned. A more skilled researcher would pick up on these areas and engage in more discussion with the women. Sometimes it was only after I had ended the data collection phase of the research and was working on the analysis, that I realized some areas could be explored more fully.

Nursing Implications

One of the reasons that I decided to do this study was that nursing care to women being diagnosed with and treated for breast cancer was based on research that had been done on women living in other countries, particularly western women, and that the findings from this research may not be the most appropriate evidence on which to base care for Malaysian women. Therefore, I wanted to try and understand these women's experiences so that recommendations for care may be more culturally appropriate. I also know that my study would be a beginning and a contribution to research on breast cancer in Malaysia. With those thoughts in mind I have identified the following recommendations for nursing practice and research.

Nursing Practice

Based on the findings from my research there are a number of ways that nursing can help to improve the lives of women being diagnosed with breast cancer and that of breast cancer survivors. The first way is in helping women become aware of symptoms of breast cancer earlier. Educational campaigns need to be designed and widely implemented that will teach women the signs and symptoms of breast cancer. Women of all ages need to be helped to pay attention to the importance of these indications and of seeking professional help when they experience these symptoms. Improved screening including opportunistic screening would greatly improve earlier detection. Nurses could be taught to use these breast screening opportunities to teach the women self-screening techniques, such as breast self-examination. Women then need to be empowered to act on any abnormality they detect and to seek medical attention.

The educational campaigns also need to target the general public so that the fear of cancer that my participants have mentioned and other studies have noted can be addressed. Attitudinal changes can only take place if this fear can be dispelled. Breast cancer survivors can be instrumental in helping to change these attitudes. If they are willing and able to help in public campaigns, the campaigns may be more successful. It is important for the public as well as women themselves to realize that in a culture with early detection and treatment, breast cancer mortality can be reduced.

Another implication for nursing practice is to develop culturally appropriate decisional aids for women in Malaysia. One of the challenges of these aids would be to factor in the degree to which women are "other-focused" and how this may affect their decision-making around treatment. Active involvement of the family with the woman's approval would help in this respect. Another challenge would be to address the women's sense of leaving things to fate and that the woman needs to be an active participant. Religious institutions could be partners in dealing with this challenge.

Nurses also need to be aware of the experiential aspects of receiving chemotherapy and radiation as adjuvant therapy. This awareness may assist them in developing strategies to help women who suffer because of their treatment. Good assessment skills of how the women are responding, what kind of side effects they are experiencing, and what interventions can be used to help the women are important areas for nurses working with breast cancer survivors to have.

The women in my study were generally positive about the support that they received through the support groups at the clinic. However, they did feel at times they protected each other and did not get some of the information they felt was important. Women wanted to know what treatment was like and what were some of the side-effects of treatment. While it is important that these groups continue to be safe and supportive places for the women, it is also necessary for the women to get the type of information they need. Nurses could encourage the women to feel comfortable talking about their condition and what is happening to them. Perhaps some of the socio-cultural attitudes in the greater society are still being reflected in the interactions in the group and group members could talk about these.

Many of the women in my study were experiencing distress over their diagnosis and treatment and I felt that many were still afraid of a recurrence of breast cancer. These issues need to be addressed with breast cancer survivors. Nurses need to be sensitive to this need and try and address it with the women or assist them to get the emotional help they need. Nurses need to work with family members as well, not only to meet their emotional support needs, but to help them to understand what is happening to the woman with breast cancer.

Nursing Education

There are implications from this study as to how we educate nurses in Malaysia. In basic nursing education we need to introduce a strong "breast health" curriculum where students can learn not only the signs and symptoms of breast cancer and when to seek treatment but some of the learning needs of women around breast cancer and breast cancer treatment. As these students work with women, they can use this knowledge in health promotion and early disease detection. Other areas to teach nursing students are some of the experiences of women with breast cancer, their health care needs, and effects of adjuvant therapy on women with breast cancer.

While the women in this study found that the nurses who worked in oncology had a good knowledge of the physical effects of adjuvant therapy on women, they also felt that the nurses could have prepared them more for experiential aspects, i.e., what it is like to receive this therapy. Nursing education for this cadre of nurses could help them with how to approach this aspect of patient counseling. Other educational needs of this group of nurses is to assist them to learn more about community outreach so they can fill some of the knowledge gaps in the wider community and in particular women's understanding of all cancers, but particularly breast cancer. The findings from this study demonstrate a need for wider educational approaches.

Nursing Research

This was a beginning research endeavour and while it contributes to our overall understanding of how women experience breast cancer and adjuvant therapy in Malaysia, there are implications for further research on women and breast cancer within that country. One of the areas to study further is women's understanding of the need for breast cancer screening and their knowledge of breast health issues especially signs and symptoms of breast cancer. Additional research is needed on cultural beliefs and attitudes toward breast cancer that could affect woman with breast cancer. In groups where negative attitudes and beliefs are held, a participatory action research project could work on changing these attitudes and beliefs.

A further study could be done on women's decision-making for diagnosis and treatment options. This study needs to include the importance of other family members in the decision-making process. Such a study may help to understand who women consult for advice, how they interpret their symptoms, and what they do when they find an abnormality. A grounded theory study on this topic would help to understand this process in some depth.

Research is needed with the spouses and partners of breast cancer survivors to understand their fears, concerns and means of coping. There is limited information on how to help families whose emotional health is affected when a spouse or mother has breast cancer (Northouse, 2005); and this might be more so in the Malaysian context. Studies of communication styles between husbands and wives may help further explore this particular area.

More research needs to be done on the quality of life of Malaysian women who have breast cancer. Initially qualitative work could be done with these women to construct a good description of what constitutes a good quality of life for these individuals. The qualitative work could result in instrument development that could then be used to measure this construct. Researchers can then see how this quality of life differs by a variety of variables. The instrument could also help clinically in monitoring the woman's quality of life and indicating areas of her life where interventions may be helpful.

Conclusion

In conclusion, this study adds to what is known about women and breast cancer in Malaysia. Using Giorgi's phenomenology methodology I identified the following seven themes: 1) *Not knowing what to do,* 2) *The meaning of a diagnosis of breast cancer*, 3) *Suffering through the treatment*, 4) *The changing body*, 5) *Trying to protect others*, 6)

Finding strength and making changes, and 7) *The importance of support*. These themes help to understand some of essential aspects of these women's experiences.

A number of the themes I identified are similar to findings from other research on women's experiences with breast cancer, such as how women experience changes in their bodies, the impact that a diagnosis of cancer has for women, the importance of support, and how a diagnosis of breast cancer enables women to find strength and make changes in their lives. However, I also noticed some differences or areas not as well explored. These were the degree to which women with breast cancer try and protect other family members, the degree of distress that a non-supportive spouse can create, and the need for women to have knowledge about the experiential aspects of receiving adjuvant therapy.

The findings will help to inform nursing practice, education, and research. In particular nurses need to help work on educational campaigns that will help women pay more attention to early signs of breast cancer. These campaigns will assist the public not to be so fearful about cancer and cancer survivors. The findings will inform nursing education in that nursing students and practicing nurses alike will have a better understanding of breast cancer survivors' needs. More research of this nature is required to understand women's beliefs and attitudes about breast cancer and breast cancer screening, spouses and other family member's experience, and women's decision- making around seeking a diagnosis and treatment, as well as quality of life studies with these women.

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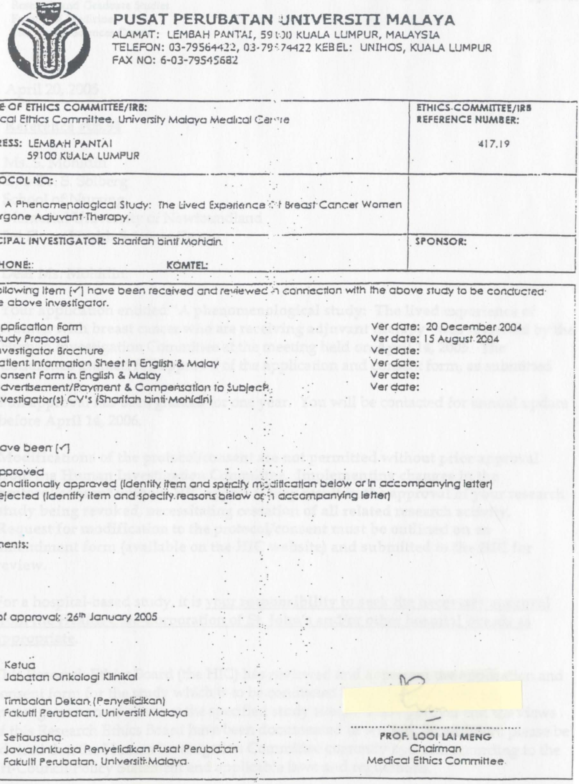
APPENDICES

Appendix A: UMMC Medical Ethics Approval



PUSAT PERUBATAN UNIVERSITI MALAYA
ALAMAT: LEMBAH PANTAI, 59100 KUALA LUMPUR, MALAYSIA
TELEFON: 03-79564422, 03-79:74422 KEBEL: UNIHOS, KUALA LUMPUR
FAX NO: 6-03-79545682

NAME OF ETHICS COMMITTEE/IRB:
Medical Ethics Committee, University Malaya Medical Centre

ADDRESS: LEMBAH PANTAI
59100 KUALA LUMPUR

ETHICS COMMITTEE/IRB REFERENCE NUMBER:
417.19

PROTOCOL NO:

TITLE: A Phenomenological Study: The Lived Experience Of Breast Cancer Women Undergone Adjuvant Therapy.

PRINCIPAL INVESTIGATOR: Sharifah binti Mohidin

SPONSOR:

TELEPHONE: **KOMTEL:**

The following item [✓] have been received and reviewed in connection with the above study to be conducted by the above investigator.

[✓] Application Form — Ver date: 20 December 2004
[✓] Study Proposal — Ver date: 15 August 2004
[ ] Investigator Brochure — Ver date:
[✓] Patient Information Sheet in English & Malay — Ver date:
[✓] Consent Form in English & Malay — Ver date:
[ ] Advertisement/Payment & Compensation to Subject — Ver date:
[✓] Investigator(s) CV's (Sharifah binti Mohidin)

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:

Date of approval: 26th January 2005

c.c Ketua
Jabatan Onkologi Klinikal

Timbalan Dekan (Penyelidikan)
Fakulti Perubatan, Universiti Malaya

Setiausaha
Jawatankuasa Penyelidikan Pusat Perubatan
Fakulti Perubatan, Universiti Malaya

PROF. LOOI LAI MENG
Chairman
Medical Ethics Committee

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

We wish you every success with your study

Sincerely,

John D. Harnett, MD, FRCPC
Co-Chair
Human Investigation Committee

Richard S. Neuman, PhD
Co-Chair
Human Investigation Committee

JDH;RSN\jjm

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

We wish you every success with your study

Sincerely,

John D. Harnett, MD, FRCPC
Co-Chair
Human Investigation Committee

Richard S. Neuman, PhD
Co-Chair
Human Investigation Committee

JDH;RSN\jjm

Appendix C: Participant's Consent Form

Medical Ethics Committee
University of Malaya Medical Centre
Kuala Lumpur, Malaysia
and
Faculty of Medicine, Schools of Nursing and Pharmacy of Memorial University of Newfoundland; Health Care Corporation, St. John's; Newfoundland Cancer Treatment and Research Foundation

Consent to Take Part in Health Research

TITLE: **A Phenomenological Study: The Lived Experience of Women With Breast Cancer Who Are Receiving Adjuvant Therapy.**

INVESTIGATOR(S): **Ms. Sharifah Mohidin**

You have been asked to take part in a research study. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explain the study.

The researchers will:

- **discuss the study with you**
- **answer your questions**
- **keep confidential any information which could identify you personally**
- **be available during the study to deal with problems and answer questions**

If you decide not to take part or to leave the study this will not affect your treatment.

1. Introduction/Background:

Having breast cancer and receiving treatment has a number of effects on the live of women. Most studies on women with breast cancer have been conducted in countries outside Malaysia. We do not know to what extent the results from these studies represent the experiences of women in Malaysia. This study will help understand the experiences of women living in Malaysia who have breast cancer and are receiving treatment for this condition.

2. Purpose of study:

The purpose of this study is to gain a better understanding of the experiences of women who have breast cancer and are receiving treatment for breast cancer especially radiation and chemotherapy - within the Malaysian context.

3. Description of the study procedures and tests:

If you agree to take part in this study I would like to interview you about your experiences with breast cancer and the treatment you have received for breast

cancer. I would like to understand how these experiences have affected your li With your consent I would like to tape record these interviews.

4. **Length of time:**
The interview will take around one hour of your time at a time and place convenient for you. A second interview may be necessary for clarification of information from the first interview. If this is necessary I will contact you.

5. **Possible risks and discomforts:**
While I do not see any risks to you, some women may become upset when they talk about these experiences. If this should happen I will stop the interview if y wish. If you would like to talk with some one from the Oncology Clinic about ar concerns I will ask one of the doctors or nurses to call you.

6. Benefits:
It is not known whether this study will benefit you personally.

7. **Liability statement:**
Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. **Confidentiality:**
All information you give me will be kept private and confidential. You will not b identified in any way in reports or presentations resulting from this research. Your name will not be used.

9. **Questions:**
If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is:

Ms. Sharifah Mohidin, Tel: 03-55122005

Or you can talk to someone who is not involved with the study at all, but can advise you o your rights as a participant in a research study. This person can be reached through:

Ethics Committee, University of Malaya Medical Centre
Tel: 03-79564422

Signature Page

Study title: A Phenomenological Study: The Lived Experience of Women With Breast Cancer Who Are Receiving Adjuvant Therapy

Name of principal investigator: **Ms. Sharifah Mohidin**

To be filled out and signed by the participant:

Please check as appropriate:

I have read the consent [and information sheet]. Yes { } No { }
I have had the opportunity to ask questions/to discuss this study. Yes { } No { }
I have received satisfactory answers to all of my questions. Yes { } No { }
I have received enough information about the study. Yes { } No { }
I have spoken to Ms. S. Mohidin. and she has answered my questions Yes { } No { }
I understand that I am free to withdraw from the study Yes { } No { }

- at any time
- without having to give a reason
- without affecting my future care

I understand that it is my choice to be in the study and that I may not benefit. Yes { } No { }

I agree to have my intetview audio taped Yes { } No { }

I agree to take part in this study. Yes { } No { }

______________________________ ______________________
Signature of participant Date

______________________________ ______________________
Signature of witness Date

<u>To be signed by the investigator:</u>

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

______________________________ ______________________
Signature of investigator Date

Telephone number: ______________________