#### **CHAPTER 2**

#### LITERATURE REVIEW

In this chapter, the literature concerning breast cancer survivors is reviewed. First, the stages of cancer survivorship are described, followed by problematic consequences of breast cancer survivorship, quality of life, self-care, and interventions based on Orem's Self-Care Deficit Theory. Last, the conceptual framework adopted in this study is summarized.

#### Stages of Cancer Survivorship

Breast cancer is the most common cancer among women and the second leading cause of cancer deaths after lung cancer (American Cancer Society, 2001). However, the advancement of medical technology has reduced breast cancer mortality annually (Turco, 1999). Such reduction, therefore, results in an increasing number of breast cancer survivors.

According to the American Cancer Society (2001), a person with cancer who lives after five years and shows no evidence of cancer recurrence, is called a five-year survivor and the cancer is considered to be arrested. In fact, cancer survivorship begins immediately after the diagnosis is made because these patients have to confront their own mortality and begin to make adjustments which will be part of

their life (Mullan, 1985). Furthermore, it is worth noting that the cancer experience is not necessarily over after treatment, but can return in the future. Therefore, cancer survivorship is defined as a dynamic and life-long process that is viewed as a continuum or ongoing event rather than an event that occurs at some deliberate period of time (Pelusi, 1997). Moreover, characteristics of cancer survivorship do not only include the length of time people live after the diagnosis, but also the experiences they live with after the diagnosis (Farmer & Smith, 2002).

Mullan (1985) classified three stages of survivorship, which he called the seasons of survival. These stages include the acute, the extended, and the permanent survival stage. The acute survival stage begins with the diagnosis of the disease. This stage is dominated and characterized by cancer treatments. In this stage, survivors will receive one or more common treatments, such as surgery, radiation therapy, chemotherapy, hormonal therapy, and bone marrow transplantation. The next stage is the extended survival stage which is characterized by remission and the termination of basic and rigorous treatments. During the extended survival stage, survivors enter a watchful waiting period and may receive periodic examinations and intermittent therapy. Mullan (1985) also counted cancer of every cancer staging without the metastasis of cancer be included in this stage. The last stage of survivorship is the permanent survival stage. It is the evolution from the extended survival stage into a period when activity of the disease or the likelihood of its recurrence is sufficiently small. The cancer is considered to be arrested or "cured."

Although Mullan (1985) delineated three stages of survivorship, there are other aspects of survivorship that are excluded. For example, Mullan's stages of survivorship assume that patients would respond to the treatment. It did not mention

survival stage for patients with no response to treatment, patients with a recurrence, or survivors who face death and dying. Therefore, the three stages of survivorship might appear to display multidirectional processes. In spite of these limitations, Mullan's stages of cancer survivorship are relevant for breast cancer survivors. Moreover, the explanation of the survivorship process is helpful for both survivors and health care providers in order to understand the difficulties and problems related to survival experience.

The present study emphasized the extended survival stage, particularly one to three years after diagnosis. The choice of this stage was justified based on the results of a previous study (Soivong, unpublished). The study showed that breast cancer survivors in this stage have to deal with the consequences of treatment and have to live with the risk of cancer recurrence. Additionally, doctors and nurses rarely have time to provide support and counseling because survivors are less likely to attend the clinic for active treatment. Thus, breast cancer survivors and their family members inevitably face and manage their own problems at home. Therefore, health care providers should pay more attention to patients in this stage of survivorship in order to help them to deal effectively with problematic consequences of disease and treatment.

## Problematic Consequences of Breast Cancer Survivorship

After the diagnosis, breast cancer patients receive a combination of local and systemic treatments (American Cancer Society, 2001). Firstly, local treatment, such as surgery or radiotherapy therapy, is intended to treat a tumor site found without affecting the rest of a patient's body. Secondly, systemic treatment including

chemotherapy, hormonal therapy, or immunotherapy, aims to reach cancer cells that may have spread beyond the initial cancer site. In addition, breast cancer patients who have positive estrogen receptor (ER+) at the surface of their tumors would receive the anti-estrogen drugs for five years after the completion of active treatments in order to reduce the chance of cancer recurrence. Breast cancer survivors experience hardships related to the nature of the disease, treatment protocol, as well as the treatment side-effects. These hardships involve physiological, psychological, and social problems which impact their quality of life. Because this study focused primarily on breast cancer survivors who are in the extended survival stage, one to three years after diagnosis, literature related to other phase of survivorship were not included in this review.

#### Physiological Problems

Physiological problems are physical symptoms and discomforts which are the result of treatments. The most common physiological problems reported by breast cancer survivors include fatigue, menopausal symptoms, weight gain, cognitive dysfunction, lymphedema, and secondary malignancy. These common physiological problems of breast cancer survivors are reviewed as follow.

Fatigue. Fatigue is the one of the most common symptoms reported by breast cancer survivors (Ferrell et al., 1997; Soviong, unpublished; Soivong & Chaprasit, 2004). The exact mechanism causing fatigue in breast cancer survivors is unknown. It may be related to menopausal symptoms (Bower et al., 2000; Broecke et al., 1998; Soviong, unpublished; Soivong & Chapprasit, 2004), difficulty sleeping

(Broeckel et al, 1998; Loveys & Klaich, 1991; Okuyama et al., 2000), anxiety (Soivong, unpublished; Soivong & Chanprasit, 2004), and depression and pain (Loverys & Klanch, 1991; Okuyama et al, 2000). Breast cancer survivors reported experience of fatigue, which varied from a low to a severe level, after the end of a treatment protocol (Bower et al., 2000; Broeckel et al., 1998; Ferrell et al, 1998; Loveys & Klaich, 1991; Mast, 1998; Okuyama et al., 2000; Soviong, unpublished; Soivong & Chanprasit, 2004; Wyatt & Friedman, 1998).

Menopausal symptoms. Breast cancer survivors may experience more prevalent or more severe menopausal symptoms than healthy women because of chemotherapy-induced ovarian failure which artificially induces menopause (Burstein & Winer, 2000), or the unpleasant side effects of anti-estrogen medications (Carpenter et al., 1998; Carpenter et al., 2002; Fisher et al., 1996; Ganz et al., 1998; Soivong, unpublished; Soivong & Chanprasit, 2004). Burstein and Winer (2000) found that adjuvant chemotherapy in breast cancer survivors results in permanent ovarian failure in 70% of women over 40 years of age and in 40% percent of younger women. Moreover, Fisher et al. (1996) found that almost 60% of tamoxifen-treated breast cancer survivors experienced menopausal symptoms, particularly hot flashes.

Menopausal symptoms reported by breast cancer survivors were joint pain, feeling tired, trouble sleeping, hot flashes/night sweats, headaches, irritability and nervousness, and the blues and depression (Carpenter & Andrykowski, 1999). The number of menopausal symptoms was related to the number of years that women were postmenopausal, with higher severity of symptoms in women who were fewer years postmenopausal (Carpenter & Andrykowski, 1999). It is interesting to note that hot flashes were the most common symptoms that were found in some studies

(Carpenter et al., 1998; Couzi et al, 1995; Finck & Barton, 1998; Fisher et al., 1996; Ganz et al., 1998). The reported level of hot flashes varied from mild to very severe (Carpenter et al., 1998; Finck & Barton, 1998). Interestingly, breast cancer survivors with severe hot flashes reported greater mood disturbance, more negative affects, and more interference with daily activities including sleep, concentration, and sexuality (Carpenter et al., 1998).

Weight gain. Weight gain has been a well-documented side effect of adjuvant chemotherapy in breast cancer survivors since the past two decades (DeGeorge, Gray, Fetting & Rolls, 1990; Loveys & Klaich, 1991). The majority of breast cancer survivors, who are treated with CMF regimen (Cyclophosphamine + Methrotaxate + 5-FU), reported more weight gain than women on FAC (5-FU + Adraimycin + Cychophosphamine) or AC (Adraimycin + Cychophosphamine) regimens. Suspected causes of weight gain include decreased physical activity, ovarian failure, overeating as a coping mechanism, and decreased basal metabolic rate (Shapiro & Recht, 2001). The average weight gain ranges from two to six kilograms (Shapiro & Recht, 2001). Approximately 62% of breast cancer patients reported weight gain at one year after starting treatment, 68 % reported weight gain after two years, and 40% after three years. A greater weight gain occurred over time in premenopausal women (McInnes & Knobf , 2001). Camoriano et al. (1990) and Tartter et al. (1981) revealed that weight gain was associated with poorer prognosis and a higher rate of cancer recurrence.

Cognitive dysfunction. Cognitive dysfunction reported by breast cancer survivors refers to the complaint of difficulties in or less ability to remember, think, and concentrate (Brezden, Phillips, Abdolell, Bunston & Tannock, 2000; Schagen et

al., 1999). The mechanism of cognitive dysfunction is unknown, but it may result from the direct effects of chemotherapy or indirect effects of decreasing estrogen levels from ovarian failure (Shapiro & Recht, 2001). Impairment of cognitive functions was found in 28% of breast cancer patients receiving adjuvant chemotherapy and 12% of breast cancer patients not receiving adjuvant chemotherapy (Schagen et al., 1999). In addition, the study by Brezden et al. (2000) showed that breast cancer survivors receiving adjuvant chemotherapy, and those who had completed adjuvant chemotherapy a median of two years earlier, reported moderate or severe cognitive impairment greater than the healthy controls.

Lymphedema. Lymphedema is a distressing problem that can develop following breast cancer treatment. Breast cancer survivors who are at risk of developing lymphedema are those receiving surgical resection of lymphatic vessels and lymph nodes, and/or those receiving radiation therapy that induces fibrosis around these structures (Petrek et al., 2000). Furthermore, metastatic disease, prolonged immobility or dependency of the extremities, obesity, and recurrent infections with lymphagitis increase the risks of developing lymphedema (Petrek et al., 2000). The incidence of lymphedema has been reported from 6% to 30% in breast cancer patients (Petrek & Heelan, 1998). The incidence varies widely depending on the research setting, length of follow-up, measurement techniques, and the definitions of lymphedema used in various studies. Lymphedema can occur at any time after axillary lymph node dissection up to thirty years after surgery (Humble, 1995). The appearance of arm swelling may be more distressing than that of a mastectomy because mastectomy can easily be hidden, but the disfigured arm or hand is a constant reminder of the disease and a subject of curiosity of others (Petrek et al., 2000).

Secondary malignancy. The development of a secondary malignancy is commonly found when a patient has contralateral breast cancer. This occurs in 0.5% to 1% of breast cancer survivors each year (Gregory, 1999). Myelodysplastic syndrome (MDS) or acute myeloid leukemia can occur as a consequence of chemotherapy. The risk of MDS is 0.2% to 1% after standard chemotherapy but leukemia may arise six months to five years after treatment (Burstein & Winer, 2000). In addition, tamoxifen can cause endometrial carcinoma (Burstein & Winer, 2000). Breast cancer survivors receiving tamoxifen had a risk of developing invasive endometrial cancer 2.53 times greater than a placebo group. However, breast cancer survivors gained benefits from adjuvant tamoxifen treatment in terms of decreasing the risk of breast cancer recurrence and mortality (Fisher et al., 1996).

### Psychological Problems

Psychological problems refer to emotional reactions following diagnosis and treatment. Most common psychological problems reported by breast cancer survivors after discharge from a hospital and persisting throughout their lives includes fear of cancer recurrence (Northouse, 1989; Soivong, unpublished; Soivong & Chanprasit, 2004), anxiety and depression (Goldberg et al., 1992; Knobf, 1986; Maguire et al., 1978; Soivong & Chanprasit, 2004). In addition, Knobf (1986) and Sammarco (2001) found that fear of cancer recurrence, anxiety, and depression were related to an uncertainty of survival, a less happy mood, a difficulty concentrating, and a more worried outlook.

#### Social Problems

Social problems refer to the impact of breast cancer on breast cancer survivors and persons surrounding them. The problems include sexual relationships, family distress, decreased ability to perform social roles, and problems with work and insurance. Each problem is described below.

Changes in sexuality among breast cancer survivors have been reported in association with menopausal symptoms (Ferrell et al., 1997). The most common sexual problems resulted from absence or reduced sexual desire, anorgasmy, lubrication difficulty, and dsypareunia (Thors et al., 2001). Breast cancer survivors have also reported a change in the frequency and quality of their sexual relationship (Knobf, 1986).

Survivors report several effects of treatment and disease on their families, such as family distress (Ferrell et al., 1997; Soivong, unpublished; Soivong & Chanprasit, 2004). In addition, the most common specific issue related to their children is worry about whether they will live long enough to see their children grow up (Gregory, 1999). Moreover, Ferrell et al. (1997) and Soivong (unpublished) found that patients were also concerned about their female relatives, particularly their daughters' risk of developing breast cancer. They also reported less open communication with their partners as result of an effort to psychologically protect each other (Holmberg, Scott, Alexy & Fife, 2001). In contrast, some breast cancer survivors reported that they gained more support and felt closer to their partners than before the breast cancer diagnosis (Taylor-Brown, Kilpatrick, Maunsell & Dorval, 2000; Soivong, unpublished; Soivong & Chanprasit, 2004).

In addition, some breast cancer patients reported that they would like to express emotional needs and concerns about cancer, but they had no one with whom to discuss their problems. They participated less in social activities and tended to isolate themselves from others due to a feeling of being indifferent (Polinsky, 1994). For example, a breast cancer survivor reported problems with seeking a partner and fear of developing a new relationship because of her breast cancer history (Ganz et al., 1996).

Concerning employment, breast cancer survivors reported that they had difficulties with getting time off from work for medical appointments, and difficulties with explaining their health situation to their employers (Polinsky, 1994). Some breast cancer survivors experienced work- or workplace-related problems such as violation of confidential medical information in their workplace, an absence of resources and support to assist with work re-entry, difficulty with management of social stigma, difficulty talking with co-workers and others about health problems, difficulty asking for and receiving assistance (Carter, 1994), job loss, demotion, unwanted changes in tasks, problems with employers and co-workers, personal changes in attitude toward work, and diminished physical capacity (Maunsell et al., 1999). Moreover, insurance was reported to have been refused or offered only with higher premiums as a result of a past history of breast cancer (Polinsky, 1994; Stewart et al., 2001).

In summary, although breast cancer survivors, particularly those who are one to three years post diagnosis, will re-enter their everyday lives with renewed wellness, they will also have to deal with the consequences of treatment-related side effects and the risk of cancer recurrence. The most common problems reported are comprised of physiological problems including fatigue, menopausal symptoms, weight gain,

cognitive dysfunction, lymphedema, and secondary malignancy; psychological problems including fear of recurrence, anxiety and depression, and uncertainty of survival; and social problems including sexual relationships, family distress, decreased ability to perform social roles, and problems with work and insurance. In Thailand, there is evidence to support that breast cancer survivors face similar problems to those in the Western countries (Soivong, unpublished; Soivong & Chanprasit, 2004). These problems have great influence on the quality of life of breast cancer survivors, especially those who are in the period one to three years following diagnosis.

#### Quality of Life

Quality of life is "a state characterized by experience of contentment, pleasure, and kinds of happiness; by spiritual experience; by movement toward fulfillment of one's self-ideal; and by continuing personalization" (Orem, 1995, p.101). The concept of quality of life has been used synonymously with the concept of well-being. According to Orem (2001), "well-being is associated with health, with success in personal endeavors, and with sufficient resources" (p.186). Individuals may experience well-being in spite of their adverse conditions, including disorders of a person's health and functioning (Orem, 2001). According to King et al. (1997), quality of life is a cognitive weighting or appraisal of positive and negative facets of life, dynamic and continuity. From these definitions, it can be inferred that quality of life has both subjective and objective aspects. Subjective aspects involve an individual's perception of him/herself while objective aspects concern measurements

of quality of life (Meeberg, 1993). There has been an effort to measure quality of life for decades. Several instruments have been developed and modified in attempt to measure this concept.

The Instruments for Measuring Quality of Life

From literature review, a variety of definitions of quality of life have been noted. Different definitions were used in various studies. Some researchers opt for unclear definitions (Mast, 1995; Pedro, 2001). Owing to the complexity and elusive nature of the concept, many researchers have attempted to develop instruments for measuring this concept in several groups. In the area of oncology, there are many instruments used to measure quality of life in breast cancer patients (See Table 1). Each instrument embraces multidimensional aspects of quality of life involving physical, psychosocial, social, role, spiritual, and other areas. It is interesting to note that many studies on quality of life of breast cancer survivors used holistic approach and attempted to cover several dimension of quality of life. Information regarding selected instruments measuring quality of life is shown in Table 1.

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Table 1

The Most Common Instruments Measuring Quality of life in Breast Cancer Patients

Authors (year)	Instrument	Dimensions
Aaronson et al.	The European Organization for	<ul> <li>Physical function</li> </ul>
(1993)	Research and Treatment of Cancer	<ul> <li>Role function</li> </ul>
	(EORTC) QLQ-C30	<ul> <li>Emotional function</li> </ul>
	= 00	<ul> <li>Cognitive function</li> </ul>
		<ul> <li>Social function</li> </ul>
9		<ul> <li>Global health status</li> </ul>
Cella et al.	The Functional Assessment of	<ul> <li>Physical well-being</li> </ul>
(1993)	Cancer Therapy Breast (FACT-B)	<ul> <li>Social/family well-being</li> </ul>
		<ul> <li>Relationship with doctor</li> </ul>
		<ul> <li>Emotional well-being</li> </ul>
300	13/13	<ul> <li>Functional well-being</li> </ul>
	1 6 M	<ul> <li>Additional concerns</li> </ul>
Ferran & Powers	Quality of Life Index (QLI)	<ul> <li>Health and function</li> </ul>
(1985)		<ul> <li>Psychological/spiritual</li> </ul>
		• Family
(3)		<ul> <li>Social and economic</li> </ul>
Padilla & Grant	The Quality of Life Index for	<ul> <li>General physical</li> </ul>
(1983)	Patients with Cancer (QOL Index)	condition
		<ul> <li>Normal human activities</li> </ul>
	E 30 60	<ul> <li>Personal attitude related</li> </ul>
		to general QOL
Schag, Ganz &	Cancer Rehabilitation Evaluation	• Physical
Heinrich	System-Short Form (CARES-SF)	<ul> <li>Psychosocial</li> </ul>
(1991)	UNIT	<ul> <li>Medical interaction</li> </ul>
		• Marital
		• Sexual
Wyatt &	Long Term Quality of Life	<ul> <li>Somatic Concerns</li> </ul>
Friedman	(LTQL)	<ul> <li>Philosophical/Spiritual</li> </ul>
(1996)		view
• 1 4 6		<ul> <li>Health habits</li> </ul>
wnght C	by Chiang Ma	(diet/exercise)
//		<ul> <li>Social/emotional support</li> </ul>

These instruments were used to assess quality of life of breast cancer survivors at various stages of survivorship in six studies. Four of them were conducted in developed countries (Ferrans, 1994; Ferrell et al., 1997; Northouse et al., 1999; Wyatt & Friedman, 1996) while the other two studies were conducted in

Thailand (Soivong, unpublished; Wonghongkul et al., 2003). The findings from these studies clearly shown that breast cancer survivors encountered problems related to cancer treatment for years after completing the treatment. These problems also had an impact on breast cancer survivors' quality of life as indicated in the following summary:

Ferran and Powers (1985) developed the Quality of Life Index (QLI) for measuring quality of life. They defined quality of life as a person's sense of well-being, which stemmed from satisfaction or dissatisfaction with the area in life that is important to him/her. Quality of life is conceptualized as a multidimensional construct composed of four domains including health and functioning, psychological/spiritual, family, and social and economic. They conducted the study in 111 breast cancer survivors post diagnosis 2 to 32 years for testing the psychometric properties of the instrument (Ferrans, 1994). The findings supported the internal consistency reliability as well as concurrent and construct validities of the QLI. However, the researcher did not report which was the highest score (the best outcome) or the lowest score (the worst outcome) in each dimension of quality of life.

Ferrell, Grant, Funk, Otis-Green & Garcia (1998) evaluated quality of life in 298 breast cancer survivors with a median time since diagnosis of 75 months by using Quality of Life-Breast Cancer Version (QOL-BC) (Ferrell et al., 1995). They defined quality of life as a personal sense of well-being encompassing the physical, psychological, social, and spiritual dimension (Ferrell et al., 1995). Results revealed that the highest score (the best outcome) was in the area of physical well-being, followed by social well-being, and spiritual well-being. The lowest score (the worst outcome) was in the area of psychological well-being. The physical problems

affecting physical well-being were vaginal dryness, fatigue, and weight problems, while burdens related to fear of recurrence and anxiety affected psychological well-being. In the social well-being domain, the greatest disruption included concern for female relatives and family distress, whereas uncertainty about the future was the greatest disruption in the domain of spiritual well-being.

Northouse et al. (1999) conducted a study to describe quality of life of 98 African American women who were approximately four years post diagnosis. Quality of life, based on Aaronson (1993), was viewed as a multidimensional concept that encompassed the individual's sense of well-being related to disease or treatment-related symptoms, physical functioning, psychological functioning, and social and role functioning. The Functional Assessment of Cancer Therapy for Breast Cancer (FACT-B) developed by Cella & Yellen (1993) was used to measure quality of life in this study. The results showed that women, who reported a fairly high level of quality of life, were generally optimistic and had effective family function. On average, their symptom distress scores were low to moderate. However, there were some symptoms that women frequently reported. Those symptoms were energy loss, sensory problems, sleep problems, pain, and mental distress.

Soivong (unpublished) explored quality of life of 107 breast cancer survivors who were post diagnosis one to three years and disease-free. The subjects ranged in age from 35-65 years old. Quality of life was defined as a state of breast cancer survivors characterized by sense of well-being which encompassed physical, psychological, social, and spiritual well-being. Quality of life was measured by using the Quality of Life-Breast Cancer Questionnaire (Ferrell et al., 1995). The results revealed that the highest score (the best outcome) was in the domain of physical well-

being, followed by social well-being, and spiritual well-being. The lowest scores (the worst outcomes) was in the area of psychological well-being. Physical well-being following a diagnosis of cancer was greatly influenced by symptoms associated with cancer or its treatment. These symptoms included weight gain, menstrual or fertility change, sleep problem, pain and vaginal dryness. In the domain of psychological well-being, the worst outcomes were fear of metastasis, distress from chemotherapy, fear of recurrence, and fear of secondary cancer, respectively. In the social well-being domain, the most influential problems included concern for female relatives, family distress, and interference in employment. In the area of spiritual well-being, the greatest disruption was related to uncertainty about the future.

Wonghongkul et al. (2003) conducted a study to identify the quality of life in 74 Thai breast cancer survivors one to three years following treatment. They used the definition of quality of life based on Ferrell et al. (1995). Quality of life was evaluated by using Quality of Life-Breast Cancer Version (QOL-BC) (Ferrell et al., 1995). The results revealed that the best outcome (the highest score) was in the area of physical well-being, followed by social well-being, spiritual well-being, and psychological well-being. The worst outcomes were distress from cancer chemotherapy, distress from initial diagnosis, concern for daughter or female relatives regarding breast cancer, and distress from cancer surgery.

Wyatt and Friedman (1996) conducted a study to identify concerns and issues related to quality of life among 188 long-term cancer survivors (post diagnosis more than 5 years). Long Term Quality of Life (LTQL) was used to evaluate quality of life. Fifty-eight percent of the sample was breast cancer survivors. The results showed that the lowest area of quality of life was in the domains of

spiritual/philosophical views, diet and exercise habits, and social/emotional support. The highest area of quality of life was physical well-being, such as the absence of somatic concerns. It can be speculated that the physical concerns of long-term survivors may be minimal compared to their concerns in psychological, social, and spiritual domains. Physical concern should be considered in early phase of survivorship while psychological, social, and spiritual concerns should be the focus in regard to long-term survivorship.

The above studies were about the quality of life in breast cancer survivors who were post diagnosis from one to more than five years. Almost all of them showed similar findings that breast cancer survivors faced problems related to treatment and disease. These problems had significant impact on their quality of life. Study findings have also shown that there were a variety of factors affecting these women's quality of life at different times after the diagnosis.

#### Research Related to Associated Factors Affecting Quality of Life

The early studies about quality of life focused not only on developing quality of life conceptual models and measurements, but also on associated factors affecting quality of life. Many studies have identified factors affecting quality of life of breast cancer survivors including age (Wenzel, et al., 1999), fatigue (Bower et al., 2000; King et al., 2000), lymphedema (Velanovich & Szymanski, 1999), menopausal symptoms (Capenter & Androkowski, 1999; Stein, Jacobsen, Hann, Grenberg & Lyman, 1999), type of treatment (Fung, Lau, Fielding, Or & Yip, 2000; Joly, Espie, Marty, Heron & Henry-Amar, 2000; Nissen et al, 2001), type of mastectomy (Dorval,

Maunsell, Deschenes & Brisson, 1998), ethnicity (Ashing-Giwa, Ganz & Peterson, 1999), weight gain (McInnes & Knobf, 2001), mood (Weitzner, Meyers, Stueging & Saleeba, 1997), exercise (Young-McCaughan & Sexton, 1991), spiritual well-being (Cotton, Levine, Fitzpatrick, Dole & Targ, 1999), coping (Carlsson, Arman, Backman & Hamrin, 2001), as well as uncertainty and perceived social support (Sammarco, 2001). These factors have either negative or positive correlations to quality of life. For example, findings showed negative correlations between quality of life and fatigue, depression or anxiety, fear of recurrence, menopausal symptoms, and uncertainty. A positive relationship was found between social support and quality of life. Moreover, breast cancer survivors who exercised had a significantly higher quality of life than those who did not exercise (Young-McCaughan & Sexton, 1991). It may be noted that factors influencing quality of life have been widely explored. In contrast, studies about effective intervention programs aimed to increase the overall quality of life of breast cancer survivors are limited.

#### Interventions for Improving Quality of Life

Most published intervention studies for improving quality of life of breast cancer survivors focused heavily on one dimension of quality of life, mainly the physical or psychological dimension in relation to the consequences of cancer treatment. With regard to the physical dimension, Carpenter et al. (2002) studied the effects of magnetic therapy on menopausal symptoms. Ganz et al., (2000) explored the effects of a comprehensive menopausal assessment intervention on menopausal symptoms. In addition, Jacobson et al. (2001) tested the effects of taking an herb

named black cohosh while Quella et al. (2002) tested the effects of soy-derived phytoestrogens on menopausal symptoms, particularly hot flashes. However, findings of these intervention studies showed insignificant effects of treatments on the alleviation of menopausal symptoms. In contrast, Davison et al. (2001) tested the effects of a sleep therapy program on insomnia and the results showed an improvement in sleep time and a decrease in fatigue level. Cox and Wilson (2003) critically reviewed the outcome of telephone intervention led by nurses. The findings revealed that telephone intervention effectively helped patients to manage their symptoms, provided immediate assistance and referral in case further care was needed, increased sense of being cared for, easy access to medical treatment with lower doctor expenses, and increased patient satisfaction.

In the psychological dimension, findings of many studies demonstrated a very interesting relationships among variables. Golant et al. (2003) tested the effect of educational conference on emotional well-being and emotional distress. The results showed the decrease in emotional distress after participating in educational conferences. Segar et al. (1998) explored the effects of aerobic exercise on self-esteem, depression, and anxiety symptoms. Montazeri et al. (2001) conducted a study to assess the effects of psycho-educational interventions on anxiety and depression. Simpson et al. (2001) studied the effects of a cognitive behavior psychosocial program on depression, mood disturbance, and overall quality of life. Findings of these studies demonstrated significant effects of interventions on decreasing mood disturbances, and relieving anxiety and depression (Montazeri et al., 2001; Segar et al., 1998; Simpson et al., 2001). Rutledge and Rymon (2001) surveyed the effects of a program named "Healing Odyssey Retreats" on quality of life and found a positive

effect of the intervention on improving quality of life. Columbia (1999) reported positive outcomes after using a telephone support group. These outcomes included obtaining supports and learning to deal with their problems. Other studies have evaluated the effects of one-on-one peer support (Ashbury et al., 1998) and a self-help group (Gray, Fitch, Davis & Philips, 1997; Trojan, 1989). The findings showed that the subjects gained informational and emotional supports from participating in the one-on-one peer support or a self-help group. Moreover, GIVIO Investigator (1994) explored the effects of an intensive follow-up program on survival rate and quality of life, but there were no significant effects found in this study. Regardless of the results of these studies, some study limitations could be identified.

These limitations included methodological weaknesses such as small sample size (Golant et al., 2003; Rutledge & Rymon, 2001; Segar et al., 1998), no comparison group (Montazeri et al., 2001; Rutledge & Rymon, 2001), lack of a randomized clinical trial using a large sample (Ashbury et al., 1998), and evaluation of the outcomes by using qualitative methods only (Golant et al., 2003). Thus, the generalizability of these study findings is limited. Another drawback related to the intervention studies is that they focus on only one domain of quality of life, mainly the physical or psychological domain. Therefore, the results of these studies were incomplete. They do not represent real quality of life from holistic perspective. A few intervention studies had committed to improve the over all quality of life (GIVIO Investigator, 1994; Simpson et al., 2001; Rutledge & Rymon, 2001). However, these studies still suffered from no significant intervention effects (GIVIO Investigator, 1994), small sample size, and no control group (Rutledge & Rymon, 2001).

In light of these drawbacks, it becomes clear that a further study is needed. A nursing intervention aimed to improve all dimensions of quality of life for breast cancer survivors one to three years post diagnosis should be developed. To accomplish this goal, the breast cancer survivors should develop self-care agency in order for them to perform self-care actions that meet their health care demands. In this way, the improvement of overall quality of life can be accomplished.

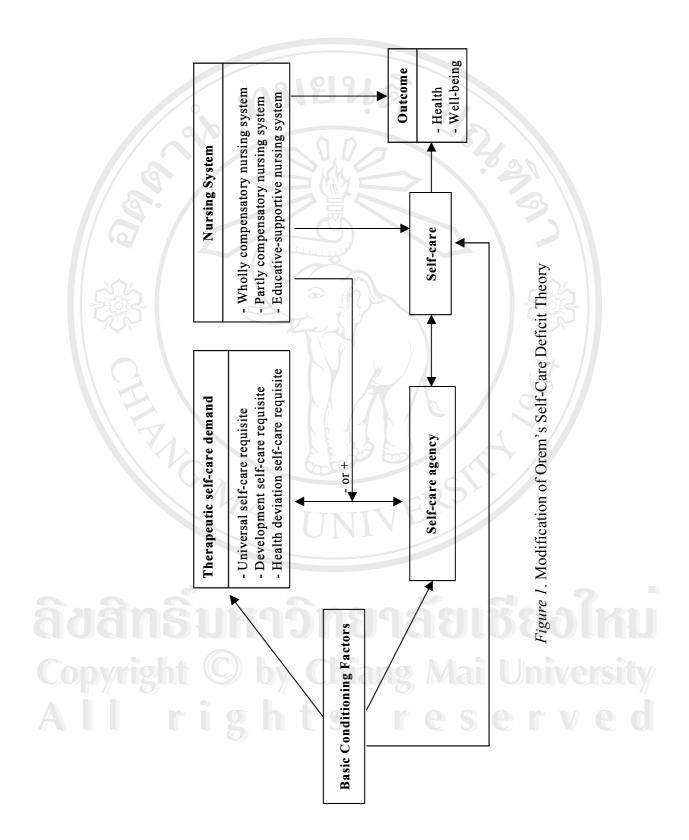
Self-care

According to Orem's Self-Care Deficit Theory (1995), human beings have potential to take care of their own health. Orem (1995) viewed a human being as a self-care agent who functions biologically, symbolically, and socially. The self-care agents have the potential of learning and developing their ability to operate self-care action by and for individuals in order to maintain their health, role functions, and well-being. Self-care agency is defined as the capability or power of individuals to perform self-care actions to resolve a self-care demand, thereby helping to ensure the person's maintenance of health and well-being (Canty-Mitchell, 2001; Orem, 2001; Slusher, 1999; Warren, 1998). Self-care agency is developed through learning. It varies depending on health status, life experiences, culture, factors influencing knowledge attainment, and the use of resources in daily living. If breast cancer survivors receive interventions that help them to develop the competence of self-care agency, they will be able to perform the self-care activities that are required by their treatments. Their quality of life also can be improved. However, individuals who perceive of their own ability to perform self-care may not be fully ready to use their

own agency to perform appropriate actions to meet the demand (Carter, 1998). Therefore, a new nursing intervention was developed in this study for the purpose of testing the effects of intervention on self-care actions, which is the ultimate outcome of self-care agency.

Self-care is defined as a deliberative action directed by an individual towards themselves or their environment to regulate their functions and development for the purpose of sustaining their lives (Orem, 1995). Hanucharunkul (1993) divided self-care actions into three categories which were therapeutic, non-therapeutic, and neutral. Orem (1991) also indicated that therapeutic self-care is a purposive action that people perform for: 1) maintaining health and normal life, 2) enhancing growth, development, and maturity, 3) preventing, controlling, or treating processes of disease and injury, 4) preventing or compensating disability status, and 5) improving security and well-being. The modification of Orem's Self-Care Deficit Theory is illustrated in Figure 1.

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In addition, Orem (1995) also indicated basic conditioning factors referring to a person's condition or living situation that influence his or her self-care ability, self-care actions, and therapeutic self-care demands. Basic conditioning factors include age, gender, developmental state, health status, socioeconomic status, elements of the health care system, family influences, patterns of living, environmental factors, and resource availability and adequacy. The effects of basic conditioning factors on self-care include changes in the adequacy of self-care agency, changes in the number or type of therapeutic self-care demands, and influences of self-care behaviors.

Self-care agency refers to the individual's capability to perform self-care operations. Orem (1995) claimed that self-care agency is comprised of three elements including; 1) foundational capabilities and disposition, 2) the ten power components, and 3) designated capabilities and dispositions for engaging in self-care. Foundational capabilities and disposition are defined as essential capabilities for the deliberate performance of any action, and for the performance of self-care. The ten power components are capabilities that empower a person to engage in self-care operations. Capabilities for self-care operations consist of three phases including: 1) estimated operations, that is investigating conditions and factors in oneself and the environment that are significant for one's self-care; 2) transitional operations, that is making judgments and decisions about self-care; and 3) productive operations, that is performing actions to meet therapeutic self-care demands.

Orem (1995) also indicated that every person has to perform self-care actions in order to meet therapeutic self-care demands. Therapeutic self-care demands refers to the summation of care measures necessary at specific times or over the duration of

time for meeting all of an individual's self-care requisites. Self-care requisites are actions performed by or for individuals in order to regulate human's functions and development. Self-care requisites consist of three types: universal, developmental, and health-deviation self-care requisites. Factors influencing the variety of self-care requisites are basic conditioning factors. Moreover, the qualitative and quantitative demands of therapeutic self-care are different from one individual to another and in the same individual from time to time. The detail of therapeutic self-care demands is summarized as follows:

Universal self-care requisites are care requirements that are common to all human beings (Orem, 1995). Universal self-care requisites are associated with life processes, maintaining the integrity of human structure and functioning, and general well-being. Eight universal self-care requisites are suggested: air, water, food, elimination, activity and rest, solitude and social interaction, protection from hazards, and a sense of normalcy. When effective universal self-care requisites are provided, positive health and well-being are fostered.

Developmental self-care requisites are associated with human developmental processes, conditions or events occurring during various stages of a person's life cycle, such as the intrauterine stages, the neonatal stage, infancy, childhood, adolescence, adulthood, and pregnancy (Orem, 1995). Each individual in society develops uniquely. Satisfaction of developmental self-care requisites is assumed to promote the processes of development, and to prevent deleterious factors affecting human development.

Health-deviation self-care requisites are associated with genetic and compositional defects, human structure and function deviations, as well as medical

diagnosis and treatments (Orem, 1995). Health-deviation self-care requisites arise when persons are ill or injured, and when persons receive diagnosis and treatment. Health-deviations may result directly or indirectly in the perception of illness or the inability to function normally. These perceptions influence what persons may choose to do. In addition, disease or injury affects physiological or psychological mechanisms and human functions, while diagnosis and treatments result in modifying personal social structures and behaviors. People with health deviations need to be helped to apply relevant knowledge to their own care.

When the three types of self-care requisites are met, they are able to support life processes, maintain human structure and function within a normal range, support human development, prevent injury and pathologic states, regulate and control the effects of injury and pathology, cure or regulate pathologic process, and promote individual well-being. Self-care deficits refer to the relationship between self-care agency and therapeutic self-care demands of individuals in which their capabilities to perform self-care are not sufficient to meet some or all of their therapeutics self-care demands. A Self-care deficit may result from the lack of power or agency. Self-care deficits can be identified as complete or partial. Complete self-care deficit means individuals have no capability to perform self-care to meet their therapeutic self-care demands, whereas partial self-care deficit means they have limitations in meeting one or several self-care demands. However, individuals' self-care agency is not a finite or static entity. Their agency can be developed and augmented by nurses or dependent care providers. When a self-care deficit arises, nurses have an important role in assisting or promoting a patient's self-care agency to meet their self-care requisites.

Nursing agency is defined as a complex capability for action that nurses need to develop. Nursing agency can be developed through education and training in the theoretical and practical courses in formal nursing education programs and through nursing practice in real world situations within a nursing system. A nursing system refers to a dynamic action system performed by nurses to meet the self-care requisites of patients and consists of three types: a wholly compensatory nursing system, a partly compensatory nursing system, and a supportive-educative nursing system. The wholly compensatory nursing system applies when a patient's self-care agency cannot or should not perform any self-care action. Partly compensatory nursing system is selected when a patient's self-care agency can perform some of the necessary selfcare actions. The supportive-educative nursing system is offered when the patient's self-care agency can and should perform all of self-care actions and nurses provide only support to maintain or to further develop the patients' self-care agency. Nurses can help patients through five methods including acting or doing for, guiding, teaching, supporting, and providing an environment to promote individuals' ability to meet current or future demands, as well as to improve their health and well-being (Orem, 1995).

Self-care Requisites for Breast Cancer Survivors

According to Orem's point of view (1995), breast cancer survivors' health status is a consequence of the effects of treatment and risk of cancer recurrence as mentioned in an earlier section. Concerning health status, breast cancer survivors' universal self-care requisites and health deviation self-care requisites have increased.

Based on self-care deficit theory (Orem, 1995) and literature related to self-care behaviors performed by breast cancer survivors (Boon et al., 2000; Demark-Wahnefried, Peterson, McBride, Lipkus & Clipp, 2000; Morris, Johnson, Homer & Walths, 2000; Rees et al., 2000; Seegers et al., 1998), details regarding universal and health deviation self-care requisites are summarized as follows:

Universal self-care requisites consists of: 1) maintaining the balance between activity and rest, 2) attending to or regulating discomfort, or the deleterious long-term effects of treatment, and 3) seeking medical assistance and keeping scheduled medical appointments. In addition, emotional distress, especially fear of recurrence as well as anxiety, may lead to depressive symptoms. Therefore, breast cancer survivors need to maintain positive mental health, by living their lives to the fullest potential despite the illness, and managing their feelings and stress. Social role problems create a need to maintain a balance between solitude and social interaction, to establish good support networks, and to continue participation in social groups and performance of their social roles.

Health deviation self-care requisites include: 1) seeking and securing appropriate medical assistance which also includes complementary and alternative medicine, 2) being aware of and attending to the effects and results of pathological conditions, 3) effectively carrying out medically prescribed measures with respect to regulating or preventing pathological processes or compensating for disability, 4) being aware of and attending to or regulating discomfort, 5) modifying the self-concept in accepting oneself as being in a particular state of health and in need of a specific form of health care, 6) learning to live with the effects of pathological conditions and the effects of medical diagnostic and treatment measures in a life style

that promotes continued personal development. Considering these self-care requisites, it is clear that breast cancer survivors need to strike a balance between their ability and these increasing demands.

In conclusion, self-care is a purposeful behavior initiated by individuals in order to maintain their health and well being. People need to perform self-care actions to meet their demands. However, self-care deficits may occur as a result of changing health status either by increasing care demands or by decreasing ability to perform self-care activities. People may not be able to achieve their therapeutic self-care demands by their own agency due to their deviated health or limited resources and capabilities. Previous studies indicated that breast cancer survivors post diagnosis one to three years suffered from treatments and disease. This problem influenced their self-care actions as well as increased their universal and health deviation self-care requisites. Therefore, nurses have an important role to assist them to meet their demands by designing effective intervention. The intervention should gear toward helping them to increase their ability. Then, the ability would help them to perform actions to meet their demands, as well as to maintain their health, role function, and quality of life.

Intervention Based on Orem's Self-Care Deficit Theory of Nursing

To achieve quality of life after being diagnosed with breast cancer, the combination of various types of interventions was recommended since breast cancer survivors have to encounter dynamic health problems (King et al., 1997). Therefore, a supportive-educative nursing system, based on Orem's Self-Care Deficit Theory

(1995), was selected as a study framework. The researcher speculated that breast cancer survivors have competence to partly perform their self-care actions in order to meet self-care demands. Thus, they still need help from nurses to fulfill the strength of their self-care agency and their ability to perform self-care behaviors. In the following section, the evidence from studies testing the effects of a supportive-educative nursing system was reviewed, followed by the components and helping methods provided by a supportive-educative nursing system. Finally, the supportive-educative nursing intervention for the present study is presented.

## The Effects of Supportive-Educative Nursing System Studies

During the past two decades, a supportive-educative nursing system has been applied to promote self-care capability, self-care practice, and improve health status in various groups of populations. This review describes 33 studies in developed countries and Thailand from the year 1988 to 2002. All of the studies were conducted either with hospitalized patients or patients that made regular visits to out-patient departments. The majority of the studies (n = 28) are Master(s) theses or Doctoral dissertations and the rest (n = 5) are published studies from peer reviewed journals. Twelve of these studies (eleven Master theses and one published article) are about cancer patients. The target populations were leukemic (Kingnetr, 1995), cervical cancer (Sukkasame, 1990; Teparux, 1992; Wattanakittisak, 1992; Wonghongkul, 1990), breast cancer (Chamnansua, 1999; Chotankran, 1996; Craddock, et., 1999), head and neck cancer (Kaweewong, 1990; Wongsunopparat, 1990), colorectal and

anal cancer (Jirajarus, 1996), and mixed-diagnosis cancer patients (Hanprasitkam, 1992).

Based on twelve studies in cancer patients, the supportive-educative nursing intervention studies focused on quality of life (Kaweewong, 1990; Kingnetr, 1996; Sukkasame, 1990), self-care deficits and symptom distress experiences (Hanprasitkam, 1992; Teparux, 1992), attitudes toward cancer and treatment (Chotanakran, 1996; Jirajarus, 1996), body weight (Chamnansua, 1999), self-care agency (Craddock et al., 1999), cancer vulnerability (Wattanakittisak, 1992), and uncertainty (Wonghongkul, 1990). Findings demonstrated that the mean scores of quality of life in the experimental groups were higher than the control groups (Kaweewong, 1990; Kingnetr, 1996; Sukkasame, 1990). According to the studies of Hanprasitkam (1992) and Teparux (1992), the experimental groups had lower scores of self-care deficits and symptom distress experiences than the control group. For attitudes toward cancer and treatment, the scores increased or seemed to improve after receiving nursing intervention (Chotanakran, 1996; Jirajarus, 1996). In the study of Chamnansua (1999), the findings indicated that body weight gain in the control group was higher than in the experimental group. For self-care agency, the experimental group trended to have a slightly higher score than that of the control group (Craddock et al., 1999). In addition, the experimental group reported a lower score on vulnerability than the control group (Wattanakittisak, 1992). The study of Wonghongkul (1990) showed that the uncertainty score of the experimental group was lower than the control group while the study of Wongsunopparat (1990) found no statistically significant difference in mean score of uncertainty between the two groups.

In conclusion, study findings reveal that supportive-educative nursing intervention has the potential to improve quality of life (Kaweewong, 1990; Kingnetr, 1996; Sukkasame, 1990), decrease self-care deficits (Hanprasitkam, 1992; Teparux, 1992), and improve self-care agency (Craddock et al., 1999) in cancer patients. Moreover, factors influencing self-care agency including attitudes toward disease and treatment (Chotanakran, 1996; Jirajarus, 1996), vulnerability (Wattanakittisak, 1992), and uncertainty (Wonghongkul, 1990; Wongsunopparat, 1990) are indicators showing the effects of supportive-educative nursing intervention. Health status was also evaluated in terms of symptom distress experience related to the side effects of treatment. This was also found to be lower in patients who received supportiveeducative nursing intervention (Hanprasitkam, 1992; Teparux, 1992). Based on research literature, it appears that supportive-educative nursing intervention shows a strong likelihood of being able to improve breast cancer survivors' self-care agency, self-care behaviors, and quality of life. However, there are only a few studies focusing on the effects of supportive-educative nursing intervention on self-care and quality of life among breast cancer survivors and, therefore, this study needs to be conducted.

### Components and Helping Methods of A Supportive-educative Nursing System

In cancer literature, the studies testing the effects of supportive-educative nursing systems were conducted with cancer patients receiving either chemo- or radiotherapy regimens. However, the components and details of supportive-educative nursing intervention in each study were different depending on patients' health status;

including the type of cancer diagnosis and side effects of chemo- or radiotherapy, and the associated self-care demands.

Components of a supportive-educative nursing system. Most of the studies combined individual intervention with group education and discussion in one program (Kaweewong, 1990; Sukkasame, 1996; Teparux, 1992; Wattanakittisak, 1992; Wonghongkul, 1990; Wonsunopparat, 1990). For individual intervention, some studies used face-to-face meeting intervention (Hanprasitkam, 1992; Kingnetr, 1995), and one study provided individual intervention via telephone calls (Craddock et al., 1999). The procedures used in the individual intervention included teaching, guiding, and/or supporting. These procedures were periodically provided to patients starting from diagnosis to the discharge of patients from a hospital. The frequency of intervention in the programs varied from two to three times per week in one program (Kaweewong, 1990; Sukkasame, 1996; Teparux, 1992; Wattanakittisak, 1992; Wonghongkul, 1990; Wonsunopparat, 1990), to three times during an intervention program (Chamnansua, 1999), to one time at the end of the treatment course (Hanprasitkam, 1992; Kingnetr, 1995). The number of appropriate times to intervene with each individual depended upon their health condition after the treatment.

Group education and discussion were also provided in the atmosphere of sharing essential information. During group education, questions and answers related to cancer disease, treatment, and health problems related to treatment side effects were encouraged. In addition, the knowledge of disease, treatment, and self-care practices were supplied to patients by videotapes (Chotanakran, 1996; Jirajarus, 1996); and by slide with audio-taped presentation (Kaweewong, 1990; Sukkasame, 1990; Teparux, 1992; Wattankittsak, 1992; Wonghongkul, 1990; Wongsunopparat,

1990). These studies have shown the positive benefits of applying multi-component intervention on patients' outcomes.

Helping methods of a supportive-educative nursing system. Orem (1995) suggested that nurses could help patients to perform self-care through four methods including guiding, teaching, supporting, and providing a developmental environment to promote an individual's ability to meet current or future demands. It was found that some existing studies adopted the method of action research as well as Orem's conceptual framework to demonstrate additional helping methods.

In Thailand, only two relevant Thai studies have been found in the literature. Both studies applied mutual collaborative action research as a process to develop or to promote self-care agency in a group of both breast cancer patients undergoing active treatment (Chotanakran, 1996) and colorectal cancer patients (Jirajarus, 1996). These two researchers used the same process of data collection but some different helping methods. Findings indicated that attitudes toward cancer and treatment as well as quality of life were significantly improved after intervention (Chotanakran, 1996). The findings from Jirajarus' (1996) showed a trend of improving positive attitudes and quality of life. Interestingly, new core helping methods were developed during the studies and were used in addition to the methods already planned for the study. The new methods were co-operating care and helping, counseling by personal interaction, encouraging or reinforcing, providing resources to assist patients and their families, promoting positive attitudes toward the disease and treatment. However, each researcher also created additional distinct helping methods: encouraging family members to support patients (Jirajarus, 1997) and correcting the myth of disease

(Chotanakran, 1996). Therefore, nurses can use these acquired new helping methods to provide a supportive-educative nursing system to patients.

The Supportive-Educative Nursing Intervention for Breast Cancer Survivors

The current intervention program designed three core interventions, namely group education and discussion, self-help group, and individual intervention to assist breast cancer survivors post diagnosis one to three years and in the remission period. The main concepts and rationales for choosing these three core components are summarized as follows:

Group education. The first core component was one session of group education providing information dissemination in a supportive environment for breast cancer survivors as a group by the researcher, followed by the discussion of related topics. The method of helping was providing informational support for breast cancer survivors according to Orem's (1995) theoretical framework. Group education was designed to provide knowledge related to breast cancer and treatment protocols as well as general self-care behaviors for maintaining life after the completion of active treatments. Group education was provided at the beginning of intervention. The effect of group education might enhance self-care behaviors by reducing intrusive thoughts about disease and encouraging self-esteem (Helgeson, Cohen, Schulz & Yasko, 1999), which were foundational dispositions that influenced self-care ability to perform more positive health practices (Muhlenkamp & Sayles, 1989). In addition, breast cancer survivors may use knowledge related to general self-care behaviors acquired during group education to perform actions to meet their demands (Helgeson

et al., 1999). Moreover, group education aims to give information and to clarify the myths and misunderstandings about disease and treatment which might help in preparing breast cancer survivors before engaging in self-help group processes.

Self-help group. The second core intervention was self-help group, referring to a group that was conducted by the breast cancer survivors themselves. The group leader rotated from one member to another. Four sessions of a self-help group were offered in the present study. A self-help group could improve an individual's ability to perform self-care by providing a developmental environment. Self-help groups are concerned with participants' empowerment and democratic decision-making (Borkman, 1990). The objective of a self-help group was to give the opportunity for breast cancer survivors to support each other and to share their experiences, feelings, and self-care strategies for dealing with their health problems and concerns. In this study, there were four reasons for selecting a self-help group as a component of an intervention to enhance self-care behaviors and quality of life.

First, breast cancer survivors reported that they need to share and exchange experiences as well as needing support from other survivors who have had similar experiences (Cope, 1995). Therefore, the use of self-help group would be a good means to provide a developmental environment and social support. A developmental environment and social support are identified as basic conditioning factors influencing self-care ability and self-care behaviors. Second, self-help groups were proved to be useful, particularly for Thai cancer survivors undergoing treatments. Patients in self-help groups reported significantly higher self-esteem (Pukwilai, 2002), which is one component of self-care agency. In addition, other reported positive effects of self-help groups are increased quality of life, improved self-care ability (Rasmeeloung-on,

1992), and emotional support received from group members (Aimmark, 1994). Third, breast cancer survivors do not have severe psychological problems; therefore, a psychological group intervention conducted by nurses or specialists may not be necessary. Fourth, structured psycho-education support groups, with arranged specific topics in each session, may not serve the needs of breast cancer survivors. Breast cancer survivors who do not experience these psychological problems may not fully participate in the group. In addition, they will not perceive or gain benefit from participating in the self-help group. Last, four sessions were offered in the present study because this is the minimum number of sessions needed in order to effectively develop a therapeutic helping process, including the initiating phase, working phase, and terminal phase (Townsend, 1999). Moreover, there was evidence to support that positive effects were seen in patients who participated in four sessions of self-help group (Kiatgungwalgri, 1997; Pukwilai, 1997)

Individual intervention. Individual intervention was provided by two telephone calls from the nurse researcher after completing self-help group sessions. The purpose of providing individual intervention was to increase self-care behaviors by enhancing the individuals' self-care agency, which is the ability and knowledge to care for oneself. The reason for doing so was because self-care demands varied from one individual to another and from time to time (Orem, 1995). At a local cancer clinic, breast cancer survivors' follow-up schedule will be arranged every three to four months, after they are discharged from a hospital. During the time between each visit, they have to face their own problems at home. Therefore, telephone calls are considered as a valuable technique to offer ongoing intervention to this group. Moreover, breast cancer survivors regain their normal life and return to work; thus,

the telephone is a practical way to communicate with them and provide intervention. The researcher conducted two telephone calls, one call every two weeks. The first call provided information based on a patient's individual health problems or needs. The second call was provided to evaluate a health problem or concern and to encourage them to perform self-care actions as well as to help them when new problems and needs arise. The duration of individual intervention was one month, which was indicated as the minimal duration that a person could adjust or change their self-care actions in order to meet their health demands (Nantachaipan, 1996; Tantayotai, 1997).

For individual intervention, the researcher developed a therapeutic relationship between nurse and breast cancer survivors in order to establish trust, and to create a safe and comfortable atmosphere of partnership interaction. Helping methods included guiding, supporting, providing information, encouraging or reinforcing self-care behaviors, motivating to perform and adjust self-care associated with their problems and needs, providing a supportive environment, teaching, individual counseling, offering referral to appropriate resources, promoting positive attitudes toward their disease and treatment, and providing modern and traditional approaches to information. More than one helping methods can be provided in correspondence to each health problem or needs. The criteria for providing each helping method during individual telephone calls are summarized below:

Guiding was used to help breast cancer survivors to be able to suitably make decisions in situations in which they had to make a choice, seek a self-care action, and adjust self-care associated with their problems and needs or to prevent cancer recurrence. Guiding was employed without direction or supervision. It occurred when the researcher provided more information whenever breast cancer survivors asked for

information about how to relieve or to deal with their health problems. The guiding method was frequently used in conjunction with the supporting method.

Supporting was designed to help breast cancer survivors to be able to perform self-care activities continually, even in the stressful situations such as when there was evidence of possible cancer recurrence. Supporting also aimed to help breast cancer survivors to learn how to deal with their deviated health. Supporting could be provided as both informational and emotional support. Informational support included providing booklets, documents, and audio-tapes with information on how to manage their health problems and concerns, and providing traditional approaches to information, whereas emotional support included encouragement, reinforcement, and increased motivation.

The providing supportive environment technique was used during self-help group and individual telephone intervention. Providing supportive environment means the researcher provided environmental conditions that help to motivate breast cancer survivors to develop an ability to take care of themselves. Breast cancer survivors were provided an opportunity to interact and communicate with other breast cancer survivors in a self-help group. On the other hand, breast cancer survivors also received providing supportive environment during telephone intervention so they could talk about their personal health problems or concerns.

Teaching was employed to help breast cancer survivors who needed instruction to develop knowledge or particular skills, such as an affected arm exercise and pursed-lip breathing, which helped them to perform self-care action correctly.

Counseling was employed by providing an opportunity to release feelings and talk about their health problems and concerns. The researcher took time to listen

to their frustrations and suffering. Then, researcher and breast cancer survivors worked together to find appropriate strategies to solve the problems.

Offering referral to appropriate resources was provided by the researcher when breast cancer survivors came up with problems related to cancer, such as the suspected evidence of cancer recurrence. The researcher worked in a joint effort with physicians or other health care providers according to breast cancer survivors' problems.

Promoting positive attitudes toward their disease and treatments was employed in order to decrease their negative impressions related to breast cancer. The researcher promoted positive attitudes by providing accurate information related to breast cancer, bringing them to look at the positive side of their situation. In addition, the researcher assured them that other breast cancer survivors also encountered similar problems.

In conclusion, the supportive-educative nursing intervention developed by the researcher included one session of group education, four sessions of a self-help group, and individual intervention by two telephone calls. The duration of the whole intervention program was one month. The goal of the intervention was to improve breast cancer survivors' ability to perform self-care tasks, helping them improve their health status and quality of life as an ultimate outcome.

Summary

In summary, breast cancer is recognized as a major health problem for women all over the world. As a result of advanced treatments, rehabilitation and

supportive programs, and early detection programs, the number of breast cancer survivors has been increased. Nevertheless, survivors have faced the long-term effects of treatments and risk of cancer recurrence that affect their quality of life. To improve quality of life, their self-care agencies need to be enhanced in order for them to perform self-care behaviors, leading to an improvement in their quality of life. Based on the research literature, it appears that a supportive-educative nursing system (Orem, 1995) is appropriate for improving breast cancer survivors' self-care agency, self-care behaviors, and quality of life. However, a specific intervention program for breast cancer survivors in Thailand has not presently developed. Thus, the researcher developed a new intervention program, a supportive-educative nursing intervention consisted of a combination of group education, self-help group, and individual intervention. This study aimed to explore the practicality and to test the effects of the new nursing intervention on self-care and quality of life among Thai breast cancer survivors.

#### Conceptual Framework

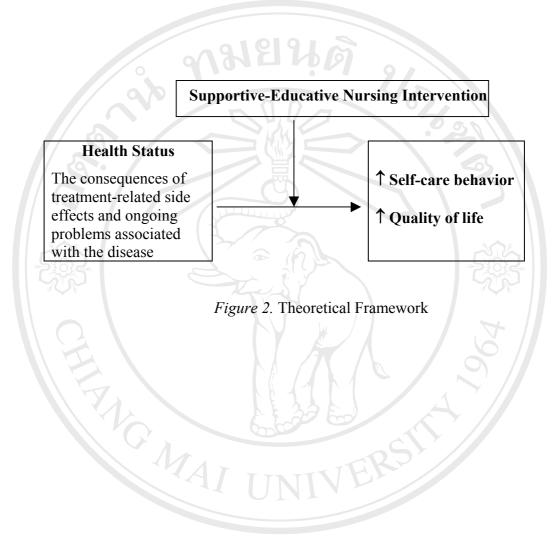
Orem's Self-Care Deficit Theory of Nursing (1995) provides a relevant framework for understanding the experience of breast cancer survivors one to three years post diagnosis. The theoretical framework for this study is summarized below:

According to Orem (1995), breast cancer survivors who are one to three years post-diagnosis and disease-free were conceptualized as the self-care agents who have the ability, called self-care agency, to perform self-care actions to meet their demands. When their health status was changed as a result of treatment side-effects

and ongoing problems associated with the disease, their self-care agency was affected. Two elements of self-care agency; foundational capabilities and disposition as well as the ten power components, are primary concerns. Limitations of essential capabilities and power lead to inadequate self-care agency for engaging in or deliberately performing self-care actions. In addition, change in health status creates new self-care requirements to be performed in order to decrease or minimize health problems, and improve quality of life. Breast cancer survivors need to strike a balance between their ability and these increasing universal and health deviation self-care demands. However, self-care deficit can occur when a breast cancer survivor's self-care agency is limited by changes in their health status and an increase in demands. When self-care deficit is detected, nurses have an important role in strengthening a breast cancer survivor's ability to perform self-care actions to meet their self-care demands by providing a supportive-educative nursing system.

In this study, the intervention called a supportive-educative nursing intervention was developed based on a supportive-educative nursing system concept and literature related to interventions among breast cancer survivors. This intervention program included one session of group education, four sessions of self-help group, and individual intervention by two telephone calls. Helping methods covered guiding, supporting in both informational and emotional supports, providing supportive or developmental environment, teaching, counseling, offering referral to appropriate resources, and promoting positive attitudes toward their disease and treatment. It is anticipated that the supportive-educative nursing intervention will increase breast cancer survivors' capability to perform self-care actions to meet self-care requisites or

demands and improve breast cancer survivors' quality of life. The theoretical framework for this study is shown in Figure 2.



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