CHAPTER 1

INTRODUCTION

Background and Significance of Research Problem

Breast cancer is a significant health problem among women worldwide. It is the most common cancer diagnosed among women in either developed countries, such as Canada (National Cancer Institute of Canada, 2003), and the United States (Jemal et al., 2004), or developing countries, such as Cuba (Garrote et al., 1998) and Thailand (National Cancer Institute Thailand, 2000). Recently, the incidence of breast cancer has increased remarkably. Beast cancer continues to be the second leading cause of cancer death in Canada (National Cancer Instituted of Canada, 2003) and the U.S. (Jemal et al., 2004), while it is the third leading cause of cancer death among Thai women (Health Information Division, Bureau of Health Policy and Planning, 2000). In order to reduce this significant health problem, some strategies, such as early detection programs, cancer prevention programs, and cancer treatment modalities have been implemented (Rowland, Aziz, Tesauro & Feuer, 2001).

As a result, breast cancer morbidity and mortality has reduced at some levels. Meanwhile, the number of breast cancer survivors has increased (Rowland et al., 2001). Surviving breast cancer, women do not always report their experience as positive. Previous studies have shown that these women have to live with the adverse consequences of treatment-related side effects, as well as the ongoing problems associated with the risk of cancer recurrence (Maguire et al., 1978; Morris, Greer & White, 1977). Therefore, it leaves the challenge for health care providers to develop strategies to enhance breast cancer survivors' state of health and well-being.

Cancer survivorship is a dynamic and ongoing life-long process (Pelusi, 1997). The determination of stage of breast cancer survivorship is based on the length of survival duration as well as women's life experiences of living with breast cancer (National Coalition for Cancer Survivorship, 2002; The Office of Cancer Survivorship, National Cancer Institute, 2002). Cancer survivors at different stages of survivorship might have different experiences and health problems. Particularly, the early period of survival, from one to three years post diagnosis, is considered as a transition or critical period. During this time, survivors have to deal with the greatest hardships, especially from the ongoing side effects of treatment and the risk of cancer recurrence (Carpenter et al., 1998; Gregory, 1999; Mast, 1998; Maguire et al., 1978; Northouse, 1981). Therefore, survivors have to learn to reorganize their lives and to adjust themselves to live with deviated health status (Gregory, 1999; Irvine, Brown, Crooks, Roberts & Browne, 1991; Knobf, 1986). The reorganization might result in frustrations and women's internal psychological conflict if they were incapable of adjusting themselves to meet social expectations of their previous social roles.

Breast cancer survivors tend to encounter problems in several different areas including physiological, psychological, and social domains. Physiological problems include fatigue (Bower et al., 2000; Mast, 1998; Okuyama et al., 2000), menopausal symptoms (Carpenter et al., 1998; Couzi, Helzlsoure & Fetting, 1995; Shimozuma, Ganz, Petersen & Hirji, 1999), sleep disturbance (Northouse et al., 1999), weight gain (Gregory, 1999), impaired cognitive function (Brezden, Philips, Abdolell, Bunston &

Tannock, 2000), lymphedema (Petrek & Heelan, 1998), and a second cancer (Mahon, Willan & Spies, 2000). Psychological problems include fear of recurrence (Northouse, 1989), depression and anxiety (Goldberg et al., 1992; Knobf, 1986; Maguire et al., 1978), and uncertainty as a result of fear of cancer recurrence (Mast, 1998; Northouse, 1981).

In terms of social problems, breast cancer survivors experience sexual dysfunction and reduced marital satisfaction (Barni & Mondin, 1997; Thor, Broeckel & Jacobson, 2001), family distress, and concerns for female relatives (Ferrell, Grant, Funk, Otis-Green & Garcia, 1997). They also experience work-related problems, such as job loss, problems with employers and co-workers, disclosure, discrimination, and insurance benefits (Gregory, 1999; Maunsell, Brisson, Dubois, Lauzier & Fraser, 1999; Polinsky, 1994; Stewart et al., 2001). The literature has shown that these physiological, psychological, and social problems have negative impact on quality of life of breast cancer survivors (Carpenter, et al., 1998; Ferrell, Grant, Funk, Otis-Green & Garcia, 1997; King, Kenny, Shiell, Hall & Boyages, 2000; Sammarco, 2001; Shapiro & Recht, 2001).

According to Soivong (unpublished), results of a pilot study in 107 breast cancer survivors in Northern Thailand supported findings from previous studies in other countries. This study was conducted during February to June 2003. Women in the study were one to three years post diagnosis and cancer-free. The findings demonstrated that women experienced physiological problems including fatigue, menopausal symptoms, sleep disturbance, weight gain, as well as psychological problems including fear of recurrence, anxiety and depression. They also reported social problems including concerns for female relatives about breast cancer risk, family distress, interference in employment, and financial burden. Further analysis also indicated that these problems were negatively associated to their perceived well-being. Based on the literature review and results of the pilot study, breast cancer survivors encounter physio-psycho-social problems affecting their quality of life. Therefore, there is a need to develop an intervention to enhance quality of life of this population.

Quality of life, used synonymously with well-being, is a personal sense of well-being encompassing the physical, psychological, social, and spiritual dimensions (Ferrell, Dow & Grant 1995; Ferrell et al., 1997). Quality of life has provided a gold standard for outcome assessment in many clinical trials during the past two decades (King et al., 1997). Studies on quality of life of breast cancer survivors have been well-documented. The studies mostly focus on four main perspectives including: 1) developing quality of life models, 2) establishing quality of life measurements, 3) identifying factors related to quality of life, and 4) developing interventions. The current knowledge of each issue of quality of life was described below.

First, at least two conceptual models of quality of life have been developed and they could be used to describe quality of life of breast cancer survivors at a certain level (Ferran & Power, 1994; Ferrell et al., 1997). Second, instruments for measuring quality of life had been developed and used to measure quality of life in several dimensions under different conceptual frameworks (Aaronson et al., 1993; Cella & Yellen, 1993; Ferran & Power, 1994; Ferrell et al., 1997; Ferrell et al., 1995; Padilla & Grant, 1985; Schag, Ganz & Heinrich, 1991; Wyatt & Friedman, 1996). Third, factors associated with quality of life of breast cancer survivors were documented. These factors were fatigue (Bower et al., 2000), menopausal symptoms

(Carpenter & Androkowski, 1999), types of treatment (Nissen et al., 2001), and mood (Weitzner, Meyers, Stueging & Saleeba, 1997). However, only a few interventions have proven to reduce these problems effectively.

Last, some interventions developed to improve quality of life put the emphasis on only one dimension of quality of life, such as physical (Capenter et al., 2002; Ganz et al., 2000; Jacobson et al., 2001) or psychological dimension (Golan, Alfman & Martin, 2003; Montazeri et al., 2001; Simson, Carlson & Trew, 2001). Therefore, the outcomes of these studies were unable to reflect all the dimension of quality of life. In addition, many of these studies suffered from some methodological weaknesses, such as small sample size (Golant, Alfman & Martin, 2003; Rutledge & Rymon, 2001; Segar et al., 1998), or no comparison group (Montazeri et al., 2001; Rutledge & Rymon, 2001). Therefore, the generalizability of study results was compromised.

In fact, only a few intervention studies have been conducted to improve the overall quality of life (GIVIO Investigator, 1994; Simpson et al., 2001; Rutledge & Rymon, 2001). Still, they had some limitations, such as results showing no significant effect found (GIVIO Investigator, 1994), small sample size and no comparison group (Rutledge & Rymon, 2001). From the drawbacks found in previous intervention studies, it becomes apparent that an effective nursing intervention to improve all dimensions of quality of life of breast cancer survivors is needed to be developed. Also, it is imperative to conduct a study with experimental design in order to prevent some methodological problems found in the previous studies.

To develop an effective nursing intervention for improving quality of life of breast cancer survivors, an integrated strategy is recommended. According to King et al. (1997), several strategies are required in order to enhance the "whole" quality of life of cancer survivors. These strategies consist of: 1) continuing a process starting from assessment to evaluation based on the quality of life dimensions, 2) providing help to patients and families for dealing with problems affecting their quality of life, and 3) providing a variety of helping methods, such as education and support groups.

In this study, a supportive-educative nursing intervention was developed based on elements of suggestion by King et al. (1997) and Orem's Self-care Deficit Nursing Theory (Orem, 1995). Moreover, literature also indicated that the supportive-educative nursing intervention had the potential to improve quality of life (Kaweewong, 1990; Kingnetr, 1996; Sukkasame, 1990), decrease self-care deficit (Hanprasitkam, 1992; Teparux, 1992), and improve self-care agency (Craddock, Adams, Usui & Mitchell, 1999) in cancer patients. In the present study, the designed intervention was comprised of three components which were one session of group education, four sessions of a self-help group, and individual intervention by two telephone calls. The objective of this intervention was to help breast cancer survivors to improve their self-care agency so they were able to perform self-care actions to meet their demands and improve their quality of life.

In Thailand, it is also important to develop and conduct an effective nursing intervention for breast cancer survivors who are in the early period of survivorship (one to three years post diagnosis) for many reasons. First, a special intervention program to improve quality of life of breast cancer survivors following treatment has not been presently developed. During the first three years, breast cancer survivors receive only clinical routine check-ups including a clinical breast examination by a physician every three to four months, a chest x-ray and a liver echography every six months, as well as an annual mammogram and bone scan. However, this intensive follow-up program failed either to improve survival rate or to influence health-related quality of life (GIVIIO Investigators, 1994). Second, the longer the survival period, the less frequent the follow-up visit. Therefore, breast cancer survivors have limited opportunity to consult with health care providers when they have problems and need help. Third, one of the main purposes of The Ninth National Economic and Social Development Plan of Thailand during 2002 to 2006 is to improve the quality of life of Thai people (Office of The National Economic and Social Development Board, 2002). Finally, the new intervention design was developed based on Western perspectives and related literature. The effectiveness of the intervention and its applicability in Eastern societies should be studied. Therefore, the practicality of this intervention for Thai breast cancer survivors was examined in the present study.

In summary, the development of an effective nursing intervention program for Thai breast cancer survivors is in great need. An effective intervention helps to strengthen breast cancer survivors' ability to manage the problems associated with cancer survivorship and improve their quality of life. It is expected that information obtained from this study will be useful for health professionals in order to develop a standard of care for breast cancer survivors in the future.

Objective of the Study

Aim of the present study was to examine the effects of a supportive-educative nursing intervention on the self-care and quality of life among Thai breast cancer survivors who are one to three years post diagnosis. In addition, this study was aimed at assessing the practicality and feasbility of intervention protocols.

Hypothesis

In order to test the effects of a supportive-educative nursing intervention on self-care and quality of life, the following hypothesis were generated:

Hypothesis I: The score of self-care in breast cancer survivors receiving the supportive-educative nursing intervention is significantly higher than those receiving routine care both immediately upon the completion of the intervention and at four weeks post intervention.

Hypothesis II: The score of quality of life in breast cancer survivors receiving the supportive-educative nursing intervention is significantly higher than those receiving routine care both immediately upon the completion of the intervention and at four weeks post intervention.

Scope of the Study

This present study explored the effects of a supportive-educative nursing intervention on self-care and quality of life among breast cancer survivors.

Participants were one to three years post diagnosis and were residing in the Northern part of Thailand. The period of data collection was from July 2003 to February 2004.

Definition of Terms

Terms used in this study are defined below:

Supportive-educative nursing intervention is defined as a process of helping and caring that the nurse provided to breast cancer survivors who are one to three years post diagnosis. The intervention was developed based on self-care deficit theory and literature review. It focuses on improving breast cancer survivors' ability to meet self-care requisite associated with treatment side-effects and ongoing health problems affecting their quality of life. The components of the supportive-educative nursing intervention were one session of group education, four sessions of a self-help group, and individual intervention by two telephone calls.

Group education refers to the information disseminated in a supportive environment for breast cancer survivors as a group. Knowledge related to breast cancer and treatment protocols as well as the general self-care behaviors to maintain life after completing the active treatments were provided. Misunderstandings about disease and treatments were clarified. The group education also allows discussion about related topics.

A self-help group refers to a group conducted by a breast cancer survivor who acted as a group leader. The group leader was chosen by group members and often rotated from one member to another. The leader of the session also was taught and guided by the research assistant who had expertise in conducting a self-help group and support group. Groups of six to ten breast cancer survivors met for 1-1/2 hours weekly for four weeks. The objectives of the self-help group were 1) to provide a supportive environment and social support for breast cancer survivors, and 2) to provide opportunity for breast cancer survivors to share and to exchange their self-care experiences as well as to support each other.

Individual intervention is the action of providing two telephone calls by the researcher every other week. The first call provided information/counseling based on the breast cancer survivors' significant health problems or needs. The second call was provided to evaluate and encourage them to perform self-care actions as well as to assist them with new problems and needs. Individual intervention began with the researcher who developed a therapeutic relationship between nurse and breast cancer survivor in order to obtain trust, and to create a safe and comfortable atmosphere of partnership. Helping methods included 1) guiding, 2) supporting both informationally and emotionally, 3) providing supportive or developmental environment consisting of motivation and the opportunity to talk about their personal health problems or concerns, 4) teaching, 5) counseling, 6) offering referral to appropriate resources, and 7) promoting positive attitudes towards their disease and treatments. A combination of helping methods could be provided for each health problem or need. Additionally, breast cancer survivors facing similar problems may receive different helping methods depending on their self-care ability and demands related to their health problems or needs.

Self-care is defined as purposeful actions performed by breast cancer survivors one to three years post diagnosis that alleviate conditions resulting from problems related to effects of treatments as well as ongoing problems associated with breast cancer. Self-care is measured by the Self-Care Behavior Log (SCB Log) developed by Dodd (1988). It is operationally defined as the sum of the self-care practice of all health problems and needs divided by the total number of experienced health problems and needs (personal communication, March, 2004). The formula is as follows:

$$\frac{\text{The sum of self-care practice of all health problems and concerns}}{\text{The total number of experienced health problems and concerns}}$$

Quality of life is defined as a state of the breast cancer survivor characterized by sense of well-being encompassing physical, psychological, social, and spiritual well-being. Quality of life is measured by the Quality of Life Breast Cancer Questionnaire developed by Ferrell et al., (1995). The questionnaire has been translated into Thai and has been used to measure the quality of life among Thai breast cancer survivors (Wonghongkul, Deachaprom, Phumvichuvate & Koedsang, 2003).

Routine care is a health care service that is usually provided by physicians and nurses in an out-patient department. This care is composed of four components. First, the health problem assessment interview and breast examination were performed by a physician. Second, advices related to individuals' health problems and concerns were provided by a physician. Third, Tamoxifen was prescribed for breast cancer survivors who had received anti-estrogen during the five years of active treatment protocol. Last, an appointment for the next follow-up visit was scheduled and encouragement was given for breast cancer survivors to continue follow-up. The follow up visit occurred every three or four months.