

**Survivors of Breast Cancer:
Exploring Post-Treatment Physical and Psychosocial
Side/Late Effects and their Interventions**

Phase 1 - Surveying the Literature

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Surveying the Literature

Introduction

In Ontario, in 2008, an estimated 8,500 women will be diagnosed with breast cancer and approximately 2,000 women will die of this disease (Canadian Cancer Society, 2008). Because of medical advances in treatment, earlier detection and ongoing rehabilitation, women are surviving breast cancer at unparalleled rates (Grunfeld, 2006). In 2001, 78,528 survivors of breast cancer were living in Ontario (Hrabar, 2002). The relative survival of women with breast cancer is 86% at five years post-diagnosis (Mols et al., 2005). Breast cancer survivors account for approximately 41% of all cancer survivors (Ganz et al., 2002).

While great strides have been made in prolonging the lives of breast cancer survivors, there has been less emphasis on designing clinical services to meet the needs of women with breast cancer following active cancer treatment and as part of follow-up care (Grunfeld, 2006).

At the conclusion of treatment, many individuals are burdened with the side and late effects of cancer treatment (Ganz, 2005b). Though cancer survivorship has been thought of as that period of time beginning from diagnosis and ending at death, “it is perhaps timely for us to think more specifically about a focused period of time in the cancer trajectory at which patients treated with curative intent have completed their initial cancer therapy and are now post-treatment and in follow-up” (Ganz, 2005b, p. 5458; Zebrack & Zeltzer, 2003).

This survey of the literature was conducted to collect together the post-treatment physical and psychosocial side and late effects/issues of breast cancer survivors, as well as interventions in order to identify the key health care issues facing breast cancer survivors post-active treatment and finally proposed models of care that integrate survivorship concerns.

Parameters of Literature Review

A review of the academic and grey survivorship literature was undertaken between July 2007 and June 2008. Given the limited number of Canadian resources about survivorship, international sources, particularly American and European sources, were examined. One hundred and sixty articles were collected for review and all articles were published between 1998 and 2008.

Articles were retrieved from the following search engines and indexing tools: Medline, Pubmed, PsychInfo, Applied Social Sciences Indexes and Abstracts, Proquest Research Library, E-journals@Scholars Portal, Web of Science, and Toxline. Keywords used in the search included: ‘neoplasm’, ‘post-treatment’, ‘follow-up’, ‘breast cancer’, ‘survivor’,

‘survivorship’. Inclusion criteria included articles written about the physical and psychosocial experiences of women with breast cancer in the post-treatment phase. The search was limited to women with breast cancer unless the article in question focused on survivorship in general or, within that article, one main group of survivors included women with breast cancer.

The articles collected are categorized into three thematic areas: 1) Post Treatment Physical and Psychosocial Side and Late Effects and 2) Interventions to Manage Physical and Psychosocial Side and Late Effects 3) Survivorship Care: Issues and Models. Each area is summarized below.

1. Post-Treatment Physical and Psychosocial Side and Late Effects

- There are numerous discrepancies in the literature surrounding quality of life (QOL) of breast cancer survivors as compared to the general population (van de Wiel et al., 2008). Some studies have found that most breast cancer survivors experience good quality of life especially if they do not require chemotherapy as part of their treatment (also Ganz et al., 2002; Kim et al., 2008b), do not experience co-morbidities (Hewitt et al., 2003), are high income and/or have social support. However, Mehnert and Koch (2008) found low QOL even years after diagnosis. Other studies found that only certain groups of patients or certain domains of QOL were affected, for example that only young patients experienced lower QOL (DiSipio et al., 2008), or that only the domains of general sense of health and vitality were lower than average (Helgesson et al., 2007).
- Cancer survivors without other chronic diseases are more likely to report being in fair or poor health as compared to cancer-free individuals who are also without other chronic diseases (Hewitt et al., 2003).
- Unfortunately, specific physical and psychosocial problems arise for breast cancer survivors following active treatment such as arm swelling, pain and sexual dysfunction (Greendale et al., 2001), lower physical functioning (Ganz et al., 2002 though not always clinically significant) and a higher prevalence of mild to moderate depression as compared to matched controls (Ganz et al., 2002; Mols et al., 2005).
- Additional side effects include: premature menopause, infertility, vasomotor symptoms, vaginal dryness, dyspareunia, weight gain, and osteoporosis, anxiety, negative body image, social difficulties, cognitive impairment, family dysfunction, fatigue, pain, lymphedema, arm difficulties, insurance and work problems (Ganz, 2005a; Hodgkinson et al., 2007).
- Some of these side and late effects occur only in the short term. Schroevers et al. (2006) found that, at eight years post-diagnosis compared to matched controls, breast cancer survivors did not differ significantly in the areas of depression, anxiety, self-esteem, life satisfaction, social support and marital satisfaction. However, these long-term survivors had more physical symptoms (such as dizziness, decreased sexual interest, lack of energy) and concomitant decreased functioning in household and social activities as well as persistent fear of recurrence (higher existential anxiety was also found in a study by Hodgkinson et al., 2007).

- Demark-Wahnefried et al. (2006) point out that survivors in general are at risk for developing other cancers, cardiovascular disease, osteoporosis, diabetes, and functional decline.

A fuller rendering of survivors' side effects and late effects or longstanding issues are provided next and can be collapsed into two main categories: physical and psychosocial. The sub categories of each of the main categories are discussed in order of severity or frequency of incidence.

Physical Side and Late Effects

The physical side and late effects explored in the survivorship literature include fatigue, insomnia, lymphedema, bone density issues, reproductive and sexual health issues, pain, obesity and cardiovascular risk, and the development of other cancers.

Fatigue

- Fatigue has been described as a common side effect among cancer patients. About 60-96% of patients in treatment experience fatigue and in one study, at 16 months post-treatment, breast cancer survivors experienced 50% higher levels of fatigue than matched controls (Cappiello et al., 2007). Similarly, a study by Jacobsen et al. (2007) found that relative to an age and geographically matched sample of women, women with breast cancer reported more days of fatigue when surveyed at the end of treatment as well as at 2, 4, and 6 months later.
- A review of behavioral symptoms in breast cancer survivors found that fatigue typically improves in the year following treatment (Bower, 2008), however, a review by Minton and Stone (2007) suggests that post-treatment fatigue can continue up until five years after treatment.
- One study revealed that 24% of breast cancer survivors surveyed had persistent, severe fatigue complaints over two years post-treatment, and that the presence of fatigue seemed to be relative to the duration of treatment, not the type (Servaes et al., 2007).
- Findings of one large study discovered that fatigue was the most profound negative effect of any symptom on the QOL of breast cancer survivors (Janz et al., 2007).
- In another study, the fatigue differences (between breast cancer survivors and age-matched women in the population) were not found at 2.8 - 3 years post diagnosis. The mechanisms underlying the development and maintenance of fatigue are poorly understood (Wagner & Cella, 2004), however, risk factors for fatigue could include younger age (under 50), pain, gastrointestinal disease, employment (Kim et al., 2008a) and predictors of fatigue could include high anxiety, high impairment in role functioning, and low sense of control over fatigue symptoms (Servaes et al., 2007).
- A study of Danish breast cancer survivors found that fatigue and psychological distress in newly diagnosed breast cancer patients negatively predicted overall survival and a lack of recurrence at a mean follow up time of 12.9 years (Groenvold et al., 2007).

Insomnia

- A study of 2645 post-treatment breast cancer survivors in the U.S. found that 39% had elevated scores on the Women's Health Initiative – Insomnia rating scale (Bardwell et al., 2008).
- As vasomotor symptoms are associated with sleep complaints, one source of sleep difficulty could be menopausal symptoms (Bower, 2008)
- A study by Cappiello et al. (2007) found that sleep difficulties were most often related to psychological concerns, namely fear of cancer recurrence, while Bardwell et al. (2008) found that depressive symptoms were the strongest risk factors for insomnia.

Lymphedema

- Lymphedema (LE) refers to the persistent swelling and abnormal levels of protein-rich fluid in the arm.
- Twenty-five per cent of women with breast cancer are likely to contract LE within 11 years of diagnosis so it features as a common physical ailment affecting daily life activities and quality of life.
- Three symptoms of LE are most common and include: larger arm size, firmness/tightness, and numbness.
- It is not known whether some arm symptoms are due to the experience of breast cancer surgery and not LE (Armer et al., 2004).
- In one study LE was found in 43.3% of women who underwent axillary lymph node dissection, in 22.2% of women who underwent sentinel lymph node biopsy, in 25% of those who underwent both treatments, and in 22.2% of those who underwent neither (Armer et al., 2004).
- In another study, authors found the incidence of lymphedema (LE) at 33.5% or 13.4% in those treated by surgery alone and 42.4% of those women who had received surgery and radiation (Deo et al., 2004). The incidence of this side effect varies because of the variety of techniques used to measure its incidence (Armer, 2005).

Bone Density

- 60-70% of breast cancers are hormone receptor positive leaving them sensitive to estrogen depletion (and subsequently at risk for increased bone loss) and some breast cancer treatments can reduce bone BMD making bone loss an issue for breast cancer survivors (Mackey & Joy, 2005).
- Chemotherapy and hormone therapy can increase bone loss, osteoporosis and the risk of fractures in breast cancer survivors (Mackey & Joy, 2005; Ramaswamy & Shapiro, 2003).
- If premenopausal women undergo chemotherapy and have ovarian failure, then they might also experience bone loss at a rate of 5% per year (Bundred, 2007; Galow, 2007; Limburg, 2007; Ramaswamy & Shapiro, 2003) – especially if they are prescribed Tamoxifen (Galow, 2007).
- Due to lower use of hormone therapy, women post-menopausal breast cancer survivors (n=209) who were at least six years post-diagnosis had lower bone

- mineral density (BMD) than did those in a noncancer reference group (n=5,759) putting survivors at increased risk for osteoporosis (Chen et al., 2005).
- Osteopenia is also present in about 30% of early breast cancer survivors (Bundred, 2007).
 - The possibility of developing fractures is increased for women with osteopenia if they are also taking aromatase-inhibitors or if their rate of reabsorption is high (Bundred, 2007).
 - Higher BMD due to higher circulating levels of estradiol has also been reported in premenopausal breast cancer survivors and in postmenopausal breast cancer survivors (without adjuvant therapy) compared to referents (Crandall et al., 2004).

Reproductive/Sexual Health

- Though menopause is a natural part of the reproductive cycle, chemotherapy can trigger the onset of unanticipated premature menopause and infertility in young women with breast cancer (Duffy et al., 2005; Ganz, 2005a; Schultz et al., 2005).
- Other side effects associated with a lack of estrogen include hot flashes, osteoporosis and sexual dysfunction (Broeckal, et al., 2002; Duffy et al., 2005; Thors et al., 2001).
- Speer et al. (2005) noted that compared to normal controls, breast cancer survivors were more concerned about their sexual relationships and had significantly poorer sexual functioning in the following areas: desire, arousal, lubrication, orgasm, satisfaction and pain.
- In survey research conducted with over 1,300 five-to-ten year breast cancer survivors, vaginal dryness increased, sexual activity decreased and urinary incontinence increased over the five year post-diagnosis period of time (Ganz et al., 2002).
- Older women had more concerns about vaginal lubrication and pain (Speer et al., 2005).
- A study by Wimberly et al. (2008) found that among post-treatment breast cancer survivors, increased optimism was associated with greater psychosexual wellbeing (feeling more feminine, attractive, and sexually desirable), partly because those who are more optimistic have more social support.

Pain

- Post-mastectomy pain is evident in up to 27% of patients and post-operative frozen shoulder can occur following mastectomy (Lyne et al., 2002).
- For survivors in general, pain management is an issue because it can signal the onset of a new cancer or an indication of recurrence (Lyne et al., 2002).
- Post-treatment pain can be the result of post-surgical or neural injury. After cytotoxic therapies, peripheral neuropathy can occur and osteoporosis can arise after long term corticosteroid use (Lyne et al., 2002).
- One third of breast cancer survivors surveyed reported having decreased shoulder mobility. Decreased mobility was most pronounced in breast cancer survivors who had been given a mastectomy (Lauridsen et al., 2008).

Obesity and Cardiovascular Risk

- Seventy percent of breast and prostate cancer survivors are overweight or obese (Demark-Wahnefried et al., 2005).
- Weight gain after treatment in breast cancer survivors can place these women at risk for recurrence, cardiovascular disease and diabetes (Herman et al., 2005). One study has found that those who were obese after treatment were more likely to be obese before treatment, were more likely to be unhappy about their body image and less likely to be currently engaged in physical activity (Herman et al., 2005). Obesity was not related to adjuvant treatment and these women were not at increased risk for cardiovascular disease. Treatment can trigger the onset of menopause in pre-menopausal women which can lead to weight gain (Herman et al., 2005).
- Weight change was found to cause distress and health concerns in a study of African American breast cancer survivors. The clients reported feeling frustrated at a perceived lack of control over the weight change (Halbert et al., 2008).

Multiple cancers

- Nearly 8% of cancer survivors in the United States have been affected by cancer more than once. Of those with multiple cancers, 25% were women whose first cancer was primary breast cancer (Mariotto et al., 2007).

Vulnerable Population Side and Late Effects

- An aging population and the increased likelihood of living longer after cancer contribute to the fact that elderly concerns are now more of an issue (Rowland & Yancik, 2006).
- Elderly long-term survivors more likely to mention physical limitations (those who were years post diagnosis have 30-50% increased odds of reporting inability to do activities requiring mobility and strength) (Sweeney et al., 2006).
- Elderly women are particularly in need of interventions in order to increase their participation in household and social activities (Sweeney et al., 2006).
- Older adult survivors of breast cancer are also at an increased risk of developing hypothyroidism (Smith et al., 2008).
- In a qualitative study without matched controls, African-American women and Latina women reported an increase in post-treatment symptoms following breast cancer surgery. These symptoms were more likely associated with decreased income, receiving chemotherapy, having a mastectomy and for the Latina women, being Latina (Eversley et al., 2005).

Table 1 - Complications and Side Effects of Cancer Treatment

- Bone and joint pain
- Cardiopulmonary syndromes
- Cognitive disorders and delirium
- Emotional concerns
- End of life issues
- Endocrine impairment
- Fatigue
- Fever, sweats, and hot flashes
- Gastrointestinal complications
- Hypercalcemia
- Learning disabilities and memory problems
- Lymphedema
- Nausea and vomiting
- Numbness and tingling
- Nutritional concerns
- Oral complications
- Pain
- Pruritis
- Radiation enteritis
- Secondary cancers
- Sexuality, intimacy, and reproductive issues
- Sleep disorders
- Superior Vena Cava syndrome

Reproduced from Jenkins, 2006

Psychosocial Issues

Quality of life and supportive care issues are central concerns in the survivorship phase (Canadian Breast Cancer Foundation, Ontario Chapter, 2006).

Hodgkinson et al. (2007) have found rates of psychosocial distress in 20-40% of breast cancer survivors in first 1-2 years following diagnosis. Distress is associated with age, relationship status, psychiatric history, coping style, social support, self-esteem, menopausal status, education level, SES, partner's distress and disease and treatment characteristics (Hodgkinson et al., 2007).

The psychosocial side and late effects/issues most often reported in the survivorship literature include anxiety/depression, cognitive dysfunction, information/communication needs, relationship concerns and work/employment concerns.

Anxiety/Depression

- Many women experience anxiety and depression and the fear of recurrence once adjuvant treatment has ceased (Gray et al., 1998; McKenzie & Crouch, 2004).

Indeed, fear of recurrence can continue to be moderately stressful years after the initial diagnosis (Lebel et al., 2007). For example, a study by Mehnert and Koch (2008) found that on an average of 47 months after diagnosis, anxiety levels were moderate to high in 38% of breast cancer survivors.

- Women with benign tumours can experience high levels of anxiety and depression and support/services for this group are lacking (Deane & Degner, 1998)
- Those who are clinically anxious report three times the number of unmet needs on the Hospital Anxiety and Depression Scale as a community sample and those who were depressed report 2.5 times as many unmet needs (Hodgkinson et al., 2007). This was particularly the situation for women who are younger, female, unmarried, metastatic at diagnosis, psychiatric history, poorer QOL, physical morbidity, lower income, rural, financial difficulties (Hodgkinson et al., 2007). Highest documented unmet need was existential survivorship. Anxiety and at least one unmet need still encountered by 2/3 of a sample of women up to 10 years post diagnosis. (Hodgkinson et al., 2007).
- Groups of women at higher risk for becoming depressed at post-treatment are those who have more children than other groups of women. Those who are more likely to vacillate between clinical depression and non-clinical depression have fewer children. Those who tend to recover from depressive symptoms over time and those who never experienced depressive symptoms were also less likely to experience anxiety (Deshields et al., 2006).
- Younger age predicts greater risk of depression, distress, and anxiety (Costanzo et al., 2007).
- Participant's primary stressors at the end of treatment included feelings of uncertainty about treatment, follow-up and symptoms; physical concerns; difficulty concentrating, attitudes about body and dealing with mortality (Lauver et al., 2007).
- Overall psychological comorbidity occurred at a rate of 43% in a study by Mehnert and Koch (2008), and was predicted by disease progress, detrimental interactions, low education level, less social support, and an age of under fifty years.
- Body image is also negatively affected by breast cancer surgery. In one study, those who underwent a mastectomy felt more negatively about their body image than did those who underwent a lumpectomy (Bukovic et al., 2005).
- Depression and performing traditional roles were associated with lower sexual desire. Being on antidepressants was related to higher levels of arousal and orgasm dysfunction (Speer et al., 2005)
- Posttraumatic Stress Disorder (PTSD) can also become manifest following breast cancer treatment. One study found that 12% of breast cancer survivors had PTSD (Mehnert & Koch, 2008), while another found that out of 74 breast cancer survivors, 12 had cancer-related PTSD and 15 had subsyndromal PTSD (Shelby et al., 2008). Half of breast cancer survivors with PTSD had anxiety disorders before their cancer diagnosis, however the breast cancer survivors with subsyndromal PTSD had no history of anxiety disorders (Shelby et al., 2008). Finally, a study of survivors of breast cancer whose mothers were holocaust survivors found that the daughters' psychological distress levels were higher than

breast cancer-free daughters of holocaust survivors, breast cancer survivors whose mothers are not holocaust survivors, and a control group (Baider et al., 2007).

Cognitive Dysfunction

- Cognitive dysfunction has been reported in between 17-75% of breast cancer patients who have received chemotherapy (Burstein, 2007; O'Shaughnessy, 2003).
- Aspects of cognitive function related to memory, concentration and language can be compromised to a great or subtle degree for up to ten years (though most studies have found these effects for up to two years post-diagnosis) following chemotherapy in breast cancer survivors (Bower, 2008; Burstein, 2007; Schagen et al., 2002; Stewart et al., 2006; Supportive Oncology, 2006).
- Variables possibly affecting/associated with this dysfunction include changes in hormones, direct effects of (high dose) chemotherapy (especially cyclophosphamide, methotrexate, and 5-fluorouracil), supportive care medications, anxiety and depression, and inflammation (Burstein, 2007; O'Shaughnessy, 2003; Schagen et al., 2002).
- Cognitive dysfunction following breast cancer treatment is more likely in women with higher education, higher IQ, in those with depression, co-morbidities, those with brain injury or with learning disabilities (Supportive Oncology, 2006).
- Over time, the severity of cognitive dysfunction decreases or resolves (Supportive Oncology, 2006). In one study, those with moderate to severe cognitive dysfunction decreased from 16% incidence (those on chemotherapy) to 4.4% incidence after one year and to 3.8% after two years (Fan et al., 2005).
- Most of this research into cognitive dysfunction has been carried out with younger women. It is not known to what extent older women with breast cancer experience encounter major cognitive limitations following breast cancer treatment and how this deterioration is affected by aging (Hurria & Lochs, 2007).
- Studies in this area are scant and more research is needed to understand the effects of cognitive dysfunction following breast cancer treatment.

Informational/Communication Needs

- Women's informational needs are focused on (Gray et al., 1998; Jenkins, 2006; Lyne et al., 2002; Raupach & Hiller, 2002; Satterlund et al., 2003; Vivar & McQueen, 2005):
 - detecting symptoms of recurrence
 - follow-up protocols
 - anti-estrogen drugs
 - lymphedema
 - early menopause
 - fertility concerns
 - pain management
 - side effects of therapy
 - prevention of breast cancer for daughters
 - loss or change in sexual function
 - talking about the cancer

- concerns in interpersonal relationships/families
- employability and insurance concerns, and
- diet and exercise
- In a review of the research on information needs of breast cancer survivors, Finney Rutten et al. (2005) found that during the post-treatment phase, these women were very interested in general information about rehabilitation. Additionally, 40% of the articles reviewed by these authors suggested that any information should be delivered by health care professionals.
- In another study investigating the information needs of pre-menopausal women found that 68% reported discussing early menopause and 34% discussed fertility with their physician even though 98% of these women reported discussing the side effects of cancer treatment with their physician (Duffy et al., 2005).
- A study by Griggs et al. (2007) found that out of 237 participants, while most were happy with availability of information surrounding treatment, only one third were satisfied with survivorship information. In addition, there was a strong positive relationship between satisfaction with information and high levels of vitality and mental health, and a negative correlation between satisfaction with information and distress.
- In a study by Mehnert and Koch (2008) on breast cancer survivors in Germany, 46% of survivors felt inadequately informed about psychosocial resources, and patients older than 65 years of age were more likely to feel less informed.
- In one study of the causes, prevalence and treatment of fatigue, the authors found that half of the 419 cancer patients surveyed did not discuss treatment options with their health professional (Wagner & Cella, 2004).
- A survey distributed by Saegrov and Lorenson (2006) to cancer patients found that most expressed a desire for better information and more systematic post-treatment programs, as well as clear guidelines on the responsibilities of hospitals and local public health services.
- In a study of the informational needs of cancer patients who contacted the National Cancer Institute's Cancer Information Service hotline, females were more likely to inquire about screening/diagnosis, support services, psychosocial issues, general cancer site information, and were less likely to seek specific cancer treatment information (Squiers et al., 2005). Compared to patients in treatment, patients experiencing a recurrence were more likely to seek out specific treatment information, screening diagnosis, and information on prevention and risk factors (Squiers et al., 2005).
- A review of the informational and emotional needs of long-term breast cancer survivors found that many continue to have informational and emotional needs during long-term survivorship, and that these needs are often unmet by the oncology team, forcing the clients to find other sources of support (Vivar & McQueen, 2005).

Relationship Concerns

- Recently the focus of long-term survivorship and its effects on the family has emerged as a concern.

- In an interview study with a large sample of cancer survivors and family caregivers, findings revealed that the survivors felt a higher quality of life, less fear of recurrence and more support than did their caregivers (Mellon et al., 2006). Among survivors, quality of life was also higher if they had a higher income, social support, were married, were male, had older caregivers, had spouses who were the caregivers, were retired or had caregivers who were retired, did not have other health difficulties such as heart disease or arthritis, had only had radiation and who had a positive meaning associated with the cancer (Mellon et al., 2006). Family caregivers who had higher incomes, older, retired, married and male and were spouses (versus those who were adult children to the survivor) also had a higher quality of life.
- In another study Lewis (2006) notes that family members demonstrate high levels of stress 2-3 years after the diagnosis of their loved one. During the acute phase, family members do not necessarily respond supportively to other family members about the cancer; families use the coping behaviours that they are used to (and not necessarily newer and more adaptive behaviours); family members try to maintain their roles even though their core functions are distressed.
- Speer et al. (2005) noted that level of relationship distress was the most significant variable associated with sexual dysfunction affecting arousal, orgasm, lubrication, satisfaction, and sexual pain.

Work/Employment Concerns

- Return to work (RTW) is usually operationalized as the rate of return (where survivors are followed for between six months and six years post-diagnosis) which is between 30-93% for cancer survivors with an average rate of return of 62%. Patients younger than 50 years demonstrate a 74% rate of return. Those over 50 years demonstrate a rate of return of 30% (Bouknight et al., 2006; Main et al., 2005; Spelten et al., 2002; Verbeek et al., 2003).
- In a study by Bouknight et al. (2006) 80% of breast cancer survivors returned to work over the course of the 18-month study period. Eighty-seven per cent of participants in this study reported that their employer was accommodating to their cancer illness and treatment.
- Of those (breast, colon, lung, prostate) working at the time of their diagnosis, 67% were employed five to seven years later. Many worked in excess of 40 hours per week. Although some reported various degrees of disability that interfered with job performance, overall, cancer survivors were able continue to work (Hoffman, 2005). Where difficulties were reported the nature of these concerns included difficulty with physical tasks (18%), lifting heavy objects (26%), stopping, kneeling or crouching (14%), prolonged mental concentration (12%) and analyzing data (11%), keeping up with colleagues (22%) and learning new things (14%) (Bradley & Bednarek, 2002).
- Findings of one study revealed that 80% of breast cancer survivors experience no change in employment after five years post diagnosis; those who did report a decrease in work five years post-diagnosis reported that the change was due to retirement or to a change from full to part-time employment (Ganz et al., 2002). In this same study 2/3 of the participants reported that their income remained

stable once returning to work, 20% of participants experienced an increase and 12% reported a decrease in salary over the course of five years.

- Where RTW difficulties arise in the literature, they are part of the experience for individuals with breast cancer, those with manual work and from non-supportive work environments (Short et al., 2005; Spelten et al., 2002).
- Work concerns of breast cancer survivors can include: job loss, demotion, job task changes, diminished abilities, non-supportive work environment, perceived employer discrimination, patient reprioritizing work, lack of discussion about RTW issues with cancer health professionals. Also, fears associated with RTW include fear of losing job, fear of changing job, fear of being less able to do the job, fear of declining productivity, fear of disappointing colleagues (Maunsell et al., 1999; Main et al., 2005).
- Five-year survivors and matched controls were interviewed about their economic situation over the previous five years. Breast cancer survivors were more likely to be functionally limited and those who were limited needed to reduce their work hours which negatively affected their income (Chirikos et al., 2002).
- In one qualitative study, Gould (2004) found that for lower-income women with breast cancer, long-term side effects (lymphadema, depression, fatigue) prevented women from returning to their previous employment.
- In a study of breast, testicular, and prostate cancer survivors surveyed two to six years after diagnosis, 17% of respondents reported making work changes due to cancer during the study's observation time period, and significantly more breast cancer than prostate or testicular cancer patients reported making work changes. Those who made changes were also more likely to have poorer physical and mental QOL and worse mental work ability (Gudbergsson et al., 2008).

Vulnerable Population Issues

- Most older women do not experience changes in emotional health following a breast cancer diagnosis. Less educated elderly women are more likely to experience a decline in their emotional health following diagnosis (Clough-Gorr et al., 2007).
- In another study with elderly women with breast cancer and matched controls, depression and anxiety symptoms were found to be similar between the groups but the breast cancer survivors scored lower on measures of positive psychosocial well-being, including life satisfaction, mastery and spiritual well-being (Robb et al., 2007).
- In a qualitative study without a matched control group, Latinas were more likely than African Americans to report an increase in the incidence of depression and fatigue over time (Eversley et al., 2005).
- A review of the literature surrounding breast cancer survivors in rural areas found that 30% of rural survivors felt that living in rural areas limited their access to health information. In addition, one study in the review found that rural breast cancer survivors have high levels of helplessness/hopelessness. Furthermore, the QOL for rural breast cancer survivors remained below average in the year following treatment, and rural survivors were likely to feel a lack of psychosocial

- support due to lack of access and a perceived stigma concerning a need for the support (Bettencourt et al., 2007).
- In a Norwegian study on the effects of living conditions on those with breast cancer (i.e., a summary of economy, health, employment, housing, and social participation), breast cancer survivors with poor living conditions received more negative scores on 4 out of 5 Negative Impact of Cancer scales (Gudbergsson et al., 2007). Additionally, a study by Bowen et al. (2007) found that being unemployed or retired was associated with poorer physical functioning in breast cancer survivors, and that unemployed breast cancer survivors reported more negative impact on care giving/financial and social/emotional quality of life scores. Finally, a study by Halmin et al. (2008) found that the risk of death up to ten years after cancer diagnosis was 19% higher in lower socioeconomic status households compared to high socioeconomic status households.

2. Interventions to Manage Physical and Psychosocial Side and Late Effects

There currently exists abundant research regarding the *need* for medical and psychosocial services for cancer survivors following active treatment in areas such as the management of side effects, fertility, employment, and making healthy lifestyle choices (Canadian Breast Cancer Foundation, 2006; Cancer Care Ontario, 2004, 2006; Gray et al., 1998; Lyne et al., 2002; Raupach & Hiller, 2002; Vivar & McQueen, 2005).

The transition from treatment to post-treatment is a time when survivors might consider behavioural and lifestyle interventions. The American Society of Clinical Oncology (ASCO), for example, is developing survivorship care guidelines on issues such as fertility, surveillance for second malignancies, cardiac late effects, osteoporosis and reproductive late effects (Ganz, 2005b). Indeed, ASCO has recently outlined a survivorship care plan. This plan would include a series of documents and interventions that would detail toxicities experienced by the breast cancer survivor, identify long-term and late effects of treatment, describe psychosocial and supportive care needs, and recommend future service providers (Ganz & Hahn, 2008).

Interventions to Manage Physical Side and Late Effects

The interventions to manage the physical side and late effects of cancer and cancer treatment for breast cancer include those focused on fatigue, loss of bone density, chronic pain, lymphedema, reproductive/sexual health, and the prevention of recurrence.

Managing Fatigue

- In a review of fatigue interventions, Wagner and Cella, (2004) encouraged health professionals to rule out anemia, thyroid problems, pain, emotional distress, insomnia, nutrition, infection, cardiac or renal difficulties. They further noted that any assessment should focus on severity, onset, duration, exacerbating and alleviating factors, and impact on QOL.
- Randomized control trials (RCT's) concerning cancer and fatigue have revealed that exercise is the most efficacious for reducing fatigue. Other promising interventions include: restorative therapy, nutrition consultation, sleep hygiene and psychosocial interventions (Wagner & Cella, 2004).

- Stress management psycho education combined with physical activity was also found to be an effective means of reducing fatigue and emotional distress in a RCT of 87 breast cancer survivors (Fillion et al., 2008).
- In another RCT, CBT led to improvements in fatigue, trait anxiety, depression, and QOL in participants with breast cancer when compared to a control group (Dirksen & Epstein, 2008).
- Residual fatigue can be addressed with education and counseling, self-management and non-pharmacologic treatments (Wagner & Cella, 2004). For example, interventions such as multi-week cognitive behaviour therapy with or without a support group component or individual psychotherapy interventions have shown to be efficacious in decreasing fatigue, anxiety, depression and mood disturbance and increasing vitality (Wagner & Cella, 2004).
- Methylphenidate, modafinil, pemoline and dextroamphetamine psychostimulants have also proved useful in fighting fatigue (Wagner & Cella, 2004).
- In an RCT, a multicomponent cognitive behavioural intervention delivered to an experimental and control group participants resulted in breast cancer survivors with chronic insomnia reporting greater self-perceived improvement in sleep over the course of treatment compared to a control group that received only an intervention of sleep education and hygiene. The multicomponent intervention consisted of stimulus control instructions, sleep restriction, and sleep education and hygiene. However, both groups improved equally over time in sleep onset latency, waking after onset, total sleep time, time in bed, and sleep quality (Harkless, 2008).
- A non-control group study of the effects of supervised exercise training on breast cancer survivors during and after treatment revealed that individualized prescriptive exercise interventions were associated with reductions in behavioural, sensory, and total fatigue, as well as improved systolic and diastolic blood pressure (Schneider et al., 2007).

Managing Loss of Bone Density

- Early identification and management of women at high risk for fracture is necessary – especially for those women prescribed aromatase-inhibitors. ASCO recommends that breast cancer survivors at high risk for osteoporosis have a baseline assessment of BMD (via dual energy e-ray absorptiometry scanning) and yearly monitoring while receiving treatment for breast cancer (Bundred, 2007; Galow, 2007).
- Tamoxifen, in particular, can stimulate bone formation and is recommended for use for two years followed by 2-3 years of aromatase inhibitors such as exemestane in order to prevent bone loss (though it might increase bone loss in premenopausal women [Ramaswamy & Shapiro, 2003] where, in the long term, Tamoxifen has been associated with thromboembolic disease and endometrial cancer [Mackey & Joy, 2005]).
- Risedronate has also been found to increase bone mineral density in the spine and hip regions, and to reduce bone turnover (Greenspan et al., 2008).
- Taking dietary calcium (1200-1500mg/d), vitamin D (400-800 U), exercising with weights and entering counseling programs about the connection between

- smoking, alcohol and bone loss could prevent bone loss (Gralow, 2007; Limburg, 2007; Ramaswamy & Shapiro, 2003).
- In a multi-pronged intervention with breast cancer survivors (who had not been prescribed Tamoxifen and who were not taking hormone replacement therapy) 21 women were prescribed weight/strength exercises, 5 or 10 g of alendronate/day, 1500 mg of calcium/day, 400 IU of Vitamin D/day and education about osteoporosis. Over the course of the 12 months, the 21 participants demonstrated improvements in dynamic balance, muscle strength for hip flexion, hip extension and knee flexion and increases in BMD of the spine and hip but decreases in the BMD of the forearm. Three participants who had bone loss at baseline demonstrated normal BMD after 12 months. Rates of adherence to calcium, vitamin D and alendronate therapy were 95%. Rates of adherence to the exercise were 85% (Waltman et al., 2003).
 - Pharmacologic intervention for breast cancer survivors with ovarian failure, who are receiving aromatase inhibitors, or who lose 10% BMD in first year of treatment is recommended (Gralow, 2007).
 - Guidelines for the management of bone loss for breast cancer survivors must be developed (Bundred, 2007; Gralow, 2007).

Managing Weight Gain

- A review of trials studying the effects of progressive resistance training (PRT) for breast cancer survivors found that PRT improved body composition, reducing waist circumferences, hip circumferences, and percentages of body fat (Cheema et al., 2008). PRT was also associated with improved aspects of QOL, namely a lessening of depression, and adverse effects due to the treatment, generally musculoskeletal in nature, were rare. PRT is an exercise that challenges skeletal muscles with loads that can be lifted for 8-15 repetitions maximum per set (Cheema et al., 2008).

Managing Vasomotor Symptoms

- In an RCT of 19 breast cancer survivors who experienced severe vasomotor symptoms, electro-acupuncture therapy (a type of electronically stimulated acupuncture) decreased vasomotor symptoms experienced by most of the women (n=15), however the symptoms tended to return during follow up. The authors suggest that future trials incorporate a placebo model (Frisk et al., 2008).
- According to Ganz (2005a), there is no justification for hormone therapy to manage vasomotor symptoms, as it increases risk for recurrence. Low dose testosterone is an option for increasing libido, however, low dose testosterone levels are associated with higher risk for breast cancer (Ganz, 2005a). Research is needed to discover safer treatments for vasomotor symptoms and to determine whether there are safe forms of hormone therapy, and are vasomotor symptoms worse than the risk of cancer (Ganz, 2005a).

Managing Chronic Pain

- Any effective intervention for managing chronic pain must include an assessment completed by all health professionals involved in managing patient care (Lyne et al., 2002).
- A psychosocial assessment must also be included in pain assessment – including emotional and spiritual pain – these issues can exacerbate physical pain (Lyne et al., 2002).
- Pain can be medically managed with opioids or invasive therapy (in the case of pain that is intractable), heat and cold therapy, massage for lymphedema pain, acupuncture, relaxation therapy and some alternative and complementary medicines (Lyne et al., 2002).
- There is a need to develop psychosocial interventions for those cancer survivors who experience pain (Osborn et al., 2006).

Managing Lymphedema

- Twice a week weight training occurring over six months was found to neither increase the risk of lymphedema nor worsen lymphedema symptoms (Ahmed et al., 2006).

Managing Reproductive/Sexual Health

- To alleviate vaginal dryness, programs of care have recommended low-dose vaginal estrogen preparations though there is a risk of elevating serum estradiol levels above postmenopausal levels (Ganz, 2005a).
- There are a paucity of interventions to address sexual dysfunction and body image (Broeckal et al., 2002; Pelusi, 2006). Forthcoming interventions should include culturally relevant programming, interventions to increase the understanding of the sexual partner about the loss of sexual functioning or body image concerns, programs to enhance self-esteem and body image, sexuality concerns for single women, encourage health professionals to become knowledgeable and comfortable discussing sexual issues with breast cancer survivors (Pelusi, 2006).

Preventing Recurrence

- Fat restrictive, plant-based, low-fat diets are associated with increased health (Demark-Wahnefried et al., 2006). Most diet interventions typically include a counseling component delivered by a trained nutritionist. Low-fat diets are also found to have protective effects against recurrence particularly for women with estrogen receptor-negative disease. However, a review by Stuart et al. (2006) concluded that there is no evidence to suggest that any particular food or diet will influence relapse.
- In a study by Mandelblatt et al. (2006), although all breast cancer survivors should have received surveillance mammography, only 61.9% did so. The odds of receiving mammograms were higher for women who had undergone a lumpectomy and women who were White (Mandelblatt et al., 2006).

Interventions to Manage Psychosocial Side and Late Effects

According to Stanton (2006), interventions to manage psychosocial side and late effects can include an education component, cognitive-behavioural therapy (CBT), support group, individual psychotherapy, coping skills training, and relaxation training. More recent studies have tended to examine the biologic and behavioural outcomes of psychosocial interventions. Psychosocial studies about fatigue and pain are ongoing and interventions and their effect on the family are increasingly appearing in the literature. Meta-analyses about psychosocial interventions tend to find robust effects on anxiety and less so on depression, a decrease of pain and no effect on survival. Finally, research is underway regarding the effects of mindfulness meditation, yoga, and massage.

Managing Depression and Anxiety and Stress

- In a survey study with breast cancer survivors findings indicated that an increase in exercise activity between pre and post diagnosis was associated with higher QOL at least 10 years after cancer diagnosis (Courneya, 2003). Exercise has been demonstrated to increase women's functional status following breast cancer (Courneya, 2003), decrease fatigue (Wagner & Cella, 2004), improve mental health and quality of life, increase feelings of control and increase the ability to handle stress (Mitchell et al., 2007; Demark-Wahnefried et al., 2006).
- Breast cancer survivors who received massage therapy treatments three times/week experienced reduced anxiety, depressed mood and anger in the short term. Over the longer term the effects of massage included reduced depression and hostility and increased urinary dopamine, serotonin values, NK cell number and lymphocytes (Hernandez-Reif et al., 2004).
- A pilot study found that breast cancer survivors who participated in a mindfulness-based stress reduction program experienced reduced stress and improved QOL up to a year following the intervention (Carlson et al., 2007).
- A psychoeducational support intervention consisting of three education and support sessions, telephone and face-to-face education and support follow up sessions, and supplemental written and recorded educational materials, was found to improve psychological and social quality of life in breast cancer survivors (Dow Meneses et al., 2007).
- In an RCT study created to investigate an intervention to manage the uncertainty of a recurrence, Mishel et al. (2005) found that breast cancer survivors who received a CBT program by telephone within which they were provided with a manual to assist them with long-term treatment side effects had significantly better and a wider variety of abilities to cognitively reframe their experience, increase cancer knowledge, improve patient-health professional communication.
- Osborn et al. (2006) conducted a meta-analysis to review the effects of CBT combined with patient education interventions to reduce depression, anxiety, pain, physical functioning and quality of life in adult cancer survivors. The CBT interventions were from between four, one-hour weekly sessions to 55, two-hour weekly sessions and patient education was defined as from one 20-minute program to six weekly one-hour sessions. The results demonstrated that CBT was found to be efficacious for reducing depression and anxiety and increasing QOL in both the short and long term. Patient education interventions were not related to

improvements along any measured parameter and individual interventions were more effective than group interventions. CBT did not assist those survivors who struggle with pain.

- In an RCT with young women with breast cancer (below age 50) in which participants received either an education intervention (about cancer in young women and how to adjust to the disease) or a nutritional intervention, the authors reported that participants' levels of depression decreased (at four months post-intervention) and their physical functioning at follow-up (13 months) increased (Scheier et al., 2005).
- Regular writing about deepest positive and negative thoughts and feelings associated with breast cancer was found to be associated with decreases in distress and physical symptoms at one and three months post-program for women low in avoidance. For women high in avoidance, writing only about positive thoughts related to the cancer experience was most helpful (Stanton et al., 2002).
- In an RCT to understand whether psycho-educational interventions could assist breast cancer patients to enter the post-treatment phase with reduced fatigue and cancer-specific distress, depressive symptoms and post-traumatic growth, participants were randomized to receive standard print materials, print materials and a peer-modeling videotape (VIDEO) or print materials, a peer-modeling videotape and two sessions with a trained facilitator and a workbook (EDU). The group receiving the peer-modeling videotape had higher energy/lower fatigue than the women in the other groups at six months. Cancer-specific distress was reduced mainly by the EDU intervention (Stanton et al., 2005).
- Mitchell et al. (2007) report that women's experience of dragon boating with other breast cancer survivors offered them hope, increased strength and increased their ability to regain control of their lives.
- In a study by Gross et al. (2002) post menopausal women who had completed treatment (with the exception of Tamoxifen) and who also participated in very hard, hard, and moderate physical activity reported higher levels of vigor.
- In a study to ascertain how post-treatment survivors coped with post-treatment concerns, authors reported that participants most frequently used acceptance, religion, and distraction as coping strategies. In open-ended interviews to ascertain self-reported coping strategies, participants reported seeking information, managing symptoms, and talking with others (Lauver et al., 2007).
- In a study by Parry (2008), interviews with 11 participants revealed that membership on a breast cancer dragonboat racing team improved not only mental, emotional, and spiritual health, but physical health as well.
- A review of the literature on cancer and psychosocial concerns by Stanton (2006) found that educational and nutritional group interventions are effective at reducing depressive symptoms in breast cancer survivors, as well as improving physical functioning. Protective factors against psychosocial complications included emotionally supportive relationships, active coping strategies, positive reappraisal and emotional expression (Stanton, 2006).
- A review by Alfano and Rowland (2006) found that group-based interventions show great promise as interventions for psychosocial concerns, though more

research is needed on better targeted, more efficacious, and more cost-effective programs.

Improving QOL

- Health-related QOL was found to be significantly improved in older breast cancer survivors who participated in an exercise self-management program (Damush, et al., 2006).
- An intervention that included exercise, sports, and psycho-education information improved health-related QOL in cancer survivors, as well as exercise capacity and musculature of the upper and lower extremities (van Weert et al., 2005).

Managing Cognitive Dysfunction

- Ferguson et al. (2007) published the results of a small pilot study to understand the efficacy of a CBT intervention on cognitive dysfunction following breast cancer treatment (mentioning that it was the only intervention in the published literature). Breast cancer survivors (average eight years post-diagnosis) who had concerns about memory loss and attention deficits took part in a Memory and Attention Adaptation Training (MAAT) program after which they reported increases in cognitive function, QOL and in their performance on neuropsychological tests at post treatment and at two and six month follow up. The MAAT program involves 1) educating participants about memory and attention, 2) training in self-awareness, 3) reducing arousal through relaxation training, scheduling and learning about pacing and 4) cognitive compensatory training.

Relationship Interventions

- In an RCT to understand the effect of psychosocial interventions on the partners of breast cancer survivors, a brief psycho-educational program to educate and support partners was implemented. Three months after the intervention, partners demonstrated a decrease in distress and mood disturbance compared to the control group. This intervention was also beneficial to patients. Patients whose partners received the intervention reported less mood disturbance, greater confident support and greater marital satisfaction (Bultz et al., 2000).
- In an RCT to determine how advanced cancer patients and their family caregivers might experience an increase in QOL, patients were assigned to a usual care control group or a usual care plus family intervention group (a program designed to provide participants with information and support during recurrent cancer phase including information and support about family involvement, optimistic attitude, coping effectiveness, uncertainty reduction, and symptom management). At three months but not at six months, patients in the experimental group were less hopeless and held less negative appraisals of the cancer than were the controls and the caregivers reported less negative appraisal about caregiving (Northouse et al., 2005).
- A study examining mental health outcomes and families talking openly about the cancer found that open communication was associated with better mental health

- outcomes. The best techniques for this type of communication include empathy and validation of the cancer patient's experience (Mallinger et al., 2006).
- In a study of social support in African American breast and prostate cancer survivors, Hamilton and Sandelowski (2004) found that participants benefited from types of social support that were not emphasized in the current cancer literature, such as the emotional support of the presence of others just "being there," as well as the instrumental support of prayers, assistance to continue religious practices, and assistance to maintain social roles.

Managing Work and Employment Concerns

- The best way that health professionals can assist patients to return to work is to refer those patients to up-to-date and relevant sources of information and to relevant physical therapy and occupational therapy and other rehabilitation providers and agencies (Short & Vargo, 2006).

Informational Needs

- A study by Satterlund et al. (2003) found that eight months following diagnosis, breast cancer survivors are more likely to use books as sources of information. Sixteen months after diagnosis the internet becomes a more popular medium for information gathering. Furthermore, survivors continued to use the internet as a source of information upon completion of treatment (Satterlund et al., 2003).

3. Survivorship Care: Issues and Models

Follow-up Care

- Cancer care follow-up is recognized internationally as a pressing issue, though few countries have well developed policies or plans specifically for survivorship (Grunfeld, 2006).
- In order to protect against psychosocial stressors, physicians can give an anticipatory guideline based upon previous survivors' strategies (Lauver et al., 2007).
- Brown et al. (1999) stated that many breast cancer patients feel dismissed by health care practitioners, and emphasize that a patient-centred clinical method should be used to address and acknowledge the client.
- In a survey of survivorship resources available to post-treatment cancer survivors at National Cancer Institute cancer centres, lymphedema management was identified in 70% of the centres, professional support groups in 49% of the centres, long term care in 38% of centres, and counseling addressing sexual concerns and fertility in 14% of centres (Tesauro et al., 2002).
- Cimprich et al. (2005) staged a trial of taking CHARGE, a self management intervention to help clients transition to survivorship after breast cancer treatment. The intervention involved building on self-regulation principles, and equips women with self management skills to address breast cancer issues, as well as provides information about survivorship concerns (Cimprich et al., 2005). Clients

- found the intervention to be timely, relevant, and very helpful for dealing with post-treatment breast cancer issues (Cimprich et al., 2005).
- A direct observation study of follow-up visits at breast cancer clinics found that consultations focused mainly on detection of recurrent disease, perhaps fostering the mistaken belief that follow-up visits exist only for the purpose of detecting recurrence. Although the visits were optimistic and patients reported a sense of reassurance, very rarely were efforts made to meet informational or psychosocial needs (Beaver & Luker, 2005).
 - A study of the first indicators of breast cancer recurrence found that while 25.9% of total relapses were detected at follow-up visits in the first 36 months after primary treatment, only 16.3% of recurrences were detected in follow-up visits after 36 months (Pivot et al., 2000). The study concluded that extensive routine lab investigations are not justifiable following primary care of breast cancer, and that it is reasonable to reduce follow-up surveillance to a careful history and physical examination only (Pivot et al., 2000). However, a meta-analysis by de Bock et al. (2004) found that approximately 40% of isolated locoregional recurrences are diagnosed during routine visits and tests in asymptomatic breast cancer survivors. Overall, though, the researchers found that the quality of studies was low (de Bock et al., 2004).
 - A study by Mandelblatt et al. (2006) revealed that although all breast cancer survivors should have received surveillance mammography, only 61.9% did so. The odds of receiving mammograms were higher for women who had undergone a lumpectomy and women who were White (Mandelblatt et al., 2006).
 - A study by Hensley et al. (2005) found that overuse of medical resources in breast cancer follow-up visits appears to be common. Khatcheressian et al. (2006) also felt that the evidence supporting follow-up care included only history taking, physical examinations, and mammography. Bone scans, chemistry panels, liver ultrasounds, chest radiographs, computed tomography scans, PET scans, MRI, and tumour markers were not recommended for routine breast cancer follow-up care in an otherwise asymptomatic patient.
 - A series of qualitative interviews with breast cancer survivors demonstrated that continuity of care and unrushed consultation were considered desirable features of follow-up care, while valued features of hospital follow-up environments were access to expertise and availability of facilities (Adewuyi-Dalton et al., 1998).
 - A survey of cancer survivors found that approximately 80% wanted counseling as part of follow-up care, and more than a third of participants were uncertain which physician was in charge of their follow up care (Miedema et al., 2003). Furthermore, about one third of participants were not satisfied with follow-up care provided by physicians, while 18% were unsatisfied with follow-up care from specialists (Miedema et al., 2003).
 - According to Ganz (2006), the medical history of cancer survivors should include a three generation family history in order to help determine survivors risk for future cancers as well as other family members' risk. Medical history should also probe into constitutional problems, skin changes, hearing loss, dental problems, dry mouth, pulmonary symptoms, vascular symptoms, renal problems, gastrointestinal problems, genitor-urinary conditions, gynecologic problems,

reproductive history, sexual functioning, hematologic problems, infections, musculoskeletal complaints, neurologic problems, psychosocial problems and issues surrounding return to work in addition to the standard dates of cancer treatment, type of tumour, and the stage and specifics of treatment exposure (Ganz, 2006).

International Follow-up Care

- New Zealand cancer control strategy aims to improve HR-QOL through support and rehabilitation (Grunfeld, 2006).
- Australian guidelines for follow-up cancer care address psychosocial care, as well as how to discuss the physical, sexual, emotional, and familial concerns of cancer survivors (Grunfeld, 2006).
- Breast cancer guidelines consistently recommend against routine tests other than mammograms, though recommendations on the frequency and duration of follow-up visits are inconsistent (Grunfeld, 2006). Another paper by Grunfeld, Dhesy-Thind, and Levine merely stipulated that frequency of follow-up visits should be according to the patient's needs, and that osteoporosis should be monitored in post menopausal breast cancer survivors (2005).
- The European Society of Mastology (EUSOMA) created a working party to develop guidelines for a breast unit (EUSOMA, 2000). General recommendations included: 1. recognized definitions of mandatory requirements for breast cancer units; 2. each country should appoint a national coordinator for the establishment and audits of units; 3. the creation of a European process of accreditation and quality assurance; 4. breast units should cover one third of a million of the total population and should include breast screening; 5. breast units should provide care of breast disease at all stages; and, 6. the unit budget must be separate from the hospital budget. Units should also be able to refer clients for psychological support, reconstruction with a plastic surgeon, provisions for prosthesis fitting, and physiotherapy (EUSOMA, 2000).

Survivorship Care Plan (SCP)

- Survivorship Care Plans can enhance communication between providers and patients by providing information about cancer type, treatments received and potential consequences, timing and content of follow-ups, recommendations on preventive practices, legal protections regarding employment, and availability of psychosocial services in the community (Hoffman & Stovall, 2006). The health care provider (HCP) should discuss the content of the SCP with the client in a formal discharge meeting (Hoffman & Stovall, 2006).
- The Institute of Medicine reported that survivorship care plans should address the chronic effects of cancer, should monitor for and prevent late effects, and should promote a healthy lifestyle (Earle, 2006). The care plan should identify providers responsible for each type of care; inform clients of available care resources; and provide information on insurance, employment, and financial concerns (Earle, 2006). Earle (2006) describes a need for research on levels of satisfaction with survivorship care, the possible presence of disparities, and comparison of different models of care plan.

- In a qualitative study of patient and health care perspectives on a follow-up care plan, cancer survivors were enthusiastic about the plan, primary care physicians felt that a follow-up care plan would improve survivorship care, and nurses felt that they could play a role in creating and implementing a care plan. On the other hand, physicians who provide oncology care saw the survivorship care plan as valuable but were disinclined to complete them because it would not reduce other reporting and communication requirements (Hewitt et al., 2007).

Models of Care

- According to a survey of American Society of Clinical Oncology (ASCO) members, 74% felt that oncologists should provide continuing care to cancer survivors and 66% of members said that they were comfortable providing continuing care although only 31% said that they already do so (Ganz, 2005a).
- A study by Grunfeld et al. (2006) found that whether a breast cancer survivor received follow-up care from a cancer centre or from her own family physician did not impact HR-QOL or recurrence-related serious clinical events.
- A study in the U.S. found that breast cancer survivors who continued to see oncologists were more likely to receive appropriate follow-up mammography, while breast cancer survivors who were monitored by their primary care physician were more likely to receive all other non-cancer related preventive services (Earle et al., 2003).
- Nurses, as well as oncology social workers, can advocate for cancer survivors by giving clients treatment information, options for counseling, and referrals to community resources (Zebrack, 2001).
- A study comparing treatment of an established care model to treatment at a surgical breast clinic with increased personnel continuity found that the care model with high continuity had a significant positive effect on the participants' emotional state, mental well-being, and perception of post-operative pain one year after surgery (Boman et al., 1999).
- Kolb (2005) recommends breast teams work across delivery paradigms in order to create maximum efficiency. All diagnostic procedures should be integrated into one visit (Kolb, 2005). Kolb also recommends that breast care units imitate care from other realms, such as hospitality (Kolb, 2005).
- Oeffinger and McCabe (2006) propose a model of follow-up care that is shared between primary care physicians and oncologists. The physician would refer the patient to the oncologist but would continue to provide routine health maintenance care, and the patient would be transferred back to the physician one to two years after treatment. The oncologist would provide the physician with a survivorship care plan.

Education and Future Research

- A report commissioned by the National Cancer Policy Board and Institute of Medicine made several recommendations including increasing the focus on survivorship in oncology nursing education and evaluation of the curricula, and an increase in support for oncology specialty education in nursing. The report also suggests promoting oncology nursing certification, exploring opportunities for

- nursing research in cancer survivorship, and increasing the focus of the Oncology Nursing Society on survivorship issues (Ferrell et al., 2003).
- Gamboshi and Ulreich (1990) describes Expo 88 in Cleveland, a nursing advocacy and intervention program with workshops and main stage events for cancer survivors and their families. Attendees found the event beneficial, and the authors suggest that such events can serve to increase nurses' and other health care professional's recognition of cancer survivorship issues (Gamboshi & Ulreich, 1990).
 - Ferrell and Winn (2006) found that survivorship issues are not well represented in the medical curricula. They propose that a new recertification program of the American Board of Medical Specialties could include a module related to cancer survivorship. Equally, they assert that there are a diminishing number of nursing graduate programs that offer a focus on oncology, and call for increased survivorship-related training amongst health care professionals.
 - The Office of Cancer Survivorship (OCS) identified six areas of development and future research: 1. descriptive data on outcomes for survivors; 2. intervention studies that develop and test strategies; 3. elucidation of patterns of care for survivors who are post-treatment; 4. information on the experiences of survivors previously underrepresented in the literature; 5. instruments that accurately reflect outcomes and experiences of post-treatment survivors; and, 6. research on the impact of cancer on the family (Rowland et al., 2001).

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