The psychosocial impact of breast cancer recurrence

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The Psychosocial Impact of Breast Cancer Recurrence

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Dedications

To my mother, who helped inspire this project and has conquered her disease twice with courage and strength. To my loving girlfriend, who was always there for encouragement and always offering to lend a hand. To my family and friends, whose constant love and support got me through not only this project, but the entire program.
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Introduction

For women in the United States, breast cancer is the most common type of cancer. One in eight women will be diagnosed with breast cancer at some point in their lives. As with many diseases, science has helped to improve the prognosis; there is now an 88% chance of 5 year survival (Tomich & Helgeson, 2006). As more women survive or live with the disease for longer periods of time, attention has been focused on long-term quality of life and psychological states, as well as the relative importance of the levels and types of social support received. Women who have successfully come through treatment and are considered disease free are called “survivors” and have become symbols of female strength and fortitude.

The term “breast cancer survivor” has become a public mainstay in recent years, especially as more fundraisers evolve, grow in popularity, and gain financial support. The public’s current acceptance of the term “breast cancer survivor” indicates there has been a significant shift in attitudes when compared to the secrecy and shame that was associated with the disease in the past. Use of the word “survivor” to describe treated women who were disease free was first used in the scientific literature in 1985 (Kaiser, 2008). Breast cancer survivors are mothers, wives, and sisters of everyday citizens; many are working with medicine to find a cure. The persona of the breast cancer survivor is a “triumphant, happy, healthy, and feminine” female (Kaiser, 2008). The shift in attitude about breast cancer and the women who survived the disease was accompanied by increased federal research dollars, as well as an increase in public interest and involvement (Kaiser, 2008).

Symbols and products promoting breast cancer research in support of the breast cancer survivor have also entered the public market. Large corporations such as Ford and Yoplait® have adopted breast cancer as their cause/charity. Multiple fundraisers have grown in the U.S.
and abroad, and none are larger than the Susan G. Komen Race for the Cure, a 5K run/walk which attracts 1 million participants per event (Kaiser, 2008). According to Klawiter (as cited in Kaiser, 2008, p. 80) the message conveyed by events like the Race for the Cure is to honor women “for their courage in fighting breast cancer and for their willingness to demonstrate to other women through their rejection of the cultural code of silence and invisibility, that breast cancer is not shameful, that it is survivable, and that it is neither disfiguring nor defeminizing.”

This survivor identity fails to address women who face a recurrence. While the initial psychosocial aspects of a diagnosis of breast cancer have been extensively researched, the psychosocial aspects of recurrent breast cancer have not. Only in recent years has recurrent breast cancer received attention. The purpose of this scholarly project is to examine the literature exploring the psychosocial effects following the completion of initial breast cancer treatment and recurrent breast cancer. Selected articles published in the last twenty years will be reviewed. In order to compare psychosocial effects beyond the initial diagnosis, a brief description of the initial diagnosis must be given. This review will discuss the etiology, risk factors, detection, diagnosis, treatment, and psychological effects of the initial and recurrent breast cancer diagnoses, as well as women’s psychological reactions to each. Key differences will be highlighted.
Etiology and Risk Factors

No definitive cause of breast cancer has been identified. Most theories of the etiology of the disease come from knowledge of known risk factors. Age is associated with risk both directly and indirectly. Risk of disease increases with age: experiencing pregnancy at a later age; experiencing menarche at a younger age or menopause at an older age. Women with an early onset of menarche or with late onset of menopause have more menstrual cycles. It has been suggested that the increase in number of cycles may make women more susceptible to DNA damage, and thus breast cancer (Muss, 2008). Family history is a strong risk factor in that twenty percent of women with breast cancer report a family history of the disease. Gene mutations or inheritance of defected genes, particularly the BRCA1 and BRCA2, appear to predispose women to breast cancer (Muss, 2008). Additional risk factors include previous benign breast disease, postmenopausal hormone replacement therapy, increased alcohol use, a sedentary lifestyle and nulliparity (a condition in which a woman has never been pregnant). A detailed discussion of the etiology of breast cancer is beyond the scope of this paper but the reader can consult *Cecil Medicine* for more information (Muss, 2008).
Detection and Diagnosis

Breast cancer most often manifests itself as a mass felt either by the patient or detected during physical exam or mammogram. Breast pain not associated with the menstrual cycle could indicate disease. Other indications include skin changes over the breast and a watery or bloody discharge from the nipples (Muss, 2008). Imaging techniques such as an ultrasound or mammogram can detect masses, but a biopsy is needed to diagnose the lesion as cancer. Following the biopsy, the cancer is staged based on the TNM system. This system stages cancer based on tumor size, lymph node involvement, and whether there are metastases. Increased tumor size, greater amount of lymph node involvement, and metastases all correlate with higher stage. The higher the stage, the more severe the cancer and the more likely the patient is to experience a recurrence after initial treatment (Muss, 2008).
Treatment

Treatment for breast cancer can include chemotherapy, radiation treatment hormone therapy, or surgery. The surgery can be the removal of a mass or a complete mastectomy. Breast reconstruction is often done simultaneously with the mastectomy to enhance psychological adjustment of the patient (Muss, 2008). For a more detailed review of treatment options and chemotherapeutic agents, please see the previous source as well as Stuart, Brennan, French, Houssami and Boyages (2006). Treatment of breast cancer can induce early menopause in some women, which brings with it additional physical and emotional consequences (Stuart, 2006). As with most cancers, support groups and counseling are offered to help patients cope with their diagnosis, treatment and symptoms (medical and psychological). Unfortunately, while the successful medical treatment of the initial breast cancer places the patient in the category of survivor, there still exists the fear of recurrence and possible recurrence itself. Fear of recurrence and disease recurrence will, for some women bring with them the same psychological problems associated with the initial diagnosis, as well as new challenges.
Psychology of the Initial Diagnosis

The initial diagnosis of breast cancer is a life altering event. Dr. Martin Abeloff summarized the need for understanding the psychology of such an event when he said, “You simply can’t treat cancer without paying attention to the psychological and social aspects of the disease” (Ganz, 2008, pp. 642). Multiple areas of life are impaired (physical, social, economic and psychological). The ensuing treatment can cause fatigue, nausea, pain, infertility, sexual dysfunction, menopause, and drastic changes to body appearance and functioning (Beatty, Oxlad, Koczwara, & Wade, 2008). Socially, many women must adapt to a new role in the family dynamic (such as the husband taking care of the house and children); economic struggles may exist (potential loss of a second income and medical bills), and a decrease in social interaction outside of the family may occur (due to feeling ill from the disease or treatment) (Beatty et al., 2008). Certain factors predispose women to have increased psychological distress. The most indicative factors are suppression of negative emotions and the tendency to become anxious when facing any type of adversity; contrary to many hypotheses, dealing with a family history of breast cancer does not predispose a woman to increased psychological distress when she faces cancer herself (Ando, Iwamitsu, Kuranami, Okazaki, Wada, Yamamoto, et al., 2009). While most women cope well with the initial diagnosis of breast cancer, anywhere from 23% to 56% experience emotional distress such as depression, anxiety, anger, confusion, and helplessness (Beatty et al., 2008). These symptoms generally decline over the following 12 months to near community levels, or that of the general public. Still, one third of women diagnosed with breast cancer will suffer long-term psychological impairment and decreased quality of life. This impairment can manifest itself as fear of recurrence or anxiety over yearly
follow-ups (Beatty et al., 2008; Ando, et al., 2009). In order to cope with the diagnosis of breast cancer and avoid long-lasting psychological effects, certain needs must be met.

Women diagnosed with breast cancer have expressed three broad categories of needs when dealing with their diagnosis. A need in this context is “the requirement of some action or resource necessary, desirable, or useful, to attain optimal well-being” according to Sanson-Fisher et al. (as cited in Schmid-Büchi, Halfens, Dassen, & van den Borne, 2008, pp. 2896). The needs are psychological health support, physical needs, and informational needs, which must be addressed early in the treatment process in order to avoid serious psychological consequences. A study of Australian women (Beatty, et al., 2008) diagnosed with breast cancer examined these three categories of needs and produced five generalized themes addressing psychological adjustment. The first theme was coping with side effects. Fatigue was listed as a major side effect of treatment that impaired daily functioning. A more specific concern for women in regard to side effects was lymphoedema. Women in the study noted that lymphoedema hampered daily functioning and was not always mentioned by doctors as a potential side effect. In general the study group needed increased amounts of information on the side effects of cancer treatment and how their daily lives would be affected (Beatty et al., 2008).

The second theme in the Australian study dealt with a change in self concept. Women undergoing treatment for breast cancer must frequently manage distressing thoughts and worries related to body image. Many women reported feeling unattractive, whether it was due to losing one or both breasts, losing hair, or weight changes (Beatty et al., 2008; Ganz, 2006). Role changes within the family were also reported with many women having difficulty relinquishing roles to their husbands or other family members. One woman commented, “I find it difficult to just sit there and just let it go” (Beatty et al. 2008, pp. 336). The needs identified as being
associated with changes in self concept included finding ways to improve self esteem, emotional support for body changes, help accepting short term role changes, and forming an identity separate from “cancer survivor” (Beatty et al., 2008; Ganz, 2006).

Stress and adjustment reactions arose as a third theme. Once diagnosed, women reported anguish, fear, shock, anger and self-blame. As treatment progressed women felt depression, isolation, helplessness, and loss of control. Another phenomenon that arose was “delayed distress.” This occurred in women who believed themselves to be coping well with their diagnosis but reached a point where they began to struggle. One woman reported, “I can’t understand it because I was so tough. Didn’t shed a tear… but now I’m hopeless!” (Beatty et al., 2008, pp. 337). The study did not address what triggered the change from coping to distress. Adjustment and stress were also related to treatment coming to an end. Feelings of isolation reportedly increased with the completion of treatment. The needs identified as being associated with stress and adjustment were need for personal choice, filtered information to avoid being overwhelmed, maintaining normalcy in day to day life, and being able to identify the positive aspects in everyday life (Beatty et al., 2008).

Theme four dealt with managing others. Women reported difficulty maintaining a “game face” or a strong front when around families and friends. Relationship and intimacy issues also arose. The women in the study also had increased concern for their immediate family members. The diagnosis of breast cancer affects everyone in the home or close to the patient. Family members also struggle with distress and adjustment issues, but typically receive less social support, which may affect their ability to cope with the situation and limit their ability to provide support to their loved one (Beatty et al., 2008, Walker, 1997). Needs associated with this theme were talking to someone who has had similar experiences, finding people who will provide
support no matter how difficult the situation, using health care providers as a source of support, and having help with domestic chores (Beatty et al., 2008; Walker, 2007).

Theme five dealt with survival and growth. Lack of closure was a commonly reported concern. There is no test to confirm the complete elimination of cancer tissue. For many women, lack of closure leads to a constant sense of insecurity about their disease. This insecurity and fear of recurrence can lead to a “waiting game” as some women coined it (Beatty et al., 2008). Some women feel as if recurrence and death are only a matter of time. Focusing on living and quality of life, rather than death, is a conscious decision; one each woman must ultimately make regardless of social and/or medical support (Beatty et al., 2008). The key needs associated with survival and growth are maintaining a positive outlook on life, having appreciation for the “little things” in life, and developing an inner strength to help cope, and prioritizing what is really important (Beatty et al., 2008). These five themes provide a picture of the psychological issues women face with the initial diagnosis of breast cancer. It is important to note that while many women face multiple psychosocial stressors, the majority of women who face an initial breast cancer diagnosis do not develop a major psychological or adjustment disorder. Also, while psychosocial distress decreases quality of life, there is no effect on a patient’s survival (Beatty et al., 2008; Lauver, Connolly-Nelson, & Vang, 2007; Phillips, Osborne, Giles, Dite, Apicella, Hopper, et al., 2008). This review will now focus on the psychosocial challenges women face following treatment for their original breast cancer diagnosis.
The Interval

For many women, the period of time following treatment can also be a period requiring psychological adjustment. The end of treatment can be particularly stressful, due to the many uncertainties women face post-treatment. Allen, Savadatti, and Levy (2009) describe the post-treatment period as “the re-entry phase” when women struggle to regain normalcy in their lives. Women in the post-treatment phase lose their “safety net” of constant surveillance and follow-ups by health care providers. The responsibility for monitoring their health falls primarily upon themselves with self-breast exams and being alert to new physical symptoms that may emerge (Allen et al., 2009). Women’s responses to potential threats during the post-treatment phase are both cognitive and emotional. An example of a cognitive process is when a current threat is compared to previous knowledge to form a new cognitive interpretation of the threatening situation. Emotional process, in contrast, is when completely new emotions are felt due to the new threat (Allen et al., 2009). Allen et al. discuss five areas women must manage post-treatment (positive life change, fear of recurrence, emotional distress, losses associated with treatment cessation, difficulty returning to normal life).

Concerning the area of positive life changes, women stated that the cancer experience helped them to appreciate life more, gave them the will and motivation to do things in life they had put off, and helped them to find and maintain a positive outlook in the face of adversity (Allen et al., 2009; Lauver et al., 2007). Many women in the study also felt a strong desire to “give back” and express their gratitude for the support they received during their disease course. These women expressed desire to be part of support groups for women dealing with cancer, join fundraisers, and speak on behalf of breast victims in general (Allen et al., 2009). Many women
also admitted that their cancer experience led to positive lifestyle changes such as increasing exercise, improving diet, and smoking cessation (Allen et al., 2009; Lauver et al., 2007).

Levanthal’s Commonsense Model (as cited in Rabin & Pinto, 2006) may explain what might influence survivors to make positive health behavior changes. According to this model, when a patient is diagnosed, a set of beliefs about the illness such as the cause, the time course of the illness, and its controllability are formulated by the patient (Rabin & Pinto, 2006). In terms of breast cancer, 85-90% of breast cancer patients held beliefs about what caused their cancer (e.g., smoking, poor diet), and 87% of cancer survivors held beliefs about what prevented their recurrence (e.g., increasing their exercise, having a healthier diet). Rabin and Pinto (2006) examined whether these survivor beliefs about the cause and/or prevented recurrence of their cancer influenced their behaviors. Although their sample size was small and they were unable to draw definitive conclusions, their preliminary data suggest the Commonsense Model is applicable. For example, if a patient believes that poor diet led to the initial diagnosis of breast cancer, she may alter her diet to prevent recurrence. Also, if a cancer survivor initially exercises more and avoids recurrence, she may believe her increased exercise is the reason for avoiding recurrence and will continue the healthy behavior. It must be noted, however, that there is no scientific proof linking improved diet and exercise to decreased rates of recurrence (Stuart et al., 2006).

Another area of post treatment management is emotional distress. Many women comment that their anxiety and/or depression can arise without a particular trigger; summed up by one woman as being on an “emotional rollercoaster” (Allen et al., 2009). Concerning the topic of loss, the biggest loss felt by women is the loss of frequent contact with other women
receiving treatment. Many of these relationships were seen by patients as friendships (Allen et al., 2009).

Two related areas of post-treatment management are fear of recurrence and difficulty returning to “normal life.” Women comment that the cancer experience will always be with them, thus making life as they knew it forever changed. Women also feel pressure to resume daily activities such as work and domestic roles once treatment has ended. Women also feel pressure to “be strong” for family and friends despite internally dealing with the lingering cancer experience (Allen et al., 2009). Strongly linked to the struggle to return to normalcy is fear of recurrence. The phrase “sword of Damocles” is often used to describe this fear (Allen et al., 2009; Lebel, Rosberger, Edgar, & Devins, 2007). Damocles was a Greek character seated beneath a sword which was suspended by a single hair; women who have initially overcome breast cancer, similarly live their lives in the shadow of cancer.

Fear of recurrence is associated with younger age, higher level of education, a short time period since cancer remission, aggressive cancer treatment, and cancer progression (metastatic cancer during the original diagnosis producing greater fear of recurrence than localized cancer; Simard & Savard, 2007). Other factors affecting fear of recurrence are beliefs about ability to cope, the degree of functional impairment experienced after the original diagnosis, the amount of support received from family and friends, and various triggers (e.g., places significant to the original cancer experience, events such as anniversaries, etc.) that may bring back unpleasant memories of the cancer experience (Simard & Savard, 2007, Lebel et al., 2007; Stuart et al., 2006).

Triggers often precipitate fear of the unknown through a re-experiencing of emotions related to the cancer experience. Common triggers include follow-up appointments, body or
functional changes, media stories on breast cancer, and hearing of another survivor’s recurrence (Gil, Mishel, Belyea, Germino, Porter, LaNey, et al., 2004; Lebel et al., 2007). Follow-up appointments can trigger fear related emotions because there is a high level of uncertainty and anxiety prior to the appointment related to the possibility of finding evidence of recurrence.

Allen et al. (2009) found uncertainty to be a significant component in fear of recurrence. However, uncertainty is not precipitated only by follow-up appointments. Uncertainty also plays a role in interpreting body and functional changes. After breast cancer many women become sensitive to changes in their bodies. Any fatigue, ache, or illness can trigger fear of cancer recurrence. This can become particularly problematic when treatment related symptoms emerge years after treatment has stopped. These delayed symptoms can include pain, numbness, skin sensitivity, breast swelling, and the most debilitating - lymphoedema (Gil et al., 2004; Lebel et al., 2007; Stuart et al., 2006). Many women are not informed of these late emerging symptoms and lymphoedema is often not mentioned by health care providers; thus when it occurs, uncertainty arises, which can precipitate increased anxiety and fear. The uncertainty often centers on whether they are experiencing a recurrence, symptoms related to treatment, or signs of the natural aging process. Uncertainty, whether from physical changes or what might be discovered in a follow-up appointment, is directly related to a decreased quality of life and emotional distress (Gil et al., 2004).

Another common trigger that leads to increased fear of recurrence was hearing about another survivor’s recurrence. Gil et al. (2004) reports Caucasian women are more likely to have a fear of recurrence triggered by hearing about someone else’s recurrence and/or cancer related media reports, than are African American women. She reports that African American women have a more negative view of breast cancer, keep the diagnosis to themselves and do not use
support groups, thus African American women may also ignore potential media triggers because the media in general does not cover the cancer experience of African American women. This does not, however, mean that African American women fear recurrence less, but that they may be less influenced by the media.

While most breast cancer survivors do not carry a psychiatric diagnosis, they do face psychological stressors that must be managed. In order to make sure that these stressors do not lead to more serious psychological problems, health care providers must act. The period following treatment cessation is described as a “window of opportunity” when interventions can help women cope with these stressors. Available interventions include encouraging women to express feelings openly, join support groups to discuss experiences with other survivors, work to identify irrational thoughts and fears, and inform women to be cautious and aware of their physical changes without being over-vigilant (Gil et al., 2004). While these interventions can help women cope with the fear of recurrence, it does not stop a recurrence from happening
Breast Cancer Recurrence

There are three types of breast cancer recurrence. Local recurrence is the return of cancer cells to the site of the original cancer. A debate exists as to whether local recurrence is an actual recurrence or simply failure of initial treatment (Muss, 2008). A regional recurrence is when cancer cells return outside of the breast and axillary lymph nodes. Common locations for a regional recurrence are the pectoral muscles in the chest, between the ribs, and the lymph nodes above the clavicle and around the neck. This type of recurrence is rare. A distant recurrence is the return and spread of cancer to distant locations in the body, also known as metastasis. Breast cancer can metastasize to anywhere in the body, but the most common locations are the bone, liver, and lungs (Muss, 2008; Stuart et al., 2006). Throughout this paper, the term recurrence will refer to the return of breast cancer in general and will not be type specific unless noted.
**Risk Factors of Recurrence**

Breast cancer recurrence is most likely to occur 2-5 years after initial treatment. The likelihood of recurrence years 5-12 post-treatment is 4.3% and less after year 12 (Gil et al., 2004). Risk factors associated with recurrence are similar to those for the initial diagnosis, including genetics, sedentary lifestyle, and weight gain/obesity. Risk factors unique to recurrent breast cancer are based on factors associated with the initial disease. Lymph node involvement in the initial disease is a risk factor for recurrence (Giordano, Buzdar, Smith, Kau, Yang, & Hortobagyi, 2004). Cancer cells can hide undetected in the lymph nodes before resurfacing somewhere in the body. Additional risk factors for recurrence are based on the aggressiveness of the original tumor. These include the size of the tumor, histologic grade, and whether the tumor has estrogen receptors (Giordano et al., 2004). The larger the tumor, the more aggressive the cancer, thus increasing the chance for recurrence. Histologic grade is an indication of how different, or differentiated, the cancer cells are from normal body cells. The higher the grade, the more differentiated the cancer is; increased differentiation indicates a more aggressive cancer and an increased chance for recurrence. Two thirds of breast cancer cells have estrogen receptors on their surface. These cells can therefore be treated with estrogen hormone therapy and have a higher success rate. Cancers without estrogen receptors tend to be more aggressive - increasing the chance for metastases/recurrence (Giordano et al., 2004).
Detection and Treatment for Recurrence

Detection of recurrent breast cancer is similar to detecting an initial diagnosis. As previously noted, all women are encouraged to perform self breast exams, but this especially applies to women who have already been treated for breast cancer. Indications of a return of breast cancer include the same breast changes as in the initial disease: breast lumps; skin changes such as dimpling; puckering, red skin, warmth; and bloody or clear discharge from the nipples (Muss, 2008; Stuart et al., 2006). Some symptoms indicating recurrence are related to the site of cancer metastasis and can include bone pain, shortness of breath, decreased appetite, weight loss, weakness, and chronic headaches (Stuart et al., 2006). Tests that can detect cancer recurrence include a chest x-ray, bone scan, CT scan, MRI, and measuring liver enzymes (Muss, 2008; Stuart et al., 2006). After treatment for the initial disease, it is important for women to have follow up appointments which are opportunities for health professionals to detect these early signs of recurrence.

The treatment options for recurrent breast cancer are the same as for the initial diagnosis. Patients can undergo surgery, chemotherapy, radiation treatment, or hormone therapy. Treatment for recurrent breast cancer is often determined by the treatment for the initial diagnosis. For example, if a woman had a lumpectomy as treatment of her original disease and then has a recurrence, she most likely will have a mastectomy. If the original treatment was a mastectomy, then recurrent treatment would most likely involve radiation treatment. Distant recurrence or metastases would likely be treated with chemotherapy. Survival rates for recurrent breast cancer have steadily improved with a recent report indicating a 5-year survival rate of 44% (Giordano et al., 2004).
Psychology of Recurrence

The recurrence of breast cancer is thought to change the life of the patient and her family as she moves from being a survivor to once more being a patient. We are just beginning to understand the psychosocial effects of recurrence as the research in this area began in earnest only 10-years ago. Studies indicate that 40% to 50% of individuals with a first recurrence of breast cancer experience adjustment problems or depression (Okamura, Watanabe, Narabayashi, Katsumata, Ando, Adachi, et al., 2000; Akechi, Taniguchi, Suzuki, Okamura, Minami; Okuyama, et al., 2007). A comparison of the psychosocial effects of recurrent breast cancer with initial in-treatment and stable breast cancer patients shows that women with recurrent cancer have poorer perceptions of their health, have difficulties with physical functioning and report a greater impact on their life than the other groups (Bull, Meyerowitz, Hart, Mosconi, Apolone, & Liberati, 1999; Hanson Frost, Suman, Rummans, Dose, Taylor, & Novotny, 2000; Yang, Thornton, Shapiro, & Anderson, 2008).

Yang, Thornton, et al. (2008) found age differences when they compared recurrent patients with those with an initial diagnosis. Younger women generally struggled with physical symptoms more than older women, and younger women tended to be angrier about their situations. The authors explain the age difference as due to uncertainty and loss of control. Younger women may feel as if they have not lived a full life and wonder if they have a future. They are also more likely to have a young family, whose future has become clouded by the cancer recurrence. In contrast, older women, who have raised a family and achieved some of life’s goals, may be more prepared to accept limitations and uncertainty in their life (Lauver et al., 2007; Okano, Okamura, Watanabe, Narabayashi, Katsumata, Ando, et al., 2001; Yang, Thornton, et al. 2008).
Contrary to the above studies, others have found no differences in quality of life, relationships and mood between a group of women with an initial diagnosis, and one with recurrent diagnosis (Oh, Heflin, Meyerowitz, Desmond, Rowland, & Ganz, 2004; Okamura, Yamawaki, Akechi, Taniguchi, & Uchitomi, 2005). This was supported in a controlled prospective study which found women with recurrent cancer experienced greater cancer specific fears, anxiety and intrusive thoughts but not a decline in quality of life, when compared to women with an initial diagnosis (Anderson, Shapiro, Farrar, Crespin, & Wells-DiGregorio, 2005). Anderson, Shapiro, et al. (2005) found this to be true even for women who experienced greater physical distress and reduced functioning as the result of the recurrence. These authors hypothesize that women, having managed an initial diagnosis may be more resilient in the face of recurrence. By previously and successfully undergoing various treatments, women with recurrent cancer may have a more positive attitude toward additional treatment, and thus avoiding a potential decrease in quality of life (Jansen, Otten, Baas-Thijssen, van de Velde, Nortier, & Stiggelbout, 2005). Persistent symptom burden does not decrease quality of life as women adjust to their physical functioning (Sarenmalm, Öhlén, Odén, & Gaston-Johansson, 2008). Lee, Son, Hwang, Han, Yang, Lee, et al. (2007) notes that once women have adjusted to the physical burden of treatment, or when treatment has ceased, their quality of life is comparable to that of disease free survivors. The mixed findings in the psychosocial consequences of recurrence call for more study in this area.

Despite the findings described above, recurrence does not come unnoticed by the patient and her family. The future is likely viewed with greater uncertainty than when one was first diagnosed and the family must face additional treatment, role changes, physical limitations and
potential loss of life. The initial hope of a cure may shift to hopelessness about both treatment and prognosis. This can create greater strain on the family of the breast cancer patient.
Family and Support

Breast cancer recurrence does not limit itself to the patient. Its effects have emotional and psychosocial effects on all persons involved: health care providers who may share the emotional rollercoaster of appointments, treatment, and prognosis; friends who provide physical, mental, and emotional support; and most significantly - family. Family members experience emotional distress, adjustment problems, and high levels of uncertainty without receiving support for themselves (Northouse, Mood, Kershaw, Schafenacker, Mellon, Walker, et al., 2002). These authors identified three key factors (self-efficacy, current concerns, and hardiness) that affect quality of life in both the patient and her family. For family members, self-efficacy is a reflection of their ability to provide care for their loved one. Current concerns encompass any and all issues that the patient and/or family must deal with while simultaneously dealing with breast cancer recurrence such as any financial crises, maintaining employment, and the chores of everyday life. Family hardiness is defined as “the family’s internal strength and collective ability to manage hardship and change” (Northouse, Mood, et al., 2002, pp. 4051-4052). Strong self-efficacy, fewer current concerns, and increased family hardiness are connected to improved quality of life and less symptom distress.

Family members suffered most in regard to their mental and emotional health. Family members’ mental health was worse than the general population, and their emotional health was sometimes worse than the patient’s (Northouse, Mood, et al., 2002; Walker, 1997). Family members had similar problems to those with serious illness, indicating the social and emotional reach of recurrence. Family members in the study noted they received less support than desired and were less likely to be satisfied with health care providers (Northouse, Mood, et al., 2002).
The presence of a partner has been shown to decrease hopelessness and increases quality of life for the patient (Brothers & Anderson, 2008). The effects on quality of life are not limited to the patient; rather they are reciprocal between patient and family and can be both direct and indirect (Northouse, Mood, et al., 2002; Walker, 1997). If family members were directly affected, their ability to provide support to the patient would be diminished, thus having an indirect effect on the patient’s quality of life. In the opposite scenario, if factors directly affected the patient, then there was potential for the family to provide additional support, leading to an indirect decrease in quality of life for the family. The relationship works the same for positive factors as well. A strong family helps to increase the quality of life for the patient. Also, less symptom distress for the patient reduces the burden the family may have in terms of providing support.

The family dynamic most significantly affected by breast cancer is intimacy. Anderson, Carpenter, Yang, and Shapiro (2007) and Anderson (2009) examined the effect of recurrent breast cancer on intimacy. When examining the negative impact of the initial diagnosis, there is a decline in frequency of intercourse over the first year which then remains nearly constant over a five year period. However, there is a decline in sexual satisfaction which does not always return to pre-diagnosis levels after a five year period. Patients with recurrent breast cancer are 50% more likely to experience significant negative effects in sexual desire and frequency of intercourse than patients going through an initial diagnosis. It is thought that sexuality may already be declining when recurrence occurs. When comparing recurrent patients to those who remained disease free, there was a decrease in intercourse for the recurrent patients. However, within one year the frequency returned nearly to the same level as the disease free patients. The site of recurrence plays a role in intimacy as patients with local recurrence will have a greater
frequency of intercourse as well as satisfaction than couples dealing with distant metastases. While it appears evident that intercourse suffers due to recurrent breast cancer, the same cannot be said for intimacy. Partners of recurrent patients are more likely to have depressive symptoms than partners of newly diagnosed patients or disease free patients. Yet as both patient and partner deal with recurrence their need for some form of intimacy remains strong. The frequency of kissing is greater for couples dealing with recurrence than couples who are currently disease free. This is important; while intercourse becomes difficult, the need for affection increases, and couples find ways to maintain their intimate connection (Anderson, Carpenter, et al., 2007; Anderson, 2009).
Interventions

While there may be some debate as to the level of distress experienced by women with breast cancer recurrence, the importance of how healthcare professionals might help women and families in distress is always apparent. Psychosocial interventions available to women include education, individual therapy (e.g., cognitive behavior) and group interventions. Education attempts to make the patient feel more in control by providing as much information as the patient wants to take in and process. Individual therapy helps the patient manage emotions and other problems related to the disease. Specifically, cognitive behavior therapy involves identifying and correcting distorted thoughts and feelings that may contribute to psychosocial stress. Group therapy attempts to expand a patient’s social network and to reduce stress by sharing common experiences with others (Akechi et al., 2007; Edwards, Hubert-Williams, and Neal, 2009). All of these techniques work to increase the patient’s ability to cope. Coping is the process of developing and using strategies to manage stressful events (Sarenmalm, Öhlén, Jonsson, & Gaston-Johansson, 2007; Yang, Brothers, & Anderson, 2008). These authors identify two styles of coping: disengagement and engagement. Disengagement coping tries to decrease the impact of a stressful event through avoidance or denial. Engagement coping is an active and positive approach associated with a higher quality of life and is thus encouraged through psychosocial therapies (Okano et al., 2001; Yang, Brothers, et al., 2008)). These interventions have been examined extensively with regards to the original diagnosis of breast cancer, but literature is lacking when examining recurrence.

One intervention developed specifically for women with breast cancer recurrence and their families is FOCUS (Family involvement, Optimistic attitude, Coping effectiveness, Uncertainty reduction, and Symptom management; Northouse, Walker, Seafenacker, Mood,
Mellon, Galvin, et al., 2002). The FOCUS program is based on both stress-coping and family stress theories. Stress-coping theory states that individual and environmental factors affect a person’s appraisal and coping ability when dealing with an illness. The FOCUS program’s goal is to reduce the negative appraisal of breast cancer recurrence. Family stress theory states that the family should be viewed as one system; thus effects on one member have indirect effects on the rest of the family. The FOCUS program’s goal in this regard is to help identify each family’s strengths and to improve on their weaknesses (Northouse, Walker, et al. 2002).

Each component of the program (family involvement, optimistic attitude, coping effectiveness, uncertainty reduction, and symptom management) has multiple interventions for helping the family. If a family is particularly strong in an area, the intervention is to encourage the family to continue their behavior in that area. Family involvement interventions include promoting open communication, encouraging teamwork, identifying family strengths, and helping the children in the family. Families are encouraged to discuss fears they have about the disease, find ways for all family members to contribute to the family dynamic, identify resources the family can lean on for support, and to openly discuss the disease with the children in the family instead of hiding the facts (Northouse, Walker, et al., 2002).

Optimistic attitude interventions include practicing optimistic thinking (participants were taught the importance of optimism and ways to practice optimism), sharing fears, and maintaining hope even in the face of death (participants were taught to live in the present). Coping interventions include dealing with overwhelming stress by helping caregivers to manage the demands of the illness, and developing healthy behaviors and coping mechanisms (relaxation techniques, open discussion, etc.). Family members are told not to be afraid to ask for outside
help and to continue to find time for their own personal well-being, such as continuing their leisure activities (Northouse, Walker, et al., 2002).

Uncertainty reduction interventions are not used to eliminate uncertainty, but rather, to help the patient and family learn to live with uncertainty. Patients and family members are encouraged to obtain as much information as possible and to be assertive when necessary in order to obtain that information. Symptom management is directed at identifying and assessing each family member’s symptoms and then providing information on outside resources and support groups. Preliminary results from the program indicate greater satisfaction with health care providers and increased quality of life for those patients and their families who participated (Northouse, Walker, et al., 2002).

Other potential psychosocial interventions for breast cancer recurrence are yoga or telephone counseling. Yoga therapy has been shown to have short-term benefits, especially with metastatic disease. These benefits include helping women with relaxation responses, accepting moment to moment experiences, and invigorating the body and mind; all of these benefits help to reduce pain, fatigue and distress (Carson, Carson, Porter, Keefe, Shaw, & Miller, 2007). To date, telephone interventions have not been found to decrease psychosocial stress in cancer patients. If more effective phone interventions can be developed, their low cost and ability to cross geographical barriers may provide one more way to help women with breast cancer better manage emotional distress (Gotay, Moinpour, Unger, Jiang, Coleman, Martino, et al., 2007).
Discussion

One in eight women will be diagnosed with breast cancer at some point in their lives, making it the most common cancer faced by women. Genetic and environmental factors play a role in the risk of developing breast cancer. Multiple treatment options exist and are increasingly successful. Research on the psychosocial effects of an original breast cancer diagnosis is plentiful. Less is known about the time period following treatment cessation, and even less about the psychosocial effects of breast cancer recurrence. Physical symptoms such as pain, fatigue, uncertainty, and social or family support are predictors of psychological distress in patients regardless of the disease phase. For women post-treatment or dealing with recurrence, anniversaries, new physical symptoms, and media coverage all add to fear and stress. Younger women appear to suffer more across disease phases, mainly related to concerns regarding their remaining family members.

Family support plays a crucial role in determining the level of psychological distress experienced with breast cancer recurrence. Both the patient and the family can suffer stress and adjustment problems. There is a fluid dynamic between patient and family, with the psychological conditions of one affecting the other. Specific interventions such as the FOCUS program aim to treat both the family and the patient. Other psychosocial interventions such as group therapy and cognitive behavior therapy attempt to teach breast cancer patients dealing with recurrence how to utilize engagement coping rather than denial or distress.

The literature is conflicted concerning differences in coping and adjustment after the initial diagnosis versus recurrent breast cancer. As noted in the body of the paper, several authors claim that patients with recurrence suffer more psychological stress due to increased fear and uncertainty and diminished social support outside of the immediate family (Bull et al., 1999;
Hanson Frost, et al., 2000; Yang, Thornton, et al., 2008). Others claim that recurrent patients have developed their coping strategies and therefore are better prepared to deal with a second diagnosis (Anderson, Shapiro, et al., 2005; Oh et al., 2004; Okamura, 2005). Interventions for the various disease phases are the same, with earlier intervention predicting better outcomes. The paucity of research examining the differences between the initial diagnosis and recurrence does not indicate that this area of research is unimportant. Breast cancer is a complex disease with complex psychosocial effects. It stands to reason that recurrent breast cancer triggers an assortment of new stressors and psychological/social needs. The window of opportunity for effectively intervening in the biopsychosocial needs of recurrent patients is narrow, and it is crucial for health care providers to identify the individual needs of their patients in order to provide the best possible overall care. Additional research is needed to identify empirically supported interventions for this population.

This review has limitations. First, the author did not include all articles in the given time period. While it is felt that key articles were cited, without an all inclusive review it is possible that important factors regarding breast cancer recurrence may have been missed, thus biasing results. Second, the time frame used was the last twenty years. By limiting the search in this way, it was felt that the most pertinent and up-to-date information would be identified. Thirdly, this review did not assess for the methodological and statistical rigor of the studies examined. Conclusions drawn from poorly designed studies would be suspect.

While the literature surrounding breast cancer recurrence is growing, many gaps continue to exist. Studies in regard to breast cancer's effects on family tend to focus on the spouse. While this makes sense because the spouse is more often than not the primary caregiver, other family dynamics are being ignored. Children are often viewed as helpless victims when their mother
has breast cancer. Little to no research has focused on children as a support mechanism for the patient and other family members. In cases of recurrence, children may play an even larger role in the support structure. Children who witnessed the struggle of the initial diagnosis may be more likely to fill potential gaps in the support system. Knowing the difficulties faced by both mother and father, children can try to be more helpful in daily activities to ease the burden of the parents. Extended family members are often overlooked, as we know little about the effects of recurrence on sisters, brothers, daughters and sons of the patient. Also unexplored are the ways in which extended family provide support or the reasons why that support may be lacking. Research into these groups is needed to provide the most complete psychosocial picture of the patient as well as to inform psychosocial treatment.

As of now there are few longitudinal studies exploring the entire cancer experience, from initial diagnosis through recurrence. Studies such as these are expensive and time consuming. However, it is felt that the potential knowledge gained from such studies would be worth the expense and effort. Snapshots of a woman’s psychological profile at initial diagnosis, recurrent diagnosis, and 3-6 months post recurrent treatment might provide crucial information about these critical stages. However, there is no literature on the long term effects of surviving a recurrence. How do women who survive a recurrence change as their life moves on to yet another stage? What new or familiar concerns still linger? How do family and friends get over not one, but two encounters with the disease? All of these questions remain unanswered and need to be addressed.

Despite the plethora of research in this area, there remain unanswered questions. More studies are needed on the emotional trajectory of breast cancer recurrence. More frequent follow-ups (e.g., monthly as opposed to 3-6 months) would allow researchers to better
understand a patient’s emotional path and the appropriate time points for interventions. We do not know whether the length of the disease free period between initial diagnosis and recurrence have an effect on coping with the recurrence. Women may choose any number of people for emotional support. Does the choice of confidant affect emotional outcome? Does a close sister or friend have the same emotional effect as a husband? A flaw in current studies is that most deal with women with distant metastatic recurrence. One study suggested that women with local recurrence suffered more psychosocial distress than metastatic disease because of the threat of another surgery (Bull et al., 1999). What differences exist for women with local or regional recurrence? Is what we know about the psychosocial effects of recurrence skewed by this focus on metastases? These are empirical questions that require further investigation.

The term survivor as previously discussed, is commonly used to describe women whose cancer is in remission. What about the women whose cancer has returned? The current public view of the breast cancer survivor does not seem to make room for recurrent patients. Fundraisers and the media focus on survivors with little attention given to women with recurrence or women dying from breast cancer. These women may feel as if they are failures even if the disease return was beyond their control. Studies need to examine how recurrent breast cancer patients view themselves, as well as how they view the survivor identity. Understanding their viewpoint can help health care providers adjust their approach to recurrent patients and not merely lump them in with other “survivors.”

Similarly, the general public needs to be made more aware of the recurrent population. The Race for the Cure is a worthy cause but may not be doing enough in the education of women about prevention and the possibility of recurrence. Too many people seem content to put on their pink ribbon and claim understanding of the disease and its psychosocial consequences.
Breast cancer has seemingly become a “fad” or the medical “hot topic” for the public to support. Support without understanding, however, can be dangerous. Ignorance of the risk factors that can lead to breast cancer and its recurrence undoubtedly leads to an increase in breast cancer patients. Lack of understanding by the general public on dealing with recurrence can lead to increased alienation and psychosocial damage for the recurrent patients. Efforts should be made to educate the public more thoroughly in this regard.

Large strides have been made in understanding breast cancer recurrence and its emotional and psychological impact. Health care providers have ready access to information that will help women with breast cancer but there are gaps in that knowledge that require additional research efforts. As more women survive the initial diagnosis, a shift in public awareness and knowledge must be made about the possibility of recurrence and the existence of women who are facing recurrence.
References


Abstract

Objective: To examine the psychosocial effects of breast cancer recurrence and compare with that with the initial diagnosis.

Methods: A literature review was conducted and found 39 articles published the last twenty years using the databases PubMed and PsycINFO.

Results: Key factors affecting psychosocial outcomes in those with breast cancer include young age; symptoms (fatigue and pain); ability to cope; social support and family. This is independent of initial or recurrent phase. Psychiatric disorders are not common after initial or recurrent disease, but psychological distress is prominent. During the period following treatment cessation uncertainty and lack of frequent monitoring by health care providers contribute to distress.

Conclusion: The literature is divided on whether women dealing with recurrence suffer more, less, or equal psychosocial consequences. More research is needed to discover what differences exist in order to provide optimal interventions for recurrent breast cancer patients.