

2006

The psychological implications of breast cancer: A review of the literature ; Shattered motherhood: Young mothers living with breast cancer

Kelly Gibson
Edith Cowan University

Follow this and additional works at: https://ro.ecu.edu.au/theses_hons



Part of the [Personality and Social Contexts Commons](#)

Recommended Citation

Gibson, K. (2006). *The psychological implications of breast cancer: A review of the literature ; Shattered motherhood: Young mothers living with breast cancer*. https://ro.ecu.edu.au/theses_hons/1054

This Thesis is posted at Research Online.
https://ro.ecu.edu.au/theses_hons/1054

Edith Cowan University

Copyright Warning

You may print or download ONE copy of this document for the purpose of your own research or study.

The University does not authorize you to copy, communicate or otherwise make available electronically to any other person any copyright material contained on this site.

You are reminded of the following:

- Copyright owners are entitled to take legal action against persons who infringe their copyright.
- A reproduction of material that is protected by copyright may be a copyright infringement. Where the reproduction of such material is done without attribution of authorship, with false attribution of authorship or the authorship is treated in a derogatory manner, this may be a breach of the author's moral rights contained in Part IX of the Copyright Act 1968 (Cth).
- Courts have the power to impose a wide range of civil and criminal sanctions for infringement of copyright, infringement of moral rights and other offences under the Copyright Act 1968 (Cth). Higher penalties may apply, and higher damages may be awarded, for offences and infringements involving the conversion of material into digital or electronic form.

USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

Running Head: MOTHERS AND BREAST CANCER

**EDITH COWAN UNIVERSITY
LIBRARY**

The Psychological Implications of Breast Cancer: A Review of the Literature

Shattered Motherhood: Young Mothers Living With Breast Cancer

Kelly Gibson

A report submitted in Partial Fulfilment of the Requirements for the Award of

Bachelor of Arts Honours, Faculty of Computing, Health and Science,

Edith Cowan University.

October 2006

I declare that this written assignment is my own work and does not include:

(i) material from published sources used without proper acknowledgement;

or

(ii) material copied from the work of other students.

Declaration

I certify that this thesis does not, to the best of my knowledge and belief:

(i) incorporate without acknowledgement any material previously submitted for a degree

or diploma in any institution of higher education

(ii) contain any material previously published or written by another person except where due reference is made in the text; or

(iii) contain any defamatory material

I also grant permission for the Library at Edith Cowan University to make duplicate copies of

my thesis as required.

Signature:

Date:

16.01.2007

Acknowledgements

The author is thankful to the women who willingly shared their story about their breast cancer experience.

Table of Contents

The Psychological Implications of Breast Cancer: A Review of the Literature	1
Abstract	2
Introduction	3
Breast Cancer	4
Body Image, Identity and Self Concept	6
Emotional Distress, Coping and Adaptation	11
Family Functioning	17
Limitations	21
Conclusion	22
References	25
Shattered Motherhood: Young Mothers Living With Breast Cancer	30
Abstract	31
Introduction	32
Body Image and Transformed Self	32
Emotional Distress, Coping and Adaptation	33
Family Life	34
The Current Study	36
Method	
Research Design	37
Participants	37
Data Collection Procedures	38
Rigour	39
Ethics	40
Data Analysis	40

Findings and Discussion	
Breast Cancer Challenged My Role as a Mother	41
Holding Onto Motherhood	44
Mothering Beyond the Grave	46
I am a Mother, not an Object	47
Help me to be a Mother	50
I am a Mother and I am Still Here	53
Conclusion	54
References	56
Appendix A	
Information Sheet	60
Appendix B	
Participant Consent Form	62
Appendix C	
In-Depth Interview Schedule	63
Appendix D	
List of Counselling Services	64

Running Head: PSYCHOLOGY OF BREAST CANCER

The Psychological Implications of Breast Cancer: A Review of the Literature

Kelly Gibson

A report submitted in Partial Fulfilment of the Requirements for the Award of

Bachelor of Arts Honours, Faculty of Computing, Health and Science,

Edith Cowan University.

August 2006

I declare that this written assignment is my own work and does not include:

(i) material from published sources used without proper acknowledgement;

or

(ii) material copied from the work of other students.

Signed: Kelly Gibson

Abstract

The purpose of this paper is to provide a critical review regarding the psychological implications of breast cancer, with a particular focus on younger women. In general due to their life stage, it appears that younger women have more problems with psychological adjustment to breast cancer compared to their older counterparts. Specifically, younger women appear to be more psychologically vulnerable to greater disruption to their daily lives due to the untimely nature of a breast cancer diagnosis, and have greater unmet practical needs, such as childcare. Limitations of the research literature are explored with specific attention to sample characteristics. Suggestions for future research are discussed based on methodological and conceptual issues. It is indicated that long-term outcome studies are required to strengthen the knowledge already attained within this field.

Kelly Gibson

Dr Moira O'Connor

Dr Colleen Fisher

August 2006

The Psychological Implications of Breast Cancer: A Review of the Literature

Chronic health problems are characterised by having complex causality, multiple risk factors, a long latency period, a prolonged course of illness, functional impairment or disability, and in most cases, the unlikelihood of cure (Australian Bureau of Statistics: Australian Social Trends, 2006; National Public Health Partnership, 2001). According to the National Public Health Partnership (2001), diseases or illnesses classified as 'chronic' include cardiovascular diseases, diabetes, chronic renal diseases, arthritis and other musculoskeletal diseases, chronic neurological disorders and cancer.

Chronic illness places considerable emotional burdens on sufferers and, as such, the psychological adjustment to chronic illness is an important focus of research (Hatchett, Friend, Symister, & Wadhwa, 1997). Cancer is of particular interest due to the range of emotional, psychological and practical challenges that accompany the physical symptoms and treatments throughout the illness trajectory. These may include: coping with the shock of their diagnosis and fears over their health and future; physical symptoms and adverse effects of treatment such as nausea, fatigue and physical changes in body appearance and functioning; financial costs, altered occupational, employment and financial status; and psychological difficulties ranging from concerns about body image and sexuality to severe disorders such as anxiety and or depression (National Health and Medical Research Council [NHMRC], 2003). Whilst developing clinical practice guidelines for the psychosocial care of adults with cancer, the National Health and Medical Research Council (2003) found that up to 66% of people who experience or who have a diagnosis of cancer experience long-term psychological distress, up to 30% experience clinically significant anxiety problems, and prevalence rates for depression range from 20%-35%. Many people report inadequate information to guide decision-making, and others feel they are disadvantaged because of a lack of knowledge

about practical support, even when such services are available (NHMRC, 2003).

Avoidance strategies, such as denial, constitute one of the several types of coping strategies people use to deal with adaptation to the disease and are dependent on the person's personality, the physical and social environment and the specific chronic health problem to which he or she must adjust (Caltabiano, Byrne, Martin, & Sarafino, 2002).

Whilst several types of chronic illnesses and their implications are acknowledged, this paper is primarily focused on the psychological implications of a specific chronic illness, namely breast cancer.

Breast Cancer

Compas and Luecken (2002) describe breast cancer as a disease affecting women (and a very small minority of men) both in Australia and internationally. Around 30% of women diagnosed with breast cancer in Australia are 50 years of age or under, and approximately 6% are 40 years of age or under (Breast Cancer Network Australia, 2005). Studies have shown that the experience of breast cancer can be more psychologically demanding for these women as they face unique needs at their earlier stage of life (Avis, Crawford & Manuel, 2004). Issues such as fertility, pregnancy, raising young children, achieving career goals, treatment induced menopause, body image, sexuality and relationship concerns may cause additional distress at diagnosis as well as during and after treatment. It is indicated that young women want effective strategies put in place to fulfil their unmet needs (Breast Cancer Network Australia, 2005).

It is noted that in 2003 in Western Australia alone, 141 (12.6%) new cases of breast cancer were recorded for women aged 15-44, with the largest number recorded (70 new cases) for the 40-44 age group. In addition, 21 (8.2%) women aged 44 or less died as a result of breast cancer in 2003 (Western Australian Cancer Registry, 2005).

For women in general, in addition to the physical effects of breast cancer, the psychological effects of the illness, largely documented by patients' self-reported mood and psychological symptoms, are wide ranging and include aspects in relation to psychological distress, such as depression and anxiety (Compas & Luecken, 2002); sexuality and body image (Pelusi, 2006); overall quality of life (Ferrell et al., 1998; Kroenke et al., 2004); and coping methods (Osowiecki & Compas, 1999). Further, in relation to identity and self-concept, it is proposed that the self is changed or transformed by the cancer experience, particularly in relation to discrepancies that occur between the way in which a woman formerly perceived herself and how she now sees herself as a result of cancer and its treatment (Pelusi, 2006). Although advances in detection and treatment have improved the prognosis and life expectancy of breast cancer sufferers, more knowledge is required regarding the psychological and emotional implications of the disease (Compas & Luecken, 2002).

The purpose of this paper is to review the literature in relation to the psychological implications of breast cancer. This paper aims to demonstrate the way in which breast cancer impacts on the ability of sufferers to psychologically adjust to the illness. The review of the literature will primarily focus on three aspects of living with a breast cancer diagnosis: body image, identity and self-concept; emotional distress, coping and adaptation; and family functioning. Focusing on these aspects, the review will explore the way in which breast cancer impacts on how women view themselves; the way in which breast cancer disrupts everyday life and the ability of sufferers to cope effectively and adjust emotionally to the diagnosis and treatment of the illness; and finally, the way in which breast cancer impacts on family functioning such as mothering roles. Within each section of the review, the research will be explored and critically reviewed. Consideration will also be given to the limitations of studies as well as

directions for future research, with specific attention given to methodological and conceptual issues.

Body Image, Identity and Self Concept

Markus (1977) proposed that attempts to organise, summarise and explain behaviour in a particular domain results in the formation of cognitive structures about the self entitled self-schemata. Self-schemata (self concept) are cognitive generalisations about the self, derived from past experience, that organise and guide the processing of self-related information contained in the individual's social experiences (Markus, 1977). Self-schemata represent the way the self has been differentiated and articulated in memory. They are generated because they are useful in understanding intentions and feelings and in identifying likely or appropriate patterns of behaviour. The union of self-schemas in various focal domains represents the unique identity of self as self-concept including special abilities, achievements, preferences, appearance and temperament (Bernstein, Nash, Clarke-Stewart, Penner & Roy, 2002). The concept of self-schema implies that information about the self in some area has been organised and then used as a basis for future judgements, decisions, inferences or predictions about the self. Therefore, the foundation of self-schemata is influenced by how an individual encodes experiences (Mischel, 1999).

It is indicated that living with breast cancer may affect personal self-concept (opinion/beliefs/views/perceptions of self); social self-concept (perceptions of how one is regarded by others); and self-ideals (perceptions of oneself with respect to how one would like to be) (NHMRC, 2003). As the most visible site of femininity, sexuality, nurturing and eroticism, breast loss is said to challenge a woman's identity as a woman (Crompvoets, 2003). It is described that diagnosis with a life threatening illness such as breast cancer can have a significant impact on one's self (Morse & Carter, 1996).

Physical changes associated with acute and chronic effects of treatment, disruptions in the ability to fulfil one's roles within the family and society, and psychological and spiritual aspects of coping with a life-threatening illness can lead to changes in attitudes, perspective, meaning, outlook and interpersonal interactions (O'Connor, Wicker, & Germino, 1990).

Body image is a component of self-concept and involves the perception and evaluation of one's body, appearance and functioning. Body image refers to the person's conception of, and feelings about one's body – its form, size, shape and the way it fits society's norms (Carver et al., 1998). Price (1990) described body image as comprising three aspects: body reality, the body as it really exists; body ideal, the picture in one's mind of how one would like the body to look and perform, including norms for body contour, body space, and boundaries and finally; body presentation, how the body is presented to the outside environment. It is indicated that breast cancer treatment changes body reality and body ideal and may affect body presentation (Price, 1990). Many women with early stage breast cancer now have a choice regarding their primary breast cancer surgical treatment, either mastectomy or breast-conserving surgery. A woman's body image including the symbolic meaning and importance of her breasts, along with societal views regarding the breast, influences her breast cancer treatment decision (Carver et al., 1998). Research suggests that alterations in satisfaction with body image related to breast cancer treatment influence women's adjustment (Yurek, Farrar, & Andersen, 2000).

A study conducted by Kraus (1999) was undertaken in order to describe women's satisfaction with body image before and eight weeks after the surgical treatment of breast cancer compared with women without breast cancer. Additional aims were to describe women's perceived participation in decisions regarding choice of

surgical procedure (mastectomy or breast-conserving surgery) to treat their breast cancer, postoperative satisfaction with their breast cancer surgical treatment, and to explore factors influencing women's decisions regarding choice of surgical procedure. The study used a prospective design comparing two groups of women (women without a history of breast cancer and women with early-stage breast cancer) at two points in time. The sample consisted of 31 women having breast cancer treatment (15 mastectomy; 16 breast-conserving surgery), and 30 women without a history of breast cancer. The breast cancer group was tested approximately one week before surgery and eight weeks after surgery; the women without breast cancer were tested on two occasions approximately eight weeks apart. The majority of participants were married, Caucasian, college educated and ranged in age from 29 to 82 years. Three instruments measuring body image satisfaction were used. Open and closed ended questions assessed participation in treatment decision-making, description of important factors in decision-making, having a treatment choice, and post treatment satisfaction.

The results of the Kraus (1999) study indicated that body image satisfaction was constant over time in the group of women without breast cancer. However, for the breast cancer group, there was a significant decrease in body image satisfaction from pre-treatment to post-treatment. In addition, a trend was found in the data suggesting that women who chose mastectomy were not less satisfied with their body image than the women who chose breast-conserving surgery. A possible explanation could be that when faced with a life-threatening situation, a woman's physical appearance becomes less important. Although the results of this study already contradict previous research results investigating body image in women with breast cancer, where women who had breast-conserving surgery had higher body image scores post-treatment than women who had mastectomies (Ganz, Schag, Lee, Polinsky & Tan, 1992; Yurek, Farrar, &

Andersen, 2000), replicating the study with a larger random sample drawn from the same population may provide improved generalisability.

In relation to decision making regarding treatment options, the results indicated that most of the women believed they had a choice regarding treatment, were active participants with the surgeon in the decision-making process, were well informed, and were very satisfied with their treatment decision eight weeks after their breast cancer treatment. Although the current study provided evidence that body image satisfaction in women undergoing breast cancer treatment decreases from pre to post treatment, the time between testing was only eight weeks. Future studies should be conducted with the post treatment testing of the women over longer time periods (possibly six months to a year) after their breast cancer treatment in order to determine whether differences in body image persist, and to investigate the stability of body image over time.

Markus (1977) proposed that self-concept is derived from the way in which individuals formulate information about the self as a result of their experiences. Similar to this concept is the notion of self-transformation, which involves redefining the self within the context of the illness experience (Carpenter, Brockopp & Andrykowski, 1999). It allows for the possibility that diagnosis with a life-threatening event can lead to self-transformation, including personal growth. Within this concept, illness is recognised both as an event that can lead to painful physical side effects, loss of role functioning, anxiety and depression, as well as an opportunity for growth or increased well-being (Carpenter, Brockopp & Andrykowski, 1999).

In order to investigate the notion that the self is changed or transformed by the cancer experience, Carpenter et al. (1999) compared self-transformation in women with and without breast cancer. The purpose of study was to describe individual differences in self-transformation, examine factors associated with self-transformation and examine

the relationships between self-transformation, self-esteem and well-being in breast cancer sufferers. Sixty breast cancer sufferers with an age range of 35-77 years participated in semi-structured interviews. Both breast cancer sufferers and disease-free healthy comparison women aged 35-78 years completed a set of self-esteem and well-being questionnaires. Breast cancer participants varied in disease severity and treatment phase, while the healthy comparison group, with no history of any cancer, were age matched within four years to a breast cancer sufferer. Participants were primarily Caucasian, married and had completed an undergraduate or graduate college degree.

Narrative analysis of the Carpenter et al. (1999) study revealed three categories of transformation among breast cancer sufferers: positive transformation, minimal transformation and feeling stuck, with the most common experience being minimal transformation (45%). It was reported that the process of positive transformation began with increased self-awareness, which was triggered by sudden awareness of personal mortality. Breast cancer sufferers reported a new understanding of themselves, which they used in order to make changes in various aspects of their lives such as relationships or work. The women in this group viewed such transformations extremely positively, as they reported feeling stronger, more courageous and more satisfied with their selves and lives following breast cancer diagnosis. Conversely, some women described minimal transformation, whereby a desire or need to make changes was less likely to occur.

Associated with minimal transformation was the fact that awareness of mortality did not have as great an impact and women were less apt to engage in a process of self-examination and introspection. Women in the minimal transformation group reported a high degree of self-acceptance and thus, reported no need for change. Finally, women who reported feeling stuck in the process of transformation were characterised by having a desire to change, but an inability to achieve change. Factors associated with

feeling stuck included a lack of mental and physical strength necessary to examine the self and move to make changes, a lack of clear expectations about how they wanted to change, and a lack of support and information from friends, family and health care professionals to make desired changes.

In addition to these findings, women who experienced positive transformation as a result of their breast cancer reported higher self-esteem and well-being in comparison to other breast cancer sufferers and disease-free healthy women the same age. However, breast cancer sufferers who reported feeling stuck had significantly lower self-esteem and well-being than other groups of breast cancer sufferers and lower well-being in comparison with disease-free healthy women the same age (Carpenter, Brockopp & Andrykowski, 1999).

Although the findings of the study provided further support for the emerging concept of self-transformation in breast cancer sufferers, it was a relatively focused study, limited to investigation of self-esteem and well-being. Further research should explore other issues related to chronic illness such as psychological distress. In addition, further qualitative research might be particularly appropriate for understanding the process of self-transformation, as opposed to the outcomes associated with self-transformation. Similar to the internal cognitive appraisals that govern body image, identity and self-concept, the following section explores breast cancer sufferers' ability to adapt emotionally and cope with the diagnosis and treatment of the illness.

Emotional Distress, Coping and Adaptation

Lazarus and Folkman (1984) define coping as a constantly changing cognitive and behavioural effort to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. It is indicated that there are two major functions of coping. The first function is to change the disturbed person-

environment relationship by acting on the environment and resolving the problem or making alterations to the source of stress, especially when the conditions are appraised controllable by action (problem-focused coping) (Lazarus & Folkman, 1984). The second function is to regulate strain and emotion by changing the relational meaning of the stressful encounter, especially in conditions, which are viewed by the person as refractory to change (emotion-focused coping).

According to Anagnostopoulos, Vaslamatzis and Markidis (2004), adjustment to breast cancer is viewed as a process of adaptation that involves the complex interaction of the characteristics of cancer and its treatment, cognitive appraisals and coping efforts. The changing demands of the stress of breast cancer such as those resulting from the shock of diagnosis, various aspects of treatment, and continued uncertainty about the future, provide opportunities for sufferers to develop cognitive appraisals of control and cope with the disease. It is indicated that both appraisals of control and coping efforts have been shown to be important predictors of psychological adjustment to breast cancer (Epping-Jordan et al., 1999).

The objectives of the longitudinal study undertaken by Anagnostopoulos et al. (2004) were to investigate and distinguish the coping strategies adopted by breast cancer sufferers in comparison to a non-malignant control group. A sample of 180 women with breast cancer and 268 women who were diagnosed with a benign disease or were disease-free participated in the study. Participants ranged in age from 18 to 75 years, were of Greek nationality, had a high school education, 78% were married and the remaining 22% were single, divorced or widowed. Eighty percent of the participants had children. Participants included in the breast cancer group were, on average, older than those who represented the disease-free/benign control group. A series of psychological questionnaires were administered, including The Ways of Coping

Questionnaire (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986 as cited in Anagnostopoulos et al., 2004). This self-report instrument was utilised in order to record the type (problem-focused or emotion-focused) and frequency of coping strategies used under the health conditions.

The results of the Anagnostopoulos et al. (2004) study indicated that breast cancer sufferers did not significantly differ from disease-free/benign women in respect to the frequency of use of the problem-focused form of coping and most of the emotion-focused forms of coping such as self-isolation, passive acceptance, positive reappraisal, distancing and wishful thinking. It was found that the only strategy that distinguished breast cancer sufferers from controls was the emotion-focused strategy of self-blame, where breast cancer sufferers had significantly lower scores indicating the infrequent use of this strategy. It was indicated that this was a coping strategy that allowed breast cancer sufferers to avoid guilt, a low self-esteem, and social distance, which in turn benefited psychological adaptation, successful coping and long-term survival.

Although the study by Anagnostopoulos et al. (2004) provided evidence in relation to coping strategies utilised by breast cancer sufferers, the cross sectional design of the study prevented establishing the consistency of coping strategies over time and across situational contexts. In addition, in this particular study, breast cancer sufferers were on average older than the disease-free/benign control group. It is indicated that older women may employ enhanced adaptive and coping skills in relation to a breast cancer diagnosis in comparison to younger women (Compas et al., 1999; Osowiecki & Compas, 1999). Thus, this may explain why the sample of breast cancer suffers in this study did not significantly differ in the frequency of use and types of coping strategies than the younger, disease-free/benign control group. Further, the sample of women included in this study was of Greek nationality. This might pose some

implications in terms of generalising the results to different cultural populations.

Finally, given that only self-report measures were utilised in this study, it was suggested that in-depth interviews might be useful in illuminating the meaning of other coping strategies used by women with breast cancer, such as hope and spirituality (Ferrell et al., 1998).

In order to explore further the coping strategies utilised by breast cancer sufferers, Osowiecki and Compas (1999) assessed the relationship between perceptions of control and coping efforts with emotional distress in 70 women newly diagnosed with breast cancer. The participants varied in disease severity and ranged in age from 36-80 years. The majority of participants were married or living with a partner and had children. Interviews and written questionnaires were completed on three separate occasions; near the time of diagnosis and again at approximately three and six months post-diagnosis. A structured interview was utilised in order to collect information on perceptions of control, while written questionnaires were used in order to assess coping strategies employed in managing a stressor (cancer) and symptoms of emotional distress (anxiety and depression). Coping was assessed with an instrument that distinguished between engagement and disengagement responses that were problem and emotion focused in their intent. Engagement coping includes responses that are orientated toward the problem or one's emotions and involve active attempts at problem or emotion management. In contrast, disengagement coping involves attempts to avoid either the problem or one's emotions (Osowiecki & Compas, 1999).

The results of the Osowiecki and Compas (1999) study indicated that sufferers' coping was related to anxiety and depression symptoms near diagnosis and again at the six month follow-up. Specifically, problem-focused engagement coping (problem solving and cognitive restructuring) was associated with lower symptoms of emotional

distress near diagnosis and again at the six month follow-up. Conversely, emotion focused disengagement coping (social withdrawal and self-criticism) were related to higher symptoms of anxiety and depression at the six month follow-up. In contrast, sufferers' perceptions of control were not associated with symptoms of anxiety and depression near diagnosis or at the three and six month follow-ups. Thus, from the results of this study it was suggested that it might be useful and appropriate to teach active problem solving skills and strategies for ascertaining opportunities for control to individuals who are confronted with a diagnosis of cancer and its subsequent treatments. However, this study included a sample of breast cancer sufferers who dramatically ranged in age from 36-80 years. Thus, the results do not specifically indicate if differences existed in perceptions of control, coping and emotional distress for women in different age groups. Further research should investigate if any differences exist in the psychological adjustment to breast cancer for older and younger women (Osowiecki & Compas, 1999).

Research suggests that elderly women experience more persistent problems with physical function after breast cancer diagnosis, whereas younger women appear to have more problems with psychological adjustment (Avis, Crawford & Manuel, 2004). While much of the decline in elderly women appears to be associated with age rather than the disease or treatment, younger women appear to experience greater life stage challenges in adapting to the unexpectedness of breast cancer diagnosis, including aspects such as a greater fear of death, possible losses in their careers, concerns about the impact on their families and lost opportunities for childbearing (Kroenke et al., 2004).

Given that Osowiecki and Compas (1999) identified that further research should be conducted to explore the negative correlation between age and emotional distress among women with breast cancer, Compas et al. (1999) investigated symptoms of

anxiety and depression in 80 women aged 36-80 years with newly diagnosed breast cancer on three separate occasions, near the time of their diagnosis and at three and six months post diagnosis. Participants varied in disease severity and a majority were Caucasian, married and had completed a college degree. A minority of participants had never completed high school, were divorced, single or widowed and identified as either African-American or Asian-American. Participants were required to take part in a 30 minute structured interview and complete several self-report measures including a symptom checklist and a coping strategies inventory.

The results of the Compas et al. (1999) study indicated that younger women experience poorer psychological adjustment near the time of diagnosis, however, this association was no longer significant at follow-up assessments, three and six months later. However, independent of participant age, employing the use of emotional expression (ventilation) coping was associated with poorer psychological adjustment at the six month follow-up. It was concluded that although these results suggest that younger women find the diagnosis of breast cancer more traumatic, they are able to adapt as well as their older counterparts once the initial stress has subsided. Thus, the results of the study indicate that the provision of additional psychological services for younger women at the time of diagnosis may be warranted. Furthermore, coping may be an appropriate target for interventions designed to assist women of all ages in adjusting to a breast cancer diagnosis. These interventions may decrease the use of avoidance coping strategies and pure ventilation of emotions, which in turn may enhance psychological adjustment to breast cancer. Whilst the study provided evidence in relation to the experience of adjustment to breast cancer in older and younger women, such studies do not provide definitive information related to women of a specific life stage or age group. The use of age-specific samples or samples that belong to a specific

life stage are useful approaches for examining special issues for women in a particular age group or life stage (Sammarco, 2001).

According to the National Breast Cancer Centre ([NBCC], 2003), approximately 6% of new breast cancer cases diagnosed in Australia each year are in women aged 40 years or younger. Although incidence is lower in younger women compared with their older counterparts, younger women are more likely to be diagnosed with larger, more aggressive tumours, and have worse disease-free and overall survival outcomes (NBCC, 2003). Specifically, younger women appear more vulnerable to greater disruption to their daily lives, and have greater unmet practical needs, such as childcare. It is indicated that further research should focus on conceptualising the experience of a breast cancer diagnosis in mothers with dependent children (Billhult & Segesten, 2004; Fitch, Bunston, & Elliot, 1999). As such, the section below provides support that mothers who are faced with a breast cancer diagnosis experience distress in relation to coping with the debilitating effects of treatment, as well as the ongoing future needs of their children.

Family Functioning

Delmore-Ko, Pancer, Hunsberger and Pratt (2000) describe that as with any other major transition, becoming a parent is considered to be a turning point during which a person's life course, regardless of age, gender and background, takes new direction, requiring adaptation or change in life and behaviours. It is indicated that challenges confronted by individuals when they become parents represent a developmental opportunity for maturation and new growth (Delmore-Ko et al., 2000). Changes that individuals undergo during this time reflect psychological implications related to thoughts about self, and roles as parents, workers, marital partners and family members (Pancer, Pratt, Hunsberger, & Gallant, 2000). In addition to these changes, for

many individuals, the opportunity to be a “good” mother or father can be disrupted if a chronic illness or disease strikes one of the parents (Elmberger, Bolund, & Lutzen, 2000).

Although it is usually thought that chronic illness only affects the lives of the elderly, it is becoming more prevalent among younger people. For instance, it is noted that in 2004 in Australia, 35% of people aged between 25 and 44 died of a chronic illness (Australian Bureau of Statistics: Causes of Death, 2006) and it is indicated that a majority of people in this age range are also most likely to be in the process of rearing children (Heinicke, 1995). This suggests that large numbers of families will experience the chronic illness of a parent at some point in their life. Steele, Forehand and Armistead (1997) found that parental chronic illness can disrupt the family system through a number of ways including emotional distress of the parents, experiencing difficulties in the parent/child relationship and adverse effects to the marital relationship and daily functioning of the family.

For parents, after a cancer diagnosis, the demands of illness are added to the normal burdens of family life, and cancer patients are often unable to fulfil their usual parental roles and the internal structures of families are exposed to change (Compas et al., 1994; Pedersen & Revenson, 2005). Caring for children involves responsibility for their well-being and knowledge about their needs and how to accommodate these (Fitch, Bunston, & Elliot, 1999). However, when facing cancer, it is indicated that the importance of being a “good” parent is altered because parental and family priorities shift and focusing on the children becomes difficult (Davis-Kirsch, Brandt, & Lewis, 2003). In particular, many mothers feel that they are letting their children down because they are unable to give them enough attention and seem to be torn between their own and their children’s needs for care (Helseth & Ulfsaet, 2005; Ohlen & Holm, 2006). The

limited research regarding young women's experiences of breast cancer presents an image of increased psychological distress for the women in this predicament (Ohlen & Holm, 2006), given research appears to focus more on the adaptation of a family in relation to the mother's breast cancer from the perspective of the family members, rather than the real world experiences of the mother (Helseth & Ulfsaet, 2005). Furthermore, Sammarco (2001) indicated that the use of age-specific samples or samples that belong to a specific life stage are useful approaches for examining special issues for women in a particular age group or life stage.

In order to mitigate this limitation, the purpose of the study conducted by Fitch, Bunston and Elliot (1999) was to explore, from a woman's perspective, the experience of being a mother living with a life-threatening illness. Specifically, the objectives of the study were to obtain an understanding in relation to what changes occur for the woman, how these changes influence her role as a mother, how the family reacts and copes when the mother has been diagnosed with cancer and finally, how relationships and communication patterns in the family change.

The participants included 47 women aged 33 to 51 years and represented eight different disease sites: ocular, melanoma, breast, gynaecologic, lung, lymphoma, leukaemia and gastrointestinal. The majority of participants were married and had children ranging in age from four to 18 years living at home. Using a qualitative research design, in-depth interviews were conducted in order to provide a window into the experiences of being a mother and living with cancer. The researchers encouraged each woman to reveal, in her own words, the meaning she attached to the illness, which provided insight into the impact of her illness on herself or her family (Fitch et al., 1999).

Various themes emerged from the study. Firstly, the women indicated that the diagnosis and treatment of cancer had an impact on them as women as well as on their partners and children. For many participants, the physical impact of the cancer (fatigue, nausea) and the hospital visits (separation) were particularly disruptive to their mothering roles. In addition, further distress was reported regarding the organisation of the children's care. Secondly, the impact of the cancer and its treatment led to changes in both roles and relationships for women and their children. The inability to do what the women normally did created tensions for these mothers. Further, if the mother was not available to play or spend time with the children, someone else had to fulfil those roles. These changes, in turn, created difficulties in relation to who was going to take on the mothering roles. Finally, the family's ability in adjusting to these differing demands was linked to their ability to utilise effective coping strategies, as well as the support available to them. The study indicated that while many women received a wide variety of instrumental support, there was very little emotional support (Fitch et al., 1999).

Although this study provided insight into the woman's perspective of living with a life-threatening illness, in particular cancer, such studies do not provide information related to women of a specific cancer diagnosis. The use of disease-specific samples would be a useful approach to examine special problems or issues for women who have a particular illness, such as breast cancer. Without this knowledge, health care systems cannot respond appropriately to the issues surrounding a mother's role during the breast cancer experience.

Billhult and Segesten (2003) used a phenomenological approach in order to investigate women's experiences of living with a life threatening illness from a disease specific perspective. In particular, the purpose of the study was to investigate the experience of breast cancer in mothers with dependent children, and the strategies

women used to cope with their illness in relation to their children in the context of parenting. Ten Swedish women with non-recurrent breast cancer were interviewed. Participants ranged in age from 32-48 years and had children ranging in age from one to 26 years. The average duration since time of initial diagnosis was 14 months.

The findings of the study revealed that the women experienced many dilemmas. Firstly, the women found it very distressing when thinking about what might happen to their children without their presence, whether precipitated by illness or death. Secondly, the women expressed a will to be strong for their children, despite experiencing debilitating side effects of treatment. Thirdly, the women needed to strike a balance between telling the truth about the seriousness of the illness and protecting the children from the truth. The strategies the women used to help them with these struggles were to carry on as usual and continue everyday life, gain strength with support from others, and try to turn things into a positive perspective. Given the study involved a relatively small sample, Billhult and Segesten (2003) indicated that further research is needed to support the findings. More importantly, similar to the implications presented by Fitch, Bunston and Elliott (1999) study, further research is needed to assess and thoroughly evaluate health care services to ascertain if they meet the specific needs of breast cancer sufferers who have dependent children.

Limitations

Although research in relation to breast cancer appears to provide valuable insight into the psychological implications experienced whilst diagnosed with this particular chronic illness, this review identified several limitations. Firstly, although previous studies have explored the psychological adjustment of a breast cancer diagnosis and its treatment in sufferers, overall, the research relies heavily on cross-sectional data with dramatic variances in age and disease severity. Although this may be

warranted to some extent, given it provides knowledge in relation to the psychological issues facing women in general, such studies do not provide definitive information related to women of a specific life stage or age group. The use of age-specific samples or samples that belong to a specific life stage would be useful approaches for examining special problems or issues of women in a particular age group or life stage (Sammarco, 2001).

Secondly, when evaluating the experiences of women living with breast cancer, the majority of literature focused on samples of women who were primarily Caucasian, were in committed relationships, had relatively high levels of education, and came from middle to high socioeconomic backgrounds. Thus, difficulties may be encountered in generalising the findings to other populations. There appears to be limited knowledge in relation to the experience of breast cancer in ethnic minority populations and women with different demographic variables. Future research focusing on individual differences within context and settings may remedy this limitation.

Finally, the majority of efficacy studies investigating the experience of breast cancer for women are relatively small, brief, and are marked by minimal long-term follow-up. Small sample sizes limit statistical power to detect meaningful differences across treatment groups. As a result, longitudinal empirical data are needed to support existing short-term implications of breast cancer and to enhance the development of new innovative intervention techniques to assist with the psychological adjustment to breast cancer.

Conclusion

Breast cancer is a chronic illness that has a significant impact on sufferers and their supportive networks. Although limitations are cited, research literature continues to support the fact that women diagnosed with breast cancer experience psychological

implications due to the emotional, psychological, physical and practical challenges related to the disease (National Health and Medical Research Council [NHMRC], 2003). It is indicated that breast cancer sufferers experience decreased body image satisfaction after surgical treatment as a direct result of that treatment (Kraus, 1999). However, from a positive perspective, women also report a transformed self due to their breast cancer experience, namely, an increased self-awareness, feeling more courageous and more satisfied with their selves and lives following breast cancer diagnosis (Carpenter, Brockopp & Andrykowski, 1999).

Examining adjustment to breast cancer indicates that younger sufferers may be particularly vulnerable to emotional distress. While much of the decline in elderly women appears to be associated with age rather than the disease or treatment, younger women appear to experience greater concerns about the impact of cancer on their partner and children, including practical issues such as income and childcare and the untimely nature of the diagnosis (Compas et al., 1999). In general, adopting an active, problem-solving style in which emotions are openly expressed appears to make coping easier. In contrast, avoiding discussing emotional and other issues has been associated with more distress (Anagnostopoulos, Vaslamatzis & Markidis, 2004; Osowiecki & Compas, 1999).

Mothers with dependent children described the breast cancer experience as particularly disruptive to their mothering roles, in particular, distress was reported regarding the organisation of the children's care, whether precipitated by illness whilst undergoing treatment or as a result of death (Fitch, Bunston & Elliot, 1999). It is indicated that in order to cope with this distress, most mothers attempt to carry on as usual and continue everyday life through the assistance of a supportive network of friends and family members (Billhult & Segesten, 2003).

In order to support existing short-term implications of breast cancer and to enhance the development of new innovative intervention techniques to assist with the psychological adjustment to breast cancer, future research should include adequate sample sizes with longitudinal empirical data, including samples from ethnic minorities, that are age-specific and those that have different socio economic backgrounds. New innovative techniques may in turn, assist women in a larger sense, such as their children, their long-term recovery and their families.

References

- Anagnostopoulos, F., Vaslamatzis, G., & Markidis, M. (2004). Coping strategies of women with breast cancer: A comparison of patients with healthy and benign controls. *Psychotherapy and Psychosomatics*, *73*, 43-52.
- Australian Bureau of Statistics (2006). *Australian Social Trends*. Retrieved July 31, 2006 from <http://www.abs.gov.au>
- Australian Bureau of Statistics (2006). *Causes of Death*. Retrieved July 31, 2006, from <http://www.abs.gov.au>
- Avis, N. E., Crawford, S., & Manuel, J. (2004). Psychosocial problems among younger women with breast cancer. *Psycho-Oncology*, *13*, 295-308.
- Bernstein, D. A., Nash, P. W., Clarke-Stewart, A., Penner, L. A., & Roy, E. J. (2002). *Essentials of psychology* (2nd ed.). Boston: Houghton Mifflin Company
- Billhult, A., & Segesten, K. (2003). Strength of motherhood: Nonrecurrent breast cancer as experienced by mothers with dependent children. *Scandinavian Journal of Caring Sciences*, *17*, 122-128.
- Breast Cancer Network Australia. (2005). *Still making a difference: Australia's second national breast cancer conference for women, 2004*. Victoria: Australia.
- Caltabiano, M. L., Byrne, D., Martin, P. R., & Sarafino, E. P. (2002). *Health psychology: Biopsychosocial interactions. An Australian perspective*. Milton, Queensland: John Wiley & Sons.
- Carpenter, J. S., Brockopp, D. Y., & Andrykowski, M. A. (1999). Self-transformation as a factor in the self-esteem and well-being of breast cancer survivors. *Journal of Advanced Nursing*, *29*, 1402-1411.

- Carver, C. S., Pozo-Kaderman, C., Price, A. A., Noriega, V., Harris, S. D., Derhagopian, R. P et al. (1998). Concern about aspects of body image and adjustment to early stage breast cancer. *Psychosomatic Medicine*, 60, 168-74.
- Compas, B. E., & Luecken, L. (2002). Psychological adjustment to breast cancer. *Current Directions in Psychological Science*, 11, 111-114.
- Compas, B. E., Stoll, M. F., Thomsen, A. H., Oppedisano, G., Epping-Jordan, J. E., & Krag, D. N. (1999). Adjustment to breast cancer: Age-related differences in coping and emotional distress. *Breast Cancer Research and Treatment*, 54, 195-203.
- Compas, B. E., Worsham, N. L., Epping-Jordan, J. E., Grant, K. E., Mireault, G., Howell, D. C., & Malcarne, V. L. (1994). When mom or dad has cancer: Markers of psychological distress in cancer patients, spouses and children. *Health Psychology*, 13, 507-515.
- Crompvoets, S. (2003). Reconstructing the self: Breast cancer and the post-surgical body. *Health Sociology Review*, 12, 137-145.
- Davis-Kirsch, S.E., Brandt, P. A., & Lewis, F. M. (2003). Making the most of the moment: When a child's mother has breast cancer. *Cancer Nursing*, 26, 47-54.
- Delmore-Ko, P., Pancer, M. S., Hunsberger, B., & Pratt, M. (2000). Becoming a parent: The relation between prenatal expectations and postnatal experience. *Journal of Family Psychology*, 14, 625-640.
- Elmberger, E., Bolund, C., & Lutzen, K. (2000). Transforming the exhausting to energizing process of being a good parent in the face of cancer. *Health Care for Women International*, 21, 485-499.

- Epping-Jordan, J. E., Compas, B. E., Osowiecki, D. M., Oppedisano, G., Gerhardt, C., Primo, K., & Krag, D. N. (1999). Psychological adjustment in breast cancer: Processes of emotional distress. *Health Psychology, 18*, 315-326.
- Ferrell, B., Grant, M., Funk, B., Otis-Green, S., & Garcia, N. (1998). Quality of life in breast cancer: Part II: Psychological and spiritual well-being. *Cancer Nursing, 21*, 1-9.
- Fitch, M. I., Bunston, T., & Elliot, M. (1999). When mom's sick: Changes in a mother's role and in the family after her diagnoses of cancer. *Cancer Nursing, 22*, 58-63.
- Ganz, P.A., Schag, A.C., Lee, J. J., Polinsky, M. L., & Tan, S. J. (1992). Breast conservation versus mastectomy. Is there a difference in psychological adjustment or quality of life in the year after surgery?. *Cancer, 69*, 1729-1738.
- Hatchett, L., Friend, R., Symister, P., & Wadhwa, N. (1997). Interpersonal expectations, social support, and adjustment to chronic illness. *Journal of Personality and Social Psychology, 73*, 560-573.
- Heinicke, C. M. (1995). Determinants of the transition to parenting. In M. H. Bornstein (Ed.), *Handbook of parenting: Vol. 3 Status and social conditions of parenting* (pp. 227-304). Mahwah, NJ: Lawrence Erlbaum.
- Helseth, S., & Ulfsaet, N. (2005). Parenting experiences during cancer. *Journal of Advanced Nursing, 52*, 38-46.
- Kraus, P. L. (1999). Body image, decision making, and breast cancer treatment. *Cancer Nursing, 22*, 421-427.
- Kroenke, C. H., Rosner, B., Chen, W. Y., Kawachi, I., Colditz, A., & Holmes, M, D. (2004). Functional impact of breast cancer by age at diagnosis. *Journal of Clinical Oncology, 22*, 1849-1856.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.

Markus, H. (1977). Self-schemata and processing information about the self. *Journal of Personality and Social Psychology*, 35, 63-78.

Mischel, W. (1999). *Introduction to personality* (6th ed.). Orlando: Harcourt, Inc.

Morse, J. M., & Carter, B. (1996). The essence of enduring and expressions of suffering: The reformulation of self. *Scholarly Inquiry for Nursing Practice: An International Journal*, 10, 43-60.

National Breast Cancer Centre (2003). *Clinical practice guidelines for the management and support of younger women with breast cancer*. Camperdown, Australia.

National Health and Medical Research Council (2003). *Clinical practice guidelines for the psychosocial care of adults with cancer*. Australia.

National Public Health Partnership (2001). *Preventing chronic disease: A strategic framework – background paper*. Melbourne, Victoria.

O'Connor, A. P., Wicker, C. A., & Germino, B.B. (1990). Understanding the cancer patient's search for meaning. *Cancer Nursing*, 13, 167-175.

Ohlen, J., & Holm, A. (2006). Transforming desolation into consolation: Being a mother with life-threatening breast cancer. *Health Care for Women International*, 27, 18-44.

Oswiecki, D. M., & Compas, B. E. (1999). A prospective study of coping, perceived control and psychological adjustment to breast cancer. *Cognitive Therapy and Research*, 23, 169-180.

Pancer, S. M., Pratt, M., Hunsberger, B., & Gallant, M. (2000). Thinking ahead: Complexity of expectations and the transition to parenthood. *Journal of Personality*, 68, 253-280.

- Pedersen, S., & Revenson, T. A. (2005). Parental illness, family functioning and adolescent well-being: A family ecology framework to guide research. *Journal of Family Psychology, 19*, 404-419.
- Pelusi, J. (2006). Sexuality and body image: Research on breast cancer survivors documents altered body image and sexuality. *American Journal of Nursing, 106*, 32-38.
- Price B. (1999). A model for body image care. *Journal of Advanced Nursing, 15*, 585-593.
- Sammaraco, A. (2001). Psychosocial stages and quality of life of women with breast cancer. *Cancer Nursing, 24*, 272-277.
- Steele, R, G., Forehand, R., & Armistead, L. (1997). The role of family processes and coping strategies in the relationship between parental chronic illness and childhood internalising problems. *Journal of Abnormal Child Psychology, 25*, 83-94.
- The Western Australian Cancer Registry (2005). *Cancer in Western Australia: Incidence and Mortality 2003*. Retrieved March 15, 2006, from <http://www.health.wa.gov.au/wacr/>.
- Yurek, D., Farrar, W., & Andersen, B. L. (2000). Breast cancer surgery: Comparing surgical groups and determining individual differences in postoperative sexuality and body change stress. *Journal of Consulting and Clinical Psychology, 68*, 697-709.

Journal of Health Psychology

An Interdisciplinary, International Journal

Editor:

David F Marks

City University, London, UK

[Click here to visit this journal's home page.](#)

Manuscript Submission Guidelines:

1. The Editorial Board of the Journal of Health Psychology considers for publication: (a) reports empirical studies likely to further our understanding of health psychology; (b) critical reviews of the literature; (c) theoretical contributions and commentaries; (d) book reviews; and (e) signed editorials (about 1000 words) on significant issues.

2. The circulation of the Journal is world-wide and articles are invited from authors throughout world.

3. Articles should be as short as is consistent with clear presentation of subject matter. There is an absolute limit on length but 8000 words, including footnotes and references, is a useful maximum. The title should indicate exactly, but as briefly as possible, the subject of the article. An abstract of 100 to 120 words should precede the main text, accompanied by up to 5 key words and a bibliographical note of 25 to 50 words. The covering letter should indicate whether the author prefers blind or open peer review.

(a) Blind peer review: Authors electing for anonymous review should provide a standard and a 'blind' electronic version of their article - one version containing names, affiliations, full mailing address plus telephone, fax, email address; and one containing the title only.

(b) Open review: Authors requesting open review may suggest three possible reviewers. If the article is accepted, substantive commentaries upon the paper may be published simultaneously. Commentaries should not exceed 2500 words.

(c) In all cases, the Editor will screen manuscripts for their overall fit with the scope of the journal. Those that fit will be further reviewed by two or more independent and internationally representative reviewers. Articles will be evaluated by the Editorial Board and refereed in terms of scientific merit, readability and interest. Unsolicited manuscripts will not be returned to the author if rejected.

4. The Journal requires authors to follow the 'Guidelines to Reduce Bias in Language' of the Publication Manual of the American Psychological Association (6th ed). These guidelines relate to level of specificity, labels, participation, gender, sexual orientation, racial and ethnic identity, disabilities and age. Authors should also be sensitive to issues of social class, religion and culture.

5. Articles submitted for publication must be typed in double spacing throughout, on one side of white A4 or US standard paper, with generous left- and right-hand margins but without justification. Titles and section headings should be clear and brief with a maximum of three or four levels of heading. Lengthy quotations (exceeding 40 words) should be displayed, indented, in the text. American or UK spelling may be used, to the author's preference. Indicate italic type by underlining, and use single quotation marks. Dates should be in the form 9 May 1994. Take note of points in USA and other such abbreviations.

Tables and figures should have short, descriptive titles. All footnotes to tables and their sources should be typed below the tables. Column headings should clearly define the data presented. Camera-ready artwork for all figures must be supplied. Artwork intended for same-size use should be a maximum size of 192:125 mm (page depth: page width). The title page should contain the word count of the manuscript (including all references).

All references cited in the text should be listed alphabetically and presented in full using the style of the Publication Manual of the American Psychological Association (6th ed).

Articles that do not conform to the fundamentals of this style will be returned to the authors for revision.

6. Authors should retain a full copy of their typescript, and send one electronic copy of the original manuscript and one blind copy, clearly labeled in doc or pdf format to d.marks@city.ac.uk. There is no need to send hard copies through the post. All figures and tables should be clearly labeled. For further details please contact: David F. Marks, Department of Psychology, City University, Northampton Square, London, UK EC1V 0HB. Tel / Fax: +44 (0)207 040 8590; email:

d.marks@city.ac.uk

7. Authors will be asked to provide a diskette, labelled with the date, title and author name, and containing only the final version of their paper following acceptance for publication. The author responsible for guaranteeing that the final hard copy and diskette versions of the manuscript are identical.

8. The corresponding author will receive page proofs for checking. He or she will be given controlled access to a PDF of the article and a complimentary copy (per author) of the whole is after publication.

9. Copyright: On acceptance of their article for publication authors will be requested to assign copyright to Sage Publications, subject to retaining their right to reuse the material in other publications written or edited by themselves and due to be published preferably at least one year after initial publication in the journal. Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere.

10. Reviews: books and suggestions should be sent to Michael Murray (Book Reviews Association Editor), Division of Community Medicine, Memorial University of Newfoundland, St John's, Newfoundland, Canada A1B 3V6 [Tel: +1 709 737 6669/6652; Fax: +1 709 737 7382; email: murraym@morgan.ucs.mun.ca].

Send mail to: webmaster@sagepub.com with questions or comments about this Web site. | [Privacy Policy](#) | Copyright © 2007

Running Head: MOTHERS AND BREAST CANCER

Shattered Motherhood: Young Mothers Living With Breast Cancer

Kelly Gibson

Edith Cowan University

A report submitted in Partial Fulfilment of the Requirements for the Award of

Bachelor of Arts Honours, Faculty of Computing, Health and Science,

Edith Cowan University.

October 2006

I declare that this written assignment is my own work and does not include:

(i) material from published sources used without proper acknowledgement;

or

(ii) material copied from the work of other students.

Abstract

Breast cancer is the most common form of cancer diagnosed in females in Australia, and approximately 6% of women diagnosed with the disease are aged 40 or less. The experience of breast cancer in mothers of dependent children and the impact of breast cancer on mothers' identities was the focus of this study. Eight women, with current or nonrecurrent breast cancer, were interviewed using multiple case qualitative methodology from a feminist perspective as a theoretical framework. Six themes emerged from conducting the research and were centred on the participants' identity as a mother: 'breast cancer challenged my role as a mother'; 'holding onto motherhood'; 'mothering beyond the grave'; 'I am a mother, not an object'; 'help me to be a mother' and; 'I am a mother and I am still here'. The research found that the needs of mothers living with breast cancer, namely lack of instrumental and emotional support, are not being appropriately or adequately met. The study has implications for health care professionals regarding the psychological and social impact of breast cancer on mothers.

Kelly Gibson

Dr Moira O'Connor

Dr Colleen Fisher

October 2006

Shattered Motherhood: Young Mothers Living With Breast Cancer

In Australia, breast cancer is the most common invasive cancer and the leading cause of cancer death in females (Australian Institute of Health and Welfare, 2006). It is a disease affecting women, and a very small minority of men (Compas & Luecken, 2002), with around 30% of women diagnosed with breast cancer in Australia aged 50 years or under, and approximately 6% aged 40 years or under (Breast Cancer Network Australia, 2005). In Western Australia alone, 141 (12.6%) new cases of breast cancer were recorded for women aged 15-44, with the largest number recorded (70 new cases) for the 40-44 age group. In addition, 21 (8.2%) women aged 44 or less died as a result of breast cancer in 2003 (Western Australian Cancer Registry, 2005). Although incidence is lower in younger women compared with their older counterparts, younger women are more likely to be diagnosed with larger, more aggressive tumours, and have worse disease-free and overall survival outcomes (National Breast Cancer Centre, 2003). Psychological effects of the illness, common to all-age women largely documented by patients' self-reported mood and psychological symptoms, are wide ranging and include aspects in relation to psychological distress, such as depression and anxiety (Compas & Luecken, 2002); overall quality of life (Ferrell et al., 1998; Kroenke et al., 2004); and coping methods (Osowiecki & Compas, 1999). However, these issues seem to be exacerbated for younger women, particularly in relation to the impact breast cancer has on their body image, emotional adaptation and family life.

Body Image and Transformed Self

Price (1999), described body image as comprising three aspects: body reality, the body as it really exists; body ideal, the picture in one's mind of how one would like the body to look and perform, including norms for body contour, body space, and boundaries and, finally; body presentation, how the body is presented to the outside

environment. Breast cancer treatment changes body reality and body ideal and may affect body presentation (Price, 1999). In addition to the physical changes associated with acute and chronic effects of treatment, disruptions in the ability to fulfil one's roles within the family and society, and psychological aspects of coping with a life threatening illness, can lead to changes in attitudes, perspective, meaning, outlook and interpersonal interactions (O'Connor, Wicker, & Germino, 1990). Alongside the negative impact of the cancer, it is also perceived as an opportunity for personal growth. Breast cancer sufferers report that the self is changed or transformed, particularly in relation to discrepancies that occur between the way in which a woman formerly perceived herself and how she now sees herself as a result of cancer and its treatment (Pelusi, 2006). Thus, living with breast cancer may affect personal self-concept (opinion/beliefs/views/perceptions of self); social self-concept (perceptions of how one is regarded by others); and self-ideals (perceptions of oneself with respect to how one would like to be) (National Health and Medical Research Council, 2003). Carpenter, Brockopp and Andrykowski (1999) found that when comparing self-transformation in women with and without breast cancer, breast cancer sufferers reported a new understanding of themselves, indicating that they felt stronger, more courageous, more satisfied with their selves and lives, and experienced higher self-esteem and well-being.

Emotional Distress, Coping and Adaptation

Both appraisals of control and coping efforts have been shown to be important predictors of psychological adjustment to breast cancer (Epping-Jordan et al., 1999). Anagnostopoulos, Vaslamatzis and Markidis (2004) articulate adjustment to breast cancer as a process of adaptation that involves the complex interaction of the characteristics of cancer and its treatment, cognitive appraisals and coping efforts. The changing demands of the stress of breast cancer such as those resulting from the shock

of diagnosis, various aspects of treatment, and continued uncertainty about the future, provide opportunities for sufferers to develop cognitive appraisals of control and cope with the disease.

Research suggests that younger women appear to have more problems with psychological adjustment to breast cancer than elderly women (Avis, Crawford & Manuel, 2004), as they may experience greater life stage challenges in adapting to the unexpectedness of their diagnosis, including aspects such as a greater fear of death, possible losses in their careers, concerns about the impact on their families and lost opportunities for childbearing (Kroenke et al., 2004). The experience of breast cancer can be more psychologically demanding for these women (Avis, Crawford & Manuel, 2004), as they appear more vulnerable to greater disruption to their daily lives, and have greater unmet practical needs, such as childcare. Issues such as fertility, pregnancy, raising young children, achieving career goals, treatment-induced menopause, body image, sexuality and relationship concerns may cause additional distress at diagnosis and during and after treatment (Breast Cancer Network Australia, 2005).

Family Life

The limited research regarding young women's experiences of breast cancer appears to focus on the adaptation of a family in relation to the mother's breast cancer from the perspective of the family members, rather than the real world experiences of the mother (Helseth & Ulfsaet, 2005). For mothers, after a breast cancer diagnosis, the demands of illness are added to the normal burdens of family life, and sufferers are often unable to fulfil their usual parental roles and the internal structures of families are exposed to change (Compas et al., 1994; Pedersen & Revenson, 2005). When facing breast cancer, it is indicated that the importance of being a "good" mother is altered because parental and family priorities shift and focusing on the children becomes

difficult (Davis-Kirsch, Brandt, & Lewis, 2003). In particular, many mothers feel that they are letting their children down because they are unable to give them enough attention and seem to be torn between their own and their children's needs for care (Helseth & Ulfsaet, 2005; Ohlen & Holm, 2006).

Fitch, Bunston and Elliot (1999) explored, from a woman's perspective, the experience of being a mother and living with cancer. It was reported that for many participants, the physical impact of the cancer (fatigue, nausea) and the hospital visits (separation) were particularly disruptive to their mothering roles and further distress was reported regarding the organisation of the children's care. The impact of the cancer and its treatment led to changes in both roles and relationships for women and their children. The inability to do what the women normally did created tensions for mothers and if the mother was not available to play or spend time with the children, someone else had to fulfil those roles. These changes, in turn, created difficulties in relation to who was going to take on the mothering roles. Finally, the family's ability in adjusting to these differing demands was linked to their ability to utilise effective coping strategies, as well as the support available to them. The study indicated that while many women received a wide variety of instrumental support, there was very little emotional support available to them.

Billhult and Segesten (2003) investigated the specific experience of breast cancer in mothers with dependent children and the strategies women used to cope with their illness in the context of parenting. The women in this study found it very distressing when thinking about what might happen to their children without their presence, whether precipitated by illness or death. Additionally, they expressed a will to be strong for their children, despite experiencing debilitating side effects of treatment and needed to strike a balance between telling the truth and protecting the children from

the seriousness of the illness. In order to deal with these struggles, women preferred to carry on as usual and continue everyday life, gain strength with support from others, and try to turn things into a positive perspective.

The Current Study

The aim of the current research was to investigate the experience of mothers who have dependent children and a breast cancer diagnosis, as well as explore the impact of breast cancer on mothers' identities. It is hoped that this research will improve our understanding in relation to mothers living with a serious illness. With this knowledge, health care professionals may be better able to tailor support to those needs and receive education regarding the psychological and social impact of breast cancer on mothers, which may benefit other mothers receiving specialist services. Thus, the current research addressed two main questions:

1. What is the impact of breast cancer on young women who are mothers with dependent children?
2. Does breast cancer have an impact on mothers' identity and self-concept?

Method

Research Design

A qualitative research design was used in order to derive an understanding of the impact of breast cancer on young mothers who have dependent children. The study adopted a multiple case research approach (Burgess-Limerick & Burgess-Limerick, 1998). An advantage of this method is that it seeks both an understanding of the individual, as an individual, and an understanding of the theoretical constructs that are relevant between individuals. Each participant's story reflected a unique vantage point on the issue under consideration whereby the researcher developed and interrelated categories of information (Burgess-Limerick & Burgess-Limerick, 1998).

The research adopted a feminist framework. This voice-centred, relational approach to research acknowledges that women's experiences are valid and explores the ways in which women view the world (Beanland, Schneider, LoBiondo-Wood, & Haber, 1999). A feminist approach implicitly focuses on personal change through empowerment, equity and new identities, as well as social change through the dismantling of structures that oppress women and developing new structures that transform institutions (Way, 1997).

Participants

The participants included eight females with either current or nonrecurrent breast cancer. Seven women were married, while one woman was a single mother. All participants were English speaking, Australian and resided in the Perth metropolitan area. At the time of their breast cancer diagnosis, participants ranged in age from 31 to 42 years (average 35 years). Time since their breast cancer diagnosis ranged from 5 months to 7 years. Seven participants had two dependent children in the home, with the single mother having one child in the home. The age of children living in the home at

diagnosis ranged from newborn to 8 years of age. Five of the women were required to have mastectomies as a result of their breast cancer, with two of those five women requiring bi-lateral mastectomies. Three women were required to have lumpectomies. In addition to their surgery, treatment consisted of chemotherapy and radiotherapy for four women, two women had chemotherapy only, one woman had radiotherapy only and one woman was required to have no adjuvant therapy.

Data Collection Procedures

Participants were recruited through the distribution of an information sheet (Appendix A) to self-help groups, the Breast Cancer Foundation of Western Australia and the Cancer Council of Western Australia. Interested participants were asked to make contact with the researcher and a mutually convenient interview date and time was scheduled. The participants were interviewed in their homes, with each participant engaging in one interview, with duration times ranging from 38 to 74 minutes (average 52 minutes). A digital audio recorder was used in order to obtain a full record of interview for each participant. Prior to the interview, the researcher introduced herself and the purpose of the research. Participants were advised that their involvement was voluntary and that they were able to withdraw at any time or not answer any question that they did not feel comfortable answering. Written consent to take part in the study as well as audio record the interview was obtained from the participants (Appendix B).

Data were collected between May and September 2006. Once collected, the interviews were transcribed verbatim by the researcher and analysed using thematic content analysis. The audio-recorded interviews were destroyed and the data collected will be stored in a secured filing cabinet at Edith Cowan University for a period of five years.

Conversational interviews embrace the social aspects of the research interview and challenge the conventional construction of the interview as a setting for data

gathering by a researcher from the participants. Each individual and situation produces a unique agenda that allows the researcher to ground the research completely in the experiences of the participants.

An in-depth conversational interview schedule (Appendix C), was used in order to gain a detailed picture of the participants' breast cancer experience. Discussion covered issues surrounding diagnosis, treatment, motherhood and identity. Probes for each question were used in order to obtain participants' feelings and thoughts in order to focus on the experience of the participant. Additionally, the use of open-ended questions allowed the women to speak about the issues of concern to them rather than what the researcher may have considered important. In-depth conversational interviews provided a window into the experiences of being a mother and living with breast cancer, and encouraged each woman to reveal, in her own words, the meaning she attached to the illness and provided insight into the impact of her illness on herself and her family.

Rigour.

According to Beanland et al. (1999), the scientific rigour of qualitative research is judged through general themes of credibility, auditability and fittingness. These criteria are important in order to validate the understandings and findings generated from qualitative research. Credibility refers to the truth as known, experienced or deeply felt by the people being studied and interpreted from the findings (Leininger, 1994). Credibility of this study was obtained through continual immersion in the analysis and conducting analysis meetings with research supervisors. Auditability refers to providing adequate information in relation to the development of the study from the research question, raw data and various steps of analysis, to the interpretation of findings. Auditability was achieved by listing passages of interview data with the researcher's summaries and memos to show how data abstraction and reduction were conducted.

Fittingness refers to the match between the findings of research and the literature. In the current study, fittingness was achieved by discussing the findings in the context of other research studies in the area and by using the literature to support or refute the concepts emerging from the data.

Ethics

The study was granted ethical approval by the Edith Cowan University Human Research Ethics Committee. Due to the possibility that participants may have experienced the interview process as intrusive or distressing, the researcher provided each participant with contact details of counselling services available within that person's locality, as well as 24 hour help lines (Appendix D). In order to ensure confidentiality, at transcription pseudonyms were given to all participants, their family members and hospitals attended for treatment.

Data Analysis

Interviews, continual immersion in the literature and analysis were conducted simultaneously and informed one another. Initially, the researcher read the text several times, in order to get close and well acquainted with the text. Salient words, phrases, sentences and passages were underlined in each transcript. The text was coded into substantive categories (descriptive categories that pattern the text), which facilitated the grouping of ideas. Memo writing and constant comparisons were used to work towards formal categories. The coding process and category making were flexible in order to permit creative and intuitive thinking, to be responsive to the participants' texts, and to avoid producing unmanageable quantities of categories. Codes were grouped together in order to examine and isolate meaningful patterns and processes to derive specific themes. When coding became difficult, the researcher conducted case analysis meetings with the research supervisors in order to challenge and assist with the development of

emerging ideas. This process had an advantage of alerting the researcher to alternative interpretations of the text (Burgess-Limerick & Burgess-Limerick, 1998).

Findings and Discussion

Six themes emerged during analysis of the data: 'breast cancer challenged my role as a mother'; 'holding onto motherhood'; 'mothering beyond the grave'; 'I am a mother, not an object'; 'help me to be a mother' and; 'I am a mother and I am still here'. The findings reveal that the emerging themes and issues were interrelated and were centred around the participants' identity as a mother.

Breast Cancer Challenged my Role as a Mother

Women described a range of responses to first hearing the news about their diagnosis such as shock, disbelief, anger, fear, numbness, depression, denial and confusion. In the words of Holly:

...of course the shock is probably the main thing you go through to start with I think, the sense of not really believing that it could happen, so from there it did feel very surreal...

Kate also described:

I think the first reaction was just shock and a bit of numbness, didn't really know what to do or where to go or anything like that.

The women in this study indicated that the inability to plan for a breast cancer diagnosis in their life at a young age caused their mothering roles to be challenged. The possibility of death as an outcome meant that mothers' expectation of the role in the home they identified with before diagnosis, such as their relationships with their children and undertaking daily tasks, was suddenly stolen from them. After Sheryl received the news about her breast cancer diagnosis, all she could recall were the words 'extensive' and 'widespread'. She described that she was distressed about the

consequences of her diagnosis and in particular, the effect it would have on her relationship with her children. When observing other young mothers socialising together with their children, she articulated:

...just mothers happy with their children and that's how I should be.

Further to the unexpected nature of their breast cancer diagnosis was the realisation of the seriousness of the illness, which precipitated feelings of intense fear and sadness about leaving their children. As a consequence, the mothers felt a need to do as many things as possible with their children due to thoughts that death was imminent. Mothers expressed concern about not being able to see their children grow up as well as their children living life without their mother. Holly described:

...I suppose it made me feel vulnerable in terms of not having control over my own life and thinking that I might not get through it, I might not be able to see my children grow up...I think a really difficult thing to go through when you're so young. I think if you're, not to say it would be easier, but I suppose the news would be less shocking, but I think that with such a young child and obviously with another one on the way, if this doesn't work out, the fact that I've got two young children who will be without a mother, obviously that was the main concern. It was at the forefront of my mind...

A year after her diagnosis, Emily expressed that she continues to face the reality that death is still a possible outcome of her breast cancer. She maintains that her time with her children is limited:

...I feel like I'm wanting to fit everything in, in case there is no tomorrow, in case five years down the track I didn't get to do something or whatever with them [children] and that's hard.

Further, the mothers described loss of control over every day events, particularly whilst undergoing treatment. The mothers indicated that they felt guilty about not being available for their children and yearning to be there for them, however, the side effects of treatment were too debilitating. Kate indicated:

In some ways, I felt like I was letting them down, because I couldn't do all those things with them.

Michelle also described:

...so they [children] would always come and sit with me in bed, but I felt very guilty for that, that I wasn't available to them and I think that was a lot of the sadness as well...Every time I'd look at them, I'd just cry, it was heart breaking it was very difficult because I didn't know what the future held...I felt very guilty and very sad for them and I just couldn't give them everything I wanted to I was just absolutely, I had no energy, I was exhausted and sick and I didn't have patience, I couldn't sit there and read them a story, I'd be gagging I just wouldn't be well enough to be there for them. So that was really difficult, really difficult, because I just love them to bits.

The findings from the current study are consistent with previous research which indicated that younger women appear to experience greater life stage challenges in adapting to the unexpectedness of breast cancer diagnosis, including aspects such as a greater fear of death and concerns about the impact on their families (Kroenke et al., 2004). In addition, the physical impact of the cancer (fatigue, nausea) and the hospital visits (separation) are particularly disruptive to their mothering roles. It is indicated that many mothers feel that they are letting their children down because they are unable to give them enough attention and seem to be torn between their own and their children's needs for care (Helseth & Ulfset, 2005; Ohlen & Holm, 2006). Fitch, Bunston and

Further, the mothers described loss of control over every day events, particularly whilst undergoing treatment. The mothers indicated that they felt guilty about not being available for their children and yearning to be there for them, however, the side effects of treatment were too debilitating. Kate indicated:

In some ways, I felt like I was letting them down, because I couldn't do all those things with them.

Michelle also described:

...so they [children] would always come and sit with me in bed, but I felt very guilty for that, that I wasn't available to them and I think that was a lot of the sadness as well...Every time I'd look at them, I'd just cry, it was heart breaking it was very difficult because I didn't know what the future held...I felt very guilty and very sad for them and I just couldn't give them everything I wanted to I was just absolutely, I had no energy, I was exhausted and sick and I didn't have patience, I couldn't sit there and read them a story, I'd be gagging I just wouldn't be well enough to be there for them. So that was really difficult, really difficult, because I just love them to bits.

The findings from the current study are consistent with previous research which indicated that younger women appear to experience greater life stage challenges in adapting to the unexpectedness of breast cancer diagnosis, including aspects such as a greater fear of death and concerns about the impact on their families (Kroenke et al., 2004). In addition, the physical impact of the cancer (fatigue, nausea) and the hospital visits (separation) are particularly disruptive to their mothering roles. It is indicated that many mothers feel that they are letting their children down because they are unable to give them enough attention and seem to be torn between their own and their children's needs for care (Helseth & Ulfsaet, 2005; Ohlen & Holm, 2006). Fitch, Bunston and

Elliot (1999) also found that the impact of the cancer and its treatment lead to changes in both roles and relationships for women and their children. Specifically, the inability to do what women normally did creates tensions for mothers. The current study provided further evidence that mothers found it difficult to accept and adjust to the way breast cancer had suddenly changed the way they had to 'mother' their children as a direct result of their diagnosis.

Holding Onto Motherhood

This theme acknowledges the mothers' determination to maintain a normal life for the sake of their children, despite the seriousness of their illness. The mothers wanted to ensure that life, as their children knew it, would not change as a result of their breast cancer diagnosis and treatment. In addition, the mothers wanted to continue to perform tasks and duties as normally done in the home in order to protect their children from any negative experiences. Maintaining normality also allowed the mothers to maintain their identity as a mother for as long as possible despite the uncertainty of how long that might be. Holly articulated:

I wanted to keep life very much normal for Jerry [son]. He obviously still had the same needs and would have no understanding of why I might not be there for him. So I think the day to day getting on with it, the routine, the structure and not letting myself feel too sorry for myself and kind of losing it and thinking this is all too hard because it wasn't a pleasant process by any stretch, but it was doable.

Kate also stated:

...I think part of it, especially with kids, you just have to get on with it. Part of my thinking as well I think was that, the more normal I can keep things for them the better it was going to be for all of us, especially for the kids, if I can still

keep a routine to a certain extent it would be better for them and them being able to cope with it as well.

In addition, the mothers did not want their children to feel neglected emotionally or physically as a result of their illness. Whilst undergoing the treatment phase of their illness, the mothers expressed a need for someone else to fulfil their children's needs because they were unable. Michelle described whilst undergoing chemotherapy she was physically exhausted and thus, not able to fulfil her children's primary needs of care. However, she felt less distressed knowing that her children were not 'missing out' on activities inside and outside the home:

...even though I couldn't do it, it was getting done. They [children] weren't missing out, they were only missing out from me doing it...they were still getting their needs met by other people...I knew they [children] were getting love and attention and new experiences and having experiences, rather than just being stuck at home with me and feeling unwell.

Similarly, Emily described:

...I just wanted someone to take them [children] away and have a fun day with them. You know when I couldn't do it and I wanted that, I wanted someone just to make them feel special and fill the role that I couldn't do...

The current research provides further evidence that women prefer to carry on as usual or for someone else to fulfil their role, in an attempt to 'cushion the blow' or to moderate the impact of breast cancer on their lives as well as the lives of their husband and children. Billhilt and Segesten (2003) also found that women carry on as usual and continue everyday life in order to help them with struggles experienced due to the debilitating side effects of treatment. In addition, Fitch, Bunston and Elliot (1999)

reported that if the mother was not available to play or spend time with the children, someone else was required to fulfil those roles.

Mothering Beyond the Grave

Thoughts about being permanently unavailable due to death were of concern to the mothers and plans for the future needed to be well organised and articulated. Mothers planned who would take on specific roles for their children in the event that they were unable to Lorraine described:

...a lot of planning about what I'd need to do, put in place, who I'd like to do this or take on that role, a lot of that.

Sheryl spoke about planning for her husband's and her children's future, ensuring their life would be financially secure through her organisation of a life insurance policy. She indicated that it was reassuring to her to know that if she died, her husband would not have the financial burden to work full time and thus, be more available for their children.

...I've got a half a million dollars with a life insurance, if anything happens and that is really, really, really reassuring to me to sort of just know...At least that side of it, that everyone will be ok. It's not just that they've [children] lost their mother, but at least their dad could be there for them and him not working long hours.

Women found it very distressing when thinking about what might happen to their children without their presence, whether precipitated by illness or death (Billhilt & Segesten, 2003). Findings from the current study, however, suggest that mothers thought about their mortality on a more profound level with specific or concrete planning and the organising of roles and responsibilities for the future. It appears that the mothers were ensuring that the nurturing nature of motherhood is not halted by their

physical absence – it would continue through careful planning undertaken in the present.

I am a Mother, not an Object

Mothers felt strongly that the medical profession objectified them. The women indicated that throughout their breast cancer experience, there was no consideration or awareness by the medical professional that they were mothers with the added responsibility of having dependent children in the home whilst dealing with breast cancer. The added stress of organising care for their children whilst attending appointments did not appear to be acknowledged, rather there was an expectation that mothers would prioritise their obligations for breast cancer treatment, regardless of their other responsibilities. Jillian explained that there was rigidity in relation to appointment times:

I know the initial appointments for the biopsies and everything, you didn't get a choice about time, it was just, this is your appointment and if it had been really awkward, I could have said something, but you didn't get that impression that you could...They [medical profession] don't necessarily see you as a mother, it's you're a breast cancer patient and it's not sort of like we've got these times, is this suitable?, it's, this is your time.

Lorraine recalled that her oncologist recognised that she was a mother during an appointment, but it was not reflective of the holistic contextual experience of motherhood:

The oncologist actually said, right at the beginning of treatment, 'so you're a mum, how old are your children? So you need to live for quite a lot longer', that was the only thing that was ever said.

In addition to the limited awareness of the medical profession in terms of the impact of treatment on caring responsibilities, mothers felt a disregard for emotional and psychological well-being throughout their entire breast cancer experience. Some mothers indicated that their experience during diagnosis and treatment was a scientific process and they were treated accordingly as a physical object rather than a person with thoughts and feelings. Lorraine stated:

...it's very much a scientific process and not personable, nothing to do with your thoughts or feeling or emotions, it's just a very scientific, is it this or isn't it.

Kate summarised her breast cancer experience as:

The doctors are all focused on how you're reacting to how you're recovering from surgery, how you're reacting to the chemo drugs, how your skin's reacting to the radiation, that's pretty much all you get asked about...there was never any, do you need to be referred to anybody for counselling or anything like that.

Similarly, the day after undergoing a mastectomy, Sheryl explained how she met her Breast Care Nurse for the first time:

...this lady bounces into the room the day after, oh here's your prosthesis and you do this and she's all smiley and I thought, it's just the Avon lady. I mean I wasn't devastated about the loss of my breast, but you know a little bit of tea and sympathy probably wouldn't have gone astray.

The women also found that objectification was not limited to the medical profession. Some mothers sensed they were no longer perceived as a mother, friend or school acquaintance, but rather objectified and labelled as a 'cancer patient'. This label was clearly identifiable by other people due to physical appearance such as hair loss or a general appearance of poor health. From the data, it emerged that this objectification is associated with isolation and confusion. Mothers appeared to unconsciously isolate

themselves from friends, acquaintances and peers because they received no validation that what they were feeling with regard to their illness was 'right' or 'normal'.

Additionally they did not *know* how to feel. In this respect, the woman is no longer thinking as a mother which is inherent to her identity, but rather, being labelled as a 'cancer patient' causes confusion about how she is supposed to feel or react. This feeling of isolation appears to be created to some extent by the lack of support services in the community, particularly targeting the specific needs of mothers.

Lorraine indicated:

...I think the strongest feeling would be, a feeling of isolation. I didn't know anyone else that this had happened to and I don't know how to feel about it and I don't know if what I'm feeling is right, just a very strong feeling of isolation, that it's happening to me and I can't do anything about it.

Emily explained the alienation and loneliness she felt from other parents at her children's school:

I felt alienated a little bit, I don't think it was an intentional thing, a lot of the mums at school were really good, but then there were the mums and dads and you would go to school and you could see that they knew there was something wrong with me, but no one said anything and I know that they obviously don't want to overstep the mark and how do they go up to someone and say are you ok? But to me, it made me feel worse, I felt lonely, I thought can you not see I've got children, I've got a little girl here that's in your kid's class, can you maybe offer me a little bit of support and that made me angry.

A major issue articulated in previous breast cancer research appears to be the impact of breast loss and subsequent alterations of a woman's body image (Kraus, 1999; Yurek, Farrar, & Andersen, 2000). Research suggests that women experience a

decrease in body image satisfaction from pre-treatment to post-treatment. As the most visible site of femininity, sexuality, nurturing and eroticism, breast loss is said to challenge a woman's identity as a woman (Cromptvoets, 2003). The current study appears to challenge this as a major issue for mothers with breast cancer. Women seem to be less concerned about losing their breast and more concerned about how they will be perceived by other people, and how this perception may impact on the psychological wellbeing of them and their children throughout their breast cancer experience.

Help me to be a Mother

The women in the current study described that during their breast cancer experience, their emotional, psychological and instrumental needs were not met. Lack of information about what reactions they could expect from their children made the family situation difficult. The mothers were the ones who told the children about the illness, treatment, hospital stay, and consequences for the family. Specifically, the mothers identified that it caused considerable distress to them that members of the medical profession could not provide them with guidance in relation to how to tell their children about their breast cancer diagnosis. In addition, many mothers struggled with deciding whether or not to tell their children. Emily expressed her distress about how to tell her children about her diagnosis when first receiving the news from her General Practitioner:

When I spoke to my GP, the only time I broke down was when I said, what am I going to tell my kids? And he just looked at me and he didn't know what to say himself, so I said what am I going to say? What am I going to tell them? And then he sort of, he guided me around the question...

However, Kate explained that she was proactive in researching about whether to tell her children and ways of going about it because there is very little guidance on the issue:

...I actually did a lot of research on the internet when I was diagnosed about how to tell them, whether to tell them, you know that sort of stuff...but there's not a lot out there to tell you how to deal with it, especially younger kids.

According to the National Breast Cancer Centre [NBCC] (2003), there has been very little research conducted into the communication of a cancer diagnosis to children. Young mothers living with breast cancer should be offered assistance about what, if and when to tell children about their cancer. Strategies to assist children need to be tailored to the specific age of the child, and children should be referred for appropriate counselling if required.

A further issue related to their need for practical help. In particular, some mothers highlighted the fact that childcare services are unavailable to them whilst undergoing treatment, especially in an emergency or if they were having a bad day and not able to cope. For instance, mothers described that attending radiotherapy was a 'hassle' at times and disruptive to their children because they were required to arrange child care on a regular basis in order to attend every day for up to a period of seven or eight weeks. On the other hand, some mothers opted to take their children with them rather than deal with the added pressure of organising childcare.

Some mothers expressed that there was a requirement for more emotional support, counselling and guidance during their breast cancer experience. Mothers indicated there was a lack of acknowledgement of the unique emotional struggle experienced by mothers compared to older women. Apart from a breast cancer support group targeting women aged 40 or less, other services and guidance were not offered about how to react to situations as a mother. Sheryl stated:

...I think there needs to be a lot more emotional support, and probably more directing people into counselling and much more printed information on dealing

with talking to children about it, especially young children and probably having more other women's stories out there to see how they went.

Kate expressed the reasons why these services are not available to mothers:

I think part of it is we [mothers] are still, it is still the minority of people who are diagnosed with breast cancer...I think cancer's kind of still seen a lot as an older person's disease rather than young people...and so it's never really been catered for, but there's more and more younger people being diagnosed with all types of cancers...I think there's a lot of people out there who would be able to use services if they were there, but they're not there.

Sammarco (2001) indicated that using samples of women in a particular age group or life stage, such as young mothers, is useful for examining special issues because it provides definitive information about that specific group. The current study identified that many women failed to receive instrumental support in relation to childcare services and there was very little emotional or psychological support throughout their breast cancer experience. According to the clinical practice guidelines for the management and support of younger women with breast cancer, the NBCC (2003) indicate that it is important for health professionals to be alert to potential psychosocial distress in younger women over time, and to continue to assess emotional adjustment regularly, including at follow-up appointments. In addition, health professionals should investigate what age-specific support programs exist in their local areas, and may consider developing age-specific programs for younger women if no such programs exist. However, the current research identified that health care services are not currently responding appropriately to the issues surrounding a mother's role during the breast cancer experience.

I am a Mother and I am Still Here

Mothers believed breast cancer was life changing for them and that they were on a journey of self-discovery, namely that they achieved positive personal growth as a result of breast cancer. The mothers explained that their personal growth was a positive aspect of their breast cancer, brought about by self-commendation for their coping and adjustment abilities and survival during a very difficult period in their life. As a result, the women felt empowered, mentally stronger and had an enhanced self-esteem. The mothers indicated that due to acknowledging the possibility of death and feeling like they had a second chance at life, they were able to re-evaluate their needs and what was important in their life. The women spoke about the realisation that life is too short and had a willingness to live for the present. Lorraine described:

...there's the whole value of life, knowing that you're not permanent here and that you could be gone, not just from breast cancer, but it's just that knowledge that life is precious and can go, that you're not controlling it.

Materialistic objects, financial reward and a successful career were not important for the mothers, rather they were grateful for the fact that they were still able to be a mother to their children. Holly articulated:

I think in terms of just financial things and I suppose with my approach to work too, I mean I haven't worked since having kids anyway and I'm kind of thinking, I'm not going to put a lot of stress on my life, I'm going to keep life pretty simple...I want to be able to be there for the kids, I want to have a life that's good and if it means that you're not able to have certain things then that's ok.

Sheryl also stated:

...I feel like I've got to stay close to my kids and probably because we may not, they may not have me all their lives...

The responses gained from the current study appear to be consistent with the transformation of self, described by Carpenter, Brockopp and Andrykowski (1999). Women in that study reported a new understanding of themselves and made changes in various aspects of their lives such as relationships or work. The women experienced such transformations, triggered by sudden awareness of personal mortality, extremely positively. They reported feeling stronger, more courageous and more satisfied with their selves and lives as well as high self esteem and sense of well-being following breast cancer diagnosis.

Conclusion

The aim of this study was to investigate the experiences of mothers of dependent children who have a breast cancer diagnosis, and to explore the impact of breast cancer on these mothers' identities. A feminist framework was used, which enabled exploration of the way mothers with breast cancer view the world, whilst acknowledging their experiences are valid. The key finding of this study was that mothers focus on their breast cancer experience in the context of their children. Despite the personal difficulties they faced as a result of the disease, women identified as a mother first, rather than being focused on their individual needs.

The main limitation of the study was that participants were primarily Australian from Anglo-Celtic descent, in committed relationships, had relatively high levels of education, and came from middle to high socio-economic backgrounds. As such, the sample was limited and findings are relevant only to this group of women. It would be useful for future research to focus on the experience of breast cancer in ethnic minority populations and women with different demographic variables, in order to gain insight into individual differences across context and settings.

In the current study, mothers expressed a need for further psychological, emotional and instrumental support, particularly in relation to their children's needs and their own needs as a mother. This is a salient clinical implication and highlights that it is important health care professionals acknowledge the unique emotional struggle experienced by mothers compared to older women, and to have an awareness of mothers' responsibilities in addition to their breast cancer obligations. Theoretically, the current study challenges the idea, which is replete in the literature, that change in body image is a major issue for mothers with breast cancer. Women in this study were less concerned about losing their breast and more concerned about their identity as a mother, how they will be perceived in this role by other people, and how this perception may impact on the psychological wellbeing of them and their children throughout their breast cancer experience.

References

- Anagnostopoulos, F., Vaslamatzis, G., & Markidis, M. (2004). Coping strategies of women with breast cancer: A comparison of patients with healthy and benign controls. *Psychotherapy and Psychosomatics, 73*, 43-52.
- Australian Institute of Health and Welfare & National Breast Cancer Centre (2006). *Breast cancer in Australia: An overview, 2006*. Cancer series no. 34. Canberra: Australia.
- Avis, N. E., Crawford, S., & Manuel, J. (2004). Psychosocial problems among younger women with breast cancer. *Psycho-Oncology, 13*, 295-308.
- Beanland, C., Schneider, Z., LoBiondo-Wood, G., & Haber, J. (1999). *Nursing research: Methods, critical appraisal and utilisation*. Sydney: Harcourt.
- Billhult, A., & Segesten, K. (2003). Strength of motherhood: Nonrecurrent breast cancer as experienced by mothers with dependent children. *Scandinavian Journal of Caring Sciences, 17*, 122-128.
- Breast Cancer Network Australia. (2005). *Still making a difference: Australia's second national breast cancer conference for women, 2004*. Victoria: Australia.
- Burgess-Limerick, T., & Burgess-Limerick, R. (1998). Conversational interviews and multiple-case research in psychology. *Australian Journal of Psychology, 50*, 63-70.
- Carpenter, J. S., Brockopp, D. Y., & Andrykowski, M. A. (1999). Self-transformation as a factor in the self-esteem and well-being of breast cancer survivors. *Journal of Advanced Nursing, 29*, 1402-1411.
- Compas, B. E., & Luecken, L. (2002). Psychological adjustment to breast cancer. *Current Directions in Psychological Science, 11*, 111-114.

- Compas, B. E., Worsham, N. L., Epping-Jordan, J. E., Grant, K. E., Mireault, G., Howell, D. C., & Malcarne, V. L. (1994). When mom or dad has cancer: Markers of psychological distress in cancer patients, spouses and children. *Health Psychology, 13*, 507-515.
- Crompvoets, S. (2003). Reconstructing the self: Breast cancer and the post-surgical body. *Health Sociology Review, 12*, 137-145.
- Davis-Kirsch, S.E., Brandt, P. A., & Lewis, F. M. (2003). Making the most of the moment: When a child's mother has breast cancer. *Cancer Nursing, 26*, 47-54.
- Epping-Jordan, J. E., Compas, B. E., Osowiecki, D. M., Oppedisano, G., Gerhardt, C., Primo, K., & Krag, D. N. (1999). Psychological adjustment in breast cancer: Processes of emotional distress. *Health Psychology, 18*, 315-326.
- Ferrell, B., Grant, M., Funk, B., Otis-Green, S., & Garcia, N. (1998). Quality of life in breast cancer: Part II: Psychological and spiritual well-being. *Cancer Nursing, 21*, 1-9.
- Fitch, M. I., Bunston, T., & Elliot, M. (1999). When mom's sick: Changes in a mother's role and in the family after her diagnoses of cancer. *Cancer Nursing, 22*, 58-63.
- Helseth, S., & Ulfset, N. (2005). Parenting experiences during cancer. *Journal of Advanced Nursing, 52*, 38-46.
- Kraus, P. L. (1999). Body image, decision making, and breast cancer treatment. *Cancer Nursing, 22*, 421-427.
- Kroenke, C. H., Rosner, B., Chen, W. Y., Kawachi, I., Colditz, A., & Holmes, M. D. (2004). Functional impact of breast cancer by age at diagnosis. *Journal of Clinical Oncology, 22*, 1849-1856.

- Leininger, M. (1994). Evaluation criteria and critique of qualitative research studies. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 95-115). California: Sage.
- National Breast Cancer Centre (2003). *Clinical practice guidelines for the management and support of younger women with breast cancer*. Camperdown, Australia.
- National Health and Medical Research Council (2003). *Clinical practice guidelines for the psychosocial care of adults with cancer*. Australia.
- O'Connor, A. P., Wicker, C. A., & Germino, B.B. (1990). Understanding the cancer patient's search for meaning. *Cancer Nursing, 13*, 167-175.
- Ohlen, J., & Holm, A. (2006). Transforming desolation into consolation: Being a mother with life-threatening breast cancer. *Health Care for Women International, 27*, 18-44.
- Osowiecki, D. M., & Compas, B. E. (1999). A prospective study of coping, perceived control and psychological adjustment to breast cancer. *Cognitive Therapy and Research, 23*, 169-180.
- Pedersen, S., & Revenson, T. A. (2005). Parental illness, family functioning and adolescent well-being: A family ecology framework to guide research. *Journal of Family Psychology, 19*, 404-419.
- Pelusi, J. (2006). Sexuality and body image: Research on breast cancer survivors documents altered body image and sexuality. *American Journal of Nursing, 106*, 32-38.
- Price, B. (1999). A model for body image care. *Journal of Advanced Nursing, 15*, 585-593.
- Sammaraco, A. (2001). Psychosocial stages and quality of life of women with breast cancer. *Cancer Nursing, 24*, 272-277.

The Western Australian Cancer Registry (2005). *Cancer in Western Australia:*

Incidence and Mortality 2003. Retrieved March 15, 2006, from

<http://www.health.wa.gov.au/wacr/>.

Way, N. (1997). Using feminist research methods to understand the friendships of adolescent boys. *Journal of Social Issues, 53*, 703-723.

Yurek, D., Farrar, W., & Andersen, B. L. (2000). Breast cancer surgery: Comparing surgical groups and determining individual differences in postoperative sexuality and body change stress. *Journal of Consulting and Clinical Psychology, 68*, 697-709.

Appendix A

Information Sheet

Thankyou for your interest in this study. My name is Kelly Gibson and I am currently completing my Psychology (Honours) degree at Edith Cowan University, Joondalup Campus.

The aim of the proposed research is to investigate the experience of mothers who have dependent children and a breast cancer diagnosis as well as explore the impact of breast cancer on mothers' identity and self-concept. It is hoped that this area of research will reveal factors that may improve our understanding in relation to mothers living with a serious illness. With this knowledge, we may be able to inform health care professionals of mothers' needs so that support can be tailored to those needs, provide education for health care professionals regarding the psychological and social impact of cancer on mothers and it may benefit other mothers receiving specialist services. Your involvement in this study will be to participate in 1-3 interviews and answer general questions in relation to your breast cancer experience. Total involvement should be approximately 1-3 hours.

The rationale and design of this study has satisfied the strict guidelines laid down by the Edith Cowan University Ethics Committee. Subject to any legal obligations, all data remains confidential and publication of the results will not disclose your identity, and at no time will your name be reported. If you are interested in the outcome of this research project, I will be pleased to share it with you upon its completion, which is scheduled for October 2006. My contact details are listed below.

Should you wish to participate in this study, it is requested that you complete the attached consent document. I would also like to audio record the interview and am seeking your consent to do that. The reason for recording the interview is to ensure that an accurate record of what was discussed during the interview can be analysed. Once transcribed, the recording will be destroyed. After the study is complete, the data collected will be stored in a secured filing cabinet at Edith Cowan University. Please understand that your participation in this study is totally voluntary and you are free to withdraw at any time without penalty, and to remove any data that you may have contributed.

Although it is envisaged that this study will not be stressful for participants, if at any time you become distressed with any aspect of this study, assistance is available to you through a number of counselling services as attached. If you have any questions about the project, please do not hesitate to contact me via the details below, or my supervisor, Dr Moira O'Connor on 6304 5593. If you have any concerns about the project or would like to talk to an independent person, you may contact Ms Kim Gifkins, Edith Cowan University Research Ethics Officer on 6304 2170 or research.ethics@ecu.edu.au.

If you are interested or would like further information, I can be contacted on following:

9447 0459 (h)

0407 192 609 (m)

rk.gibson@bigpond.com

Yours sincerely

Kelly Gibson

Appendix B

Participant Consent Form

I _____ have read the information sheet provided and agree to participate in the research study conducted by Kelly Gibson of Edith Cowan University. I understand the purpose and nature of the study and am participating voluntarily. Any questions I have asked have been answered to my satisfaction. I grant the permission for the data to be used in the process of completing an undergraduate Psychology degree and acknowledge that it may be published. I understand that my name and other demographic information, which might identify me, will not be used. I understand that I can refuse to answer questions and can withdraw from this study at any time. I realise there will be no penalty, should I decide to cease my participation. I also grant permission for the interview to be audio recorded and understand that the recording will be erased once the interview is transcribed.

Signed: Research Participant

Date

Contact Number

Signed: Primary Researcher

Date

Appendix C

In-Depth Interview Schedule

1. I am interested to know about your breast cancer diagnosis. Can you tell me about your experience when you first heard the news?
How did you feel?
What was going through your head at the time?
2. Can you tell me about your experience with treatment of your breast cancer?
What kind of coping strategies did you use?
Was it difficult to get out of bed some days? If yes or no, then why?
3. I am really interested in your experience of having breast cancer and being a mother with dependent children. Can you please tell me what it is like to have breast cancer and be a mother with dependent children?
Can you give me an example of a typical day in your household?
Do you receive any support?
If yes, who provides you with support?
If no, how does that make you feel?
4. Do you feel that your needs are met in relation to being a young mother with breast cancer?
If yes/no, can you tell me in what way?
How does it make you feel?
5. Can you tell me in what way if at all that having breast cancer has changed the way you see yourself?
How does this make you feel?
Do you think this is positive / negative? Why?

Appendix D

List of Counselling Services

Breast Cancer Foundation of WA INC	9324 3703
	9485 2593
Cancer Council Counselling Service	9382 9338
Cancer Council Helpline	13 11 20
Care Ring	13 61.69
Edith Cowan University Psychological Services Centre	9301 0011
Lifeline	13 11 14
Mental HealthDirect:	1800 220 400
Royal Perth Hospital Social Work Department	9224 2711
Brownes Cancer Support Centre	9346 7630
Sir Charles Gairdner Hospital	

Journal of Health Psychology

An Interdisciplinary, International Journal

Editor:

David F Marks

City University, London, UK

[Click here to visit this journal's home page.](#)

Manuscript Submission Guidelines:

1. The Editorial Board of the Journal of Health Psychology considers for publication: (a) reports of empirical studies likely to further our understanding of health psychology; (b) critical reviews of the literature; (c) theoretical contributions and commentaries; (d) book reviews; and (e) signed editorials (about 1000 words) on significant issues.

2. The circulation of the Journal is world-wide and articles are invited from authors throughout the world.

3. Articles should be as short as is consistent with clear presentation of subject matter. There is an absolute limit on length but 8000 words, including footnotes and references, is a useful maximum. The title should indicate exactly, but as briefly as possible, the subject of the article. An abstract of 100 to 120 words should precede the main text, accompanied by up to 5 key words and a brief bibliographical note of 25 to 50 words. The covering letter should indicate whether the author prefers blind or open peer review.

(a) Blind peer review: Authors electing for anonymous review should provide a standard and 'blind' electronic version of their article - one version containing names, affiliations, full mailing address plus telephone, fax, email address; and one containing the title only.

(b) Open review: Authors requesting open review may suggest three possible reviewers. If their article is accepted, substantive commentaries upon the paper may be published simultaneously. Commentaries should not exceed 2500 words.

(c) In all cases, the Editor will screen manuscripts for their overall fit with the scope of the journal. Those that fit will be further reviewed by two or more independent and internationally representative reviewers. Articles will be evaluated by the Editorial Board and refereed in terms of scientific merit, readability and interest. Unsolicited manuscripts will not be returned to the author if rejected.

4. The Journal requires authors to follow the 'Guidelines to Reduce Bias in Language' of the Publication Manual of the American Psychological Association (6th ed). These guidelines relate to level of specificity, labels, participation, gender, sexual orientation, racial and ethnic identity, disabilities and age. Authors should also be sensitive to issues of social class, religion and culture.

5. Articles submitted for publication must be typed in double spacing throughout, on one side of white A4 or US standard paper, with generous left- and right-hand margins but without justification. Titles and section headings should be clear and brief with a maximum of three orders of heading. Lengthy quotations (exceeding 40 words) should be displayed, indented, in the text. American or UK spelling may be used, to the author's preference. Indicate italic type by underlining, and use single quotation marks. Dates should be in the form 9 May 1994. Take care with points in USA and other such abbreviations.

Tables and figures should have short, descriptive titles. All footnotes to tables and their sources should be typed below the tables. Column headings should clearly define the data presented. Camera-ready artwork for all figures must be supplied. Artwork intended for same-size use should be a maximum size of 192:125 mm (page depth: page width). The title page should contain a word count of the manuscript (including all references).

All references cited in the text should be listed alphabetically and presented in full using the format of the Publication Manual of the American Psychological Association (6th ed).

Articles that do not conform to the fundamentals of this style will be returned to the authors for revision.

6. Authors should retain a full copy of their typescript, and send one electronic copy of the original manuscript and one blind copy, clearly labeled in doc or pdf format to d.marks@city.ac.uk. There is no need to send hard copies through the post. All figures and tables should be clearly labeled. For further details please contact: David F. Marks, Department of Psychology, City University, Northampton Square, London, UK EC1V 0HB. Tel / Fax: +44 (0)207 040 8590; email:

d.marks@city.ac.uk

7. Authors will be asked to provide a diskette, labelled with the date, title and author name, containing only the final version of their paper following acceptance for publication. The author is responsible for guaranteeing that the final hard copy and diskette versions of the manuscript are identical.

8. The corresponding author will receive page proofs for checking. He or she will be given controlled access to a PDF of the article and a complimentary copy (per author) of the whole journal after publication.

9. Copyright: On acceptance of their article for publication authors will be requested to assign copyright to Sage Publications, subject to retaining their right to reuse the material in other publications written or edited by themselves and due to be published preferably at least one year after initial publication in the journal. Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere.

10. Reviews: books and suggestions should be sent to Michael Murray (Book Reviews Association Editor), Division of Community Medicine, Memorial University of Newfoundland, St John's, Newfoundland, Canada A1B 3V6 [Tel: +1 709 737 6669/6652; Fax: +1 709 737 7382; email: murraym@morgan.ucs.mun.ca].

Send mail to: webmaster@sagepub.com with questions or comments about this Web site. | [Privacy Policy](#) | Copyright © 2000