PhD Thesis Title:

Young Australian Women with Breast Cancer: Perspectives of their Illness Experiences.

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ABSTRACT

Young women with breast cancer have been found to experience their disease more negatively and more intensely than their older counterparts. However ‘young’ is not uniformly defined within the literature. Studies have reported on a wide range of ages considered to be ‘young’, such as samples simply divided by menopausal status or other researcher-defined parameters. For the purpose of this study, young women with breast cancer were defined as those diagnosed at 40 years of age or younger. The overarching aim of the study was to explore the problems faced by this group of young women using qualitative methodology, guided by constructionist epistemology, and grounded in symbolic interactionism and social constructionism. The study was conducted longitudinally, with data collected three times over a 12-18 month period using one-to-one in-depth semi-structured interviews. Baseline data were collected in the first phase of the study (n=35). A sub-group of participants (n=13) were chosen to be followed twice more approximately six months apart, which made up the next two phases. Themes derived from the literature guided the first phase of the study, data collection and analysis. Data analysis was performed after each data collection phase, with findings informing the next phase/s of the study. Thematic and content analysis were utilized in regards to the analysis of the first phase of the study, providing a framework identifying the most pressing concerns, such as those centred around children and partners, emotional aspects and negative physical consequences of treatment. Interrelationships between these themes were apparent. Findings suggest that the emotional support needs of this group of young women remains a challenge. Basic analytical principles of data reduction, data display and drawing conclusions guided the following phases of the analysis. NUD*IST (N6) software was utilized to help undertake in-depth analysis of all follow-up data. The literature concentrates on infertility as a concern for young women with breast cancer, however the study found that fertility per se was a concern for this group of women. Issues of maintained and regained fertility were reported, i.e., concerns surrounding suitable, safe and reliable contraception, pregnancy and breastfeeding after breast cancer. Over time, perceptions of fertility changed. Decisions related to unplanned pregnancies and breastfeeding were particularly onerous. The study also provided other insights into the participants’ lives. Body image is suggested to be of greater concern for younger women with breast cancer than their older counterparts. Perceptions of breast symbolism, societal and personal, were explored, as were perceptions of the external portrayal of their bodies. In addition, the participants reported how their experience of breast cancer differed from that of older women with breast cancer, e.g., to be and dress more sexually. Theories and notions of social constructionism and the social construction of the body helped explain the participants' experiences. The women were acutely aware of the sexual importance society placed on women's breasts. Social norms and expectations and cultural trends, that is the youth and beauty culture, were found to greatly influence the participants' perceptions and hence decisions made. Prosthesis use and breast reconstructive surgery were viewed as normalising efforts undertaken by participants to reduce stigma related to breast loss/disfigurement and to enhance body image. The findings from this study provide a greater understanding of the issues, concerns and experiences of young women with breast cancer and provide information that could be utilized in the redesign of educational/information resources to provide these women with relevant information. Currently available support services may also benefit from these findings as greater understanding of these women's experiences may facilitate and promote the provision of more age-appropriate support for young women with breast cancer diagnosed in the future.

KEY WORDS

- Breast cancer
- Young women
- Children
- Partners
- Support
- Reproduction issues
- Fertility/infertility after breast cancer
- Contraception after breast cancer
- Pregnancy after breast cancer
- Breastfeeding after breast cancer
- Breast symbolism
- Generational differences
- Body image
- Social norms
- Social expectations
- Cultural trends
- Qualitative
- Longitudinal

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LIST OF ACRONYMS

AACR ---------------------Australasian Association of Cancer Registries
ABS------------------------Australian Bureau of Statistics
AIHW ---------------------Australian Institute of Health and Welfare
APA -----------------------American Psychological Association
ART ----------------------Assistive Reproductive Technology

BC or bc ------------------Breast Cancer
BCNA ---------------------Breast Cancer Network of Australia
BCT------------------------Breast Conserving Therapy
BI---------------------------Body Image

CGHFBC-----------------Collaborative Group on Hormonal Factors in Breast Cancer

GP -------------------------General Practitioner

IPPF ---------------------- International Planned Parenthood Federation
IVF ------------------------Invitro Fertilization

NBCC ---------------------National Breast Cancer Centre
NH & MRC --------------National Health and Medical Research Council
NUD*IST -----------------Non-numerical, Unstructured, Data Indexing Searching and Theorizing

PA --------------------------Pregnancy Associated
PhD ------------------------Doctorate of Philosophy

QCF -----------------------Queensland Cancer Fund
QOL or QoL -------------Quality of Life

SES - ----------------------Socio Economic Status

UHREC ------------------University Human Research Ethics Committee

WHO –--------------------World Health Organisation

YWBC -------------------Young Women with Breast Cancer
YWN ---------------------Young Women's Network

STATEMENT OF ORIGINALITY

The work contained in this thesis has not been previously submitted for a degree or diploma at any other higher education institution. To the best of my knowledge and belief, this thesis contains no material previously published or written by another, except where due reference is made.

Name: Shirley Elizabeth Connell

Signed:……………………………

Date:……………………………..

Copyright Statement

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INTRODUCTION CHAPTER

CHAPTER 1

1.1 INTRODUCTION

Cancer is one of the six national health priority areas in Australia (Commonwealth Department of Human Services and Health, 1994). Approximately one in 11 Australian women will be diagnosed with breast cancer during their lifetimes and in the year 2000, 11,314 (female) cases were recorded, with 685 of those being of women aged 39 or younger (approximately 6%) (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries [AIHW & AACR], 2003).

Consumers of health and care services want professionals to treat them as partners in their care and to communicate sufficient information to them in a comprehensible way (Irvine, 1996). The provision of information and choices has been found to be essential components of psychosocial care of women with breast cancer (Rankin, Newell, Sanson-Fisher & Girgis, 2000). As consumers can act in their own best interest if they are given enough information from more than one source (Williamson, 1993), young women with breast cancer (YWBC), as consumers of health and care services, need relevant information (to their age and situations) to enable them to become informed partners in their care. In addition, as appropriate support and interventions for YWBC are minimal (Breast Cancer Network of Australia [BCNA], 2001), improvements are also necessary in this regard. This study explored the lived experiences of YWBC, as it is these women who know what factors impinge on their day-to-day lives, to help inform professionals to better focus support services and information/educational materials.

Issues and concerns of YWBC are slowly being separated from that of all women with breast cancer, however the literature fails to define ‘younger’ uniformly, with younger presently representing a wide variety of age groups. Hence the issues and concerns of YWBC diagnosed at 40 year of age or younger have been blurred with those identified for a much wider age group. For example, much of what has been found which relates to the experiences of YWBC has been extrapolated from data of women with breast cancer in general with data being separated by various age groups, menopausal status or other researcher defined ‘younger’ categories. Even so, of the themes found within the literature, young women report similar breast-cancer concerns and issues as their older counterparts, however much of the literature suggests they do so more negatively and more intensely (Mor, Malin & Allen, 1994b; Trief & Donohue-Smith, 1996). In addition, YWBC are potentially going to deal with survival issues for a longer period than older women with breast cancer. Due to treatment consequences, young women also report unique concerns and issues, such as those related to young families and reproductive issues.

Infertility has been documented as a specific concern for YWBC, as they can be swiftly thrown into early menopause due to cancer treatment (Bloom & Kessler, 1994b; Dunn & Steginga, 2000; Schaefer, Ladd, Lammers & Echenberg, 1999; Siegel, Gluhoski & Gory, 1999; Singer & Hunter, 1999). As approximately 50% of women aged under 40 will retain their ovarian function following cancer treatments, future pregnancies remain a possibility (Reichman & Green, 1994). This fact, coupled with the current trend to delay childbearing (AIHW, 1997; AIHW, 2001), the push for ‘fertility friendly’ treatments and the surge in Assistive Reproductive Technologies (ART) (Dow & Kuhn, 2004), not only suggests that more YWBC in the future will still want to have (more) children, but also brings to the forefront psychosocial, social and physical issues related to contraception, pregnancy (and termination), and breastfeeding after breast cancer.

Although body image is not a unique concern of young women, intrusiveness of breast cancer in the lives of YWBC has been significantly related to body image and symptom distress (Bloom, Stewart, Johnston & Banks, 1998). Schover (1994) suggests that younger women may suffer greater distress than their older counterparts, due to their high youthful aesthetic expectations. In addition, YWBC are more likely to be influenced by media portrayals of body image, and hence what are considered to be societal norms (Golden, 1983), as society in general tends to evaluate women by their appearance (Fallon, 1994; Freund & McGuire). As such, emotional distress can be intensified by body image changes (Trief & Donogue-Smith, 1996).

Breasts have gone from representing fertility to that of a symbol of sexuality (Beckmann, Johansen, Richardt & Blichert-Toft, 1983b), and as such, are highly symbolic of the processes that make up the construction of femininity (Carter, 1995). Early socialization and cultural views of the appearance and worth of women, together with social expectations of sexuality and femininity, are 'unseen powerful forces' which influence the social construction of how women perceive their bodies (Kasper, 1995, p, 214). Breasts are often perceived by women to be objects for others to view and use (Kasper, 1995), and are an important measure of their desirability and acceptance (Mead, 1949). Therefore body image issues, which are intensified in YWBC, are also magnified in those who undergo mastectomy (Beckmann et al. 1983b).

The literature review reveals there are gaps in relation to understanding how YWBC experience their illness, specifically with regards to their reproduction capacity and subsequent issues and of how social and cultural influences construct, and impact on, their experiences. Hence, much more needs to be known about the lived experiences of YWBC. This thesis addresses some of the gaps in knowledge concerning the experiences of YWBC offering new insights, e.g., identifying issues of most importance to them and looking at their experiences of the external portrayal of their bodies via social and cultural means, but more specifically that of maintained and regained fertility incorporating issues of contraception, pregnancy and breastfeeding after breast cancer.

1.2 SIGNIFANCE AS A PUBLIC HEALTH ISSUE

Cancer is a significant public health issue and is currently targeted by the National Goals, Targets and Strategies for Better Health Outcomes into the Next Century, of which breast cancer is the leading site for women (Commonwealth Department of Human Services and Health, 1994). Young women make up a small but significant number of women who are diagnosed with breast cancer each year (AIHW & AACR, 2003). The news of a diagnosis of breast cancer is devastating for any woman, however the impact on young women, due to the life stage they are in and subsequent life demands and aspirations, is profound (National Breast Cancer Centre, 2004). Survival issues of YWBC may not only be more intense, but also may differ in some regards to that of older women, such as issues surrounding fertility. Social and cultural processes and trends impact on the experience of all women who have breast cancer, however YWBC may experience more intense influences. Future research needs to not only delve deeply into epidemiological issues of being a young woman with breast cancer, but also survival issues, i.e., psychosocial issues and social and cultural processes and influences which may impact on their quality of life.

1.3 AIMS AND RESEARCH QUESTIONS

Consideration of the literature lead to the following aims.

Aim 1. ***Overarching Aim – To explore problems faced by young women with breast cancer.***

<u>*Research Questions*</u> - *What problems/issues do young women with breast cancer experience?*

Aim 2. ***To identify what influences the way in which young women with breast cancer experience their illness trajectory.***

<u>*Research Question*</u> – *How do social networks of, and the professional and lay services utilized by, young women with breast cancer assist or hinder them to adjust to their diagnosis?*

Aim 3. ***To follow over time young women's perceptions of their illness experience.***

<u>*Research Questions*</u> – *Do young women with breast cancer experience a change over time in their perceptions of the problems/issues they face? If changes are identified, why does this occur and what internal and external factors are responsible for such changes?*

Aim 4. ***To identify the major issues faced by young women with breast cancer as a basis for recommendations of appropriate service provision, such as support and/or educational materials provided by health professionals (this term encompasses clinicians, public health and other allied and care professionals and support organisations).***

Research Questions – *How can the experiences of young women with breast cancer inform the redesign of health services and resources to match consumer needs? What information is specifically required by young women with breast cancer?*

1.4 ASSUMPTIONS

This study was conducted from a constructionist viewpoint, in particular grounded in symbolic interactionism, focusing on how people experience their social world and 'how they come to interpret behaviour, theirs and others' (Jackson, 1998, p, 62). However symbolic interactionism could not totally provide explanation of these participants' experiences; hence theories of social constructionism were also employed, which is underpinned by the philosophy of phenomenology, of which central concerns are understanding and meanings given to everyday events (Cheek, Shoebridge, Wilis & Zadorozny, 1996). Hence issues of social structure and cultural influences were also taken into account. Theories of the social construction of the body were also considered in analysing participants' accounts via ideas of how social processes and cultural influences construct the body. Therefore it was assumed that participants' perspectives of their experiences of breast cancer were constructed via social and cultural influences.

1.5 SCOPE AND BOUNDARIES

The perceptions of YWBC were reported in the study. The issues and concerns of the participants were explored over time. The study sought to capture, explore, interpret and understand the construction of the experiences of the participants.

The Literature

The literature reviewed in Chapter 2 failed to uniformly define what constitutes being 'young'. Hence women were defined as young by various definitions, such as those aged 35 up to 50 years, pre-menopausal status, or just the younger portion of the study samples. Therefore, this study sought to classify YWBC by investigating the issues and concerns of women diagnosed at 40 years of age or younger. Due to the longitudinal nature of this study, not only were issues and concerns of the participants identified and explored but also were followed over time.

The majority of the literature surrounding fertility issues after breast cancer concentrates on infertility as a consequence of cancer treatment. However, this study also documented other issues of fertility, i.e., issues of maintained or regained fertility, contraception, pregnancy and termination decisions. Breastfeeding after breast cancer has received little attention within the literature, with that available being mostly concerned with the mechanical ability of the breast to lactate. Unlike the literature, this study explored the decision to breastfeed after breast cancer and other relevant psychosocial issues.

Much has been documented within the literature on body image problems following a diagnosis of breast cancer, however this study sought to understand why and how YWBC, in particular, perceived the external portrayal of their bodies after a diagnosis of breast cancer. In addition, much literature suggests reasons why YWBC would experience their disease more negatively than that of older women; this study documents reasons given by participants.

What The Study Did Not Attempt To Do

It is useful to consider the study in terms of what it did not attempt to do. Corroboration of views and information supplied by the participants documented within the study with medical/health and allied professionals was not attempted, nor were their opinions or views sought or hypothesized. Confirmation of the disease and treatment details of the participants via medical records also fell outside the scope of the study, instead such information was checked in subsequent interviews to provide reliability of the data gathered. In addition, this study did not attempt to investigate the views and opinions of the partners and/or children of participants, rather it was the perceptions of the participants in regards to their partners and children that were sought. The sole purpose of the study was to elicit the perceptions of the participants and how time affected these perceptions.

Characteristics of the Participant Pool

The demographic features of the participant pool were similar, with the majority of participants being highly educated. All participants volunteered to take part in the study; hence it is not known how the participants differ to the population of YWBC in general. Even so, the follow-up participants differed greatly in their life circumstances, e.g., some participants had young adult children while other participants’ still desired to have (more) children, and some participants were single while most participants had partners.

Time and Resource Constraints

Some of the boundaries imposed on the study were related to the resource and time constraints of a PhD project. In particular, limited internal funding defined the scope of the project.

1.6 OVERVIEW OF THE THESIS STRUCTURE

This thesis comprises seven chapters. Although this thesis is written in the passive voice, papers developed from the study findings are presented in the active voice.

Chapter 1 - Introduction

The introduction chapter briefly outlines the purpose, aims and research questions of the study. In addition, this chapter presents an overview, and introduction to all successive chapters, providing both a brief theoretical and literature-based justification for the research undertaken together with a clear indication of what the study purpose was. The American Psychological Association (APA) referencing system was utilized throughout this thesis.

Chapter 2 – Literature Review

The literature review chapter provides a comprehensive overview of the literature concerning many aspects of being a young woman with breast cancer. Together with relevant epidemiological evidence, relationship and family issues, such as fertility, contraception, pregnancy and breastfeeding after breast cancer, have been comprehensively documented. Emotional aspects of being a young woman with breast cancer have also been described, with an emphasis on body image issues as well as sex-related difficulties, and other consequences of treatment. Details of breast reconstruction and prosthesis use are discussed as well as consumer-related issues, such as information, received and required, and support.

Chapter 3 – Methodology and Methods

The methodology and theoretical framework which underpinned the study is explained in this chapter as well as the methods utilized. This chapter together with related appendices provides, in meticulous detail, an audit trail of all the study processes employed, i.e., from recruitment, though data collection, analysis and to the final summary of findings.

Chapter 4 – Results 1

Title: **Issues and concerns of young Australian women with breast cancer.**

Chapter 4 documents the findings from the baseline interviews, providing the knowledge from which to build the study. This chapter outlines the issues and concerns of this group of participants, together with demographic and treatment information. In particular, reported are: changes participants had experienced since their diagnosis; what helped and/or hindered their adjustment to their diagnosis; their worst side effects experienced; the greatest general concern for YWBC; their major present concerns; and greatest unmet need. This chapter displays a collection of tables that highlight the findings reported. This chapter was developed into a paper and was submitted to the international peer-reviewed journal '*Supportive Care in Cancer*'.

Chapter 5 – Results 2

Title: **A qualitative analysis of reproductive issues raised by young Australian women with breast cancer.**

Reproductive issues of YWBC are the focus of Chapter 5. This chapter explores and reports on various avenues of reproduction after a breast cancer diagnosis, from infertility through to problems associated with maintained or regained fertility. As some participants became pregnant during the interview phases, their experiences were documented over time, some right up to breastfeeding. Contraception was raised as an issue, as was the fear of a pregnancy and subsequent breastfeeding causing or accelerating further cancer. The decision to breastfeed was also found to be onerous, though not as difficult as the decision relating to termination. Chapter 5 was developed into a paper and was submitted to the international, peer-reviewed journal '*Health Care for Women International*'.

Chapter 6 – Results 3

Title: **Young women with breast cancer: How does their perception of social and cultural influences impact on the external portrayal of their bodies?**

Social and cultural processes and influences impact on the experiences of YWBC. Chapter 6 delves deep into the social and cultural trends, norms, expectations and processes which made an impact on how the participants perceived and experienced the external portrayal of their bodies, taking into account breast symbolism from both social and personal perspectives. In addition, how these YWBC perceived their experiences to differ from that of older women were also explored and explained within this chapter. A paper developed from this chapter will be submitted to the journal '*Health Care for Women International*'.

Chapter 7 – Discussion

All the threads of the study are brought together in the discussion chapter. Those issues raised in Chapters 4, 5 and 6 have been further explored and suggestions made to improve support and information services and materials. Advantages of undertaking qualitative, longitudinal research have been documented, together with the study's strengths and limitations. How the aims of the study were met is also discussed. Questions and topics for further research have also been suggested, with some practical suggestions provided.

CHAPTER 2

LITERATURE REVIEW

This chapter documents the literature that was critically reviewed relevant to the study topic, covering aspects of the incidence and mortality rates among young women with breast cancer (YWBC), problems faced by YWBC with regards to emotional issues, relationships and family, reproductive issues, treatment choices and effects, and consumer-based issues. The documented literature was located by extensively searching MEDLINE, PubMed, CINAHL, PsycArticles, various Internet search engines and cancer organizations and other relevant web pages. The complexities of issues relating to YWBC required extensive reading from a wide variety of disciplines, hence this review did not lend itself to a systematic review process. The disciplines explored include public health, nursing, medical science, psychology, psychosocial, sociology and health consumerism.

2.1 INTRODUCTION

Breast cancer is the most common cause of cancer death among Australian women (AIHW & AACR, 2003). It is expected that approximately one in eleven Australian women will, during their lifetime, develop breast cancer (AIHW & AACR, 2003). Many studies focus on the disease etiology, treatment and short-term side effects, however survival issues are coming to the forefront as treatments and detection improve and more women survive their ordeal (McPhail, 1999).

Young women make up a small, but significant, number of those who are diagnosed with breast cancer each year. Some issues faced by these young women are different from those facing older women and need addressing to assist them to cope with their diagnosis and to adjust to their post-treatment lives. Siegel et al. (1999) state that ‘a diagnosis of breast cancer constitutes a profound psychological insult for any woman’.

Such an insult is heightened for young women, particularly in relation to their expected life course, crushed social and life expectations and limited support services available to them (BCNA, 2001; Kasper, 1995).

Young women who have breast cancer are consumers of health and care services and as such deserve to have their voices heard. However, the notion of 'consumer' has been paralleled to that of patients, 'the final, passive recipient of services' which has been a manifestation of the social and structural factors as to why consumer perspectives of health care and services dealing with their illness have not greatly impacted on political processes (Peterson & O'Connor, 2001, p, 1). The first step to assist YWBC to have their needs met is to investigate such needs and issues using a valid research methodology and protocol. Once service and information gaps are identified, public health professionals can address such issues to enhance current practice in appropriate ways.

2.2 DEFINION OF 'YOUNGER' WOMEN WITH BREAST CANCER

When studying issues of younger women who suffer breast cancer, it is imperative to consider the developmental psychology based life stage and role identities the women are experiencing (Glanz & Lerman, 1992; Bloom & Kessler, 1994b). Dunn and Steginga (2000) approached their study of YWBC via the developmental perspective, looking at the stage of the family life cycle the women were in at the time of diagnosis, and how it affected them. As women reach the various family developmental stages at different ages, depending when they started a family, Dunn and Steginga (2000) thought it best to study their participants with regards to where in the family life cycle the participants perceived themselves to be rather than by age divisions, such as 25 to 35 years of age and so on. The above provides an example of how the term 'young women' can be defined by researchers.

As a clear definition of what constitutes 'younger' in the population of women who have breast cancer does not exist within the literature, the candidate developed a definition to limit confusion of who could and could not participate in the study. 'Younger' for the purpose of the study is defined as adult women who are diagnosed with breast cancer at 40 years of age or younger. With such a definition, a clear line is drawn for participation in the study, as using the developmental perspective (specifically) may create uncertainty of eligibility. Chronological age brings with it specific physical milestones, particularly concerning reproductive capacity. The differences brought to the study by the various life stages and family stages of the women in this age group enhanced and enriched the study findings.

2.3 BREAST CANCER INCIDENCE AND MORTALITY

Australia recorded 11,314 new cases of breast cancer in 2000 (AIHW & AACR, 2003). With reference to the ‘younger’ focus of the study, the age group of 39 years or under recorded 685 new cases in 2000 Australia-wide (AIHW & AACR, 2003). Due to screening practices and advanced treatments now available the mortality rate from breast cancer declined by an average of 2% per year from 1990 – 2000 (AIHW & AACR, 2003). Within Australia, between 1995 and 1998, 453 deaths were recorded from breast cancer among women 39 years of age or younger.

International studies of breast cancer in younger women have found that young women (various definitions - ranging from under 50, 40 and 35 years of age) are not only more likely to present with a palpable mass with more nodal involvement (Gajdos, Tartter, Bleiweiss, Bodian & Brower, 2000), but are also at risk of suffering a more aggressive cancer and hence poorer 5-year survival than their older counterparts (Chung, Chang, Bland & Wanebo, 1996; Golledge, Wiggins & Callam, 2000; Grosclaude, Colonna & Hedelin, 2001; Winchester, Osteen & Menck, 1996; YilDirim, Dalgic & Berberoglu, 2000). All of the above information demonstrates that breast cancer is a life-threatening disease experienced not only by older women, but also by younger women.

Younger women who suffer breast cancer, however, can potentially (with regards to their younger age) experience an increased period of survival than that of older women. Even though their numbers are in the minority of those who suffer from breast cancer, their life/family stage experiences (which can differ from that experienced by older women) (Siegel et al. 1999), coupled with the potential emergence of long-term survival issues, indicates a need for investigation into the issues which are pressing for these women.

2.3.1 Pregnancy Associated Breast Cancer

Pregnancy associated (PA), or gestational breast cancer, is usually defined as that breast cancer diagnosed during pregnancy and up to one-year post-partum (Puckridge, Saunders, Ives & Semmens, 2003). Earlier study findings suggest that the further a woman is away from a pregnancy (either before or after a diagnosis of breast cancer) the greater her changes of survival (Guinee et al. 1994), and that PA breast cancer only results in a worse prognosis if it is diagnosed at a more advanced stage (Petrek, 1994a). More recent literature adds further substance to claims that the prognosis of women diagnosed while pregnant is similar to that of their non-pregnant counterparts, when matched for age and stage (Gemignani & Petrek, 2000; Moore & Foster, 2000; Woo, Yu & Hurd, 2003), at least in the early stages (Gemignani & Petrek, 2000). Woo et al. (2003) claim that PA breast cancer tends to be diagnosed at a later stage and is estrogen receptor-negative, hence impacting negatively on survival. Middleton, Amin, Gwyn, Theriault and Sahin (2003) found a breast cancer diagnosed during pregnancy shares many histologic and prognostic similarities with those found in other young women, hence suggesting the poor prognosis may have more to do with young age than pregnancy in itself. The results of the Middleton et al. study were strengthened due the use of follow-up information (2-163 months, mean = 43 months), however the sample size was small (n=39) limiting the generalisability. Even so, the general consensus is that a pregnancy following a breast cancer diagnosis does not increase the risk of mortality from the disease nor of recurrence (Blakely et al. 2004; Collichio, Agnello & Staltzer, 1998; Kroman, Jensen, Wolfahrt & Mouridsen, 1997; Mueller et al. 2003; Velentgas et al. 1999). For more study details see Appendix 1.1, Table A1.1.

According to Gemignani and Petrek (2000), for those women who are diagnosed with breast cancer during pregnancy, adjuvant treatments may affect the risk of teratogenicity and subsequent fetal development. Other complications can arise, such as premature birth and a risk of congenital abnormalities, hence chemotherapy is not advised for women diagnosed during pregnancy, at least not in the first trimester (Moore & Foster, 2000; Puckridge et al. 2003; Woo et al. 2003). Radiotherapy too should be avoided during pregnancy (Moore & Foster, 2000; Puckridge et al. 2003; Woo et al. 2003).

Breast cancer in pregnancy is rare hence population representation in studies is extremely difficult. Often physicians’ memories of such cases are used in retrospective reviews, as pregnancy is usually not noted as a disease in medical records (Reichman & Green, 1994). More studies are needed in the area of diagnosis of breast cancer during pregnancy, concentrating on treatment effects on the fetus, and subsequently the delay of treatment ramifications on the mother. Such information would allow YWBC to make informed decisions concerning the future of their pregnancies.

2.3.1.1 *Psychosocial Consequences of Pregnancy Associated Breast Cancer*

According to Middleton et al. (2003, p, 1056) ‘breast carcinoma is the most common cancer associated with a pregnancy’, bringing with it the potential to be equally devastating for the mother and child. The psychological and psychosocial ramifications of being diagnosed with a cancer during pregnancy have barely been researched, though Schover (2000) attempts to shed light on the topic. Schover (2000) claims that these women have to deal with lots of issues at this time, those of fertility concerns and/or issues of subsequent pregnancies causing complications, the present and future health of the unborn infant (including concerns of cancer in the child) and possible deformities of the unborn infant. Thomas (2004) found that the experiences of women, with medically complicated pregnancies, had much to be desired. The needs of women with continuing medical problems can become lost amongst what is considered to be normal, ‘due to rigid hospital systems without scope for individual experience’ (Thomas, 2004, p, 86). This leaves open another area for research: that of the trajectory of the pregnancy (rather than the breast cancer) and birth experience in the context of serious illness. As breast cancer is likely to be diagnosed in more pregnant women in the future, and considering the enormous distress diagnosis of a breast cancer during pregnancy could induce (Schover, 2000), psychosocial research on this topic is needed which will inform and enable helping and health/medical professionals to understand such a woman's situation, concerns and feelings.

2.4 PROBLEMS FACED BY YOUNG WOMEN WITH BREAST CANCER

According to Wang, Cosby, Harris & Liu (1999), a woman's concerns determine her needs. Many issues experienced by women with breast cancer are common regardless of age, however the bulk of the literature reviewed suggests that younger women experience many such common issues more intensely and more negatively, such as emotional distress (Mor, 1994), which can be intensified by body image changes (Trief & Donohue-Smith, 1996). Issues surrounding developmental and family life stages provide a unique set of concerns for younger women, such as fertility concerns caused by early menopause (and the corresponding sexual dysfunctions associated with menopause) (Bachmann, 1994; Reichman & Green, 1994; Schaefer et al. 1999; Singer & Hunter, 1999; Thewes, Butow, Birbis & Pendlebury, 2004) and raising young children (Bloom & Kessler, 1994b; Dunn & Steginga, 2000; Glanz & Lerman, 1992; Siegel et al. 1999).

2.4.1 Beyond the Bio-Medical Model of Disease

Shapiro et al. (2001) suggests that the bio-medical model of disease, though vital, does not explain all the many facets of the cancer experience. Shapiro et al. (2001) hypothesizes that good health is not just facilitated by good emotion, but rather is an expression of all emotions. According to Halford, Scott and Smythe (2000), some evidence suggests that cancer-free periods and survival rates are affected by better psychological adjustment, hence the importance of psychosocial research among YWBC.

Shapiro et al. (2001, pp, 513-514) state that 'the most salient factors of care for women with breast cancer are to acknowledge the significant role psychosocial variables play on their total well-being', such as isolation being detrimental to health (Bleiker & van der Ploeg, 1999). Social contacts and supports, such as friends and work colleagues, have been found to be statistically associated with survival, which suggests that wide social networks and contacts improve survival rates (Waxler-Morrison, Hislop, Mears & Kan, 1991). Emotional supports have also been found to buffer the effects experienced from stresses faced while improving mental well-being of YWBC (Bloom, Stewart, Johnston, Banks & Fobair, 2001). The findings from the Waxler-Morrison et al. (1991) study are strengthened by its prospective nature and rather large sample size, together with self-report measures of social factors (rather than reports from a third observing party) and the use of multivariate analytic methods. The 'younger' women within this study were aged under 55 years at diagnosis.

Studies have attempted to correlate psychosocial variables to increased survival and overall improved well-being. One such study found that quality of life (QOL) was significantly related to psychosocial variables (such as sense of coherence, sense of control) (Shapiro et al. 2001). However the sample was small and homogeneous which restricts the generalisability of the results to other stages of breast cancer, various treatment phases and other cancers and illnesses. Such correlations should be viewed more as exploratory than definitive (Shapiro et al. 2001); a replica study with a larger sample size is needed to verify these findings.

A recent mixed-methods longitudinal study of psychosocial and QOL issues among YWBC (diagnosed at 51 years of age or younger, five years previously; 40% of participant pool were 44 years of age or younger) found, via qualitative inquiry, that there still exists lingering effects of treatments, which was missed by quantitative evaluations, with many participants regretting treatments received (Bloom, Stewart, Chang & Banks, 2004). Depression was also commonly reported but was not reflected in the quantitative part of the study suggesting, as some of the other qualitative results, that some effects are lost in quantitative analysis (Bloom et al. 2004). Over the five years, however, there were significant improvements in surgical symptoms, body image, worry about the future, physician communication, and intrusiveness of treatment (Bloom et al. 2004). There were also significant decreases in emotional support and the size of the social networks, although the findings of this study were limited as only disease-free participants were recruited thus reducing generalisability; a non-cancer comparison group was not included hence age-related normal changes became entangled with cancer-related issues (Bloom et al. 2004).

Interventions have been conducted with the aim of improving survivorship and well-being. A study of such an intervention (of women with stage I breast cancer and men with prostate cancer) found that those who participated in the psychosocial intervention lived significantly longer at seven and four years follow-up, respectively, than their matched controls. The prostate cancer intervention group recorded half the death rate of the matched control group (14% as compared to 28%). Of specific interest is the breast cancer group who all survived to the seven-year follow-up, whereas 12% of the matched control group died (Shrock, Palmer & Taylor, 1999). These results could suggest that psychosocial interventions may improve survival rates.

However, as the intervention only consisted of six two-hour health psychology classes, it is difficult to speculate that it was the intervention alone that produced the results, as all bias and confounding factors could not be eliminated. The authors state that participants felt ‘listened to, cared for and supported’, explaining how being involved in an intervention was perceived as doing something positive and constructive for oneself, hence, the participants may have gained a sense of control which may have enhanced longevity (Shrock et al. 1999, p, 6).

Such studies encourage continuous development in the field of psychosocial oncology. As stated by Shapiro et al. (2001), health care professionals should be helping women with intrapersonal issues (sexuality), interpersonal issues (family relationships) and existential issues (confronting mortality). As treatments for YWBC are often very aggressive, the emotional and instrumental (tangible) needs of young women are critical to their overall well-being (Bloom et al. 2001). More replicable studies need to be conducted to provide sufficient evidence to allow scientists to state that attention paid to psychosocial status, in the form of suitable interventions, can prolong life.

The themes displayed in Figure 2.1 (original concept map), derived from the initial literature review conducted prior to data collection, provide a simple framework of issues that are relevant to YWBC. The remainder of this chapter addresses and expands on these themes.

2.4.1.1 *Emotional Issues*

2.4.1.1.1 *Confronting Mortality/Grief*

Young women are thought to grieve the possible loss of future developmental milestones, within the family life cycle or their own, such as seeing children grow up (Siegel et al. 1999). An example of young women dealing with a diagnosis of breast cancer was provided by Siegel et al. (1999) and Ghizzani, Pirtoli, Bellezza and Velicogna (1995), commenting on the vulnerability to distress of young women as they had not previously had to deal with such a grave situation. This suggests that older women, who are in a different life stage, are able to cope better with a life-threatening disease due to their life experience and possible encounters with others who had suffered similarly. I acknowledge the importance of existential issues for YWBC. This literature review (and the study) concentrates on issues I have the potential to so something about, leaving the study of existential issues to professionals more qualified to address such concerns, i.e., psychologists. Hence, further exploration of existential issues is beyond the scope of this study.

2.4.1.1.2 *Other Emotional Issues*

There is growing evidence to suggest that YWBC suffer elevated levels of overall distress, such as: anxiety, depression and/or anger (Mor et al. 1994b; Trief & Donohue-Smith, 1996); symptom distress (Bloom et al. 1998); a negative impact on self-esteem compared to older women (Wang et al. 1999); are less happy and have a significantly higher number of unmet needs across all domains than older women (Mor et al. 1994b); and prolonged emotional distress secondary to the fear of the illness and to mourning the affected breast (Ghizzani et al. 1995).

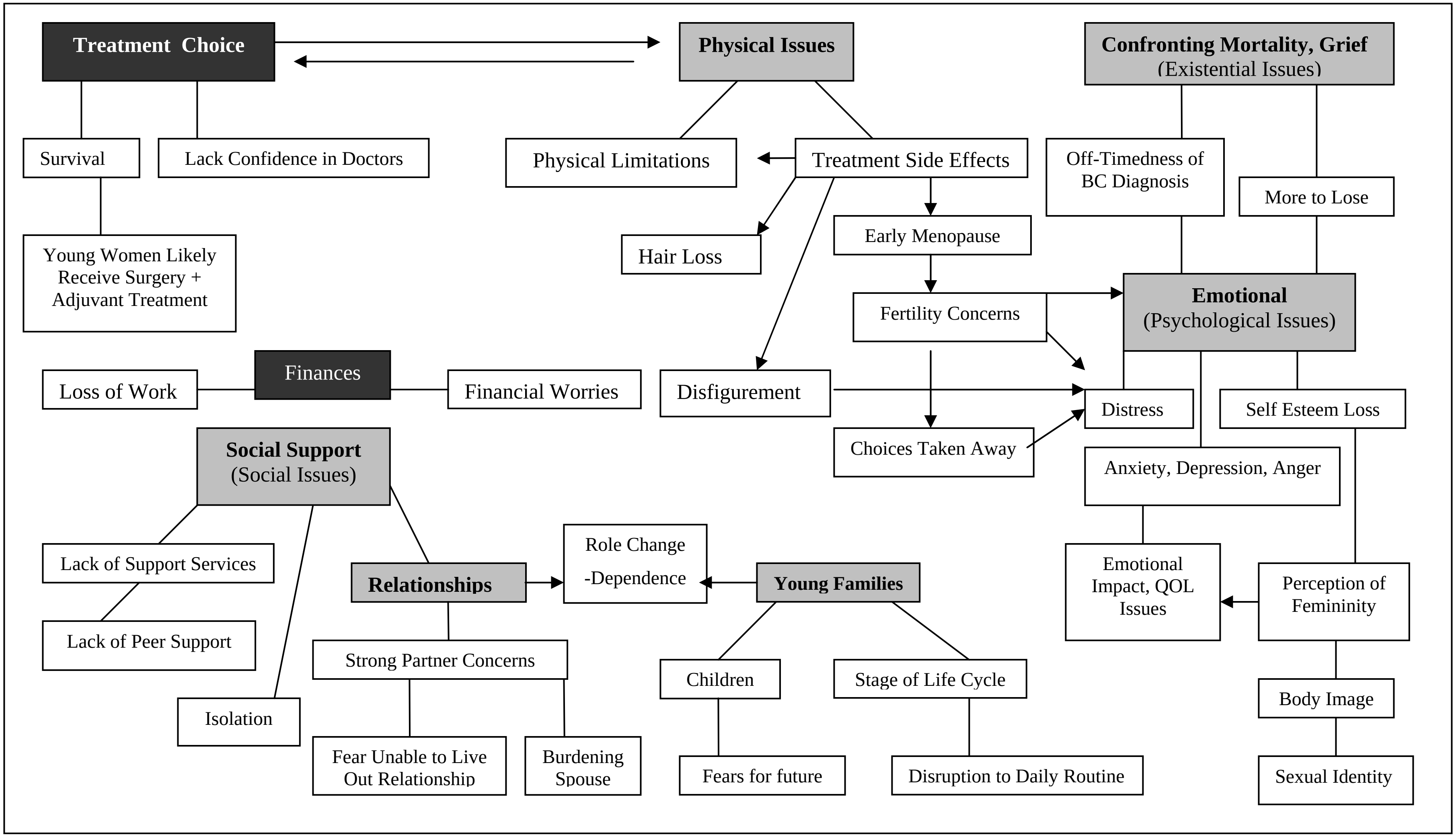


Figure 2.1. Concept map of issues facing YWBC derived from a literature review *(Original Concept Map)*
Note: The themes in lightly shaded boxes (5) are the main focus of this study.

Note for Figure 2.1: Arrows indicate how one issue can lead to another, such as fertility concerns can lead to YWBC feeling as though their choices are taken away. Straight lines indicate how issues are linked to the main theme presented (in shaded boxes), in effect, subheadings of a main theme.

In a multi-institutional, randomised study of 304 breast cancer sufferers, younger women reported significantly greater QOL disturbances than their older counterparts (Wenzel et al. 1999). Quality of life was found to be significantly worse for younger women globally (P=0.021) and with regards to domains of emotional well-being (P=0.0002) and of breast cancer-specific concerns (P=0.022) (Wenzel et al. 1999). Symptoms for depression (P=0.041) and disease-specific intrusive thoughts (P=0.013) were also significantly worse for younger women (Wenzel et al. 1999). Body image, which could be regarded as an emotional issue, is discussed in detail further within this chapter in section 2.4.3.1.

2.4.1.2 *Relationships and Young Families*

2.4.1.2.1 *Single Women*

As young women who suffer from breast cancer can be single, further academic literature in this field is necessary as little was found. Issues identified via a qualitative study of 16 single women (age range 22-42), were: pessimism regarding future relationships; fears of disclosing the illness; negative body image; fears of partner rejection; a sense of isolation; and inadequate support (Gluhoski, Siegel & Gorey, 1997). Almost all of these women spoke of how their marital status influenced their cancer experience. A consequence of their experiences was a fear of starting a new relationship and commitments (Gluhoski et al. 1997). This study was part of another study of decision making about pregnancy – not specifically of those women who were not married or partnered. Therefore, the findings would need to be verified with other studies specifically of single women with breast cancer. Single women have their own set of issues following a diagnosis of breast cancer. The realm of single women (all age groups) with breast cancer needs much attention.

2.4.1.2.2 *Family*

According to Winchester (1996, p, 284), family demands on a young woman are often at near ‘saturation point’, amplifying any negative psychosocial effects of the disease. This, coupled with life in general, such as career demands, family structure, deflated body image, and effects of treatments, can be overwhelming (Bloom et al. 2001). Hence, as stated by Greer (1999, p, 238), it is ‘the patient who gets cancer, treatment should involve the whole patient, not just her malignant cells’, thus incorporating her family.

Issues surrounding family and relationships were of great concern to YWBC. The findings from the Davis-Ali, Chester and Chesney (1993) study suggests that cancer should be conceptualised as a family disease, rather that a disease purely experienced by the individual diagnosed. All family members (partners, children and other women members) are in need of support, not just the women with breast cancer (Ferrell, Grant, Funk, Otis-Green & Garcia, 1997) as cancer impacts on the whole family (Hilton, Crawford & Tarko, 2000).

Many functions and aspects of the family and family life have been studied in regards to how the woman with breast cancer finds support and solace in the family (Dow, Harris & Roy, 1994), to how the illness (and its related demands) impacts on the family as a system, and its individual members (Ferrell et al. 1997). Another function of family life is communication. Family communication patterns of younger families (mean age 46.2 years) have been found to be significantly different to that of older family age groupings (P=0.001), with younger families being defined as ‘talkers’ as compared to medium talkers and non-talkers (older families) (Hilton, 1994). This puts the younger family at an advantage to disseminate vital information, providing the information received is accurate and relevant. This also implies that YWBC should be encouraged to communicate openly with their families. More studies on communication patterns of young families may further break down such a classification, which could assist health and allied professionals to identify such categorisations of families. This in turn may allow professionals to better assist such families.

Spouses/partners play a vital role in the family system. Following a diagnosis of breast cancer, and throughout the treatment regimen, it is the spouse/partner who often shoulders much added family and domestic responsibilities (Hilton et al. 2000). Spouse/partners have been found to be concerned with trying to keep the family life going while focusing on the illness experiences of the ill partner with breast cancer (Hilton et al. 2000).

Parent-child interactions are vital to assist children to function better throughout a crisis period. Parenting functions and abilities are often affected when the mother suffers from breast cancer. Mothers and their partners are, however, affected in different ways, thus impacting on children (Lewis & Hammond, 1996). Women in unhappy marriages, who experience further negative effects from a breast cancer diagnosis, subsequently experience negative interactions with their offspring. Whereas interactions of spouses/partners with their offspring, which are paramount to healthy functioning, are compromised more by negative family coping behaviours (Lewis, Hammond & Woods, 1993). In addition, when parenting quality is low, due to illness demands on the parents, so too is the self-esteem of adolescents (Lewis & Hammond, 1996). Therefore, the parenting functions of both the woman with breast cancer and her spouse/partner need further investigation to establish how best such can be addressed.

It appears that the research sways towards the woman with breast cancer being affected by internal emotional factors, whereas the partners are affected more by external factors, such as the family’s coping behaviour (Lewis et al. 1993). Lewis and Hammond (1996) suggest that mothers may view themselves to be the centre of the family’s problems, rather than the cancer itself. These mothers need to be counselled to allow them to interpret illness-related demands in ways that reduce their personal guilt and burden (Lewis & Hammond, 1996).

Finances

Family relationships can suffer in times of financial hardship, hence a decrease in family income only serves to heighten the distress experienced (Mor et al. 1994b; Spencer et al. 1999; Wang et al. 1999). As many young mothers now contribute to the family's weekly income, a diagnosis of breast cancer can severely disrupt the family budget with the treatment routine of breast cancer forcing many young women to give up their jobs. Older women may have had more time to accumulate a 'nest egg' on which to fall back on in times of need, which a younger woman may not have had an opportunity to achieve. Financial problems experienced in this way can also provide more tension within the family unit (Wang et al. 1999). A summary table of family studies can be Appendix 1.2, Table A1.2.

Limitations and Summary: Family

Research into the psychosocial aspects of being a single YWBC is scarce. Findings were difficult to compare and integrate due to the different family structures reported in studies, such as one-and two-parent families and stages of the family life cycle, such was the case in the Hilton (1994), Lewis and Hammond (1996) and Hilton et al. (2000) studies.

The reviewed studies of families dealing with breast cancer, though not exhaustive of the literature, struggle to inform clearly what the state of play is for these families. Some literature found during data searches was not located at the time of writing this review, and numerous dissertations, not yet published, have been written on various topics related to family and breast cancer.

Clearly family and relationship issues are a major concern for YWBC, while financial problems have the potential to create further anguish. The majority of the studies reviewed examined families with children and adolescents, with the age range of the women and their partners being mainly in the high 30s to late 40s, thus appropriate for YWBC. However, with studies being extremely focused on various minute aspects of the family, together with a lack of definitions of various family structures and factors, concise conclusions are difficult to frame. As family structures change over time, future family studies will need to keep abreast of social expectations and perceptions of families. Studies investigating families who experience advanced breast cancer, together with those with younger children, may produce very different realities. .More studies are needed to investigate young women's perspectives of the impact the breast cancer diagnosis has on the family as a system.

2.4.1.2.2.1. *Couples/Spouses/Partners*

Spouses/partners play a vital role in the illness trajectory of YWBC. According to Halford et al. (2000), most people, when threatened by the possibility of having a cancer through to diagnosis, treatments and finally recovery, look to their partners for support (if they are in a committed relationship). Spencer et al. (1999) found that younger women reported stronger partner-related concerns than older women. However, the concern of younger women was not being able to live out the relationship rather than breakdown of the relationship with regards to the breast cancer (Spencer et al. 1999). It must noted that this may not be the case for all young women in close-partnered relationships.

The quality of the marital relationship is the strongest predictor of the impact the cancer will have on marital functioning. Weihs, Enright, Howe and Simmens (1999) found that an unsatisfying marriage elevates the distress experienced by women who have breast cancer in the long term regardless of earlier levels of distress. The negative effects of a breast cancer diagnosis can produce depression in the spouse as illness demands increase, impacting on marital adjustment (Lewis, Woods, Hough & Bensley, 1989). However, rather than the husband's perception of the marriage affecting distress levels of the woman, it was found that it is the woman's perceptions of the relationship which influenced the distress levels (Weihs et al. 1999). Even so, marriages which were not rated as ‘good’ before the breast cancer diagnosis have been found to become more disruptive and distressing (Sturesteps & Darroch, 1986).

Couples are affected by the breast cancer experience in relation to communication (O’Mahoney & Carroll, 1997; Rees & Bath, 2000), sexual relationships (O’Mahoney & Carroll, 1997; Sormanti & Kayser, 2000; Sturesteps & Darroch, 1986), and role identities (O’Mahoney & Carroll, 1997; Zahlis & Shands, 1991). The role reversal involved can produce various challenges in regards to the care of children, and the uncertain future (Zahlis & Shands, 1991). Partners who adjust reasonably well to a diagnosis of (metastatic) breast cancer and engage in open communication of difficulties and conflict may, by such a communication style, benefit the women rather than trying to buffer the effects of the cancer, such as down-playing any illness issues, i.e. death (Giese-Davis, Hermanson, Koopman, Weibel & Spiegel, 2000).

Partner Support

Ghizzani et al. (1995) found that older women coped with their breast cancer primarily through their spouses’ support, though friends and other family support did supplement such spousal support if it was not forthcoming. However, Pistrang and Barker (1995) claim that no other support can emulate the unique support given by a spouse. Therefore, younger women’s acceptance of the illness may depend on the degree of intimacy shared with their spouses (Ghizzani et al. 1995; Pistrang & Barker, 1995).

Women, in a study of partnered relationships of women with life-threatening illnesses, who reported higher levels of perceived mutuality received more satisfying emotional support, together with a greater variety of supports (Sormanti & Kayser, 2000). However a study to investigate if partners/spouses were more helpful to the women with breast cancer than volunteers who had survived breast cancer, found that volunteers were more helpful than partners if the women were greatly depressed (Pistrang & Barker, 1998). This study had various design faults (which did not allow sufficient analysis) and multiple limitations, such as the observers and the participants differed in their view of what was helpful, and the data collection only consisted of taped 10-minute general conversations. More studies are needed to tease out the helpfulness of support given by spouses.

As both women with breast cancer and their partners have been found to be equally involved in the cancer treatment (David-Ali et al. 1993), support groups for partners can help relieve distress experienced due to a breast cancer diagnosis. Bultz, Speca, Brasher, Geggie and Page (2000) found reduced mood disturbance and greater confidant support and martial satisfaction, of partners, after attending such a group. Women with breast cancer have been reported to benefit from their partners receiving support (Giese-Davis et al. 2000). A longitudinal study found that those who report receiving more support also reported fewer symptoms of emotional distress and physical maladjustment (Hoskins, 1995). Therefore, focusing support on the couple, rather than solely on the women with breast cancer, may alleviate more distress in both partners (Giese-Davis et al. 2000).

Partners and Information

Partners have been found to depend largely on their wives/partners with breast cancer to provide them with information concerning the disease (Hilton et al. 2000; Rees & Bath 2000). Such information flow was found to hinge on the communication desired by the woman (Rees & Bath, 2000). Some men (partners) studied have been found to be happy with the level of information given to them by their wives, however other men have become more engaged in not only seeking out additional information, but also with decision making (Hilton et al. 2000). Rees and Bath (2000) found that much information obtained by partners from health professionals was actively sought rather than offered. Any information offered to the partner by health professionals can be shared with others, which in itself offers reassurance (Borwell, 1996). See Appendix 1.3, Table A1.3, for more details of couples and partner-related studies.

Limitations and Summary: Couples/Spouses/Partners

The mean ages of partners within studies ranged from 43.7 years (Zahlis & Shands, 1991) to 53.1 years (Davis-Ali et al. 1993). Specific age ranges of participants were very wide, e.g., the Sturesteps and Darroch (1986) study of 26-72 years, as were relationship durations, from 2-41 years (Zahlis & Shands, 1991 and Sturesteps & Darroch, 1986, respectively). Marriage/relationship duration ranges were also very wide, such as in the Zahlis and Shands (1991) study of 2-27 years, the Pistrang and Barker (1998) study of 3-34 years and the Sturesteps and Darroch (1986) study of 3-41 years. Such wide variations could bias a study, because short, as compared to medium or long, duration marriages/relationships (which would need to be defined) may produce differences. Earlier literature, such as Sturesteps and Darroch (1986), may present findings that are no longer relevant in 2005, as families and social structures change over time. As younger women are more likely to be in a marriage/relationship for a short to medium time, research findings that reflect such marriage/relationship durations would be more appropriate to inform professionals. Even so, the literature provides a basic understanding of the important role that spouses/partners play in the psychosocial realm of YWBC, and how the diagnosis may affect the spouse/partner. However the literature does not offer clear indications of the specific problems YWBC face in regards to their spouse/partner. The concerns older women have for their spouse/partner, or the support they provide, as documented in the literature, cannot be generalized to women diagnosed at 40 years of age or younger, hence studies which concentrate of YWBC and their spouses/partners are needed to identify and understand their specific issues.

As spouses/partners appear to be a vital source of support, they need to be included in any treatment plan, together with being acknowledged by health and care professionals for their potential important contribution to their wives'/partners' recovery. Studies of such professional acknowledgement were lacking. Therefore further studies concerning the significant and specific role partners play in such recovery are needed. More psychosocial research is needed of the role of partners and the influence partners have on the illness trajectory of YWBC.

2.4.1.2.2.2. *Children*

Seriously ill young women (and men) express concern regarding the rearing of children (BCNA, 2001; Brock & Perry, 1995; Northouse, 1994; Siegel et al. 1999), together with the disruptions caused by treatment routines. According to a review conducted by O'Mahoney and Carroll (1997), families with young children rely on external resources and tend to experience greater family conflict. However young women (those 40 years of age or younger) may not only have young children (babies, through to school-age children) but may also have offspring into their early adulthood years.

Studies have found that adolescent daughters are at a higher risk of distress from their mothers' breast cancer than other age groups of children (Turner & McGrath, 1998; Welch, Wadsworth & Compas, 1996). However, adolescents (aged 11–18 years) regardless of gender were found to suffer more distress than school-age children (aged 6-10 years) (Welch et al. 1996). Such distress was not recognised by some parents (due to their own distress) (Welch et al. 1996). Over time, children's distress was found to weaken, however some parents' perceptions of such distress did not decrease (Welch et al. 1996). Mothers who describe and report their children's adjustment difficulties may be influenced by their own illness and disability, hence under- or over-reporting difficulties is possible (Turner & McGrath, 1998). Therefore health professionals may need to help parents to recognise the distress experienced by their children (Redman, 1998).

Studies conducted by Birenbaum, Yancey, Phillips, Chand and Huster (1999) and Hoke (2001) did not find children of mothers with breast cancer to have adjustment problems, though some children did display some risk of behavioural problems (Birenhaum et al. 1999). Such findings contradict that of others, such as presented by Welch et al. (1996). The Birenbaum et al. (1999) study could have been improved if it presented some form of base-line (retrospective report) data on the children's behaviour patterns before the onset of the mother's cancer. A further limitation of the study was that the school-age children did not self-report. Self-reported data, viewing the situation through the experience of the school-age children rather than by an observer, may have provided different findings.

Hoke (2001) brings attention to the fact that (approximately) 40% of those mothers approached about her study declined the offer. This may be because their own problems, and that of their children, were too distressing to share with researchers hence participation bias may be a factor in these results. As the study population consisted of those of middle to higher socio-economic status, their access to resources may also explain why the participant pool did not display adjustment difficulties. The children and adolescents may have also displayed a brave face to not distress their mothers further, adding a component of social desirability. See Appendix 1.4, Table A1.4, for further details of studies on the impact of cancer on children.

Resources for Children

As issues surrounding children are major concerns for YWBC (Bloom & Kessler, 1994; BCNA, 2001; Dunn & Steginga, 2000; Siegel et al. 1999), resources to assist children to cope with their mothers' illness are explored. In search of resources for children, Turner and McGrath (1998) contacted Australian State Cancer Councils concerning support/interventions for children of mothers with advanced (in particular) breast cancer. Lack of funding was reported as the reason why materials were not developed specifically for these children. The information resources used were those developed for cancer patients in general. Support groups for these women were mentioned, however, specific help for children was unavailable unless severe difficulties arose and assistance was actively sought by the woman with breast cancer, at which point referral to counselling was provided. Even British and American Cancer Societies contacted reported few specific resources for children whose mothers had breast cancer (Turner & McGrath, 1998). These findings elaborate how children, whose mothers have breast cancer, are in need of specific resources to help them to cope.

Limitations and Summary: Children

The populations of children studied vary in the mother's disease state that made comparing findings difficult. The mean ages of the women with breast cancer represented in these studies ranged from the late 30s to the mid 40s, which reflects closely the age range of the women in this study. However, such studies do not offer any solutions to problems faced by the mothers and their children. Therefore, more studies are needed to ascertain problems faced by various groups of children, with the aim of providing solutions to such problems

2.4.2 Reproduction Issues of Young Women with Breast Cancer

2.4.2.1 *Fertility Issues Due to Breast Cancer Treatment*

Infertility has been found to be a major issue for some YWBC as they can be thrown into early menopause due to cancer treatment (Bloom & Kessler, 1994b; Dunn & Steginga, 2000; Schaefer et al. 1999; Siegel et al. 1999; Singer & Hunter, 1999). The closer a woman is to her natural menopausal age the more likely her induced early menopause will be permanent (Winchester, 1996). Approximately 50% of women younger than 40 years will retain their ovarian function after cancer treatments; hence future pregnancies remain a possibility (Reichman & Green, 1994; Winchester, 1996). Despite this, information regarding fertility and menopause are considered insufficient or unavailable (Thewes, Meiser, Rickard & Friedlander, 2003). Therefore, as more women delay childbearing (Dow et al. 1994; Gemignani & Petrek, 2000;), as indicated by the increase of the Australian trend for age at first birth (AIHW, 1997: AIHW, 2001), so too does the possibility that more YWBC will desire children following diagnosis and treatment. In addition, future fertility-preserving treatments and technological advances will allow even more YWBC to conceive after breast cancer (Oktay et al. 2003).

2.4.2.2 *Contraception and Breast Cancer*

The literature advises that a pregnancy following a diagnosis of breast cancer should not be attempted for at least two years, due to recurrences occurring most often in that time (Isaacs, 1995; Petrek, 1994b; Saunders & Baum, 1993). Research has found that some contraceptive methods can increase the risk of breast cancer, e.g., hormonal contraceptive pill, hence the use of hormonal contraception after a breast cancer diagnosis is contraindicated (Althuis et al. 2003, International Planned Parenthood Federation (IPPF), 1999; Weisberg, 2003). Puckridge et al. (2003, p, 502) conclude that avoiding pregnancy in the short term brings forth a 'quagmire of issues related to contraceptive methods, though little concrete evidence exists on which to base medical advise'; non-hormonal, mechanical methods of contraception are preferred for this group of women, a notion supported by the IPPF (1999). In addition, the psychological and psychosocial factors surrounding contraception after breast cancer have been neglected to date and YWBC have reported that information regarding contraceptive practices after a breast cancer diagnosis is lacking (Thewes et al. 2004).

2.4.2.3 *Pregnancy After Breast Cancer*

2.4.2.3.1 *Epidemiology*

As stated by Neifert (1992, p, 678) 'pregnancy and parenthood after breast cancer may not be a frequent event, but it is no longer an oddity' as approximately 7% of premenopausal breast cancer survivors conceive (Puckridge et al. 2003). The current general consensus in the literature is that pregnancy after breast cancer treatment (usually 10 months or more from diagnosis) does not increase risk of mortality from the disease (Collichio, Agnello & Staltzer, 1998; Dow et al. 1994; Mueller et al. 2003). No definite evidence exists to suggest that elevated hormonal levels of a pregnancy after breast cancer will cause a recurrence (Mintzer, Glassburn, Mason & Sataloff, 2002), though it has been stated that a 'healthy mother' affect may be responsible for such results, i.e., only those women with a good prognostic outcome may attempt/continue a pregnancy. However a recent review conducted by Upponi, Ahman, Whitaker & Purushotham (2003), utilizing 40 references dated from 1954 to 2002, failed to bring forward any firm conclusions as to the safety of pregnancy after breast cancer, stating large prospective studies are needed to confirm suggestions that pregnancy after breast cancer does not increase mortality risks to the woman. Research on the mortality and/or morbidity risk to women who become pregnant after breast cancer is extremely limited, and of what is available, the strength of findings is hampered by small sample sizes (due to the rarity of pregnancy after breast cancer). Thus any findings must be treated with caution.

2.4.2.3.2 *Age at First Birth Trends*

Though it is considered rare and uncommon for young women in their 20s and 30s to be diagnosed with breast cancer (Neinstein, 1999), America's breast cancer incidence in young women of child-bearing age is increasing. This appears to be following the trend of delayed childbearing (Dow et al. 1994; Gemignani & Petrek, 2000). Similarly in Australia, since 1994, the average age at first birth increased from 26.3 years of age to 27.1 years of age in 1999 (AIHW, 1997; AIHW, 2001).

The 'Australia's Mother and Babies 1999' document reported that the number of women who have their first child at 35 years of age or older, has doubled in the past decade from one in 20 of first-time mothers in 1991 to one in 10 of first-time mothers in 1999 (AIHW, 2001). Hence, figures for all births have also risen as approximately 11% of women who gave birth in 1991 were 35 years of age or older and in 1999 an increase to 16% of such mothers was recorded (AIHW, 1997; AIHW, 2001). With many women now starting their families at older ages, women who have breast cancer at 40 years of age or younger are more likely to have small children and/or still desire to have children.

2.4.2.3.3 *Psychosocial Elements*

Psychosocial findings to date have identified concerns, either perceived or experienced, of YWBC who desire and/or have subsequent pregnancies after treatment; these are: the difficulty of finding important breast changes in a pregnant/lactating breast (Dow, 1994; Schover, Rybicki, Martin & Bringelsen, 1999); the fear of recurrence and its consequences (Dow, 1994; Saunders & Baum, 1993; Schover et al. 1999; Siegel, Gorey & Gluhoski, 1997; Vickberg, 2003), which centres around future treatment, threats to health and the fear of death (Vickberg, 2003); the possibility of passing on the breast cancer gene (Saunders & Baum, 1993; Siegel et al. 1997); not seeing their children grow up (Dow, 1994); fears for treatment-related deformities in the child or future susceptibility to any cancer; and that caring for a child would be too stressful (Siegel et al. 1997). The participants in the Siegel et al. (1997) study (n=50, mean age 33.4 years at diagnosis) expressed concerns whether it was morally right to have a baby when a mother's survival was compromised, together with feelings of associated guilt or conflict. It was also reported that it was unfair to jeopardize mothers' survival if they already had children (Siegel et al. 1997).

In addition, positive outcomes and/or expectations of pregnancy after breast cancer which have been found are: return to normalcy; affirmation of life; a cherished life goal (Dow, 1994; Dow et al. 1994; Siegel et al. 1997); pleasing the husband (Siegel et al. 1997); and feeling cured (Dow et al. 1994). Having a baby after breast cancer provides strong motivation for the mother to survive (Dow, 1994; Siegel et al. 1997). Having children after breast cancer was cloaked in meanings of anchoring (turning the participants' thoughts outwards instead of inward), getting well again and feeling complete. Children gave their mothers equal reason to live for the future, rather than concerns over dying in the future (Dow, 1994). Women who have had pregnancies after breast cancer claim they are very vigilant about their children's health and they reconnected with family and peers (Dow et al. 1994). View Appendix 1.5, Table A1.5, for more details of pregnancy after breast cancer studies.

Limitations and Summary: Reproductive Issues

Infertility, caused by cancer treatment, has been found to be a major concern for YWBC, however ART and maintained or regained fertility pose additional challenges. Due to delayed childbearing trends, more women are likely to be diagnosed with breast cancer while still wishing to have children (Dow et al. 1994; Gemignani & Petrek, 2000). In addition, advances in ART coupled with the push for fertility friendly treatments (Dow & Kuhn, 2004) may lead to many more women conceiving after breast cancer in the future. Most available literature concerning maintained or regained fertility subsequent to breast cancer treatment concentrates on epidemiology, physiological elements and outcomes. Currently there is no firm evidence to suggest that pregnancy after breast cancer (at least 10 months post-diagnosis) increases the risk of mortality (Collichio et al.

1998; Dow et al. 1994; Mueller et al. 203).

The majority of the research reviewed was conducted retrospectively hence losing important information during the pregnancies, rather concentrating on survival times and recurrence rates. Of what literature is available most is derived from small qualitative studies due to the small numbers of women who conceive after breast cancer treatment. Minimal research has focused on the psychosocial ramifications of pregnancy after cancer treatment. Considering the relatively recent emphasis on psychosocial concerns of women who become pregnant after breast cancer, it is understandable that this research is in its infancy. Therefore much more research is needed to expand the knowledge base in this area. In particular, prospective longitudinal studies are needed to capture experiences as they occur, including social and cultural perspectives, and to explore changes over time.

2.4.2.4 *Breastfeeding and Breast Cancer*

Breastfeeding has been widely documented to reduce risk of breast cancer (Collaborative Group on Hormonal Factors in Breast Cancer [CGHFBC], 2002; Daniels, Merrill, Lyon, Stanford & George, 2004), particularly in women who have longer lifetime duration of breastfeeding (CGHFBC, 2002). However breastfeeding after breast cancer has received little attention.

2.4.2.4.1 *Breastfeeding After Breast Cancer*

Two issues have been identified as important for YWBC who breastfeed after breast cancer. These are the mechanical ability to breastfeed after irradiation (Petrek, 1994a) and the risk of further breast cancer activation due to breastfeeding (Schover, 1991). Small case studies have documented women successfully breastfeeding from an affected breast (irradiated and/or having undergone some form of surgery), though stating some difficulties experienced, such as the infant favouring the non-affected breast, and subsequent nipple problems, and low milk supply (Higgins & Haffty, 1994; Neifert, 1992; Tralins, 1995; Varsos & Yahalom, 1991; Wobbes, 1996).

2.4.2.4.1.1 *Politics, Social Expectations and Breastfeeding*

Political Aspect

The political aspect of breastfeeding has, over recent decades, experienced a firm swing towards breastfeeding policies within worldwide organisations, such as the World Health Organisation (WHO), and individual institutions, such as maternity hospitals (Van Esterik, 1997). Breastfeeding has emerged as a means to improve public health (ABS, 2003) together with economic and environmental advantages, particularly in developing nations (Palmer, 1993; Van Esterik, 1997). The many benefits of breastfeeding, for the infant and the mother, are undisputed hence the current health promotion focus regarding breastfeeding is justified (Schmied & Lupton 2001). Breastfeeding is widely identified as the optimal method of infant feeding and as such has implications for the evaluation of maternal behaviour due to social expectations and issues of morality (Murphy, 1999). Therefore, the political aspects of breastfeeding are likely to impact on the breastfeeding decisions and experiences of young women who conceive after breast cancer.

Social Expectations

Since the 1980s, social and medical pressures on women to breastfeed their infants has increased (Maher, 1992). Motherhood in itself carries social expectation (Hartrick, 1997). Hartrick (1997) found, via a study of mothers' experiences of self definition (n=7, aged 35-45 years), that women define themselves as mothers via three main elements: those of non-reflective doing; living in the shadows; and reclaiming and discovering self. Non-reflective doing involves taking up roles and acting out life as modeled by parents and others in society. Living in the shadows presents a time when one can no longer ignore the voices of discontent, hence the secure foundation of one's life begins to crumble. Reclaiming and discovering self represents the redefining of one's life from a different perspective. Hartrick's (1997) findings illuminate how and what social forces are involved when deciding how to nourish an infant, that of being acknowledged (approved and recognized) for undertaking socially prescribed roles, which can result in denying other parts of themselves, thus the women often choose the safety of social norms. Hartrick (1997) goes on to explain that to be connected to others one must succumb to socially prescribed roles (such as what constitutes a good mother), as not conforming to social norms can result in feelings of isolation (living in the shadows), within such isolation turmoil confusion and despair can result (Hartrick, 1997).

In addition to motherhood being influenced by social expectations, breastfeeding not only involves the biological function of the breast but also entails culturally determined behaviours (Maher, 1992; Stuart-Macadam & Dettwyler, 1995) and as such breastfeeding is ‘the ultimate bio-cultural phenomenon’ (Stuart-Macadam & Dettwyler, 1995, p, 7). Social expectation pressures flow onto choices made regarding breastfeeding as women equate the act of breastfeeding to that of being a ‘good’ mother (Murphy, 1999; Schmied & Lupton, 2001). Murphy (1999) examined, using discourse analysis and a framework drawn from the sociology of deviance, how mothers perceived themselves to be morally judged by others and themselves for their infant-feeding decisions. Infant-feeding decisions can arise for YWBC as the ‘good mothers’ breast feed’ rule is so rigid as to be binding under all circumstances’ (Murphy, 1999, p, 189). Breastfeeding can be ‘treated as not only compatible with, but also indicative of, maternal morality’ (Murphy, 1999, p, 201). Murphy concludes that how mothers decide to feed their babies is a highly accountable matter and ‘carries with it considerable moral baggage’ (p, 205). Infant-feeding decisions are drawn from a repertoire of culturally acceptable legitimations. Not only is being a good moral mother bound with decisions made, but also that of being ‘good partners’ and ‘good women’ (Murphy, 1999, p, 205).

As breastfeeding provides health benefits (for both mother and child) and economic benefits (particularly in developing countries), much research probes why some women choose not to breastfeed or why they initiate and discontinue breastfeeding prior to advised duration (such as six months) (Arora, McJunkin, Wehrer & Kuhn, 2000; DiGirolamo, Grummer-Stawn & Fein, 2003; Hoddinott & Pill, 1999). Difficulties arise when going through the decision-making process regarding how to feed an infant. It is not as simple as one might expect; many cultural and social beliefs together with one's own lived experience and personal and social expectations come into play (Hartrick, 1997; Murphy, 1999; Schmied & Lupton, 2001). Considering the above mentioned political and cultural influences on a woman's decision to breastfeed, it could be suggested that those who cannot breastfeed, or who wish to not breastfeed, as is the possibility for YWBC due to recurrence fears and not wanting to revert their focus back to their breast/s, feel pressured by societal expectations to breastfeed and hence potentially suffer great distress and resentment. View Appendix 1.6, Table A1.6, for breastfeeding after breast cancer study details.

Limitations and Summary: Breastfeeding after Breast Cancer

After extensive literature searching, no specific studies were located that dealt with the psychosocial experiences of breastfeeding after breast cancer. Rather snippets of information were extracted from literature dealing with breast cancer survivorship issues. As breastfeeding after breast cancer (or other serious illnesses) has not been addressed widely within the literature I presume the general opinion is if one breast is either missing or not lactating as desired, the other is expected to compensate. Available literature (small qualitative studies mostly) of breastfeeding after breast cancer concentrates on the physiological ability of the affected breast to lactate sufficiently to feed an infant. No mention is made of women who had mastectomy and do not have to deal with issues of 'the affected breast'. Experiences of social expectations and cultural norms, beliefs and practices related to motherhood and breastfeeding may differ between cultures and as such is beyond the scope of this work.

More decisions regarding breastfeeding after breast cancer are going to be made in the future due to trends towards delayed childbearing (Dow et al. 1994; Gemignani & Petrek, 2000). Hence understanding women's experiences of breastfeeding after breast cancer may be needed in the future to assist health professionals advise and help future

YWBC. More research is needed of the perceptions of women concerning breastfeeding after breast cancer, of their decision-making and personal experiences to direct information resources for the future.

2.4.3 Breast Cancer Treatment: Choices and Affects

2.4.3.1 *Treatment Choices and Body Image*

Body image can be defined as 'the way individuals perceive themselves and, equally important, the way they think that others see them' (Fallon, 1994, p, 127). In addition, Fallon (1994) states that 'women equate self-worth with attractiveness whereas men judge themselves in terms of what they can do' (p, 128). Body image is not only related to women's self-respect and self-value (Bertero, 2002), which are important aspects that affect QOL, but also to the body as a symbol or social expression and as a way of being in the world, and the existential sense that one needs a body in be in the world (Cohen, Kahn & Steeves, 1998).

Choice of surgical treatment has been linked to body image outcomes with breast conserving therapy (BCT) being associated with a less impaired body image (Avis, Crawford & Manuel, 2004; Hartl et al. 2003; Mock, 1993) and QOL (Hartl et al. 2003). However, Beckmann, Blichert-Toft and Johansen (1983a) infer that women who undergo BCT, such as lumpectomy, do not change their self-view, such as body image, sexuality or sexual functioning. The small number of participants (22 women, 11 who had mastectomy and 11 who had breast-conserving surgery) in this study limits generalisability of these findings. Conversely Kraus (1999) found women were more satisfied with body image before and after mastectomy than those who had BCT, however the strength of Kraus's findings are limited as the sample size was much smaller (n=31) than that of Avis et al. (2004) (n=204), Hartl et al. (2003) (n= 274) and Mock (1993) (n=257).

Psychological and social views of one's age could influence choices of treatment (Mor, 1994). According to an Italian study conducted by Ghizzani et al. (1995), older women accepted a diagnosis of breast cancer more easily than younger women. Body-altering treatments and their side effects, such as mastectomy (breast loss) and chemotherapy (possible hair loss), may impact more on younger women (Siegel et al. 1999; Trief & Donohue-Smith, 1996). Decisions made, even against doctors' advice, have been found to be wound up with body image issues, fears of deformity, loss of femininity (Long, 1993) and psychosexual well-being (Baldry & Walsh, 1999). A case-control study comparing the body image of 31 women who had breast cancer to 33 women who did not have breast cancer, found that women who have breast cancer experienced a significant decrease in the satisfaction with body image after surgery ($P<0.004$), regardless of active participation or not in treatment decisions (Kraus, 1999). Nonetheless, this may implicitly infer that the reasons behind choosing a surgery option, such as wanting to obtain a 'normal' body image, impact on adjustment after the fact.

2.4.3.1.1 *Social and Cultural Aspects of Body Image*

Over time, breasts have become sexualized in Western culture (Carter, 1995) and hence are 'universal symbols of femininity and sexuality and therefore constitute an important element in a woman's self image' (Ghizzani et al. 1995, p, 57). Breasts are also highly symbolic of the processes that make up the construction of femininity (Carter, 1995). Body image is specifically a concern for women who suffer breast cancer due to the breasts' symbolic sexual importance (Golden, 1983; Neinstein, 1999). A woman's perception of her sexual desirability is often based on the appearance of her breasts, creating an early awareness that the image of her breasts is a mark of her desirability (Mead, 1949). The female body beautiful brings with it a sexual promise to attract and entice men and as such the female role 'makes women vulnerable in unique and significant ways' (Golden, 1983, p, 14).

Social rules attached to breasts are entrenched and dictate how, when and where breasts should be viewed and used and by whom (Carter, 1995), though women often do not disassociate themselves from these social expectations (Kasper, 1995). The terrible sense of violation and loss many women feel when breast cancer is diagnosed can be explained by the learned experience from early childhood that ‘breasts define their public status as women, thus creating a context in which women are forced to play out the importance of appearance’, often for life (Kasper, 1995, p, 208).

Kasper (1995, p, 208), on studying the social construction of women’s experience of breast loss and reconstruction (n=29), claims that “losing a breast extends beyond expected dimensions of a health crisis to that of a social and emotional crisis”. Gender socialisation has taught women that their breasts are a public as well as a private matter and as such are influenced by social expectation of how society views breasts (Kasper, 1995, p, 204). Similarly, Crouch and McKenzie (2000) claim that their participants (n=7 women who had mastectomy) wanted to maintain a normal body image, to continue to present as normal and to appear to others as unchanged, hence the use of prosthesis and reconstruction achieved the hiding/disguising of breast loss. Kasper (1995, p, 209) suggests that issues of ‘survival and cosmesis force women to attempt an uncomfortable balance between the two’, as culture has established a profound connection between women’s appearance and self-worth (Kasper, 1995, pp, 209-210). Kasper (1995) found that women perceive that survival and cosmesis weigh equally in society’s calculus of women’s worth, hence to lose a breast, then, “poses not only the threat of a cancer death but the loss of the self as well” (Kasper, 1995, p, 210). Details of Kasper’s study can be found in Appendix 1.7, Table A1.7 - summary table of reconstruction studies.

Bloom et al. (1998) found that the intrusiveness of breast cancer to young women’s lives was significantly related to their body image and symptom distress, hence body image concerns are emotionally charged. Theoretically, the loss or disfigurement of a breast would distress younger women more than older women as their youth provides high aesthetic expectations (Schover, 1994). In addition, the emphasis of the cult of the body within the current consumer culture (Featherstone, 1991a; 1991b), in particular the cosmetic interest in the body, that is to keep fit, slim and young (Nettleton, 1995), could theoretically impact more on YWBC than their older counterparts. In contemporary society it is crucial to ensure that bodily appearance is as alluring and conforming to accepted social norms as possible (Lupton, 1994), hence the youth and beauty culture has an intense effect on women with breast cancer, as Broom (2001) claims that sociocultural perceptions of sexuality and femininity frame women's choices and experiences. Women are vulnerable to the ideals portrayed by the media of what a woman should look like; internalising such body image concepts, younger women's ramifications of breast cancer are intensified (Golden, 1983).

Limitations and Summary: Body Image

The literature suggests that younger women may suffer greater body image problems than older women, due to their high youthful aesthetic expectations (Schover, 1994). However, little evidence is available to inform discussion on the issue of body image following breast cancer treatment among young women specifically. It would be prudent to explore and compare younger women's experiences of breast cancer and body image with that of their older counterparts to ascertain how experiences of body image differ between age groups and why. Even so, studies of the social construction of the experiences of women with breast cancer in general provided some sociological theoretical application of body image issues.

Women who have mastectomy mostly suffer more disruption to their body image than those who undergo BCT. Choice of treatments could be influenced by psychological and social views of one's age and by body image concerns. Body image relates to self-respect and self-value which contribute to QOL. Body image as a concept encompasses issues of social norms and expectations. Breasts are a universal symbol of femininity and sexuality. Within Western culture, breasts bring with them entrenched social norms of when, where and how breasts can be viewed and used and by whom. Hence women who lose a breast suffer greatly. The current consumer culture, in particular the cult of the body, to keep fit, slim and young, together with the media's portrayal of what women should look like, could impact more on YWBC than their older counterparts.

2.4.3.2 *Breast Reconstruction*

2.4.3.2.1 *Rates of Breast Reconstructive Surgery*

The Connecticut breast reconstruction uptake rate in recent years has increased (Polednak, 2001). Similarly, the number of Australian women undergoing reconstruction following breast cancer surgery has increased 1.6% (from 8.3 to 9.9%) over 18 years, although the uptake of breast reconstructive surgery is still uncommon (Hall & Holman, 2003). Access to Australian reconstructive surgery has not been equitably distributed (Hall & Holman, 2003). A recent retrospective Australian study conducted by Hall and Holman (2003) found that the provision of breast reconstructive surgery is deficient in Australia, especially in disadvantaged groups of women, such as those of lower socioeconomic status (SES) and indigenous women.

2.4.3.2.2 *Characteristics of Women Who Undergo Breast Reconstruction*

The literature demonstrates that younger women undergo breast reconstruction more often than older women (Desch et al. 1999; Hall & Holman, 2003; Morrow, Scott, Menck, Mustoe & Winchester, 2001; Polednak, 2001; Reaby, 1998; Rowland et al 2000; Schover et al, 1995). An earlier study conducted by Rowland, Holland, Chaglassian and Kinne (1993) found that women of all ages sought out and shared similar hopes of breast reconstruction, thus suggesting that attractiveness is not primarily a concern of younger women. However this, in part, could be due to patients not being given a choice to undergo reconstruction and could also reflect the attitudes of physicians (Morrow et al. 2001). Significant predictors of reconstruction uptake are affluence (Morrow et al. 2001; Rowland et al. 2000) and being college educated (Rowland et al. 2000). Rowland et al. (2000) and Polednak (2001) found different relationships with the partnered status of those who have reconstruction. Rowland et al (2000) found women more likely to be have reconstruction were more likely to be partnered while Polednak (2001) found reconstruction uptake was not related to marital status. Race differences were found to be conflicting as Polednak (2001) reported that the use of reconstructive surgery was not found to be related to the patients' race (black versus white), however Morrow et al. (2001), Hall and Holman (2003) and Rowland et al. (2000) found race was a factor in reconstruction rates with more whites undergoing reconstructive surgery. Tumour size is not related to the use of reconstructive surgery (Polednak, 2001).

An American study by Polednak (2001) found that the reconstruction rate declined with increasing age at diagnosis and with poverty rate. A Finnish study also found that older age was a factor in women deciding not to undergo reconstruction, with those under 45 wishing to undertake reconstruction at the rate of 75%, 50% of other patients between 46-55 want it, but only 3% of those over 65 years (Korvenoja, Smitten & Asko-Seljavaara, 1998). These findings suggest that age could be a cross-cultural predictor of breast reconstructive surgery choices.

2.4.3.2.3 *Decision Making in Relation to Breast Reconstructive Surgery*

Younger women may be more accepting of breast reconstruction (Reaby, 1998), hence explaining why more young women choose to undergo such surgery (as documented above). Decisions to undergo reconstructive surgery are influenced by doctors and the information they provide (Neill, Armstrong & Burnett, 1998). Women have also been found to seek the support of, and information from, other women who previously had breast reconstruction to obtain reassurance and relief of anxiety (Neill et al. 1998).

Issues relevant to decision making concerning breast reconstruction are a negative self-image and fear of rejection by men post-mastectomy, and dissatisfaction with wearing prostheses (Rassaby & Hill, 1983). Opinion appears to be divided concerning the major organizing principle that determines whether or not women choose to have breast reconstruction (Schain, 1991), however it appears that women who choose to undergo breast reconstruction score higher on tests for self-esteem which could be explained by such women’s attitudes: considering themselves worthy to ‘improve their discomfort and rectify a set of circumstances that contribute to a feeling that they are physically defective’ (p, 1173). Schain (1991) states that regardless of possible personal, interpersonal and/or economic obstacles, women will ‘pursue their goal to correct their altered body image’ (p, 1173).

Schain (1991) and Reaby (1998) differ in their opinion of how society, and women themselves, view breast reconstruction. Schain (1991) claims that breast reconstruction is no longer seen as a cosmetic indulgence of women struggling with their body image after mastectomy, a notion supported by other findings that women view the reconstruction as ‘a positive, self-initiated step rather than a reaction to a life-threatening illness’ (Baldry & Walsh, 1999, p, 41). Reaby (1998), on the other hand, found that some women view reconstruction as a cosmetic treatment for vanity rather than a legitimate means to restore a lost body part. These differences could be explained by the social construction of women’s decisions to undergo breast reconstruction, which is illuminated by Kasper’s statement that “women’s early socialization and the culture’s view of women’s appearance and worth, and social expectations of femininity and sexuality are arrayed powerfully as unseen forces framing the decision a woman must make” (1995, p, 214). Hence how women themselves and society perceive breast reconstruction will ultimately influence their decisions to undergo such surgery. Regardless if a woman chooses to have breast reconstruction or not, the decision in itself enables the woman with breast cancer to gain some control over her psychosocial health outcomes (Neill et al. 1998).

2.4.3.2.3.1 *Reasons to Undergo Breast Reconstructive Surgery and Expectations of Outcomes*

The literature is divided as to why some women choose to have breast reconstruction (Harcourt & Rumsey, 2001). Making a decision, whether or not to undergo reconstruction can be hampered by perceived time pressures and hospital systems (Harcourt & Rumsey, 2004). Reasons to undergo breast reconstruction were: to prevent the anticipated devastating effects of losing a breast on well-being (Kasper, 1995); to get rid of the external prosthesis (Kasper, 1995; Neill et al. 1998; Rowland et al. 1993; Spencer, 1996); to be able to wear a wider variety of fashion; to regain femininity and to feel whole again (Reaby, 1998; Rowland et al. 1993); to return to normalcy (Baldry & Walsh, 1999; Neill et al. 1998), specifically a ‘normal’ body image and lifestyle (Baldry & Walsh, 1999); to restore symmetry and thus decrease self-consciousness about appearance (Rowland et al. 1993); and to forget about the cancer (Nissen, Swenson & Kind, 2002). Surgical literature views breast reconstruction as a means to improve women's QOL when mastectomy has been performed, and assumes that breast reconstruction can help adjustment to diagnosis and treatment of breast cancer though such assumptions, as reported by Harcourt and Rumsey (2001), go largely unsupported by sound research evidence.

2.4.3.2.3.2 *Reasons to Not Have Breast Reconstructive Surgery*

In contrast, reasons cited to not undergo a breast reconstruction were: not essential for physical or emotional well-being (Korvenoja et al. 1998; Reaby, 1998); inadequate information about the procedure; do not want anything unnatural in the body; do not want to undergo any more surgery; belief that risks of complications outweighed the benefits; not impressed with what was seen (of other reconstructions) in terms of results (Reaby, 1998); the expenses involved; too old (Korvenoja et al. 1998; Reaby, 1998); long recovery time; and fears of the operation (Korvenoja et al. 1998). Some women in the Reaby (1998) study felt it would be selfish to undergo a reconstruction as it may bring hardship onto their families and they also feared the pain associated with the surgery.

It has been found that the decision to not undergo reconstruction can also be difficult due to the lack of family support, inability to have a specific type of reconstruction performed and the perception that friends and acquaintances would see the surgery as cosmetic (Reaby, 1998). Opposition to reconstruction from family, friends, and some health professionals was found by Rassaby and Hill (1983). Such a difficulty (deciding to not undergo reconstruction) may be interpreted as a social construction of conforming to an acculturated social norm; to regain social acceptance of the female identity. There remains a 'widely held assumption that breast reconstruction is a necessary part of the treatment for recovery from breast cancer' and that 'medicine, as does much of society, presumes that a woman is somehow less a woman without a breast' (Kasper, 1995, p, 216). Therefore a 'disjuncture between socially imposed expectations of reconstructive surgery and the perceptions of women's experiences' of breast reconstruction may eventuate (Kasper, 1995, p, 216).

2.4.3.2.4 *After Breast Reconstruction*

2.4.3.2.4.1 *Positive Aspects of Breast Reconstruction*

The reasons given to undergo a breast reconstruction are closely linked to the benefits of breast reconstruction reported after the operation, which include: a greater ease of being able to wear 'normal clothes' (Nissen et al. 2000; Rassaby & Hill, 1983; Yurek, Farrar & Anderson, 2000); the freedom associated with no longer having to wear an external prosthesis (Yurek et al. 2000); feeling whole again; physical functioning improved; helped close the book on cancer; regained physical balance; increased self-confidence; and an enhanced figure (Rassaby & Hill, 1983). Rowland et al. (1993) reported an unexpected benefit of undergoing breast reconstruction, that of a decrease in both concern about health and self-consciousness about having had cancer.

Women who undergo reconstruction sometimes report significantly better emotional well-being than those who undergo lumpectomy or mastectomy alone (Arora et al. 2001), although other authors found that those who underwent reconstruction fared worse than those who undergo breast conserving treatment (lumpectomy) (Fung, Lau, Fielding, Or & Yip, 2001; Rowland et al. 2000). It appears at first glance that cultural boundaries may be less influential when it comes to women's QOL after breast cancer, as the Fung et al (2001) study of Chinese women's experiences of breast cancer reported findings similar to Western studies, however it must be noted that the instrument used to obtain these data had to be altered to suit the culture and was not validated prior to the study.

Rowland et al. (1993) found that women who had undergone breast reconstruction were more comfortable with their sexuality ($P<0.001$) compared to pre-reconstruction (after mastectomy) and satisfaction with sexual activity increased to pre-mastectomy levels, though frequency of sex did not. Wilkins et al. (2000) found that those women who underwent a delayed reconstruction had a significant gain ($p<0.001$) in body image score, most probably because they had lived with their disfigurement for some time, unlike those who underwent an immediate reconstruction (p, 1014). Wilkins et al. (2000) conclude that both immediate and delayed reconstruction provide substantial psychosocial benefits for mastectomy patients.

2.4.3.2.4.2 *Negative Aspects of Breast Reconstruction*

Disappointment can emerge as expectations of reconstruction are dashed (Nissen et al. 2002). Reported problems associated with breast reconstruction were: the reality of the cancer was not erased; a return to a sense of normalcy was not achieved; the unnaturalness of the reconstructed breast (Kasper, 1995; Nissen et al. 2002), including the reconstructed breast feeling different to touch, both externally and internally (Nissen et al. 2002; Rassaby & Hill, 1983; Yurek et al, 2000); feelings of tightness and hardness and loss of sensation, and unnatural asymmetry of breasts and nipple appearance (Harcourt & Rumsey, 2004; Rassaby & Hill, 1983); the need to still wear a prosthesis (Harcourt & Rumsey, 2004); and post-operative complications such as infection, pain and itching (Harcourt & Rumsey, 2004; Rassaby & Hill, 1983). Harcourt and Rumsey (2004) report that some of their participants (n=93) had such intense problems with their reconstructed breast that they had their implants removed. Concerns were also reported that an implant may interfere with accurate interpretations of future mammograms (Neill et al. 1998). Considering all the problems listed, many studies reported that overall their participants were satisfied with their surgical choice (Baldry & Walsh, 1999; Harcourt & Rumsey, 2004; Nissen et al. 2002; Rassaby & Hill, 1983; Rowland et al. 1993).

Psychosocial problems relating to breast reconstruction have been found to be more prevalent in some groups of people. Predictors for psychosocial morbidity related to breast surgery are: a troubled marital relationship; feeling unattractive and dissatisfied with a sexual relationship; having undergone chemotherapy; or being less educated (Schover et al. 1995). Women who have unrealistic expectations prior to surgery, such as improved sexual relations and/or relations with partners, are at risk of being disappointed (Rowland et al. 1993). Considering this statement it could be asked why Rowland and colleagues' (1993) explored their participants' sexual lives, perceptions of sexuality and frequency of sexual relations, if improvements in sexual functioning were deemed to be an unrealistic expectation of reconstruction. Expectations of breast reconstruction have not been widely researched. Such expectations need to be explored and examined qualitatively prior to any reconstruction operation and then followed longitudinally to clarify if expectations had been met, and continue to be met, or change over time. View Appendix 1.7, Table A1.7, for additional details of reconstruction studies.

Limitations and Summary: Reconstruction

The rate of reconstruction uptake is low but increasing. Young women undergo breast reconstructive surgery more often than older women and cross-culturally the uptake of breast reconstruction decreases with increasing age. The literature fails to directly explain why younger women uptake breast reconstruction surgery more than older women. Possible explanations are younger women may: be more accepting of reconstructive surgery (Reaby, 1998); wish to regain control over their psychosocial health outcomes (Neill et al, 1998); and pursue a corrected body image thus are more likely to uptake breast reconstructive surgery (Schain, 1991). In addition, social pressures bestowed upon younger women may also be responsible for higher reconstruction rates (Kasper, 1995).

Overall women appear to be satisfied with their reconstructed breasts, although a variety of problems can be encountered. Expectations of what a breast reconstruction will achieve for a woman are mostly realistic, though some expectations are not met. Most reported problems regarding breast reconstructive surgery over the past 20 years are of a physical nature, such as hardness of the reconstructed breast, loss of sensation, infection (Rassaby & Hill, 1983), persistent pain and asymmetrical breasts (Harcourt & Rumsey, 2004). How these problems influence psychosocial factors is not clear, hence more research in this area is needed. In addition, the reasons why women expect a breast reconstruction to erase the reality of the cancer and provide a return to normalcy have not been suggested.

It may be prudent to also study perceptions of health professionals to ascertain what they believe to be women’s expectations of breast reconstruction, as differing expectations of the women and the health professionals involved in their care may clash resulting in poor communication and misunderstandings, weighing further on these women’s psychosocial morbidity

2.4.3.3 *Prosthesis Use*

For the most part, women express negative experiences with wearing external breast prosthesis, such as the prosthesis not being conducive to a ‘normal life’ (Neill et al. 1998), the prosthesis being viewed as a foreign object, a nuisance, or an irritating reminder of the disease coupled with feelings of vulnerability (Reaby, 1998). Schag et al. (1993) found women at risk of developing psychosocial problems report more issues with the use of their external prostheses one-year post treatment. The Schag et al. (1993) findings confirm that body image issues, such as problems with clothing and the wearing of prosthesis, are central concerns of women.

It has been found that older women (those 65 years of age and older) tolerate external breast prosthesis well, while those women under 65 years found external prosthesis bothersome, interfering with choice of clothes and other fashion-related concerns (Korvenoja et al.1998). Younger participants were found to experience more difficulties and inconvenience with prostheses while working and enjoying leisure-time pursuits. Education was not related to any of the problems encountered in wearing prosthesis (Korvenoja et al. 1998).

<u>Limitations and Summary: Prosthesis Use</u>

Little research attention has been given to women’s experiences of wearing external breast prostheses. No specific research attention has been given to the prosthesis experiences and problems faced by women diagnosed at 40 years of age or younger. Exploring this group of women’s prosthesis experiences would extend the literature in this area. Most issues surrounding prosthesis use were extracted from literature concerning psychosocial issues of mastectomy and reconstruction. The Finnish study conducted by Korvenoja et al. (1998) was the only study located which dealt with prosthesis use as a separate issue. More studies are needed on the issues surrounding prosthesis use, which could then inform health professionals of the possible negative experiences encountered by women who wear external breast prostheses. It must be noted that women who have a partial mastectomy may also wear partial prostheses. Women who become pregnant after breast cancer may also need temporary prostheses for visual balance due to the affected breast not enlarging to the extent of the other breast, or in the case of a woman who had a breast removed and becomes pregnant, the usual prostheses may begin to look too small next to the normal enlarged breast – again causing cosmetic asymmetry. A study of women who conceive after breast cancer treatment may increase understanding of these women's prosthesis problems.

2.4.3.4 *Issues Around Sexual Functioning*

Breasts have gone from representing fertility to being a symbol of sexuality, thus the potential to affect sexuality following mastectomy (Beckmann et al. 1983b). The extent to which one experiences body image and sexual difficulties is correlated with the type of cancer treatment undertaken (Halford et al. 2000). All cancers affect sexual functioning via changes to body/self-image, together with possible lowered libido and physical limitations (such as a dry vagina) (Burbie & Polinsky, 1992). Schover (1994, p, 177) explains the increased negative effect on younger women by stating, " breast cancer has the potential to be most devastating to the sexual function and self esteem of premenopausal women".

2.4.3.4.1 *Predictors of Sexual Problems*

Factors which have been found to be predictors of the sexual health of women with breast cancer are: vaginal dryness; quality of partner relationship (Ganz, Desmond, Meyerowitz & Rowland, 1999; Meyerowitz, Desmond, Rowland, Wyatt & Ganz, 1999); emotional well-being, body image, sexual problems in the partner (Ganz et al. 1999); hormonal status (Meyerowitz et al. 1999); and pre-breast cancer marital and/or sexual difficulties (Schover, 1991). Broeckel, Thors, Jacobsen, Small and Cox (2002) found vaginal dryness, as a result of treatment, to be significantly related to poorer sexual functioning among long-term breast cancer survivors (p=<0.05). Comparing breast cancer survivors (n=58, mean time since diagnosis 7.65 years; range 5.2-15.2 years) to healthy controls (n=61), Broeckel et al. (2002) found breast cancer survivors reported significantly worse sexual functioning (p=<0.01) than controls, which was related to greater lack of sexual interest, inability to relax and enjoy sex, difficulty becoming aroused and difficulty achieving orgasm. The breast cancer survivors in this study consistently reported that their lack of sexual interest and pleasure was of concern to them, more so than it was for controls. Those who reported more sexual difficulties also reported significantly worse fatigue, depression, hot flashes, vaginal dryness and marital problems (Broeckel et al. 2002). However the Broeckel et al. (2002) findings are limited as the data collection instrument consisted of a four-item sexual functioning scale, hence more comprehensive measures of sexual functioning should be used in future studies. In addition the sample size was small and the recruitment method for the comparison group consisted of a peer nomination procedure, reducing generalisability.

Regardless how researchers try to capture the sexual issues relevant to women who have breast cancer, such women view their sexuality as ‘much broader than the way it has been operationalised in many measures of sexuality’ (Wilmoth, 2001, p, 284). A recent qualitative study of women who had breast cancer described aspects of sexuality, such as “including comfort with their self, whether they felt attractive, fat, old or not” (Wilmoth, 2001, p, 284). Wilmoth’s (2001) participants also stated that sexuality was more than the act of sex, that it included companionship, touching, and affection, and that their sexuality was the gestalt of feelings toward another and their partner’s feelings toward them. They alluded to the need for re-evaluating their feelings about their sexual self at diagnosis and during treatment for breast cancer (Wilmoth, 2001). Thus sexuality issues of women with breast cancer are more than that of arousal, desire, frequency of intercourse, and orgasmic ability, which are often used as measurement variables. Fresh qualitative studies would best be conducted periodically of YWBC to ascertain their interpretation of their sexuality and any sex-related concerns, as opened ended data collection would capture valuable insights and changes in perceptions. Such studies would inform future quantitative studies to ensure the interpretations of the researchers, and choice of measurements used, are current and relevant.

2.4.3.4.2 *Treatment Induced Sexual Problems*

Not only has surgery type been associated with sexual problems of women who have breast cancer but also various adjuvant treatments. Opinions differ as to the impact of various surgeries on sexual functioning. Arora et al. (2001) and Ganz et al. (2002) found that the type of surgery undertaken (mastectomy versus lumpectomy) resulted in relatively little to no long-term impact on the QOL of women with breast cancer. While Yurek et al. (2000) found that those who undergo reconstruction have their immediate post-surgery sexual behaviour and sexual responses disrupted, significantly more so than those who have lesser surgery. In addition, it has been reported that sexual self-schema, how one perceives oneself as a sexual entity, can impact on coping ability after surgery and on surgery decisions (Yurek et al. 2000).

Chemotherapy and radiotherapy have been found to impact on women's sexual functioning (Arora et al. 2001; Ganz, Rowland, Desmond, Meyerowitz & Wyatt, 1998; Meyerowitz et al. 1999; Ganz et al. 2002; Schover, Fife & Gershenson, 1989). In particular, those who undergo chemotherapy are at high risk for sexual dysfunction (Thors, Broeckel & Jacobsen, 2001). Moreover the convergence of treatment-induced menopause with breast cancer, especially in younger women, leads to poorer sexual functioning (Ganz et al. 1998; Schover, 1994). Wenzel et al. (1999), however, found, after studying age-related differences in QOL of breast cancer patients, no significant sexual dysfunction or body image differences among those aged 50 years or younger. However Ganz et al. (1998) found that while reporting more frequent physical and menopausal symptoms than healthy women, the sexual health-related QOL and sexual functioning of breast cancer survivors was comparable to that of healthy age-matched women. In addition, radiotherapy for gynaecological cancer has been found to produce a delayed sexual dysfunction, such as sexual desire and arousal problems (Schover et al.

1989), whereas the sexual adjustment of YWBC who had radiotherapy improved at the end of the radiotherapy, suggesting a treatment-related pattern of sexual adjustment (Dow & Lafferty, 2000). The differences in these findings could be due to the site of the radiotherapy.

2.4.3.4.3 *Information of Sexual Matters*

As information and support concerning cancer, treatment, and possible sexual problems are often not directly offered by treating doctors to partners, it is ‘not surprising that communication is compromised, misapprehensions persist and sexual relationships flounder’ (Cull et al. 1993, p, 1219). Women who suffer gynaecological cancers have been found to receive little to no information on possible sexual difficulties following treatments (Bourgeois-Law & Lotocki, 1999). Of those who did receive information (n=55 women), only 28 were satisfied with the information received. Even among women who did not report sexual difficulties, 40.6% said they would like more information (52.9% under 50 years of age and 26.7% over 50 years of age) (Bourgeois-Law & Lotocki, 1999). The study sample concurred that the most desired way to receive sexual-related information was via a health professional on a one-to-one basis (Bourgeois-Law & Lotocki, 1999). YWBC probably suffer similar information deficits. Considering that breasts are symbols of female sexuality, it is surprising that very little consideration was given to sexual issues by medical professionals (Ferrell et al. 1997). A summary table of the literature pertaining to sexual matters can be found in Appendix 1.8, Table A1.8.

2.4.3.4.4 *Advice For Professionals*

There is a growing body of evidence suggesting that sexual problems, and other adverse effects on physical health status, can persist long term following breast cancer treatment (Bloom et al. 2004; Broeckel et al. 2002; Ganz et al. 2002; Kornblith et al. 2003; Rogers & Kristjanson, 2002; Schag et al. 1993; Thors et al. 2001). Kornblith et al. (2003) found that even after 20 years, 29% of participants (total n=153) reported at least one sexual problem occurring since their diagnosis, caused by the cancer treatment, with reports of:

decreased interest in sex (13%, n=20: 95% CI, 8-20%); decreased sexual activity (12.5%, n=19: 95% CI 8-19%); and feelings of sexual unattractiveness (14.5%, n=22; 95% CI, 9-21%). Therefore, as sexual difficulties often go unidentified by cancer care teams, resulting in cancer sufferers receiving little or no assistance in dealing with the sexual and intimacy ramifications of cancer treatment, 'treatment of sexual dysfunction in patients with cancer should become standard practice' to enhance patients' QOL (McKee & Schover, 2001, p, 1008).

Limitations and Summary: Issues Around Sexual Functioning

Sample sizes of studies varied widely from 18-61 participants in qualitative studies (Wilmoth, 2001 and Schover et al. 1989, respectively) to over 800 in population-based studies (Ganz et al. 1998; Meyerowitz et al. 1999). Many studies used different styles of measurement, making comparisons difficult, and some measurements used could be deemed unimportant to many women who have breast cancer (Wilmoth, 2001), such as intercourse frequency, which may be more appropriate when measuring males' sexual issues. The ages of participants in the studies reviewed were broad, ranging from 22 to 88 years of age.

It is clear that breast cancer treatment impacts on women's sexual functioning, both physically, such as a dry vagina and lowered libido, and emotionally, such as those mentioned in the body image section. Various predictors of sexual problems after breast cancer treatment have been identified. Some women are more susceptible to problems than others, such as those who have relationship or sexual problems prior to diagnosis.

Some surgical procedures (mastectomy) can impact negatively (short term) on women's sexual functioning more than others (BCT). Chemotherapy has been found to greatly impact on sexual functioning, and can continue to do so for prolonged periods, mostly via the abrupt onset of menopause and related symptoms. Radiotherapy appears to have a lesser impact on sexual functioning of YWBC. The physiological ramifications, related to sexual functioning, of breast cancer treatment are well documented within the literature, however differences are likely to lie in personal perspectives of the experience together with variations of social and cultural norms and expectations of one’s sexuality.

Opinions and findings differ in regards to whether YWBC experience greater sexual difficulties than older women (Ganz et al. 1998; Schover, 1994; Wenzel et al. 1999). The sexual issues of YWBC should be examined qualitatively on a regular basis to ensure suitability of study measures, i.e., what is important to these women, and to provide various cultural views of the experiences of YWBC. Studies relating specifically to the sexual problems of YWBC are few. Fragments of information were extracted from ‘younger’ portions of study findings, not necessarily aged 40 years or younger. Qualitative and quantitative comparison studies of YWBC and their older counterparts in regards to sexual issues may identify any specific difficulties faced by YWBC, and what problems such sexual difficulties may pose. Hence, more attention needs to be given to the sexual morbidity of YWBC following breast cancer treatment by health professionals and researchers; these women need to be informed of what to expect.

2.4.3.5 *Early Menopause*

The average age for natural menopause is around 51 years (Knobf, 1998). A young woman who experiences a diagnosis of breast cancer, can be abruptly thrown into early menopause via the effects of adjuvant therapies, such as chemotherapy and other drug treatments and radiation therapy. Early menopause mirrors the effects experienced by young women who have menopause surgically induced. Ganz (2001, p, 278) likened the experience to that of being ‘surgically castrated’. Induced menopause can be experienced within weeks or months rather than transitionally over a period of several years, which is the usual natural course of the life stage (Bachmann, 1994), producing severe symptoms due to the sudden drop in hormones (Ganz, 2001). In addition, the abrupt commencement of early menopause may be experienced more traumatically both physically and psychologically than by those who gradually experience menopause (Bachmann, 1994).

2.4.3.5.1 *Treatment-Induced Menopause*

According to Reichman and Green (1994), combination chemotherapy has resulted in long-term cures for diseases such as: Hodgkin's disease; leukemia; lymphoma; and testicular (in men), breast and ovarian cancers. Women who suffer such diseases and subsequent chemotherapy-induced menopause do so because ovarian functions cease, due to the destruction of ovarian follicles and subsequent loss of steroid-producing cells. With this decrease in serum estrogen levels, the normal cycling of gonadotropins is interrupted (Reichman & Green, 1994).

Treatment-induced menopause can result in the woman developing short-term symptoms such as: vasomotor instability such as hot flashes; sleep pattern disturbances; mood changes; and vaginal discharge and/or dryness (Bachmann, 1994; Reichman & Green, 1994). Long-term menopausal consequences can include osteoporosis, heightened risk of cardiovascular disease and atrophic conditions, such as vaginal atrophy (Bachmann, 1994; McPhail, 1999). Other possible menopausal consequences include psychological distress and sexual dysfunction, such as lowered libido (Bachmann 1994; Reichman & Green, 1994). The use of the drug Tamoxifen is usually less troublesome for YWBC as hot flashes or vaginal symptoms are less frequent (Ganz, 2001). Therefore it is understandable that the physical changes, which young women experience when thrust into menopause, 'renders them strangers within their own bodies' (Schaefer et al. 1999, p, 227). As young women survive breast cancer, these issues become prominent concerns.

2.4.3.5.2 *Societal Meanings of Menopause*

The purpose of this research lends itself to the examination of the meanings bestowed on menopause in general and more specifically the perceptions of those who are thrown into menopause before their natural time.

> *"A culture's conception of gendered bodies is determined more by social constructions than by the nature of reality and as such, reflects a specific historical, social and political context"* (Jones, 1994, p, 43).

Many have suggested that medicine, together with other influences, is responsible for the negative social connotation given to 'menopause' as medical narratives reflect specific historical, social and political contexts of the meaning of menopause (McPhail, 1999, p, 165, Singer & Hunter, 1999). "Menopause appears to be both a bodily process and a social and emotional event loaded with primarily negative cultural meaning" (Singer & Hunter, 1999, p, 70). Such an explanation reduces women's experiences of menopause to that of biological decline and failure of the reproductive organs of the body (Jones, 1994). Such construction of meaning can negatively impact on young women as they enter the realms of treatment-induced menopause.

Jones (1994) found, via a qualitative study (n=17 middle-aged women), that menopausal women attempt to construct new aesthetic meanings to their lives. This suggests that women are aware, possibly sub-consciously, that a definite change of how society views them is apparent, thus striving to redefine themselves. However changes which these women experienced were also in line with their chronological age, not necessarily a consequence of their menopausal state. Hence the experience of menopause in women in the 'natural' menopausal life stage and that of young women could be vastly different, due to the life stage in which it occurs. As expressed by Singer and Hunter (1999, p, 70) "early menopause seems to be a woman's problem within a woman's problem and as such almost disappears from view", thus requiring specific consideration.

The Jones (1994) study was grounded in sociological theory, and expressed well the experiences of the women involved. A replica study of young women's experiences of early menopause would greatly enhance understanding of these women's experiences by uncovering the social construction behind women's beliefs concerning menopause.

2.4.3.5.3 *Menopause in Young Women*

Menopause has been negatively associated with aging, ill health, distress and social undesirability (Singer & Hunter, 1999). As two camps debate issues of menopause, such as those who want to medicalise it as an undesirable condition, to feminists who claim it to be a natural unproblematic transition, the actual experiences of ordinary women are often misrepresented (McPhail, 1999). Young women, therefore, can understandably develop a negative connotation of what the menopause experience will entail and how it will affect their lives (Singer & Hunter, 1999).

The negative social context given to menopause was found, during a study of young women who had premature (early) menopause, to be problematic. Emotional upheavals ranged from shock, denial, anger and loss. The women involved struggled with gender issues, together with reproductive and aging issues, trying to maintain their self-esteem and control over their lives as society largely constructs menopause as a negative life stage (Singer & Hunter, 1999). When a young woman who still desires to have children is thrust into menopause, she becomes increasingly dependent on fertility science and medical technology. Such an event may only produce further ingrained feelings of failure of the body system, allowing medicine to dominate (Singer & Hunter, 1999).

A young woman of childbearing age who finds herself menopausal can suffer social isolation, as her relationships can change with significant others and friends as her experience finds her out of kilter and synchrony with her peers (Schaefer et al. 1999; Singer & Hunter, 1999). The ability to confide in, and identify with, her peers is often damaged, reducing her to a social outcast at a time when additional support would be beneficial (Schaefer et al. 1999). Though receiving comfort from other women was potentially beneficial, specific support needed is difficult to find. Schaefer et al. (1999, p, 236) found support groups did not provide what these women needed and 'sexuality and intimacy were often in conflict', thus specific support groups for young women who experience early menopause are needed.

Infertility as a result of cancer treatment is problematic for many women, however infertility in itself is not the only problem encountered by women who endure early menopause (Schaefer et al. 1999; Singer & Hunter, 1999). Other issues identified are: a preoccupation with loss of youth and unfettered choice; personal and social isolation; repercussions on one's self-esteem; body image; not feeling like a real woman; menopause as a taboo subject (Singer & Hunter, 1999); unfairness of menopause; body changes; and life-patterns disruptions for which the women were not prepared (Schaefer et al. 1999). The women in the Singer and Hunter (1999) study expressed how they could not trust their bodies, which reflects in part a preoccupation with physiological changes such as hot flashes and other symptoms. The problem appeared to be with the word 'menopause', which suggests that another term for early menopause may help with young women's acceptance of the life stage (Singer & Hunter, 1999). YWBC suffer a double jeopardy with the onset of early menopause as Western culture's sexual significance of the breast only adds to the negative construction of the menopausal state (Neinstein, 1999) to be endured simultaneously with a life threatening disease. A summary table of literature reviewed concerning early menopause can be found in Appendix 1.9, Table A1.9.

2.4.3.5.4 *Health Care Professionals and Menopause*

Bachmann (1994) states that YWBC treated with chemotherapy should be counselled with regards to possible short-term and long-term problems they may encounter. The experience of early menopause only adds to the woman's distress if inadequately prepared by health professionals (Ganz, 2001). According to an academic review by Ganz (2001) of research in menopause and breast cancer, little information is available concerning the relationship between breast cancer, menopause and sexual matters. A lack of suitable information only fuels internalized negative feelings of menopause (Singer & Hunter, 1999). In addition, Bachmann (1994, p, 161) advises that the best time to educate a woman on such matters is during the immediate period after diagnosis.

Schaefer et al. (1999) states that explaining menopause, and other effects of treatments, must be a continuous process for health professionals.

Women in the Ferrell et al. (1997) and Singer and Hunter (1999) studies expressed how medical professionals played down their experiences of drug-induced menopause. Statements, such as: ‘no one ever died from menopause’, and ‘you’re lucky to be alive’ (Ferrell et al. 1997, p, 19), were illustrations of callous remarks made. In addition, doctors were reported to underestimate the distress caused by early menopause (Singer & Hunter, 1999). Problematic effects and frustration of seeking suitable interventions for relief of symptoms was reported by participants in the Ferrell et al (1997) study. The awareness of health care professionals should be raised regarding the affect that being plunged into early menopause can have on young women.

Limitations and Summary: Early Menopause

The literature reviewed concerning the experiences of women who endure early menopause was not exhaustive, however an overview of the physical symptoms experienced is documented. Snippets of information of the more in-depth lived experiences of YWBC who experience early menopause as a consequence of treatment are provided throughout the literature.

Qualitative studies grounded in sociological theories, of young women who experience early menopause, were not found in abundance. However, the use of a social constructionism theoretical framework provides many useful underlying meanings of the experiences of menopause in general (Jones, 1994). The Singer and Hunter (1999) study provides a basic understanding of young women’s lived experiences of menopause while the Schaefer et al. (1999) findings provide insight into early menopause as experienced by young women with ovarian cancer. Clearly, early menopause is a major concern for YWBC, both physically and emotionally. While infertility may be a prominent consequence of early menopause, it is only one aspect of the experience of early menopause. Being out of step with peers, social isolation, premature aging and not feeling comfortable within one’s body were other aspects reported.

Health professionals have been found to not consider the experience of early menopause to be troublesome nor worth much consideration or attention. This attitude needs to change. With further research into the experiences of early menopause, as experienced by YWBC (and other young women who experience early menopause), health and allied professionals who interact with this group of women can be made aware of the real life experience of being thrust into early menopause.

2.4.3.6 Complementary/Alternative Medicine

A qualitative, longitudinal study of the use of complementary/alternative medicine (CAM) by women who have breast cancer found that younger women were more likely than older women to use such treatments (Alder, 1999). Eighty-six women, of six different ethnic groups, were interviewed over four in-depth, semi-structured interviews. The younger group consisted of a 35-49 age group and the older group was comprised of 60-74 year olds. Seventy-eight percent of the younger age group used (CAM), as compared to 58% of the older group. This study, although providing a clear critique of qualitative methodology and analysis methods, did not provide any explanation as to why it is that YWBC use CAM. This article was the only literature found on CAM and YWBC. More qualitative, well designed and theoretically grounded studies of CAM use amongst YWBC are needed to supply understanding as to why younger women are more frequent users.

2.4.4 Social Support

Social support can be defined as the endorsement of an individual’s behaviours, perceptions, and expressed views, and/or giving of symbolic or material aid to another (Kahn, 1979). Thus, social support is viewed as an interpersonal phenomenon that is conveyed through expressions of caring, reassurance, and validation of personal worth (DiMatteo & Hays, 1984), reducing an individual’s sense of isolation and temporary disorganization (Feather & Wainstock, 1989). The absence of a social support network has been linked to negative health outcomes (Thomas & Duszynski, 1974; Woods & Earp, 1978) and increased progression of disease (Reynolds & Kaplan, 1990). Study results indicate that social support provided by partners, family (immediate and extended), friends and medical professionals is important for the survival of women with breast cancer (Carlsson & Hamrin, 1994), as social support is found to be associated with good adjustment (Feather & Wainstock, 1989, p, 294). Women with breast cancer also report that support groups and volunteer survivors who visit them are important sources of support (Marlow, Cartmill, Cieplucha & Lowrie, 2003). In addition, an individual who is well adjusted to his/her illness also finds it easier to elicit social support (Feather & Wainstock, 1989), resulting in a cyclic positive effect.

Theoretical Aspects of Social Support

Social support is divided into two aspects, functional support and structural support (Thoits, 1995). Functional support includes but is not limited to information, tangible (also referred to as instrumental) assistance and emotional support (Schaeffer, Coyne, & Lazarus, 1981; House, Robbins & Metzner, 1982; Wortman, 1984). Informational support does not only refer to information given to an individual about one’s illness, but also information regarding other issues, such as how to select a health care professional. Tangible support refers to the more practical support, such as childcare and financial assistance. Emotional support provides the individual with feelings of love, esteem, value and care (Bloom, 1982; Wortman, 1984). Structural support refers to the network of relationships that exist between people, such as friends and relatives, neighbours, co-workers and so on that bind an individual to his/her community (Bloom, 1986). It is suggested that a critical aspect of this network is being part of a mutual obligations system together with reciprocal relationships with those who have common interests and concerns (Bloom, 1986; Cutrona & Russell, 1990).

Buffering and Direct Effects

Two hypotheses of the effects of social support are explained within the literature; the buffering effects and direct effects hypotheses. Both of these hypotheses indicate that support is beneficial to health and well-being. The 'buffering effects' hypothesis claims that 'support given at times of crisis provides a buffer against morbidity' (Marlow et al. 2003, p, 320). The 'directs effects' hypothesis states that support is helpful to health and well-being regardless of the amount of stress people are experiencing (Cohen & Willis, 1985; Wortman & Dunkel-Schetter, 1987).

Emotional supports (Bloom et al. 2001) and psychological and social resources (Bloom, 1982; Bloom & Kessler, 1994b) have been found to buffer the effects of the intrusiveness of the disease and treatment, improving mental well-being (Bloom et al. 2001), thus impacting on QOL (Bloom, 1982; Bloom & Kessler, 1994a). However, a study of YWBC (those diagnosed before age 51 years) found that psychological and social resources have only direct effects on QOL (Bloom et al. 1998). This finding further indicates that YWBC experience their disease differently to that of older women with breast cancer.

Emotional, Informational and Tangible Support

Bloom's concept of psychosocial support provides a useful theoretical model with its key elements: emotional support, informational support and tangible (instrumental) support (1986). Research findings have lead some authors to believe that the availability of emotional or tangible support, being positively related to physical well-being, is more important than its actual use (Seeman & Syme, 1987; Thoits, 1995). However Bloom et al. (2001) found that the greater the perceived availability of instrumental supports, the poorer rather than the better the woman's physical health. Evidence of a protective effect derived from tangible support was not found (Bloom et al. 2001). This differs from previous study findings, which only measured perceptions not actions.

The Bloom et al. (2001) study also found that married young women (total sample n=336 YWBC, 41% 22-44 years old, 59% 45-51 years old) received more emotional and tangible support than those who were unmarried ($p < 0.05$). More emotional support was received by participants who were on chemotherapy ($p<0.01$), had reported positive lymph nodes ($p<0.05$), and received more tangible support (participants who had mastectomy) ($p<0.01$) (Bloom et al. 2001, p, 1518). In addition, larger networks were found to be related to the greater availability of emotional support, and high self-esteem was independently related to greater availability of emotional support (Bloom et al. 2001, p, 1520).

The social network index was the strongest predictor of tangible support, i.e., 'the larger a woman's social network and the more integrated she is within it, the more emotional support and tangible support available to her' (Bloom et al. 2001, p, 1521). The size of, and one's integration within, the social network thus appears to be important. Sammarco (2001a) claims that a larger support network may provide a woman with more avenues of tangible aid together with an increased security in relation to economic concerns, however an earlier study conducted by Feather & Wainstock (1989) found that the larger the social network the less frequency of interaction was reported. Thoits (1995) claims that social integration does not buffer the physical or emotional impact of stressors, although the size and degree of integration within a network is a necessary, but not sufficient, condition for gaining social resources. Even so, 'individuals who have few social ties regardless of their quality have less tangible and emotional support available to them' (Bloom et al. 2001, p, 1521). These study results illuminate 'the importance of social resources on well-being following life-threatening illness' (Bloom et al. 2001, p, 1513).

Informational and emotional support and effective communication have been found to not only improve patient wellbeing, but also improve satisfaction and compliance with treatment recommendations (Williams et al. 2002). Depression rates and length of hospital stays have been reduced due to appropriate information and psychosocial support (Devine & Westlake, 1995; Hathaway, 1986; Johnston & Voegele, 1993; Meyer & Mark, 1995). However, as YWBC find it difficult to access age-appropriate support services and information during and after treatment (Thewes et al. 2004), they may not receive the above-mentioned benefits afforded to older women with breast cancer.

Spiritual Support

Spiritual support is critical for meeting the QOL needs of breast cancer survivors (Ferrell, Grant, Funk, Otis-Green & Garcia, 1998) as these women face existential issues, emphasizing their mortality (Landmark, Strandmark & Wahl, 2001). Studies reporting on the existential dimension of living with newly diagnosed breast cancer are few (Landmark et al. 2001), even so there is a growing interest in the spiritual well-being of cancer survivors with the development of measures for spirituality (Holland et al. 1998). Literature reviews demonstrate that religious/spiritual beliefs can play a positive role in optimal health and adjustment to ill health (Fitchett, Peterman & Cella, 1996; Larson & Greenwold-Milano, 1995; Matthews, 1997), and can influence improved recovery and pain levels (Oxman et al. 1995; Pressman, Lyons, Larson & Strain, 1990; Yates, Chelmer, St James, Follansbee & McKegney, 1981). Reports regarding the spiritual well-being of cancer sufferers remain scarce (Bloom et al. 2004). Nevertheless, research has linked spiritual support to recovery from breast cancer (Brandt, 1987; Johnson & Spilka, 1991). In addition, religious beliefs and other activities related to spirituality, together with diet and exercise, have also been found to provide the greatest positive impact on the lives of women with breast cancer (Ganz et al. 2002).

Spirituality as a domain of QOL is conceptualized by Ferrell (1996) together with the domains of physical, psychological and social well-being. Ferrell and Dow (1997, p, 566) define the spiritual well-being domain as “the ability to maintain hope and derive meaning from the cancer experience that is characterized by uncertainty”. ‘Hope enables a person to tolerate the burden of sickness and suffering’, hence hope, as described by Landmark et al. (2001, p, 225), can counterbalance the hopelessness felt by women newly diagnosed with breast cancer, thus being a supportive element. Fromm (1968) describes hope as an imperative element in achieving change, ‘in making life more livable for oneself and others' (Landmark et al. 2001, p, 225).

Spiritual well-being not only refers to religious aspects but also encapsulates other sources of spiritual support (Ferrell, 1996). Ferrell (1996) explains that spiritual well-being encompasses feelings of uncertainty, hopefulness, purpose for living, positive spiritual change, increased life meaning, and the importance of spiritual activities. It has been suggested that spirituality may buffer the negative effects of stressors (Shapiro et al. 2001). Religious service attendance has been found to be significantly associated with emotional health outcomes, both general and breast cancer-related, for older women (55 years and older), hence religious inactivity is a risk factor for poor emotional outcomes for this group of women (Silliman, Dukes, Sullivan & Kaplan, 1998). Religious support has been reported not only through churches and other formal religious practices but also via informal existential faith or beliefs (Ferrell et al. 1998).

Although it is 'not surprising that major concerns for breast cancer survivors also include re-examining their spiritual and philosophical views of life and coming to grips with their own mortality' (Bloom et al. 2004, p, 150), the spiritual needs and supports offered to and/or received by YWBC have barely been investigated. Bloom et al. (2004), on examining the QOL of younger women (n= 185 women with breast cancer under age 50 years), found that religion played a positive role for about half of the participants. Also there was no significant decrease in participants' attendance at religious services or frequency of prayer over a five-year period (Bloom et al. 2004). The Bloom et al. (2004) limitations are documented earlier in section 2.4.1, paragraph 4. The lack of research into the spiritual and religious concerns, needs and experiences of YWBC needs to be addressed to provide this group of women with holistic supportive care.

Social Support and Perceptions

Sammarco (2001a) defines perceived social support as the perception that leads individuals to believe that they are cared for and loved, esteemed and valued, and that they belong to a network of communication and mutual obligation. The perception a woman holds of her support relates to how she believes she is understood and supported by others, which in turn impacts on how she copes with her disease (Feather & Wainstock, 1989). Perception is an important aspect of the definition of psychosocial support, as it is the perception of the support provided which is pivotal rather than the actual support in it self (Peters-Golden, 1982; Sarafino, 1994).

Study results indicate that women's perceptions of support determine their psychological adjustment and are often different to the perceptions of significant others (e.g., family and friends) (Pistrang & Barker, 1995). Women's perceptions of support offered or received from one person (a friend) may be received with thanks where as the same support offered by another person (a physician) could be perceived negatively (Sammarco, 2001a). Therefore, support offered and/or received can be viewed either negatively or positively. Perception has been found to be an important factor in women's adjustment to breast cancer, e.g., how a woman feels supported (Bloom et al. 2001; Mor et al. 1994a) and has been associated with better quality of family life (Sammarco, 2001a). Support perceived as positive by women with breast cancer has been found to enhance adjustment and lessen the burden of the disease; conversely, negatively perceived support adds burden of psychological difficulties (Mor et al 1994a).

Perception of the breast cancer experience is indicated in study findings. Single and divorced women perceive they received less aid compared to those married or widowed (Feather & Wainstock, 1989). Women with higher education perceive they receive less emotional support than their less educated counterparts (Feather & Wainstock, 1989). Bloom and Kessler (1994b) found that younger women (under 40 years) had poorer perceptions of personal resources, emotional strength and social support than women older than 60 years. In addition Silliman et al. (1998) found that women's (55 years of age and older) perceptions of their abilities to communicate with their physicians were significantly associated with both general and breast cancer specific emotional health outcomes.

Unmet Needs

Significant changes have been identified in the psychosocial life stages of women post World War II (Sammarco, 2001b). Sheehy (1995) explains that contemporary young women juggle marriage, children, careers, and completion of education experiencing the maximum role demands of each. It has been suggested that the pressures of modern life and associated roles of younger women results in them being particularly vulnerable to psychosocial morbidity when faced with a breast cancer diagnosis and the negative physical consequences of treatment (Bloom & Kessler, 1994a; Mor et al. 1994a). Younger persons face multiple responsibilities inherent in midlife, and may have spouses who work full time to support their families (Mor et al. 1994a).

Breast cancer is experienced differently by women of distinct psychosocial life stages thus having divergent needs, concerns, and QOL issues (Ferrell et al. 1997; Sammarco, 2001b). Ferrell et al. (1997) divides women with breast cancer, for QOL study purposes, by their different developmental levels (<40 years, 40-60 years and >60 years). Hence, the needs of women with breast cancer can be unique to their age group and/or be shared (needs of both groups) (Thewes et al. 2004). Thewes et al. (2004) found, via a qualitative study of Australian women with breast cancer (n=18, nine younger women – those pre-menopausal or have primary school aged children, and nine older women, 6-24 months post diagnosis), that younger women reported more needs than their older counterparts, of which several needs reported were directly related to being of younger age or pre-menopausal status at the time of diagnosis. Both groups in this study report ongoing needs relating to emotional and practical support from family and friends, access to professional counselors and the need to learn coping strategies to deal with fear of recurrence and to manage day-to-day stress (Thewes et al. 2004, p, 186).

The younger women within the Thewes et al. (2004) study indicate they want a more holistic approach to their care, addressing psychological, social and sexual well-being together with their physical health needs. Interestingly, it was the older participants within this study who reported wanting more physical (home) help, possibly due to widowhood or age. Thewes et al. (2004) suggest that the younger women within their study may have reported more unique needs to that of the older group due to younger breast cancer survivors being a vulnerable group or because younger women are better at communicating their needs for psychosocial support and/or are more assertive in such communication.

The social consequences of unmet needs for assistance have been found to be less prevalent and less intensive among older women with breast cancer (Mor et al. 1994a). Young people with cancer (31-60 years) report higher levels of unmet needs than those aged 70 years and older, which may reflect younger persons' attitudes towards reporting unmet needs which may differ to that of older persons who may believe they should be able to cope and hence do not express their needs (Sanson-Fisher et al. 2000). Families of YWBC often exhibit an increased need for social support (Davies et al. 2004; Northouse, 1994), hence the provision of specific social support for partners/husbands and children could significantly enhance the quality of family life outcomes (Sammarco, 2001a). The 'planning and implementation of care tailored to reflect the unique differences demonstrated by age and psychosocial life stage' to enhance the QOL for YWBC is important (Sammarco, 2001a, p, 213). Hence the unmet needs of women with breast cancer, particularly YWBC, should be routinely monitored to allow health services and health care and allied professionals to introduce evidence-based practice in regards to support-related interventions and other oncology care to best meet their needs (Sanson-Fisher et al. 2000).

Health Care Professionals and Social Support

Doctors may supply supportive care when providing services to patients, as the behaviours of physicians have been linked to patient satisfaction (Gray, Goel, Fitch, Franssen & Labrecque, 2002, p, 648; Ong, de Haes, Hoos & Lammes, 1995). Davis, Williams, Parle, Redman & Turner,. (2004) found that the majority of women turn to their treating medical practitioners, particularly their surgeons, for information and support, and a minority access trained mental health professionals. In addition family members also rely heavily on the breast surgeon or family doctor for support (Davis et al. 2004). Gray et al. (2002), having found that younger women (those under 65 years) more readily sought and received help (supportive care), raised concerns that women 65 years and older had less access to supportive care (from health professionals) possibly due to them not initiating a conversation about psychosocial concerns. A small proportion of physicians also assisted the participants with family concerns and issues of meaning or spirituality (Gray et al. 2002). Breast care nurses have also been found to provide supportive care resulting in significant reductions in anxiety and depression experienced by women with breast cancer, via counseling interventions (McArdle et al. 1996; Watson, Denton, Baum & Greer, 1988). There is a lack of research into the perceptions of YWBC in regards to the social support provided by health care professionals.

Limitations and Summary: Social Support

Social support provides benefits to the health and well-being of women with breast cancer via both buffering and direct effects. Emotional, informational and tangible supports are elements of social support. Study findings differ in relation to the benefits of the knowledge that these forms of support are available (Bloom et al. 2001; Seeman & Syme, 1987; Thoits, 1995). Even so, an individual's perception of social support is pivotal rather than the actual support received (Peters-Golden, 1982; Sarafino, 1994). Support offered and/or received can be viewed as negative or positive. In addition, perceptions have been found to differ between younger and older groups of women with breast cancer, with YWBC fairing worse (Bloom & Kessler, 1994b)

The size of, and integration within, an individual's social network has been linked to the greater availability of emotional and tangible support (social resources) and higher self-esteem, thus social resources are important for the well-being of women diagnosed with breast cancer (Bloom et al. 2001). Health care professionals have been found to contribute to the social support of their patients (Davis et al. 2004). Hence, the role of the health care professional, including specialist breast care nurses, in the social support network of women with breast cancer must be enhanced at every opportunity. In addition, informational support has been associated with improved satisfaction and treatment compliance (Williams et al. 2002) amongst other beneficial effects. Research into the information needs of YWBC and appropriateness of available information resources is scarce. However, Thewes et al. (2004) found that Australian YWBC have difficulty accessing age-appropriate information (and support services). More evaluation studies of the suitability of information resources to YWBC are needed to inform the redevelopment of informational resources for future YWBC. Some of the findings of this study may help in this regard.

While research into spiritual support and recovery is not new, studies concentrating on the spiritual well-being of cancer sufferers are few (Bloom et al. 2004). The importance of spiritual well-being is highlighted by its inclusion as a domain of QOL (Ferrell, 1996). Due to the life threatening nature of breast cancer, the provision of spiritual support, which encapsulates religious aspects and other sources of spiritual support (Ferrell, 1996), is crucial to meet QOL needs (Ferrell et al. 1998). However, investigation into the spiritual support, needs, concerns and experiences of YWBC is in its infancy (Bloom et al. 2004). Much work needs to be done in this area of research to provide a holistic approach to social support needs of YWBC.

The psychosocial life stages of women have undergone change since World War II (Sammarco, 2001b). Today’s young women juggle many life demands that in turn produce various pressures (Sheehy, 1995). YWBC have been found to share needs with older women with breast cancer (Thewes et al. 2004), although they also have needs unique to their age group (Ferrell et al. 1997; Thewes et al. 2004). The partners and children of YWBC have also been found to exhibit an increased need for social support (Northouse, 1994). Hence, contemporary times need contemporary-based solutions.

Studies exploring the needs of YWBC must be conducted periodically to ensure continued relevance.

2.5 CONSUMER ISSUES

Through the vision set out for primary health care by the WHO Declaration of Alma-Ata, which states ‘people have the right and duty to participate individually and collectively in the planning and implementation of their health care’, the principle of consumer participation in health care emerged (WHO clause IV, 1978). The health-consumer movement, as a social movement, struggles with bureaucracy and health and allied professionals to attain changes in social and political relationships, such as the shift of power to the public away from professionals and bureaucrats (Irvine, 1996). Health-care consumers, as social actors, can be viewed not only as the individual undertaking medical care and treatment, but also as the ‘others’ who may be potential users of the service or those who are directly or indirectly affected by such a service, such as family members and carers (Irvine, 1996).

It has been suggested that consumers of health care want professionals to treat them as partners in their care, and to communicate sufficient information to them in a comprehensible way (Irvine, 1996). If enough information from more than one source is forthcoming, consumers can act in their own best interests (Williamson, 1993). As consumers gain information on the nature of their illness, such as the risks and benefits of various treatments, they can then make informed decisions, even if the health professional thinks such a decision is not right for that person (Williamson, 1993). The women’s health movement has been successful in presenting consumer challenges, such as women being able now to choose home births, to have or not have birthing interventions, and the rise of women’s health centres (amongst other successful initiatives). YWBC need specific information relating to their situations. Hence providing YWBC with accurate relevant information concerning their illness is paramount.

Consumers, due to their life experiences of living with an illness, know what factors impinge upon the illness and their day-to-day lives. They also have specific and first-hand knowledge of the health system and how it works, and can evaluate if what is delivered is what is needed (Wood, 1994). Health service managers and practitioners are beginning to appreciate that sharing information with consumers (that is patients, their carers and the wider public) can significantly impact on factors such as: encouraging informed use of health services; assisting the public to understand treatment options including issues of effectiveness and uncertainty; helping to reflect consumer values to set priorities; and encouraging professionals to develop heightened communication (professional-patient) skills (Gann, 1997).

A goal of cancer management is to maintain the QOL of patients, their carers and families, which is a concern of consumers of breast cancer services and care (Commonwealth Department of Human Services and Health, 1994). The Consumer's Guide for Early Breast Cancer states that 'patients should be encouraged to make their own decisions' (National Health and Medical Research Council, 1995, p, 10). To do so in an informed manner, information specific to one's circumstances is needed.

The need for specific information relating to women diagnosed with breast cancer at 40 years of age or younger was recognized, hence the 'Clinical practice guidelines for the management and support of younger women with breast cancer' publication was released in 2004 (National Breast Cancer Centre, 2004). Within this publication, the latest literature has been combined to provide current understanding of these women's potential physical and psychosocial issues. However as the literature does not comprehensively cover this group of women's issues, limited information was available from which to develop such guidelines. For example, no mention of breastfeeding after breast cancer was made. Little is stated about contraception after breast cancer with only a recommendation against the use of oral contraceptives. Issues of breast symbolism were also neglected. Hence further research of the experiences, issues and concerns of YWBC is necessary to broaden these areas of knowledge.

2.5.1 General Information Sources

Studies have suggested that women who are diagnosed with breast cancer have at that time, and during treatment regimes, high information requirements as the situation is new and daunting, irrespective of what the diagnosis is or what treatment is followed (Bilodeau & Degner, 1996; Cawley, Kostie & Cappello, 1990; Galloway et al. 1997; Graydon et al. 1997; Harrison-Woermke & Graydon, 1993). The information needs women most reported have been those concerning a cure (Bilodeau & Degner, 1996), the treatment routine and tests involved and issues surrounding emotions and concerns (Gallaway et al. 1997; Graydon et al. 1997; Harrison-Woermke & Graydon, 1993).

It has also been found that women who suffer breast cancer require more information on: pain (and the meaning of it); the impact the breast cancer has on their daughters; normalcy of life; menopause and its effects; infertility; survivor guilt; body image; and dreams/nightmares (Ferrell et al. 1997). These findings reflect subjectively the physical, psychological, social and spiritual well-being of the women studied (n=21, age range 22-71 years).

Cawley et al. (1990) found younger women (85% of 50 years age group) were more satisfied with the information provided to them than older women (61% of 60-70 years age group), suggesting that older women are treated more paternalistically. A later study found that young women desired more information than older women (no specific age groupings reported) (Galloway et al. 1997). Galloway et al (1997) suggested that younger people may expect to be better informed, than older people, and be active participants in decision making regarding their treatment and care. Alternatively, personal and social responsibilities of younger people may increase their need for information (Galloway et al. 1997). A qualitative study may uncover the reasons why YWBC want to be better informed than older women. Regardless, these findings do not provide understanding of the specific information needs and/or expectations of YWBC (aged 40 years or younger at diagnosis). These studies were retrospective, hence a longitudinal design may capture differing results over time. Even so, the information which is given to (all) women with breast cancer should not only be accurate, relevant to their situation and considered important by the women themselves (Harrison, Galloway, Graydon, Palmer-Wickham & Rich-vander, 1999), but also be clear, detailed and jargon free (Baldry & Walsh, 1999).

Earlier in this chapter other issues related to information were discussed. See section 2.4.1.2.2.1 concerning partners and information, and 2.4.1.2.2.2 concerning resources for children, and section 2.4.4 concerning informational support.

Internet

With all manner of health and care information available on the internet, Berland (2001) suggests that consumers find difficulty in trusting and/or believing such health information, as a vast array of types and quality now exist. An effective future avenue of investigation would be of young breast cancer sufferers' habits of internet usage concerning health matters, together with guidelines for how to identify good quality information.

2.5.1.1 *Information and Health Professionals*

2.5.1.1.1 *Informed of Diagnosis*

How a woman is informed of her breast cancer diagnosis was found to impact on how she copes with her illness. Being told such information via a telephone conversation was found to be distressing, especially if the call is taken at a workplace (Maunsel, Brisson, Dubois, Lauzier & Frazer, 1999). Young adults also found, in general, that being told a positive diagnosis over the telephone was problematic (Kyngas et al. 2001). Diagnoses being communicated in insensitive ways, such as in a waiting room, affects the woman's ability to cope with the distressing information, in the first instance, being greatly influenced by the demeanor of the consulting doctor (Baldry & Walsh, 1999).

Being alone when receiving such information was found to also exacerbate the distress experienced (Baldry & Walsh, 1999). Consideration should be given to the way in which distressing news, such as a diagnosis of breast cancer, is given.

Premature reassurance of prognosis outcomes, was found to be problematic (Baldry & Walsh, 1999). It could be assumed that women with breast cancer prefer to be told information of their condition in clear and uncoloured terms. Clarity of such information given by health professionals is vital (Maunsel et al. 1999). Though it must be noted that there will always be a percentage of people who do not want information about their disease (McGrath et al. 2000), therefore permission should be sought before giving such information.

2.5.1.1.2 *Professional Communication*

In the experience of gynaecologist William Hindle, the fear of breast cancer, coupled with powerful emotions and subsequent denial, affects not only the woman involved but also her significant others, relatives and physician (Hindle, 1994). Such fear disrupts the information flow from the health professional to the woman diagnosed with breast cancer, and visa versa – resulting in the physician inappropriately responding to the woman’s needs. It has been found that the use of an audio-tape recorded consultation with a health professional did not reduce psychological morbidity, however fewer trips to GPs were recorded (Hogbin, Jenkins & Parkin, 1992). Hence there appears to be some positive effects present with such a communication system.

Time is a crucial resource when it comes to health professionals informing and educating women with breast cancer of their disease. It must be realised that not only treating doctors are deliverers of disease/illness information, but nurses, in particular, have been found to be very good informers, which is why they are often sought for information (Rees & Bath, 2000). Nursing responsibilities and their relative availability could explain why they are good information disseminators as compared to other health professionals (Wilkes, Beale, Cole & Tracy, 1999). Earlier in this chapter issues of professionals and information were discussed in relation to advice for professionals concerning sexual matters of YWBC (section 2.4.3.4.4) and issues of menopause (section 2.4.3.5.4). Further studies are needed of other allied health professionals who may find themselves in the position of disseminating information for YWBC.

2.5.1.1.2.1 *Australian Breast Cancer Care Guidelines*

An Australian telephone survey of 140 women (aged 24-79, M=53) found approximately 50% of the participants rated 28 of 52 items, of the Breast Cancer Care Guidelines released in Australia by NH&MRC in 1995, essential components and identified as the most important aspects of psychosocial care the provision of information and choices, and doctor-patient communication (Rankin et al. 2000). This suggests that there is further need to research consumers' concerns and issues to reflect consumer opinion within the Australian psychosocial clinical guidelines for women with breast cancer.

2.5.2 Support

Appropriate support for young women with breast cancer appears to be limited (BCNA, 2001). However, YWBC have been found to have enhanced social supports available to them compared to their older counterparts (Mor et al. 1994b), which suggests that subjectively, younger women do not consider available support sufficient, or they may need different support than that utilized by older women. Young adults with cancer stated that social interaction with peers was vital, as many reported being surrounded by older persons with cancer when going through treatments (Brock & Perry, 1995). Support groups, as claimed by Bloom and Kessler (1994b), may explain up to 15% of the variance, reducing the impact of breast cancer on younger women. The above information suggests that support available could be made more age sensitive.

Consumers groups, as natural partners in advocating for supportive care improvements, have lobbied for change at all levels of the Australian government using the *Making a difference* report, which resulted in positive change (Redman, Turner & Davis, 2003).

Improvements in supportive care, for women with breast cancer, hinges on consumers being active partners with their clinicians and cancer organizations (Redman et al. 2003). YWBC need to form age-specific consumer groups to lobby for supportive care change relevant to their life stage.

Other issues of support were discussed earlier in relation to social support generally (section 2.4.4) and in relation to partners specifically (section 2.4.1.2.2.1).

2.5.2.1 *Interventions*

Smeardon (2001) discussed the intervention in the UK for YWBC (those under 55 years of age) 'Fighting Spirit' – a psycho-educational group. This group was formed in direct response to requests for support specifically for younger women so that they could share common experiences, such as family concerns. *Ad hoc* support sessions were offered to partners and children when specifically requested by the women – explaining the aims and rationale of the group (Smeardon, 2001). The presence of those women who had advanced breast cancer and were in palliative care had, at times, disturbed other members. With appropriate care and support, provided by the facilitator, the group members learned to manage the feelings aroused by the circumstances (Smeardon, 2001).

As a robust evaluation had not been conducted at the date of this publication, Smeardon (2001) suggests anecdotally that the participants valued the group. The informal environment of the venue, which was private and easily accessible, and the friendly supportive atmosphere of the group, was appreciated by the group members. Networking with other women in a similar situation was a most important aspect of the group (Smeardon, 2001).

The Queensland Cancer Fund (QCF) provides support services, i.e., emotional, practical and informational support programs, to persons with cancer (and their families) (Steginga & Dunn, 2001). The programs offered by QCF for women with breast cancer include one-to-one peer support, psycho-educational programs, and self-help material (Steginga & Dunn, 2001, p, 383). The informational and educational aspects of these support services inform the women of ways to effectively manage their concerns (Steginga & Dunn, 2001). The Queensland Cancer Fund (QCF) has developed a similar group to that of the ‘Fighting Spirit’ group mentioned above, which is ‘The Young Women’s Network’ (YWN), i.e., a peer-support network for YWBC (Steginga & Dunn, 2001). This group aims to address specific psychological and social needs of these young women, as Steginga and Dunn (2001) acknowledge young women’s support needs are largely unaddressed. As with Smeardon’s (2001) intervention, YWBC approached the QCF and requested an opportunity to speak with peers (other women in similar situations, such as mothers of young children and with similar family structures) about their experiences, therefore sparking the interest in formulating such a group.

The formulation of the problem, together with the development of the action plan, was informed continually by the experiences of young women, via consumer participation. An age criterion for being in the YWN does not exist, rather the women themselves define the membership, such as being: of child-bearing age; having young children; being pre-menopausal (at diagnosis); together with those women who identify themselves as young (Dunn & Steginga, 2000). Twelve months after the inception of the YWN, five regional groups, from Tweed Heads in New South Wales to Cairns in Queensland, were in operation. To cater for those who cannot geographically access such networks, a website chat room and teleconferencing were considered (Steginga & Dunn, 2001). The website is now operating on the QCF website (URL: http:www.qldcancer.com.au/ywn/, accessed 24-8-04) though the chat room is not. Interventions aimed at increasing the women’s network of friends and improving their relationships with relatives either through face-to-face support groups or possibly through the Web are important (Waxler-Morrison et al. 1991). The development and planning for the YWN was guided principally via consumer feedback distinguishing it from standard psycho-educational programs (Steginga & Dunn, 2001).

Little is known of the cost effectiveness of interventions as research to date has not focused enough on collecting information to underpin improvement in health service delivery or health policy (Redman et al. 2003). Valid improvements in supportive care for women with breast cancer can be made if cost effectiveness guides supportive care programs, service delivery and policy formulation (Redman et al. 2003). Of concern, approximately 30% of Australian women with breast cancer live in rural or remote parts of Australia, where some health-care and supportive services are often unavailable (Redman et al. 2003). 'If the information and support needs of cancer patients are to be met, there is a need to change health-care systems to encourage the adoption of supportive care programs with demonstrated efficacy into routine practice' (Redman et al. 2003, p, 521-522).

Interventions and/or programs for YWBC were difficult to find in the literature, suggesting that such interventions are rare. The findings from this study may help improve such interventions and programs. In addition, increased research into the cost effectiveness of supportive care interventions for YWBC specifically may lead to improved service delivery and health policy for this group of women, thus impacting positively on their lives.

Limitations and Summary: Consumer Issues

If YWBC, as consumers of health and care services, are given sufficient information in a comprehensible way (Irvine, 1996) they can make informed decisions concerning their care and personal circumstances. However studies into the information needs of YWBC (and other life-threatening diseases) and evaluations of such information, are scarce, hence more work needs to be done in this area. A series of qualitative studies would help pin point information needs, and thus help to design a robust quantitative evaluation study of information received. This study aimed to inform such information resources. In addition, many problems exist with the dissemination of information from professionals to women with breast cancer. Further studies are needed to investigate issues of doctor-patient communication in relation to YWBC. The publication, 'Clinical practice guidelines for the management and support of younger women with breast cancer', released by the Australian NH&MRC (2004), is a good start to improved communication in this area, however additional information can only enhance information flow. Specific support structures and interventions for YWBC are also limited (BCNA, 2001). More focused research on the cost effectiveness of breast cancer-related interventions for YWBC would provide the catalyst for improved service delivery and health care policy to provide improved evidence-based interventions.

2.6 OVERALL LIMITATIONS

This literature review was greatly limited due to the lack of a universal definition of what constitutes a woman with breast cancer as 'young'. The age range of studies specifically addressing YWBC varied widely. Snippets of information were extracted from findings of the 'younger' categories of general breast cancer studies. Few studies reviewed were conducted longitudinally, which prevented the identification of changes over time. Recruitment methods often produced homogeneous groups, i.e., those involved in support groups, Caucasian, middle- to upper-class, higher socio-economic groups and those highly educated. The vast majority of study participants within the literature reviewed did not have advanced disease. Considering that YWBC are often diagnosed with more advanced disease than their older counterparts, a broader mix of stages of disease may be beneficial to study findings, in particular qualitative studies to understand experiences. Effects of social desirability may be present in some studies. Limited variation of ethnic representation within and across study samples limited the generalisibiltiy of findings reported, specifically in relation to psychological and psychosocial problems associated with breast cancer treatment. The majority of the studies reviewed were of Western developed origin (e.g., Australia, Canada, UK, USA), hence findings from comparative studies conducted in dissimilar cultures may differ significantly. Misinterpretations of subjective meanings of qualitative components of studies may also add to limitations.

2.7 CONCLUSION

There is a serious lack of literature pertaining to issues specifically of younger women (40 years or younger) who have breast cancer. Of the information available, results were often obtained simply by dividing the study population into researcher-determined younger/older categories, such as using menopausal status. Even so, a variety of problems encountered by YWBC were analysed. YWBC report concerns of heightened emotional distress including issues related to mortality, grief, body image and concerns for young families and relationships. Social support was found to be perceived more negatively by YWCB. Reproductive issues of YWBC were comprehensively explored with many gaps in the current literature identified. Treatment choices and their effects, included body image issues (including social and cultural influences), surgical choices, reconstruction and prosthesis use, and side effects of treatment (such as sexual dysfunctions mostly resulting from early menopause) were also examined.

In particular, literature addressing the psychosocial issues of YWBC was minimal, hence the need for this study. Peripheral information, regarding topics such as family issues (including that of children and spouses/partners) was obtained by searching databases for breast cancer (in general) and family issues, however minimal literature was found pertaining specifically to YWBC and their family concerns. Similar difficulties emerged when searching for other information on YWBC and issues such as early menopause, maintained or regained fertility and informational needs. Other than medical/clinical information, literature dealing with the reproductive (including breastfeeding) experiences of YWBC appears limited. Much emphasis has been placed on infertility as a consequence of cancer treatment (Bloom & Kessler, 1994; Dunn & Steginga, 2000; Reichman & Green, 1994; Schaefer et al. 1999; Schover, 1994; Siegel et al. 1999; Singer & Hunter, 1999; Spencer et al. 1999), however literature surrounding the psychosocial factors of women maintaining or regaining fertility, dealing with personal experiences of contraception, pregnancy and breastfeeding after breast cancer treatment, are scarce. Hence, the findings reviewed were based on studies comprised of diverse women with breast cancer, i.e., differing disease stages and wide variations of marriage/relationship durations and age ranges. Limitations and biases in study design and sample selection were evident in many studies, as stated in the shaded 'limitations and summary' sections of this review.

Studies of other life-threatening diseases, which focused on younger women, also varied greatly in the above-mentioned areas. Pregnancy and breastfeeding literature was also scarce in regards to any serious/life-threatening illness. Even so, the general experience of having breast cancer at a young age appears to be very similar to experiences of women of similar ages who are diagnosed with other life threatening diseases, such as gynaecological cancers, i.e., early menopause and other treatment side effects. However, as the partial, or full, removal of the breast can be particularly visually obvious, unlike the surgical removal of gynaecological cancers, the symbolic sexual importance bestowed on breasts by Western cultures may exacerbate young women's distress, which subsequently affects all family members. Social and cultural trends and processes also impact on the experience of breast cancer and thus must be considered when dealing professionally with this group of young women. YWBC need to have their experiences investigated to ascertain, and understand, their perceptions of their experiences, which in turn will allow health and allied professionals to inform and assist this group of young women to not only make informed decisions, but also to adjust to their post-treatment lives.

To address the many gaps in the literature concerning the psychosocial issues faced by young women diagnosed with breast cancer at 40 years of age or younger, this study explored the problems and major issues experienced by this specific age group of YWBC, together with what influenced their illness experiences. In addition, this study also captured changes in the perceptions and experiences of YWBC over time, and the reasons for such changes, an avenue of inquiry scarcely mentioned within the literature. Qualitative inquiry into such realities best served this purpose. As YWBC are consumers of health and care services, the documentation of their experiences and needs will inform the future design of services and informational materials.

CHAPTER 3

METHODOLOGY AND METHODS

This chapter addresses the issue of methodology and its implications for the analysis, together with the study design, methods used and issues of rigour. However, as historical aspects of some sociological theories are difficult to differentiate, and considering this study is public health based rather than sociology based, the sociological underpinnings of this chapter are discussed at the level of depth necessary to inform the public health context. Hence a more comprehensive explanation of sociological theories and notions are outside the scope of this study. In addition, this study concentrates on the consumerist activist perspective.

3.1 METHODOLOGY

3.1.1 Theoretical Framework

The study was guided by constructionist epistemology, taking an interpretative approach. Jackson (1998, p, 9) states that the interpretative approach encompasses ‘how people make sense of their lives; how they define their situation; and how their sense of self develops in interaction with others’. Schwandt (1998, p, 224) claims that the interpretative position proposes that ‘language and history are both the condition and limit of understanding’. Constructionist and interpretative theoretical frameworks focus on the process of the creation, negotiation, sustenance and modification of meanings within a ‘specific context of human action’ (Schwandt, 1998, p, 225). Hence the study sought to interpret how experiences were constructed. In unison with the study’s theoretical framework, the theoretical perspective, symbolic interactionism, aids in interpretations of experiences.

3.1.1.1 *Theoretical Perspective: Symbolic Interactionism.*

The study was grounded in symbolic interactionism, which emerged from the interpretative approach and evolved from constructionist epistemology, a phrase coined by Herbet Blumer in 1938 (cited in Crotty, 1998, p, 50). As constructionists view knowledge and meaning as something which is constructed rather than revealed, uncovered or created, so products of history and social structure play a role in the negotiation of meaning (Sapsford & Jupp, 1996; Crotty, 1998).

Symbolic interactionism examines how people make sense of their experiences and their social worlds through using a set of common symbols which have and generate meaning through shared interaction (Rice & Ezzy, 1999). The premises which underpin symbolic interactionism are:

1. *Human beings act towards things on the basis of the meaning that the things have for them;*
2. *The meaning of such things is derived from, or arises out of the social interaction that one has with one's fellows; and*
3. These meanings are handled in, and modified through, an interpretation process used by the person in dealing with the things he (sic) encounters (Blumer, 1969, p, 2).

According to Denzin and Lincoln (1998, p, 233), symbolic interactionism assumes that people engage in an active way, via their minds, to their world rather than merely 'responding to its environmental stimuli'. However symbolic interactionism does not go far enough to capture the true essence of the participants' experiences as the social structures which shape such experiences also need to be considered (Cheek et al. 1996), hence elements of social constructionism, in combination with symbolic interactionism, better serve the study's purpose.

3.1.1.1.1 *Social Constructionism*

Social constructionism is underpinned by the philosophy of phenomenology, of which the central concern is the 'meaning and understanding given to everyday actions, events and institutions by the individual actor in a world already present', looking for subjective meaning (Cheek et al. 1996, p, 137), and assumes that it is people's social interchanges that create their world (Denzin & Lincoln, 1998). The focus of social constructionism is on society, as formulated by individuals' interactions, stemming from knowledge of biases of social, historical and political factors of the times (Cheek et al. 1996), and of culture, as 'humans depend on culture to direct behaviour and to organize experience' (Crotty, 1998, p, 52). Culture, according to Crotty (1998, p, 52), is best viewed as a 'source rather than a result of human thought and behaviour, and as such human thought emerges as both social and public'. Hence social and cultural influences should not be underestimated in relation to participants' experiences. Therefore, investigating the participants' perceptions of their illness trajectory, their attitudes and beliefs, together with their experiences of support sought and barriers to these, this study delved into the historical, social and cultural production of issues related to pregnancy and breastfeeding, body image, including perceptions of femininity, breast symbolism and differences between younger and older women (generational differences).

3.1.1.1.1.1 *Social Norms*

Social norms are socially constructioned notions which are 'imposed on people regardless of their own beliefs' (Freund & McGuire, 1999, p, 119). Foucault (1979, p, 304) claims that an instrument of power, a form of social control, is normalising judgement, that is actions or attributes of individuals are assessed, compared with, and measured against, that of others to establish norms. Individuals then internalise such norms, which shape, manipulate and control behaviour (Cheek et al. 1996, pp, 153-154). Sickness in itself, seen as a form of deviance, has been indicated as a breach of an ideal or norm of society and thus can be disruptive (Durkheim, [1895] 1938, p, 68-65), thus social norms can influence and impact on experiences of illness.

3.1.1.1.1.2 *Social Construction of the Body*

Notions of the body as socially constructed may explain participants' experiences further, leading to greater understanding. Views of the body as socially constructed have been influenced by anthropologist Mary Douglas, social and cultural history of the human body, writings of Michel Foucault and studies of Erving Goffman (Shilling, 1993, p, 71). 'The human body is a natural symbol' and the meanings bestowed on it are not intrinsic but are socially constructed and then attached to it, thus 'social structure shapes individual bodily expression' (Freund & McGuire, 1999, pp, 133-144). Turner (1992) suggests that society is moving towards what he refers to as a 'somatic society' in which the major concerns of society are in the regulation of the body, rather than increasing populations. Turner, in *Regulating Bodies* (1992), identifies four basic social tasks that are central to social order, the fourth being representation of the body, which, similar to that of body image, is concerned with the physical presentation on the world stage (Nettleton, 1995, pp, 111-112). Shilling (1993) goes further and states that social expectations may have an affect on bodily structure, as the body, having a material base, is moulded and modified by social practices within its social context. With regards to this study, these notions may explain why participants' hide/disguise their breastlessness/disfigurement.

Douglas (1970) puts forward that social influences, such as the classification and organisation of a social system, reflect how the body is perceived (p, xiii). Thus, the physical experience of the body, which is constrained by the social body, is modified by social categories through which it is know. Societal views, and the continual exchange between these two modes of experience, reinforce the category of the other (Douglas, 1970). Hence the social systems in which participants were raised and now live greatly impact on their interpretations of their physical appearance.

3.1.1.1.1.3 *Stigma*

Goffman (1963) too recognized the relationship between the presentation of the self and the influence of social forces; that health was increasingly associated with appearances. Goffman (1963), in theorising on the concept of stigma, explains that the body mediates between self-identity and social-identity. Stigma is a socially constructed attitude derived from certain deviations from somatic norms, which depend on social context (Susman, 1993), hence 'stigma, by definition, has the potential to discredit the self the individual is trying to present to others' (Freund & McGuire, 1999, p, 141). A person is discreditable if his/her differentness is not immediately apparent or not known beforehand though has the potential to be found out. The issue for a discreditable person is to manage the information about his/her failings, i.e., to manage undisclosed discrediting information about the self (Goffman, 1963). The visibility of the symbol of the stigma is a crucial factor in one's social identity and it is via the sense of sight that the stigma of others becomes evident (Goffman, 1963). The social meanings associated with stigma, that of meanings given to particular body forms (and/or behaviours), when internalised influence greatly an individual's sense of self and worth (Goffman, 1963). Shilling (1993, p, 5), hence, views the body as a personal resource and a social symbol, which projects and communicates a person's identity.

3.1.1.1.2 *Implications for Analysis*

Analysis of the study was a reconstruction of the viewpoints of the participants, which is, as stated by Flick (1998, p, 17), the 'instrument for analysing the social world'. Therefore, the methodology in which this study was grounded assists in the illumination of how young women with breast cancer (YWBC) construct the meaning of their attitudes and beliefs which encompass their realities, such as exploring their needs and concerns and their experiences of maintained or regained fertility, contraception, pregnancy and breastfeeding after breast cancer, changed body image, breast symbolism and societal expectations and norms in relation to hiding and/or disguising their breastlessness/disfigurement and perceptions of how their experiences differ to that of older women with breast cancer. The meaning of the experience of having breast cancer at a young age, and all it entails, is wound up with how other persons respond to such an event. Blumer's (1969) first premise (as mentioned in 3.1.1.1) served the study well as understanding these young women's perspectives of their situations is paramount to tailor education programs, information resources and support and health care services to their specific needs. In addition, consideration was given to theories and notions of social constructionism, social norms, the social construction of the body and issues of stigma throughout the study.

The design of the study allowed these perspectives to be gathered and analyzed to determine shared meaning as well as some individual perspectives by analysis of both individual and collective data. Thematic analysis was used as a method of analysis. According to Daly, Kellehear and Gliksman (1997), the themes that are important for participants emerge from the data and become the categories and sub-categories in the analysis. For this study, thematic analysis began with the major issues identified corresponding to the study aims. Though pre-determined themes were identified in the literature, the questions asked were open-ended allowing concentration on issues which were most salient to the participants. As described by Barbour (2000), this process allowed different perspectives to be explored. As much as the analysis of this study was technically systematic and methodical, it also incorporated a creative aspect (Patton, 1999, pp, 1190-1191). Further explanation of analysis processes can be found later in this chapter in sections 3.4.6.1.1; 3.4.6.2.2; 3.4.7.1.1 and 3.4.9.

3.2 POSITION OF RESEARCHER

The principal researcher has not experienced breast cancer personally nor participated in any breast cancer research prior to this study, and is not associated with any breast cancer service or organization, thus providing a fresh approach to this study.

3.3 STUDY DESIGN

The design of this study was drawn from a qualitative approach to research. Rather than measuring participants' experiences, the focus of the study was on the construction of experience while seeking meaning and understanding. The study was longitudinal, exploring the participants' perceptions of their illness over time. Consistent with the theoretical foundations described in section 3.1 the experiences of the participants were captured by the use of semi-structured, one-to-one interviews, either face-to-face or via a telephone conversation. A diagram of the study design can be found below in Figure 3.1. A pilot study was conducted which helped refine and focus the remainder of the study. Analysis was undertaken in stages. Each phase of the study was analysed separately and the findings were used to further inform, refine and focus the study at each subsequent phase. Participants were studied at an individual level and collectively.

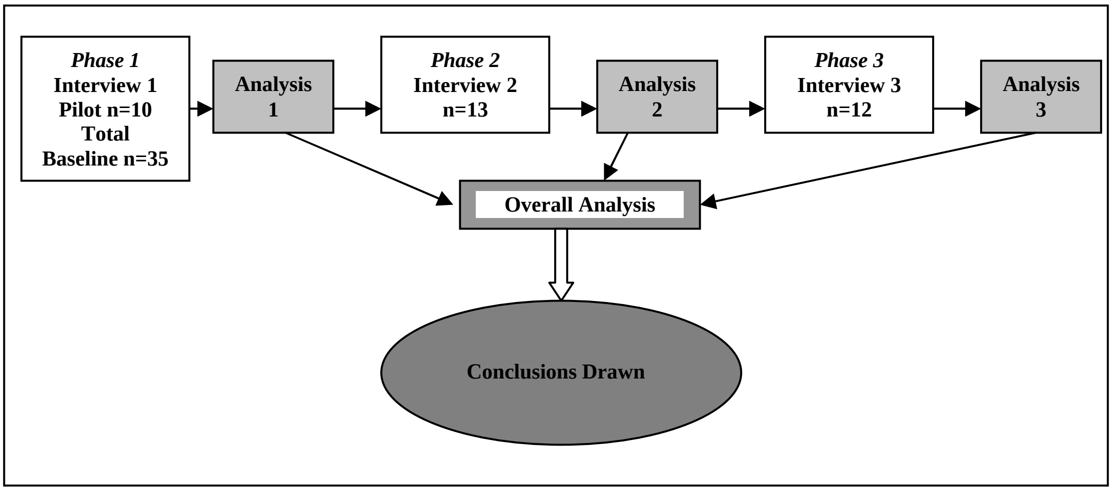


Figure 3.1: Diagram of study design.

3.4 METHODS

The following sections explain, in detail, issues of recruitment of participants including inclusion and exclusion criteria, ethical procedures, participants in the study, and the settings in which the data were collected, together with a rationale for selection of follow-up participants. Particulars of the data collection process and analysis are documented subsequently. In addition, the methods described were used for both the pilot and main study as the pilot study data, and subsequent findings, were pooled with that of the main study. As can be seen in section 3.4.6.1.1, analysis of the first 10 participants' data was undertaken before proceeding with further interviews to determine whether saturation had been achieved.

3.4.1 Recruitment of Participants

Approximately 600 women aged 39 or younger are diagnosed with breast cancer each year throughout Australia (AIHW & AACR, 2003) therefore it was anticipated that recruitment could be difficult. It was decided that interviewing 25 women in the first instance, and then a sub-group of 10 twice more, would be appropriate for answering the research questions posed in the study, together with considering the resource constraints of a PhD study. As qualitative sampling aims to reflect diversity within a given group (Kuzel, 1992), 'capturing variation rather than filtering it out' (Safman & Sobal, 2004, p, 11), the study sought to ascertain multiple views of having breast cancer at a young age, rather than getting at the 'truth'. Recruitment was undertaken at places that YWBC were most likely to frequent (convenience sampling). Such sampling was the most appropriate method for participant selection due to time and resource constraints (Daly et al. 1997). The recruitment strategy was employed as follows.

In September 2001, recruitment flyers were distributed at a breast cancer seminar held at the Wesley Hospital, Brisbane (see recruitment flyer in Appendix 2.1), and at the Brisbane 'Field of Women', an occasion devoted to acknowledging women (and men) who have been diagnosed with breast cancer. Simultaneously, a media release about the study was distributed by QUT (Appendix 2.2), was placed on the QUT media web page, and was subsequently taken up by various suburban newspapers. The 'Women's Health Centre' and the 'BreastScreen Clinic' in Ipswich, also displayed the recruitment flyers. In addition, the Advanced Breast Cancer Support

Group held in Brisbane was contacted and given information concerning the study. The Breast Cancer Network of Australia (BCNA) (a consumer group of breast cancer survivors), published the media release within the 'Beacon', a newsletter of the BCNA, which is distributed throughout Australia. These strategies recruited more than sufficient numbers of participants for phase 1 of the study (participant details are documented in section 3.4.3 'Participants in the Study'). The recruitment for this study was completed in four months. Recruitment flyers informed potential participants they would receive twenty dollars for compensation of their time. All eligible women were accepted into the study. The inclusion and exclusion criteria were as follows:

- *Inclusion Criteria:* adult female diagnosed with breast cancer at 40 years of age or younger, and speaks English.
- *Exclusion Criteria:* diagnosed with breast cancer more than four years ago, suffering extreme distress, and/or in palliative care (not being treated curatively at onset of study), as it was considered unethical and inappropriate to expect such women to take part in this study.

3.4.1.1 *Rationale for the Age and Time Lag Since Diagnosis Cut Off*

On reviewing the literature, no uniform definition of 'young' was identified; therefore it was important to define 'young'. Breast screening within Australia is specifically aimed at women aged 50 to 69 years, hence women aged 40 or younger are not actively targeted (AIHW, 2000). This group of women too are more likely than older groups to have small children and/or desire to have (more) children. In addition, the cancer registry classifies breast cancer incidence and mortality data into five-year intervals. By defining younger by the category of 40 – 44 years (women entering middle age), findings may have been blurred. Rather the sub-group of 35 – 39 years (AIHW & AACR, 2000) was considered to be more appropriate, hence it was decided to define the age of young women at 40 years or younger (to round the figure up). The cut off of four years after diagnosis was used to reduce recall bias, while still ensuring a wide variety of the illness experiences, i.e., women at various stages from diagnosis and those with various stages of disease; early stage through to advanced.

3.4.2 Ethical Considerations

Ethical approval was given for this study by the Queensland University of Technology, University Human Research Ethics Committee (UHREC): Ref no 2390 H. Arrangements were made, prior to any data collection, that the QUT counselling services were available to the study participants, at no cost, at any time throughout the study process, should they deem it necessary. Prior to contacting the follow-up participants, an application for minor changes to the study was forwarded to the UHREC for further approval. This included an updated information package and consent form, which covered the follow-up portion of the study. Approval was given**.** Question guides were forwarded to the UHREC for their information prior to data collection of phases 2 and 3 of the study.

3.4.2.1 *Consent*

- Participants were either sent or given an information package and consent form (see Appendix 2.3 for the information package including the consent form used).
- Written informed consent was sought for the initial data collection session, and then again when the follow-up portion of the study began. After signed consent was given, permission was again sought verbally, together with verbal permission to tape record the interview.
- In the case of the participants interviewed via telephone, they were also sent a reply-paid envelope to send back their demographics questionnaire and signed consent form. All of these participants were informed that they would not be interviewed until the signed consent form was returned.
- Consent was constantly sought from participants throughout the interviews, particularly when intimate and potentially distressing topics were discussed.

Telephone interviews were conducted by placing a dictaphone next to a speakerphone telephone in a private location to ensure confidentiality.

3.4.3 Participants in the Study

In total 42 women volunteered to take part in the study, however only 36 women were eligible. Ineligibility was due to participants being either older than 40 years at initial diagnosis or more than four years had lapsed since their diagnosis. Considering the study was consumer-based, all eligible participants were included in the study. Once the participants made contact via a telephone call, email or return slip from a recruitment flyer, an appointment was made at a mutually convenient time. Over the duration of the study, 36 participants were interviewed, 12 of these three times and one participant twice between September 2001 and July 2003. Section 3.4.6.3 'Rationale to Choose the Follow-Up Participants' explains further the selection of follow-up participants. The demographic characteristics of the participants at baseline can be found in Chapter 4, Table 4.2, and for the follow-up participants in Chapter 5, Table 5.1.

Throughout the analysis and reporting procedures of this study, the notation given to the data excerpts coincide with the phase of the study the interview was conducted, such as Time 1 (Phase 1: Baseline), Time 2 (Phase 2: Follow-up Interview 1), and Time 3 (Phase 3: Follow-up Interview 2), while the participants are identified by a 'P' and then the participant code number, such as P38.

3.4.4 Data Collection Method: One-to-One Interviews

The mode of data collection was one-to-one, semi-structured interviews over the three data collection phases. In total 61 one-to-one interviews were conducted which include the 38 interviews which make up the follow-up portion of the study. The interviews were 30 minutes to three hours in duration, with the average time being one hour per interview and, where possible, participants were interviewed six months apart to capture changes in opinions and experiences over a short term. From phase 1 (baseline) to phase 2 (follow-up 1) five participants were interviewed 12 months apart and eight participants were interviewed six months apart. The time lapse between phase 2 and phase 3 (follow-up 2) interviews was six months for all participants. However due to the nature of the illness and life demands in general of YWBC, interviews could not always be conducted when first scheduled, hence the study design allowed flexibility in this regard (explained further in section 7.6).

3.4.4.1 *Justification for the Use of One-To-One Interviews*

Interviewing is simply 'a conversation with a purpose' with the aim of gathering information (Berg, 2001, p, 66). Use of the one-to-one interview was chosen as the interview provides a powerful way to acquire insight into issues via the gaining of understanding of the experiences of others (Seidman, 1991, p, 7). Understanding a person's experience is at the root of the one-to-one interview, which is achieved by listening to his/her story (Seidman, 1991). Information gathered via the one-to-one interview avenue of inquiry is one of the most common and powerful ways to understand individual experiences (Denzin & Lincoln, 1998). The act of interviewing a participant signifies to that person that his/her story is important (Seidman, 1991). The interview allows the researcher to clarify assumptions and to delve deeper into issues which appear important (Seidman, 1991). The act of the young women telling the researcher their stories, in itself, breathed meaning into their experiences, as order is brought to such meanings as they reflect on their memories (Seidman, 1991).

Not only can interviewing be conducted face-to-face, but also via a telephone conversation (Denzin & Lincoln, 1998). The use of telephone interviews allowed the researcher to access women in inaccessible (due to resource restraints) geographical locations. Berg (2001) states that the telephone interview does not allow body language cues, which assist the researcher to pace the interview, to be interpreted. Therefore verbal cues must be distinguished. Regardless of this problem, the telephone interview is an effective, and viable, mode of data collection (Creswell, 1998).

3.4.5 Setting

Recruitment strategies provided a geographically diverse participant pool. Face-to-face interviews were mostly conducted with participants who resided in the Brisbane-Ipswich area (16) although a North Queensland participant was also interviewed while she was in Brisbane for treatment (1). Other face-to-face interviews were also conducted at Toowoomba (1) and at the Gold Coast (1). One telephone interview was conducted with another participant who resided in North Queensland while the remaining telephone interviews were conducted with interstate participants, i.e., New South Wales (1), Victoria (6), Australia Capital Territory (2), South Australia (2), Western Australia (3) and Tasmania (1). In summary, 20 participants were interviewed face-to-face and 16 were interviewed by telephone for the baseline phase of the study.

3.4.5.1 *Justification for Interview Settings*

The setting for one-to-one interviews needs to be that which provides maximum privacy and is distraction free (Creswell, 1998), hence the interviews were conducted face-to-face in the participants' homes where possible, or else by telephone in the case of participants who lived outside of traveling proximity. This data collection method allowed the young women to control their level of distraction (such as use of childcare). As 'settings are intricately related to the data' collected (Berg, 1995, p, 226), participants' homes were chosen to help participants feel relaxed in a familiar environment. It was anticipated that this would improve the quality and depth of data gathered. The majority of participants chose to be interviewed in their homes, whether in person or via telephone, however one participant chose to be interviewed in her workplace (by telephone) as she felt it was more private than her home and another participant was interviewed in her friend's home as she was visiting to undergo treatment close by.

3.4.6 Phase 1: Baseline.

3.4.6.1 *The Pilot Study Process and Analysis*

Themes displayed in the original concept map (Figure 2.1), which were derived from an initial literature review conducted prior to data collection, informed the development of the pilot study question guide (see Appendix 2.4 for original question guide). Even though the age of the 'younger' categories of subjects differed in the majority of the literature reviewed (see Chapter 2 section 2.2 concerning definition of YWBC), the use of this concept map provided a basis for comparison with responses from the pilot study participants.

The first 10 eligible participants recruited were interviewed for the pilot study, nine face-to-face in participants' homes and one participant via a telephone conversation. The nine participants interviewed face-to-face resided in South East Queensland and the participant interviewed via the telephone lived interstate. Throughout the interviews, the researcher often paraphrased issues back to participants to allow the participants to clarify meanings to increase understanding.

3.4.6.1.1 *Analysis Procedures*

Analysis of the data was performed in accordance with basic analytical principles, of data reduction, data display and drawing conclusions (Miles & Huberman, 1994). Data reduction refers to the process of selecting, focusing, simplifying, abstracting and transforming the data that appears in written transcripts (Miles & Huberman, 1994, p, 10). All 10 interviews were audio-tape recorded and transcribed verbatim by the principal investigator (SC). The transcripts were thoroughly read and summaries were written of each participant's story. As suggested by Miles and Huberman (1994), the reduction began early in the study process with the initial literature review and the development of the original concept map (starting to formate categories) (Figure 2.1). Hence the data were divided into 20 sections (see Appendix 3.1 for pilot analysis categories/findings) relating to the questions asked which corresponded to the literature-derived themes**.** Summaries were developed of all sections of data and were compared and contrasted against the original concept map (Figure 2.1). This map was then refined to better reflect the participants' perspectives, utilizing a similar structure as the original concept map (Figure 3.2). A new concept map was then developed which reflects the issues most pertinent to the participant pool (Figure 3.3). The concept maps provide a conceptual framework of the themes, and their presumed relationships, which formed the basis for the issues studied (Miles & Huberman, 1994).

3.4.6.1.2 *Relationship to Main Study*

It was considered that the information of the 10 participants was not enough to formulate any concrete assumptions about this group of younger women. However, the conclusions of the pilot study provided the researcher with insight into the feasibility of the recruitment and data collection processes and an overview of the topics discussed. As no further modifications were necessary, the data from these women were pooled with those attained subsequently to provide a larger number of baseline interviews.

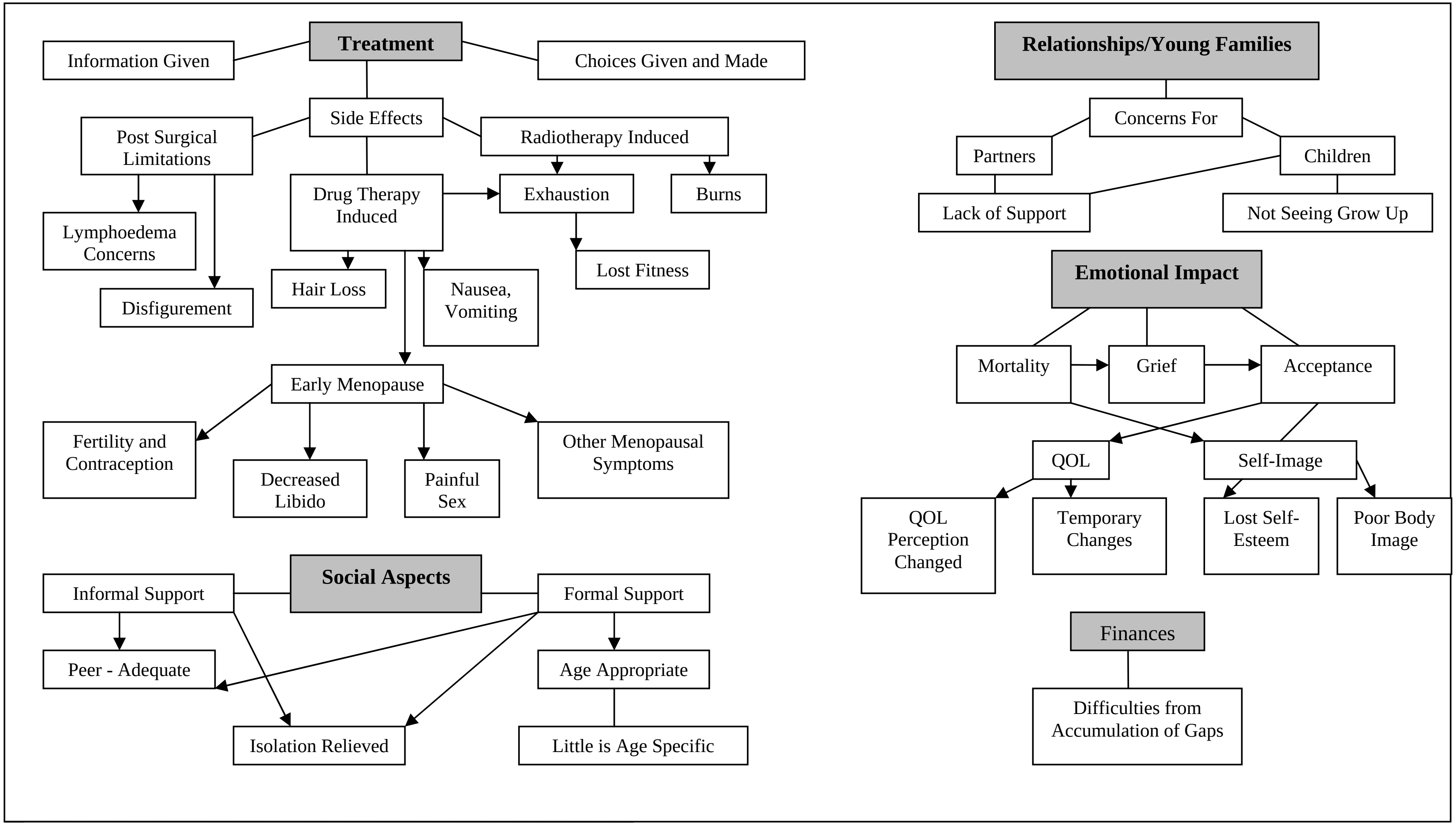


Figure 3.2: Refined concept map of issues of YWBC.

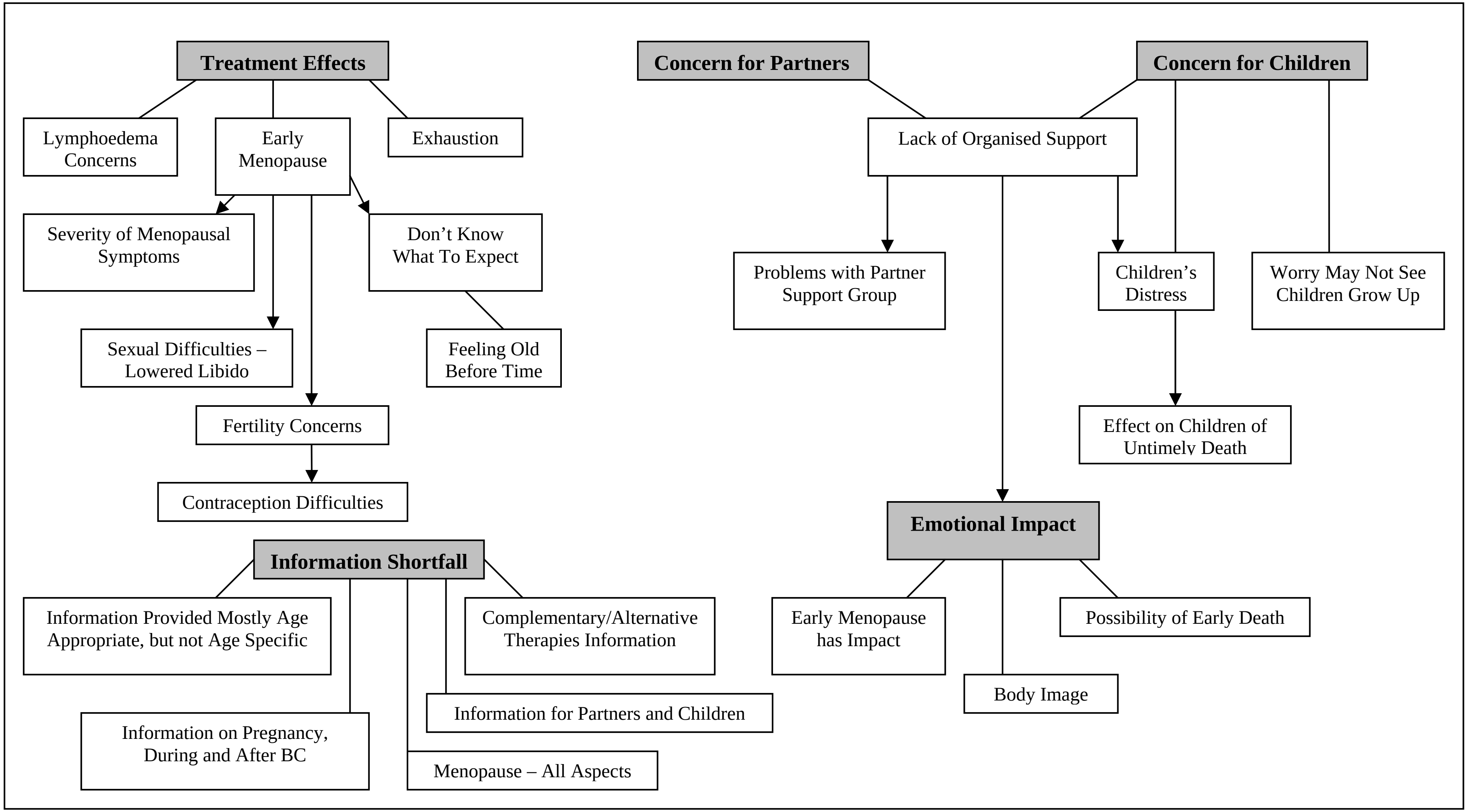


Figure 3.3: New concept map – most important concerns and problems faced by YWBC from pilot study.

Notes for Figures 3.2 and 3.3: Arrows indicate how one issue can lead to another. Straight lines reflect how issues are linked to the main theme presented (in shaded boxes), in effect subheadings of a main theme.

3.4.6.2 *Extension to Baseline Study Process and Analysis*

The remaining 26 participants who were eligible to participate in the study were then interviewed, 11 face-to-face and 15 via telephone conversations. At this point, saturation of data was achieved, as no new themes were forthcoming. Eleven of these participants resided in Queensland (nine in South East Queensland and two in North Queensland) and 15 resided interstate. Ethical and interview procedures were repeated as stated in section 3.4.2 and 3.4.6.1, respectively.

3.4.6.2.1 *Quality Assurance*

The remaining 26 audio-taped recorded interviews were transcribed verbatim, most by a professional independent transcriber. In the first instance the transcriber transcribed two tapes, one recorded face-to-face and one from a telephone interview, and returned them for verification of quality against the tapes. Though the transcriber did not enter as much detail as was expected, it was decided the transcription did not lose any context. Instructions were then given to the transcriber to include inclines and declines in voice, silences and periods of upset and the regaining of composure, to maintain emotional essence. One participant resided in the same suburb as the transcriber, hence on ethical grounds the transcriber did not transcribe the tapes of that participant, such transciption was performed by the principal investigator (SC).

3.4.6.2.2 *Analysis Procedures*

The data were separated into 44 sections that corresponded to the questions asked and were then coded and entered into an Excel document. Some responses were simply dichotomous answers (yes/no). However there was a group of questions to which the answers were more complex and such responses were categorised and coded. Simple counts of all answers were then recorded within these categories to direct the focus of the results to the most relevant and common concerns experienced by the participants. This step was taken to help condense the findings while maintaining the qualitative nature of the study (Mays & Pope, 1995). Some participants gave more than one answer per question, and some participants did not answer all questions. Despite this, all answers were considered valid and were hence included in the analysis.

The coded Excel results were assembled into various categories to provide a cohesive picture of the participants' issues and concerns. More tables were then formulated bringing together issues surrounding family and friends, emotional aspects of YWBC, and the negative physical consequences of treatment. See Chapter 4 to view Tables 4.3, 4.4 and 4.5, respectively.

To help provide a rationale to purposefully sample the follow-up participant pool, Excel data were analysed by age, time since diagnosis, number of children, and so on, in an attempt to identify any trends. This proved difficult due to the small number of participants and the large range of responses to individual questions. No obvious trends, such as more concerns for young women with small children, were found. Further data reduction lead to data display within more tables (Miles & Huberman, 1994). Tables were developed of issues which were either specific to YWBC (reproductive issues) or were likely to impact greatly on YWBC (such as reconstruction issues). See Appendix 3.2, Tables A3.1, A3.2 and A3.3 for fertility information and Tables A3.4 and A3.5 for reconstruction information. The various displays of the data allowed conclusions to be drawn. As this study was longitudinal, movement backwards and forwards between data reduction, data display and drawing conclusions was constant. These steps helped to move the study process forward, with one phase of the study informing the following phase/s. Further detail on how one phase informed the next is provided later in section 3.4.7.2.

3.4.6.3 *Rationale to Choose the Follow-Up Participants*

Following analysis of all 36 interviews, and in consultation with supervisors, a rationale was formulated to select which participants were to be followed over time. Three criteria were identified to select the follow-up participants, where were: something that had the potential to change (over the short term); something within the scope of the research that the principal researcher had the ability to do something about; while keeping in the forefront the 'younger' aspect of the study, which contributed to narrowing the focus. After deciding which topics covered in the interviews could coincide with such criteria, it was found that many of the participants' greatest unmet needs were related to a lack of support, be it physical or emotional. Therefore, the rationale formulated for the selection of the follow-up participants to be followed over two more interviews (approximately six months apart) was that their greatest unmet needs were related to support, an issue which had the potential to change over the short term, rather than a specific theme such as reproductive concerns. Hence, the follow-up participants (n=14) were selected, via purposeful sampling (Berg, 1995), from the baseline study. One of these participants was very ill at the time of the first interview, hence due to her advanced disease and observed diminished cognition level her data were removed from the study, on ethical grounds. No further contact was made with this participant (other than a summary of findings), therefore 13 participants were followed over time.

3.4.6.4 ***Development of Question Guide for Follow-up Interview 1*** *(Phase 2)*

Once the participants were chosen for the follow-up portion of the study their individual details were again studied to ascertain if any easily identifiable commonalities existed between them, such as age, number and ages of children, fertility status, and more. Deeper literature searching was then performed looking at issues which were neglected in earlier literature reviewing. The literature together with the findings of the baseline study guided the formulation of the interview guide for the Follow-up Interview 1 (phase 2).

The semi-structured interview guide formulated for the Follow-up Interview 1 was uniform as well as individualised. Specific issues and concerns of each participant were noted and revisited to identify any changes, and why. As a lack of support was noted as the entry criterion into this phase of the study, specific support needs of each participant were clarified and followed. A copy of the question guide for Follow-up Interview 1 (phase 2) can be found in Appendix 2.5.

3.4.7 Phase 2: Follow-up 1

3.4.7.1 ***Follow-up Interview 1: Process and Analysis***

Following approval by the University Human Research Ethics Committee, the follow-up participants were contacted by mail to inform them of their inclusion in the temporal portion of the study; all 13 participants agreed. Participants were not informed of the reason they were chosen to be followed over time, as it was felt this information could alter their responses and hence bias the study. All the remaining participants were contacted to inform them of not being included in the temporal portion of the study, and were reminded that at the end of the study they would be sent a summary of findings. All 36 participants were sent a brief summary of the first phase of the study.

Between October 2002 and January 2003, the 13 follow-up participants were interviewed, eight face-to-face in their homes and five via telephone conversations. Ethical and interview procedures were followed as stated previously (see sections 3.4.2 and 3.4.6.1, respectively). Prior to each follow-up interview, the participant's last transcript, and any other relevant documentation concerning the participant, was read no more than 12 hours before an interview to refresh the memory of the researcher. Some aspects of participants' data were checked to provide an element of reliability, such as demographic, illness and treatment details. Some preliminary conclusions drawn from the preceding interview were presented to participants for their verification and feedback.

3.4.7.1.1. *Analysis Procedures*

The analysis of the data from Follow-up Interview 1 (phase 2), built on the baseline findings. The possible avenues of further inquiry for the follow-up study were: fertility concerns; contraception; pregnancy and breastfeeding; prothesis issues and reconstructive surgery; support and services; and issues surrounding children and partners. Analysis was again performed in accordance with basic analytical principles as described earlier in this chapter (see section 3.4.6.1.1). The procedures followed are listed below.

- Transcripts were thoroughly read and a basic summary was constructed of the story of each participant, taking into account individual specific issues together with major themes of the question guide.
- Summaries of these notes were then entered into a table (see Appendix 3.3, Table A3.6) allowing columns for corresponding follow-up information and for any new issues which emerged that may require further investigation in the next phase of the study. Very little in-depth qualitative interpretation was done at this stage; answers were mostly taken on face value.

- The results recorded in this table were then examined to find what changes, if any, had occurred over time and the reasons for such changes were noted.
- The new issues which emerged from this phase of the study were examined and compared to existing issues (themes) found in the initial interview, then a list of all feasible and relevant issues which could be followed over time was made, keeping in mind the ‘younger’ aspect of the participant pool. See Appendix 3.4 for a list of issues to be pursued in Follow-up Interview 2 (phase 3).

3.4.7.2 *Development of Question Guide for Follow-up Interview 2 (Phase 3)*

Considering the variety of answers given, it was considered important to ask each participant, at the next interview, how she perceives her own breast/s, i.e., what does/do her breast/s (and breasts in general) symbolize to her before and after breast cancer. Answers to these questions may help clarify what meaning each participant actually gives/gave to her breast/s, to assist in the interpretation of how each participant experiences life after a breast cancer diagnosis and treatment. Worthwhile avenues of further inquiry were also raised by participants, such as the issue of generation differences, how YWBC perceive their experience to differ from that of their older counterparts. Much of the information collected (to this point) had implicitly explored this notion, however some direct questions, and hence explicit answers were considered beneficial to the next phase of data analysis.

The findings from this analysis informed and inspired the development of the interview guide for the next interview phase: Follow-up Interview 2 (phase 3). In addition, it was felt it was constructive to again ask participants what their major present concern was, how they were presently feeling about their breast cancer, together with issues of their reported greatest unmet need. A copy of the question guide for Follow-up Interview 2 (phase 3) can be found in Appendix 2.6.

3.4.8 Phase 3: Follow-up 2.

3.4.8.1 *Follow-up Interview 2: Process and Analysis*

Approximately six months after Follow-up Interview 1 (phase 2), each participant was contacted via telephone to make a date for Follow-up Interview 2 (phase 3). Six participants were interviewed face-to-face in their homes and six participants were interviewed via telephone conversations. One participant who had previously been interviewed in her home opted for a telephone interview due to convenience. These 12 participants were interviewed between April and July 2003. One participant chose not to continue with the study due to relocation. Ethical and interview procedures were followed as stated in sections 3.4.2; 3.4.6.1 and 3.4.7.1, respectively.

3.4.8.1.1 *Analysis Procedures*

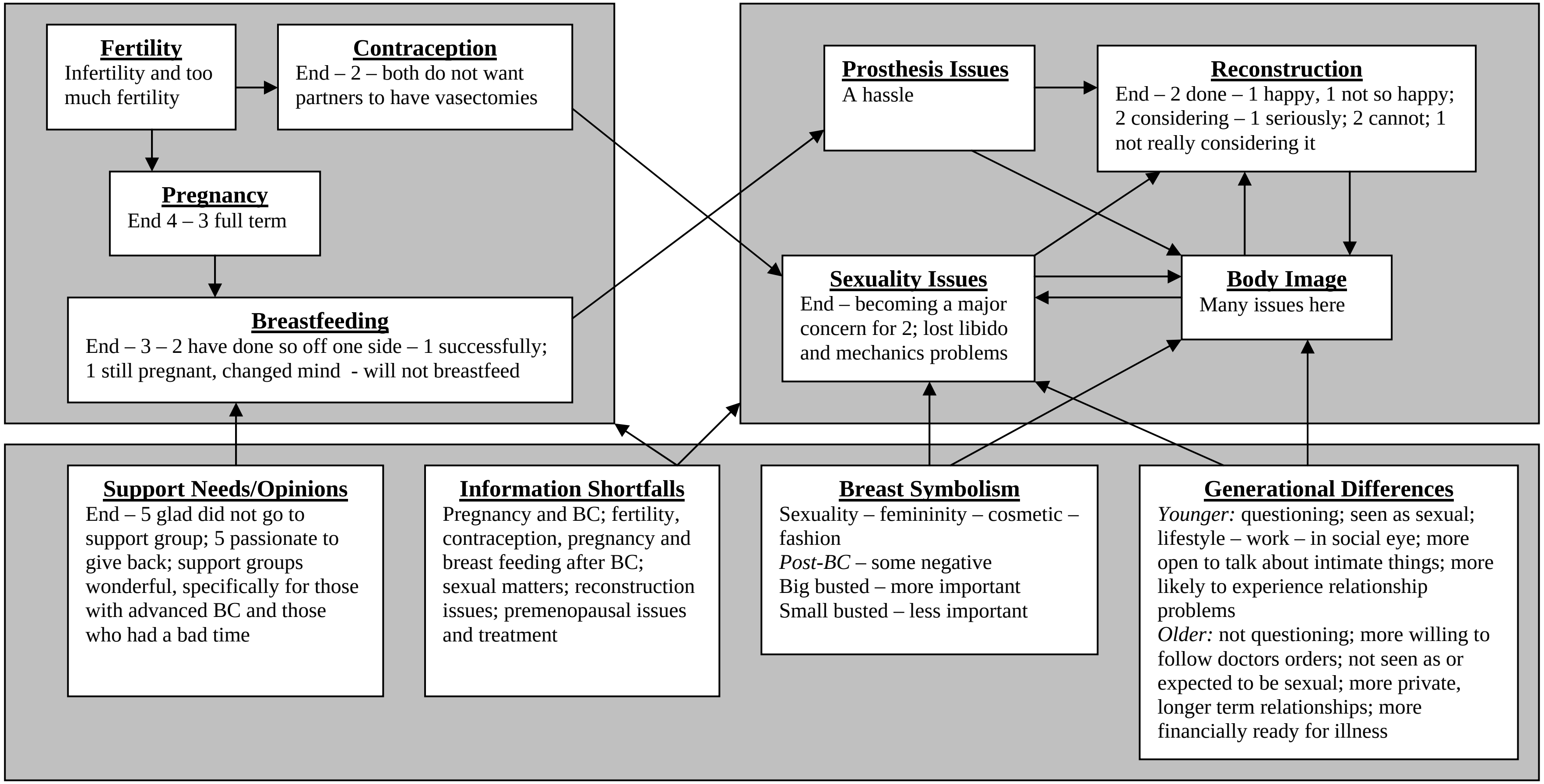
Transcription and analysis processes and principles utilized for phase 2 of the study were repeated (see earlier sections 3.4.6.1.1 and 3.4.6.2.1). Comparisons were made across all interview phases; changes were noted. Tables were updated (see Appendix 3.5, Table A3.7 for fertility information and Table A3.8 for reconstruction information).

3.4.9 Overall Analysis of Data

An overall preliminary analysis was undertaken across all data. An overall summary was then developed and presented to supervisors and other interested parties (view summary in Appendix 3.6). A concept map of these findings was also developed at this time (Figure 3.4). NUD*IST qualitative software package (N6 – version six) was then utilized to deepen the analysis. Web (1999) describes the use of the NUD*IST qualitative software as using a ‘top-down’ approach to data analysis, that is starting with broad themes and breaking the data down into finer concepts. The 38 transcripts of the follow-up participants (from the three time phases) were entered into N6.

3.4.9.1 *Further Breakdown of Data Using NUD*IST Qualitative Software*

The more in-depth analysis was initiated with data being sub-divided into five major first level categories: 1. *Consumer Issues*; *2. Family and Friends; 3. Consequences of Treatment*; *4. Personal Concerns*; and *5. Other*. Ample data were included in these first level codes to maintain the context and essence of the data (Miles & Huberman, 1994). The first category reflects the original focus of the study, the participants as consumers of health and care services. The following three categories reflect the major findings from the baseline study, as described in Chapter 4. The *‘Other’* category contains the responses to three major questions asked/followed at each interview phase, these questions were: what is your greatest unmet need; what is



Fertility
Infertility and too much fertility

Contraception
End – 2 – both do not want partners to have vasectomies

Pregnancy
End 4 – 3 full term

Breastfeeding
End – 3 – 2 have done so off one side – 1 successfully; 1 still pregnant, changed mind - will not breastfeed

Prosthesis Issues
A hassle

Reconstruction
End – 2 done – 1 happy, 1 not so happy; 2 considering – 1 seriously; 2 cannot; 1 not really considering it

Sexuality Issues
End – becoming a major concern for 2; lost libido and mechanics problems

Body Image
Many issues here

Support Needs/Opinions
End – 5 glad did not go to support group; 5 passionate to give back; support groups wonderful, specifically for those with advanced BC and those who had a bad time

Information Shortfalls
Pregnancy and BC; fertility, contraception, pregnancy and breast feeding after BC; sexual matters; reconstruction issues; premenopausal issues and treatment

Breast Symbolism
Sexuality – femininity – cosmetic – fashion
Post-BC – some negative
Big busted – more important
Small busted – less important

Generational Differences
Younger: questioning; seen as sexual; lifestyle – work – in social eye; more open to talk about intimate things; more likely to experience relationship problems
Older: not questioning; more willing to follow doctors orders; not seen as or expected to be sexual; more private, longer term relationships; more financially ready for illness

Figure 3.4: Preliminary findings across 3 interviews of follow-up participants.
Note: End – denotes: at last interview, numbers signify how many participants experienced the issue/event. Arrows show interaction of issues.

your major present concern; and how are you presently feeling about your breast cancer?

The next step transformed each of the main level categories (free nodes) into tree nodes. Data were then further subdivided into sub-categories (second level), sections (third level) and sub-sections (fourth and subsequent levels) to formulate a tree of connecting information. See Appendix 3.7, Figure A3.1 for visual representation of the NUD*IST ‘code’ tree developed. A diary of code definitions was developed and refined via independent code checks (see Appendix 3.8 for those codes utilized to develop Chapters 5 and 6).

Code Reliability

By checking codes with another researcher, definitions became sharper following discussions of initial difficulties. This aided definitional clarity and acted as a good reliability check (Miles & Huberman, p, 64). Reliability checks were performed on randomly selected portions of data within the major first level categories, sub-categories, sections and sub-sections by an independent researcher. Disagreements in coding, where the independent researcher placed data within a different code to that of the principal researcher, and sections of data which were questionable, where the independent researcher could not identify a clear code under which to place the data, were recorded, discussed and resolved. Inter-rater reliability scores, which should be around 80% for initial code-recode reliability (Miles & Huberman, 1994, p, 64), were then calculated using the formula below:

$$\text{Reliability} = \frac{\textit{total number of agreements}}{\textit{total number of agreements} + \textit{total number of disagreements}}$$

A summary of the disagreements and questionable areas identified following independent researcher coding checks are documented below.

<u>*First Coding Check:*</u> *Code-Check of Data Utilized for Chapter 4*

Eight disagreements were due to the principal researcher placing data into more overlapping codes (due to being more intimate with the data and the participants). A further four disagreements were due to confusion over similar definitions of codes and the remaining eight disagreements were incorrect coding, with three of these disagreements being considered minor errors, in that the data coded into these incorrect codes were irrelevant. All disagreements were further clarified with the independent researcher. The first level major code, 2. *Family and Friends,* was originally just ‘*Family*’. From this exercise, this code was renamed refining the definition to incorporate all levels of personal relationships. Another area of concern was that some definitions of codes were very similar hence further clarification was necessary. The inter-rater reliability score was 90%.

Second Coding Check: *Code-Check of Data Utilized for Chapter 5*

Ten of the 11 disagreements were a case of the principal researcher placing data into more overlapping codes (due to being more intimate with the data and the participants). The other one disagreement was incorrect coding. If the 10 disagreements were not counted (as it was not so much a case of missing codes but rather missing all overlap) the reliability would have been 98%.

Third Coding Check : *Code Checking of Codes Utilized for Chapter 6*

Fourteen of the 17 disagreements were a case of the principal researcher placing data into more overlapping codes (due to being more intimate with the data and the participants). The remaining three disagreements were coded incorrectly. From this exercise the definition for code *1.8.2 (Breast Symbolism) Personal* was specifically refined, together with refining the wording in most definitions to better reflect the data each code contains. If the 14 disagreements were not counted (as it was not so much a case of missing codes but rather missing all overlap) the reliability would have been 93% (see Appendix 3.9 for a breakdown of the reliability tests).

3.4.9.1.1 *In-depth Analysis of Coded Data*

Summaries were developed, of each participant’s three interviews, from the raw data within each sub-category, section and sub-section relating to the specific topic areas chosen. Another summary was then written of the above-mentioned summaries and was entered as node memos. This process deepened understanding of the experiences of participants. As these understandings developed, the literature was again consulted to help explain the findings. At this point, some summaries within memos were reanalysed and developed into more tables, which helped draw the analysis together, combining data across all participants and time phases (See Appendix 3.10, Table A3.9 for an example of such a table). Conclusions were then draw concerning each sub-category, section and sub-section. More tables were then developed (see Appendix 3.11, Tables A3.10, A3.11 and A3.12 for examples). The transcripts were a constant source of reference throughout these processes.

3.4.9.2 *Theoretical Aspects of Analysis*

Theoretical context was considered in relation to reproductive issues, that of political and social issues relating to breastfeeding. In addition, theories of social constructionism, social norms and stigma, and in particular, the social construction of the body, were utilized to provide deeper analysis and subsequent understanding of the data of specific sub-categories and sections, such as body image, breast symbolism and more (see Chapter 6).

3.4.9.3 *Verification of Findings*

Once the analysis had gone as far as possible, two summary documents were developed (*1*. reproductive issues; *2*. issues of the body and generational differences) and sent to selected participants (to assure a good mix of participants' viewpoints), requesting feedback (see Appendix 3.12 for validation documents and response tables; Tables A3.13 and A3.14). This feedback was then taken into consideration and hence worked back into the analysis and write-up.

3.4.10 Attention to Rigour

Miles and Huberman (1994) more clearly outline miscellaneous factors which need to be considered to ensure rigour. Rigour, in part, relates to what can be done to increase the confidence of the researcher and his/her readers, in what has been found (Miles & Huberman, 1994, p, 263). Not only was it necessary to provide the 'what' of the study, i.e., findings and description, but also the 'how' factors; encompassing how data was reduced, displayed and analysed, and how conclusions were ultimately derived (Miles & Huberman, 1994, p, 262). These elements have been comprehensively covered within the majority of the earlier sections of this chapter (see 3.2 through to 3.4.9.2). To avoid what Miles and Huberman (1994, p, 262) describe as a 'vertical monopoly of the research process', i.e., 'the qualitative researcher being a one-person machine via defining the problem, recruiting, designing instruments, collecting, reducing and interpreting the data, coupled with final write up', steps to ensure rigour were applied to this study.

3.4.10.1 *Trustworthiness*

To establish the trustworthiness of qualitative research, the following standards have been suggested (Guba & Lincoln, 1989; Miles & Huberman, 1994). See Table 3.1 below for corresponding terminology across paradigms.

Related To:	**Traditional 'Scientific Paradigm Criteria' Terminology**	**'Constructionist Paradigm Criteria' Qualitative Terminology**
	Objectivity	Confirmability
Consistency	Reliability	Dependability / Auditability
Truth Values	Internal Validity	Credibility / Authenticity
Applicability	External Validity	Transferability / Fittingness
	Utilization	Application / Action Orientation

Table 3.1: Pairing of traditional (Scientific Positivist Paradigm) to qualitative (Constructionist Paradigm) research rigour terminology (Adapted from Guba & Lincoln, 1989; Miles & Huberman, 1994).

In practical terms, aspects of the above standards to evaluate qualitative research will be highlighted throughout the remainder of this chapter.

3.4.10.1.1 *Confirmability*

Confirmability relates to the replicability of a study (Miles & Huberman, 1994). Sufficient information about the processes of this study has been documented to allow other researchers to replicate the study, leaving an audit trail. Researcher effects were documented via researcher reflexivity (see section 3.2, and later in this chapter 3.4.10.1.3.1, and later in the thesis in Chapter 7, section 7.6.1.1, for details). All raw data are available for secondary analysis by other researchers on request (see Appendix 2.7 for an example of raw data).

3.4.10.1.2 *Dependability/Auditability*

Guba and Lincoln (1985) suggest an audit trail provides information of decisions made, be they theoretical, methodological and/or analytical. Dependability /auditability was achieved via the use of clear research questions coupled with a study design that was congruent with such questions (longitudinal aspect to follow experiences and perceptions over time). Rationales and justifications have been provided for decisions made throughout the study. Data were often replicated in follow-up phases of the study providing some reliability of data generated. Quality checks of transcription of raw data, to ensure the transcriber's professional expertise, were performed (see section 3.4.6.2). An independent researcher checked codes and inter-rater reliability rates were within acceptable limits with the overall average of tests performed at 83% (see section 3.4.9.1 'Further Breakdown of Data Using NUD*IST Qualitative Software – Code Reliability' for more details). Experts in the field of breast cancer/public health research reviewed preliminary findings (Appendix 3.6), providing suggestions for further clarification.

3.4.10.1.3 *Credibility/Authenticity*

Patton (1999) claims there are three distinct but related inquiry elements in relation to credibility issues: *1.* credibility of the researcher, i.e., his/her training, experience, track record, status and presentation of self; *2.* philosophical belief in the value of qualitative inquiry, i.e., a fundamental appreciation of naturalistic inquiry, qualitative methods, inductive analysis, purposeful sampling and holistic thinking; and *3.* rigorous techniques and methods to gather high-quality data, careful analysis with attention to validity, reliability and triangulation (p, 1190). These elements are discussed further below.

3.4.10.1.3.1 *Credibility of Researcher and Philosophical Belief in the Value of Qualitative Inquiry*

It is suggested that credibility is enhanced when researchers describe and interpret their experiences as researchers together with participant feedback of findings (Guba & Lincoln, 1989; Patton, 1999). Participants were given the opportunity to comment on findings and to add any information/opinions they felt necessary (see Appendix 3.12 for validation documents). This validated, to a point, the conclusions drawn. Due to the nature of the illness and the design of the study (longitudinal) changes did occur in how the participant pool perceived their illness trajectories (see Appendix 3.12, Tables A3.13 and A3.14 for validation responses). Miles and Huberman (1994, p, 276) explains that participants can sometimes reject findings of studies as the information may conflict with their basic values, beliefs or self image, they may feel threatened (their self-image) by the information, or they may just construe the information differently.

The researcher is the instrument of qualitative inquiry, and as such, the credibility of the researcher impacts on the quality of the findings and conclusions drawn (Patton, 1999, p, 1198). The research experience of the principal researcher at the beginning of this study was modest. Formal academic training of the researcher was achieved by undertaking a postgraduate unit in qualitative methods (theoretically based) together with a Summer School unit concerning the practical aspects of qualitative research and attendance at weekly qualitative research workshops conducted by the Centre for Health Research, School of Public Health. In addition, experience with qualitative research was gained by conducting an Honours project and a consultancy. Preparation for this study was achieved by reviewing relevant literature. The researcher leans towards a constructionist view of meaning, viewing interpretations of experiences as constructed, thus incorporating this into public health research.

At phase 1 of the study, the researcher did not have any connection with the participant pool, however as the follow-up portions of the study progressed, a friendly connection was developed with follow-up participants, while keeping a professional distance. Funding for this study was achieved mostly via the QUT PhD allocation, with the remainder self-funded. The researcher, at the time of phase 1 of the study, had similar demographic characteristics to the participant pool (for further information see section 3.2).

3.4.10.1.3.2 *Rigorous Techniques and Methods*

Triangulation has been indicated as a tactic to test and confirm qualitative research findings (Miles & Huberman, 1994). The term ‘triangulation’ in qualitative research refers to ‘dealing with a phenomenon’ by the use of a combination of study methods, participants, settings and theoretical perspectives (Flick, 1998, p, 229). Denzin (1989) advocates the use of the technique ‘triangulation’ to help validate qualitative data. Within the broadest sense, as stated by Mason (1996, p, 148), triangulation refers to the ‘use of a combination of methods to explore one set of research questions’. Denzin (1989) differentiated four categories of triangulation: data source triangulation; investigator triangulation; theoretical triangulation; and methodological triangulation. Data source triangulation can include data collected from different persons, times and places (Miles & Huberman, 1994, p, 267; Patton, 1980, p, 467). Consistency of data collected can be verified by checking what people say about the same thing over time (Patton, 1999, p, 1195). The most suitable, and practical, forms of triangulation, considering the time and resource constraints of a PhD study, were utilized for this study. These were data source triangulation, as the data were collected from the same source at different points in time, investigator triangulation, as an independent researcher conducted reliability tests on coding definitions (as explained in section 3.4.9.1 paragraph 2 and Appendix 3.9), and theoretical triangulation via the use of sociological theories.

The cross-checking of data, by triangulation of data sources through interviewing participants at different times, according to Sapsford and Jupp (1996, p, 91), provide ‘a more direct’ check of the validity of the study. Within the parameters of qualitative research, validity has been summarized as ‘a question of whether the researcher sees what he or she thinks he or she sees’ (Kirk & Miller, 1986, p, 21). Mishler (1990, p, 417) defined validity as the ‘evaluation of trustworthiness’ of a study. Data source and investigator triangulation provide validation of conclusions made via the analysis process (Sapsford & Jupp, 1996). Data source triangulation not only confirmed prior data but also helped to explain many aspects of the data, such as how the women were feeling at the time of interviews, due to internally or externally based events, and how this impacted on their disclosures (for further explanation, see Chapter 7, section 7.6.1). Flick (1998) claims that study findings are enriched by such triangulation methods, and the understanding developed through the analysis can be deepened.

Preexisting bodies of theory, most commonly those derived from social science, once applied to the study findings/conclusions can provide theoretical validity (generalisability) and can often allow argument to be extended, hence providing added value (Barbour, 2000, p, 158). Theoretical validity was achieved with regards to the application of theories of social constructionism, social norms, stigma and the social construction of the body (see Chapter 6) (all of which have been explained in detail within section 3.1.1).

3.4.10.1.4 *Transferability/Fittingness*

Transferability/fittingness refers to findings being transferable to other contexts, and whether these can be generalized (Miles & Huberman, 1994, p, 279). Some findings could be transferred to that of other young women who suffer life-threatening illnesses and experience support and information deficits, disruption to family, treatment consequences, in particular fertility issues and contraception concerns, pregnancy and breastfeeding issues and disfigurement issues. However some findings of this study are specific to YWBC, such as those surrounding pregnancy and breastfeeding which would not necessarily be relevant to women who have pregnancies and then breastfeed after other life-threatening diseases. In addition, as breasts hold significant sexual importance within Western cultures (Schover, 1994), issues of body image of YWBC may also be specific to these women who suffer breast loss or disfigurement.

Characteristics of the participant pool, and the settings in which the study was undertaken, have been thoroughly described allowing comparisons with other groups of young women (see Chapter 4, Table 4.2 for demographic details of all participants, and for interview settings details see section 3.4.5). Limitations of the study have been considered in depth and documented (see Chapters 4, 5 and 6 for details, and for further discussion see Chapter 7, section 7.8), leaving little room for misunderstandings of the transferability/fittingness of the study findings to other groups of YWBC.

In addition to the use of sociological theories to provide theoretical validation (see section 3.4.10.1.3.2, paragraph 3), theoretical and conceptual rigour of this study has been achieved as the theoretical framework and concepts chosen were appropriate, making the research strategy consistent with the research aims (Rice & Ezzy, 1999, p, 35) (also see section 3.1.1).

3.4.10.1.5 *Application/Action Orientation*

The findings from this study can be utilized to achieve change, as it will inform the development of recommendations for improved service provision and educational materials for YWBC (see Chapter 7 Boxes 7.1, 7.2, 7.3, 7.4, 7.7 and 7.9). Ethical issues have also been considered and issues dealt with within this report (see earlier sections 3.4.2 and for 3.4.6.3).

3.4.11 Final Pleasantries

A summary of the overall findings of the study was developed and sent to all (known living) participants, as was indicated at the end of the initial interview phase. The summary letter can be found in Appendix 3.13.

CHAPTER 4

RESULTS 1:

Issues and Concerns of Young Australian Women with Breast Cancer.

This chapter reports on the first phase (baseline) of the three-phase longitudinal study, documenting findings from the data collected from the 35 participants via one-to-one, semi-structured interviews. This phase of the study explored the ongoing issues and concerns of the participants, extending available knowledge in this area to provide insights into the relative importance these women assign to various issues and concerns. Moreover, as other researchers often were more inclusive of who was considered young, and/or defined it on the basis of menopausal or childbearing status (Bloom & Kessler, 1994b; Ghizzani et al. 1995; Reichman & Green 1994; Schaefer et al. 1999; Schover, 1994), previous results reflect views of a wider age range up to 50 years of age (Bloom et al. 1998; Wang et al. 1999). In contrast, this study focused specifically on those aged 40 years or younger at diagnosis. This group of young women are not only more likely to have small children or desire (more) children, but are also not actively targeted for breast cancer screening, as breast screening within Australia is specifically aimed at women aged 50 to 69 years (AIHW, 2000). Moreover, this study reflects those common themes that appeared most salient to this group of young women with breast cancer, namely family and friends, emotional aspects and negative physical consequences of treatment. A full explanation of the methods employed to undertake this phase of the study can be viewed in Chapter 3, section 3.4.6.

FINDINGS

This chapter focuses on common issues raised by this group of young women with breast cancer. Recurrence and future uncertainty was the leading major concern of the participants. However family and friends (personal relationships), emotional aspects of having breast cancer at a young age, and the consequences of various breast cancer treatments were additional repeated concerns.

Demographics and Treatment

The median age of the 35 participants was 36 years (range 23-43 years) and the median age at diagnosis was 35 years (range 20-40 years). The median time since diagnosis was 21 months (range 4-39 months). Participants reported having various stages of the disease, from stages I to IV, although 17 participants were unsure of the status of their disease. These details were not essential for the purpose of this study, as a broad range of experiences was sought rather than consensus. Checking such details against medical records fell outside the scope of the study. Table 4.1 displays the range of treatments undertaken by the participants. Thirty-one of the participants lived with a partner. Ten participants were either pregnant, breastfeeding or trying to begin a family at the time of their diagnosis.   Other relevant demographic details are summarised in Table 4.2.

Surgery	**Total Number Treated**	**Number as Sole Surgery**	**Adjuvant Therapy**	**Total Number Treated**	**Number as Sole Adjuvant Therapy**
Lumpectomy	25	16	Chemotherapy	30	5
Mastectomy	18	7 [a]	Radiotherapy	25	2
Oophorectomy	2		Tamoxifen	11	1
Reconstruction	2		Stem Cell	3	
Other Surgeries	2		CAM [b]	18	

Table 4.1: Range of surgery and treatments undertaken by the participant pool at baseline.

[a] Includes one double mastectomy

[b] CAM – Complementary and Alternative Medicines

Location	n [a]	Time Since Diagnosis (Months)	n[a]	Education Level	n [a]	Occupation	n [a]	Number of Children	n [a]	Ages of Children (Years)	n [b]
SE Qld	18	<7	4	Up to Year 10	1	Home Duties	4	0	8	0-5	15
Nth Qld	2	7-12	5	Up to Year 12	9	Shop Assistant	2	1	11	6-12	14
NSW	1	13-18	7	College/ University	18	Physical Job	3	2	11	13-17	6
Vic	6	19-24	8	Post Graduate	6	Trade	3	3	4	18+	4
ACT	2	25-30	4	No Answer	1	Administration	3	5	1		
WA	3	31-36	3			Business Owner/ Manager	6				
SA	2	>36	4			Professional	11				
Tas	1					Other	3				

Table 4.2: Demographic details of participants (n=35) at baseline.

[a] Number of participants in corresponding left column

[b] Number of participants who have children in corresponding age group; sums to >27 because of multiple children in families of women

Family and Friends (Personal Relationships)

Issues surrounding children, partners and relationships were found to be a concern for many participants, in particular, concerns for their children and partners' future welfare in the case of their early death, as well as the strain placed on relationships (Table 4.3).

	Major Personal Concerns	**Helped Adjustment to Diagnosis**	**Greatest General Concern for YWBC**[a]
Children/Partners	XX	XX[b]	XXXX[c]
Family/Friends		XXXXXX	XX[d]

Table 4.3*:* Issues surrounding the family and friends (personal relationships) of YWBC.

Note. Participants could (and often did) give more than one response to particular questions.

XX - Raised by some participants

XXXX - Raised by many participants

XXXXXX - Raised by most participants

[a] The question leading to these data sought an opinion rather than actual experiences.

[b] Partners only

[c] Children only

[d] Family only

<u>*Children*</u>

Some participants who did not have (or desire) children stated that children would be the greatest concern generally for young women with breast cancer (an opinion rather than experience), hence children were a perceived general concern to more participants than who reported children as their major personal concern (experience rather than an opinion) (Table 4.3, columns 3 and 1 respectively). Children-centred concerns not only were related to the participants' sense of loss, but also to how the children themselves were going to cope with the possible death of their mother. (All quotes displayed within this chapter were derived from baseline [Phase 1] study data, hence Time 1). (Participant code and age at diagnosis in parentheses.)

> *(P4, age 34):…my survival's not as long as I'd like it to be, the biggest concern is what impact that would have on them (children), in fact I think it would be just dreadful…*

Many issues arose concerning children, with most hinging on the fear of not seeing children grow up, the illness forcing their children to grow up more quickly, and concern over the effect of a mother’s early death on their children’s development. Most concerns were for very young children and how partners were going to cope raising a young child without a mother.

> *(P3, age 34):...like if he [partner] hadn’t married me he could have had more children. Now he’s got to worry whether I’m going to live or, you know, and if I die then he’s got to look after x [son – 4 years of age] all by himself.*

The concerns for older children (those 6-17 years) related mostly to how these children were being forced to grow up more quickly, and being compelled to take on more responsibilities in the home, though not necessarily a negative consequence.

> *(P8, age 39):…the kids [12 and 14 years of age] have had to grow up a lot quicker than they should have, but at the same time they are developing responsibilities and they help me…*

In addition, older children had a more developed perception of what the cancer means.

> *(P34, age 37):…the older one [daughter – 13 years old] got really stressed to the point where she was quite ill…*

Partners

The major factors concerning partners were found to be how health professionals view the role of partners in the illness trajectory and that of role changes and social expectations of coping behaviours of the partner. Some participants stated that their partners were a major ongoing concern for them while other participants stated they had been of concern but the passage of time (incorporating grieving and acceptance) had worked out some of their issues.

> *(P6, age 40): You know what they need, help for husbands really, because they have less idea than we do about what's going on and they don't know what to do, they need help. I mean we're busy being caught up in the roller coaster and you just sort of tend to go with it because you've got no choice whereas these poor buggers are left standing going mad.*

Some participants stated that partners were not valued by health professionals as being important to the recovery phase, while other partners were left in the dark relying on the participants to relay information to them. Many participants stated that society assumed partners were able to take on the extra responsibilities when a young woman is diagnosed with breast cancer, i.e., child care and looking after the affairs of the house, as well as undertaking their usual work to pay for the medical bills.

> *(P23, age 32):...it's very hard because you see all these people who are older and they get meals on wheels...I'm not begrudging these people, but as soon as you say, yes I've got a husband, you can't get anybody to help you, but your husband has to keep going out so he can pay for all your bills so you can afford to stay in the damn hospital...*

With regards to support for partners of young women with breast cancer, participants overwhelmingly felt their partners would not seek, or accept, much in the way of support (often referred to as the 'male thing').

Family and Friends in General

Most participants stated that family and friends had assisted them to adjust to their diagnosis in some way, such as by supplying emotional support (Table 4.3, column 2).

Emotional Aspects

Recurrence was recorded as the major personal concern of most participants, while emotional support was reported as the greatest unmet need of many participants. However, many participants also stated that they had experienced positive, as well as negative, emotions since their diagnosis (Table 4.4).

	Major Personal Concerns	**Changes Since Diagnosis**	**Helped Adjustment to Diagnosis**	**Hindered Adjustment to Diagnosis**	**Greatest Unmet Need to Date**	**Greatest General Concern for YWBC**[a]
Uncertain Future / Recurrence	XXXXXX					XXXX
Personal and Emotional Issues	XX	XXXX[b] XX[c]	XX	XX		XX
Emotional Support					XXXX	

Table 4.4 : Emotional aspects of YWBC.

Note. Responses are not restricted to one answer per participant.

XX - Raised by some participants

XXXX - Raised by many participants

XXXXXX - Raised by most participants

[a] The question leading to these data sought an opinion rather than actual experiences.

[b] Positive emotional experiences

[c] Negative emotional experiences

Recurrence

The fear of recurrence and future uncertainty was clearly the greatest major personal concern of most participants (Table 4.4, column 1), particularly those diagnosed up to 12 months, and between 24 to 36 months prior to the interview**.** In addition, almost double the number of participants whose primary surgery was lumpectomy, as compared to those who had mastectomy, reported recurrence fears as their major personal concern. Other than the grief of being diagnosed, and living with a potentially life-threatening illness, negative emotional experiences extenuating from the experience of breast cancer were not generally reported.

Personal Emotional Issues

Approximately half of those participants who were diagnosed up to 24 months previously and the majority of those interviewed when they were between 25 to 39 months since diagnosis, stated, perhaps surprisingly, how being diagnosed at such a young age had improved their sense of self and had helped them to refocus their lives, enabling them to say ‘no’ and filter out negative influences.

> *(P40, age 40): I’m happier, I’m healthier, I’m more positive about life, I’m much more a giving person, I’m more knowledgeable, I’ve read so much and I’ve read all manner of things about relationships, men and women, cancer and how people come with grief...yeah everything is really very good...*

Emotional Support

Emotional (and physical) support was reported by many participants to be their greatest unmet need to date and those diagnosed 25 to 36 months prior to the interview reported support as their only greatest unmet need. In addition many participants stated that support they had received had not been appropriate to their age.

> *(P30, age 34):...the support groups I’ve been to locally, 95% of the women are over 60 and even some of them, most of them are over 70 and they simply can’t relate to the younger women and to the problems that they’re having, and I can’t talk to any of them about the gynaecological problems I’ve had or fertility issues or the sex issues because they’re not an issue for them...*

Half of the participant pool felt there was a shortage of support services for young women with breast cancer. Many participants reported the need for peer support, i.e., to be linked with other young women with breast cancer to share and compare experiences. It was suggested by some participants that physical supports be put in place to assist young women with the practical and/or emotional tasks of being a mother, such as affordable childcare and home help.

Negative Physical Consequences of Treatments

The surgeries and adjuvant therapies undertaken (see Table 4.1) produced a variety of negative physical consequences generating common concerns related to early menopause, fertility, pregnancy, sexuality and body image issues, whether the participants had personally experienced such problems or not (Table 4.5). Although early menopause, fertility, sexuality and body image concerns were collectively quite strong amongst the participants, the general opinion was that sexuality and body image issues were not the most salient problems that could eventuate from a breast cancer diagnosis, stating issues of recurrence, children and partners to be of greater concern (Comparison of column 1 in Table 4.5 to column 1 in Table 4.4).

	Major Personal Concerns	**Hindered Adjustment to Diagnosis**	**Worst Side Effect**	**Greatest General Concern for YWBC**[a]
Early Menopause	XX		XX	XX
Fertility/ Pregnancy Issues	XX		XX[b]	XX
Sexuality/ Body Image Issues	XX	XX[c]	XX[c]	XXXX

Table 4.5: Negative physical consequences of treatments among YWBC.

Note. Responses are not restricted to one answer per participant.

XX - Raised by some participants

XXXX - Raised by many participants

[a] The question leading to these data sought an opinion rather than actual experiences.

[b] Fertility issues only

[c] Body image issues only

Early Menopause

Early menopause was considered a major personal concern and was among the worst side effects reported. Some issues surrounding early menopause were interwoven with fears of permanent infertility, while others related to sexuality issues and feeling old before their time and being unprepared for the symptoms they experienced.

> *(P27, age 37):...I thought oh yes with menopause I don’t get a period, that’s it. But I didn’t think that my bones would be this sore. I didn’t think that I would sleep as bad as I do. I didn’t think that I would get as tired as I do...*

Fertility Concerns

The importance of fertility and pregnancy issues among young women with breast cancer were highlighted again, as personal and *general* concerns related to treatment side effects. Ten participants, who were diagnosed between 13 and 36 months prior to the interview, had ongoing fertility concerns. Many participants were offered assisted reproductive services before their treatments began, although only three participants reported utilizing such services.

> *(P31, age 35):...I was offered IVF before I went in and that was one of the most painful decisions that I've ever had to make with my partner and we decided that in order to go through that treatment I would have to be shot full of hormones, oestrogen in particular, which may complicate the cancer even more...so we chose not to.*

Some participants had resigned themselves to the fact that future pregnancies were out of the question due to physical impossibilities, being too old to become pregnant and/or the age gap between children being too long (after being on Tamoxifen for five years), and they did not want to pass on a breast cancer gene.

Contraception: Fertility was not only a concern among those wanting more children, but also for those who did not, or at least not in the near future. Some participants reported concerns about suitable contraception following breast cancer, with hormonal methods being undesirable.

> *(P1, age 32):…you can't take the pill anymore, what else do you do I mean they suggested to me that I could probably take the progesterone only pill…how successful have people been with that…I just don't want to take any kind of hormones …I think it's too much of a risk…*

Body Image/Sexuality

Body image concerns, which were woven into issues of sexuality and femininity, were reported equally by those who had lumpectomy or mastectomy as a general concern of all young women with breast cancer (an opinion rather than experience). Those who had mastectomies appeared to suffer greater body image distress than those who had lumpectomies. Below are quotes from participants who had mastectomy.

> *(P15, age 33): I was proud of two things as a young woman, and that was my hair, I had waist length hair, and my cleavage – I lost both – and your self image... I mean I feel like a freak, an absolute freak...*

> *(P18, age 33): ...I must admit I don't like my husband to touch me on that side of my chest, not that I feel that he will think it's yucky or anything like that, but more a case of I don't want to be that person for him…*

It must be noted that body image issues found within the participant pool did not only emerge from breast loss and/or disfigurement, but also from treatment-related weight loss/gain, hair loss and other physical consequences of breast cancer treatments.

Breast Reconstruction: Half of the participants who had mastectomies had either undergone reconstructive surgery, had started or were about to start the process, or were at least thinking about it. The relationship between reconstructive surgery and body image appears to be both physically and emotionally charged.

> *(P 27, age 37): I think the main reason why I wanted to go through it [reconstruction] was that if I could mask the surgery, then it would be another signal that it was over and it was all finished.*

However, for another participant, who had a reconstruction, closure did not occur:

> *(P19, age 37): I think that's probably the hardest thing to adjust to, for me, the reconstruction doesn't give you a breast back...*

DISCUSSION

The findings of this study confirm those of others with regards to the major concerns of young women with breast cancer, such as recurrence and related uncertainty of the future (Ghizzani et al. 1995; Siegel et al. 1999), concerns for children (BCNA, 2001;

Northouse, 1994; Siegel et al. 1999), partners and relationships (Ghizzani et al. 1995; Pistrang & Barker, 1995; Spencer et al. 1999). As Davis-Ali et al. (1993) found, family and friends remain important to young women with breast cancer long after the initial diagnosis.

Common negative physical consequences of treatment were related to the female reproductive system (i.e., early menopause and possible infertility) and body image issues (i.e., disfigurement). In addition, body image issues overlapped with sexuality concerns (emotional and physical) and had the potential to add to partner concerns. The fertility concerns expressed not only relate to the participants' desire/ability to have children after the breast cancer, but also to concerns of contraception options, and the safety of conceiving after a breast cancer diagnosis and treatment, i.e., concerns regarding hormone-related recurrences. Contrary to the literature-derived concept map (see Chapter 2, Figure 2.1), breast reconstruction arose as a prominent issue. Harcourt and Rumsey (2001) state that the psychological implications of breast reconstruction are not clear nor researched comprehensively.

The literature-derived concept map (see Chapter 2, Figure 2.1), which guided the data collection, was found to not wholly represent the issues and concerns of this younger participant pool. Issues concerning family and friends were mostly around children and partners. Zahlis (2001) found that children, too, had many concerns and worried about their mother's illness, supporting, in part, how the participants' felt, such as death-related concerns. I did not interview the participants' children but this represents a useful direction for future studies of young women with breast cancer. As described in the literature (Hilton et al. 2000; Siegel et al. 1999), disruptions to the family life cycle (naturally occurring growth of a family) were also reported.

Similar to that found by others (Lewis et al. 1989; Wilson & Morse, 1995), partner concerns were aired, such as how society expects partners to take on, and cope with, more home responsibilities when a diagnosis of breast cancer is made. Socialization and the male gender role have been found to influence partners' coping and adjustment to the breast cancer diagnosis (Sabo, Brown & Smith, 1986). Some participants' felt that the role partners play in the illness trajectories was not taken seriously by health professionals, a concern not found in the literature, although Davis-Ali et al. (1993) and Northouse (1994) also suggest that health professionals should focus more broadly on the couple especially when these relationships are often of shorter duration, which is the likely situation of young women with breast cancer compared to their older counterparts. Hilton et al. (2000) and Rees and Bath (2000) similarly found that partners often rely on the breast cancer sufferer to relay information to them.

Many participants acknowledged that partner-focused support may prove difficult in light of the social stigma associated with men not coping with life’s circumstances, and the expected behaviours of men. As young women with breast cancer are a relatively small group for whom age-appropriate support is limited (BCNA, 2001), partners of these women are even more likely to find suitable support lacking. The answer to this problem is not immediately apparent; however, due to these difficulties, consideration should be given to investigating how other forms of support for young men could provide the assistance needed by those partners willing to accept it.

Similar to that found by Hartl et al. (2003), mostly women who had lumpectomy rather than mastectomy reported recurrence fears, although why most participants who reported recurrence fears were diagnosed between 12 to 23 months prior to interview is unclear. Unlike reported deepened distress levels of young women with breast cancer in the literature (Beckmann et al. 1983; Bloom et al. 1998; Ghizzani et al. 1995; Golden, 1983; Mor et al. 1994b; Schover, 1994; Wang et al. 1999), this study found that most participants’ experienced positive emotions once they had adjusted to the diagnosis. Ganz et al. (1996) also found evidence of positive emotions among women with breast cancer. Even so, these findings may be explained by the self-selected nature of the participant pool, such as their high education level, although Inoue, Saeki, Mantani, Okamura & Yamawaki (2003) found that young women with breast cancer who were highly educated and had young children displayed negative emotional outcomes. It is also possible that only those young women with breast cancer who felt positive volunteered, as Rice & Ezzy (1999) claim that participants who volunteer for a study typically present bias. Some participants dealt with their loss well, while others struggled with a sense of lost femininity and sexual attractiveness, a notion expressed within the literature (Beckmann et al. 1983b; Bloom et al. 1998; Golden, 1983; Schover, 1994).

Support was the greatest unmet need of many participants, and was the only unmet need of those diagnosed between 25 and 36 months prior to the interviews. Half of the participant pool felt there was a shortage of support services for young women with breast cancer, a notion also supported by the BCNA (2001). It was not clear whether the discontent with support services was due to a serious lack of services that met the needs of young women with breast cancer, the failure to inform participants of what was available to them, or higher or different expectations of support services from that of older women. Of the support that was sought and received, many participants stated that it was not appropriate for their age group and did not meet their needs.   Suggestions to provide enhanced support services to young women with breast cancer can be found in Chapter 7, Boxes 7.1, 7.2 and 7.3.

Participants' reported issues and concerns relating to early menopause are mostly consistent with the literature (Bloom & Kessler, 1994b; Dunn & Steginga, 2000; Ganz, 2001; Schover, 1994; Siegel et al. 1999; Singer & Hunter, 1999; Spencer et al. 1999). There appears to be a need for relevant information for this group of women concerning the physical and emotional consequences of early menopause, an issue also identified by Thewes et al. (2003). Health professionals, too, need to be aware of these issues and endeavour to inform these women of the physical symptoms and emotional turmoil they are likely to encounter.

The literature strongly implies that infertility is a major concern for young women with cancer (Bloom & Kessler, 1994b; Dunn & Steginga, 2000; Reichman & Green, 1994; Schaefer et al. 1999; Schover, 1994; Siegel et al. 1999; Singer & Hunter, 1999; Spencer et al. 1999), however such results are not altogether replicated in the findings of this study. In addition, only those diagnosed between 13 and 36 months prior to interviews reported such a concern. It is possible that these participants, at the time of interview, were in the adaptation stage of their illness trajectory, a notion suggested by Northouse (1984), and hence were concerned with future planning. Information concerning reproductive issues, i.e., fertility, IVF, contraception, pregnancy during and after breast cancer, and breastfeeding after breast cancer, appears to be scarce. More research is needed in this area. Chapter 5 explores the reproductive issues of the follow-up participants over time.

Body image, though a possible concern for any woman with breast cancer, could theoretically be a more salient issue for young women due to high youthful aesthetic expectations (Schover, 1994). Body image concerns were found to be woven into issues of sexuality and femininity, as suggested by Beckmann et al. (1983b). Similar to the literature, this study found those who had lumpectomy reported less impairment of their body image (Avis et al. 2004; Hartl et al. 2003; Mock, 1993). However, little evidence is available concerning the specific body image concerns of young women with breast cancer (those diagnosed at 40 years or younger), nor how social and cultural influences impact on such experiences. The literature demonstrates that younger women undergo reconstruction more than older women (Desch et al. 1999; Hall & Holman, 2003; Morrow et al. 2001; Polednak, 2001; Reaby, 1998; Rowland et al. 2000; Schover et al. 1995). Presumably, reconstruction surgery could help young women with breast cancer regain a positive body image removing, to a point, as also found by Nissen et al. (2002), the constant reminder of the breast cancer – creating some closure, as stated by some participants. The literature is divided as to why some women choose to have a reconstruction (Harcourt & Rumsey, 2001), although the return of normalcy has been suggested (Baldry & Walsh, 1999; Neill et al. 1998). These body image issues could also amplify partner concerns. Social and cultural influences, which impact on the experiences of young women with breast cancer, are pursued in Chapter 6.

The major limitation of the study lies with the selected nature of the participant pool. Another limiting factor is recall bias, as reliance on memories of past events was central to many issues explored. Nevertheless, the study also has several strengths. By restricting recruitment to women diagnosed with breast cancer before age 41, it highlights the relative importance of various issues for this particular subgroup, which differs in some cases from older women. Findings from this study may be transferable to young women with breast cancer from other Western countries with similar cultures to that of Australia.

The flexibility of qualitative methodology enabled the interviewer (SC) to check assumptions and clarify meanings of what the participants were conveying at the time of the interviews, reducing greatly any researcher-constructed assumptions/perceived meanings being bestowed on the study results. The reporting along common themes provided some indication of the potential importance of the issues.

In summary, the participant pool of younger women brought to the study a broad range of experiences of breast cancer and the heterogeneity within the group provided the study with richness of scope. Complex interrelationships among the three focal points were apparent, i.e., family and friends, emotional aspects and negative physical consequences of treatment. Issues surrounding sexuality were not only perceived to be a negative physical side-effect of breast cancer treatment, but also related to relationship/partner problems together with body image and femininity issues. Children, partners and relationships were major concerns reported by participants, a close second to the fear of recurrence and possible death. Many partner-related issues were reported. One concern not reported in the literature was how some participants felt that health professionals do not take the role played by partners in the recovery of the participants seriously. The next two phases of this longitudinal study will help illuminate changes in these women’s experiences over time, to pinpoint those issues that are most worthy of ongoing attention, and to identify those that tend to be resolved with time.

CONCLUSION

This chapter explores issues and concerns expressed by women diagnosed with breast cancer at 40 years of age or younger. Themes found within the literature about ‘younger’ women up to 50 years of age provided guidance for the one-to-one, semi-structured interviews conducted with 35 participants. The data were categorised according to the literature-derived themes. Content analysis was performed on the data revealing the most pressing concerns of participants, such as issues relating to children and partners, emotional aspects and negative physical consequences of treatment. Interrelationships between these themes were apparent. Concerns related to early menopause, infertility, fertility, contraception and pregnancy after breast cancer also emerged. Meeting the emotional support needs of this group of women remains a challenge.

CHAPTER 5

RESULTS 2:

A Qualitative Analysis of Reproductive Issues Raised by Young Australian Women with Breast Cancer.

Fertility issues, specifically concerns of infertility, have been documented within the literature as a potential major concern of YWBC (Bloom & Kessler, 1994b; Dunn & Steginga, 2000; Schaefer et al. 1999; Siegel et al. 1999; Singer & Hunger, 1999). Hence, fertility-related concerns and/or events of the 13 follow-up participants were recorded over the course of this three-phase longitudinal study. During this study some participants became pregnant. Due to confidentiality concerns, considering the low incidence of pregnancy after breast cancer and that only four participants were either pregnant at the onset of this study or became pregnant during this study, no further identification of individuals is documented within this chapter beyond age at diagnosis. Throughout the study, the status of pregnancies ranged from miscarriage to still being pregnant at interview through to already given birth. Issues of pregnancy after breast cancer coincide with issues of breastfeeding after breast cancer. This portion of the study followed these participants' breastfeeding thoughts, opinions, decisions and experiences. This chapter reports longitudinally on the participants' perceptions of their experiences of infertility as well as issues related to maintained or regained fertility after a breast cancer diagnosis and treatment, i.e., contraception, pregnancy and breastfeeding after breast cancer. The methods utilized to undertake this study, including the analysis procedures, are documented in Chapter 3.

FINDINGS

Reproduction as a survival issue of young women with breast cancer not only hinges on potential infertility caused by treatment but also on uncertainty of fertility status; suitable, safe and reliable contraception; pregnancy and subsequent breastfeeding. Demographic characteristics of the follow-up participants can be found in Table 5.1**.**

Age at Diagnosis (Years)	n[a]	Time Lag Since Diagnosis (Months)	n[a]	Education Level	n[a]	Main Surgery	n[a]	Number of Children	n[a]	Ages of Children (Years)	n[c]
29-32	3	5-12	4	< Year 12	1	Lumpectomy	6	0	5	0-5	4
33-36	3	13-24	2	Year 12	2	Mastectomy	7	1	3	6-12	3
37-40	7	25-36	6	Tertiary	9			2	5	13-17	5
		> 36	1	No Answer	1					18 +	1

Table 5.1: Demographic details of follow-up participants.

[a] Number of participants in corresponding left column

[b] Number of children at first interview

[c] Number of participants who have children in corresponding left column

Fertility

Over time not only did changes occur in fertility status of various participants but also in their perceptions of infertility as an issue. For some participants, infertility concerns remained constant, while other participants, who had in earlier interviews stated infertility was not an issue for them, had a change in perspective by the last interview. Such changes were centred around regret that fertility-preserving choices in early diagnosis had not been utilized. The quote below depicts a participant's deepened level of regret by the last interview. (Time 1, 2 or 3 depicts the study phase from which the data were collected. Participant code and age at diagnosis in parentheses).

> *Time 3 (P15, age 33):…you don't think that further out…that's my biggest regret because I could've had eggs frozen…it's as time goes by and as life becomes a little bit more back to normal, as it can be, and you see the holes, big holes that are left…*

Other participants, who thought they were not fertile, found out they were via unexpected, and in some cases unwanted, pregnancies, while for unpartnered participants a different view developed.

> *Time 3 (P38, age 29): My periods came back to normal, and as far as I understand, I have as much chance of conceiving as anyone else...you don't know until you try and I haven't tried…that would be a big deal to me if I couldn't conceive.*

Contraception

Safe, reliable contraception became a relevant concern for some participants as they did not want more children nor did they want their partners to have a vasectomy in case they were to die. Permanent sterilization on the part of some participants was a consideration, although with reservations. When participants became pregnant, hence their fertility confirmed, contraception after delivery became an issue. Below is a quote from such a participant.

> *Time 2 (P35, age 37):…it really is incredibly difficult… what do you do…you don't want your husband to go and have a vasectomy because if you're going to die [laughs] anyway…and so there's no way you'll force them to go and have one…you go and have a tubal ligation because it's a non-hormonal form of contraception and you're going to die anyway [laughs]… but you're menopausal anyway, why go through a tubal ligation which has some inherent risks.*

These participants do not wish to take any hormone-based contraception regardless of how safe professionals may say it is. Below is a quote from a participant who was pregnant at the second interview.

> *Time 2 (P1, age 32): Well, it's risky, isn't it… it's just my personal belief, I suppose, it won't matter what people in the medical field say to me, like they say that you can take certain types of pills and things like that, and I just don't want to have anything that's hormone altering and I mean, that's why it was a risk to get pregnant because there's nothing more hormone altering than pregnancy…so I have the belief that anything like that is tempting fate.*

It should be noted that some participants were surprised to become pregnant, due to contraceptive use together with not expecting to be fertile as a consequence of treatment. Failed contraception for this group of women is about more than the possibility of an unwanted pregnancy, it is also about their fear and anxiety of possible recurrence. Below is a quote from a participant who experienced failed contraception prior to the last interview.

> *Time 3 (P4, age 34): [after failed contraception] I was horrified at the thought of being pregnant, really didn't want to be pregnant because of the breast cancer… I really just thought that being pregnant would be a very bad idea…*

Pregnancy

Pregnancies occurred within the participant pool during the interview phases. Most participants were elated they were pregnant, whereas some participants encountered initial trepidation, debating whether or not to terminate the pregnancy. Below is a quote from a participant who was pregnant at the first interview although did not disclose this as she was deciding if she would terminate.

> *Time 2 (P35, age 37): I probably was in the early stages [of pregnancy at first interview] but it was very difficult for me…because I really didn't know whether, what I was going to do, or whether it was going to be something that I was going to keep or not. It [the pregnancy] wasn't something that was planned or was supposed to happen. I really didn't know if I was going to go through with it.*

Not only were fears of recurrence expressed in relation to the mortality of the participants, but also of being selfish having another child when their lifespan may be compromised.

> *Time 2 (P35, age 37)…not being alive in five years time, having a child…are you being selfish bringing a child into the world when you have got this cloud…*

All participants who became pregnant reported fears that a pregnancy could either cause or accelerate further cancer although professionally informed otherwise.

> *Time 2 (P1, age 32):…I don't think I'd want to risk it again [pregnancy] even though I felt that I would take that risk to have a second child, I don't think I would again. I mean, two is lucky...*

A specific concern of the participants was the inability to detect any significant breast changes during pregnancy.

> *Time 2 (P11, age 38)…checks don't really help. As your breast gets bigger and fuller and everything, it is harder to find stuff…when I found this lump [original diagnosis], I went off and had a mammogram and that didn't see anything and then I had an ultrasound, and that didn't see it. I mean I could feel it. It was like a bloody olive in my breast, anybody could feel it but like*

> *they couldn't see it on the ultrasound because I was breastfeeding. So I mean, that's a bit of a worry, so if they're trying to find something little, the chances are they're not going to find it.*

Such fears carried across all interview phases once participants became pregnant. Even so, balancing out the negative emotions associated with a pregnancy after breast cancer were positive emotions, including closing the book on the breast cancer as well as having something positive to focus on and look forward to.

> *Time 2 (P35, age 37):…that's one thing pregnancy does, it makes you think more about living than the other… really that's been the rock, that it just all of a sudden shocks you into, listen, you can't dwell on it, you've got to go forward…you've really got to live and plan.*

Another concern expressed by the women was that of breast changes due to pregnancy (and subsequent breastfeeding). All participants who had viable pregnancies found they needed to either use, for the first time, a temporary prosthesis or needed a larger prosthesis for balance as the affected breast did not respond to the pregnancy and enlarge like the unaffected breast. Some participants stated that three months after they had finished breastfeeding they still needed the temporary prosthesis to maintain cosmetic balance.

Breastfeeding

All participants who had viable pregnancies during the course of the interviews wanted to breastfeed their new babies. Participants did not want lactation to occur/continue in their affected breasts.

> *Time 2 (P1, age 32):…I spoke to a lactation consultant…and she said that she has known some people who will get, even after radiation, they will have some milk come in…I said I do not want anything happening at all on that side [forced laugh]. I just have an aversion to it…I just wouldn't feel comfortable breastfeeding from that affected breast.*

Minor breastfeeding problems were encountered by participants, such as low milk supply and sore nipples. Still, in general, positive remarks were made of the experience, even in light of recurrence fears. Participants perceived breastfeeding as a positive life event.

Some breastfeeding decisions changed over time. Reasons to breastfeed were numerous, such as convenience factors and various benefits for the infant, social expectations, such as beliefs about what they should do, and wanting to experience breastfeeding. The two quotes below display how one participant's desire to breastfeed her infant changed over time.

> *Time 2 (P11, age 38): I'd like to breastfeed…I mean it's very good to breastfeed obviously. There are a lot of reasons why I should be doing it. I don't know about supply and all that sort of stuff, whether I'd have to complementary feed or whatever.*

> *Time 3 (P11, age 38): I was very positive about it [breastfeeding] but I'm going to try and feed for the first couple of weeks, do the colostrum business but no I think … I've discussed it with my husband and as much as I feel that I should, I think it's important to get past that and go off and have a mammogram …*

Pregnant and breastfeeding participants also reported major concerns related to the difficulty of detecting a breast cancer in a lactating breast, and that usual breast checks could not continue until the breast/s was/were back to the non-lactating state.

> *Time 3 (P35, age 37): I actually ended up having a mammogram ultrasound about 3 months ago which was marred by the fact that…I was breastfeeding… which means that mammograms and ultrasounds are totally useless.*

The fear of recurrence was so great in one participant she decided, very late in her pregnancy, to only breastfeed her baby for a few weeks so she could get her breast tissue back to the non-lactating state to continue usual breast checks. The quote below carries on from the quote presented above by Participant 11 at time 3 interview.

> *Time 3 (P11, age 38): …if I breastfeed for another 6 months that's going to be a period of time that I won't be able to [have regular breast checks], I mean you can have mammograms but they don't show anything.*

Participants were generally told by health professionals that breastfeeding after breast cancer was no different to one-sided feeding, such as in the case of twins. For one participant the decision to breastfeed was straightforward with elements of caution, while for others the decision was onerous. Breastfeeding was considered and/or undertaken within a different context to that of the participants' first breastfeeding experience**.** The quote below was from a participant who was diagnosed while breastfeeding her first child.

> *Time 3 (P35, age 37): Well, a different set of circumstances, absolutely. I had my baby and I thought, well, if I can feed a little bit, then that's a bonus…once I knew I could feed, I was invigorated by that…I really enjoyed it.*

Having to make a decision about whether to breastfeed or not was difficult for some participants as their pre-breast cancer attitudes towards breastfeeding were often in conflict with post-breast cancer fears.

> *Time 2 (P35, age 37): I'll probably be a one-sided feeder…I'm not sure whether I want to take that risk since I developed breast cancer feeding last time…but I haven't quite decided on that because I'm a staunch follower of nursing mothers… I mean I was one of the real converts, so it's going to be difficult …*

Even so, the decision to breastfeed or not was not as great a stressor as the decision whether or not to terminate a pregnancy.

DISCUSSION

This chapter discusses four specific and unique survival issues of young women with breast cancer, those of fertility, contraception, pregnancy and breastfeeding after breast cancer. The life-changing experience of breast cancer encroaches on post-diagnosis events of pregnancy and breastfeeding. Young women may not deem subsequent fertility a priority during life-saving treatments and surgeries, however as life returns to normal, infertility can become a major concern (Thewes et al. 2003). Conversely too much fertility also generates anxiety, raising interest in suitable, ‘safe’ and reliable contraception for this group of women. Permanent sterilization of the couple may be a viable option for some, although other participants did not want their partners to undergo a vasectomy, and do not, themselves, want to undergo any further surgery. Trust in, and desirability of, hormonal and non-hormonal methods of contraception appear to be minimal.

It is important to note that as fertility status can change over time, due to treatment routines, so too can fertility concerns (Thewes et al. 2003). Confusion over fertility status is evident. Consistent with the findings of others (Dow, 1994; Ives, Semmens, Saunders & Puckridge, 2002; Schover et al. 1999), concern about what hormonal changes of pregnancy and lactation could do to the risk of breast cancer recurrence was expressed by participants, although there is no firm evidence within the literature that would endorse such fears (Collichio et al. 1998; McTiernan & Thomas, 1986; Mueller et al. 2003). This may suggest that health professionals need to communicate such findings clearly to help quash the fears of young women with breast cancer.

The participants perceive the experience of having a child as closing the door on the cancer and of having a future to look forward to, a finding confirmed by Dow (1994) and Siegel et al. (1997). However participants’ interpretations of the news of a pregnancy were influenced by their fears of further breast cancer activation. As suggested by others (Ives et al. 2002; Schover et al. 1999), women were concerned that they might be diagnosed with a recurrence while pregnant. However such fears may be justified as a diagnosis of breast cancer during pregnancy, which is more likely to be coincidental rather than caused by the pregnancy (Collichio et al. 1998; McTiernan & Thomas, 1986; Mueller et al. 2003), significantly increases the risk of dying compared to women not pregnant at diagnosis (Guinee et al. 1994). This is due in part to pregnancy/lactation-related physiologic changes in the breast reducing sensitivity of imaging modalities, such as mammography (Talele, Slanetz, Edmister, Yeh & Kopans, 2003). Participants were acutely aware of this. Participants who had fertility concerns and/or pregnancies reported mixed feelings about wanting a child. The thought of bringing a child into the world with a mother who may have a compromised lifespan was expressed, equating to feelings of guilt and selfishness, further supporting findings of Siegel et al. (1997).

The literature neglects perceptions of young women with breast cancer related to breastfeeding experiences following diagnosis and treatment, concentrating on the physiological ability to breastfeed from an affected breast (Higgins & Haffty, 1994; Neifert, 1992; Tralins, 1995; Varsos & Yahalom , 1991; Wobbes, 1996). The decision to breastfeed, for this group of young women with breast cancer, was fringed with fear and anxiety of further breast cancer activation and difficulty in detecting breast cancer. The participants' fear of recurrence being caused, or accelerated, by breastfeeding appears to be mixed with wanting to be a good mother and doing the right thing, which is largely a social construction, and is consistent with Schmied and Lupton's (2001) findings. Breastfeeding after breast cancer can also be emotionally healing, a notion also expressed by Neifert (1992). Regardless of how young women feel about breastfeeding after breast cancer, it is obvious from these findings and others (Neifert, 1992) that they are in need of support, encouragement and relevant information.

More psychosocial and psychological information on all topics related to reproduction after breast cancer, including breastfeeding, is needed by medical/health professionals and young women who are diagnosed with breast cancer. Such information could ultimately benefit these women by increasing their ability to make informed decisions. A broader understanding of these women's experiences and reproductive issues could raise the awareness of various medical/health professional staff, particularly GPs and breast cancer clinicians, as well as those who work in the field of reproduction, assisted fertility and child health. Such awareness may help these professionals to be better equipped to assist and advise such young women of their reproductive and breastfeeding options. Support services and networks, including those focused on breast cancer as well as more general cancer organisations, also could benefit from raised awareness of reproductive and breastfeeding issues and concerns of young women with breast cancer. Young women with breast cancer who decide not to breastfeed also need support. Recommendations, concerning future research directions and questions and information dissemination regarding reproductive issues after breast cancer, can be found in Chapter 7, Boxes 7.4 – 7.8.

As this participant pool was small, Australian, and well educated, some results may not be generalisable to other groups of young women with breast cancer, such as those who have different cultural norms, beliefs and practices related to fertility, contraception, pregnancy and breastfeeding, and those who are less educated. However the findings provide other researchers and medical/health professionals with some deeper understanding of the needs of this group of women. Findings, in part, may be transferable to other groups of young women who suffer from life-threatening illnesses but retain their fertility.

As fertility status can change over time for young women with breast cancer, so too can their perspectives on fertility. With the continuance, or return, of fertility after breast cancer treatment comes the issue of safe, effective and reliable contraception as the occurrence of failed contraception raises serious issues, not only that of bearing an unplanned (or unwanted) child, but also the fear of further breast cancer. Rather than concentrating solely on the biological possibilities of the affected breast to lactate, important psychosocial issues need to be further explored, such as the social expectation to breastfeed equating to good mothering (Schmied & Lupton, 2001), as well as the breast/s again being a focal point amplifying mortality fears. This study extends understanding of the reproductive issues of young women with breast cancer, in particular concerns related to contraception and breastfeeding after diagnosis and treatment.

CONCLUSION

The literature concentrates on infertility concerns of young women with breast cancer, while attention to psychosocial issues related to maintained or regained fertility is scarce. As part of a longitudinal, qualitative study of issues experienced by young women with breast cancer (diagnosed at 40 years or younger) (n=13), concerns about fertility, contraception, pregnancy and breastfeeding after breast cancer were expressed. With the use of semi-structured, one-to-one interviews over three time phases, these women's experiences were explored. Over time, perceptions of fertility changed. Contraception issues were raised together with recurrence fears related to pregnancy and breastfeeding after breast cancer. Decisions related to unplanned pregnancies and breastfeeding were particularly onerous.

CHAPTER 6

RESULTS 3:

Young Women with Breast Cancer: How do Social and Cultural Influences Impact on their Perception of the External Portrayal of their Bodies?

Body image has been reported as a specific concern for women who have breast cancer, especially following mastectomy (Beckmann et al. 1983b). Younger women in particular are prone to the negative effects of breast cancer on their body image due to their high aesthetic expectations (Schover, 1994). However, this chapter does not report solely on the body image concerns of participants, rather a deeper understanding of their experiences from a sociological viewpoint is documented. While body image issues and concerns were explored during each phase of the study, it was the preliminary analyses of the first two phases of the study which provided the inspiration for this in-depth exploration within phase 3 of the study and analysis of the issues of breast symbolism, the external portrayal of the participants' bodies and generational differences. Data from the first two phases of the study (follow-up participants only) were also reanalyzed in regards to the above mentioned areas of interest. Hence this chapter reports on findings from this three-phase, longitudinal qualitative study of the experiences and perceptions of the 13 follow-up participants surrounding social processes involved with their perceptions of breast symbolism, generational differences, and the external portrayal of their bodies. A full explanation of the theoretical framework which underpins and helps explain these aspects, together with the methods and analysis procedures employed, can be viewed in Chapter 3. In addition, participants' demographic characteristics are documented in Chapter 5, Table 5.1

FINDINGS

Although there are areas of overlap, the findings are discussed under the headings of breasts: social norms, expectations and experiences, generational differences and external portrayal of the body: normalising efforts and associated issues.

Breasts: Social Norms, Expectations and Experiences

All participants were acutely aware of social norms and expectations of women's bodies; that is to have two whole breasts. Some participants, however, felt societal views and expectations of women's breasts were trivial and superficial. Even so, these participants did not wish to challenge such social norms, hence the wearing of prosthesis and undergoing reconstruction (hiding/disguising breast loss/disfigurement) and at times feeling defeated and coerced by social pressures to reflect such social norms. (Time 1, 2 or 3 depicts the study phase from which the data were collected. Participant code and age at diagnosis in parentheses.)

> *Time 3 (P15, age 33):…it's a male dominated environment and they make women more conscious of their breasts…it [breastlessness] should be something that we [women who have had mastectomy] should be proud to display, 'I had cancer and I beat it'. We cow, we cover up, we put jellow moulds on our chests…we hide it, its shameful, you're only half a woman. What a load of shit and unfortunately this is not going to change and if I meet a woman and she said – 'oh look I'm not wearing a prosthesis' – I'd say, 'good on you, how courageous are you', and the rest of us, meanwhile, are cowards…*

Hence, by internally challenging social norms, though not externally achieving this, this participant had many issues trying to re-establish normalcy in her life, to reconstruct the meaning of her life. The text below continues on from the previous quote.

> *Time 3 (P15, age 33): We talk about wearing a prosthesis so nobody will know. Why should nobody know, why shouldn't you go out there and sing it from the roof tops, 'I had cancer, I had a mastectomy and I won'?   No we hide it – nobody will ever tell that we've got a prosthesis. See, we are*

> *looking at it from the wrong angle. We shouldn't be hiding, but then I know if I went to work without wearing a prosthesis even some of the women would stare and make comments. We should be encouraging it, instead we tell them to hide and then they wonder why we get depressed and become reclusive and don't get over the surgeries as well as we should.*

Much of the discussion about breast symbolism, both societal and personal, centred on male-dominated views/expectations of breasts, and how if one deviates from the expected norm, consequences would have to be endured. Participants often discussed how societal expectations/perceptions impacted on their experiences, like that expressed by the following quote.

> *Time 3 (P34, age 37): People who I told I had cancer and I had to have a breast off, focused more on the losing of the breast, including people very close to me, than they did on the fact that I might die. So society is very much switched on to, you know, they think that's horrific that you would have to have that done…the point is you are fighting for your life…*

Regardless whether participants had mastectomy or lumpectomy, the sexual importance of breasts was acknowledged. Participants perceived their breasts to be a mark of femininity, a draw card for men and a symbol of sexuality. Again male-dominated sexual attitudes towards breasts, breasts existing for men's pleasure, was evident.

> *Time 3 (P27, age 37): They [breasts] are very sexual and especially because my breasts were quite large and my husband is a boob man so that was a big thing between him and I that he always thought my boobs were quite nice, so the thought of, at the time, being told that one has to go, I remember my first thought was, oh God, he won't like me any more because my biggest, well in his eyes, sexually my biggest asset was going down by half…*

However, no participant discussed how her breasts were important for her own sexual gratification. Rather answers to questions of a sexual nature were expressed in relation to the participants' partners'/potential partners' perception of breasts.

All participants who had mastectomy (except one) experienced changes in their perceptions, over the duration of the study, regarding the remaining breast, with some stating the pride they had in their bust line diminished to shame. Grieving the lost breast was ongoing for some participants. In addition, some participants view their remaining breast as a site of potential grief.

> *Time 3 (P34, age 37):…it[remaining breast] actually feels like more of a threat because it's something that you've got to check every month…sometimes it is more of a burden actually.*

Generational Differences

It is interesting how the participants perceive their experiences to differ from that of older women with breast cancer. Much discussion surrounded the topic of being socially expected to be, and appear, sexual, that a young woman is seen as a sexual being (implying older women are not) and to have the potential to still seek/attract a mate. The participants also stated that young women: may not yet have a life partner; are more vain and hence appearance sensitive; wear more revealing clothes than older women; are more attuned to social expectations and hence more sensitive to media messages; and young women's breasts are the focus of much social attention.

Differing lifestyles was another issue raised as explained by the quote below.

> *Time 3 (P10, age 40): Women have to get out there and work whereas years ago, my mother's generation, they didn't have to work, so we (young women with breast cancer) are more in the limelight than in our mothers' day.*

Lifestyle-related issues raised by young women included being more likely to be pursuing a career; still having an active social life; and being expected to be more physically active.

External Portrayal of the Body: Normalising Efforts and Associated Issues

Problems associated with prosthesis use were expressed by participants to varying degrees, as were problems associated with clothes (among those who had mastectomies). Experiences and expectations of breast reconstruction were also varied. In addition, the partners' perceptions of reconstruction impacted on participants' thoughts about reconstruction outcomes. Ongoing body image issues for this group of women relate to physical consequences of treatment.

Prosthesis Use

All participants who wore external breast prostheses expressed some problems. For some, prosthesis use was nothing more than an inconvenience and a hassle, while for others it signified something much more sinister, a loss of lifestyle.

> *Time 2 (P15, age 33): I'm not going to a workout centre to do yoga without wearing prosthesis, I can't do exercise in a prosthesis…but I won't not wear one…They say they can do it [exercise] in candle light, where do you put the prosthesis? What, you stick it on the floor beside you! I mean the logistics of it; you'd feel even more uncomfortable…I won't go swimming so you limit yourself again…*

Problems with clothing were paramount for most participants who had mastectomy. Some participants complained they had to wear 'granny clothes' to hide and disguise the breast loss/prosthesis. Participants expressed how modern fashions are cleavage focused and often skimpy hence making the wearing of age-appropriate clothing very difficult once one had lost a breast.

> *Time 1 (P8, age 39):…have you had a look at the clothes these days, seen the nice little thin straps that they have, if you have a prosthesis where are you going to hide it?…*

Lymphoedma, in relation to clothing, was raised as an issue as expressed in the quote below.

> *Time 2 (P15, age 33): They put on fashion parades [for young women with breast cancer], what good is that when you can't wear normal clothes because one arm is bigger than the other because you've got lymphoedema, I mean why aren't there fashion ranges for lymphoedema problems? Why can't someone do a range of clothes with adjustable sleeve sizes on one side…*

Partners (Paternalism) and Breast Reconstruction

Partners were not interviewed for this study, however from participants' accounts, partners generally are not bothered by their breastlessness, at times questioning why they would want to have a breast reconstruction.

> *Time 2 (P34, age 37): I showed him [partner] some pictures [of reconstructed breasts] that I'd found and he said, "but it doesn't actually look like a breast", his thoughts were that it's a lot of trauma to go through and you may not like the end result anyway.*

This could be seen as a partner not wishing to encourage a participant to have a reconstruction or possibly trying to seem neutral in the situation, not wanting a participant to think she has to do it for him. Even so some participants stated they might consider reconstruction for their partners' sake. Partners did not want to touch the reconstructed breasts, mostly due to not wanting to hurt participants and also, in one case, as the partner did not view the reconstructed breast as sexual. Partners' reactions to, and comments concerning, reconstruction had an impact on how participants think about the whole process. By questioning the expected results of, and motives to undergo, reconstruction, partners may inadvertently incite participants to belittle and/or suppress their own needs.

Expectations and Outcomes of Reconstruction

Two participants underwent different types of reconstruction during the study (implant and TRAM flap). Both participants felt the reconstruction had boosted their body image, though one participant expressed that she still felt one-breasted. Early in this participant's reconstruction journey she expressed she would always feel one-breasted. The other participant, totally pleased with her reconstruction outcome, stated she expected the reconstruction would finalise her breast cancer experience.

Other participants who either could not, or did not wish to, undergo reconstruction procedures expressed hypothetical expectations of reconstruction as: to feel part of society instead of an outcast; to boost body image via cosmetic improvements; to increase choice of clothing; to be more comfortable with their bodies; to remove problems with prosthesis use; to increase self-esteem and confidence; the reconstructed breast would not look totally normal, though not abnormal either; and to normalise them, and more specifically to normalise for a young daughter's sake.

> *Time 1 (P11, age 38):…I'm a bit worried about that sort of issue later on in life, the fact that I have a breast missing and obviously I undress in front of my daughter now, but as she gets older, I don't want her fixating on that fact. So that's an issue that I'm going to have to deal with because I don't want her worrying when she gets to an age where she starts worrying about things like that, because they're always on about the family history…*

Hence, all participants who had mastectomy, regardless whether they were a viable candidate for reconstruction or not, stated that an expectation of reconstruction would be to reduce the stigma associated with breast cancer and breastlessness. Even so, not all participants who were viable candidates for reconstruction wished to undergo such surgery.

DISCUSSION

As the perception of the body is a reflection of the organisation of the social system, the participants' perceptions of their experiences reflect societal views and expectations (Douglas, 1970). The social constructionist approach to the body 'argues that the body is socially created or invented and as such is contingent on its social and historical context' (Nettleton, 1995, p, 104). Thus the participants reflect the current social trend and culture, that is the cult of the body in a consumer culture (Featherstone, 1991a;1991b). In particular, the cosmetic interest in the body; that is to keep fit, slim and young (Nettleton, 1995). The youth and beauty culture has a poignant effect on participants, as Broom (2001) claims that sociocultural perceptions of sexuality and femininity frame women's choices and experiences. In particular, participants perceived that their experiences differed to that of older women with breast cancer.

The findings clearly reflect other reports in the literature that those participants who undergo mastectomy suffer much more body image concerns than those who have lumpectomy ‘only’ (Avis et al. 2004; Fung et al. 2001; Hartl et al. 2003; Mock, 1993). In agreement with findings of Cohen et al. (1998), the participants were acutely aware of the societal importance placed on women’s breasts. However, rather than overtly expressing personal feelings of less self-worth in relation to their disfigurement, as was found by Kasper (1995), participants instead reflected on social norms and expectations and how society projects less self-worth onto them. Hiding/disguising breast loss/disfigurement reflects the participants’ desire to conform to social norms and expectations and thus, as explained by Crouch and McKenzie (2000), to continue to maintain their body image, to continue to present as normal, and to appear to others as unchanged. In addition gender socialisation, that is participants viewing their breasts as a private as well as a public matter, was evident, reflecting a notion put forward by Kasper (1995).

The bulk of the literature reviewed suggests that younger women experience common issues, such as emotional distress, more intensely and more negatively. (Mor et al. 1994b). Emotional distress can be intensified by body image changes (Trief & Donohue-Smith, 1996). In addition, research findings have indicated that intrusiveness of breast cancer to young women’s lives is significantly related to their body image and symptom distress (Bloom et al. 1998). The literature suggests that young women with breast cancer would potentially suffer more distress than older women due to high aesthetic expectations (Schover, 1994). This study did not have a control ‘older’ group of participants for direct comparison, however the results reflect the participants’ perceptions in perceiving their experience to be different to that of older women.

The participants felt they were more sensitive to, and hence more influenced by, media portrayals of young women’s body image ideals than their older counterparts, a concept expressed by Golden (1983). In contemporary society it is ‘imperative to ensure that the appearance of the body is as attractive and conforming to accepted norms as possible’ (Lupton, 1994, p, 37).

Much literature surrounds partners' experience of women's breast cancer (and other life-threatening illnesses) (Lewis et al. 1989; Sturesteps & Darroch, 1986; Zahlis & Shands, 1991), however no literature has been found which specifically reflects the influence partners have on women's reconstruction decisions. More generally it has been stated that the perceptions of family and friends concerning reconstruction could result in women feeling pressured one way or the other (Reaby, 1998). In addition, Rassaby and Hill (1983) also found family, friends and some health professionals to oppose breast reconstruction. This study demonstrates how simple comments made by partners can impact on how the participants think about reconstruction. Hence young women with breast cancer are influenced, and impacted upon, by paternalistic and male-dominated views of women, their breasts and reconstruction.

As Baldry and Walsh (1999) and Reaby's (1998) opinions differ as to why women choose to undergo reconstruction, this study found the expectations of, and reasons to undergo, reconstruction closely reflect the perceptions women hold of their breasts within society as discussed by Kasper (1995). Not only were these women aware of social norms and expectations of women to have two breasts, but also that society expected them to hide/disguise their breastlessness/disfigurement, as beliefs and values are institutionalised they become a given in society (Berger & Luckmann, 1967).

The expectation of a return to normalcy, which could be said to be the need for reconceptualization of self-image (Lupton, 1994), following reconstruction, as expressed by Baldry and Walsh, (1999) and Neill et al. (1998), was also found within this study. In accordance with findings of others (Crouch & McKenzie, 2000), participants underwent reconstruction to go from being discredited in society to being discreditable, a notion put forward by Goffman (1963). Participants also appeared to be aware of the great rewards accrued to those who can pass as normal (Goffman, 1963). Thus the stigma experienced by these women impacts on their illness experience as social life depends on the successful presentation and interpretation of bodies (Turner, 1992).

This study provides insight into the social processes involved when one is diagnosed with breast cancer at a young age, in particular how current culture and trends impact on how young women experience the illness. As well as increased awareness, the insights gained from this study could also be used to help formulate age-appropriate information packages and support services. Changing embedded social and cultural expectations and influences remains challenging, however with raised public awareness of the experiences of young women with breast cancer, social acceptance of their differentness may be achieved in the long term. The fashion industry, which has begun to raise funds for breast cancer research, should be made aware of the difficulties young women with breast cancer face with regards to the external portrayal of their bodies. This could result in the fashion industry designing and supplying suitable fashions and accessories that are stylish, age appropriate and affordable for these young women, which could subsequently reduce their distress. In addition, uptake of suggestions made in Chapter 7, Box 7.9, may assist young women with breast cancer to adapt to social and cultural influences they encounter. Future research has been suggested in Chapter 7, Box 7.10, to further the understanding of how social and cultural trends and influences impact on the experiences of YWBC and to ascertain how the lived experiences of YWBC differs to that of their older counterparts.

As this participant pool was small, Australian, and well educated, some results may not be transferable to other groups of young women with breast cancer, such as those who hold different cultural meanings and norms of body image and sexuality, and those who are less educated. Even so, the findings provide other researchers, and medical/health professionals, with some understanding of this group of women.

Social norms and expectations of women's breasts frame how these young women interpret their breast cancer experience. Male-dominated views of the sexual significance of breasts were paramount in participants' interpretations of their experiences. This study's findings clearly indicate that modern consumer culture (Turner, 1992), including media influences (Golden, 1983) and the current cosmetic interest in the body (Nettleton, 1995), together with the somatic society (as described by Turner, p, 103) in which the ‘body constitutes the central field of political and cultural activity’, impacts greatly on how young women experience breast cancer.

CONCLUSION

Young women with breast cancer experience heightened body image difficulties compared to their older counterparts. With the use of semi-structured, one-to-one interviews over three time phases, a longitudinal, qualitative study of young women with breast cancer (diagnosed at 40 years or younger) (n=13) explored participants’ perceptions of social norms, expectations and experiences related to breasts, generational differences, together with the external portrayal of their bodies and accompanying normalising efforts. Theories of social constructionism and the social construction of the body grounded this study. Social norms and expectations were found to influence perceptions, and hence decisions made.

CHAPTER 7

DISCUSSION

This chapter provides an overview of the findings of the study, together with suggestions to improve services, education materials and general information given to YWBC. Future research topics and questions have been suggested. Advantages of undertaking longitudinal, qualitative research, together with how the aims of the study were met, are discussed.

7.1 INTRODUCTION.

This longitudinal, qualitative study of YWBC has sought to explore and follow their experiences over time. The findings from this study may assist medical/health and allied professionals to understand issues and concerns of YWBC. Note also that these issues may not be static. Subsequent recommendations may help other young women diagnosed with breast cancer in the future to make informed choices and to reduce distress they may suffer. The following discussion briefly highlights findings from each of the results chapters, presented in the previous three chapters, and then discusses these in more general format.

7.2. OVERVIEW OF FINDINGS FROM CHAPTERS 4, 5 & 6.

The findings of this study are discussed in the results chapters (see Chapters 4, 5, and 6). The first results chapter (see Chapter 4) deals with the initial phase of the study, i.e., identifying and classifying the general concerns of the original participant pool (n=35). The findings from the study as a whole (over three interview phases) were utilized for the second and third results chapters (see Chapters 5 and 6). Infertility has been identified as a specific concern for YWBC (Bloom & Kessler, 1994b; Dunn & Steginga, 2000; Schaefer et al. 1999; Siegel et al. 1999; Singer & Hunter, 1999). However, over the course of the study, some participants became pregnant, hence fertility also became a focus of the study and was explored in Chapter 5, i.e., infertility concerns together with maintained or regained fertility and its consequences. YWBC experience their illness trajectory via social and cultural processes and contexts. The literature claims YWBC experience more intense body image concerns than their older counterparts (Schover, 1994; Trief & Donogue-Smith, 1996), hence the social and cultural influences surrounding issues of the body were explored in Chapter 6. Male-dominated views of the sexual importance of breasts influenced how the participants' viewed the symbolism of their breasts. In addition, participants perceived that their experiences of breast cancer differed to that of their older counterparts due to societal expectations to be, and dress, more sexually than older women.

7.2.1 Chapter 4: *Title:* Issues and concerns of young Australian women with breast cancer.

Issues of YWBC are beginning to be researched internationally (Dow et al. 1994, Dunn and Steginga, 2000), although no universal definition exists with which to classify a woman as 'young'. Research findings have been reported for young women based on specific age groupings, such as 55, 50, 45, 40 or 35 years and younger, or by menopausal status or some other researcher definition of what constitutes younger (Dunn & Steginga, 2000). Chapter 4 reports on the general issues that were important for participants, keeping in mind the focus of 'younger women'.

In particular, issues of family were paramount being ranked highly as participants' major present concern, i.e., concerns for partners, children and reproduction in general, a close second to recurrence and death-related fears. Fears of recurrence and death were also related to the fear of leaving children, of leaving partners to raise children, and fears of children not coping with their mothers' early death and of having to grow up quicker. Reproductive issues raised were not only that of infertility concerns resulting from treatment-induced early menopause, but also of maintained or regained fertility and issues of contraception.

Partner concerns were evident, including the social expectation that partners will cope with the situation, i.e., taking on added responsibility when a diagnosis of breast cancer is made while maintaining usual social roles, such as being the provider. What was referred to as 'typical male behaviour', reported to inhibit partners from seeking outside support, could be viewed as internalised social expectations of partners (men), more specifically engendered acculturation of typical male behaviours (Douglas, 1970). However societal expectations of partners were also likely to impact on partners' experiences and decisions made concerning outside support (Sabo et al. 1986). Emotional and physical support also were found to be lacking for this group of women, hence available support services could be made more age sensitive and appropriate for YWBC. Many information deficits were reported, particularly in relation to early menopause and subsequent sexual difficulties, and contraception and pregnancy after breast cancer.

7.2.2 Chapter 5: *Title:* A qualitative analysis of reproductive issues raised by young Australian women with breast cancer.

The literature concentrates on infertility as a unique concern of YWBC (Bloom & Kessler, 1994b; Dunn & Steginga, 2000; Schaefer et al. 1999; Siegel et al. 1999; Singer & Hunter, 1999). Over the duration of the study some participants became pregnant and hence had to deal with maintained or regained fertility after the breast cancer diagnosis. Chapter 5 explores the various elements of fertility after a breast cancer diagnosis. The findings from this study demonstrate that not only can infertility be a concern and an issue for YWBC but fertility, i.e., maintained or returned fertility, can bring with it not only the joy of pregnancy and a new baby but also concerns of reliable, suitable and safe contraception. Other issues identified were fears that pregnancy and breastfeeding could cause or accelerate a recurrence or other cancer activation, issues of pregnancy termination, and concerns regarding bringing a new child into the world whose mother may have a shorter than average lifespan.

Some participants became pregnant after their breast cancer treatment, despite not expecting to be fertile. Most of these were using non-hormonal methods of contraception. Hence reliable, suitable and safe contraception became an issue for these women. Not all participants wished to have themselves, or their partners, permanently sterilized for a variety of reasons. Some participants had to first consider termination, as their fears regarding a pregnancy were so great.

Throughout the phases of the study these pregnancies were followed, some right up to breastfeeding and beyond. The decision to breastfeed was not taken lightly, as again participants felt lactation could further activate the cancer. The difficulty of finding a cancer in a breast preparing to lactate, or lactating, was expressed by all pregnant participants. Some of these participants also had their initial cancer diagnosed during pregnancy or while breastfeeding, thus deepening their fears. During pregnancy and breastfeeding the participants' focus was again on their breast/s. Literature surrounding breastfeeding after breast cancer treatment is scarce, and of what is available, most concentrates on the affected breast's ability to lactate (Higgins & Haffty, 1994; Neifert, 1992; Tralins, 1995; Varsos & Yahalom, 1991; Wobbes, 1996). This was not an issue for the study participants as they did not want their affected breast to lactate, and in the case of participants who had had mastectomy, this was not relevant. Rather, the issues surrounding breastfeeding were related, in part, to the time prior to the birth - the breastfeeding decision-making process - and to fears of breastfeeding causing or accelerating recurrence or other cancer activation and not being detected early due to breast checks relying on manual means during that time.

7.2.3. Chapter 6: *Title:* Young women with breast cancer: How does their perception of social and cultural influences impact on the external portrayal of their bodies?

The current social trends and culture, that is the cult of the body in a consumer culture (Featherstone, 1991a; 1991b) and in particular the cosmetic interest in the body (Nettleton, 1995), to which women are most susceptible (Golden, 1983), is the social environment in which the participants experience their breast cancer. Hence the youth and beauty culture has a poignant effect on participants' experiences due to sociocultural perception of sexuality and femininity, framing women's choices and experiences (Broom, 2001). The literature states that younger women are more prone to body image difficulties following breast cancer treatment than their older counterparts (Trief & Donogue-Smith, 1996) due to high youthful expectations (Schover, 1994). Therefore by analysing participants' experiences surrounding the external portrayal of their bodies, together with exploring their perceptions of how they and society symbolise their breasts and utilizing views and writings on the social construction of the body, a deeper understanding of these women's experiences was achieved. In addition, participants expressed how they perceived their experience of breast cancer to be different from that of older women who have breast cancer.

Rather than focusing on an issue over time, this chapter reflects on the underlying constructs that emerged as important over the phases of the study, i.e., instead of merely reporting on the obvious (YWBC experience negative body image issues), this study endeavoured to gain understanding. The views and writings on the social construction of the body by Foucault (1979) in relation to social control and norms, by Douglas (1970) in relation to the body being a reflection of the organisation of the social system, and by Goffman (1963) in relation to his theories on the concept of stigma, assisted in the analysis of participants' experiences.

The participants were found to be acutely aware of societal norms and expectations in regards to breasts in general and often struggled, not wanting to challenge such norms. Personal views of breasts mirrored closely male-dominated views of the sexual importance of breasts, implying that such views became beliefs and helped make up personal values, an internalised construct (Berger & Luckmann, 1967). Interestingly, when asked how they perceived their experiences to differ from that of their older counterparts, participants expressed again how male-dominated views of the sexual expectations of women's appearances impacted on their self-concept, i.e., stating that young women are expected to be and dress more sexually than older women and still have the potential to attract a mate.

From participants' accounts of their experiences emerged issues of stigma, in particular in relation to their breastlessness. Attempts were made to alleviate stigma by controlling how they externally portrayed their bodies by hiding/disguising their breastlessness via prosthesis use and breast reconstructive surgery. As has been found by others (Crouch & McKenzie, 2000), societal influences, norms and expectations impact on participants' experiences and decisions relating to breast reconstruction. Partners were found to inadvertently influence participants' decisions concerning reconstruction, a notion not specifically addressed within the literature. Male-dominated views of the sexual significance of the breast, together with more general cultural and societal trends and processes, influenced participants' decisions and interpretations, and my understandings, of their experiences.

7.3. HETEROGENEITY OF PARTICIPANT POOL.

As consensus was not being sought but a wide range of experiences was desired, a specific circumstance of participants was not the criterion for follow-up, such as fertility status. The rationale used to select the 13 follow-up participants (see Chapter 3, section 3.4.6.3) resulted in a variety of women being followed over time, that is: six participants had lumpectomy only while seven had mastectomies; some desired reconstruction while others did not, some could not have reconstruction while others underwent the surgery; some were single though most were partnered; some had been in their partnered relationships for a reasonable time (10 years or more) while others were in such relationships for relatively short periods prior to breast cancer, such as only a couple of years; some had no children, while others had babies and toddlers right up to young adults; some were fertile while others were not; some had finished their families prior to the breast cancer while others wanted children, first or subsequent; some were only months out from diagnosis at the first interview while others were three years or more out; some had advanced disease, though most did not (one participant had advanced disease at first interview while another participant was diagnosed with advanced disease prior to the second interview); some participants worked outside the home, while others did not; and some participants were from urban areas while some were from regional areas. The heterogeneity of the participant pool provided a broad base of experiences of YWBC.

7.3.1. What Made the Follow-Up Group Unique?

As these participants were selected via purposeful sampling (see Chapter 3, section 3.4.6.3), no one single avenue of inquiry was the focus of the follow-up portion of the study and each participant’s individual story was examined to supply individual context for follow-up. However the study was focused on ‘younger’ women, hence fertility became a major issue as were expectations and experiences of reconstruction, consistent with the literature which discussed YWBC as having a more negative body image following breast cancer treatment (Bloom et al. 1998). Sexual matters were also a focus. Even so, some issues found within the follow-up participants’ stories potentially differ to those other participants who, for instance, may have maintained or regained fertility and wanted to become pregnant (if this was the criterion for follow-up). In this case, those who had advanced breast cancer (or whose disease degenerated into advanced disease during the interview phases) would not have been included in the follow-up study, hence their perspectives not captured. If maintained/regained fertility was the criterion for follow-up, those who had finished their families would also not have been included, hence also their experiences not captured.

This study reflects a variety of issues and concerns of YWBC. Women aged 40 years or younger have experienced up to 22 years of adulthood. Contemporary women's lives do not necessarily follow a prescribed pattern of the paternalistic society of old, that is getting married young and having children – rather many women choose to delay permanent relationships and childbearing (Dow et al. 1994; Gemignani & Petrek, 2000), instead pursuing careers and other life interests and goals. This study displays this mixture – those who married and had children early in adulthood to those who were just starting, or not yet ready to start, a family.

7.4 FURTHER DISCUSSION OF CHAPTERS 4, 5 & 6.

7.4.1 The Necessity of Additional Support Services

As indicated in Chapter 4, support systems available to YWBC need to be highly visible, as many participants in this study disclosed that support was their greatest unmet need. Of the support that was utilized (not including support from family and friends), much was said to be not age appropriate, i.e., geared towards the average breast cancer sufferer who is a much older woman. In particular, it has been proposed that YWBC suffer higher levels of overall distress (Beckmann et al. 1983b; Bloom et al. 1998; Ghizzani et al. 1995; Mor et al. 1994b; Schover, 1994; Wang et al. 1999). In addition, recent research states that YWBC have concerns less frequently faced by their older counterparts (Avis et al. 2004). Hence, younger women's needs should be identified and subsequently addressed with regards to appropriate support systems.

With breast cancer survival rates rising, more emphasis needs to be placed on survival issues, e.g., premature menopause, infertility, fear of recurrence, family distress and uncertainty (Ferrell et al. 1997). Consequently, 'psychosocial interventions aimed at increasing social support beyond the acute phase of treatment may have a vital role in the ongoing care of breast cancer survivors' (Ganz et al. 2002, p, 48). Psychosocial interventions can facilitate coping with breast cancer and potentially improve the quality of life for the majority of sufferers (Bloom & Kessler, 1994b). According to Bloom and Kessler (1994, p, 1994b), psychosocial interventions should not only 'follow phases of the cancer diagnosis, treatment, rehabilitation and continuing care but also consider the interactions between phases of treatment and the women's life stages and role identities'.

In consideration of the literature, and the study findings, support needs to entail elements of physical, such as child care, and emotional assistance. YWBC are inflicted with this illness at a time in their lives when their family responsibilities and general life demands could be at a peak (Winchester, 1996). Considering YWBC are more likely to have small children, the physical demands of a young family are likely to be immense and hence physical support may need to be available to this group. These needs may not be specific to YWBC but are more likely to apply to young women having any ongoing illness. While some of these supports may be available already, the point here is to identify a group of services that may be useful for this particular group. Integrating services for families, especially with young children, is currently a big issue, i.e., the Department of Families is currently funding Integrated Service Hubs to meet needs identified by specific communities – one could see how such an identified 'facility' could be an add-on to this program (Tayler, Farrell & Tennent, 2004). On reflection of the study findings, the suggestions presented in Box 7.1 to improve support services for YWBC were formulated.

BOX 7.1: Suggestions to improve support services for YWBC.

- **Currently available forms of support, such as home help, respite care and counsellors, may be made (more) available to YWBC via a means test and a 'support needed' checklist to ascertain need and severity of situation, taking into consideration the quantity and quality of their informal support systems available (such as close family members).**
- **Such support needed (physical and emotional) may be sourced from current community helping organisations and government departments, such as QCF, Blue Care, the Salvation Army and HACC.**
- **One central body should be responsible to facilitate and link the means and 'support needed' test results with suitable support.**
- **The government (state or federal) could supply further financial assistance for emergency childcare placement for a predetermined period of time, such as 12 months, to be reassessed periodically according to need.**

Box 7.1: Suggestions to improve support services for YWBC.

7.4.2 Specific Areas of Focus for Support

Currently available breast cancer support materials and structures should also include elements of what would be considered to be specifically important to YWBC. This could be achieved by providing a forum in which sensitive issues can be raised and by providing information surrounding topics such as sexual difficulties following treatment, dealing with children after diagnosis, issues of early menopause together with fertility and contraception concerns. Additional findings, not reported in chapters 4, 5 and 6 were that the participants felt younger women were more assertive and questioning and able to talk about intimate matters more readily than older women with breast cancer, hence a forum-style support system has a good chance of providing age-appropriate support and information to YWBC. However, the present challenge is how can this happen because of the small number of young women diagnosed with breast cancer at any one time.

Other findings not reported within the Chapters 4, 5 and 6 suggest that the consequences of early menopause can go on for many years after treatment due to altered hormone levels creating problems such as a dry vagina and painful intercourse and lost/lowered libido, as confirmed by others (Thors et al. 2001), and can subsequently impact on intimate relationships. This provides a rationale for an agenda for suggested forums to be focused on issues related to sexual difficulties and subsequent relationship dynamics caused by treatment consequences.

The Breast Cancer Network of Australia currently has in place a web-based email link-up specifically for YWBC (BCNA, 2004), and the Queensland Cancer Fund (QCF, 2004) has a young women's network which caters specifically for young women's support and information needs, as does the Kim Walters 'More Choices Program' which also has a young women's group (based at the Wesley Hospital in Brisbane). However many of the participants in this study did not know these existed. The relatively new placement of Breast Care Nurses could address this gap in effective communication although other mechanisms for informing women of resources are also needed. Due to the small number of young women diagnosed with breast cancer, technology could be further harnessed to improve support availability and accessibility. Another challenge ahead is to make existing support services more relevant to YWBC, and to make them more effective in addressing their needs. The first three points in Box 7.2 reflect not only participants' suggestions for improved support for YWBC, but also addresses their experiences of not knowing what support was available to them. Box 7.3 provides suggestions for the use of technology to alleviate the support needs of YWBC.

BOX 7.2: Suggested solutions to provide specific support for YWBC.

- **Databases of YWBC could be made more effective in linking YWBC together to established greater peer support.**
- **A similar Australia-wide database could also be established, which may have a better chance of linking YWBC up with similar background/circumstances.**
    - **Confidentiality issues would need to be addressed with regards to the above-mentioned suggestions. Technological safeguards would need to be put in place on such a database.**
    - **Written consent would also need to be obtained from YWBC prior to being entered into such a database.**
- **Forms of support specifically geared towards YWBC, such as the email link-up, need to be better advertised/promoted. Marketing strategies may help in this regard.**
- **Primary medical/health care providers should be informed of these services, and provided with promotional materials, for referral purposes.**
- **Two versions of a booklet could be produced regarding available support systems that YWBC can utilize and/or visit, one suitable for YWBC and one specifically for medical/health and helping professionals providing more specific details.**
- **Currently available pamphlets on specific support systems could be left in places where YWBC are likely to frequent, health service related and otherwise. Such materials should be revised and refined annually to keep them up to date and relevant.**

Box 7.2: Suggested solutions to provide specific support for YWBC.

BOX 7.3: Suggested solutions to address support needs of YWBC via technology.

- **Telephone conferencing, which has been successfully utilized by the Advanced Breast Cancer Support Group at West End Brisbane, would allow YWBC to talk with other YWBC from a wide variety of locations, such as interstate. A professional facilitator (such as a social worker) would ensure all YWBC connected would have a turn to speak.**
- **Video conferencing may also be a suitable form of support, however this form of communication is currently limited by the cost of such technology and may not be a viable option for many YWBC who do not have a computer, do not have sufficient computer knowledge, or do not have video link up.**

Box 7.3: Suggested solutions to address support needs of YWBC via technology.

Due to difficulties related to securing childcare at a specific time, internet chat rooms, telephone and video conferencing would allow these women to engage in a support group without leaving their homes. Telephone conferencing is likely to appeal to most YWBC, due to the almost universal use of telephones. Partners of YWBC also need to be considered in relation to appropriate support facilities and information materials, as reported by participants (see Chapter 4).

Generally, information materials given to YWBC need to be updated and made more relevant to this age group. This study found many information deficits in relation to many aspects of being diagnosed with breast cancer at a young age (see Figure 3.4). YWBC experience some other unique issues as a result of treatment, in particular those related to their reproductive organs and subsequent reproduction capacity (Bloom & Kessler, 1994b; Dow & Kuhn, 2004; Dunn & Steginga, 2000; Reichman & Green, 1994; Schaefer et al. 1999; Schover, 1994; Singer & Hunter, 1999; Spencer et al. 1999), that is being plunged into treatment-induced early menopause (Avis et al. 2004). Not only are reproductive issues related to early menopause, but also to subsequent sexual difficulties, both mechanical and emotional. Lost interest in sex (lost/lowered libido) was found by Avis et al. (2004) to be a particular concern of YWBC. Concerns surrounding contraception choices and the safety of pregnancy after breast cancer were also raised. These issues need to be addressed and presented in a way that this group of women relate to and are not made to feel like outcasts.

Chapter 5 indicates how the experience of contraception, pregnancy, and breastfeeding after treatment for breast cancer is undertaken in a different context to that of healthy women, and as such needs to be dealt with differently to effectively address these issues. The trend to delay childbearing (Dow et al. 1994; Gemignani & Petrek, 2000), as demonstrated by the Australian trend for age at first birth (AIHW, 1997; AIHW, 2001), together with current improvements in Assisted Reproductive Technology (ART), which includes IVF, both make it clear that more YWBC will proceed to become pregnant after breast cancer (Dow & Kuhn, 2004).

7.4.3 Fertility Status and Contraception After Breast Cancer Treatment

The fertility status of those participants who maintained or regained menstruation following breast cancer treatment was unclear, with participants who became pregnant stating they did not expect to be fertile. Hence health professionals need to help clarify the fertility status of YWBC following treatment and thus also need to address issues of contraception. As was demonstrated in this study, contraception may not be an immediate concern shortly after treatment; rather over time it became an issue. As posed in Chapter 5, these women need to be informed about, and have access to, reliable, suitable and safe contraception. This is an issue that may need to be revisited at various points along the illness trajectory continuum as fertility may be regained without the woman’s knowledge. In addition, it may be prudent to educate YWBC on alternative forms of contraception and their correct use for maximum protection, as an unplanned pregnancy after breast cancer may not only result in an unwanted pregnancy but also contribute to further emotional distress due to intensified recurrence fears. In consideration of the study findings in relation to fertility issues and contraception, the suggestions documented in Box 7.4 may help inform YWBC of these issues.

BOX 7.4: Suggestions to ensure YWBC are informed about contraception issues and methods.

- **The contraception needs of YWBC should not be ignored or underestimated by medical/health and allied professionals.**
- **Contraception issues should be addressed periodically throughout the illness trajectory, as fertility can be maintained or regained.**
- **A checklist could be developed and attached to the medical records of all premenopausal women who are diagnosed with breast cancer reminding medical/health care professionals that fertility may become an issue as time goes on. Due to records in many instances being computerised, this should be easy to implement. This checklist could record fertility-related hormonal levels and menstruation history, together with a record when last spoken to about reproductive choices, including contraception.**
- **Health promotion principles and strategies could be utilized to promote alternative, suitable contraceptive practices after breast cancer, similar to safe sex messages already developed.**
- **Marketing strategies, which have been found to impact on young women’s purchasing habits in the past, could be employed to highlight messages concerning contraception after breast cancer, making campaigns trendy/catchy.**

Box 7.4: Suggestions to ensure YWBC are informed about contraception issues and methods.

7.4.3.1 *Pregnancy and Breastfeeding after Breast Cancer Treatment*

Recent literature has found no correlation between increased risk of recurrence or new primary tumours and the hormonal changes of pregnancy (Collichio et al. (1998; Dow et al. 1994; Mueller et al. 2003); rather beneficial effects of breastfeeding to breast cancer risk have been documented internationally (Blakely et al. 2004; CGHFBC, 2002; Collichio et al. 1998; Mueller et al. 2003). The findings suggest that medical/health care professionals have not communicated this information clearly to YWBC as participants held great fears of further cancer activation being caused or accelerated by pregnancy and breastfeeding.

The current literature concentrates on the breast’s ability to lactate (Neifert, 1992; Petrek, 1994a) and largely neglects the psychosocial issues involved with breastfeeding after breast cancer. The findings from this study suggest that much more needs to be considered than the ability of the affected breast to lactate with regards to breastfeeding after breast cancer. (See Box 7.5 for suggestions for future research with regards to post-treatment pregnancy and breastfeeding issues.)

BOX 7.5: Focus of, and practical suggestions for, future research regarding pregnancy and breastfeeding after breast cancer.

- **What are the attitudes and beliefs concerning pregnancy and breastfeeding (and contraception) of YWBC?**
- **How do YWBC form their opinions and beliefs about post-treatment reproductive issues?**
- **What information sources are YWBC relying on concerning post-treatment reproduction issues?**
- **How do social norms and expectations of breastfeeding behaviour impact on post-treatment breastfeeding decisions and experiences of YWBC?**
- **What politics are involved in societal breastfeeding norms and practices? How does this impact on YWBC who have an infant after breast cancer?**
- **Is it possible that theories of ‘the illness experience’ and of the ‘social construction of the body’ may help unravel these issues and enhance understanding further?**
- **Is it possible that these women are feeling suspended between ‘the sick role’ and that of normalcy? It is possible that YWBC feel they do not fit in either category due to confusion over their health status.**
- **Surveys could be given to all YWBC at a predetermined time out from diagnosis, such as 2 months, to ascertain their level of understanding of what risk is associated with becoming pregnant, and subsequent breastfeeding, after breast cancer.**
- **This survey could inquire where YWBC received such information.**
- **An open-ended section of the survey could ascertain whom these YWBC would like to speak to about reproductive issues.**
- **Further qualitative research could be conducted with YWBC who become pregnant after breast cancer to explore what social and cultural influences impact on their experience of becoming pregnant and breastfeeding after breast cancer.**

Box 7.5: Suggestions for future research of pregnancy and breastfeeding issues of YWBC post-treatment.

In addition, health professionals need to rethink how they are communicating information about post-treatment reproduction and contraception. It may be useful to check if relevant health professionals understand the current position of the scientific literature in regards to pregnancies (and breastfeeding) after breast cancer treatment. Even so, finding ways to better inform YWBC will remain a challenge as numbers of young women developing breast cancer are few. (See Box 7.6 for questions that need to be answered in the future). Among the deficits of information reported by the participants (as seen in Figure 3.4), all issues related to reproduction after a diagnosis of breast cancer were found lacking. Hence Box 7.7 provides suggestions to assist medical/health and allied professionals, and the YWBC themselves, to increase their knowledge of pregnancy and breastfeeding issues post-breast cancer treatment.

BOX 7.6: Questions that need to be asked in the future concerning professional referral systems and communication.

- **How is the majority of reproductive information after breast cancer disseminated? Is it provided personally by health professionals or by lay information literature, or other sources/groups/persons?**
- **Could timing of information be an important consideration?**
- **Who do allied professionals refer YWBC to when questions need answering regarding pregnancy and breastfeeding after breast cancer?**
- **Are referral systems adequate and relevant?**
- **Who (what professional base) may be more qualified to inform YWBC of these matters, more easily understood by YWBC, and more in-tune with (can identify with) YWBC, to efficiently communicate with, and be understood by, YWBC.**

Box 7.6: Questions that need to be asked in the future to help improve professional referral systems and communication.

BOX 7.7: Suggestions to increase the knowledge of medical/health and allied professionals and YWBC of any associated risk related to pregnancy and breastfeeding after breast cancer.

- **Periodically provide a summary of up to date current scientific literature and findings surrounding risk associated with pregnancy and breastfeeding after breast cancer to medical/health and allied professionals.**
- **This summary could be published in various professional journals and newsletters, such as those sent periodically to various medical/health and allied professionals to capture a wide audience, such as reproductive specialists and their staff, GPs, obstetricians, oncologists and other cancer specialists, oncology nurses, breast care nurses and nurses in general, midwives and lactation consultants, and social workers.**
- **To develop a list of professionals who are deemed best to advise YWBC of reproduction matters, such as breast care nurses, lactation consultants, midwives, maternal and child welfare nurses, fertility specialists and their nurses. This list would be made available to all medical/health and allied professionals.**
- **Within States, such a list could include the name and contact details of these professionals.**
- **For wider dissemination, this list of professionals could also be supplied to the various breast cancer networks and support groups to have on hand if required.**
- **Web pages of the various breast cancer networks, support groups and organisations, such as the Australian Breast Cancer Network (a consumer group), 'Young Women's Network' QCF, and other states/territory's cancer organisations and their affiliated support groups, the Wesley Hospital (Brisbane) 'More Choices Program' and 'Young Women's Group', and the Australian Breast Feeding Association, could provide links to these professionals bodies and other relevant information.**

Box 7.7: Suggestions to increase the knowledge of medical/health and allied professionals, and of YWBC, of any associated risk related to pregnancy and breastfeeding after breast cancer.

It may be found that regardless of who informs YWBC of risks associated with pregnancy and breastfeeding after breast cancer, recurrence fears overrule everything else, even intellectual comprehension.

7.4.3.1.1 *Future Research*

Longitudinal, prospective studies may identify if the trend to conceive after breast cancer will have any detrimental effects on YWBC, their children and family and the population at large. In addition, as technology and treatment routines improve, leading to increased survival rates (Avis et al. 2004) in conjunction with the push to make treatments 'fertility friendly' (Dow & Kuhn, 2004), maintained and regained fertility is likely to bring with it increased demand for reliable, suitable and safe contraception. (See Box 7.8 below for additional research questions for the future.)

BOX 7.8: Additional future research questions regarding reproduction issues following breast cancer diagnosis and treatment.

- **What are the emotional, physical and public health implications of Assistive Reproductive Technology (ART) produced pregnancies of YWBC?**
- **Does the experience of an ART pregnancy differ to that of a natural pregnancy after breast cancer, if so how and why?**
- **Does this impact on mother/child health outcomes, breastfeeding decisions, expectations and experiences?**

Box 7.8: Additional research questions regarding reproduction issues following breast cancer diagnosis and treatment.

Much of the research to date has been hampered by small numbers of women achieving a pregnancy after breast cancer treatment, from which to draw conclusions of the associated risks. Hence future research should continue to monitor those women who become pregnant after breast cancer treatment to further knowledge in this field. High-profile young women who are diagnosed with breast cancer, such as Australian celebrities Belinda Emmit and Kylie Minogue, may help focus public and scientific attention to these issues in the future.

7.4.4 Relevant Social and Cultural Contexts

Participants' perceptions of social and cultural influences impacted on their experiences of the external portrayal of their bodies. In addition to sex-related issues being associated with treatment consequences, these concerns could be exacerbated by the cultural transition of breasts going from representing fertility to being considered a symbol of sexuality, thus the potential to affect sexuality following breast disfigurement (Beckmann et al. 1983b; Ghizzani et al. 1995). To be able to assist YWBC with their post-treatment lives, one must first understand not only the issues they face but also how and why such issues are experienced and interpreted.

As society tends to evaluate women by how they look and men by what they do (Fallon, 1994), women are generally more influenced and affected by their appearance (Golden, 1983). Studies have indicated that experiences of intrusiveness of illness among YWBC are significantly related to their body image and symptom distress (Bloom et al. 1998). While authors suggest possible reasons why YWBC may experience more negative consequences of breast cancer than their older counterparts, such as higher youthful aesthetic expectations (Schover, 1994), Chapter 6 suggests why this would occur using sociological theories.

As society changes, so too will the social expectations and norms bestowed on YWBC. However some views are entrenched in modern society (of Western cultural origin), such as male-dominated views of the sexual significance bestowed on breasts. Such a view has become a given in society (Berger & Luckmann, 1967) and hence internalised by participants. In addition, the current consumer culture of youth and beauty impacts greatly on how YWBC experience their illness trajectory (Broom, 2001). As social and cultural norms and expectations are imbedded in society (Berger & Luckmann, 1967), rather than trying to make society change, which could be a long-term goal due to the difficulty involved, it is better to help YWBC to reduce the impact of such social forces and processes on their lives in the short-term. YWBC need to feel comfortable and accepted within society whether they choose to conform to social norms and expectations (to wear prosthesis or undergo breast reconstruction) or not. Box 7.9 provides suggestions which may assist YWBC to adapt to social and cultural influences. Additional findings not reported in Chapters 4, 5 and 6, i.e., participants’ suggestions to assist young women cope with the treatment for breast cancer, inspired the development of the last three points in Box 7.9.

BOX 7.9: Suggestions to assist YWBC adapt to social and cultural influences.

- **Provide YWBC with an information pamphlet explaining in simple terms how basic social and cultural processes can impact on their experiences.**
- **On the back page of such a pamphlet, provide a list of tips which could help YWBC to lessen the impact of such processes on their lives, such as practice telling themselves in a mirror once a day that it is acceptable to have breast cancer at a young age, and that being different to other young women is neither bad nor shameful.**
- **YWBC need professional assistance, such as speaking with a counsellor, to accept their bodies' differences, to help them feel comfortable with whatever decision they make in regards to the use, or not, of prostheses or reconstructive surgery.**
- **YWBC could be encouraged to attend self-esteem/assertiveness workshops to help them to move past any issues they have with the external portrayal of their bodies.**
- **Rather than working on hiding or disguising their cancer/disfigurement/breastlessness, YWBC should be encouraged to focus their attention inwards, to help them to see themselves as more than just a body.**
- **A list of suitable motivational/inspirational books and videos, such as 'Spirited Women' by Petria King, could be compiled and made available via booklists on the internet, or from venues such as QCF or be made available via public libraries. YWBC need to be notified that these resources exist.**

Box 7.9: Suggestions to assist YWBC to adapt to social and cultural influences.

Breast symbolism, as an avenue of inquiry, was not an issue followed over time, rather it was an issue that appeared relevant to unravel participants' experiences which emerged via the various analysis stages undertaken. To understand the ongoing issues of body image, one must first understand how these women think and feel about their own breasts and breasts in general. By exploring the notion of breast symbolism various elements of social norms and expectations being bestowed upon participants were uncovered. Not only were participants' perceptions of societal norms and expectations related to having breasts, but also to what one must do to avoid social consequences of not adequately hiding/disguising breastlessness and/or other disfigurement. This is an issue of conforming to societal somatic norms to maintain normalcy as much as possible (Turner, 1992). Not only did male-dominated views of the sexual importance of breasts influence participants' experiences of breast cancer, but also elements of partners paternalism, in relation to their breastlessness and subsequent views and expectations of reconstructive surgery. From discussions of prosthesis use and breast reconstruction plans, experiences and expectations, it was clear that participants strived to increase their credibility within society (to be viewed as/considered normal), i.e., to be considered discreditable (possessing the potential to be discredited if their difference to what is considered normal was made public/found out) rather than discredited (their difference made public/found out), a notion put forward by Goffman (1963) on explaining issues of stigma.

The above-mentioned issues were entwined with how participants perceived their experiences of breast cancer to be different to that of older women with breast cancer. To be able to make information materials relevant to YWBC it must be first ascertained how this group of women perceive their experience to be different to that of older women.

Social and cultural forces hence surround and impinge on the participants' experiences; such forces make up the lens through which participants interpreted their experiences, reflecting social views and expectations (Douglas, 1970). Research in the future could focus equally on older women's experiences and a comparison made to that of younger women's experiences to truly understand the complexities of social and cultural influences in women's experiences of breast cancer. (See Box 7.10 for further future research suggestions.)

BOX 7.10: Future research suggestions concerning social and cultural influences on the experience of breast cancer.

- **Conduct a qualitative study to compare the post-treatment experiences of younger (aged 40 years or younger at diagnosis) versus older women with breast cancer.**
- **Issues explored could range widely – letting the participants lead the research with the objective to discover the biggest differences between the groups with regards to experiences. Small discrete, though important, differences may also be identified.**
- **To apply relevant sociological theories to the analysis to ascertain what social processes are at play, such as theories of the 'illness experience', the 'sick role', 'medical dominance', the 'social construction of the body', and 'feminist' theories.**
- **Subsequent quantitative research could then be carried out to measure the significance of any differences found within the qualitative study.**

Box 7.10: Future research suggestions concerning social and cultural influences on the experiences of breast cancer.

7.5 WHY IS IT IMPORTANT TO THINK ABOUT THIS AGE GROUP OF WOMEN SEPARATELY?

YWBC are worth studying as a specific group as their experience is physically and emotionally magnified compared to older women with breast cancer (Mor et al. 1994b). Also, by the evidence provided in this study, YWBC perceive that their experiences differ from that of older women specifically via social and cultural trends and processes. Unique concerns also are experienced by YWBC, i.e., reproductive issues. Not only does this study extend knowledge in this area (see earlier this chapter, section 7.4.3), but also asks further questions (See Box 7.5). In addition to studying the psychosocial issues of YWBC to improve their post-treatment lives, Dow and Kuhn (2004) suggest that YWBC may hold the key to unravelling possible causative factors for breast cancer due to their closer chronological proximity to puberty, i.e., to the commencement of their menses, which will decrease recall bias in future epidemiological studies.

Recently the National Breast Cancer Centre released ‘Clinical practice guidelines for the management and support of younger women with breast cancer’ (2004) thus demonstrating further that young women (defined as aged 40 years or younger at diagnosis, identical to this study) are indeed a specific group of breast cancer sufferers worthy of specific attention and research due to the profound impact the cancer and its treatment can have on their body image, sexuality and fertility status.

7.6 ADVANTAGES OF A LONGITUDINAL QUALITATIVE STUDY

As the new public health puts emphasis on not only describing people but also on understanding them, qualitative methods are relevant to this study as meanings and interpretations were the focus of this work (Rice & Ezzy, 1999). Undertaking qualitative research provides various advantages over undertaking quantitative work. Qualitative research is the desired method to use when studying a population that is not great in numbers (Berg, 1995). The number of young women who are diagnosed with breast cancer each year is approximately 6% of the total incidence (AIHW & AACR, 2003), hence a qualitative approach allowed the research to be undertaken with a good-sized, and diverse, participant pool. Quantitative studies are difficult to perform on this population, as their numbers are too small to ensure adequate statistical power for significance of results.

Qualitative research has been said to be more ‘fluid and flexible in its approach’ than quantitative work (Rice & Ezzy, 1999, p, 2). As consensus was not sought, ‘flexible’ qualitative research design allowed a heterogeneous group to be studied effectively (see earlier this chapter section 7.3 for details), as measurement, and subsequent statistical testing of commonalties, was not the aim of the study. In the development phase of this study a participant pool of 25 was thought sufficient to undertake a substantial PhD study. More potential participants volunteered to take part in this study than were needed, however considering the consumer nature of this research and due to the flexibility of qualitative work (Miles & Huberman, 1994), all those who were eligible were included. Participants were not always available at prearranged times for interviews, as sometimes they were too ill at that time; again the flexibility of qualitative work allowed the interviews to be rescheduled without disrupting the flow of the study. As analysis was ongoing throughout the study, with one interview phase informing the next and so on, the flexibility allowed by qualitative methods enabled the research focus to shift as required to capture the lived experiences of the women.

Throughout the study, topics were included and excluded as necessary. All interview question guides were both uniform and individual. Topics, which had the most relevance to specific participants were followed comprehensively, while the relevance to other participants was weighed and in some cases topics were not pursued, e.g., certain lines of inquiry, such as raising issues of sexuality with someone who had advanced disease and was easily upset, were left entirely to the woman to bring up rather than overtly queried. Qualitative design also allowed the participants to be studied in depth and detail (Patton, 1980), examining the nature of social phenomena, and data collection was conducted in participants' own natural environments, another feature of qualitative research (Mays & Pope, 2000). Additionally, qualitative research undertaken in natural settings studies phenomena in the local context and takes it into account rather than having the context stripped away (Miles & Huberman, 1994). Connecting participants' meanings of their experiences to that of the social world was also allowed by the use of a qualitative design (Miles & Huberman, 1994).

7.6.1 What Was Found Longitudinally That Would Not Have Been Found Otherwise?

If this study was conducted using only one time point to collect data, much would have been missed. For instance by studying the participants over time the researcher was able to follow their changing fertility status and hence follow pregnancies, some right through to breastfeeding and beyond. This was a particularly fruitful and interesting avenue to pursue. Additionally the researcher was able to follow the reconstruction thoughts, i.e., decisions, expectations and experiences, of participants over time. If this study was not conducted longitudinally, the outcome of some of these issues would have been missed. The consequences of early menopause was another fruitful aspect to follow over time, as sex-related difficulties reported by some participants resolved with time while for others these issues escalated, threatening intimate relationships.

The longitudinal nature of the study allowed not only issues to be followed over time, but also allowed new issues to be gathered along the way. At times participants made profound statements that ignited the researcher's curiosity, i.e., how do the other participants feel, think, about this? For example, P16 stated in the second interview how she felt her experience was different to that of older women, that the older generation were raised in a different way in a different time hence their experiences were likely to differ. From this comment the researcher lunged into issues of generational differences – how participants felt their experiences were different to that of their older counterparts. This proved, too, to be a fruitful avenue of inquiry. These types of instances also allowed the researcher to think creatively and abstractly about the reasons why the participants felt the way they did. Hence the longitudinal design of this study allowed the boundaries of the study focus and analysis to be stretched as much as possible.

Between each interview phase, preliminary analysis of data was conducted, therefore each interview phase informed the next. Also the longitudinal aspect of the study allowed reliability checks on much of the data to be performed, such as age at diagnosis and marital status and more at subsequent interviews. Together with these reliability checks, preliminary validity checks were also performed by paraphrasing issues back to participants throughout the interviews, together with taking findings back (from previous interview/s) to participants to check, and increase, the understanding of participants' meanings (see Chapter 3 sections 3.4.6.1 and 3.4.7.1 for more details). This proved fruitful, as interpretations were, at times, incorrect.

Several examples summarising the temporal advantages for individual participants follow.

Example 1: P8 at interview 1 was extremely sarcastic and upset very easily. Considering this participant had advanced disease I felt her responses were justified, however in the subsequent interviews I found out that this participant was in great pain at first interview and did not disclose this to me, hence darkening her responses.

Example 2: P35 also was very distressed at first interview (a telephone interview). Considering this participant's diagnosis and prognosis, I was a little puzzled why she was so distressed. At the next interview this participant announced she was almost ready to have a baby – she was in early pregnancy at the first interview, struggling with the decision whether or not she should terminate the pregnancy (P35 was diagnosed with breast cancer while breastfeeding her first child, hence heightening her fears). In addition I found out this participant had a strong Catholic background, which further caused her much grief regarding this decision.

Example 3: P10 was also extremely distressed at interview 1 due to her breast loss. This participant had just begun reconstruction processes (expander in) at interview 1. I put this level of distress down to that fact she was only five months out from diagnosis and had not yet adjusted to her situation. However over the following two interviews, though her distress level dropped considerably, I found, via in-depth investigation, that this participant always had issues with her breasts – she was never happy with her natural bust-line, feeling it was too small. Hence having breast cancer and losing a breast exacerbated her feeling of low self-worth.

Much of what was disclosed in interview 1 was reported retrospectively, i.e., events and feelings from diagnosis to the day of interview, however current issues were also captured, such as how participants were feeling emotionally and physically at that point in time. From there the study was prospective. As interviews were mostly six months apart (with some 12 months) at any given time, the participants were not very far (in time) away from any occurrences (physical and/or emotional) since the previous interview – hence there was less chance of recall problems affecting the validity of the study.

It was often the case that participants did not answer all questions directly, and during the interview process this was often missed, though identified during analysis.

This allowed the researcher to be creative and attempt to represent the topic to the participant in a different way (after getting to know participants this became easier) to have a better chance at having the question answered. Also gaps in the stories of participants were identified, or sometimes data did not seem to match events, hence subsequent interviews allowed missing data to be captured and areas in question clarified.

7.6.1.1. Rapport

Undertaking a longitudinal qualitative study allowed me to build an excellent level of rapport with the participants, i.e., due to the one-to-one in-depth interviews together with the number of times I communicated with participants (whether by telephone or email to arrange interview times or other necessary correspondence). I felt this rapport was built equally with those participants who I interviewed via the telephone. I disclosed information about myself, at times, that was relevant to participants' stories (trying to find common ground). This also assisted with rapport building, as I was able to identify with participants (or they could identify with me). In addition, I was 40 years of age and married with three (near adult) children when I began the interview process; these facts also assisted with rapport as participants were 40 years of age or younger at diagnosis. In addition, the follow-up participants may have felt special in some way because they were chosen to be interviewed twice more; this also helped build rapport as they may have felt that I saw their experiences worthy of further exploration for the further good of young women diagnosed with breast cancer in the future.

This rapport allowed participants to quickly relax into subsequent interviews, and as each interview unfolded, more rich (intimate) data were disclosed. Selected participants were sent two summaries of findings to allow them to provide feedback concerning the study findings; it could be also assumed that the rapport built impacted on the high level of return of these documents (refer to Chapter 3 section 3.4.9.3 and Appendix 3.12 for further details of validation processes and documentation). Not only did the rapport make participants feel more at ease to disclose more in-depth information but also allowed me (via my increased level of comfort) to ask more personal questions. Getting to know the participants and their personalities helped in this regard. This level of rapport would not have occurred in a study that entailed one data collection time.

7.7. MEETING AIMS OF STUDY

Aim 1. Overarching Aim – To explore problems faced by young women with breast cancer.

Research Question: What problems/issues do young women with breast cancer experience?

The overarching aim of this study was met as the main issues and concerns of YWBC were identified and reported specifically within Chapters 4, 5 and 6 and within the discussion chapter (Chapter 7).

Aim 2. To identify what influences the way in which young women with breast cancer experience their illness trajectory.

Research Question: How do social networks of, and the professional and lay services utilized by, young women with breast cancer assist or hinder them to adjust to their diagnosis?

This aim was met; however rather than being reported in its own right, it is discussed in relation to the topics explored and reported on. Some elements of such professional and lay services were discussed in relation to participants' experiences within Chapter 4 generally and Chapter 5 specifically (in relation to reproductive matters) and elaborated on within the discussion chapter (Chapter 7).

Aim 3. To follow over time young women's perceptions of their illness experience.

Research Questions: Do young women with breast cancer experience a change over time in their perceptions of the problems/issues they face? If changes are identified, why does this occur and what internal and external factors are responsible for such changes?

This aim was achieved throughout the last two phases of the study. Changes over time in participants' experiences are documented and explained within Chapters 5 and 6. The discussion chapter (Chapter 7) elaborates on findings not reported in the three results chapters (Chapters 4, 5, and 6). In particular, Chapter 6 discusses in-depth much of the internal and external factors responsible for some changes of experiences in relation to body image.

Aim 4. To identify the major issues faced by young women with breast cancer as a basis for recommendations of appropriate service provision, such as support and/or educational materials provided by health professionals (this term encompasses clinicians, public health and other allied and care professionals and support organisations).

Research Questions: How can the experiences of young women with breast cancer inform the redesign of health services and resources to match consumer needs? What information is specifically required by young women with breast cancer?

This aim has been reached. Boxes 7.1, 7.2, 7.3, 7.7 and 7.9 found within the discussion chapter (Chapter 7) provide many suggestions to improve the psychosocial outcomes of YWBC. Suggestions have been made within Boxes 7.4 and 7.8 concerning improving not only professionals' knowledge of possible issues experienced by YWBC, but also improving and formulating new information/educational materials. Implementing these suggestions is outside the requirements of this thesis, however dissemination of this information, to the relevant medical/health and allied professionals, by conference presentations, publications in academic/health and professional journals and various professional/department newsletters, is needed and will be pursued.

7.8 STRENGTHS AND LIMITATIONS

The strengths of this study emerge from the design and methodology utilized, that of a qualitative, longitudinal design (as explained earlier in section 7.6). Much was revealed in this study that may not have been found in a single data collection study design or via quantitative methods. The methodology chapter (see all Chapter 3) comprehensively details the theoretical framework of this study together with providing an audit trail of all processes undertaken, thus providing transparency enhancing the study's trustworthiness, as did findings which confirmed those of others further (as detailed in Chapters 4, 5 and 6).

Limitations have been documented within Chapters 4, 5 and 6. Recall bias was a relatively minor limiting factor mostly evident at the first interview phase as participants spoke (mostly) retrospectively of their experiences. As respondents volunteered to participate, self-selection bias must be taken into account. Many aspects of the possible pitfalls of qualitative research are documented in the methodology chapter (see Chapter 3 sections 3.4.10), and were considered throughout the data collection, analysis and write-up procedures. Attention was paid to rigour throughout the study process and is documented in section 3.4.10. The limited generalisability of the findings, an issue for all qualitative research, has been documented within all three results chapters (Chapters 4, 5 and 6), although possible avenues of transferability are suggested. Regardless of all limitations encountered, this study identified, explored and explained the experiences, issues and concerns of a wide demographic range of YWBC (see earlier section 7.3).

7.9 FUTURE RESEARCH DIRECTIONS

It is important to establish the separate needs of YWBC. Ongoing research could be focused on ascertaining if the needs of YWBC are met in the future, and should examine how ongoing information developments can be kept up to date in a co-ordinated way. In addition, the issue of maintained or regained fertility after breast cancer brings with it a much-needed area requiring future research, especially due to advances in ART and the trend to delay childbearing thus creating further potential for women to be diagnosed with breast cancer at an age when they still desire to have (more) children (Dow & Kuhn, 2004). Areas of further investigation could look at suitable, safe and reliable contraception options and education, together with issues surrounding pregnancy after breast cancer, including the risk associated with a pregnancy after breast cancer, how best to educate YWBC about the scientific facts, and psychosocial issues of breastfeeding after breast cancer. Future research could also look more deeply into social and cultural norms, expectations and processes that impact on and/or influence the experiences of YWBC. As social and cultural trends change, research should attempt to keep abreast of how the changing fabric of society impacts on the experiences of YWBC. More specific details of proposed future research can be found in Boxes 7.5, 7.6, 7.8, and 7.10.

7.10 CONCLUSION

In agreement with the literature (BCNA, 2001; Brock & Perry, 1995; Davis-Ali et al. 1993; Northouse, 1994; Siegel et al. 1999; Ghizzani et al. 1995; Pistrang & Barker, 1995; Spencer et al. 1999*)*, this study found that second to recurrence and death fears, partners and children were participants' major concern. Rather than dealing with specific concerns surrounding children (already born), Chapter 5 focuses on future children of YWBC, i.e., issues of fertility, pregnancy and breastfeeding after breast cancer treatment. The findings of this chapter demonstrate that the reproductive issues after breast cancer treatment do not solely hinge on infertility caused by treatment effects. Chapter 6 delves deeply into the social and cultural processes and influences that impact on participants' experiences, in particular in relation to breast symbolism, generational differences, and the external portrayal of their bodies, incorporating body image issues. The social and cultural environment in which participants' experienced their breast cancer was pivotal in the development of their perceptions of their experiences.

This study provides additional detailed knowledge about YWBC, both confirming and extending research available in the literature. The challenge now is to use this information so the questions and uncertainties for YWBC can be answered, and wherever these young women may be, someone can point them in the right direction.

APPENDIX 1

LITERATURE REVIEW SUMMARY TABLES

The documents which make up Appendix 1 are presented in the order as follows:

Page

APPENDIX 1.1: Breast Cancer and Other Serious Illnesses in Pregnancy Studies

Table A1.1: Breast cancer and other illnesses in pregnancy studies.

Author/Date/ Country	Title	Research Design/ Methods	Sample Characteristics	Conclusions

Guinee, V. F. et al. (1994) USA Though study participants came from a variety of countries.	Effect of pregnancy on prognosis for young women with breast cancer.	Study – Quantitative Retrospective
		Clinical presentation and course of breast cancer was documented from 9 cancer centres – looking at history of pregnancies, before, during and after the breast cancer diagnosis. At each centre records were reviewed from Nov 1991 – Feb 1992.
			n=407 women, aged 20-29 years who registered between 1978 and 1988 at one of nine cancer centres.
			n=87 Houston;
			n=79 New York;
			n=53 Moscow ;
			n=51 Rotterdam;
			n=49 Amsterdam;
			n=44 Bordeaux;
			n=19 Lund;
			n=15 Mount Vernon;
			n=10 Buffalo
				For those women diagnosed during pregnancy, the risk of dying from the cancer was significantly greater than that of those who had never had a pregnancy (relative risk 3.26 [95% CI 1.81-5.87], p=0.0004). Adjustment for number of axillary node involved and tumour diameter reduced relative risk only slightly (2.83 [1.24-6.45] p-0.023). Previous pregnancies decreased the risk of dying by 15% for each year further away from diagnosis (relative risk 0.85, p=0.011). Recent or concurrent pregnancy adversely affects survival of young women who are diagnosed with breast cancer. The size of the effect is so large it probably contributes substantially to the poor prognosis of breast cancer in this age group as a whole (p, 1587).

Petrek, J. A. (1994a) USA	Breast cancer during pregnancy.	Report 93 references – 1929-1993 Extensive report covering: incidence; problems of biopsy; considering the foetus & RT; staging procedures; breast preservation; chemo; metastatic disease in foetus and placenta; anaesthetic considerations; therapeutic abortion; prognosis; and steroid hormone receptors.		Pregnancy-associated BC provides a worse prognosis, but only because it is associated with more advanced disease at presentation.

Gemignani, M. L. & Petrek, J. A. (2000) USA	Pregnancy-Associated breast cancer: Diagnosis and Treatment	Report – Dilemmas in Breast Disease 53 references – 1929-1999 Covering: diagnosis, treatment and prognosis.		Pregnancy associated BC has a poorer prognosis, though this could be because of advanced disease at presentation. When matched with non-pregnant controls there is an equal survival rates, at least in the early stages.
Moore, H. C. F. & Foster, R. S. (Jr) (2000) USA	Breast cancer and pregnancy.	Essay 41 references – 1962-1999 Covers: pregnancy and breast cancer risk; diagnosis; prognosis; local and regional therapy; systemic chemo; adjuvant hormonal therapy; metastases during pregnancy; long term effects for offspring; pregnancy after BC.		Pregnancy associated BC is similar in prognosis to those diagnosed non-pregnant when matched for age and stage. However BC is often diagnosed in a more advanced stage in pregnant women, thus providing a generalised view that BC diagnosed during pregnancy provides a poorer survival rate. Breast surgeries can usually be performed safely (for the foetus), in particular in the 2nd and 3rd trimesters, as is the relative safe administration of doxorubicin-based chemo. RT generally should be avoided during pregnancy. RT can be delayed following surgery until after delivery of baby. No evidence exists to advise therapeutic termination to increase survival. The course of BC does not appear to be affected by continuing, or subsequent, pregnancies. Recurrence risks after a 2-year period should be disclosed to YWBC. Fertility may be affected by treatments.

Schover, L. R. (2000) USA	Psychosocial issues associated with cancer in pregnancy.	Report – cancer in general 22 references – 1990-1999 Covering: emotional impact of a cancer diagnosis during pregnancy; making a decision about pregnancy termination; concerns about the future – children's health - desire to reproduce -Pregnancy after cancer anxiety.		A cancer diagnosis during pregnancy is a medical and psychosocial crisis. Post cancer treatment, women often have to deal with fertility concerns and/or issues of subsequent pregnancies causing medical complications. Concerns about the child's future health are evident, that of development, deformities and subsequent cancers in the child. Infertility problems may be overcome with the aid of reproductive technologies or adoption, though both of these methods: involve complex psychosocial adjustment, often require long waiting periods; and are expensive and unlikely to be in the reach of most people. Those who are fertile, pregnancies after cancer can cause many medical complication hence consultation with a high-risk obstetrician is advised prior to conception.
Middleton, L. P., Amin, M., Gwyn, K., Theriault, R. & Sahin, A. (2003) USA	Breast carcinoma in pregnant women: Assessment of clinicopathologic and immunohistochemical features.	Histologic review and immunohistochemical evaluation to determine the status of prognostic and predictive markers including estrogen receptor (ER), progesterone receptor (PR), Her-2/neu, Ki-67, and p53. Medical records also reviewed. Follow-up information was available for 35 participants from 2-163 mths (M=43 mths). 27 references – 1981-2003.	n=39 women with BC, aged 24-44 (M=33 years) n= 38 diagnosed during pregnancy and n=1 diagnosed 12 days post-partum. 32 found a mass, 1 bloody nipple discharge, 1 diffuse erythema (inflammatory BC). At diagnosis: 2@ stage I, 19@ stage II, 16@ stage III, 2@ stage IV.	Women who present with BC in pregnancy generally have advanced-stage disease, and the tumours have poor histologic and prognostic features. Follow-up data indicated that these tumours do not follow an aggressive clinical course as has been proposed in earlier studies. BC presenting in pregnancy shares many histologic and prognostic similarities with that found in BCs in other young women.

Puckridge, P. J., Saunders, C. M., Ives, A. D. & Semmens, J. B. (2003) Australia	Breast cancer and pregnancy: A diagnostic and management dilemma.	Literature Review 51 references – 1943-2001 Purpose: review current knowledge of pregnancy concurrent with a diagnosis of BC, how best to manage these women, and women who conceive subsequent to BC. Covering: Gestational BC - incidence and diagnosis pathology, management; and subsequent pregnancies		Most research of this topic comes from small, specialized institutions and may not reflect what occurs in the wider community. The literature suggests an incidence rate between 0.7 and 3.9% of gestational BC. The prognosis of these women is thought to be similar to that of non-gestational BC sufferers, except when cases have a delayed diagnosis is associated with advanced disease. Treatment is similar to that of non-gestational BC sufferers, with the exception of contraindications of RT in pregnancy and chemo in first trimester. For those who conceive after a BC diagnosis, no worse pregnancy or BC outcomes are expected, though not many women conceive post-diagnosis, thus minimal data is available.
Woo, J. C., Yu. T. &, Hurd, T. C. (2003) USA	Breast cancer in pregnancy.	Literature Review 95 references – 1943-2001 Obj – to review the literature on diagnosis, staging, treatment and prognosis. Covering: imaging; diagnosis; genetics; pathologic characteristics; treatment – irradiation, chemotherapy, hormonal therapy; prognosis.	More than 100 articles were reviewed, including 7 prospective and 40 retrospective studies, 6 case-reports and at least 47 review articles on various aspects of pregnancy and cancer.	Diagnostic delays, though still common, are shorter than in the past. Mammography has a high false-negative rate during pregnancy. Pregnancy-associated BCs tend to occur at a later stage and be estrogen receptor-negative. When matched for stage and age, pregnancy associated BC has a similar prognosis to other BCs. RT is contraindicated during pregnancy, as is chemotherapy in the first trimester. Tamoxifen may need to be avoided throughout the entire pregnancy, or at least the first trimester.

Thomas, H. (2004) UK	Women’s postnatal experience following a medically complicated pregnancy.	Study - Qualitative 10 references 1979-2000 Recruitment – One hospital in the South of England. Explored ways in which women resolved or continued to endure and manage health problems beyond pregnancy and consider the variable levels of help given by their health care providers (p, 78). In-depth interviews	n=15 women delivered a baby in previous year to study, either was ill prior to the pregnancy or became ill during the pregnancy – all participants were public patients (received all their care from the National Health Service). (No participants had BC). 8 different illnesses recorded of the 15 participants.	Themes found – regaining normality; feelings of neglect or abandonment; and possible future threats to health. This study displays the importance of considering the health of the mother after the birth. These women often found hospital policy in areas such as delivery and breastfeeding to be a rigid system, without scope for individual experience (p, 86). The mediatisation of normal childbirth, which also encompasses the hospital as the organisational site, the needs of women with continuing medical problems can become lost amongst what is considered to be normal. Postnatal events and processes are consequential rather than substantive (p, 87).

Table A1.1: Breast cancer and other serious illnesses in pregnancy studies.

APPENDIX 1.2: Family Studies

Table A1. 2: Family studies.

Author/Date/ Country	Title	Research Design /Methods	Sample Characteristics	Conclusions
Davis-Ali, S., Chesler, M. &Chesney, B. (1993) USA	Recognizing Cancer as a Family Disease: Worries and Support Reported by Patients and Spouses	Comparative Design: Mailed Questionnaires (some open ended questions) and Group Interviews Quantitative (Mostly)	n=91 adults with cancer and 78 spouses of adults with cancer Mostly completed secondary education; Income around $22,000 a year, 84% married Cancer Sufferer mean age = 52.3 years (52% female, 48% male) Spouse mean age = 53.1 years (64% female, 36% male)	Persons with cancer and their partners report participating equally in the treatment process – though cancer sufferers report receiving significantly more social support. Suggests that cancer should be conceptualised as a family disease, rather than purely individual.
Lewis, F., Hammond, M. & Woods, N (1993) USA	The Family's Functioning with Newly Diagnosed Breast Cancer in the Mother: The Development of an Explanatory Model	Part of a 3 year longitudinal study, Exploratory Study, Self Report Questionnaires: Path Analysis Quantitative	n=40 well-educated, middle class families with a young school-age child. Average age of women with breast cancer = 39.32 years, average age of partners = 41.25 years, Median length of time since initial diagnosis 13 months Children aged from 6-12 years,; Mean age of children = 9.28 years	More frequent illness demands. were associated with high levels of depressed mood. A less well adjusted marriage negatively affected the family's coping behaviour. Heightened coping activity and higher levels of marital adjustment positively affected household functioning. Those families who coped more frequently with their problems and in which the non-ill parent more frequently interacted with the children, heightened children's functioning.

Dow, K., Harris, J. & Roy, C. (1994) USA	Pregnancy After Breast-Conserving Surgery and Radiation Therapy for Breast Cancer.	Case-Matched Study Mailed survey of two self-report quality of life instruments – including an evaluation of satisfaction with and importance of health, family, social well-being and psychological well-being. Quantitative	n=23 matched sets of young women with breast cancer. Caucasian 96%; married, 96%, some college education 77%, working 70% - Control group similar except 38% married. Mean age = 30.4 years (25-37 years)	With relation to family – Those with subsequent pregnancies perceived family issues had greatest impact on QOL. Young women who have had breast cancer are at no higher risk for parental stress due to the cancer than the normal population
Hilton, A. (1994) Canada	Family Communication Patterns in Coping With Early Breast Cancer.	Longitudinal Semi-Structured Interviews conducted at diagnosis and at 4 points after diagnosis Qualitative: Grounded Theory Triangulated with Quantitative Design	n=41 (partnered) families Women newly diagnosed at stage I or II breast cancer. Majority of women less than 55 years of age, 1/5 were older than 65 years of age 80% partners under 55 years of age, 20 % older than 65 years of age. Duration of relationship range 1 – 35 years 20% had no children and 33% had children at home, almost 50% had adult children living elsewhere. Cultural groups represented: Canadian, Chinese, Japanese, Portuguese and German. Middle class.	Younger age group mostly were talkers, as compared to median talkers and non-talkers. Communication was enhanced if both partners shared similar views of the importance of talking. Three themes emerged: discussion patterns about fears, doubts and emotional issues.

Mor, V., Malin, M. & Allen, S. (1994) USA	Age Differences n Psychosocial Problems Encountered by Breast Cancer Patients	Secondary analysis of data from 2 other studies Quantitative	Analyzed breast cancer data only n=262, 143 aged 24-54 119 aged over 55 years – Of younger age group: -67.7% married; 53.2% some college; 49.7% family income .$30,000; 10.2% non-white; 59.9%Children living at home; 31.7% children live near-by.	Younger women report significantly more unmet needs across all domains- significantly greater difficulty tolerating treatment and maintaining daily routines. Concerns of financial needs of children, as often primary care giver and bread-winner.
Lewis, F. & Hammond, M. (1996) USA	The Father's, Mother's and Adolescent's Functioning with Breast Cancer.	Part of Longitudinal Path Analysis Data Obtained from 2 Consecutive studies – this article derived from occasion 2 out of 5 occasions Self-Report Questionnaire Quantitative	n=70 mother with breast cancer, Mean age = 42.9 years and 70 spouses/ partners, Mean age = 46.9 years and 70 adolescents, Mean age = 16.3 years (44.3% male, 55.7% female). Mean length of time since diagnosis = 23.6 months Medium as above = 18.5 months. Women and their partner were well-educated and middle class	Low parenting quality associated with low self-esteem in adolescents Higher levels of illness demands perceived to impinge on the family predicted higher levels of depressive mood in the woman, poorer marital adjustment and lower parenting quality.
Ferrell, B., Grant, M., Funk, B., Otis-Green, S. &Garcia, N. (1997) USA	Quality of Life in Breast Cancer Survivors as Identified by Focus Groups	Focus Group Methodology and Semi-Structured Individual Interviews 3 focus groups – age grouping <40 years, 40-60 years and >60 years - intended to represent different developmental levels. Qualitative	n=21 women, age range 22-71 (M=50 years) 62% Caucasian, 13% Hispanic, 13% African-American and 13% other ethnic groups. Annual income levels varied between $30,000 to over $40,000. Time since diagnosis 16-71 months.	Absence of support for their families often resulted in their children believing that the diagnosis of breast cancer meant certain death. Hope needs to be created for the family. Each sub-group within the family needs specific assistance to cope with the breast cancer diagnosis – such as the woman diagnosed, her children and her partner. Difficulties relating to sexual matters were also highlighted.

Spencer, S., et al. (1999) USA	Concerns About Breast Cancer and Relations to Psychosocial Well-Being in a Multiethnic Sample of Early-Stage Patients.	Questionnaire Quantitative	n=223 women with early stage breast cancer Age range 27-87 years (M=53,75 years) Selected at 3, 6, and 12 months post surgery 210 English Speaking : 13 Spanish Speaking 151 White; 48 Hispanic; 24 African American Average education 14.39 years. 157 in partnered relationship; 29 separated/divorced; 24 widowed; 13 single.	Financial concerns for children’s future – dealing with medical bills. Sexuality and relationship concerns in younger women (not defined).
Wang, X., Cosby, L., Harris, M. & Liu, T. (1999) USA	Major Concerns and Needs of Breast Cancer Patients.	Questionnaire via Interview Quantitative	n=102 women with breast cancer between 1989-1991 86 White, 16 non-white Marital status; 4 Single; 70 Married; 8 Widowed; 18 Divorced/separated; 2 unknown. Health Insurance: Yes 95; 7 No.	Women’s concerns in order of importance: family; health; future; finances/work; and self esteem. Younger women (<50 years) report greater concerns about finances and work and self-esteem compared to older women. Younger women play an important role in the family, economy and social activity.
Hilton, A., Crawford, J. & Tarko, M. (2000) Canada	Men’s Perspectives on Individual and Family Coping with Their Wives’ Breast Cancer and Chemotherapy.	Semi-Structured Interviews Participatory Action Research Qualitative	n=10 spouses/partners of women with breast cancer Spouses/partners age range 39-58 years (M=47.1 years). Women with breast Cancer age range 39-51 years (M=45.3 years. 1-4 children in families, age range 4-28 years (M=12.3 years). English Speaking Caucasians	2 major themes identified: focusing on a wife’s illness and care; and focusing on the family to keep life going. Men’s major concerns – being marginalized, not being informed – don’t know what to expect, feelings of helplessness, not sure how to assist spouse – particularly in the domestic domain, unprepared for financial burden of illness.

Table A1.2: Family studies.

APPENDIX 1.3: Couples/Spouses/Partner Studies

Table A1.3: Couple/spouses/partners studies.

Author/Date/ Country	Title	Research Design/ Methods	Sample Characteristics	Conclusions
Sturesteps, V. & Darroch, R. (1986) Australian.	Adjustment and Mastectomy: The Experiences of Husbands.	Questionnaires, some open ended Quantitative and Qualitative	n=41 couples Men's age at wives' mastectomy 26-72 years (M=44.49 years) Women's age at mastectomy 27-69 years (M=41.8 years) length of marriage 3-41 years (M=18.2 years) time since mastectomy 3 months – 26 years Number of children still at home 1-4. A slight mix of ethnic groups.	Husbands need information –aspects of breast cancer and psychological reactions. Speaking to other couples who had experienced breast cancer was more helpful than talking to professionals. Some problems with children – no help sought specifically. Most practical help – family. Sexual behaviour severely affected in first year post surgery – improved with time.
Lewis, F., Woods, N., Hough, E. & Bensley, L. (1989) USA	The Family's Functioning with Chronic Illness in the Mother: the Spouse's Perspective.	Part of a longitudinal study Data from 2nd occasion Exploratory Study Standardized Questionnaires – self-administered Path Analysis Quantitative	n=48 fathers with young school-age children whose wives had breast cancer, diabetes or fibrocystic breast disease (FBD). Average age: Men 39.46 years; Women 37.79 years Average age of spouse of breast cancer suffer 39.63 years; FBD 40.12 years; and diabetes 38.38 years	Partners of women with breast cancer had higher levels of marital adjustment. Higher illness demands resulted in higher depression scores. More depressed spouses had lower levels of martial adjustment.

Zahlis, E. & Shands, M. (1991) USA	Breast Cancer: Demands of the Illness on the Patient's Partner.	Demands of Illness Interviews Qualitative	n=67 partners of women with breast cancer Age range 28-63 years (M=43.7 years) Average number of children living at home 2 (1-5) 84% white, 62% employed, 86.4% tertiary educated, Middle-class.	Role Identities can change- involving a challenge – domestically. These partners requested further information of the disease and its treatment. Partners suffer (subjectively) a significant impact from his wife/partner having breast cancer.
Ghizzani, A., Pirtoli, L., Bellezza, A. & Velicogna, F. (1995) Italy	The Evaluation of Some Factors Influencing the Sexual Life of Women Affected by Breast Cancer	Semi-Structured clinical interviews – follow up blood test (for hormonal imbalances which could explain loss of sexual desire) Qualitative	n=50 women, 28 had regular menses, 22 were menopausal, mean age 59 years (45-72) 1st group – mean length of relationship 18 years, 2nd group mean length of relationship 35 years.	Older women accept breast cancer easier than younger women (those who still regularly menstruate). It is the husband's loving attention which help overcome sense of inadequacies, younger women had longer periods of distress, ability to accept breast cancer hinged on intimacy level with spouse.
Pistrang, N. & Barker, C. (1995) England	The Partner Relationship in Psychological Response to Breast Cancer.	Part of a longitudinal study Structured Interviews and a questionnaire Quantitative	n=113 women diagnosed within previous year, mean age 53 (24-73), 60% married or partnered, 2 were gay, mean length relationship 21 years (1-51 years), 45 women with out partners of which 14 were widowed. Time since surgery 10-58 weeks (M=28 weeks)	Social support, other than that supplied by partner, did not compensate for partner specific support if such was not forthcoming. Satisfaction with partner helping relationship associated with psychological well-being. Partners play an important role in the adaptation of the women to breast cancer.
O'Mahoney & Carroll, R. (1997) USA	The Impact of Breast Cancer and Its Treatment on Marital Functioning.	Literature Review (80 References)	Reviews literature surrounding the impact of the breast cancer, and its treatment, on the woman with breast cancer and her marital relationship.	Breast cancer impacts on the husband as well as the wife. Suggest that the strongest predictor of the impact of the cancer experience is the quality of the relationship prior to the diagnosis. Sexual relationships, role identities and communications of the couple are impacted upon by breast cancer.

Pistrang, N. & Barker, C. (1998) England	Partners and Fellow Patients: Two Sources of Emotional Support for Women with Breast Cancer.	Observational – Exploratory Study 2 recorded conversations (10 minutes) – one with a volunteer helper and one with the patient's partner. + questionnaire about perception of the conversation Quantitative	n=26 breast cancer patients Diagnosed in previous year Patient maximum age 55 years (M= 43 years, 28-55 years). Partner mean age 44 year (30-60 years). Volunteer Helpers maximum age 55 years (M=46 years 33-55 years) diagnosed within 3.5 years – treatment finished. Volunteer Helper matched as much as possible to patient (within 10 years age gap)	Volunteer Helper most helpful to patient if patient was greatly depressed. Volunteer Helpers and women with breast cancer differ in their view of what is helpful.
Spencer, S. et al. (1999) USA	Concerns About Breast Cancer and Relations to Psychosocial Well-Being in a Multiethnic Sample of Early-Stage Patients.	Questionnaire Quantitative	n=223 women with early stage breast cancer Mean age 53.75 years (27-87) Selected at 3, 6 and 12 months post surgery Tri-ethnic Sample 157 women married or partnered relationship, 29 separated/divorced, 13 single.	Younger women had stronger sexual and partner-related concerns than older women. Worry they won't live out relationships. Life, pain and sexual concerns contributed to emotional and psychosexual disruptions.
Weihs, K., Enright, T., Howe, G. & Simmens, S. (1999) USA	Marital Satisfaction and Emotional Adjustment After Breast Cancer.	Longitudinal Questionnaire Assessment Quantitative	n=44 couples Women's mean age 49.9 years (34-81 years), Each couple had at least 1 child 10 years of age or older. Caucasian – 70.5%, African American 25%, Hispanic 2.3%, Asian 2.3%. Marital status – 93.2% in first marriage, 6.8% in second marriage. Tertiary Ed 88.6%	It is a woman's perception of the marital relationship which influences, + or - ,her distress, not the spouse's. A satisfying marital experience is related to less stress in the long term. Suggested that marital satisfaction could be used as an indicator of a breast cancer sufferer's distress trajectory over time.

Bultz, B., Speca, M., Brasher, P., Geggie, P. & Page, S. (2000) Canada	A Randomized Control Trial of a Brief Psychoeducational Support Group for Partners of Early Stage Breast Cancer Patients.	Randomized Control Trial Intervention Study Psychoeducatonal Program for Partners Only 15 Partners randomized into intervention group. Pre-test, Post-test and at 3 months follow-up. Quantitative	n=34 patients with breast cancer and their partners Breast cancer sufferers' mean age 50 years (35-61 years) Partners' mean age 51 years (32-67 years). Mean years in relationship 21 (3-43 years) 28 partners tertiary educated	At 3 months follow-up partners had less mood disturbance than controls, and had greater confidant support and greater marital satisfaction.
Giese-Davis, J., Hermanson, K., Koopman, C., Weibel, D. & Spiegel, D. (2000) USA	Quality of Couples' Relationship and Adjustment to Metastatic Breast Cancer.	Cross-Sectional and Longitudinal Questionnaires Interviews Psychological Assessment Randomized Trial – Intervention Quantitative	n=125 women with metastatic breast cancer (Mean age 53 years – 30-80 years) – base line data taken – n=48 women and their partners drawn for partner section of study, all partners male 87% Caucasian, 6% Asian American, 2% Hispanic-Latina, 2% Native American, 1% African American, 2% other. 57% Married or partnered, 9% single, 34% separated/divorced middle-class and tertiary educated mostly	Women with metastatic breast cancer can benefit from open engagement of difficulties and conflict with their spouses, rather than spouses trying to buffer the women from facts and emotions to save them distress. When a partner reports lower mood disturbances, and the woman rates their relationship higher in cohesion-expression and in conflict, the woman with breast cancer is less distressed. The alleviation of the woman's distress may be achieved by focusing on the couple's relationship rather than on her individual coping.

Rees, C. & Bath, P. (2000) England	Exploring the Information Flow: Partners of Women with Breast Cancer, Patients and Healthcare Professional.	Descriptive Study Postal Survey – Self-Administered Questionnaire Theoretical Framework – Family Systems Theory and Theory of Stress, Appraisal and Coping Quantitative	n=109 partners of women with breast cancer up to 10 years since diagnosis No evidence of metastases Partners age range 32-80 years (M=58.02 years) Partners mean age at diagnosis 54.22 years. 99% white, 95% married, %5 living with a partner, SES status mixed – though 53% in middle to higher levels.	Partners satisfied with information given and time spent discussing it from the women with breast cancer. The majority of partners sought additional information from other sources. The communication flow , between the woman, her partner and health care professionals was largely dependent on the amount of communication desired by the woman.
Sormanti, M. & Kayser, K. (2000) USA	Partner Support and Changes in Relationships During Life-Threatening Illness: Women's Perspectives.	Semi-Structured Interviews Use of Women's Narratives Self-Administered Questionnaire Content Analysis Qualitative and Quantitative	n=40 women 40% breast cancer, 18% leukaemia, 15% lymphoma, 13% Hodgkin's' disease. Diagnosed 2month – 2 years M=9.9 months age range 27-48 years (M=36.3years) 35 married, 2 divorced, 2 single, 1 widowed Number of children 1-4 (at least 1@12 years of age or under) 38 women Caucasian, 1 Asian, 1 American Indian	The type of support provided by the partner as well as the mutuality of the relationship contributes positively to the woman's coping. Role reversal was reported by 90%of the sample, and 89% reported changes in sexual activity. Not all support supplied by partners was found to be adequate.

Table A1.3: Couples/spouses/partners studies.

APPENDIX 1.4: Children Studies

Table A1.4: Children studies.

Author/Date/ Country	Title	Research Design/Methods	Sample Characteristics	Conclusions
Northouse, L. (1994) USA	Breast Cancer in Younger Women: Effects on Interpersonal and Family Relations.	Literature Review – Discussion (45 References)	Literature on family aspects of the breast cancer experience.	The mother's breast cancer diagnosis impacts on children to varying degrees, depending on their developmental stage.
Brock, C. & Perry, D. (1995) Australia	Report on the Social and Emotional Impact of Cancer Diagnosis on Young Adults	Literature Review – Discussion (37 References)	Explores literature surrounding psychosocial needs of young adults with cancer.	Issues of young families concerned young adults with cancer.
Welch, A., Wadsworth, M. & Compas, B. (1996) USA	Adjustment of Children and Adolescents to Parental Cancer.	Questionnaires Quantitative	n=71 families, 57 patient mothers (of which 28 had breast cancer) , 19 patient fathers Total mother patients mean age 39.7 years Children – n=55 adolescents, 60% female, mean age 14.5 years N=34 preadolescent children, 50% female, mean age 7.9 years.	Adolescent girls at higher risk of distress. Parents do not always perceived their children's distress adequately. Parents' report of their children's distress differs from that reported by the children themselves – with parental observed distress and disruptive behaviour being less than that reported by the children.
Turner, M. & McGrath, P. (1998) Australia	Children of Mothers with Advanced Breast Cancer: A Review of Needs and Services.	Literature Review – Review of services, needs and resources for children. (36 References)	Children of mothers who have advanced breast cancer. Cancer societies, Australian and International, reviewed of resources available to such children.	Developmental stage of child is a major influencing factor in their adjustment. Adolescent daughter described as being most vulnerable to distress. Parents do not always recognise the distress in their children. Family coping impacts on these children. Minimal, to no resources available for children of mothers with advanced breast cancer.

Birenbaum, L., Yancey, Z., Phillips, D., Chand, N. & Huster, G. (1999) USA	School Age Children's and Adolescents' Adjustment When a Parent Has Cancer	Retrospective Population Control Study Quantitative	n=66 families – 57 two parent, 9 single parent. 52 mothers with cancer and 14 fathers with cancer 54 participating partners Ill parents' mean age 43 years (28-60 years) Mostly Caucasian, well educated. n=116 school age (6-10 years) children (10 males and 21 females) and adolescents (11-18 years) (43 males and 41 females) living at home with a parent.	Behavioural problems were found at levels more than expected in children who had a parent with cancer. Most children and adolescents of a parent who has a cancer are well adjusted, however a subset displayed tendencies for behavioural problems.
Siegel, K., Gluhoski, V. & Gorey, E. (1999) USA	Age-Related Distress Among Young Women with Breast Cancer.	Part of a study about decision making about pregnancy after breast cancer. Unstructured In-Depth Interviews. Thematic Analysis Qualitative	n=34 women - 22-35 years of age (M= 30.6 years) Mean time since diagnosis 38 months (13 months – 8 years) 29 women white, 5 black 22 married, 2 divorced, 10 never married Majority well educated.	These women expressed strong concerns for their children, together with issues of coping with the untimeliness of their illness; impact of the illness on partners; sadness of infertility; being different and isolated; and uncertain future. Altered belief systems of the women themselves and the world filtered throughout the narratives.
Breast Cancer Network of Australia [BCNA], (2001) Australia	The Beacon.	Informal Questionnaires to Members Quantitative and Qualitative	Women how have had breast cancer who have children.	Young families are a particular concern of young women who have breast cancer.

Hoke, L. (2001) USA	Psychosocial Adjustment in Children of Mothers With Breast Cancer.	Semi-Structured Interviews, Separate for mothers and their children. Questionnaires Quantitative	Mothers with breast cancer compared to mothers with benign biopsies with children aged 8-16 years (M=11.6 years). Breast cancer group – n=34 children (14 male, 20 female. n=28 mothers aged 36-53 years (M=43.7 years) Benign Group – n=34 children (17 male, 17 female) n=24 mothers aged 31-52 years (M=41.5 years) Mothers mostly highly educated and middle to upper class.	Some adolescents of mother with breast cancer did better in social and academic activities as compared to adolescents in mother with benign biopsies. No differences of adjustment were found between other groups of children.

Table A1. 4: Children studies.

APPENDIX 1.5: Pregnancy After Breast Cancer Studies

Table A1.5: Pregnancy after breast cancer studies.

Author/Date/ Country	Title	Research Design/ Methods	Sample Character tics	Conclusions
Dow, K. H. (1994) USA	Having children after breast cancer.	Retrospective – cross-sectional interview format Mostly Qualitative – semi-structured interviews – analysed via content and thematic analysis Quantitative – some demographics and review of radiation oncology treatment records – analysis SPSS-X *Research Questions*: To explore reasons why young women decide to become pregnant after BC treatment; To address concerns of young in having children after BC; To describe helpful behaviours in decision-making process; and to examine the meaning of having children after BC treatment.	n=16 YWBC identified by radiation oncologists and oncology nurses - 15 white and 1 from Greek decent – middle class social status Mean age at time of interview was 38.8 years (32-45). Mean age at diagnosis was 29.6 years (25-35). Most highly educated and working, all married at interview.	Pregnancy after BC provides a powerful stimuli for YWBC to get well. Recurrence was an ongoing concern. Reasons for having children: a cherished goal; normalcy; reconnect with others. Concerns for being pregnant and having children after BC: having a normal pregnancy and a healthy infant; recurrence concerns juggling demands of disease surveillance (difficulty of detecting breast changes); breastfeeding – not feeding from affected breast – not a great concern. Concerns for children: recurrence, hyper vigilant about children's health; living one day at a time; intensified maternal concerns. Helpful behaviours in decision for subsequent pregnancies post-BC: Spouse, healthcare team; family; other cancer survivors Meaning of having children after BC: anchoring; getting well again; feeling complete.

Dow, K. H., Harris, J. R. & Roy, C. (1994) USA	Pregnancy after breast-conserving surgery and radiation therapy for breast cancer.	Study – Quantitative 40 references – 1937-1993 Case-Control Evaluated treatment outcomes and QOL of patients treated with conservative surgery and RT between 1968-1985 (Stage 1 or 11) QOL – evaluated using two self-report measures. Data collection methods: 1. review of RT oncology treatment records (history, treatment and follow-up status); 2. mailed survey of 2 self-report QOL instruments. Qualitative – in-depth interviews with n=20 patients.	Of n = 1624 patients treated at the Joint Center for RT between 1968-1983, n = 23 Mean age 30.4 years (25-37) BC patients who had subsequent pregnancies compared to n = 23 patients without subsequent pregnancies matched by age and stage at diagnosis and time to pregnancy without recurrence. Mean time to pregnancy 30 mths (6-84 mths). 32 pregnancies, 30 live births. 4 participants adopted 5 children	No difference in recurrence or distant metastasis between matched groups. Those with subsequent pregnancies perceived family issues had the greatest impact on QOL, and were not at higher risk for parental stress due to BC than the general population. Psychosocial elements of having children after BC – YWBC focus on the overall experience of reproducing, not just the pregnancy. These women felt 'cured' when pregnant and they now had something to look forward to, they reconnected with family and peers. These women stated they gained a sense of wisdom of what they had been through and were very vigilant with their child's health. One of their major concerns was living long enough to reach important family milestones, such as birthdays etc. Their lives had become richer for going through breast cancer and subsequent pregnancy.

Siegel, K., Gorey, E. & Gluhoski, V. (1997) USA	Pregnancy decision making among women previously treated for breast cancer.	Study - Qualitative 21 references 1962-1995 In-depth focused interviews (open ended) -average of 2 hours in duration A central objective: to explore what the women perceived as the possible risks and expected benefits of having a baby after bc. Retrospective and prospective, depending if participant had already had a pregnancy prior to the interview.	n=50 women (n=42 white, n=8 black) who completed treatment for bc at least 6 months earlier. Mean age 33.4 years (22-44) at diagnosis. Mean time lag since diagnosis – 33 months (8 months – 8 years). At the time of the interview 33 were married, 14 were single and had never married, and 3 were divorced. 7 women had been pregnant, 10 times since diagnosis, 2 were pregnant at time of interview. 4 women had had a recurrence.	Deterrents related to risks and dangers of having a child. Associated with these perceived risks were negative emotions, such a conflict or guilt. Themes of deterrents were: recurrence; defects in the child due to treatment; possibility of susceptibility to cancer increase in the child; caring for the child would be too stressful. Themes of incentives to have a child after breast cancer were having a baby: is a cherished part of a life plan; makes life affirming; pleases the husband; and would enhance QOL. Concerns if it was morally right to have a baby when a mother's survival was compromised, together with feelings of associated guilt or conflict. Also unfair to jeopardize mothers' survival if already have children. Having a baby after bc provides strong motivation for the mother to survive. A pregnancy after bc reaffirms the woman's feminine identity and capacity, to herself and others.
Collichio, F.A., Agnello, R. & Staltzer, J. (1998) USA	Pregnancy after breast cancer: From psychosocial issues through conception.	Literature review. – Extensive. 80 references – 1962-1997 Covering: sexual functioning; infertility; congenital anomalies; breast-feeding; monitoring for BC recurrence; risk of recurrence breast cancer; antiestrogen therapy.		Breast surgical decisions do not affect sexual functioning. Infertility is a consequence of some cancer treatment, related to age and dose of alkylating agents. No apparent increase in birth defects in children of those exposed to chemotherapy before conception. Lactation within the irradiated breast is likely to be limited and breastfeeding appears to reduce BC risk. Pregnancy does not appear to increase risk of recurrent BC. Adjuvant tamoxifen therapy is not advised for pregnant women as detrimental effects have been found in laboratory animals.

Schover, L. R., Rybicki, L. A., Martin, B. A. & Bringelsen, K. A. (1999) USA	Having children after cancer: A pilot survey of survivors' attitudes and experiences.	Quantitative - retrospective Cross-sectional mailed survey Looked at: health related QOL; demographics; medical background; reproductive and fertility history; and a variety of concerns about having children after cancer.	n= 43 men and 89 women diagnosed before age 35 and were aged 18 years or more at the time of the survey 47% response rate	18% of the female participants feared a pregnancy could trigger a cancer recurrence. 57% received information about their fertility after cancer from their health care providers. Most participants saw their cancer experience as potentially making them better parents. Those who are childless want to have children in the future. Many are left with significant anxieties and insufficient information about reproductive issues (ab).
Mueller, B.A., Simon, M.S., Deapen, D., Kamineni, A., Malone, K.E. & Daling, J.R. (2003) USA	Childbearing and survival after breast carcinoma in young women.	Quantitative, cohort study (case-control) using data from 3 population-based cancer registries in the USA linked to birth certificate data. Relative mortality was assessed using multivariable statistical methods.	Cases - n=438 women younger than 45 years with primary invasive BC having births after diagnosis Controls – n=2775 women matched for age at the time of diagnosis, race/ethnicity, year of diagnosis, disease stage and presence of previous non- breast primary tumours without births after diagnosis.	After adjusting for stage of disease, age at diagnosis, study region, diagnosis year, and race/ethnicity, childbearing subsequent to BC diagnosis is unlikely to increase the risk of mortality, providing the delivery is 10 months or more after the diagnosis. This group of women had a significantly reduced risk of dying (RR=0.54, [95% CI, 0.41-0.71]) compared to those without subsequent births. Those pregnant at diagnosis had a mortality rate similar to those who did not give birth (RR=1.10 [95%CI, 0.80-1.60]).

Upponi, S.S., Ahmad, F., Whitaker, I.S. & Purushotham, A.D. (2003) UK	Pregnancy after breast cancer.	Literature review 40 references – 1954-2002. Covering: influence of subsequent pregnancy on survival; healthy mother effect; methodology of studies; duration of BC to pregnancy; treatment; QOL.		Firm conclusions are difficult to reach considering the quality and quantity of available literature, however to date survival of women who become pregnant subsequent to BC treatment and controls compare favourably. Large prospective studies are needed to confirm this assumption.

Table A1.5: Pregnancy after breast cancer studies.

APPENDIX 1.6: Breastfeeding After Breast Cancer and Other Relevant Studies

Table A1.6: Breastfeeding after breast cancer and other relevant studies.

Author/Date/ Country	Title	Research Design/ Methods	Sample Characteristics	Conclusions
McTiernan, A. & Thomas, D. B (1986) USA	Evidence for a protective effect of lactation on risk of breast cancer in young women.	Retrospective – case-control Quantitative interviews	N=329 aged 20-54 years – diagnosed between 1981 – 1982 and lived in King Country, Washington at diagnosis	Risk of BC decreased with increasing duration of lifetime lactation experience of both pre- and post-menopausal women, though this effect was consistently stronger for pre-menopausal women.
Varsos, G. & Yahalom, J. (1991) USA	Lactation following conservation surgery and radiotherapy for breast cancer.	Short review of cases of lactation after breast irradiation and 1 case report. 17 references, 1936-1989.	Case report – 38 year old woman at diagnosis. Following surgery and radiation this woman became pregnant approximately 2 ½ years after diagnosis. The affected breast activated however within 2 weeks this breast was abandoned as the baby favoured the non-affected side due to low supply from the affected breast.	If surgery does not resect the main sub-areolar mammary ducts – lactation should not be affected – though radiation can affect lactation ability. From the literature, there have been 9 reported cases of lactation after BC - but only 2 breastfed fully. The ability to lactate from an irradiated breast depends on the radiation doses given. Some women fed from 10 months to 6 years post-radiation treatment. No cases reported any effect on the non-affected breast to lactate. The prospects are poor for full volume lactation from the treated breast. It is not advisable to nurse from the affected breast due to scanty evidence.
Neifert, M. (1992) Colorado, USA	Breastfeeding after breast surgical procedure or breast cancer.	Essay from clinical expert in the field – 29 references, 1936-1992. Covering: breast augmentation; a variety of surgical procedures; BC and lactation.		Chief risk of breast operations can be attributed to periareolar incisions, severing milk ducts. Radiation of normal adult breast tissues causes fibrosis and massive destruction of lobules. Evidence to date suggests full volume lactation from affected breast is poor. In authors clinical experience, an affected breast can only contribute 25% or less of milk yield and usually cannot be increased due to damage.

Higgins, S. & Haffty, B. G. (1994) USA	Pregnancy and lactation after breast-conserving therapy for early stage breast cancer.	Retrospective - Interviews Appears qualitative, though no mention of how analysis was done other than some basic counts.	n=11 experienced 13 pregnancies after breast cancer Median age – 31years (20-41) BC patients who had had radiotherapy	All reported little or no swelling of the affected breast during the pregnancy. After delivery – lactation from affected breast was present in 4 instances, absent in 6, suppressed in 3 and 1 successfully breastfed for 4 months. Time since treatment did not influence lactation ability. Successful breastfeeding from the treated and untreated breast is possible after conservative surgery and RT. Problems encountered with affected breast– reduced volume; nipple did not extent adequately; baby showed strong preference to untreated beast, skin irritation due to overuse of 1 breast.
Tralins, A. H. (1995) USA	Lactation after conservative breast surgery combined with radiation treatment.	Retrospective – cross-sectional survey 9 references, 1908-1989. Research question – what is the true incidence of radiosensitivity to inhibit lactation of the breast? Surveys sent o 2582 members of the American Society of Therapeutic Radiology and Oncology in the USA and Canada – n=294 responded + a case report	n=53 respondents of survey reported having patients who became pregnant after conservative surgical management and radiation treatment. Case – 36 years old – breast fed for 4 weeks from both breasts	Of the 53 women who had pregnancies, 34% exhibited some lactation from the affected breast and 24.5% of these successfully breastfeed from the affected breast. Of the 5 who did not breast feed – 3 reported insufficient milk as a reason, 1 stopped voluntarily via hormone and 1 baby refused to feed from the affected breast. Of these 18 women- 5 described the affected breast as smaller, 9 reported on milk volume, of these 6 stated less but adequate and no essential difference in quality. Prognosis was not affected by pregnancies in this group with a 82% survival rate mean follow-up for 5.4 years. Case – breastfeed for 4 weeks from affected breast. The mother experienced no pain or discomfort, and the baby showed no preference for either breast. Breastfeed ½ as long from affected breast compared to unaffected breast.

Wobbes, Th, (1996) The Neverlands	Effect of a breast saving procedure on lactation.	Case report - descriptive	n=1 - 31 year old YWBC at diagnosis – became pregnant 1 year after diagnosis	Treated breast was totally dry throughout breastfeeding – no activation of affected breast. This woman fed her baby for 3 months off of the unaffected breast. Conclusion – eventual affect of radiotherapy on breastfeeding ability is Time Dose Fractionation (TDF) dose related (over 77). Breast conserving treatment will reduce or stop lactation and may have a possible effect on composition of milk.
Hartrick, G.A. (1997) Canada	Women who are mothers: The experience of defining self.	Qualitative Phenomenological and feminist inquiry Recruitment – purposeful convenience sampling Data collection methods: 2xindepth interviews with each participant; focus group of all participants; letters written by some participants. 21 references – 1978-1994	n=7 Caucasian women aged 35-45 (M=39 years) Socio-economic status mixed 2 stay at home mums; 2 tertiary students and 3 employed 3 were single, 4 married to biological father of children Each participant had 1-3 children aged 3-16 years.	3 main elements of these women's experiences defined as: nonreflective doing; living in the shadow; reclaiming and discovering self. Relevant to the PhD study at hand: these women were acknowledged (approved and recognized) for undertaking socially prescribed roles, which can result in denying other parts of themselves, thus choosing the safety of the cocoon of social norms. To be connected to others one must succumb to the social prescribed roles (such as what constitutes a good mother). Not conforming to social norms can result in feelings of isolation (living in the shadows), within such isolation turmoil, confusion and despair can result.

Murphy, E. (1999) Nottingham (UK)	"Breast is best": Infant feeding decisions and maternal deviance.	Article – findings part of a longitudinal qualitative interview study. Participants interviewed 6 times each, just before birth and 5 times through 2 years post partum. Discourse analysis, framework drawn from sociology of deviance – looks at how mothers are judged and how they judge themselves morally. 22 references – 1957-1997	n= 36 first time mothers Participant pool heterogeneity to occupational class and mothers age (to reduce predetermined biases).	How mothers decide to feed their babies if a highly accountable matter and 'carries with it considerable moral baggage' (p, 205) . Not only is being a 'good mother' bond with decisions made, but also that of being 'good partners' and 'good women'. This is related to both breast and formula-feeding. This study talks about mothers being 'deviance', that of not simply one who breaks the rules (of socially constructed morality fitting a mother) but also of knowing she has broken a rule. Breastfeeding is widely identified as the optimal method of infant feeding hence has implications the evaluation of maternal behaviour. The 'good mothers breast feed' rule is no rigid as to be binding under all circumstances (p,189). Those who chose to formula- feed attempted to 'bridge the gap' between their knowledge of breast feeding benefits and their intended behaviour, with the use of excuses and justification of various actuality. Those who intended to breastfeed presented themselves as moral and knowledgeable. For these women, 'breastfeeding was treated as not only compatible with, but indeed, indicative of, maternal morality' (p, 201). Some issues arose of breastfeeding, such as risk compromising their responsibilities to their partners. Mothers who formula-fed were concerned to demonstrate that formula-feeding, which seems irreconcilable with responsible motherhood, is perfectly justified (p, 205). Infant feeding decisions are drawn from a repertoire of culturally acceptable legitimations. The women in this study wanted to present themselves, to themselves and others, as moral mothers, partner and women (p, 205).

Schmied, V. & Lupton, D. (2001) Australia	Blurring the boundaries: breastfeeding and maternal subjectivity.	Qualitative Feminist perspective on the body and subjectivity + study Study – Qualitative – incorporating phenomenological and symbolic perspectives Longitudinal – first-time parenthood Series of semi-structured interviews from late pregnancy - 3 years post birth ie. Just before birth, 10 days after, then intervals of 4 to 6 weeks, 10-14 weeks, 5-6 months, 1 year, 18 months, 2 years and 3 years Research questions – expectations and experience of first-time motherhood – breastfeeding was one aspect.	n=25 women living in Sydney Australia – of these 15 were employed in white-collar occupations and held post-school qualifications but none with university degrees. Remaining 10 held or more university degrees. Recruitment via from 1994 – early 1997, most were volunteers attending antenatal classes at a Sydney hospital + some snowball sampling. Age of participants 23-35 years (M=28.2 years)	These results focus on period of up to 5 – 6 months after birth. Breastfeeding was found to be central to the women's experience of motherhood. Much was expressed of the positive aspects of breastfeeding, such as emotional bonding and closeness, though the views as breastfeeding being disruptive and disconnecting were also expressed. "All the women in the study believed that breastfeeding was 'natural', and therefore desirable, crucial to their relationship with their baby and best for their baby's health. Furthermore, breastfeeding represented 'good' mothering. Most women were prepared to 'persevere' with breastfeeding to achieve their identity as a breastfeeding mother" (p. 238). Conclusion – "Incited by the desire to experience a different form of sexuality, an 'authentic' feminine identity and a more rewarding experience of mothering, women may embark upon breastfeeding as an avenue for self-definition. If they are unable to achieve this ideal, women are susceptible to disappointment and feelings of failure and a sense that somehow they are 'bad mothers'". (p, 246).

Table A1.6: Breastfeeding after breast cancer and other relevant studies.

APPENDIX 1.7: Reconstruction Studies

Table A1.7: Reconstruction studies.

Author/Date/ Country	Title	Research Design/ Methods	Sample Characteristics	Conclusions
Rassaby, J. & Hill, D. (1983) Australia	Patients' perceptions of breast reconstruction after mastectomy.	Study – Qualitative Questionnaire sent to participating surgeons – technicalities of surgery and patient anonymous open-ended questionnaires looking at the thoughts and feelings of those who had breast reconstruction. Participants recruited via 14 plastic surgeons – response rate of participants was 60%.	n=54 patients Age range 33-68 years, with 57% under age 50. 78% of participants were married	No participants expressed regret of undergoing reconstruction surgery. Factors relevant to the decision making process to undergo a reconstruction were: physical and emotional effects of mastectomy; sources of information and support. 20 participants indicated a negative self image post-mastectomy; seven participants had a fear of rejection by men post-mastectomy; 13 participants were dissatisfied with the wearing of the prosthesis; 17 participants sourced information from women's magazines and 7 from television; 11 participants mentioned receiving support for reconstruction from doctors though some mentioned opposition from these sources; 9 participants expressed opposition from family and friends. **Benefits:** No longer felt restricted in a fashion sense; feeling whole again; physical functioning improved; helped close book on the cancer; physical balance; increased self-confidence; enhanced figure. **Problems:** tightness hardness of new breast; asymmetry of breasts and nipple appearance – unnatural; post-operative complications such as infection; pain and itching; loss of sensation – though 30% stated no problems. **Participant advice:** women need more access to information and educate medical profession about it. Surgeons should offer women realistic expectations of outcomes and complications as women are often disappointed with the results. Medical professionals should not view reconstruction as purely a cosmetic procedure.

Schain, W. S. (1991) USA	Breast reconstruction: Update of psychosocial and pragmatic concerns.	Literature review 50 references 1977-1991 Covering: patient satisfaction; public sentiment and regulatory concerns; and psychosocial sequelae.		'The major organizing principle that determines whether or not women choose to have breast reconstruction has not been universally agreed on' (p, 1174). As times change so too does public opinion and expectations. Breast reconstruction is no longer seen as a cosmetic indulgence of women struggling with their body image after mastectomy. Rather it has been found the women with high self-esteem choose reconstruction more often, as they find themselves worthy of positive change.
Rowland, J.H., Holland, J.C., Chaglassian, T. & Kinne, D. (1993) USA	Psychological response to breast reconstruction: Expectations for and impact on postmastectomy functioning.	Study – Quantitative Prospective cohort study Plastic surgeon assessment of: status of reconstruction site and type; amount of reconstructive surgery necessary; and degree of surgical success anticipated. Brief semi-structured clinical interview and self-report questionnaire	=83 women (median age 42.8 years, range 32-64) who underwent delayed breast reconstruction surgery Majority of participants were highly educated and predominantly upper to middle-class, employed full or part-time (63%), white (89%), married (77%) Time lag since reconstruction mean 10.8 months (2-27.6 months)	Sexual difficulties were reported, with approximately' half of participant reporting impaired sexual functioning since mastectomy, including diminished frequency and satisfaction with sexual relations as well as a sense of general discomfort with sexuality, often attributed to feelings of self-consciousness about their disfigurement' (p, 244). Women were rated as more comfortable with their sexuality post-reconstruction ($P<0.001$), though the frequency of sex did not increase, though satisfaction with sexual activity did increase to pre-mastectomy levels (p, 247). The participants' expectations of the physical and psychological benefits of reconstruction were rated as realistic (p, 245). Most frequently sited reasons to undergo reconstruction were: to be rid of prosthesis; to feel whole again; and to restore symmetry and thus decrease self-consciousness about appearance (p, 246). Most women sought the surgery for themselves. 83% of participants were satisfied with their overall reconstruction results while 10% were dissatisfied and 5% were neutral.

Kasper, A.S. (1995) Bethesda MD (USA?)	The social construction of breast loss and reconstruction.	Study – qualitative Exploratory Feminist methodology Interviews – long history Study undertaken in late 1980's prior to public controversy of problems with silicone implants	n=29 women, average age 47 years (29-72) – 25 heterosexual, 4 lesbian 3 mths – 10 years since diagnosis n=20 had mastectomies, of these n=16 had reconstructions n=9 had lumpectomies	Reasons to undergo reconstruction were: return to normalcy, replacing the lost breast, erasing the memory and reminder of the cancer, and a chance to feel whole again 'Reconstruction fails expectations of the women involved, as the women identify disjuncture between social expectation and their own interests in health and well-being' (p, 197). The social construction of the participants' feminine identity impacted greatly on their choice to have reconstruction and hence of any expectations of the procedure.
Schover, L.R. et al. (1995) USA	Partial mastectomy and breast reconstruction: A comparison of their effects on psychosocial adjustment, body image, and sexuality.	Study – Quantitative Retrospective study comparing psychosocial adjustment, body image, and sexual function in women who had either breast conservation or reconstruction. Also examining influence of age, menopausal status and systemic treatment. Questionnaires – mailed survey	n= 218 women with n=72 women who had partial mastectomy (47% return rate) (mean age 54.6 years) and n=146 women who had immediate breast reconstruction after mastectomy (42% return rate) (mean age 47.9 years). Time lag since diagnosis mean = 4 years At time of surgery – mean age 50.1 years, at study - mean age 54. 2 years. 23% of sample not menopausal; n=56 premenopausal and n=162 post menopausal	The 2 groups did not differ in overall psychosocial adjustment to illness, body image, or satisfaction with relationships or sexual life. Those who had partial mastectomy had a specific advantage over those who had reconstruction as they maintained pleasure and frequency of breast caressing during sexual activity. However, those who underwent chemotherapy suffered more sexual dysfunction, poorer body image and psychological distress. Predictive factors of greater psychosocial distress included marital problems, a poor body image, sexual dissatisfaction, less eduction and chemotherapy treatment. The aftermath of chemotherapy was associated with long term impairments, where as choice of local treatment had little psychosexual impact.

Korvenoja, M.L., Smitten, K.V. & Asko-Seljavaara, S. (1998) Finland	Problems in wearing external prosthesis after mastectomy and patient's desire for breast reconstruction.	Study – Quantitative Questionnaire 63% response rate	n=176 Mean age 58 years, 91% wore an external prosthesis, of those under 65 years 46% wished to have reconstruction, and only 1 participant over 65 wished to have reconstruction. Ed levels: primary 56%; secondary 27%; tertiary 17%	Those women under 65 years of age who wear an external prosthesis have considerable problems with them in every-day life. Interest in reconstructive surgery did not decrease with time. Younger participants had more difficulties and inconvenience with prosthesis while working, enjoying leisure time pursuits and in wearing clothes. Education was not related to any of the problems encountered in wearing a prosthesis, nor to the desire to have breast reconstruction. Reasons given to not undergo a reconstruction were: too old (16.5%); perceived as unnecessary (7%), high cost of operation (4%), long recovery time (8%), and fear of operation (7%)
Neill, K.M., Armstrong, N. & Burnett, C.B. (1998) USA	Choosing reconstruction after mastectomy: A qualitative analysis.	Study – Qualitative Exploratory, descriptive. Ob: to describe women's perspectives on factors that influenced their decision to have reconstructive surgery after a bc diagnosis. Face-to-face interviews within 1 month of reconstruction. Intensive in-depth interviews	n=11 women who underwent mastectomy and reconstruction, mean age 48 years (39-61: n=10 of these reconstructions were performed at the time of mastectomy. Participants all were recruited from a Mid-Atlantic academic health centre which draw from the metropolitan area and surrounding states (same plastic surgeon)	Seeking normalcy. 3 themes were: getting my life back – in terms of information seeking, talking it over (expressing their thoughts) and seeking normalcy. Some women in this study expressed that they wished they had been informed of the loss of sensation, however participants indicated that they were satisfied with what information was provided to them during their decision making process. Support was sought from other women who had undergone similar surgeries. The plastic surgeon and other physicians greatly influenced the women's decision-making process. A concern that arose was that of an implant interfering with accurate interpretations of future mammograms. Not having to deal further with prosthesis was a definite factor in the decision for many.

Reaby, L.L (1998) Australia	Reasons why women who have mastectomy decide to have or not to have breast reconstruction.	Study – Quantitative mostly and Qualitative (open ended questions at end of interview to expand findings) Participants recruited via 3 general surgeons from metropolitan Sydney Australia – 50.5% response rate (of those eligible) Semi-structured questionnaire interviews	n=95 women of which n=64 had external prosthesis and n=31 had successful reconstructions 70% married at mastectomy 80% Australian white 59% Protestant, 58% completed secondary schooling 83% had private health insurance More young women were in reconstruction group (mean = 49.5 years) compared with prosthesis group (mean = 63 years). Reconstruction group had a higher annual household income compared to prosthesis group (p=0.015)	The most common endorsed reasons for not undergoing reconstruction were: not essential for physical or emotional well-being; not having enough information about the procedure; and not wanting anything unnatural in the body. 75% did not want to undergo any more surgery and 65% believed the risks outweighed the benefits. Some women stated they were not impressed with what they had seen and it would be too expensive. Some women felt it would be selfish to undergo a reconstruction, bring hardship on their families and also feared the pain associated with it. Two major reasons why they did not have reconstruction were: fear of complications and perceiving themselves to be too old for the procedure. 12 participants (prosthesis group) had difficulty in making the decision to not have reconstruction due to lack of family support, inability to have specific type of reconstruction and the perception that friends and acquaintances would see the surgery as cosmetic. Reasons for reconstruction were: get rid of external prosthesis; to be able to wear different types of clothes to regain femininity and to feel whole again. The least influential factors were to improve martial and sexual relations. The major reason cited was to feel whole again.

Baldry, E. & Walsh, A. (1999). Australia	Social and emotional support for women being treated for breast cancer: Social workers' involvement.	Study – Qualitative Grounded Theory Interviews	n= 20 women with bc, 3@30-39 years; 8@40-49 years; 9 @50-59 years of age. 13 decided prior to, or shortly after, mastectomy to have reconstruction 2 had reconstruction in 1 year 3 within 1-3 years and 2 between 5-10 years. Participants were diagnosed with breast cancer during 1979-1994 – with majority between 1990-1994.	Emergent themes from this study were: information provision; counselling and support; and overall management. The information needed on various aspects of breast cancer, mastectomy and reconstruction were: a range of information sources to be provided by doctors such as literature, pictures, photos and videos illustrating and discussing requirements, process, outcomes and possible complications. These women also mentioned it would be helpful to speak with other women who have also had reconstruction to exchange ideas, obtain practical advice and suggestions, clarify expectations and prepare for the treatment procedure (p, 40). The participants expressed 'less stress on unmet needs for counselling and support during the reconstruction phase of their illness trajectory as the support networks established during the diagnosis and treatment phase of their illness continued to be utilized. The reconstruction was viewed as a positive, self-initiated step rather than a reaction to a life-threatening illness' (pp, 40- 41). These participants expressed expectations of the reconstruction as returning to a more 'normal' body image and lifestyle, to have a breast again, and to lead a normal life again – a most important aspect of the psycho-sexual well-being (p, 39).
Desch, C.E. et al. (1999) USA	A sociodemographic and economic comparison of breast reconstruction, mastectomy, and conservative surgery.	Study - Quantitative	n=592 women who underwent breast surgery; breast-conserving surgery 26%, mastectomy 58% or mastectomy + reconstruction 16% (60% of these at time of mastectomy – mostly implant)	Increasing age reduced the use of breast reconstructive surgery. Choice of reconstruction surgery was not affected by tumour size, nodal status, or race. 'As age increased the likelihood of reconstruction decreased by 5% per annum. Increasing age was the most important factor driving the choice towards mastectomy alone over reconstruction' (p, 444).

Rowland, J.H. et al. (2000) USA	Role of breast reconstructive surgery in physical and emotional outcomes among breast cancer survivors.	Study – Quantitative Two large cohorts of breast cancer survivors from 2 major metropolitan areas assessed in 2 waves using a self-report questionnaire. Compared psychosocial outcomes of women who had lumpectomy, mastectomy alone and mastectomy with reconstruction.	n=1957 breast cancer survivors 1-5 years after diagnosis Lumpectomy group (57%) mean age = 55.9 years, mastectomy alone group (26%) mean age = 58.9 years and mastectomy and reconstruction group (17%) mean age = 50.3 years (P=.0001)	Body image and feelings of attractiveness are the psychosocial variables which are impacted by the type of primary surgery undertaken, and those who had lumpectomies experiencing the most positive outcomes. After the first year post diagnosis, women's QOL is more likely to be influenced by their age or exposure to adjuvant therapy than by the breast surgery they underwent (p, 1422). The three groups did not differ in relation to emotional, social, or role function. Those who underwent mastectomy and reconstruction were more likely to report bc had had a negative impact on their sex lives (45.4% versus 29.8% for lumpectomy and 41.3% for mastectomy alone; P = .0001). Those in the mastectomy with reconstruction group were more likely to have a partner, be college educated, affluent and white.
Wilkins et al. (2000) USA	Prospective analysis of psychosocial outcomes in breast reconstruction: One-year postoperative results from the Michigan breast reconstruction outcome study.	Study – Quantitative Prospective - cohort Comparing prospectively psychosocial outcomes for 3 common options for mastectomy reconstruction. Data collected before reconstruction and 1 years post reconstruction using questionnaires	Preoperative – n=273 patients, procedure type was reported in n-250 patients, of whom 56 received implant reconstruction (mean age 48.5 years), 128 pedicle TRAM flaps (mean age 49.4 years) and 66 free Tram flaps (mean age 46.4 years). A total of 161 immediate and 89 delayed reconstruction were performed.	'Delayed breast reconstruction provides substantial psychosocial benefits for mastectomy patients. Although the choice of reconstructive procedure does not seem to significantly affect improvements in psychosocial status with immediate reconstruction, the data suggest that procedure type does have a significant effect on gains in vitality and body image for women undergoing delayed reconstruction' (Ab p, 1014). The group who had delayed reconstruction had a significant gain ($p<0.001$) in body image scale.

Fung, K.W., Lau, Y., Fielding, R., Or, A. & Yip A.W.C. (2001) Hong Kong	The impact of mastectomy, breast-conserving treatment and immediate breast reconstruction on the quality of life of Chinese women.	Study – Quantitative Retrospective Interviews at 6 mths – 2 years following their primary surgery. QOL aspects measured: general psychological well-being, body image, sexual and social functioning.	n= 49 Chinese women with early bc of which n=17 had BCT (mean age 47.4 years), n=15 had mastectomy (mean age 50.4 years) , and n=17 had mastectomy with immediate breast reconstruction (mean age 44.2 years). M - time lag since surgery 1 year	Those women who had BCT scored significantly better on body image scores compared to those who had mastectomy with less concern for appearance, more freedom with regard to fashion, felt more accepted by their partners and were concerned less of change to their bodies. 'Compared to those who had mastectomy and mastectomy with immediate breast reconstruction, the most significant benefit of BCT is preservation of better body image' (p, 202).
Harcourt, D. & Rumsey, N. (2001) UK	Psychological aspects of breast reconstruction: A review of the literature.	Literature review. 67 references, 1971-2000		The area of psychological aspects of breast reconstructive surgery is limited and not sufficiently conclusive to inform changes to policy and care. More methodologically rigor in this research is needed (p, 477).
Morrow, M., Scott, S.K., Menck, H.R., Mustoe, T.A. & Winchester, D.P. (2001) USA	Factors influencing the use of breast reconstruction postmastectomy: A national cancer database study.	Study – Quantitative Retrospective – national cancer data base study. Evaluation Large convenience sample	n= 155,463 cases reported between 1985 – 1990 and n=68,348 between 1995-1996.	Those cases 50 years of age or younger were 4.3 times more likely to use reconstruction than older cases., though in part this could be due to patients not being given a choice to undergo reconstruction. Those who had ductal carcinoma in situ were twice as likely to have reconstruction than those with invasive cancer. Other significant predictors of the use of reconstruction were high income ($40,000 or more) (OR 2.0), ethnicity other than African American (OR 1.6), surgery performed at a National Cancer Institute-designed cancer centre (OR 1.4) and that performed in other geographical locations that the Midwest or South (OR 1.3).

Polednak, A. P. (2001) USA	How frequent is postmastectomy breast reconstructive surgery? A study linking two state-wide databases.	Study – Quantitative Retrospective Linking of a state-wide population-based central cancer registry with a state-wide hospital discharge database. Connecticut based	n=585 cases of reconstruction (diagnosed from 1992-1996) which was 12.5% of all those recorded as having had a mastectomy (n=4688) during the above period: out of total sample (n=4688) those who had reconstruction made up as follows: < 45 years 34.6% ; 45-54 years 24%; 55-64 years 9.4%; 65+ 1.9%. White 12.6% and black 10.5%	‘Reconstruction was not related to the patient’s tumour size, marital status, or race (black versus white), but declined with increasing age at diagnosis and with poverty rate’ (Ab, p, 73).The reconstruction rate decreased with age and more extensive disease at diagnosis. ‘The odds ratio for the highest versus lowest quintile of poverty was 0.22 (p<0.001) for patients aged <45 years 0.22 (p=0.001) for patients aged 45-54 yeast and 0.38 (p=0.177) for patients’ age 55-64 years’ (p, 76). Reconstruction rate was thus 14.9%.
Nissen, M.J., Swenson, K.K. & Kind, E.A. (2002) USA	Quality of life after postmastectomy breast reconstruction.	Study – Qualitative Focus group study – 2 focus group sessions using semi-structured open-ended questions about perceptions of preparation, experience and satisfaction of reconstruction.	n=17 Caucasian women who had mastectomies and immediate reconstruction (4 bilateral) between 1.4 - 5 years previously, mean time lag 37 months (17-60 months) Current mean age =53 years (40-65)	Recurrence anxiety was persistent. The participants wished they had been more informed of some issues, though the women felt well informed about the surgery. Satisfaction with the surgery was high though some concerns of cosmetic outcome was evident. Reconstruction did help the participants to feel more comfortable in fashion, though recovery can be difficult – reconstruction does not neutralize recurrence fears (p, 547).

Hall, S.E. & Holman, C.D.J. (2003) Australia	Inequalities in breast cancer reconstructive surgery according to social and locational status in Western Australia.	Study – Quantitative Retrospective	Western Australian (WA) Record Linkage Project was used for hospital morbidity, cancer and death records of women with bc in WA from 1982-2001. n=1021 women underwent reconstruction between 1982-2000	9.1% of women received breast reconstructive surgery after bc surgery. Those more likely to have reconstruction were: younger women with less co-morbidity and non-indigenous women. Women in lower SES group were significantly less likely to receive reconstructive surgery (RR 0.78: 95% CI 0.54 – 1.06) as were rural women as compared to those from metropolitan areas (RR 0.54; 95% CI 0.25 – 1.15) and those treated in rural hospitals (RR 0.78; 95% CI 0.66-0.92). Independent increases in the likelihood of reconstructive surgery were: being treated in a private hospital (RR 1.25; 95% CI 1.10 – 1.42) or with private health insurance (RR 1.25;95% CI 1.08-1.39). The number of women undergoing reconstruction following breast cancer surgery doubled from 167 in 1982 – 1986 to 335 in 1997 – 2000. The breast reconstructive surgery rate increased by 1.6 % points (from 8.3 to 9.9%) over the 18 years of the study. Overall breast reconstruction surgery was uncommon being untaken by only 1.9% of patients. Access to reconstructive surgery has not been equitably distributed.

Harcourt, D. & Rumsey N. (2004) UK	Mastectomy patients' decision –making for or against immediate breast reconstruction.	Study - Qualitative Prospective - longitudinal Multi-centred (3) study Semi-structured interviews conducted prior to undergoing surgery - to examine how these women decided for or against immediate breast reconstruction, whilst follow-up interviews 6 and 12 mths later examined participants' experiences of surgery and their views on their decision.	n=93 women who had mastectomy mean age 55 years (29-78) Of these n=37 underwent immediate breast reconstruction and n=56 decided against it. Of each group 70% married; 85% had children; 5% had adjuvant radiotherapy and 25% had a family history of bc – while post secondary education 45% mastectomy group and 49% reconstruction group. Only n=65 completed all data collection phases.	'Three decision-making styles were identified. 76 women reported making quick, instant decisions whiles 14 sought further information before making a choice. 3 women deliberated over their option and found decision-making particularly difficult '(Ab p, 106). This section of data was collected retrospectively; after the decision had been made but prior to surgery. A 'good decision' was made in a short period of time by these participants. 'Seeking professional expert advice may be a positive way of coping with anxieties around decision-making' (p, 114). 'Decision making around the time of diagnosis can be hampered by perceived time pressures and hospital systems' (p, 114). Some participants were still adjusting to their reconstructed breast one year after surgery reporting scarring, pain and discomfort, though satisfaction was high. 'Women appeared to increase their satisfaction by justifying their decision and by focusing upon positive aspects of their decision' (p, 114). Some participants were disappointed with their reconstructions with some needing further surgery, experiencing persistent pain and lack of sensation, the need to wear prosthesis, and asymmetrical breasts. Some women had their implants removed. Generally it was felt that no surgery could recreate the participants' 'appearance and in essence, reconstruction was seen as a substitute rather than a preference' (p, 113) .

Table A1.7: Reconstruction studies.

APPENDIX 1.8: Studies Related to Sex and Breast Cancer and Other Illnesses

Table A1.8: Studies related to sex and breast cancer and other illnesses.

Author/Date/ Country	Title	Research Design/ Methods	Sample Characteristics	Conclusions
Schover, L.R., Fife, M. & Gershenson, D.M. (1989) USA	Sexual dysfunction and treatment for early stage cervical cancer	Assessment of sexual frequency, function and behaviour, marital happiness and psychological distress Qualitative, longitudinal. Follow-up at 6 months, 1 year and after the end of initial treatment, interview and questionnaire	n=61 women with stage Ia, Ib or IIa invasive cervical cancer. n= 7 menopausal Mean age 38 (23-60)	Most important finding – the delayed impact (around 1 year) of RT on women's sexual function. At 1 year out women who had RT faired worse sexually than those who had hysterectomy alone- having more sexual desire and arousal problems.
Schover, L.R. (1991) USA	The impact of breast cancer on sexuality, body image, and intimate relationships.	Literature review 35 references 1955-1990 Covering: indicators of sexual function; impact of mastectomy; effects of breast conservation; breast reconstruction; systemic therapy and sexual function; sexual rehabilitation of the BC patient.		Some sub groups of women are more susceptible than others to sexual difficulties following mastectomy – such as those already experiencing sexual and/or martial difficulties and/or poorer psychological adjustment. Most women do not develop severe sexual dysfunction. However sexual dysfunction may be more due to menopausal symptoms than to the loss of a breast.

Burbie, G. & Polinsky, M. (1992), USA	Intimacy and Sexuality After Cancer Treatment: Restoring a Sense of Wholeness.	Literature Review 27 References Aim - To enlighten the oncology social workers of sexuality and intimacy concerns following cancer treatment of both sexes.	Review of common psychosocial problems associated with changes in sexual functioning and intimacy following cancer treatment, timing of such an assessment, the oncology social worker's role, and approaches to interventions for couples.	All cancers impact on a person's perception of their body-image and self-image, therefore having the potential to negatively affect sexual functioning.
Cull, A., Cowie, V., Farqharson, D., Livingsrone, J., Smart, G. & Elton, R. (1993),UK	Early Stage Cervical Cancer: Psychosocial and Sexual Outcomes of Treatment.	Cross-sectional Self-Report Questionnaire and Semi-Structured Interviews Quantitative	n=83 women, mean age 45 years (25-77 years) Time since diagnosis ranged from 17-171 weeks (mean = 97 weeks).	This group suffers much distress relating to their disease. Sexual function post-treatment was significantly poorer than pre-morbid function ($P<0.005$). Psychological and physical problems were highly correlated with sexual outcome ($P<0.01$).
Schag, C.A.C. et al. (1993) USA	Characteristics of women at risk for psychosocial distress in the year after breast cancer.	Study – Quantitative Systematic interviews by clinical social worker –participants classified for risk of psychosocial distress in year after diagnosis.	n=227 women newly diagnosed with bc, stage I and II.	Those at low-risk and at-risk (of psychosocial problems) participants, 1 month after treatment, were found to have substantial sexual problems related to interest and performance of sexual activity though fewer problems remained at 1 year follow-up of those at low risk. Those at high risk of psychosocial problems experienced more issues with the use of prostheses 1 year post treatment, and the data confirms that body image, problems with clothing and the wearing of a prosthesis as central concerns of these women.
Schover, L. (1994),USA	Sexuality and Body Image in Younger Women With Breast Cancer.	Literature Review 58 References	Reviewed various articles on sexuality following a diagnosis and treatment for breast cancer. Physical, psychosocial and psychological aspects were explored.	Many sexual difficulties emerge following the diagnosis and treatment for breast cancer. In theory, younger women are more distressed of the loss, or deformity of a breast due to higher aesthetic expectations. Regardless of surgery type, overall sexual frequency, martial satisfaction and psychological distress do not differ in all age groups.

Ferrell, B., Grant, M., Funk, B., Otis-Green, S. & Garcia, N. (1997),USA	Quality of Life in Breast Cancer survivors as Identified by Focus Groups.	Focus Group Methodology and Semi-Structured Interview in Individual Interviews 3 focus groups – age groupings <40 years, 40-60 years and > 60 years – intended to represent different developmental levels. Qualitative	n=21 women, mean age 50 years (22-71 years). 62% Caucasian, 13% Hispanic, 13% African-American and 13% other ethnic groups. Annual income levels varied between $30,000 to over $40,000. Time since diagnosis 16-71 months.	Women angry that so much attention was given to the loss of a breast while little attention was given to their problems with sexuality- such as menopausal symptoms. Other major concerns are families and children.
Ganz, P.A., Rowland, J.H., Desmond, K., Meyerowitz, B.E. & Wyatt, G.E. (1998) USA	Life after breast cancer: Understanding women's health-related quality of life and sexual functioning.	Study –Quantitative Cross sectional Mailed questionnaires	n=864 women had BCS – mean age 55.8 years (31-88 years) 77.4% white; 14% African American; 8.6% other . Education level: secondary or less 14.5%; Some college 36.9%; college grad; 13.8%; post grad 34.8%.	'bc survivors report more frequent physical and menopausal symptoms than healthy women, yet report Health Related Qol and sexual functioning comparable to that of healthy, age-matched women. Nevertheless, some survivors still experience poorer functioning. Sexual dysfunction occurred more frequently in women who had received chemotherapy (all ages) and in younger women who were no longer menstruating. In women 50 and younger, tamoxifen therapy was unrelated to sexual functioning' (p,501).
Bourgeois-Law, G. & Lotocki, R. (1999) Canada	Sexuality and Gynecological Cancer: A Needs Assessment.	Self-Report Questionnaires Some open ended Questions Quantitative (mostly)	n=73 women aged 25-82 years, ½ above and below 50years of age, with few under 30 and few over 70 years. At least 3 months post-treatment.	Cancer effect on sexual functioning – reduced interest in sex; painful intercourse; difficulties learning to deal with illness and treatment effects on sexuality; need more education about cancer and sexuality. Women with gynecological cancer need permission to talk to professionals about sexuality.

Ganz, P.A., Desmond, K.A., Belin, T.R., Meyerowitz, B..E. & Rowland, J.H. (1999) USA	Predictors of sexual health in women after a breast cancer diagnosis.	Study – quantitative Retrospective Analysis – multivariable regression analysis to estimate sexual interest, dysfunction and satisfaction in both samples	n= 472 sample 1 (1994-1995) n=662 sample 2 (1996-1997) Participants - between 1-5 years post diagnosis, disease free	Predictors of sexual health were vaginal dryness, emotional well-being, body image, quality of partnered relationship and sexual problems in the partner.
Meyerowitz, B.E., Desmond, K.A., Rowland, J.H., Wyatt, G.E. & Ganz, P.A. (1999) USA	Sexuality following breast cancer.	Study – Quantitative Descriptive Survey Recruitment via tumour registry, offices of surgeons, medical oncologists and hospital and clinic records in Washington DC and Los Angeles. Data compared to that of healthy women from another study.	n=863 bc survivors diagnosed with non-metastatic disease 1-5 years (mean 3 years) prior to study. Mean age 55.8 years. All treatment completed except some still on tamoxifen. 77% white; 4% Hispanic, 14% African America, 3% Asian, 2% other,; 62% married; 8% single	Overall findings from the larger project indicted that bc survivors had QOL and relationship adjustment similar to or better than healthy age-matched controls. Sexually inactive women were: older, less likely to have lumpectomy and/or reconstruction or to have received chemotherapy. Sexually inactive women were more depressed than those who were sexually active. Around one third of the sample reported that bc had a negative impact on their sexuality, though more likely in those who were sexually active prior to bc. This study drew from a large sample.
Yurek, D., Farrar, W. & Andersen, B.L. (2000) USA	Breast cancer surgery: Comparing surgical groups and determining individual differences in postoperative sexuality and body change stress.	Study – quantitative 3 groups: lumpectomy (Breast Conserving Therapy [BCT]); Modified Radical Mastectomy with reconstruction (MRMw/R); and MRM (MRM)	n= 190 women diagnosed and surgically treated from stage II or stage III bc – 36 days post surgery and pre-adjuvant therapy. Mean age 51 years (30-84) n=78 BCT; n=29 MRMw/R; n=79 MRM + n=4 elective bilateral mastectomy.	Those women who had reconstruction had their immediate post-surgery sexual behaviour and sexual responses disrupted, and significantly more so than those who had lesser surgery. Sexual self-schema – how one perceives oneself as a sexual entity – impacts on coping ability after surgery and can impact on surgery decisions.

Thors, C.L., Broeckel, J. A. & Jacobsen, P.B. (2001) USA	Sexual functioning in breast cancer survivors.	Literature review 36 references, 1982-2001 Covering: prevalence and nature of sexual difficulties, relationship between specific bc treatments and sexual difficulties, treatment of sexual dysfunction following completion of bc treatment.		"A growing body of evidence suggests that sexual problems can be a long-term side effect of bc treatment. "There is little evidence of a link between type of surgical treatment or treatment with tamoxifen and sexual functioning outcomes". (p, 442) Those who undergo chemotherapy are at high risk for sexual dysfunction after treatment.
Wilmoth, M.C. (2001) USA	The aftermath of breast cancer: An altered sexual self.	Study – Qualitative Descriptive – using grounded theory methods. Study purpose – to describe aspects of sexuality that were important to women after breast cancer treatment.	n=18 white women with breast cancer aged 35-68 years (mean=50.5 years) Time lag since diagnosis ranged from 6 months – 10 years Primary surgeries: n=7 lumpectomies and n=11 had mastectomy. Most participants received chemotherapy n=17 participant stated they were menopausal due to chemotherapy.	Two primary categories emerged from the data analysis – losses and influencing pieces. Losses encompassed: missing parts; loss of bleeding - becoming old; loss of sexual sensations; and loss of womanhood. Influencing pieces comprised of relationships and information control. 'The core concept identified was an altered sexual self. Those who sought information about sexual matters of cancer treatment and who had strong intimate relationships appeared to experience a more successful adjustment. The altered sexual self was viewed as either positive or negative. Central to the task of adjustment to living with bc was coming to terms with a new sexual self that emerged after treatment' (p, 278).

Broeckel, J.A., Thors, C.L., Jacobsen, P.B., Small, M. & Cox, C.E. (2002) USA	Sexual functioning in long-term breast cancer survivors treated with adjuvant chemotherapy.	Study – Quantitative Case-control, cross sectional. Recruited from Moffitt Cancer Centre Set of questionnaires (standardized self-report measures of sexual and marital functioning, depression, fatigue and menopausal symptoms) and review of medical records	Cases – n=58 women with bc, time lag mean 7.65 years (5.2 – 15.22 years). Mean age 56.19. Controls – n=61 health women with no cancer history, mean age 54.64 years) All participants had a spouse or partner.	BC survivors reported significantly worse functioning (p=/< 0.01) than their healthy counterparts. This related to greater lack of sexual interest, inability to relax and enjoy sex, difficulty becoming aroused and difficulty achieving orgasm. Vaginal dryness was significantly (p=/<0.05) related to poorer sexual functioning among these long-term bc survivors.
Ganz, P.A., Desmond, K.A., Leedham, B., Rowland, J.H., Meyerowitz, B.E. & Belin, T.R. (2002) USA	Quality of life in long-term, disease-free survivors of breast cancer: A follow-up study.	Study – Quantitative Longitudinal – prospective (follow-up study).	n=763 disease-free survivors of bc – Mean age 55.6 years, diagnosed an average of 6.3 years previously. At initial data collection (of first phase of study) participants were diagnosed with a stage I or II bc and were between 1-5 years out.	Physical and emotional well-being were excellent – results reflect only expected age-related changes. Energy levels and social functioning unchanged. Adjuvant therapies were associated with poorer functioning on several dimension of QOL. Vaginal dryness, urinary incontinence increased over time and sexual activity with a partner declined significantly (from 65% to 55%, P=.001). Sexual discomfort was significantly worse among those who had chemotherapy compared to those who had tamoxifen or no therapy (P<.001). Psychosocial impact is worse for younger women. The type of surgery performed does not impact on long-term QOL. 'Adverse effects of systematic adjuvant therapy on physical health status appeared to persist and worsen when evaluated 5-10 years after diagnosis' (p, 48).

Rogers, M. & Kristjanson, L.J. (2002) Australia	The impact on sexual functioning of chemotherapy-induced menopause in women with breast cancer.	Literature review 92 references, 1960-2000 Covering: short and long term impact of adjuvant systemic therapy; physical sequelae assoc with sexual functioning; psychological sequelae assoc with sexual functioning.		Chemotherapy induced premature menopause, by depleting estrogen levels, affects sexual functioning at both a physical and emotional level. However other elements which also impact on sexuality are: history of sexual problems in the woman; sexual problems of the partner; woman's psychological reaction to her disease; response of partner; relationship issues; and body image concerns. Sexual dysfunction can be either short or long term.
Kornblith, A.B. et al. (2003) USA	Long-term adjustment of survivors of early-stage breast carcinoma, 20 years after adjuvant chemotherapy.	Study – Quantitative Telephone interviews using standardized measures.	n=153 women previously diagnosed with bc. Current mean age 65 years (41-87); at diagnosis mean age 45 years (23-66)	In relation to sex – there was no significant difference in sexual problems of younger compared to older participants. However 29% of the sample reported at least 1 sexual problem occurring since their diagnosis with reports of: decreased interest in sex; decreased sexual activity; and feelings of sexual unattractiveness.

Table A1.8: Studies related to sex and breast cancer and other illnesses.

APPENDIX 1.9: Early Menopause and Other Menopause Studies

Table A1.9: Early menopause and other menopause studies.

Author/Date/ Country	Title	Research Design/Methods	Sample Characteristics	Conclusions
Bachmann, G. (1994) USA	Nonhormonal Alternatives for the Management of Early Menopause in Younger Women With Breast Cancer.	Literature Review - Discussion (107 References)	Articles were reviewed concerning nonhormonal therapies and treatments for menopause experience by women due to breast cancer treatment.	Description of various long and short term consequences of menopause (in general) together with specific effects experienced by younger women (defined as premenopausal at time of diagnosis). Lack of literature on nonhormonal treatments for early menopause.
Reichman, B. & Green, K. (1994) USA	Breast Cancer in Young Women: Effect of Chemotherapy on Ovarian Function, Fertility, and Birth Defects.	Literature Review - Discussion (35 References)	Articles concerning ovarian function, fertility and birth defects following adjuvant chemotherapy treatment for women with breast cancer, were reviewed.	Discussion of the possible physical effects of chemotherapy on the unborn child. Second and third trimester fetuses, exposed to chemotherapy, appear to have no increased risk of teratogenesis. Information is limited.
Jones, J. (1994) USA	Embodied Meaning: Menopause and The Change of Life.	Semi-Structured In-depth Interview Social Constructionism Narrative Analysis Qualitative	No actual sample size mentioned. Sample consisted of menopausal women: 2 were gay; rest heterosexual; 16 had children,;9 were married,;8 had been married. Homogeneous group – white, middle age, middle class, relatively highly educated, majority worked outside of home.	Sample attempt to construct new aesthetic meanings to their lives. The sample attached negative meanings to their state of menopause – such is a social construction of meaning, as menopause is seen to be a time of body failure and physical and mental decline.

Knobf, M. (1998) USA	Natural Menopause and Ovarian Toxicity Associated with Breast Cancer Therapy.	Literature Review – Discussion (131 References)	Published articles, lay publications of women's health and menopause reviewed in the aim to provide essential knowledge of the physiologic changes and symptoms associated with menopause to assist premenopausal women who are diagnosed with breast cancer.	The natural occurrence of menopause, and its associated physical changes, informs the understanding of that experienced by premenopausal women who are diagnosed with breast cancer. A variety of physical symptoms and physiological consequences of menopause are described and explained.
McPhail, G. (1999) UK	Menopause as an Issue for Women with Breast Cancer.	Literature Review – Discussion (98 References)	Reviews literature of natural menopause and its symptoms, discusses general (nursing) management and then reflects on implications of breast cancer and treatment.	As more premenopausal women survive breast cancer, menopause management after this cancer is becoming important. Various menopausal symptoms are described and discussed.
Schaefer, K., Ladd, E., Lammers, S. & Echenberg, R. (1999) (study approved by Institutional Review Board at Allentown College of Saint Francis de Sales – Country?)	In Your Skin You Are Different: Women Living With Ovarian Cancer During Childbearing Years.	Longitudinal – 3-4 in-depth Interviews Phenomenological Study Qualitative	n=5 women, of childbearing age, with ovarian cancer diagnosed minimum 1 year prior to study (1-10 years) (specific ages not given).	Themes: serendipitous diagnosis, managing treatment, horrible hair experience, hysterectomy violating one's sense of being, unfairness of menopause, body changes, intimate dreaming, being with other, being normal/different, being vigilant, being heard and trying to make sense of it.

Singer, D. & Hunter, M. (1999) England	The Experience of Premature Menopause: A Thematic Discourse Analysis.	Semi-Structured Interviews Thematic Discourse Analysis Qualitative	n=13 menopausal women aged 23-40 years (M=31 years). Youngest 16 years of age at menopause, and oldest 40 years of age. Mean age at menopause 28 – own diagnosis and 29 medical diagnosis. Most were white, middle-class and college educated, 1 Asian, 6 single, 4 in current relationship, 5 married, 2 divorced (but partnered), 4 had supportive partners, 8 had children, (2 adopted).	Issues of gender, reproduction and aging arose. The women struggled to maintain self-esteem and control over their lives in a largely negative social construct of menopause. The word ’menopause’ was problematic. Early stages of early menopause, women experienced varying degrees of shock, denial, anger and loss.
Ganz, P. (2001) USA	Menopause and Breast Cancer: symptoms, Late Effects, and their Management.	Literature Review – Discussion (54 References)	Common menopausal syndromes in breast cancer survivors examined.	Survivorship and quality of life issues are now becoming prominent issues. Descriptions of how premenopausal women experience menopause following treatment for breast cancer, such as being likened to being surgically castrated.

Table A1.9: Early menopause and other menopause studies.

APPENDIX 2

STUDY MATERIALS

The documents which make up Appendix 2 are presented in the order as follows:

APPENDIX 2.1: Recruitment Flyer

Breast Cancer in Young Women

ARE YOU INTERESTED?

This is an invitation for you to find out more about my study.

WHO IS CONDUCTING THIS STUDY? My name is Shirley Connell and I am a PhD student at the School of Public Health, QUT, Kelvin Grove. I am interested in the experiences of young women who have breast cancer. I have a Bachelor's degree in Health Science (Family and Consumer Studies) Honours. This study is a part of my doctoral program.

WHAT IS THE STUDY ABOUT? This study is a pilot for a larger study to be conducted next year. I will be looking at the specific concerns of young women who have breast cancer. The study is based on the perceptions of such young women as consumers of health and care services. I will be conducting one-to-one interviews.

WHO WILL MAKE UP THE STUDY? Women who were aged between 18-40 years when diagnosed with breast cancer, and who were diagnosed with breast cancer no more than 3 years ago, will make up the study.

WHAT DOES THE STUDY HOPE TO FIND? I aim to find information which will help other young women, who are diagnosed with breast cancer, to adjust to their situation via the use of appropriate services and support.

WHAT WILL PARTICIPATING WOMEN GET OUT OF BEING IN THE STUDY? As this research aims to help develop appropriate services and programs, participating women in this study may not benefit in a direct way. Other young women who are diagnosed with breast cancer in the future may benefit more.

WHAT WILL HAPPEN TO WOMEN WHO VOLUNEER TO BE IN THE STUDY? I will ask the volunteer participant if she would like to be interviewed in her own home or in a private room at QUT, Kelvin Grove Brisbane. A telephone interview is possible if it is preferred. I will ask for the participant for her consent to audio-tape record the interview. The interview should take between 1 to 2 hours. The participant will receive $20 for taking the time to speak with me. After the interview the participant will be invited to take part in the main study next year.

WHAT IF A PARTICIPANT DECIDES SHE NO LONGER WANTS TO TAKE PART IN THE STUDY? Participation will be voluntary at all times. The participant will be free to stop the interview at any time, or ask that the information collected not be used in the study. At no time will the participant's decision to withdraw cause her any negative consequences from QUT or from any other service/support group.

ARE PROFESSIONALS INVOLVED IN THIS STUDY? I have 3 professional supervisors involved in the study. Two of my supervisors have extensive experience in breast cancer research and my other supervisor specialises in consumer health issues.

IF I WISH TO FIND OUT MORE ABOUT THE STUDY, WHAT DO I DO? If you wish to find out more about the study fill in the bottom section of this flyer and send it to me. My details are:
Shirley Connell, PhD Student, School of Public Health, Victoria Park Rd, Kelvin Grove, 4059. Or you can contact me by telephone on - (07) 3864 5872 or by email at - se.connell@student.qut.edu.au. Thank you for taking the time to read this flyer.

(Breast Cancer In Young Women Study: Researcher - Shirley Connell PhD Student, QUT)

I would like more information about your study.

Name: ………………………………………………………………..
Contact Details : ……………………………………………………………………………..
……………………………………………………………………………………………
Telephone: …………………………..Email:………………………………………………..

APPENDIX 2.2: Media Release

Researcher investigates services for young women with breast cancer

A QUT researcher is looking for volunteers for a study into the adequacy of services and information resources for young women with breast cancer.

PhD student in QUT's School of Public Health Shirley Connell said the study would attempt to understand the special needs of women diagnosed with cancer aged 40 and under as a means of helping them better cope with breast cancer.

Breast cancer is the most common cause of cancer death in Australian women with Australian Institute of Health and Welfare figures showing that one in eleven Australian women develop breast cancer during their lifetime.

Australia recorded more than 10,000 new cases of breast cancer in 1997 – 704 were in women aged 39 years and under.

"Yet because more women aged 55 and above are diagnosed with breast cancer, most of the research is conducted on their experiences and services are developed for them," she said.

"The emotional impact of having breast cancer at a young age is extraordinary and when they go looking for resources and find they're either not there or they are targeted at women who are much older, they don't know where to go," she said.

The study aims to find out about the major concerns and issues faced by young women with breast cancer, including social issues, financial concerns, family and relationship issues, treatment choices, physical concerns and their emotional experiences.

"Anecdotal evidence suggested that cancer support volunteers were often much older and young women found it difficult to identify with them," she said.

She said young women were also at an earlier stage in their relationships where they did not yet have children or had very young children and the impact on their family life cycle was very different to older women.

Ms Connell's hopes the findings of the research will inform government policy, program development and education campaigns.

Further information: Shirley Connell (07) 3864 5872

Email: se.connell@student.qut.edu.au

APPENDIX 2.3: Participant Information Statement and Consent Form

PARTICIPANT INFORMATION STATEMENT

‘Young women with breast cancer as Consumers of Health and Care Services: How can their perspective of their illness inform health professionals to better focus support services and patient/consumer information/educational materials?’

CONTACT DETAILS:

PhD Candidate : Shirley Connell
Centre for Public Health Research
School of Public Health
Queensland University of Technology
Victoria Park Road
Kelvin Grove

Phone: (07) 3864 5773
Fax: (07) 3864 3130
Email: se.connell@student.qut.edu.au

Principal Supervisor : Assoc Prof Carla Patterson
Director – Centre for Public Health Research
School of Public Health
Queensland University of Technology
Victoria Park Road
Kelvin Grove

Phone: (07) 3864 3018
Fax: (07) 3864 3130
Email: c.patterson@qut.edu.au

EXPLANATION OF PROJECT:

This study is about the concerns of young women who have been diagnosed with breast cancer. I aim to find information which may help health and allied professionals, support services/groups and other interested parties, to assist young women who are diagnosed with breast cancer to adjust to their situation. This research is being conducted as part of my PhD program. I will be supervised by a team of experienced academics - two who have expertise in breast cancer research and one who specialises in consumer health issues.

Due to the pilot study findings, you have been chosen to be interviewed twice more, this will allow me to follow your experiences over time. During the first of the 2 follow-up interviews that I will conduct with you, either in person or by telephone, I will ask you questions about your experience of breast cancer, building on our previous interview. The main topic covered during this interview will be of issues surrounding your past and present support needs and how you have dealt with such issues up until now. I will contact you again in approximately 6 months to conduct a third and final interview with you, to discuss how your support needs are being, or not being, met at that point in time. I will, with your consent, conduct the interviews in your home or via the telephone if you live a long distance from Brisbane. If you prefer to be interviewed at the Queensland University of Technology, Kelvin Grove, a private room will be available.

The personal interviews should take 45 minutes – 1 ½ hours to complete, however if you wish to shorten or lengthen the interviews, that is fine. You will be given a small amount of money ($10) after the interviews in appreciation for your time and effort.

BENEFITS OF THE PROJECT:
The results of this project may assist other young women who are diagnosed with breast cancer. This could be achieved by an increased insight gained by health and allied professionals who are responsible for education and service/support strategies, programs and development. The study may benefit other young women who are diagnosed with breast cancer in the future more than it may benefit you in a direct way.

RISKS OF THE PROJECT:
Sometimes women find it distressing to talk about their breast cancer experiences. We can stop the interviews at any time if you like and take it up later, or discontinue altogether. If you experience any distress as a result of your participation in this project, you can contact the Queensland University of Technology's Counselling Services on: (07) 3864 3488 for assistance, free of charge.

CONFIDENTIALITY:
With your permission, the personal interviews will be audio-tape recorded. This allows me to concentrate on you and your experiences rather than trying to take notes. However, if you do not wish to be audio-tape recorded, I can take notes. Any identifying information which you give to me, such as your name and address, will not be kept with the tape recordings or their transcribed form. No identifying information that you tell me will be transcribed from the tape recordings. Only those persons directly associated with this study will have access to the tape recordings and/or transcripts, such as myself and my supervisory team.

PARTICIPATION:
At all times your participation in the study is totally voluntary. Even after the personal interviews you may request your information not be used in the study. You can withdraw from the study at any time without comment or penalty from the Queensland University of Technology or from any other service/support group.

QUESTIONS:
If you think of any questions you may like to ask about the study, feel free to contact me as per contact details on the front page of this information package.

ETHICAL CONDUCT:
If you, at any time during the study, have concerns about the ethical conduct of the research, myself or others involved in the study, you may contact the Secretary of the University Human Research Ethics committee by telephoning (07) 3864 2902.

FEEDBACK:

You may request a summary of the study outcomes by either stating so after the personal interview or by contacting myself via the contact details on the front page of this information package. I will also ask you for your feedback, such as if you thought the questions I asked you were relevant to your experiences.

QUT Letterhead

Consent Form

Queensland University of Technology
SCHOOL OF PUBLIC HEALTH

‘Young women with breast cancer as Consumers of Health and Care Services: How can their perspective of their illness inform health professionals to better focus support services and patient/consumer information/educational materials?’

Participant’s

Name:………………………………………………………………………………

The research procedures involved in this study have been explained to me and I have been given the opportunity to ask questions regarding this project and the interview process involved.

I acknowledge that:

(a) The possible effects of participating in the study have been explained to me;

(b) I have been informed that I am free to withdraw from the study at any time, without comment or penalty;

(c) The project is for the purpose of research and not for treatment;

(d) I have been informed that the confidentiality of the information I will provide will be safeguarded.

I consent to further participate in this project.

Signature:………………………………………………….
Date:………………………...
Participant

I consent to my interview being audio-tape recorded. (Please circle) Yes No

APPENDIX 2.4: Question Guide for Pilot/Baseline (Phase 1)

Basic Demographics dealt with separately.

Questions will be strategically sequenced to allow for a funnelling effect

1. BASIC OPENING QUESTIONS

1.1 Tell me something about yourself.

1.2 How is life treating you at present?

2. MOVING GENTLY INTO THE TOPIC

2.1 Tell me about your experience of breast cancer.

2.2 Tell me about the events leading up to your diagnosis.

2.3 Where have you found information about breast cancer?

Library ☐ Internet ☐ Magazines ☐ Books ☐ Other ☐

2.4 In your experience, what has been the best information source about breast cancer?

Library ☐ Internet ☐ Magazines ☐ Books ☐ Other ☐

2.5 What has helped you to adjust to having breast cancer? (expand)

Persons ☐ Professionals ☐ Organisations ☐ Services ☐ Groups ☐

2.6 What has hindered your adjustment to having breast cancer? (expand)

2.7 (if diagnosed a year or more ago) How have things changed for you since you were first diagnosed?

Emotionally ☐ Physically ☐ Psychologically ☐ Family ☐ Socially ☐

Financially ☐

2.8 In your experience, what do you consider to be the greatest concerns for young women with breast cancer?

Confronting Mortality/Grief ☐ Finances ☐ Young Families ☐

Relationships ☐ Social Concerns ☐ Treatment Choices ☐ Physical ☐

Emotional ☐

3. SOCIAL CONCERNS

3.1 What roles did you play before your diagnosis of breast cancer?

Social Community Roles ☐ Mother ☐ Wife/Partner ☐

Primary Care-giver ☐ Other ☐

3.2 Have any of your roles before your diagnosis changed since your diagnosis – treatment- how – why? How do you feel about that?

3.3 Social Support – Informal Support Groups – Formal Support/Service Provision Are you currently, or have you in the past received any support for your breast cancer experience?

Emotional ☐ Psychological ☐ Physical ☐ –(let participant interpret the word support – explore her meaning)

3.3.1 What types of support have been offered to you?

Formal (Professional) ☐ Informal ☐

3.3.2 What type of support do you feel you need/would like to take up?

Formal (Professional) ☐ Informal ☐

3.3.3 Has the support you have sought/received been helpful for you? In what way?

Age Appropriate ☐ Peer Support ☐ Lack of Support Services ☐

*3.4 * Informal Support*

3.4.1 Are you a member of any type of self-help support group?

3.4.2 (if yes) Which one/s and why and how did you find out about it/them?

3.4.2.1 Do such support groups help you? In what ways?

3.4.2.2 How could these groups' support be improved?

3.4.2.3 Did you initially have high expectations of such support groups?

3.4.2.4 Would you recommend other young women with breast cancer to attend a support group? Why?

3.5 *Formal Support/Service*

3.5.1 Do you, or have you, received support and/or services from a formal style (professionally organised and operated) of health or care service?

3.5.1.1 (if yes) Which formal support/services?

Blue Nurses ☐ Qld Cancer Fund ☐ Breast Cancer Volunteer ☐

Breast Cancer Nurse ☐ Community Health ☐ Social Worker ☐ Counsellor ☐

Hospital Support Service ☐ Lymphodemia Services ☐ Transport Services ☐

3.5.2 Has this/these support/service/s helped you to adjust to having breast cancer?

3.5.2.1 (if yes) Tell me about it.

3.5.2.2 **(if no)** How would you suggest such service provision could be improved to better help young women with breast cancer?

Age Appropriateness ☐ More Services for Younger Women ☐ Other ☐

3.5.3 Did you initially have high expectations of such support/services?

3.5.3.1 **(if yes)** Tell me about it.

3.5.3.2 **(if no)** Why not?

(Put following in middle of interview, very sensitive area)

4. CONFRONTING MORTALITY – GRIEF and EMOTIONAL

4.1 How do you feel about having breast cancer at the moment?

More to Loose ☐ Off Timedness of Breast Cancer Diagnosis ☐ Other ☐

4.2 Can you describe to me the emotional impact you have experienced since being diagnosed with breast cancer at such a young age.

Distress/Symptom ☐ Self-Esteem Loss ☐ Anxiety, Depression, Anger ☐

Emotional Impact, Quality of Life Issues ☐ Perceptions of Femininity ☐

Body Image Concerns ☐ Sexual Identity ☐

4.3 How long did it take you to accept your diagnosis? What type of difficulties did/do you experience?

4.4 What do you see as your major concerns at present?

4.5 How do you see the future? **(**May not need to be asked, may come out of other question) (concerns)

5. FINANCES

5.1 Are money worries a specific concern for you? Why? This may come up in major concerns)

Loss of Work ☐ Loss of Superannuation ☐

5.2 How has having breast cancer effected your abilities to undertake your usual work?

6. YOUNG FAMILIES – RELATIONSHIPS

6.1 In general, how are your family/friend relationships going?

6.2 Are your relationships, with your spouse/partner, family and/or friends, different now as compared to before your diagnosis? How and in what way?

6.3 (If concerns are apparent) What concerns you about your relationships?

Role Change ☐ Strong Partner Concerns ☐ Burdening Spouse/Partner ☐

Fear of Unable to Live Out Relationship ☐

6.4 How has having breast cancer impacted on your family life?

Children ☐ Fears of Future ☐ Stage of Family Life Cycle ☐

Disruption to Daily Routine ☐

7. TREATMENT CHOICE – PHYSICAL

7.1 In what ways did health professionals inform you of your treatment choices including possible side-effects?

Verbal ☐ Reading Materials ☐ Videos ☐ List of Resources ☐ Other ☐

7.2 Did you get to make your own choice of treatment?

7.2.1 (if yes) Do you think you made a well-informed treatment choice?

7.2.2 (if no) Why is that?

7.3 What do you think may have influenced your choice of treatment?

Survival ☐ Lack of Confidence in Doctors ☐

Young Women Likely to Receive Surgery and Treatment ☐

7.4 What were some of the worst side-effects of your treatment?

Physical Limitations ☐ Early Menopause ☐ Fertility Concern ☐ Hair Loss ☐

Choices Taken Away ☐ Disfigurement ☐ Other ☐

7.5 Were you prepared for such side-effects?

7.6 How did such side-effects impact on you? How do you feel about this?

7.7 Do you feel your diagnosis and treatment has influenced your self-esteem and self-confidence?

Body Image ☐ Femininity ☐ Other ☐

8. Opportunity to Disclose Unexplored Issues

8.1 Are there any other issues/problems that you have experienced, that you feel are important for young women newly diagnosed with breast cancer to know?

8.1.1 (if yes) What are they?

8.1.1.2 How do/es they/it impact on your well-being?

8.1.1.3 How have you dealt with such a problem?

8.1.2 (if no- On to closing questions)

9. CLOSING QUESTIONS

9.1 What is your greatest unmet need to date?

Emotional ☐ Social ☐ Physical ☐ Financial ☐ Choices ☐

Family ☐ Relationships ☐

9.2 What would be your advice to a young woman newly diagnosed with breast cancer?

9.3 Where would you suggest are the best avenues of help, services, support, informational resources available for her to go?

Formal/Professional ☐ Informal ☐ Internet ☐ Books ☐ Other ☐

9.4 What services/support/informational resources would you suggest the person stay away from? (could prove to be a humorous end to the interview**)**

10. INTERVIEW CONCLUSION

At the end of the interview I would thank the participant for her contribution and ask her if she would like to take part in the main study, and if so, would she agree to being followed over time - such as -

10.1 Would you like to take part in the main study?

10.2 Do you think you would like to be followed up over time, via interviews and a diary?

Offer the participant $20 for taking the time to speak with me. Ask participant to sign the receipt book.

APPENDIX 2.5: Question Guide for Follow-Up Interview 1
(Phase 2)

This question guide is for the specific use of the researcher only, it will not be viewed by the participant.

Question Guide (Only) For First Semi-Structured Interview of the Follow-Up Portion of the Study

Basic Demographics were dealt with separately in pilot study and extension to baseline.

Questions will be strategically sequenced to allow for a funnelling effect

1. __Basic Opening Questions__

* How are you? *(keep it general and positive)*

* How is life treating you at present?

2. __Discuss Where Participant is in the Illness Trajectory and Treatment Routine__

* *How long has it been now since your diagnosis?*
* *What is happening for you at the moment?* (go on with any specific details of any medical updates)

Notes from Previous Interview - Specific Details of the Participant's BC history**.**

Age at diagnosis: -----------------Date of diagnosis: -------------------------------------

- Time Lag since diagnosis: -----------------------Surgery: -------------------------------

---- Treatment: ---Public/Private: ---------------

------Other Issues: ---

***** Are you still in treatment for the breast cancer?

If Yes - What treatments are you under going at the moment?

If No – When did the treatment stop? *(any other issues around this time)*

* Tell me, how have things been for you since I last talked with you?
(Remind participant when the first interview took place. Ask specific questions relating to the participant's1st interview)

Notes from Previous Interview:

- **Need to cover –**

----

3. More Detailed Personal Issues – Feelings

(Most Sensitive Section hence in Middle of Interview)

* How are you feeling just at the moment about having breast cancer, just where you are now in the journey? *(avoid discussion as much as possible about how the participant felt at any other time than the present moment)*

* How do you feel about yourself since the last time I spoke with you?

* What do you see as your major concern just at the moment?

4. Issues Surrounding Dealings with Medical/Health Professional at this Point in Time.

* When was the last time you had contact with the medical/health profession concerning your breast cancer? * Who was it? * How was that experience?

* Are you still having regular contact with medical and health professionals concerning your breast cancer?

* Do you think you have enough contact with medical and health professionals/services at this point in time?

* How are you reminded of appointments – check-ups?

* In what ways are you contacted by medical/health professionals/services?

* In what ways would you like to be contacted, and how often – up until what point do you think? Why do you think that is?

(if lost contact with Breast Cancer related medical/health professional/services and/or support groups/agencies)

* How do you feel about no longer having any contact with these services and professionals?

Alone ☐ Isolated ☐ No problem ☐

Expand here on any answer given

5. **Support Issues**

Notes: Participant's specific support received as per previous- interview:-------------

----

----

* Have you received any further support since I last spoke with you?

* How has the support you have received made you feel?

* Did you feel supported or unsupported?
  * Why do you think that is?
   If a problem
  ***** How could this be rectified?

  * Are you in contact with any support group/agency? Tell me about it.

* When we spoke last time, I asked you what you thought was your greatest unmet need, your answer was ---

-

Lack of support, is this still an issue for you?

Yes ☐ - Increased ☐ Decreased ☐ Static ☐

No ☐ *Expand on any answers here*

* Have you done anything, or has anything happened, to make this situation better for you?

If so:

- What has happened?
- What have you done about it?
- Why was that?
- When did you do it?
- What has been the outcome for you?
- How have you coped in this time?
- Can you suggest anything that could have made solving such a problem easier for you?
- Who do you think would be the best person, professional, service, organization – etc to approach to help to deal with such support issues?
- What would a good support system for young women with breast cancer look like?
- What would you like it to contain?
- How would you suggest such a support system operate?
- Who do you think should run it?

If have done nothing about situation/problem

- Why have you not tried to do something about your situation/problem?

* Do you currently feel in control of your situation/illness?

If Yes: *Why do you think that is? Can you give me an example?*

If No: *Is this a problem for you?*

If Yes: * *Why do you think this is?*
* *How do you think you could change this?*
* *Who could help you to take more control of your situation/illness?*

6. Other issues

* Have you noticed any specific or troubling issues around about the 2 year mark since your diagnosis?

If Yes: Could you tell me about that?

* Any specific personal issues relating to:

Early Menopause ☐ Infertility ☐ Sexuality ☐

Body image ☐ Family concerns – Partners/children ☐

* Any specific other issues relating to:

Medical/ health professionals ☐ Support services/organization ☐

Information resources ☐

7. Opportunity to Disclose Unexplored Issues

* Has anything else occurred since I spoke with you last that you feel is important to talk about that we have not covered?

* How do you see your next 6 months – what will be happening for you?

* In your opinion, what is the most important thing that medical/health professionals should know about young women who have breast cancer?

The End of the Interview

Proceed to inform the participant of next interview phase. Offer the participant $10 for taking the time to speak with me. Ask participant to sign the receipt book.

APPENDIX 2.6: Question Guide for Follow-Up Interview 2
(Phase 3)

This question guide is for the specific use of the researcher only, it will not be viewed by the participant.

Question Guide (Only) For Second Semi-Structured Interview of the Follow-Up Portion of the Study

Basic Demographics were dealt with separately in the pilot study and extension to baseline.

Questions will be strategically sequenced to allow for a funnelling effect

1. Basic Opening Questions

- How are you? *(keep it general and positive)*

- How is life treating you at present?

2. Discuss Where Participant is in the Illness Trajectory and Treatment Routine

Make general comments about time lag since diagnosis

What is happening for you at the moment? *(go on with any specific details of any medical updates)*

Notes from Previous Interviews - Specific Details of the Participant's Breast Cancer History**.**

Age at diagnosis: -----------------**Date of diagnosis:** --------------------------------------

---**Time Lag since diagnosis:** ----------------------**Surgery:** -----------------------------

-----**Treatment:** --**Public/Private:** ---------------

------**Notes** --

- What is your current breast cancer status?
- Are you still in treatment for the breast cancer?

If Yes: *What treatments are you undergoing at the moment?*

If No: *When did the treatment stop? (any other issues around this time)*

3. *Follow Up on Issues Raised in Last Interview*

* Tell me, how have things been for you since I last talked with you?
(Remind participant when the last interview took place. Ask specific questions relating to the participant's first and second interviews)

Notes:

4. *Specific Topics of Interest –Relevant to Young Women with Breast Cancer*

If the following topics of inquiry are not relevant to the participant, but an X in the box provided.

Issues regarding partner:

* How is your partner? ☐

* How is he concerning your breast cancer?

Issues regarding children: ☐

* How are your children at the moment?

* Do you have any concerns regarding your breast cancer and the children?

Issues regarding pregnancy: ☐

(If Participant has had a baby since last interview, inquire generally about the baby before proceeding)

* Did you have any problems with your prosthesis during the pregnancy? ☐
Tell me about it.

* What sort of breast changes did you experience during the pregnancy?

* How did your breasts compare to each other during the pregnancy? ☐

* Was that a problem for you?

* How did the pregnancy progress, was there any specific problems?

* How did you feel while you were pregnant?

Issues regarding breastfeeding:

- Are you breastfeeding at the moment? ☐

If Yes:

- Have you experienced any difficulties breastfeeding so far?
- Tell me how breastfeeding is going?
- How long do you intend to breastfeed?
- Have the health professionals been helpful concerning the breastfeeding?
- Do you have any concerns about breastfeeding?

If No:

- Is there any particular reason why you are not breastfeeding?
- Did you seek any help to breastfeed your baby? From who/what?
- Do you have any concerns about breastfeeding – or not breastfeeding your baby?
- What do you think may have helped you to breastfeed?
- Did you get information about breastfeeding after breast cancer? Where from?
- Is there enough information available concerning breastfeeding after breast cancer?
- Where would you suggest the best avenue of assistance to obtain information about breastfeeding after breast cancer to be?

If participant had previously breastfeed ☐

- How did breastfeeding this time compare with last time?

Issues regarding reconstructive surgery: ☐

For those who have had reconstructive surgery: ☐

- How is it going?
- How do you feel about it (physically and emotionally), has it fulfilled your expectations? Tell me about it.

If No:

Why do you think it has not been what you expected?

For those who have not had it done but are considering it in the future? ☐

- What thoughts do you have on the matter?
- How do you generally feel about reconstruction?
- Why are you considering reconstructive surgery?
- What personal physical and/or emotional changes are you expecting reconstructive surgery to produce?
- Have you gone looking for information about reconstructive surgery?
- What sort of information have you been given on reconstructive surgery?
- What choices have you been given?
- Do you feel you have enough information about reconstructive surgery to make an informed decision?

Questions for all relevant participants ☐

- Is there any aspect of reconstructive surgery that you feel health professionals have neglected to elaborate on or inform breast cancer sufferers of?
- How do you think partners would feel/ do feel about/see a reconstructed breast? ☐

Issues regarding fertility concerns: ☐

- Are fertility concerns still an issue for you?

If Yes:

Tell me about it.

If No:

Why has it changed for you?

5.More Detailed Personal Issues – Emotional Element

(this section has the potential to be quite sensitive hence is in the middle of the interview)

* How are you presently feeling about having breast cancer now that you are ___months since your initial diagnosis?

* How is your self-esteem, self-confidence since I spoke to you last?

***** The first time I spoke with you, you stated that your major concern was

____

____ and then the last interview you stated that your major concern was

____

____

____

* How is that now, what would you consider to be your major concern at the moment?

* What does your breast/s mean to you? What does it / do they symbolize to you?

* Has contraception been an issue for you? ☐

If Yes:

Why?

6. Consumer Related Information

Issues Surrounding Dealings with Medical/Health Professional at this Point in Time.

* How have your encounters with health professionals been since last time I spoke with you?

Support Issues

Notes: Any specific support issues aired in previous interview

* Are you attending a support group regularly for either cancer in general or breast cancer specifically?

If Yes:

Tell me about it.

* During your first interview I asked you what your **greatest unmet need** was and you stated support (particular details)___________________________________

And at the last interview you stated that this need was then

* How is it for you now, has anything changed in regards to that?

If Yes:

How and why?

If No:

Why not?

* Do you feel at the moment that you are in need of any type of support?

If Yes:

What type of support do you feel you need? Why would that be, what has happened?

Information Issues

* What, if any, information do you feel you are in need of at the moment?

* How are you going about finding what you need?

7. *Extra Questions in General – Observing Participants Perceptions of Differences*

- What, if any, generational differences do you perceive there to be between younger women (40 years and under) and older women with breast cancer?
- How do you think younger women experience being diagnosed and treated for breast cancer differently to that of older women ?

8. *Checklist – make sure have not missed any topic (tick if covered)*

- Any specific personal issues relating to:

early menopause ☐
body image ☐
reconstructive surgery ☐
medical/ health professionals ☐
information resources ☐
infertility ☐
contraception ☐
pregnancies ☐
sexuality ☐
partners/children ☐
breastfeeding ☐
support services/organization ☐
generational changes ☐

9. *Opportunity to Disclose Unexplored Issues*

- Is there anything else that has occurred during your time since diagnosis of breast cancer that you feel is important to talk about that we have not covered over the series of interviews?

If Yes – please tell me about it

If No – proceed on to end

- Could you give me just a few closing comments of your experience of having breast cancer at a young age.

The End of the Interview

Proceed to inform the participant about a summary of findings to be forwarded onto her when it becomes available, probably February - March 2004. Offer the participant $10 for taking the time to speak with me. Ask the participant to sign the receipt book. Thank the participant very much for taking part in this longitudinal study – stating without the collective contribution of all the young women in the study, this study would not of been possible.

APPENDIX 2.7: Example of Raw Data.

Below is a 9-page extract from Phase 3 (Time 3) of the study: Follow-Up Interview 2.

M – Moderator
P – Participant

M: Right. Okay. So we'll start with the pregnancy and work our way through. Last time I talked to you, you were about six weeks off having bubs. So where will I start… Was this pregnancy much different from your first one?

P: Oh, yeah, very much so.

M: In what regard?

P: Um… Well, number one it was totally unexpected [laughs] and I had a lot of back problems… Yeah, and I had some back problems with it, yeah. The other reason was that I was very concerned about my age and being pregnant and also in the first stage of my pregnancy I was, I had a lot of symptoms which I was concerned that I might have had secondaries, so I ended up having investigations at about 18 weeks including MRI scan of my head which was, to my great relief, was normal. So I was 20 weeks before, you know, I was half-way through my pregnancy before I even sort of accepted that I was pregnant or thought that it was going to continue and that I wasn't going to die in the meantime. But yeah, the rest of it was marred by back pain but apart from that, the old body, it was fine.

M: Right. Okay. So breast changes.

P: Breast changes. Interesting, yes.

M: Mmm. Elaborate.

P: Well, hey, the one-sided cow! [laughs]

M: Oh, no!

P: Yes. Yeah, I mean, there's a lot of… I'd done a lot of research on feeding… Oh, during the pregnancy, that's where we're at, are we? The breast changes during the pregnancy?

M. Yeah. Yeah.

P: Okay. I had a lot of breast changes in my unaffected breast but in the surgery, it was a lot smaller, the one that I had radiotherapied so I actually was quite lopsided through the pregnancy but even more so after I'd had her because, yeah, radiotherapy just stopped any of the prolactin hormones from causing enlargement of my affected breast. So yeah, that was interesting, having to wear an insert for the first time.

M: Oh, like sort of a prosthesis in there?

P: A prosthesis, yeah. Because I had one feeding side and that was like normal and the other side was quite, you know, had been unaffected so, yeah, I had to do all of that, get a prosthesis and [… 52] bras and all that sort of stuff, so that was interesting.

M: So was that just for aesthetics? Just for cosmetics…

P: Oh, yeah. But I couldn't really… Yeah, absolutely. Well, I mean, it was just so obvious!

M: It didn't feel too unbalanced, you know, physically?

P: Ahh, well, I was, yes. Yeah. But, you know, I didn't get… I wasn't bothered by it. Psychologically it didn't bother me at all. I mean, I was able to get a nice pair of togs that I could put the prosthesis in and, yeah, that worked well, but I must admit I'm now five months and I only fed… Yeah, I fed from one breast fully, well, almost fully for the first month and it gradually, yeah, I couldn't keep up with the demands of my bub from one feed, especially when I went back to work, so she's actually, we've slowly… Well, I haven't had to wean her. She just completely, yeah, she's completely on bottle now, has been for the last week, I guess, because I just couldn't keep up. Even though they say that even from one breast you should be able to keep your supply going, I just couldn't and I don't know whether that was because I didn't try hard enough or just with everything else, and also in the back of your mind is that, you know, I did develop my first breast cancer when I was feeding my first baby, and it's been on my mind ever since. And then when I had my… You know, I went to have my breast check at three months, I was told, oh well, I can't have a mammogram and that was really… And I said, well, why can't I? Oh, because you're feeding and it won't show up anything, but of course they didn't… I don't think, like the radiologist or the radiographer really understood what radiotherapy does to the breast, you know, like they were saying to me I couldn't have a mammogram and I got really upset and I said, "Yes I can" because I have one breast that's not actually stimulated by the hormones and they're saying, "Oh, but you're breastfeeding" and it was actually quite upsetting for me because I was saying, "Well, you know, I developed breast cancer when I was breastfeeding, I should be able to have investigations" and, yeah, so that's probably the worst thing that's happened. I was really… You know, I think they really hadn't thought it through or didn't really understand that with a radiotherapied breast, your breast, the hormones don't affect it so therefore you SHOULD be able to do mammograms and ultra… You know, a mammogram and ultrasound on that particular breast anyway because it's not any different from any other time. Do you know what I mean?

M: Yeah. Yeah.

P: Yeah, so there was a misunderstanding… There was a lot of…

M: For you to go to get a mammogram, I'm assuming, did you have to have some sort of referral from your oncologist or something like that?

P: Well, from my surg… Well, I don't see my oncologist any more mainly because he comes up from Brisbane and so I just go and have my checks with my surgeon, okay, and I was due for a regular check and so I rang my surgeon and said I need my mammogram and ultrasound and he just faxed over the report, do you know what I mean? I guess he probably didn't sort of think about it either.

M: I just found that peculiar that, okay, you've got a referral from your surgeon and the radiologist is still questioning it.

P: Yes. Yes. Oh, well, yes, especially when they know I'm a doctor!

M: That's right. I mean, that's a double whammy!

P: But still, yeah… But at the time I was feeling very much like a patient! And I was saying, well, you know… Certainly it is true that if you have, that when you're breastfeeding that a mammogram and an ultrasound probably won't show up a breast cancer in a breastfeeding breast but I mean, my issue was that I only had one breastfeeding breast at the time.

M: So you were only wanting the mammogram done on the one side.

P: Well, I wasn't really. I went up there to have them both but keeping in mind that the one on the affected side is probably what we're more interested in but anyway, as it turned out, they did it, they did them both anyway.

M: Oh, they did.

P: Yeah. Yeah, but there was a kafuffle about it, yeah. Mmm. Yeah, figure that one out!

M: Yeah. So now that you're finished breastfeeding, are you considering having another one done sort of once the breast settles down [… 98]?

P: Well, I'll need to, yeah. Yeah, well, I guess I will discuss that at my… I have an appointment to see my surgeon in September, which is another three months…

M: Oh, that's not that far away.

P: Yeah, another three months so we'll discuss it then whether I need to have another one then or whether we just wait for another, for twelve months.

M: Mmm. Your breasts should be settled down completely.

P: They should be, yeah. Yeah. They should be settled down completely but whether we just go and… I go and have one twelve months from when I had the one this year or whether we go and have another one then in my unaffected breast. I don't know.

M: Mmm. Just talking about the prosthesis, I just thought physically, did it cause you any problems like shoulder pains or anything like that with one breast getting so much bigger than the other, with a bit of unbalance there?

P: Ahh, well, um… Look, I think it probably did. I think it probably did. I mean, I had a lot of, you know, with a new babe, I had a lot of thoracic pain, actually I had a lot of back pain during the pregnancy as well so it's a bit hard to know whether that was the cause or not, but I think it probably did to a certain extent. Yeah, and the prosthesis was, it was great, I thought it was great. I thought it worked well but it was hot and sweaty.

M: Right, so because you've actually got that breast still there, so did you wear sort of the prosthesis on top of it?

P: Yes. Yes. Yeah, I've forgotten what it's called now. Yeah, it was a partial one.

M: A partial type one, right, okay. Where did you pick that up from?

P: From Wayne Daniels actually, yeah, Wayne Daniels Surgical which is the medical supplier place in Rockhampton and in fact that was, yeah, when I was in hospital, day five after my caesar, I just rang the breast prosthesis lady up from down there and she came straight… Actually it was great service, she came straight up from there and she said, look, these are the things we have, she brought up a sample and she ordered one and two weeks later I had it.

M: Okay. So you didn't actually use this until after the birth?

P: Oh, yeah, sorry. Yeah, it wasn't really needed until after the birth. I mean, I was certainly a little bit uneven during the pregnancy but sort of once the milk came in…

M: Day three!

P: It was obvious that I was quite uneven.

M: Yeah. Okay…

P: Yeah, it'll be interesting to see whether I go right back to, you know, not needing one.

M: Yeah, I was just thinking, because you were saying that you found it difficult to completely breastfeed so you only breastfed for a month and then you comp fed till just recently, I was just thinking about you know how if you've got worries and things it tends to stop milk supply as well…

P: Yes. Yes.

M: So do you think that sort of impacted on the milk supply as well? If you sort of had in the back of your mind about, you know, "that cancer came when I was breastfeeding"…

P: Yeah, yeah… Ohh, I actually don't think that's a significant part because I really… Because once I knew I could feed, I was sort of, invigorated by that, I guess. You know, like I thought, oh well, look, I can feed. I didn't… I worried about that more before the pregnancy… Before the birth than I did after. Once I started feeding, I don't think that had a negative impact. I think it was more, I think I stopped more because she was very hungry, I couldn't keep up and I had to go back to work, and I mean, really I persisted with feeding until I started going back to work and then I sort of cut down the feeds, the breastfeeding just came down to three times a day anyway and then that naturally… Then my supply naturally dried up after there so I don't think psychologically really… I mean, I don't think I was ever going to feed for twelve months anyway, you know. So I don't think so. I don't think I had that in the back of my mind because I was so pleased that I could feed a little bit. Do you know what I mean? Like the fact that I could actually breastfeed her for three months I think was such a bonus to be able to do that, so I felt more positive about that than negative.

M: Okay. I remember last time you were saying with the first bub you were a real convert of breast feeding and you even took the pump to work and all the rest of it…

P: Mmm. [… 147]. Sure was, yeah. Very different!

M: So this time…

P: Well, different set of circumstances. Absolutely. You know, as I said, I had my baby and I thought, well, if I can feed a little bit, well then, that's a bonus and if I can't and I knew from early on that she, you know, that she needed at least some comping and as I said, plus when she just thrived, you know, she's a really fat, chubby, hungry bub. You know, when they look healthy and thriving and you think, well, like I didn't really… I just think, she's survived and, yeah, healthy.

M: So therefore I'm getting from this that in your experience, it's much more difficult to keep supply going on one side than if you had both going.

P: Absolutely. Absolutely.

M: Yeah. Because it's sort of double the work sort of thing, is it, double the effort?

P: Yeah. Yeah. Look, but when I think about with my first baby, like I did have trouble keeping that supply going anyway with two, because I used to feed from one and pump from the other at the same time and that was the only way I could keep the supply going. So yeah, even though they say that you should be able to, there's just no way I could. But, you know, I'm sure different… I know that other mothers, they have heaps of milk. They could easily feed off one breast. You know, my baby always needed two sides initially, with my first one, to actually fill her so I just think that there are some women who do supply, do have more milk than others.

M: Yeah. And do you think it's also your work situation that you're working three plus days a week and it's just extra effort…

P: Mmm. It's all too hard!

M: Effort-wise, yeah, exactly.

P: Yeah, and as I said, I was so motivated with the first but things are just so different. Things are so different this time. Yeah, and when you see her, she seems so healthy anyway you think, oh well, it's not worth being, certainly not worth worrying about. I mean, that was not a high priority this time.

M: I just don't have your other notes in front of me, but how long had you been breastfeeding when you found the cancer the other time?

P: I'll have to work this out [calculating]. Sixteen months, she was.

M: Sixteen months. Oh yeah, that's a fair whack. Okay. So have you experienced any other difficulties breastfeeding, normal type breastfeeding type problems people have?

P: Did I experience any normal… No… I mean, infections and stuff?

M: Cracked nipple…

P: And mastitis, nothing like that. No.

M: No cracked nipple or anything because it's just the one side?

P: No. Oh, okay, all right. Well, for the first five days, yes.

M: Ooh, ouch!

P: I did. But so we got into the rotating the baby instead of the breast. So you football hold one feed and then hold her the other way and that really worked well, do you know what I mean? Like you rotate under, you feed her underneath you like a football hold one feed, and then the next feed you feed her the normal way so like you're rotating the baby round the breast so that she'd suck at different angles.

M: Suck a different way, oh yeah.

P: And that worked very well. It's such a simple thing, and I said, well, if you can't rotate your breasts, we'll rotate the baby and one of the midwives said that to me and I said, well, that makes sense and it worked. So then after a week it toughened up, yeah, it toughened up so it really wasn't a major problem. I guess it'd get sore intermittently but nothing to complain of.

M: Okay. So have the health professionals been helpful concerning the breastfeeding, like the nurses in the hospital or anything like that?

P: Yes. Yes, that was one very helpful advice from one. Yeah… I mean, certainly, and I stayed in for seven days so I made sure that I was as comfortable as I could.

M: So had any of your nursing staff experienced this before?

P: No. No, none of them had had, knew about the fact that radiotherapied breasts, you can't really… Well, actually at the time I was attaching her to my affected breast and I actually had taken with me some letters that I had. I mean, I'd done some research on breastfeeding after radiation and [wide dissection? 202] and I had a couple of articles and it talked about individual cases who could actually feed a little bit from that affected side and so I took them along with me and of course one of the nursing staff was really interested and so she ended up photocopying all the notes and using it as a resource! So I was probably more of a resource rather than them helping me! But that's fine. But yeah, even though the reports that I had said that there were isolated cases of milk production from affected breasts, I would honestly say that, you know, I used to attach her to that side but there was nothing, nothing was coming out. So I sort of quickly, I think by the end of the week I'd even stopped trying to attach her.

M: Okay. So did the irradiated breast, did you get peripheral activity around, not the breast itself but the tissue around it?

P: Actually, yes, I did. Yeah, underneath my axil… Well, I think I did because underneath my axilla I panicked at one stage thinking, oh my God, you know, I've got a lump there, but I'm sure that that's what it was. You know, just in the axillary tail area, I'm sure that I had some, I certainly had some tenderness but it didn't last for very long and, yeah, in reflection I'm sure that that's what it was, which makes sense, doesn't it?

M: Yeah. Yeah.

P: But I didn't any, I can't recall ever getting any milk, seeing any visible milk from the nipple even though I used to try and attach her as a young babe.

M: Okay. So you found some information about breastfeeding after breast cancer but this information was more scientific literature, I take it?

P: Yes. Yeah, I got that… Now I had to search for that and I'm just trying to think… I ended up getting it through Nursing Mothers. Yeah, I rang up Nursing Mothers Association and then their national library in Melbourne, I think it was. Yeah, I think that's how I got through, and I got them to do a lit search for me and they sent me a list of like, yeah, twenty articles. Yeah, the literature search was on, I think the key words were, yeah, radiation, breast cancer radiation and nodal, you know, axillary [dissection? 230] and… Wide axillary node dissection, they were the three words that we used and there were a number of articles and I just chose three and they basically all said the same. Are you interested in them?

M: Yeah, I was just jotting down where you got all that from.

P: I could send you a copy. I'm sure I could put my hand on them if you're interested.

M: Yeah, you could send me them down, good. Great.

P: All right. I can do that.

M: Great. Because it's very few a far between finding this sort of information.

P: Yes. Well, I know, that's why… Well, I wasn't quite sure where to start and that was…

M: Well, it's like you're a professional person and you have a health background so you've got a fair idea where to go, but like the normal person on the street doesn't have much hope at all.

P: Yeah. Yeah, well, I thought… I first of all thought, oh well, I'll ring up the Breast Cancer Association, the National Breast Screening Association, National Breast Cancer, what's it called, NCC…

M: Council…

P: Council, yeah. Anyway, I rang up and I said I wonder if you've got any information about breastfeeding after breast cancer and she just sort of said, "What?" [laughs] And it was like, hey listen, we don't deal with that basically!

M: Oh really? Well, they should!

P: It was like this blank and I was thinking, hmm, maybe I'm barking up the wrong tree. Maybe they've got heaps of literature on people with secondaries and malignancies and terminal care and all that sort of stuff, so I thought maybe I've got this wrong. Don't concentrate on the cancer bit, concentrate on the breastfeeding bit so that's why I thought, oh well, Nursing Mothers is the obvious choice and they'll be useful, helpful.

M: Yeah, and most of this was just basic case studies, was it?

P: Yeah, there was… No, there were a couple of studies done, yeah, there were some prospective studies done on the incidence of breastfeeding in pregnancies post breast cancer. There weren't very many numbers and then they made anecdotal comments about particular cases, yeah. Okay, but I will, if you're interested in it.

M: Yeah, that'd be very interesting, yeah.

P: I think they're at home actually.

M: Yeah. Okay. So therefore if somebody asked you about where would they find information, would you pass them on then to Nursing Mothers yourself?

P: Yeah, probably. But I mean, the local Nursing Mothers wouldn't have any idea either but certainly that's what they've got, they've got national, yeah, they've got a good library service. I think it cost me about twenty bucks to get them but that was all right.

M: Yeah. It sounds like they've been used well.

P: That's right!

M: Okay. So you were saying about how different, I think what you meant was breastfeeding, either that or the whole experience of having a baby…

P: Yes. Yes.

M: How different it was first time and second time. So how did the breastfeeding compare… I know we've talked a lot about it, but is there anything else specifically…

P: Oh, I still, you know, really, really enjoyed it. I don't think there's any question about that, but I wasn't… But I enjoyed it as something extra that I could do, not as something that I needed, that I HAD to do, I had to prove. Yeah.

M: Yeah. Okay. Right, I don't have to talk to you about that… Okay. So fertility concerns.

P: You betcha! [laughs]

M: You betcha! Now you're scared of getting pregnant again? Is that more the problem?

P: Yes! Yes. One of us is going to have to have the chop, I think. Well, it is a croc… It's a real… It's actually an issue for us at the moment. Absolutely. Because I'm not… I don't know. I don't trust anything!

M: So you were saying last time that you didn't want your partner to have a vasectomy.

P: No.

M: Just in case.

P: Yeah.

M: And you did mention tubal ligation but I think it was in jest!

APPENDIX 3

STUDY FINDINGS

The documents which make up Appendix 3 are presented in the order as follows:

APPENDIX 3.1: Pilot Study Findings

Preliminary Findings of Pilot Study (Participants 1-10) only

SECTIONS TO ANALYSIS

A – Information looked for other information needs details

B - Adjust to BC what helped

C - What hindered adjustment to BC

D - How have things changed since diagnosis

E - Greatest Concern for young women with BC

F - Roles – and if changed

G - Support

H - Emotion Impact

I - Current major concerns/ future

J - Finances

K - Relationships

L - Information before treatment and choices

M - Worst side effects

N - Other issues

O - Greatest unmet need

P - Advice to newly diagnosed young woman with BC

Q - Best avenue of help for a newly diagnosed young woman with BC

R - Anything a newly diagnosed young woman with BC should stay away from

S - Other important issues

T - Alternative – complimentary therapies

BC – Breast Cancer
B/care – Breast Care (Nurses)
P # - Participant Code
QCF – Queensland Cancer Fund
QOL – Quality of Life
( ) – number in bracket denotes the number of participants stating that issue

A – Information Given or Looked For

Sections: ***Information Given***

Organisations (QCF) Health Professionals Institutions (Hospitals) Other People

Information Sought Rather Than Offered

(Special Case) - Neo Natal Ward Internet Public Libraries

What Was Missing
Pregnancy and BC information; don't know the right questions to ask doctors; information about alternative therapies; and information about support groups from doctors.

General Overview – Wesley hospital and QCF were very good at providing information as were B/care nurses and BC volunteers. However not everybody received a visit from the QCF or a BC volunteer. Doctors were mentioned but not strongly. Not all information received or sought was considered to be good or adequate.

B – Adjustment to the Diagnosis of BC

Sections:
Informal Social Networks ***Formal Social Networks*** ***Other***

Informal Social Networks: Social Networks other than health professional run or organised.

Formal Social Networks: Any health professional run or organised element of help.

Other: Anything other than person-to-person contact style of assistance.

General Overview – A QCF visitor and/or BC volunteer and associated information was very strong in this regard. Some stated the support of their family and friends was also instrumental in their adjustment. Two participants, who are relatively newly diagnosed, have not yet adjusted to the diagnosis. Talking to someone of a similar age who has gone through BC seemed to be the best information source; maybe as the additional witnessing of a person close to their age who has survived is helpful.

C – Hindered Adjustment to the Diagnosis of BC

Sections:
Support Related ***Within Self*** ***Diagnosis/Treatment Related***

General Overview – Unsupportive family was mentioned here, but not strongly. Participants' own attitudes were mentioned also as a hindrance. Specialists' who were arrogant and did not treat the participants like worthy people were mentioned too.

D – How Things Have Changed Since Diagnosis

Sections:
Physically ***Family Relations*** ***Psychologically***

General Overview - Some participants felt that things had changed for the better, such as: being able to appreciate life more; making changes earlier in life rather than later; becoming closer to family and some friends. It was fairly unanimous that life does change after diagnosis, however there was a mixture of answers as to whether they perceived themselves to be cured (breast cancer is now gone) or to having breast cancer for the rest of their lives. A few participants can no longer take part in the paid workforce, mainly due to the nature of their employment, as their jobs were physically demanding. Their usual work was often disrupted by the treatment routine, depending on their individual reaction to such treatments. Participant 8 (P8), who has advanced breast cancer, claimed how 'once you have a diagnosis of breast cancer you have it for the rest of your life – as around check up time it always niggles at you, every time you have an ache or pain you think it has come back'.

E – Greatest Concern For Young Women With BC (Opinion)

Sections:
Emotional ***Physical*** ***Other***

General Overview - Concerns varied – however in the main it fell around concerns of long term survival as compared to short term and the issues of seeing children grow up. Recurrence was as issue for most the women interviewed. To a lesser degree – there was concern for partners/spouses coping with the situation and with the possible participants' death and subsequently raising of children alone. Early menopause and fertility concerns were evident as were issues surrounding sexuality and physical appearance (body image) and emotions. The costs associated with treatment and access to such treatments was expressed by one of the participants.

F – Roles At Time Of Diagnosis, And If They Had Changed

Sections:

Family (10) ***Community/Social (3)*** ***Career (5)***

General Overview - No role change - 50% of participants, some degree of role change – 50% of participants. The roles of the women involved in the pilot study varied, however the vast majority were mothers (8 out of 10), hence motherhood was a vital role. Some of the participants had roles in careers, but only a couple had community roles. All but one participant was a spouse/partner. Changes in roles were not immense – the lowering of fitness levels due to the disease and treatment meant a few women had to postpone or cancel such community or work roles which involved physical fitness. A change of role of primary care giver to children did occur for a few participants, particularly those in early treatment phases and the participant who suffers from advanced breast cancer. In the case of those only months since diagnosis, this role change has a good chance of changing back to normal – however the participant with advanced breast cancer is not expecting this role to be returned.

G – Support - Informal and Formal

Informal Support – social networks other than health professional run or organised.

Formal Support – any health professionally run or organised element of support.

Sections:

Informal Support		***Formal Support***
Peer Support	Age Appropriateness of Support	Recommend to Other Young Women

Informal Support:

Family Friends Others (ie. Internet, Support Groups)

Formal Support:

- * Cancer Organisations (QCF, Canberra Cancer Council)
- * Transport Related
- * Doctors
- * Wesley Hospital Based BC Programs and Groups
- * Other Health Professionals (eg., Dietician)

Peer Support:

Limited Enough

Age Appropriateness: Mostly fine though need more ‘age specific’

Recommend To Other Young Women With BC:

Phone Support QCF Choices Program Support Groups

Support Informal General Overview – The support received by the participants fell into two basic categories, formal and informal. Informal support appeared to be vital, though not all participants felt they received enough. Some participants found support was forthcoming only while undergoing treatment, with some family and friends not realising that the need for support goes on for quite some time after treatment has finished. Most participants found out who their real friends were – which turned out, at times, to be surprising. Most support received was emotional with minimal financial and physical (housework) style support.

Support Formal General Overview – Formal support was very wide spread. The Wesley hospital and all it offered to women with BC was exceptional, as was the assistance provided by the QCF (and similar organisations). Health professionally organised transport assistance was greatly appreciated. Support provided by doctors (from GPs to Specialists) varied, some was very good while others left a lot to be desired. It was the opinion of one participant that doctors should provide information of available support groups and organisations. QCF helped in this regard though not all participants received a visit from a QCF volunteer. A mixture of other health professionals also provided support to this group of participants, such as: acupuncturist; nutritionists; nursing services; sex therapist; social worker (hospital based); and physiotherapists.

Convenience emerged as a vital factor in the attendance of support groups/programs. Factors, such as working and child minding, stopped young women from attending such support.

In General: Peer support appeared to be adequate, except in the case the P1 who was pregnant at the time of diagnosis. The age appropriateness of support provided was not an issue, rather it appeared that there is not much which is age specific.

Not all help offered was taken up, and some additional help was sought in some cases.

G – Support – Suggestions and Further Comments

Suggestions:

- Need social group for children of young BC suffers
- Need physical home help support
- Spouses/partners need support too (3)
- Need a group of young mothers with young children at STRETCH (physical support service – Wesley Hospital) and have child minding
- Would be good to have a list of phone numbers of young women who have BC – for phone support
- Need to know what you are going to look like after surgery
- Should be more support at the beginning
- Need individual life coaching
- Need support group for couples – relationship support
- Peer support - would have been good to know someone with BC in similar situation, eg., single, working
- Hospitals should have support services
- BC volunteer who visits should ask if you want to have your details put on a mailing list for support services, such as Choices (Wesley Hospital)

- Physiotherapists could have been more understanding – need to be more in touch with emotional effects of BC
- Need early menopause support group
- Need more services for young women with BC (2)
- Counselling from day one would be good (2)
- Need a list of services in the area, as its hard to ask for what you need
- Need child minding at support groups (more generally)

Other Comments:

- Need to talk to someone not close to you
- Found no real support after treatment finished
- Once you have advanced BC - ostracized – scare others
- A lot of help was not offered but rather was sought out
- Some help offered was not taken up

H – Emotional Impact

Sections:
Mortality Grief Lost Acceptance Self-Image Quality Of Life (QOL)

General Overview – The emotional impact of being a young woman with BC was very difficult for the participants to verbalize. The comments made fell into the categories of Mortality – fears of future and dying; Grief - described in words and of what was already Lost; Issues of Acceptance; how the Self-Image was damaged and QOL issues. Overall, self-image concerns were not greatly damaged; as the fight for survival seemed to override this, however it was evident that self-image was tied up with self-esteem lost and poor body image. QOL had not changed a great deal for most participants. Overall QOL dipped while undertaking treatment, though returning as health improved – in the case of P8, who has advanced bone metastases, she felt her QOL was fine – though now defined it differently.

I – Current Major Concerns / Future

Sections:
Physical Medical Other

Many of the participants stated that survival and issues surrounding survival were paramount in their current concerns. One participant was particularly concerned about the prospect of having to guard against lymphoedema for the rest of her life. Early menopause was the major concern for one participant, above survival and recurrence. The issue of contraception following breast cancer was also raised. The participant who was pregnant when diagnosed, is keen to have more children, but is concerned there is very little information concerning pregnancy and breast cancer risk. One participant, who was diagnosed not long ago, was concerned that life will never be the same, together with issues of future employment.

J – Finances

Sections:
Superannuation Lost ***Some Strain*** ***Difficulties*** ***No Financial Concerns***

General Overview **–** Superannuation loss and income loss due to inability to work was not a great factor with this participant group, rather the gap between the cost of frequent consultations, treatments and tests and Medicare/private medical insurance coverage presented as the major financial strain. Such an accumulation of gaps caused participants financial concerns.

K – Relationships

Sections:
Spousal/Partner (+& -) ***Family (+ & -)*** ***Children*** ***Friends***

General Overview **–** There was a variety of positive and negative interactions and responses from spouses/partners and other family members. Some relationships improved while others deteriorated. Relationships with children were paramount therefore given their own category. The issues of children being stressed and having to grown up quicker seemed to dominate concerns. P 7 spoke of how her diagnosis and early treatment had a developmental effect on her preschool child. 'Friends' generally fell into 'you find out who your friends are', and 'some people who you would not expect to rally did and other young women who had BC become special friends'.

L – Information Given By Professionals Before Treatment – Choices

Information Given Section:

Given By Who or What: Health Professionals

Sections:
B/Care Nurses ***Doctors***

Health Institution - Organisation

Sections:
Hospital Based Library ***Information Session At Various Hospitals***

B/Clinic + Other Treatment Clinics ***QCF***

Forms In Which Information Was Given:

Sections:
Internet Sites ***Videos*** ***Verbal*** ***Written***

Informed Status:

Sections:

Felt Well Informed ***Felt Not Well Informed***

Information Missing:

Not Encouraged to Read Post Surgery Effects Pregnancy and BC

General Overview Information Given – Information was given to participants by B/care nurses and doctors, hospital services, programs and QCF. Information given was verbal, written, via videos and internet sites. Not all information was received well, some appeared to be irrelevant and not age specific, as well as too elementary.

Choices Section

Sections:

No Choices ***Influencing Factors Of Choice Made*** ***Extended Choices***

Extended Choices led to Chemotherapy Choices

General Overview Choices – Not many choices were given, standard type treatments were administered in most cases. Some choice of drug/treatment was reported and choice of whether to reconstruct or not. Choices were made on hope and faith together with recommendations from doctors. At times no choices were given, or the choice was given in such a way that there was no choice. Some choices were given concerning chemotherapy treatment, however success statistics were of women aged 60+. In two cases no choice was given. Three participants made the choice to either not have the treatment (chemotherapy) or to have it while pregnant, which was not recommended by doctors. Choices seemed to be very limited for these participants.

M – Worst Side Effects

Sections:

Drug Induced (ie, chemotherapy) ***Radiotherapy***

Post Surgical ***Emotional/Psychological***

Most Important Finding - From drug induced – chemotherapy or tamoxifen early menopause – including symptoms below:

- Memory Loss
- Sleeplessness
- Hot Flushes (even if had gone through natural early menopause)
- Painful sex
- Sexuality issues – lost libido
- Feel old before time
- Not offered practical solutions
- Not prepared
- Not told – or told periods may become irregular
- Side effects very severe

- Most information comes from other young women suffering early menopause
- Health professionals focus on infertility – it is so much more

General Overview – Early Menopause – The issue of early menopause stood out from the rest. The uncertainty of it made it very difficult for the women to cope with. The women did not know if they were going to go through menopause to the stage of full infertility and cessation of periods, or if it was temporary and cycles would return. The women seem to associate menopause with being an old woman, and this does nothing for their self-esteem. As professionals mainly focus on infertility, the women find it very difficult to cope with all of the other issues as mentioned above. Some of the women have been through this before and the drugs induce it all over again. One woman had been through early menopause (drug induced) twice (with very bad affects) and was about to go through it again. Infertility is certainly an issue for some women who have either not started a family or wished to extend their family, however for others (who have finished their family) the effects of early menopause should not be underestimated, infertility aside, it greatly impacts on their very being. The worst of it seems to be that no one can give them answers to their questions, they needed to know prior to the event of what it may entail. The early menopause issues were very distressing for most of the participants.

N – Other issues

- Sexuality
- Told some people can't work, should have been told ' some people can work' – would make one feel less inadequate if can't work
- Had to beg doctors to change nausea medicine, should not have to do that
- Young women need to know about psychosocial factors on survival – optimise life
- The way it changes your life – never going to leave you
- Recurrence – no one tells you it is a huge possibility

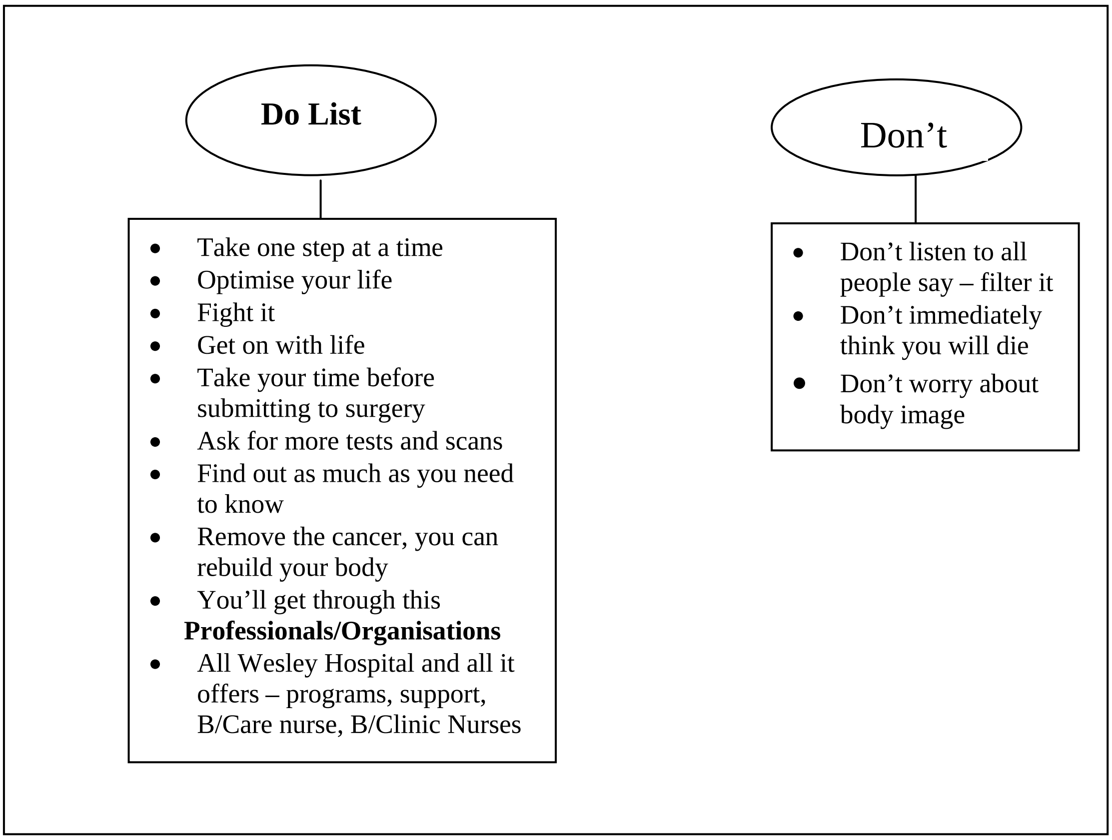
O – Greatest Unmet Need

Sections:

Support ***Information***

General Overview: The greatest unmet needs fell between support and information needed. The most pressing issued seemed to be that of child minding to attend programs and support meetings and the need for some kind of practical physical assistance, i.e., home help. Additional information is needed on issues relating to early menopause, tamoxifen use, and sexuality after treatment and surgery; confidence in such information is also needed.

P – Advice To Newly Diagnosed Young Women With BC



Do List

- Take one step at a time
- Optimise your life
- Fight it
- Get on with life
- Take your time before submitting to surgery
- Ask for more tests and scans
- Find out as much as you need to know
- Remove the cancer, you can rebuild your body
- You'll get through this

Professionals/Organisations

- All Wesley Hospital and all it offers – programs, support, B/Care nurse, B/Clinic Nurses

Don't

- Don't listen to all people say – filter it
- Don't immediately think you will die
- Don't worry about body image

Figure 1: P – Advice To Newly Diagnosed Young Women With BC.

Q – Best Avenue Of Help For Newly Diagnosed Young Women With BC

Sections:

BC Support ***Other Medical*** ***Non-Medical***

The best avenues of help advised for a newly diagnosed woman with breast cancer range from all aspects of the Wesley Breast Clinic (such as STRETCH and the More Choices program) to QCF (and other cancer societies and councils) to B/care nurses and breast cancer support volunteers. One participant particularly liked the Wesley Breast Clinic as they encouraged the participation of the partner, included in support/treatment as a part of a unit. Speaking to a woman of a similar age who had been through the experience of breast cancer was found to be of vital importance. One participant mentioned the value of religious help for those of faith. Another participant, when asked this question, stated that the best avenue of help does not exist as yet, stating that another layer of support services is needed. This participant was a health professional.

R – Advice For Young Women Newly Diagnosed With BC to Stay Away From

Sections:

Information ***Other***

Only eight of the participants answered this question – the responses were very individual – from their own bad experiences. This list contains: make sure the seminars/workshops you go to are what you expect them to be; leave books alone, they are scary; do not go into the internet expecting to find good quality information; you don't have to start chemo straight away – have some say; stay away from bad/sad stories, such as the Kim Walters story; don't go to private mammogram clinics, they won't let your partner in; watch out for unsympathetic physiotherapists; and don't look at picture of women with nice breasts (such as would be found in a woman's magazine in bra advertisements). Outdated information booklets (and other information sources) were raised more than once as a problem.

S – Other Important Issues

Sections:

Partner Concerns ***Medical Profession*** ***Support***

Partner Concerns General Overview – Partners do not realise the emotional and mental issues of having BC; partners and BC sufferer needs to be seen/treated as a unit; and partners need to be recognised for the role they play in BC sufferer's recovery.

Medical Profession General Overview – Felt rail-roaded into surgery; doctors/professionals not respecting consumer's decisions to not undergo treatment; previous treatment of consumers by professionals retards early presentation of symptoms; alternative – complementary therapies not taken seriously by some doctors; and being put in a ward with end stage BC sufferers when put in for 1st chemo session – very frightening.

Support General Overview - Being pregnant when diagnosed with BC was very isolating; and need to talk to someone early in diagnosis.

T – Alternative / Complementary Therapies

Sections:

Diet Related ***Other***

Diet Related:
Vitamin Supplements
Naturopath
Dietitian/Nutritionist (Cancer Prevention Diet)
Gerson

Other:
Acupuncture

Only four participants mentioned alternative therapies – these were acupuncture, the use of a naturopath, the use of vitamin supplements and ‘Gerson’, a style of alternative therapy involving the monitoring of the participant’s blood of nutrients and other components and the use of supplements and (in P8’s case) 13 juices a day – freshly juiced vegetables and fruits – the eating of only organic fruits and vegetable mainly and being a vegan. P8 stated that the professional doctors (her first set of specialists) did not encourage her to read or to look for complementary therapies, she was told they don’t work and that she was wasting her time – the Gerson therapy has made an immense difference to her quality of life.

APPENDIX 3.2: Fertility-Related Table and Reconstruction-Related Table Derived From Findings of Baseline, and Other Related Information

Issues Within All 35 Transcripts Concerning Fertility Concerns

Table A3.1: Baseline participants' fertility status and/or concerns**.**

Code	Issues Concerning Fertility of Participants
P1	Wants more children - diagnosed while pregnant – 21 weeks (1 child under 6 years) (24 mths)
P2	In EM – desperately wants more children – does not know if infertile (has 1 child under 6 years) (18 mths)
P3	Would not attempt to have more children – would not risk it (has 1 child under 6 years) (18 mths)
P4	Finished family – no desire for more children (2 children 1 school age and 1 under 6 years) (11 mths)
P5	Single participant – not really worried about fertility, but may change mind (no children) (23 mths)
P6	Finished family – had already been through natural early menopause (3 children - 1 school age, 2 high school age) (4 mths)
P7	Finished family – but still sad at EM and possible infertility (5 children - 2 under 6 years and 3 school age) (18 mths)
P8	Finished family – does not want any more children (Advanced) (2 high school age children) (37 mths)
P9	Was just about to try and get pregnant when diagnosed - no children – would of liked to of had children but do not want to pass on gene (21 mths)
P10	Finished family – do not want any more children – had had hysterectomy previously to breast cancer (2 children – high school age and young adult) (6 mths)
P11	Wants more children – diagnosed while breast feeding (1 child under 6 years) (12 mths)
P12	No desire for children (alternative lifestyle) (no children) (37 mths)
P13	Family Finished - Fertility not an issue (P21) (2 children 1 under 6 years and 1 school age) (24 mths)
P15	Single participant – fertility not an issue anymore had to have a hysterectomy as a side-effect of treatment – no hope ever (could of borrowed an egg from twin sister) (no children) (30 mths)
P16	Would of liked to of had children, no longer an option – tamoxifen cannot try to become pregnant for 5 years (41 at interview – feels would be too old to start) (no children) (30 mths)
P17	Would like another child – had a pregnancy after diagnosis (and termination to allow treatment to begin) (1 child under 6 years) now not really concerned about having more children – after tamoxifen too old to have more children don't want to be 43/44 and pregnant (17 mths)
P18	Fertility is a big concern – was seeing a Dr about infertility when diagnosed had section of ovary frozen (no children) (26 mths)
P19	Would of liked more children – found breast cancer after breast feeding had finished (2 children – 1 under 6 years 1 school age) fertility of a concern (35 mths)
P22	Finished family – not planning on having any more children (2 children – 1 under 6 years and one school age) (Advanced) (38 mths)
P23	Would like more children, fertility is of a concern – diagnosed while pregnant (17 weeks) – though lump was there before pregnancy – breast feed for 2 weeks (1 child under 6 years) (14 mths)
P24	Family finished – not planning any more children – fertility not a concern (2 children - 1 under 6 years, 1 school age) (12 mths)
P25	Not really concerned about fertility – does not know yet if infertile – if had another child after tamoxifen big gap between children – diagnosed while breast feeding (baby 15 mths old) – happy to of had 1 child – can't think about having babies until the 5 years of tamoxifen is over (27 mths)
P26	Family finished – no fertility concerns – (3 children – 2 high school, 1 young adult) (39 mths)
P27	Family finished – no fertility concerns – (2 children – high school age) (26 mths)

P28	Family finished – no fertility concerns – (3 children – 1 school age, 2 high school age) husband already sterilised. (16 mths)
P29	Family finished – no fertility concerns – (2 children – school age) (22 mths)
P30	Family finished - fertility not an issue, had already decided no more children (1 child – school age) (17 mths)
P31	Fertility is an issue – was just about to try and get pregnant when diagnosed (P4) does not know if infertile (no children) (11 mths)
P33	Family finished – was not planning any more children – no fertility concerns (1 child – school age) (31 mths)
P34	Family finished – not planning any more children – husband already sterilised (2 children – school age) (33 mths)
P35	Had not really planned any more children – but choice was taken away – fertility a concern (1 child – under 6 years) (28 mths)
P37	Family finished – no fertility concerns (2 children – school age) (19 mths)
P38	Fertility issues is of a concern – has had ovary tissue frozen (no children) (5 mths)
P39	Fertility is a concern – but fell pregnant after breast cancer diagnosis – nearly ready to have first child at time of interview – breast cancer did not bring family plans forward, just happened – but no not know if will be able to have any more – tamoxifen - had IVF before chemotherapy – harvested eggs and stored 9 embryos – but fell pregnant naturally – will be interesting to see if can breast feed off affected side (19 mths)
P40	Family finished – fertility not a concern – infertility would be good (3 children – 2 school age and 1 young adult) (5 mths)

Table A3.1: Baseline participants' fertility status and/or concerns.
Note: Number in ( ) time lag since diagnosis

See breakdown of Table A3.1 below:

- 2 participants diagnosed while pregnant (P1&23) P 23 knew had lump before pregnancy – thought nothing
- 1 participant became pregnant after diagnosis – aborted to begin treatment (P17)
- 1 participant had successful pregnancy since diagnosis and treatment – was nearly ready to deliver at time of interview (P39)
- 2 participants were diagnosed while breast feeding (P11&25)
- 1 participant was diagnosed just after finished breast feeding (P19)
- 2 participants were just about to start a family when diagnosed (P9&31)
- 17 participants had stated they had finished their families hence no fertility concerns (P4,6,7,8,10,13,22,24,26,27,28,29,30,33,34,37,40)
- 10 participants stated that fertility concerns were an issue – wanting a child or more children in future (P1,2,11,18,19,23,31,35,38,39) – 1 of these participants (P18) was seeing a fertility doctor at the time of diagnosis
- 1 participant did not ever desire to have children (P12)
- 7 participants stated fertility was not an issue due to various reasons (4 of these participants did not have any children) such as - too old after treatment to become pregnant – too big a gap between children after tamoxifen – did not want to pass the breast cancer gene on – knew definitely pregnancy no longer possible – fertility was not a specific concern at the time of interview (P3,5,9,15,16,17,25)

Note: 25 participants (71.42% of participant pool) did not have fertility concerns and 10 (28.57% of participant pool) did.

See the breakdown of issues surrounding fertility in Table A3.2 and A3.3 below.

Table A3.2: Details of baseline participants for whom fertility is not a concern.

Code	Participants who do not have fertility concerns
P3	Would not attempt to have more children – would not risk it (has 1 child under 6 years) (18 mths)
P4	Finished Family – no desire for more children (2 children 1 school age and 1 under 6 years) (11 mths)
P5	Single Participant – not really worried about fertility, but may change mind (no children) (23 mths)
P6	Finished Family – had already been through natural EM (3 children – 1 school age, 2 high school age) (4 mths)
P7	Finished Family – but still sad at EM and possible infertility (5 children – 2 under 6 years and 3 school age) (18 mths)
P8	Finished Family – do not want any more children (Advanced) (2 children – both high school age) (37 mths)
P9	Was just about to try and get pregnant when diagnosed – (no children) would of liked to of had children but do not want to pass on gene (21 mths)
P10	Finished Family – do not want any more children- had had hysterectomy previously to breast cancer (2 children – high school age and young adult) (6 mths)
P12	No desire to ever have children (alternative lifestyle) (no children) (37 mths)
P13	Finished Family – fertility not an issue (2 children – 1 under 6 years and 1 school age) (24 mths)
P15	Single participant – fertility not an issue anymore, had to have a hysterectomy as a side-effect of treatment – no hope ever (could of borrowed an egg from twin sister) (no children) (30 mths)
P16	Would of liked to of had children, no longer an option – tamoxifen cannot try to become pregnant for 5 years (41 at interview – feels would be too old to start) (no children) (30 mths)
P17	Would of liked another child – had a pregnancy after diagnosis (and termination to allow treatment to begin) (1 child under 6 years) now not really concerned about having more children- after tamoxifen too old to have more children don’t want to be 43/44 and pregnant (17 mths)
P22	Finished Family – not planning on having any more children (2 children – 1 under 6 years and one school-age) (Advanced) (38 mths)
P24	Family finished – not planning any more children – fertility not a concern (2 children – 1 under 6 years and 1 school age) (12 mths)
P25	Not really concerned about fertility – does not know yet know if infertile – if had another child after tamoxifen big gap between children – diagnosed while breast feeding (baby 15 mths old) – happy to of had 1 child – can’t think about having babies until the 5 years of tamoxifen is over (27 mths)

P26	Family Finished – no fertility concern (3 children – 2 high school age, 1 young adult) (39 mths)
P27	Family Finished – no fertility concerns (2 children – both high school age) (26 mths)
P28	Family Finished – no fertility concerns (3 children – 1 school age, 2 high school age) husband already sterilised (16 mths)
P29	Family Finished – no fertility concerns (2 children school age) (22 mths)
P30	Family Finished – fertility not an issue, had already decided no more children (1 child – school age) (17 mths)
P33	Family Finished – was not planning any more children – no fertility concerns (1 child – school age) (31 mths)
P34	Family Finished – not planning any more children – no fertility concerns (2 children – school age) Husband already sterilised (33 mths)
P37	Family Finished – no fertility concerns (2 children – school age) (19 mths)
P40	Family Finished – fertility not a concern – infertility would be good (3 children – 2 school age and 1 young adult) (5 mths)

Table A3.2: Details of baseline participants for whom fertility is not a concern.
Note: Number in ( ) time lag since diagnosis

Code	Participants for Whom Fertility is a Concern
P1	Wants more children – diagnosed while pregnant – 21 weeks – (1 child under 6 years) (24 mths)
P2	In EM – desperately wants more children – does not know if infertile (1 child under 6 years) (18 mths)
P11	Wants more children – diagnosed while breast feeding (1 child under 6 years) (12 mths)
P18	Fertility is a big concern – was seeing a Dr about infertility when diagnosed – had section of ovary frozen (no children) (26 mths)
P19	Would of liked more children – found breast cancer after breast feeding had finished (2 children – 1 under 6 years and 1 school age) fertility is of a concern (35 mths)
P23	Would like more children, fertility is of a concern – diagnosed while pregnant (17 weeks) – though lump was there before pregnancy – breast feed for 2 weeks (1 child under 6 years) (14 mths)
P31	Fertility is an issue – was just about to try and get pregnant when diagnosed – does not know if infertility (no children) (11 mths)
P35	Had not really planned any more children – but choice was taken away – fertility a concern (1 child – under 6 years) (28 mths)
P38	Fertility is a concern – has had ovary tissue frozen (no children) (5 mths)
P39	Fertility is a concern – but fell pregnant after breast cancer diagnosis – nearly ready to have first child at time of interview – breast cancer did not bring family plans forward, just happened – but do not know if will be able to have any more – tamoxifen – had IVF before chemotherapy – harvested eggs and stored 9 embryos – but fell pregnant naturally – will be interesting to see if can breast feed off affected side (19 mths)

Table A3.3: Details of baseline participants who did have fertility concerns.
Note: Number in ( ) time lag since diagnosis

Note: After examining the ages of participants at the time of interview against their stated experience of fertility concerns, it was found that no pattern of age existed, rather looking at both those with concerns for fertility and those who are not concerned, the ages ranged widely.

IVF: * 2 participants had ovary tissue frozen (P18, 38), 1 participant had eggs harvested and has 9 embryos frozen – many offered IVF – but due to hormonal complications – many did not, but participants were not asked about IVF specifically.

Issues Within All 36 Transcripts Concerning Reconstruction

Code	About Reconstruction
P2	Had mastectomy - had reconstruction at time of mastectomy (18 mths)
P5	Had mastectomy – having a reconstruction (23 mths)
P6	Had Mastectomy – not planning on reconstruction – maybe later (4 mths)
P7	Had Mastectomy – Not planning on reconstruction – wanted to be home with children – can’t afford time in hospital (18 mths)
P8	Had mastectomy – not planning reconstruction (Advanced) (37 mths)
P10	Had mastectomy – started reconstruction (expanders in) (6 mths)
P11	Had mastectomy – Dr said cannot have reconstruction (12 mths)
P12	Had mastectomy – did not come into conversation (37 mths)
P15	Had mastectomy – cannot have reconstruction due to heavy duty radiation on the chest skin (30 mths)
P18	Had mastectomy – did not come into conversation (26 mths)
P19	Had mastectomy – had reconstruction at time of mastectomy (35 mths)
P22	Had mastectomy – did not come into conversation (Advanced) (38 mths)
P24	Had mastectomy – in first stage of reconstruction (12 mths)
P27	Had mastectomy – had decided in early days ‘no way’ have reconstruction – now yes is happening in 2 weeks after interview(26 mths)
P28	Had mastectomy – thinking about it – cost $3000 even with private health insurance and Medicare – did not know could have reconstruction at same time as mastectomy – probably would of went for that option (16 mths)
P29	Had mastectomy – did not come into conversation (22 mths)
P33	Had lumpectomy – was considering reconstruction – Drs say probably wouldn’t be any better – participant said a reconstruction would mean it is over (the breast cancer) (P10) (31 mths)
P34	Had mastectomy – not considering a reconstruction at this point (33 mths)
P37	Had mastectomy – has seen Drs about reconstruction (therefore considering it) (19 mths)
P40	Had a double mastectomy – by choice – one breast definitely breast cancer the other one questionable – turned out it was alright, planning on having a reconstruction later (in public system) vanity (5 mths)

Table A3.4 : Issues arising out of the baseline data concerning reconstruction surgery.
Note: Number in ( ) is the time lag since diagnosis.

A breakdown of Table A3.4 below:

- 4 participants did not mention reconstruction during their interviews.
- 4 participants were not considering reconstruction surgery at the time of the interview.
- 10 participants were either thinking about reconstruction surgery, or had either started or completed the process.
- 2 participants were told by doctors that for one reason or another they could not have reconstructive surgery.

See Table A3.5 for grouping:

Code	More About Reconstruction
P2	Had mastectomy – had reconstruction at time of mastectomy (18 mths)
P5	Had mastectomy – having a reconstruction (23 mths)
P10	Had mastectomy – started reconstruction (expanders in) (6 mths)
P19	Had mastectomy – had reconstruction at time of mastectomy (35 mths)
P24	Had mastectomy – in first stage of reconstruction (12 mths)
P27	Had mastectomy – had decided in early days 'no way' have reconstruction – now yes- is happening in 2 weeks after interview (31 mths)
P28	Had mastectomy – thinking about it – cost $3000 even with private health insurance and Medicare – did not know could have reconstruction at same time as mastectomy – probably would of went for that option (16 mths)
P33 *	Had lumpectomy – was considering reconstruction – Drs say probably wouldn't be any better – participant said a reconstruction would mean it is over (the breast cancer) (31 mths)
P37	Had mastectomy – has seen Drs about reconstruction (therefore considering it) (19 mths)
P40	Had a double mastectomy – by choice – one breast definitely breast cancer the other one questionable – turned out it was ok, planning on having a reconstruction later (in public system) (vanity) (5 mths)

Table A3.5: Details of baseline participants who have either started or finished or are planning/thinking about having a reconstruction.

Note: * *This participant had a lumpectomy where as others who stated issues of reconstruction had mastectomies.*
Number in ( ) time lag since diagnosis

Appendix 3.3: Follow-up Interview 1 Table of Findings

The following 8 pages display the ‘Follow-up Interview 1 Table of Findings’:

Table A3.6: Findings from Follow-Up Interview 1 to inform Follow-Up Interview 2.

Code	***Issues First Interview***	**Issues Over Time (Change?)**	**Extra Issues**
P1	*** Major present concern** - *wants more information about contraception and pregnancy and BC, recurrence, relationship strain* * Pregnant with 1st child when diagnosed. * Security of Relationship Challenged * Relationship with mother * Fertility an issue **Greatest unmet need**: → * *support, information needs, sexuality issues, practical help as partner has to work*	*** Major present concern –** *hell bent to get breastfeeding to work – hormonal time bomb? Pregnant and breast feeding* * Sexual difficulties still present - emotional element – heals slower than physical (my perception) * Relationship with mother still strained – something that big you don't get over * P1 pregnant – nearly ready to deliver at TPI 1 * *Mostly ok now*	* Had shingles while pregnant * Will be interesting to see how breast feeding goes * Found lump in other breast – cysts – feared same was happening BC while pregnant * Contraception maybe an issue
P4	*** Major present concern –** *recurrence, long term survival* * Children are a concern – if died how would children fair * Thinks medical profession could play a bigger role in support BC patients * Into life coaching – maximise survival – optimise life * Support and service problems were experienced * Finished family – no fertility concerns **Greatest unmet need:** → ***** *baby sitter – physical support*	*** Major present concern –** *get life more balanced – have no regrets – do not become blasé about BC* * Says still more assertive however after discussion found that P4 seems to be working too much again – maybe not as assertive as thought – has a busy life * *nothing to do with breast cancer (need a holiday)*	* Concerned about becoming blasé about BC – life gets so much back to normal start to forget about BC
P8	**Advanced: * Major present concern -** *dying* * Partner and children concerns * Partner was ignored by professionals * Need physical support * Not planning a reconstruction * Finished family – no fertility concerns **Greatest unmet need :** ↗ ***** *physical support and information* ↘	*** Major present concern –** *not over doing it as feel well* * Children and partner concerns still (impending death) * *GP noticed P8 was very distressed and suggested some physical support – and blue care – hence support issues greatly reduced – very good* * *Now feels has enough information*	* Would like to see support agencies linked – co-ordinated with each other for BC sufferers benefit * Need to get information out to YWBC what support is available

P9	*** Major present concern –** *staying healthy* * Physical limitations – low energy and pain in arm * In early menopause * Had not come to terms in what treatment had done to her * Lost 10 kg with treatment – struggles to gain weight * Fertility is not a concern – would of liked to of had children – but accepted won't, don't want to pass gene on. → **Greatest unmet need:** ***** Lack of young women with BC support groups – no stated no lack of support for YWBC (goes to Bosom Buddies support group) Trying to establish a YWBC group in ACT	*** Major present concern –** *to get better* *Back in treatment – chemotherapy as has been diagnosed with metastasizes in her neck * P9 still does not want to pass on BC gene – hence fertility not a concern * Weight has been up and down but now seems to be under control * Still goes to a support group (Bosom Buddies) in ACT ** P9 last interview had not looked far enough into support for YWBC, now ok*	*** Since last interview now has secondaries:** * Ovaries have been removed but P9 is still going in and out of early menopause due to treatment

P10	*** Major present concern -** *Work issues – finding a new job (type as used to work physically - not only to do with the BC) – never going to be the same* * Not happy anymore (in early days) * Body Image concerns great * Partner Concerns Great – felt like carrying the whole burden * Had not accepted the disease * Would like a list of YWBC phone numbers * Started to have reconstruction – expanders in * Trying to find someone to talk to who has had nipple reconstruction as well as reconstruction ***** No fertility concerns, finished family – had already had hysterectomy Greatest unmet need: → * *Emotional support*	*** Major present concern –** *cancer is still in her – recurrence -work is still of a concern – does not know where can work* * P 10 had lots of medical problems since last interview – is up for a bone scan shortly after TPI1 * Partner issues – were more to do with how P10 felt about herself * Still on antidepressants – it helps * Had reconstruction – not overly happy with it – still does not make you feel a whole woman – nipple graph – did not find anyone to talk to * Still has ovaries * *feels lonely at times – not as bad as last interview – has not ventured to a support group*	* Feels there is a real lack of information concerning reconstruction – implants, nipple graphs * How P10 perceives her breasts is important to her self image-esteem-confidence
P11	*** Major present concern –** *move past cancer personal internal issues* * Should be over it been 12 months – emotional issues seeing a counsellor at Wesley * Living with the diagnosis after treatment – when contact with medical professionals is over fear sets in, friends think you're over it * Concerns for partner * Lacked confidence in doctors not well informed of choice * Worst side effect – fertility concerns * Told can't have reconstruction - really wanted it * Going to put fertility to test * Support has not been age appropriate * Lack of support for YWBC **Greatest unmet need:** → * *Emotional support*	*** Major present concern -** *Recurrence during pregnancy* * Fertility issues tested and now pregnant about 3 months at TPI 1 * Stopped taking supplements * Saw Wesley counsellor ¾ times * No concerns for partner * Reconstruction – P11 will revisit this issue after breast feeding finished – will be more opinions * *Support issues – ok now not needing any support*	* Pregnancy – see how it goes and breast feeding if had bub by next interview * Breast feeding – Drs don't have much experience with breast feeding after BC * Cosmetic issue - problems with prothesis while pregnant – one breast size b cup, other d cup – balance – weight distribution *Reconstruct-ion – is now a big cosmetic issue for P11

P15	* **Major present concern -** *recurrence* * Lack of information of her particular cancer – but now probably have enough * Just started back at work * Was just starting to tackle the emotional issues * Big self image problems – gained over 30 kg * Has lymphoedema * Lots of side effects (including surgeries) * Had not accepted diagnosis * Went to a support group Redlands – still felt isolated – she was the information for others - does not feel supported (other than by family and a few good friends) * Can't have reconstruction due to high levels of radiation * No fertility concerns – accepted won't happen – had hysterectomy as consequence of tamoxifen **Greatest unmet need:** → * *Emotional support – as just getting past physical problems*	* **Major present concern –** *get through next 6 months with no more complications – no more broken bones – like to get some energy back* * Has enough information * Went to work based counsellor – he had to go to counselling – too hard won't try and deal with emotions again * Again went to Redlands support group – feels much better about it, though says does not receive support but gives it * Weight gain due to treatments worse * Acceptance of BC does not change outcome * P15 is mostly over depression at time of last interview – due to good pain management – seems much brighter and more positive * Has not found anyone to help her – family is enough, gave up on counsellor or support group	* Giving rather than receiving support has appeared to help P15, not depressed like she was * Have to be careful of what professional you see – counsellor – make sure suit your condition * Prothesis etc holds P15 back – changed lifestyle to suit prothesis * Need a fashion range for lymphoedema sufferers – sleeve size * Twin sister - see self as could of been all the time * P15 says Body Image is not as issue – but it shines through

P16	*** Major present concern -** *low energy levels – get tired easily – get stressed easily – uncertain future* * Unorganised medical services (Radio institute) * Had been seeing psychologist at Wesley * Inconvenient times YWBC functions are on * Feels big lack of certainty of future * In early menopause – tamoxifen – inconvenience of periods coming whenever * Priorities changed * Had loss of self confidence * Going to a naturopath * Mixed feeling of fertility concerns – does not want to start a family at 44 after tamoxifen **Greatest unmet need:** → ** Opportunity to meet other YWBC and see how they are going – share experiences as friends think she is over it*	**Major present concern –** *none really though be glad when 3 year check is over* * Stopped going to naturopath – lost faith, cost too much did not add value to life – how felt * Now uses olive leaf extract * Rarely has hot flushes ** Support needs ok now, met up with YWBC*	* Young women have grown up in an age when they make decisions – not so much like the older generation of women (who take on faith what is told to them by health professionals)

P18	* **Major present concern –** *impending check up* * Is a natural worrier – now worries about bigger issues * Some work issues * Already had fertility problems before diagnosis * Suggest ovarian tissue removal prior to treatment * Wants to deal with own illness not others * Does not want lots of information * Fertility issue is a big concern * Experiencing lots of early menopause symptoms * Reconstructive surgery did not come into conversation * Lost self esteem – big body image concerns - also sexuality problems * Just saw a counsellor at B/Clinic Choices * Feels like a time bomb – treatment over, now what? **Greatest unmet need:** → * *emotional support - support and counselling*	* **Major present concern -** *recurrence* * Still a natural worrier – this has not changed * Intends to go to a nutritionist – for weight loss (gained weight since BC) * Still feels challenged by other people's stories * Still does not want lots of information * Fertility – has not given up hope – looking into overseas adoption * Thinking may have reconstructive surgery at 5 year mark as a reward * Body image not improved – not worse – static * Went once to counsellor – was emotionally ok at time * Still feels like a time bomb ***** Support need is static – P18 feels the same and is trying to fix it internally (meditation)	*Ovary tissue is frozen (was as at last interview – just had to check) * Had previously thought would not have a reconstruction – feared the pain and had seen not nice picture of reconstructed breasts * Body image – nothing to do with her partner – it is about how she feels about herself * P18 is feeling doctored out – does not want to see any new doctors – health professionals
P27	* **Major present concern –** *recurrence* * Was going in for reconstruction 2 weeks after first interview – t TRAMflap – and getting ovaries out at same time – but states is in early menopause * Feels BC is utterly over once ovaries are out and reconstruction done * No partner/children concerns * Says lack of support for YWBC – support groups too old – different issues * A new support group starting – might go * Convenience a bit factor – 1 hour drive to support group * When treatment stops – scary * Fertility not a concern – finished family **Greatest unmet need:** → ***** *Support for YWBC*	* **Major present concern –** *recurrence and not recognising symptoms – leaving it too late* * Reconstruction went well – but numb * Ovaries are out – has not produced any worse symptoms of early menopause * Says reconstruction finished BC – but also not finished until 5 year make - always fear recurrence * P27 did not got to a new support group - but got phone number of 'Young Ones' * Last time – P27 had pain in arm and lacked energy to drive distances – is now ok * *Support – no longer an issue has contact details for 'Young Ones' – do not need support*	* 5 year mark is an issue – striving to get to it * Partner does not want to touch new breast – not in a sexual manner – fears will cause pain * Keeps moving goal posts – said reconstruction would finish the BC – not says the 5 year mark will finish the BC * P27 has no libido – probably part of early menopause

P34	* **Major present concern -** self *esteem and self confidence was an issue* * Life after tamoxifen then what * Death of dog upset her – mortality issues – going to speak to someone from cancer foundation about it * Has not dealt with all issues of dying * Has some lymphoedema * Felt would like to go to a support group but hadn't * No Fertility issues – finished family * Not considering a reconstruction at this point * Trouble finding credible information concerning tamoxifen and uterine cancer (mostly) **Greatest unmet need:** → * *To go to a support group*	* **Major present concern –** *to lose weight* * More positive now * Took control of situation – sought a doctor who would take concerns seriously (uterine cancer concerns) – got an ultra sound done – peace of mind * Went to 6 counselling sessions at cancer association – good * Lymphoedema – ok * Children not a concern – they have forgotten it – partner ok * Has thought about reconstruction – but has not done anything about it * Found what needed in information about tamoxifen and uterine cancer via GP and Cancer Helpline – now has a list of credible web sites * *Support – no longer feels need to go to a support group – though curious about what she is missing – this need probably fixed by seeing counsellor 6 times*	* Early menopause – got dry skin – skin changes – but do not know if due to early menopause treatment side effects or just natural aging * Counselling sessions made a huge difference

P35	* **Major present concern -** *recurrence* * Fertility is a concern - not really planning any more children but feels choice is now taken away * Had to go to Brisbane for treatment (from North QLD) * Depression a bit of a concern * Confidence was a problem * Have had some issues with early menopause – but have a good GP * Saw Jane Turner psychologist in Brisbane * P35 is the support for other women who have BC as a GP * Support was appropriate * Was feeling isolated – felt could not talk to anyone about it * A GP in a small community * Would like to speak with a social worker or counsellor once a month **Greatest unmet need:** → * *Support*	* **Major present concern –** *getting through next 12 months – coping with life with a new baby and life in general* * P35 was very depressed and teary in 1st interview – found out she was pregnant and was deciding if she should terminate or not * This interview P35 was in a good frame of mind – 6 weeks off delivery of baby – very focused on baby * Now had good GP can talk to – does not feel so lonely * Self confidence is now ok * *P35 feels she does not need support at this time*	* Need to follow breast feeding issues * Mixed emotions about pregnancy whether to abort to not – religious guilt * Felt selfish – will have 2 children if dies * Still had menopausal symptoms and blood tests confirmed menopause and still fell pregnant * Contraception an issue – don't want partner to have a vasectomy – as if she dies he may re-partner
P38	* **Major concern –** *recurrence – not looking forward to chemo* * Fertility is a concern – had ovary tissue frozen (No children) * Support issues – concerns for YWBC * Lack of information concerning women under 30 – single – unknown * Body image for those under 30 bigger – cosmetic aspects * Stay away from internet * Didn't feel needed support * Was put in drug induced early menopause to try and protect ovaries **Greatest unmet need:** → * *Lack of contact with other YWBC*	* **Major concern –** *none* * Fertility is still a concern – won't know until she tries to get pregnant (single) * Feels support for YWBC is needed – some of her own support needs somewhat satisfied * Body image and sexual identity ok * Out of early menopause - periods are back – but can she conceive? * *To a point need fixed – more contact with YWBC has been good – though P38 did not directly answer question relating to this topic*	* P 38 feels that BC organisations/websites are agist * P38 has the perception that BC support is outdated and daggy, but had never been to experience it for herself

Table A3.6: Findings from follow-up interview 1 to inform follow-up interview 2.

APPENDIX 3.4: List of Issues Which Could Be Followed in Follow-up Interview 2 (Phase 3)

Three participants were pregnant at the time of follow-up interview 1 (Of which 1 participant had had a mastectomy and 2 participants have had lumpectomies) (Participant code identified by a P and a number) (**P1, 11, 35)**

Possible Avenues to follow:

Pregnancy/Breastfeeding

- how have the pregnancies progressed
- all manner of breastfeeding issues – what has come up during pregnancy concerning breastfeeding, and how has breast feeding gone since delivery (if they have breast feed)
- have the health professionals been able to assist them to breast feed – is there any gaps in information required as to information given
- prosthesis during pregnancy (**P11**) – have there been any problems there, any concerns (such as weight differences)
- what breast changes have occurred during the pregnancy – and after the birth – are the changes what they expected (this line of inquiry could be most interesting in those participants who have had lumpectomies (**P1,35**), how has/is the affected breast reacting
- compare this pregnancy and breast feeding events to that of previous pregnancies
- any new pregnancies with in the participant pool – explore

Contraception

- (**P 10, 15 – have had hysterectomies and P 4,8,10,27,34 finished families) -** what, if any contraception is being used by participant pool – any issues there –
- after babies are born – is contraception going to be an issue – how is participant planning to deal with it
- contraception could particularly be an issues for **P 1,9,11,16,18,35,38**
- has any participant, or is any participant planning, permanent contraception – sterilization - why

Fertility Concerns

- this could still a specific concern for **P 18,38** – check
- how are the participants currently feeling about fertility concerns – explore both sides – those who do and those who do not have fertility concerns (for participants who would of liked to of had children but have come to terms with the fact that they will not)

Reconstructive Surgery

- ***for those who have had reconstructive surgery*** **–** how is it going **–** (**P 10, 27**)
- how does having reconstructed breasts make the participants feel (both emotionally and physically)
- has having reconstructive surgeries made the participants feel like they thought it would – has the operation lived up to their expectations (both emotionally and physically)
- do the participants have any concerns, problems with their reconstructions
- how does the participants' partners feel about them having reconstructed breasts (emotionally and physically)
- ***for those participants who were considering having reconstructive surgery done at the time of follow-up interview 1*** **–** what thoughts the participants have on the matter at present (looking into issues of body image, sexual identity and perceptions of femininity)
- how do the participants feel about reconstruction at the moment
- how are the participants expecting to feel after having the reconstruction done (emotionally and physically)
- how do the participants think that their partners will feel about their reconstructed breast (emotionally and physically)
- what sort of information have the participants been given concerning reconstructive surgery
- what choices have the participants been given concerning reconstructive surgery
- do the participants feel they have enough information – what other sort of information would they like to be given and by who
- is there any aspect of reconstruction surgery that the participants feel that health professionals have neglected to cover

Support and Services

- a follow on to see how any earlier issues of support and services are going – follow each participant's specific issues
- have support/services issues been resolved since last interview
- are there any new support/services problems since last interview
- do the participants feel they are in need of support and/or services presently, if so what type, if not why not
- ***of any changes that occur*** **–** what do the participants contribute to the changes what caused the change – what influenced the change and why

Children and Partners

- inquire generally how children and partners are and probe if any concerns are due to the breast cancer

Prosthesis

- how do particular participants get on with their prostheses, are there any concerns there

Variety Of Other Issues To Look Into

- how presently are the participants feeling about having breast cancer at a young age
- what is the participants' major present concern
- follow up on what the participants stated as their 'greatest unmet need' in the initial interview – are there any changes there, if so why
- follow what participants said was happening for them over the 6 months between follow-up interview 1 and 2
- what do 'breasts' symbolize to the participants (checking social belief)
- how do the participants see any generational differences between younger women and older women who have breast cancer
- how do younger women with breast cancer (the participants) experience breast cancer differently to older women who have breast cancer and why do they think that

APPENDIX 3.5: Tables of Fertility and Reconstruction Issues Overtime of Follow-Up Participants

Table A3.7: Fertility issues of follow-up participants over 3 time phases.

Code	Interview 1	Interview 2 (TPI1)	Interview 3 (TPI2)
P1	Fertility was an issue – diagnosed while pregnancy – hence had 1 child wanted another one Contraception interests P1 – have to find alternatives to Pill	Now Pregnant – fertility no longer an issue Contraception – not a current issue	Had baby – fertility no longer an issue No contraception concerns as partner had a vasectomy shortly after baby born
P4	No fertility concerns – finished family Contraception – condoms? (has 2 children)	No fertility concerns Contraception – condoms?	Had fertility concerns hence had tubal ligation – then found very fertile. P4 had a tubal ligation (as she did not want her partner to have a vasectomy due to a family history of prostate cancer and he is an avid push bike rider) however this failed and P4 became pregnant – it was ectopic so then had tubes removed altogether No further contraception concerns
P8	No fertility concerns – finished family (has 2 children)	No fertility concerns	No fertility concerns Contraception - partner had a vasectomy prior to the BC
P9	No fertility concerns – but was about to try to begin a family when diagnosed – P9 is sure she can never conceive – accepted it (does not want to pass on BC gene anyway) (no children) Contraception – not talked about	No fertility concerns (P9 became advanced since last interview)	No fertility concerns – it is sad did not have children
P10	No fertility or contraception concerns – had hysterectomy prior to BC – finished family (has 2 older children)	No fertility or contraception concerns	No fertility or contraception concerns
P11	Fertility concerns – has 1 child would like another Contraception?	No fertility concerns – is pregnant (about 3 months) Hence no contraception concerns presently	Nearly ready to give birth, does not want any more children – Contraception is a concern as she knows she is fertile – does not want partner to have a vasectomy in case she dies – most options are ugly - to be decided
P15	No fertility concerns – No contraception concerns - had a hysterectomy as a	No fertility concerns No contraception concerns	Fertility concerns in that regrets not having ovarian tissue (eggs)

	consequence of tamoxifen – accepted it (has no children – single)		frozen as sister would have had a child for her now no choice No contraception concerns – says she is now asexual
P16	Mixed feelings on fertility – does not want to start a family at 44 (5 years after tamoxifen) (no children) Contraception?	Went through grief of lost opportunity of possible pregnancy – so fertility is not a major concern Contraception?	**Left Study**
P18	Fertility is a concern – P18 already was having fertility problems when diagnosed – has ovary tissue frozen (no children) Not menstruating Contraception (presumably not a concern)	Fertility is still a concern but P18 has not given up hope of becoming pregnant one day – still not menstruating Hence contraception not a concern (difficult sex life too, P18 does not engage)	Fertility still a big concern – but there may still be hope – has not yet looked into adoption Contraception still not a concern
P27	No fertility concerns – finished family (2 children) Contraception not a concern – partner had vasectomy prior to BC	Fertility and contraception not concerns – P27 had ovaries out since last interview	Fertility and contraception not concerns
P34	No fertility concerns – finished family (2 children) Contraception not a concern – partner had vasectomy prior to BC	Fertility and contraception not concerns	Fertility and contraception not concerns
P35	Fertility is a concern – not really planning any more children but option has been taken away (in early menopause) Contraception – condoms but no not really need them	Fertility is no longer a concern as P35 is now pregnant. P35 was in early pregnancy when I interviewed her last, she was deciding whether to terminate or not (and did not tell me) No present contraception concerns	Had baby - too much fertility now - Contraception is now a bit of a problem – as P35 knows she is fertile - does not really want partner to have a vasectomy in case she dies – thought partner is willing to do it – using condoms and abstinence presently – P35 can't afford to take the time off work (and expense involved) to have a tubal ligation - to be decided
P38	Fertility is a concern – had ovary tissue frozen – no children and single	Fertility is still a concern – but not immediately pressing – P38 won't know until she tries to conceive (presently not in a relationship)	Fertility issue is static – could be a major concern in the future if can't conceive (is menstruating regularly) Contraception – P38 does not presently need it as has no partner Has not really considered contraception as an issue as has not been told she could have problems in this regard

Table A3.7: Fertility issues of follow-up participants over the 3 time phases.

Table A3.8: Reconstruction issues of follow-up participants over 3 time phases.

Code	Interview 1	Interview 2 (TPI1)	Interview 3 (TPI2)
P1	***Lumpectomy*** N/A	N/A	N/A
P4	***Lumpectomy*** N/A	N/A	N/A
P8	**Mastectomy** Not planning a reconstruction	Static	Static P8 was about to have a reconstruction when diagnosed with metastasises – now P8 cannot have reconstruction, thought she wishes she did (P8 has also lost most of her other breast)
P9	***Lumpectomy*** N/A	N/A	N/A
P10	**Mastectomy** Started reconstruction – expanders in (Public, PA). P10 wants to see what a graphed nipple looks like, she would like to talk to some other women who have had reconstruction to see what they think and see what it looks like.	Had reconstruction done (implant in), however P10 is not overly happy with results. P10 did not find anyone to talk to about it (a fellow reconstruction recipient). P10's breast surgeon wants to fix the reconstruction – it is too high. Had a nipple graph, needs to have areola tattooed. Took a year to have expanders in/out and implants in. No feeling in new breast or nipple. Reconstruction does not give you back your breast. P10 is happy with the nipple	P10 had small breasts and always had a thing about her breasts not being good enough. P10 also had an implant put in her natural breast, now bigger busted. The reconstructed breast is still not fixed, waiting on public waiting list, not urgent. P10 and her doctor are still not happy with the reconstructed breast, to P10 it is like a ball on her chest- regardless of this disappointment – P10 does not regret getting it done.
P11	**Mastectomy** P11 was told she could not have reconstruction (TRAMflap – as no extra tissue) and P11 really wanted it.	P11 is thinking about getting more opinions of reconstruction and will revisit the issue after she finishes breastfeeding her new baby (due in 6 months).	To P11, reconstruction is very cosmetic – she also is toying with the idea of having the other breast off as well, get rid of all breast tissue. P11 decided to only breast feed for 1 or 2 weeks to get breast back to normal for testing. P11 said she never had great breasts.
P15	**Mastectomy** P15 cannot have reconstruction due to high level of radiation used on her chest wall. P15 states hair loss was worse than breast loss.	Static	P15 cannot have reconstruction surgery as there is a high likelihood that cancer will come back in her scar tissue. However P15 wishes she'd had a double mastectomy (she hates the hassle of prosthesis)
P16	***Lumpectomy*** N/A	N/A	N/A
P18	**Mastectomy** Reconstruction did not	P18 is thinking she may have a reconstruction at the 5 year	P18 is not yet ready for reconstruction. Her priority

	come up in conversation.	mark as a reward.	is to investigate what can be done about having a baby first – reconstruction is a cosmetic decision, having a baby is a lifestyle and emotional decision. As reconstruction is purely cosmetic, P18 is happy to wait until techniques improve as all reconstructions P18 has seen do not look good anyway.
P27	**Mastectomy** P27 said she had said she would not have a reconstruction (due to an infection she suffered after her mastectomy) – however P27 is going to have reconstruction started in 2 weeks.	Reconstruction went well – but numb – P27 says reconstruction finished her breast cancer – but also not finished until the 5 year mark. Partner doesn't not want to touch the reconstructed breast (fear of hurting P27)	P27 was due to have a nipple graph, but it has not happen as yet. P27 is very happy with her reconstruction. There is no feeling in the reconstructed breast. Reconstruction is easier than using a prosthesis. Prior to reconstruction P27 thought she had no body image concerns – but she must of as reconstruction has boosted P27's confidence
P34	**Mastectomy** P34 is not considering reconstruction at this point in time.	P34 thought about reconstruction but has not done anything about it.	P34 says maybe will undergo reconstruction in 5 years time. Presently major surgery that is not for life and death purposes does not appeal to P34. One day P34 might get fed up with using prosthesis – which may motivate P34 to think about reconstruction. Would do reconstruction for cosmetic reasons and for partner. But photos partner and P34 have seen – reconstructed breast does not look normal. P34 is big busted.
P35	***Lumpectomy*** N/A	N/A	N/A
P38	***Lumpectomy*** N/A	N/A	N/A

Table A3.8: Reconstruction issues of follow-up participants over 3 time phases.

Note: N/A – Non applicable
Shaded Cells – Participants who had lumpectomy 'only'

APPENDIX 3.6: Summary of Preliminary Analysis of Data from All Three Interviews

Code	**Age at diagnosis**	**Time lag at first interview (Months)**	**Time lag between first 2 interviews**	**Locus**	**Education level (Usual Job)**	**Main Surgery**	**Number of children at first interview**
P1	32	24	12 months	QLD	No Answer (Home Duties)	L	1 < 5 y
P4	34	11	12 months	QLD	Post Grad (GP)	L	2 5-12 y
P8 Mets	39	37	12 months	QLD	Tertiary (Manager)	M	2 13-16 y
P9	34	21	12 months	ACT *	Tertiary (other)	L	0
P10	40	6	12 months	QLD	Up to Year 12 (Physical Job)	M	2 16-23 y
P11	38	12	6 months	QLD	Tertiary (Professional)	M	1 <5 y
P15	32	30	6 months	QLD	Tertiary (Professional)	M	0
P16	39	30	6 months	QLD	Post Grad (Professional)	L	0
P18	33	26	6 months	QLD	Up to Year 12 (Administration)	M	0
P27	37	26	6 months	VIC *	College (Physical Job)	M	2 14-17 y
P34	37	33	6 months	WA *	College (Trade)	M	2 7-9 y
P35	37	28	6 months	QLD * (North)	Post Grad (GP)	L	1 < 5 y
P38	29	5	6 months	VIC *	Up to Year 12 (Manager)	L	0

Table 1: Demographic information of follow up participants.

Note: Mets – Had metastases at first interview
* - Interview by telephone due to distance (for all interviews)
L – Lumpectomy
M – Mastectomy

Mean age at diagnosis of follow up participants = 35.46 years of age range 29-40 years (the mean age of the initial 35 participants was 35 years range 20-40 years).

Mean time lag since diagnosis of follow up participants at first interview = 22.23 months range 5-37 months (the mean time lag since diagnosis of the initial 35 participants was 21 months range 4-39 months).

Issues which were the basis of what was followed:

- Treatments and any further surgeries
- **Partners and children –** Most concerns were resolved with time, other than for those with advanced disease.
- **Fertility issues** and **contraception –** *Fertility* - In the first interview 5 participants expressed concerns for their fertility, wanting to have children, 1 participant had mixed feelings about it, 2 participants stated they were sterilized by treatment consequences – both of whom had no children, both were accepting of this. Two participants had ovarian tissue frozen before treatment begun. By the end of all interviews, only 1 participant had specific fertility concerns, and 1 other participant wished she had eggs frozen so her sister could have had her child. Four participants feel pregnant, 3 by interview 2 and 1 by interview 3, however one participant did not want any more children (failed tubal ligation – ectopic anyway). *Contraception* – Contraception was a concern for some participants however by the last interview contraception was only an issue specifically for 2 participants who had just had (or was about to have) their second baby, not wanting: anymore children; their partners to have a vasectomy; nor to go on hormonal contraception. One participant was single and was not concerned at the present time about contraception.
- **Pregnancy issues** (4 participants – 3 full term, 1 ectopic)
- **Breastfeeding** (3 participants) – All 3 participants who fell pregnant wanted to breastfeed their new babies, however only 1 participant successfully fed from 1 breast, 1 participant tried to feed from the affected breast for 1 week, no milk production – fully breastfed from 1 breast for 1 month and comp fed for a further 2 months – a supply problem (also had a supply problem with first baby with 2 functioning breasts). One participant who wanted to breastfeed in interview 2 decided by interview 3 (1 week off having her baby) to only breastfeed from 1 breast for 1 or 2 weeks, to get her breast back to a normal non-lactating condition to allow breast checks to continue. Of these 3 participants 2 were diagnosed with breast cancer during breastfeeding of their first children and 1 was diagnosed during her first pregnancy (had chemotherapy while pregnant and delivered, early, a healthy baby).
- **Reconstruction surgery** (7 possible participants, of which 2 had reconstruction - 1 at initial interview and 1 at second interview) – varies issues here.
- **Prosthesis issues** (affecting 8 participants of which 2 temporarily while breastfeeding). Other than the use of a prosthesis being a hassle, in the main no real concerns here. One participant had great difficulties with her prosthesis, though other issues seemed to be interwoven in her experience.
- **Body image, sexuality issues and early menopausal consequences –** Collectively quite a lot here – some issues were resolved over time, some not, others became worse. Body image – not only about breast loss/disfigurement, but also about loss of other chest tissue, hair loss, weight gain/loss, other scarring such as from radiation and portacaths, and lymphoedema. These 3 factors, body image, sexuality issues and early menopause consequence can be interwoven, or experienced in isolation to each other.
- **Self -esteem and self-confidence –** Most participants had regained any lost self-esteem and self-confidence by the last interview. Two participants accredited their raised self-esteem/confidence to their reconstruction surgeries. One participant, who was diagnosed with advanced disease by interview 2,

stated in her last interview her self-esteem/confidence was shattered. One other participant only reported minor improvements over time.

- **Major concerns** – Recurrence could be said to be a given of all participants other than those who already had advanced disease, hence their major concerns differ. Other major concerns changed overtime, some resolved without intervention. New problems arose. 'As you get back to normal, you see the holes' P15. Two participants' major concerns turned to problem with their sexuality, lost libido and mechanical problems. By the last interview many participants stated they no longer had any major concerns, while acknowledging that recurrence was always a possibility.
- **Greatest unmet need** - Participants were chosen for the follow up interviews on how they answered this question in the initial interview. All 13 participants stated a lack of emotional and/or physical support as their greatest unmet need. These needs appeared to mostly fade as time went on or participants' either found the support they needed or they gave up trying. One participant, who could not find anyone to give her emotional support, found support by helping others – it was in the giving.
- **What breasts symbolize to participants** – new question last interview - Most participants felt breast symbolized sexuality and femininity and were cosmetic and important for fashion. After the breast cancer some participants had a negative view of breasts – seen as a threat. Two participants had quite good feelings about their breasts after reconstruction. The bigger busted women seemed to bestow more importance on their breasts than smaller busted women, though there was a contracting example in each category.
- **Generational differences** - new question last interview – Participants opinions were sought here, the differences expressed were: older women are more likely to follow doctors orders, not questioning; older women are not expected to be sexual; older women more private and do not talk openly about their cancer; younger women more likely to experience relationship problems; younger women in shorter term relationships; lifestyle issues such as younger women more likely to work and be social eye; younger women more likely to be optimistic.
- **How participants are currently feeling about their breast cancer –** Most participants felt by the last interview that their cancer experience was behind them, though always acknowledging the risk of recurrence. Many participants expressed positive outcomes of their experiences. The 5-year mark was also mentioned by most participants, the need and desire to get there – to get over the hurdle. Two participants expressed particularly negative experiences of the cancer, one of these two had advanced disease and was in a lot of pain at the time of the last interview.
- **Health professional encounters** and **other consumer issues -** Varied
- **Support issues/needs** – links with greatest unmet needs section – By the last interview most participants no longer felt support was lacking. This occurred in 3 ways, needs waned as time went on, support needed was found and/or had given up looking. Five participants stated in the last interview that they were glad they either no longer, or never did, go to a support group as many thought it would be confronting. Five participants were passionate about giving back support to other women newly diagnosed with breast cancer.
- **Informational needs –** The information needs of the participant pool varied as time went on. Their needs reflected what was going on for them at the time of

the interview, such as one participant needed information on breastfeeding after breast cancer once she found out she was pregnant. The areas of information that need attention are: breast cancer in pregnancy, pregnancy and breastfeeding after breast cancer – risks involved and mechanical issues; fertility and contraception after breast cancer; life after tamoxifen for pre-menopausal women; sexual issues – such as lost libido, dry vagina and emotional consequences of damaged body image; and issues surrounding reconstruction – including photos of young women who have had successful reconstruction operations.

APPENDIX 3.7: NUD*IST Tree Diagram

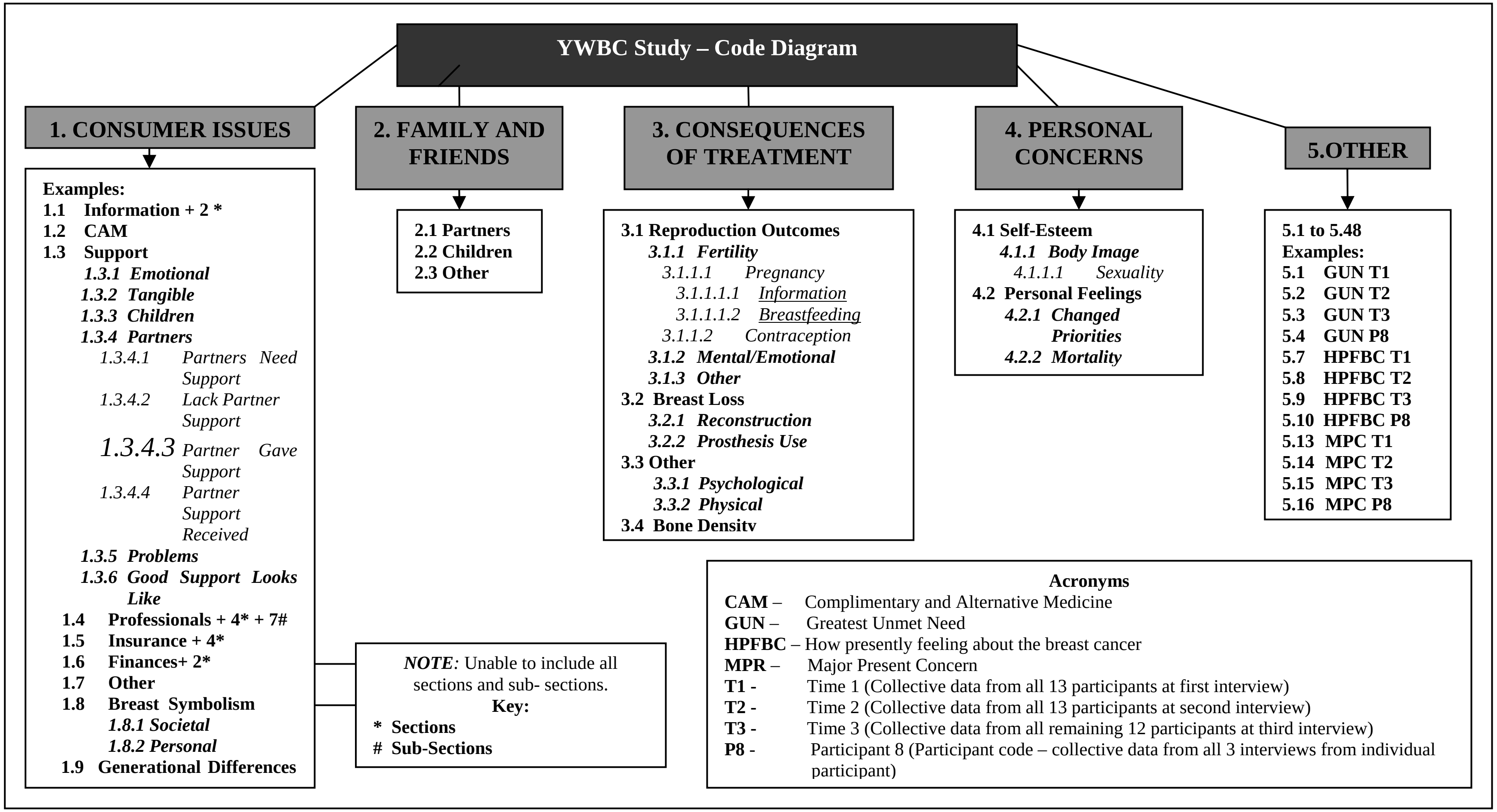


Figure A3.1: NUD*IST Tree Diagram.

APPENDIX 3.8: NUD*IST Diary

In-Depth Sub-Division of Data (Utilizing NUD*IST (N6) Software).

Initial Phase.

In the first instance the raw data from 38 interviews (all interviews of participants followed over time) were subdivided into 5 major first level categories, labelled: 1. *Consumer Issues; 2. Family and Friends; 3. Consequences of Treatment; 4. Personal Concerns;* and *5. Other.* Below are these labels with relevant definition, example/s and exclusion information (if pertinent).

Note: Much data overlapped into more than one category so is included in each relevant category. For example, data placed in Label *5.* the *Other* category, that is answers given to 3 major questions asked over the 3 phases of the study, were also coded into relevant corresponding categories (at this initial phase of analysis). As many aspects of participants' experiences were interrelated, much overlap of data in categories occurred hence arbitrary decisions were made in regards to category content. Enough data were included in categories to preserve the context of the text, again producing overlap.

1. **Label**: <u>Consumer Issues</u>

Definition: *Generally surrounding topics of sub-categories: 1.1 Information; 1.2 CAM use 1.3 Support issues; 1.4 Professionals - experiences of interactions with health professionals/services; 1.5 Insurance matters; 1.6 Financial issues; 1.7 Other consumer issues not in prior sub-categories, such as data relating to choices made; 1.8 Breast Symbolism; and 1.9 Generational Differences.* Participants discuss issues surrounding: information required, received, sought and problems; CAM use and participants' thoughts on CAM, including the taking of vitamins and minerals, juices, changed diet, meditation, acupuncture and other complementary and alternative therapies; support, be it formal style support which is organised and run by professionals, or informal support, such as from friends and family and informal breast cancer/cancer support groups; experiences with health professionals/services – good or bad; issues surrounding health/income/life insurance; financial and work related issues such as cost of treatments, loss of work, job insecurities and future prospects and other work related issues; other consumer issues are those not in previous sub-categories such as data concerning choices made; breast symbolism in regards to personal and perceived societal views; and issues of generational differences between younger an older women with breast cancer. (Time 1, 2 or 3 depicts the study phase in which the quotes were collected. Participant code in parenthesis.)

Examples:

- *1.1* <u>Information</u>: Time 1 (P40): *I went to the internet and to Time magazine and I've read I don't know how many books on breast cancer.*
- *1.2* <u>*CAM:*</u> Time 1 (P11): *I see a naturopath now and take lots of vitamins and antioxidants and things like that, I drink juices.*
- *1.3* <u>Support</u>: Time 1 (P40): *The support of the staff down here at the Wesley hospital was just beautiful.*

- *1.4* *Health Professional/Services Interactions:* Time 1 (P16): *My surgeon is not Mr Humanity - um he's very cold and very difficult to connect to - having said that I think he's done a very good job - like I'm pleased from a physical point of view - I guess with what I look like as a result of it - so technically he's good - I'd probably go back to him again because I trust him technically but I wish he had a bit more personality.*
- *1.5* Insurance: Time 1 (P15): *I can't get income protection insurance; unless you've got a life benefit associated with your superannuation you could end up with nothing.*
- *1.6* Finances/Work: Time 1 (P10)*: I went to see if my money's in the bank today, there's no money in the bank, x (partner) doesn't get paid until Friday, so financially it's very hard, very hard.*
- *1.7* *Other (eg., Choices):* Time 1 (P1): *Even though I made the choice about having the chemo whilst I was pregnant, I felt, even though it was a pretty horrible decision, I felt a little more in control cause I'd made the decision.*
- *1.8* Breast Symbolism: Time 3 (P15): *It's a male dominated environment and they make women more conscious of their breasts – that's why women have all their enlargements and everything else..*
- *1*.9 Generational Differences: Time 3 (P1): *Well there's different issues isn't there? You know, when you're younger, you're looking at a lot different lifestyle and work and fertility and all those other things to what you're looking at when you're an older person, and also your relationship is different.*

Note: Data overlap within this category and others, such as informal style support overlaps with the major first level category of *2.* *Family*, was unavoidable.

2. **Label:** *Family and Friends*
Definition: *Generally surrounding topics of family and friends.* Participants discuss issues surrounding family, such as in regards to immediate family, extended family, those other persons the participants define as their family, and friends.

Example:

- Time 1 (P8): *But as a family, I don't think we coped as well as the first time round because when they – when Mum was getting up and around again they sort of thought that she was alright – they've had – the kids have had to do – to grow up a lot quicker.*

Exclusion Information: Sections of text where family was mentioned in passing, though not specific to issues under exploration, were not included in this category.
Note: Much of the data found within this category overlaps with all major first level categories.

3. **Label:** *Consequences of Treatment*
Definition: *Generally surrounding topics of physical consequences of breast cancer treatment.* Participants discuss physical consequences of breast cancer surgeries and adjuvant treatment, such as chemotherapy, radiotherapy and more. The side effects discussed range from minor (eg., niggling pain) to

major (eg., hysterectomy, due to tamoxifen) physical ramifications. 'Consequences of treatment' data were subdivided into sub-categories *of 3.1 Reproductive Outcomes, 3.2 Breast Loss, 3.3 Other* (which includes all other mention of physical side effects that does not relate to the previous sub-divisions), and *3.4 Bone Density.*

Examples:

- A general example of what would fit in the '*Other*' sub-category: Time 1 (P9): *The worse side effect oh – the nausea and throwing up – its very hard to differentiate or to separate any of those, and the fact that you feel as flat* as a carpet and you just can't get above it – loss of control.
- Breast Loss – A more specific example: Time 1 (P11): *Well, waking up and not having a breast, that was a pretty major side effect.*

Exclusion Information: Specific issues of psychological and/or emotional consequences of treatment were not sought for this category.

Note: Some data found in this category overlaps with issues recorded in the major first level category *1.* *Family*, eg., discussing issues of fertility/infertility. Psychological and emotional consequences may appear in this category, depending how the data were linked with physical consequences reported, though physical consequences are the main focus. Psychological and/or emotional consequences are comprehensively documented in the major first level category of *4.* *Personal Concerns*.

4. **Label:** *Personal Concerns*

Definition: *Generally surrounding issues of a personal (internal) nature.* Participants discussed how they felt personally (emotions) about experiences of their breast cancer illness trajectory.

Example:

- Time 1 (P10): *But I feel like, don't know – it might be because my partner…sometimes when you get out of hospital they [family and friends] say, "well its all over now", you know, but its not, its still mentally and emotionally; its draining I feel.*

Exclusion Information: Tangible issues were not sought for this category.

Note: Much data found in this category overlaps with all other major first level categories. For example, feeling associated with some issues were discussed at time of disclosure of such issues, such as personal concerns (eg., depression, anxiety) about specific physical consequences of treatment (eg., disfigurement).

5. **Label:** *Other*

Definition: *Generally surrounding issues of greatest unmet need, major present concern and how participants were feeling about their breast cancer at the time of interview.* This major first level category specifically contains the answers given to 3 major questions asked and/or followed at each interview phase. These questions relate to participants' greatest unmet need, major present concern, and how they were feeling at the time of the interview about their breast cancer.

Examples:

- Greatest Unmet Need: Time 1 (P8): *Answer to question, what Participant felt was her greatest unmet need – reply, 'Support, physical support.*
- Major Present Concern: Answer to question, what Participant felt her major present concern was (if she had one) – reply - Time 2 (P15): *Major concern at the moment, well bones breaking isn't too flash.*
- How Presently Feeling About Their Breast Cancer: Answer to question, how Participant felt about her breast cancer – reply – Time 1 (P1): *I don't even feel like saying cured…I used to think about death and dying and now I don't put it in the same category as like what I've had…*

Exclusion Information: Answers to any other questions were not included in this category.

Note: Data within this category overlaps with other major first level categories, depending on replies given, eg., if the answer was related to family the data was also placed in category *2. Family*. This first level major category '*5. Other'* was developed to provide a quick reference to the answers to these 3 major questions.

Subsequent Phases

In the subsequent phases of analysis, the above 5 main categories were sub-divided further as displayed in the NUD*ST coding tree (see Appendix 3.7). Each sub-category (second level), section (third level), and sub-section (fourth plus levels) was given a separate label, definition, example, and exclusion information (if pertinent). Only those sub-categories, sections and sub-sections will be demonstrated which were utilized for manuscripts 2 and 3 (Chapters 5 and 6).

1.8 Label: *(Consumer) – Breast Symbolism*

Definition: *Generally surrounding issues of symbolism of breasts; both personal and societal.* Participants discuss how they felt about their breasts before and after their breast cancer diagnosis, together with their perceptions of how society generally views/symbolises women's breasts. All replies given when asked about breast symbolism were also included in this sub-category.

Example:

- See Below for specific examples of *Societal* (in 1.8.1) and *Personal* (in 1.8.2) views of breast symbolism.

Note: This sub-category contains primarily data collected during Interview 3, when the question relating to breast symbolism was asked. This sub-category was sub-divided further into sections 1.8.1 - *Societal* aspects and 1.8.2 - *Personal* aspects.

1.8.1 Label: *(Consumer – Breast Symbolism) – Societal*

Definition: *Generally surrounding perceptions of societal views of women's breasts.* Participants discuss breast symbolism generally and more specifically in regards to society-based views of women's breasts. All replies given when asked about societal breast symbolism were also included in this section.

Example:

- Answer to question about societies' view of breasts – reply – Time 3 (P15): *It's a male dominated environment and they make women more conscious of their breasts - that's why women have all their enlargements and everything else.*

Exclusion Information: Personal related views of breasts and breast symbolism were not sought for this sub-section.

Note: Data found within this section overlaps into sections 1.8.1 – *Societal* and 1.8.2 - *Personal* issues of breast symbolism. This was unavoidable due to the close relationship between the two.

1.8.2 Label: (Consumer – Breast Symbolism) – Personal

Definition: *Generally surrounding personal views of breasts.* Participants discuss breast symbolism generally, and more specifically about their personal views of theirs, and others' women's, breasts before and after their breast cancer diagnoses. All replies given when asked about personal feelings about breast symbolism were also included in this section.

Example:

- Answer to question concerning how participant felt about her breasts reply – Time 3 (P11): *Well, it [breast] really had very little function for me. I mean, we can all do without them. Like I can have a baby and not breastfeed, that's no big deal and that's really what your breasts are there for, aren't they, to feed milk through, and you know, I can stuff a piece of silicone in my bra and I look pretty normal so it's nothing, it's really not that big a deal, but you think about losing your arm* or your leg, that's not going to be an easy thing to replace.

Exclusion Information: Societal related views of breasts and breast symbolism were not sought for this sub-section.

Note: Overlap of data found in sections 1.8.2- '*Personal*' and 1.8.1 '*Societal*' issues of breast symbolism was unavoidable due to the close relationship between the two.

1.9 Label: (Consumer) – Generational Differences

Definition: *Generally surrounding issues of generational differences between younger and older women which may be responsible for difference in experiences.* Participants discuss how their experiences of breast cancer differs to that of older women in relation to what they perceive to be a result of generational differences between younger and older women. All answers given to questions about generational differences are within this sub-category.

Example:

- Answer given when asked about generational differences – reply – Time 3 (P15): *The older women - I mean I'm just looking at my mother, not necessarily the self image but sexual image, like my mother considers herself far too old to even look at getting a bloke - where as theoretically I'm not …being a younger woman theoretically I should still have an active social life with men…an older woman; she's not as necessarily as likely to date...*

Note: The data in this sub-category derives primarily from a question asked in Interview 3 about generational differences.

3.1 **Label:** *<u>(Consequences of Treatment) – Reproductive Outcomes</u>*

Definition: *Generally surrounding experiences related to reproductive outcomes as a result of treatment.* Participants discuss the reproductive outcomes of having breast cancer; how they felt about their experiences and if they were prepared for such outcomes.

Example:

- Time 1 (P1*): Because I was going through like early menopause I had no idea what menopause even was, I mean I knew what it was theoretically, you don't know what the effects are until … I had no idea.*

Exclusion Information: This second level sub-category does not deal with comprehensive physical aspects of reproductive outcomes, rather it concentrates on the women's experiences and what problems they encountered.

Note: This second level sub-category was further subdivided into the below sections of *3.1.1 -Fertility, [3.1.2 – Mental/Emotional Issues and 3.1.3 – Other..*

3.1.1 **Label:** *<u>(Consequences of Treatment – Reproductive Outcomes) – Fertility</u>*

Definition: *Generally surrounding issues of fertility; infertility, fertility concerns and problems.* Participants discussed their fertility status, desired status, uncertainty of fertility status, and concerns of being either fertile or infertile, and how their fertility issues impacted on their lives.

Example:

- Answer to question about concerns of fertility status – reply –Time 1 (P16): *But then I guess I went through a stage of thinking, gosh, did I make the right choice not having children.*

Exclusion Information: Physiological related data of fertility status and/or problems were not paramount for this study, hence were not specifically identified within this third level section.

Note: Data related to the physiological aspects of fertility status and/or problems, though not sought specifically unless related to contraception issues, at times appeared with fertility-related data retrieved. This section was further sub-divided into the fourth level sub-sections of *3.1.1.1 - Pregnancy and 3.1.1.2 – Contraception* found below.

3.1.1.1 **Label:** *<u>(Consequences of Treatment – Reproductive Outcomes – Fertility) Pregnancy</u>*

Definition: *Generally surrounding issues of pregnancy and breast cancer.* Participants discuss their experience of being pregnant at the time of diagnosis or conceiving after their breast cancer diagnosis. Specifically exploring how participants felt about being pregnant when diagnosed or after their breast cancer diagnosis, exploring what problems they encountered and how they dealt with such problems and concerns. All data relating to pregnancy and breast cancer' were included in this sub-section.

Example:

- Time 2 (P11): *And that was one of the things we actually took into account [mortality] when we thought about whether to go ahead with the pregnancy at this stage.*

Exclusion Information: Data relating to fertility, not specifically pregnancy, were excluded from this sub-section unless it was necessary to include such data to retain the context of the text.
Note: The data found within this sub-section overlaps with data found in the major first level category *4. '<u>Personal Concerns</u>'.* This sub-section was further broken down into fifth level sub-sections *3.1.1.1.1 - Information and 3.1.1.1.2 - Breastfeeding.*

3.1.1.1.1 **Label:** *<u>(Consequences of Treatment – Reproductive Outcomes – Fertility - Pregnancy) – Information</u>*
Definition: *Generally surrounding information regarding 'pregnancy and breast cancer'.* Participants discussed what information they felt was lacking in regards to 'pregnancy and breast cancer'; where they have sourced such information, and if what information found was appropriate and extensive enough for their needs. Narratives signposts which flag information issues are: the use of the word 'information' in questions or replies; and looking for more opinions and not being satisfied with what was being told to them by health professionals about the pregnancy/baby, eg ., wanting/looking for more information.

Example:

- Time 1 (P1*): I needed to speak to someone about the baby…I had to just take what they said for granted and accept what they were saying to me, and I felt I wasn't happy about it …I just like to have more opinions.*

Exclusion Information: Any 'pregnancy and breast cancer'- related data which did not relate to information issues were excluded from this section, unless it was necessary to include such information to retain context of the text. Any data discussing information issues of other aspects of reproduction after breast cancer, such as contraception, are not included in this sub-section.
Note: Data in this fifth level sub-section were broadly defined hence attention had to be paid to all aspects of 'pregnancy and breast cancer' to extract participants' perceptions of available information, and/or the lack of information.

3.1.1.1.2 **Label:** *<u>(Consequences of Treatment – Reproductive Outcomes – Fertility - Pregnancy) – Breastfeeding</u>*
Definition: *Generally surrounding issues of diagnosis whilst breastfeeding and breastfeeding after a diagnosis of breast cancer.* Participants discuss their experiences of being diagnosed with breast cancer whilst breastfeeding and/or breastfeeding after a diagnosis of breast cancer. In this fifth level sub-section Participants discuss not only the physiological aspect of breastfeeding, but also issues surrounding the decision making process to breastfeed, their plans related to feeding the

infant, emotional aspects, concerns they had and/or their experiences of breastfeeding after breast cancer. All data mentioning 'breastfeeding' were included in this category.

Example:

- Time 2 (P1): *I've got so much hormonal activity going on at the moment and then with breastfeeding, like I'm really hell-bent on trying to get that to work this time, so that's more hormonal stuff going on and I'm a little bit, like I think, oohh, it is risky. I know I'm taking risks but then I think, well, what's life without a risk, you know, you've got to take some risks and this is what we want to do and then hopefully it'll be until I stop breastfeeding and I settle back down and I start cycling again and, you know, then I'll feel like everything's okay again.*

Note: To maintain the context of the text much overlap of data was unavoidable when separating the above sub-sections (*3.1.1.1 – Pregnancy* and *3.1.1.1.1- Information)* relating to 'pregnancy and breast cancer'.

3.1.1.2 **Label:** <u>*(Consequences of Treatment – Reproductive Outcomes – Fertility) – Contraception*</u>

Definition: *Generally surrounding issues of contraception after breast cancer.* Participants discuss their experiences of contraception after breast cancer, information they either sought, or wanted, about contraception after breast cancer, what contraception methods they were using (at time of interviews) and why, and any problems associated with such use.

Example:

- Time 2 (P11): *Well, see I took the pill until I fell pregnant with A... (child) which was only like two years ago, or two and a half years ago, and then so soon after that I got the breast cancer so I haven't taken the pill for all of that time, and I really didn't explore alternative contraception. So no, basically we were abstaining [laughs] but obviously not at the right time! So I mean, we weren't terribly careful about contraception. I suppose we probably got a bit lax towards the end.*

Exclusion Information: Any data not related to preventing pregnancy were not included in this fourth level sub-section, unless included to retain context of the text.

Note: Some overlap of data in the sections and sub-sections *3.1.1 – Fertility Pregnancy; 3.1.1.1.1; Information;* and *3.1.1.1.2 – Breastfeeding* was unavoidable due to the relationship between these and contraception.

3.2 **Label:** <u>*(Consequences of Treatment) Breast Loss*</u>

Definition: *Generally surrounding issues of breast loss and disfigurement.* Participants discuss their disfigurement, due to breast cancer treatment, in both physical and emotional terms. Specifically this sub-category encompasses issues of breast loss.

Example:

- Time 1 (P27): *It's almost like a grieving thing. It's like you go through different stages. I think because I had that chemo before, I had a really good three months of what was going on. I was very prepared to go into surgery and get rid of it [breast]. When I woke up out of surgery, I looked down and it was almost like, 'Thank God that breast is gone', where a lot of women, they just look down and they're horrified.*

Exclusion Information:

Note: This sub-category was further divided into sections *3.2.1 – Reconstruction* and *3.2.2 Prosthesis Use,* hence overlap into these sections is unavoidable as is overlap with category *4. Personal Concerns*.

3.2.1 **Label:** *(Consequences of Treatment- Breast Loss) Reconstruction*

Definition: *Generally surrounding issues of breast reconstructive surgery.* Participants discuss their thoughts on, and/or experiences of breast reconstructive surgery, depending if they had undergone reconstructive surgery at time of last interview.

Example:

- Time 1 (P10): *I'm getting an implant put in but I want to get a nipple done as well cause I feel I'm too young and I want to get that done too.*

Exclusion Information: Data not related to participants' feelings, thoughts, and/or experiences of breast reconstructive surgery were not included in this section.

Note: Data specifically related to reconstructive surgery were sought for this section, be it physical, emotional, in relation to information, and/or interactions with health professionals, regardless if they wished to, or were able to, undergo such surgery. Data within this section also overlaps with section *3.2.2 – Prothesis Use,* and various other sub-categories, sections and sub-sections which include data of emotional consequences of breast reconstruction, such as *1.8.1 (Breast Symbolism) Societal* and *1.8.2 – (Breast Symbolism) Personal, 4.1 – Self-Esteem, 4.1.1 – Body Image* and *4.1.1.1 – Sexuality.*

3.2.2 **Label:** *(Consequences of Treatment – Breast Loss) Prosthesis Use*

Definition: *Generally surrounding issues of prosthesis use.* Participants discuss their experiences of prosthesis use, both practical and emotional.

Example:

- Time 1 (P8*): Have you had a look at the clothes these days – [have you] seen the nice little thin straps that they have? If you have prosthesis, where are you going to hide it…I'm not in the category where I'm having a reconstruction. You can either wear grannies clothes or nothing.*

Exclusion Information: Data not mentioning prosthesis use, or prosthesis matters of any kind, were not included in this section.

Note: Overlap of data found in this section with various other sub-categories and sections and sub-sections was unavoidable, such as *1.8.1 – (Breast Symbolism) Societal, 1.8.2 – (Breast Symbolism) Personal, 3.2 – Breast Loss,* *3.2.1 Reconstruction, 4.1 Self-Esteem, 4.1.1 – Body Image,* and *4.1.1.1 – Sexuality,* due to their emotional and physical relationship with the use of prosthesis.

4.1 **Label:** *(Personal Concerns) – Self-Esteem*

Definition: *Generally surrounding issues of how participants' feel about, and see, themselves.* Participants discuss how, after having breast cancer, they perceive and feel about themselves generally. This sub-category includes discussion of self-esteem and self-confidence.

Example:

- Time 1 (P16): *I don't think I'd say I lost self esteem, I lost quite a lot of confidence, particularly in the early days.*

Note: Data stating issues of self-esteem and self-confidence were included in this sub-category regardless if these issues were concerns for participants or not. Overlap between this sub-category and many other categories, sub-categories, sections and sub-sections were unavoidable as when discussing various aspects of their experiences the participants also include discussion of emotional aspects.

4.1.1 **Label:** *(Personal Concerns – Self-Esteem) – Body Image*

Definition: *Generally surrounding issues of self-image and body image.* Participants discuss how they perceived themselves in regards to physical issues (physical consequences of treatment) affecting their emotional state; how they present themselves to the world. All replies given when asked about body image (or other participant derived similar terms such as self-image) were included in this sub-category.

Example:

- Time 1 (P15): *I was proud of 2 things as a young woman, and that was my hair, I had waist length hair, and my cleavage - I lost both - um and your self-image. I mean I feel like a freak - an absolute freak and therefore I don't have a social life.*

Exclusion Information: Personal feelings which did not directly, or indirectly, relate to body (self) image, were not included in this section.

Note: Overlap of data found within this sub-category and other categories and sections was unavoidable, such as *4.1 - Self-Esteem, 3.2 - Breast Loss* and related sections, *1.8.2 (Breast Symbolism) - Personal* and *4.1.1.1 – Sexuality.*

4.1.1.1 **Label:** *(Personal Concerns – Self-Esteem – Body Image) – Sexuality*

Definition: *Generally surrounding issues relating to sexuality.* Participants discuss how they feel about their sexuality after their breast cancer diagnosis in emotional and physical terms. Changes in sexual matters (be they physical and/or emotional) were identified, such as changes in libido due to treatment and emotional issues. Any replies given when asked about sexual matters was included in this sub-section.

Example:

- Time 1 (P1): *I was at one stage considering going on antidepressants but, because my libido was an issue, I had no libido whatsoever, and antidepressants all effect you and your libido.*

Exclusion Information: Data not specifically related to sexuality matters, physical and/or emotional, were not included in this sub-section.

Note: Physical and emotional issues of sexuality were closely linked and near impossible to think about one without considering the other. Overlap of data found within this sub-section and many other sub-categories, sections and sub-sections was unavoidable, in particular overlap with *4.1.1 Body Image, 1.8.1 – (Breast Symbolism) Societal* and *1.8.2 (Breast Symbolism) – Personal.*

APPENDIX 3.9: Reliability Tests (of NUD*IST Codes)

First Coding Check: ***Code-Check of Data Utilized for Chapter 4***

An independent researcher code-checked 25 pages of raw transcribed data (from Time 2 interviews) into the main five first level major codes: *1. Consumer Issues; 2. Family and Friends; 3. Consequences of Treatment; 4. Personal Concerns;* and *5. Other*. During this phase the independent researcher also coded some data into obvious second, third and fourth level codes.

Data utilized: Three documents – total of 25 pages of raw transcribed data.
Observations: 199 total observations + 8 questionable areas.

Divided into Participant coded data:

P10 – 65 agreements; 5 disagreements + 4?: 4 not relevant
P15 – 40 agreements; 10 disagreements + 1?: 1 not relevant
P18 – 74 agreements; 5 disagreements + 3?: 3 not relevant

All 8 questionable areas were deemed not relevant, hence disregarded, and were not counted in the final equation.

Total observations = total agreements (179) + total disagreements (20) = 199

$$\text{Reliability} = \frac{179}{199} = 90\ \%\ \text{ for the first coding check}$$

Second Coding Check: *Code-Check of Data Utilized for Chapter 5*

An independent researcher code checked another 28 pages of transcript – this time in relation to codes: 3.1 Reproductive Outcomes; 3.1.1 Fertility; 3.1.1.1 Pregnancy; 3.1.1.1.1 (Pregnancy) Information; 3.1.1.1.2 Breastfeeding; and 3.1.1.2 Contraception.

Data utilized: Documentation was taken from a variety of participants’ transcripts.
Observations: 62 observations + 1 questionable area.

The one questionable area was deemed correct and was thus added into agreed observations.

Total observations = total agreements (52) + total disagreements (11) = 63

Reliability = $\frac{52}{63}$ = 82.5% for the second coding check.

Third Coding Check : ***Code Checking of Codes Utilized for Chapter 6***

An independent researcher code-checked another 18 pages of transcript – this time in relation to codes *1.8 Breast Symbolism, 1.8.1 (Breast Symbolism) Societal, 1.8.2 (Breast Symbolism) Personal, 3.2 Breast Loss, 3.2.1 Reconstruction, 3.2.2 Prosthesis Use, 4.1 Self-Esteem, 4.1.1 Body Image, 4.1.1.1 Sexuality Issues.*

Data utilized: Documentation was taken from a variety of participants' transcripts.
Observations: 70 observations + 2 questionable areas.

One of the questionable areas was deemed correct hence was added to total agreements. The other questionable area contained insufficient data for the independent researcher to make an informed decision hence such area was not counted.

Total observations = total agreements (54) + total disagreements (17) = 71

Reliability = $\frac{54}{71}$ = 76% for the third coding check.

APPENDIX 3.10: Body Image Table and Notes Derived from Analysis Using NUD*IST Software

NUD*IST Code 4.1.1 Body Image

Table A3.9: Body image issues of follow-up participants over 3 time phases.

Code	Time 1	Time 2	Time 3
P1 (L)	BI – a big problem: no libido or hair; weight gain; problem fitting bras; lumpectomy site looks disgusting; not comfortable dressing in front of others. (12 months to next interview)	(6 months to next interview)	*P1 is currently breastfeeding.* BI not an issue.
P4 (L)	Loss of hair was a big issue, not disfigurement as lumpectomy site is fine. Hair grew back different, P4 liked her old hair better – hair loss and regrowth were main BI issues. P4 feels this is vain (self critical). Early menopause was another BI concern – P4 was quite distressed by it (12 months to next interview)	(6 months to next interview)	No BI issues, affected breast is a little smaller than the other, but it is fine.
P8[a] (M)	P8 was not prepared for emotional side of mastectomy, Patria King's book 'Spirited Women' helped. BI issues are apparent when it comes to clothing – it is difficult to find age appropriate suitable clothes – P8 has to wear 'granny' clothes to hide prosthesis. (12 months to next interview)	P8 was not sure about her BI – P8 obtained 1½ proper prostheses since last interview. P8 generally avoided questioning in relation to BI. (6 months to next interview)	P8 would of liked to have had a bigger bust line prior to breast cancer. Fashions are cleavage focused. In first instance P8 felt losing a breast was not a big deal, now it is. The norm is to have 2 breasts (social norms), P8 is not comfortable displaying her breastlessness so she covers up. P8 does not want to dress like a granny. P8 feels she needs to be part of society again, not an outcast. Clothes need to hide prosthesis. Reconstruction would of helped to normalise P8. YW dress more sexual – seen as sexual – P8 still feels young. BI is an ongoing problem and she does not know if she has ever dealt with it – it is part of reinventing herself – seeing herself as a different person. BI issues have not yet worked out.
P9 (L)	BI problems for P9: hair loss and weight loss. P9's hair was her crowing glory (long thick curly). Hair loss was not as bad as some other aspects of breast cancer. Losing eye lashes and eye brows makes you feel really bad. No disfigurement issues. (12 months to next interview)	*P9 now has advanced disease.* No body image issues (6 months to next interview)	BI not an issue

P10 (M) *In process of recon-struction at time 1 Interview.*	*(4 months since diagnosis)* P10 has many BI issues: does not want partner to see her naked or touch her reconstructed breast; sex is not what it used to be; BI issues impinged on sex life; her looks and emotions – wonders if she will ever be the same; clothing issues especially in summer; not feeling good in herself; lost her sex appear; worries that her partner does not find her attractive anymore; feels not whole; does not feel feminine; not accepted how she looks; will always have 1 false breast; worried about final result of reconstruction; disfigurement is a big issue; no one can prepare you for breast loss; equates breast loss to arm/leg loss; aware men look at breasts she now hides her disfigurement in public; photos of nice breasts upsets P10; envies women who have 2 breasts as she will never have them again (ME: P10 appears to be still grieving loss of her breast) (12 months to next interview)	*(Expander out and implants in, nipple graph done).* P10 is happy with reconstruction results; this has made her feel much better. Visually she has 2 breasts but internally it is still not ok. The reconstruction has not fixed P10 emotions. Still not feeling like a woman when she has her clothes off due to physical feeling of new breast – numbness and hard – not real. When partner touches new breast it still concerns P10 – this is purely how P10 feels about it, not partner – he is fine with it. Emotional problems – new breast is not quite right – needs more surgery. Still self-conscious in clothes – worse when P10 looks at herself – not a whole woman without 2 breasts. (social norms) Losing a breast so young was a terrible blow to P10. P10 equates reconstruction to the road to recovery for YWBC. Seeing photos of nice breasts still upsets P10, though probably not so much. P10 stated she had BI issues with her breasts prior to breast cancer – breasts were too small. (6 months to next interview)	*Repair surgery of reconstruction still not done.* Due to the reconstructed breast not being quite right, P10 is bothered by wearing low cut tops and this affects P10 emotionally. P10 is pinning her hopes on the next surgery to fix her breast. BI issues are an ongoing concern for P10.
P11 (M) *Just prior to time 1 P11 was told she could not have a recon-struction*	Since diagnosis P11 is limited in what she can wear and this is a current issue – she felt if she had a reconstruction this summer she could wear low cut tops – then P11 goes on to criticise herself that she is getting older and that worrying about fashion is petty. P11 indicated she did not have any major BI issues though she would prefer to have 2 breasts. (6 months to next interview)	*(P11 was in early pregnancy at time 2)* (6 months to next interview)	*(P11 almost ready to deliver baby at time 3)* BI is still a concern. P11 will pursue more expert opinions about reconstruction after her baby is born. P11 is always conscious of her lost breast. P11 no longer gets dressed in public (such as swimming change spaces) she now hides in cubicles. P11 no longer gets dressed up to go to bed. After a reconstruction she can wear sexy gear again.
P15 ^{s}(M)	P15 uses the term 'self-image'. P15 experiences difficulty purchasing suitable clothes. BI issues include: lost 2 most prized possessions – most proud of, cleavage and hair. P15 feels like a freak, people go out of their way to look at her. Self-image changes are the hardest thing for YWBC. Thinking of BI, sexuality and femininity makes P15 sick. It is one thing to be told you will have self-image problems it is another to live it. Things may have been different if P15 had a	Other BI issues include: lymphoedema issues (fat arm) difficulty with clothes – have to buy everything x-large to fit arm – why is this problem not catered for? ; also scarring, portacath and radiation – have to wear high necklines; prosthesis never looks right. P15's fingernails are now a high priority (ME – shifting focus to something she has control over – self-preservation and reinventing self). Physical looks are now a lesser priority – budget for clothes has dropped. No one teaches you how to create a new normal (ME – reinventing self). It is not only lost body parts (BI	P15 is now supporting other women with breast cancer, states YWBC do not want a 60 year old woman to tell them how to deal with BI issues. P15 still claims hair loss was worse than breast loss – breast loss is more of a hassle. P15 is more conscious of her hair (has not grown back as before) and lymphoedema. She feels she can grow her hair back but cannot do anything about her arm. (ME- there seems to be 2 levels of consciousness working here – the practical/conscious

	partner. P15 feels she will never get over her self-image problems. Taking away a breast and hair is the worst thing you can do to a woman. P15 acknowledges she practices self-preservation as she will not do anything to compromise her BI any further (such as partner rejection). Glossing over self-image issues (such as the look good feel better program) does not change it. (6 months to next interview)	issues) but also lost lifestyle. P15 states she does not care what she lost (also lost fertility) - states BI sucks (contradiction). Identical twin sister – constant slap in face what P15 would of looked like now. P15 states that BI is not a high priority – she is incensed how society pushes BI ideals. States she has more problems to worry about than BI and she doesn't care what other people say – but then goes on to state she hates what she looks like. After seeing a photo of herself, P15 was shocked how bad she looked when she is the same person inside – then describes this as 'the real vanity coming out' (ME-again self criticism). BI is a hassle to worry about. P15 does not want to be treated differently. Societal issues of BI – P15 feels she cannot change it (ME – social rules/norms). P15 had BI issues prior to breast cancer, now intensified. Stigma. P15 glad she does not have to test a relationship against breast cancer. P15 never goes out without a prosthesis – it is asking people to look at you. (6 months to next interview)	mind – what is socially acceptable and the subconscious mine – how she really feels –with worry of what she and others would think of her real feelings). Hair loss is so obvious (public). P15 has also gained a lot of weight – it is obvious this has impacted on her BI though she states until her doctors worry about it she will not. Hair loss impacted of her sense of being a woman – not the breast or uterus loss. Mastectomy should be worn like a badge. P15 had a great bust line prior to breast cancer, now she feels that is shallow (self-criticism) – now she wants to hide her bust line. Society makes women with 1 breast feel like ½ a woman (social norms). Prior to breast cancer P15's breasts were symbols of her sexuality. P15 criticises herself for not going out in public without a prosthesis – she feels she is not brave enough (ME – to challenge social norms/ rules) – P15 feels if she did not wear a prosthesis her self-image would be damaged if people reacted badly (ME – self preservation). P15 presumes society is not going to let go of BI ideals to allow women to not wear prostheses. P15 would like to lose weight (health) and retain a healthy respect for life.
P16 (L)	BI is fine, P16 can look at herself in the mirror. This may have been different if P16 had a mastectomy. (6 months to next interview)	No BI concerns	*(P16 Left the study prior to time 3)*
P18 (M)	P18 is not concerned she lost a breast, she just has to dress in a way that does not draw attention to it. Fertility is a bigger issue for P18 than BI. BI – not just breast loss but also other lost tissue. P18 is self-conscious in some clothes – appearances. P18 has a problem with her partner touching her – this has been constant and has not decreased over time. The scar area is unattractive – equates to being a sexual thing – visually P18 is not embarrassed naked in front	P18 is not impressed with her appearance at present – even so P18 modelled in a fashion parade for breast cancer survivors. P18 is comfortable with her looks as long as she does not see a photo of herself she is fine (weight wise) like most women. P18 is more accepting of her appearance now – she does not worry about it – stepped away from obsessing over her looks. P18 was more concerned for her partner than herself when she lost her breast (social norms?) When undressed, P18 does not feel sexy – though not embarrassed for her partner to	P18's partner is comfortable with how she looks, though P18 herself is not comfortable/happy with her appearance. This aspect may have worsened over time. Looking considerably better would come at price. P18 feels good as a person so she chooses to concentrate of being the best person she can be. P18 is fine with her BI as long as she doesn't see herself in a mirror, she can undress and look at scar and think nothing of it (contradiction)

	of her partner but reverts from touching as her partner may find another lump while being intimate. P18 feels her partner touching her unaffected breast is more of a check up than intimacy. (6 months to next interview)	see her naked – but when it comes to intimacy her breastlessness worries her. – she does not feel attractive at all – this feeling has been static over time. P18 is beginning to consider reconstruction possibly after 5 year mark as a reward for getting there. (6 months to next interview)	Problem seems to be more about weight gain, though this can be a consequence of treatment. P18 cringes when her partner touches her chest wall – it is not attractive – she does not like the feel of it; bony and tight – this feeling is about the same as stated in previous interviews. P18's sex life is abysmal and is tied to BI. P18 does not feel sexy – weight gain just makes matters worse. The further P18 get away from treatment the more things get back to normal – as previously everything that changed was tied up with the cancer and treatment - now what is it? It was important in early days to show people her scar – most people said how good it looked, if people had reacted badly it would have been a different story – now P18 is not keen to show off her scar (ME – in early days scar meant survival now it may mean disfigurement?). P18 is no longer sad about breast loss (ME – finished grieving breast).
P27 (M)	P27 feels BI was a bigger issue than she first thought – in early days she felt breast loss could be disguised – prosthesis, as a lost arm or leg would be more difficult to disguise. Recently P27 became more self-conscious of her prosthesis due to a social situation hence she is undergoing reconstruction soon. (6 months to next interview)	*(P27 has had her breast reconstruction)* P27 feels she must have had some real BI issues, as now after reconstruction she feels so much better. BI is not currently a concern. (6 months to next interview)	P27 had large breasts and saw her breasts as very sexual and her partner liked them - they were a big thing between them. When she was told she was going to lose 1 she was concerned her partner would no longer like her. After the mastectomy she almost hated her breasts – they caused her grief. P27 is now glad she did not lose both breasts. P27 no longer views her breasts as sexual. P27 still sees breasts as a feminine marker (ME – social norms) – you take one breast away you have a disfigured woman – that is how society would see it. Since her reconstruction, P27 feels much better about her BI.
P34 (M)	Breast cancer and mastectomy impact on BI, it is hard to feel comfortable with your body. P34 does not think about BI – shuts it out. Disfigurement was a problem for P34 in the early days but now she has adjusted and gotten used to it (learned to live with it).	P34 has BI issues, she has gained weight and feels physically unfit and uncomfortable. As she has lost a breast P34 feels she must compensate for it (reinventing self). Initially after mastectomy P34 had big BI issues – she felt like a freak – now she is beyond that – it is a nuisance sometimes – have to adjust fashion wise.	P34 was greatly upset when hearing how some women equated stretch marks to mutilation – (maybe issue of how society sees breast loss). P34 asked partner if that was how he saw it, he said no. P34 was angry with these women's pettiness. P34 said all women are more

	Partner is fine with her breastlessness – though she does not go around showing it off either. (6 months to next interview)	Issues of weight gain and BI are not related to breast cancer. (6 months to interview)	sensitive when pre-menstrual. P34 is more self-conscious about breast loss during sexual relations than her partner – maybe reconstruction would remove this, but them P34 is very concerned that if she had a reconstruction, maybe the emotional aspects will not improve. Presently BI is fine.
P35 (L)	P35 has no problems with her appearance. P35 would show off her breasts in a breast cancer magazine to show other women how good they can look after surgery. P35 had a weight gain problem due to early menopause. Presently no BI concerns. (6 months to next interview)	*P35 now heavily pregnant – and was in early pregnancy in time 1 interview though did not disclose this.* No BI concerns. (6 months to next interview)	*P35 had baby and finished breastfeeding by time 3 interview)* No BI issues. P35 experienced some breast lopsidedness after the baby was born – she is now wearing a temporary partial prosthesis – no problems.
P38^{s} (L)	BI – as well as can be expected – disfigurement has not been a problem (P38 avoided in part this line of query) (6 months to next interview)	No BI problems, lumpectomy scar is very neat. (6 months to next interview)	P38 has adjusted to lumpectomy scar – she was concerned at first that men would not want her, now she is fine with it. Younger women are more sensitive and vain about their appearance and tend to wear more revealing clothes. Younger women more sensitive to media images/messages of breasts and BI. P38 doesn't presently have any BI issues other than the usual ones 'weight' – her breasts do not bother her.

Table A3.9: Body image issues of participants over 3 time phases.

Note: L – denotes participant had a lumpectomy only
M – denotes participant had a mastectomy
BI – Body Image
YW – Young Women
YWBC – Young Women with Breast Cancer
^{a} denotes the participant has advanced disease at first interview
^{s} denotes participants who are single.

Note: I noticed those who had mastectomies had more issues than those who had lumpectomies – as expected. Overtime, those with long standing body image issues - it finally came out somewhat, where as those who were up front stating body image concerns – their concerns lessened over time. This could be a case of those who suppress body image concerns to help self-preserve end up suffering more than those who talk about it (admit to it) up front. I think there were some problems with the women even admitting it to themselves that they had some body image issues. It was like they had to be thankful they were alive, therefore it was not right to complain about something that many would think trivial – this is a good point. These women do not want to be seen as vain, thinking only of there own person looks and feelings about their looks – how they are presented to the world. They may feel it is selfish to think such thoughts when maybe they should be thinking more about how their illness impacts on others (children and partner). Self-criticism almost launches into self-chastisement for thinking about body image issues.

APPENDIX 3.11: Body Image Tables and Notes Resulting from Reanalysis of NUD*IST Categories.

Body Image Reanalysis

Issue	P1 (L)	P4 (L)	P8^{a} (M)	P9^{a*} (L)	P10 (M)	P11 (M)	P15^{s} (M)	P16 (L)	P18 (M)	P27 (M)	P34 (M)	P35 (L)	P38^{s} (L)
Lost Libido	T1												
Hair Loss	T1	T1		T1			T1,3						
Weight Change	T1			T1			T1,3						
Disfigurement	T1				T1	T1	T1		T1		T1		
Early Menop		T1											
Lymphoedema							T2,3						
Other Scarring							T2						
Prosthesis Use			T1							T1			

Table A3.10: What impacts on body image of follow-up participants after breast cancer treatment.

Note: Shaded columns indicate Participants who did not express body image concerns**.**

L – denotes a participant who had a lumpectomy only
M – denotes a participant who had a mastectomy
^{a} - denotes a participant who had advanced disease at interview 1
^{a*} - denotes a participant who had advanced disease at interview 2
^{s} – denotes a participant who was single throughout all interviews.

Note: Three participants (P16, 35, 38) did not report any body image issues specifically. Five participants' (P1, 4, 9, 27, 34) body image issues resolved, or became less important, over the interview phases. Often in interview 1 the participants would discuss body image issues they had experienced since their diagnosis and some participants' issues had resolved by the time of the first interview (they spoke retrospectively). However for another five participants (P8, 10, 11, 15, 18) body image issues were ongoing. In the case of P10 and P27, who had breast reconstruction before the last interview, the reconstruction was said to be responsible for greatly relieving body image concerns. However, P10 expressed ongoing body image concerns (though to a lesser degree). In saying this it must be noted that P10 expressed she had struggled with body image issues (having small breasts) prior to her breast cancer, hence it could be assumed that P10 is particularly sensitive to body image issues. Seven participants who underwent mastectomy expressed body image concerns in comparison to 3 participants who had lumpectomy only.

As disclosing information about one's body image is potentially distressing, some participants may experience more body image issues than they disclosed. This was the case for P8 who had advanced disease at first interview. By the final interview, P8 disclosed that body image was a very distressing issue for her and hence could not express how she felt, thus limiting the scope of the data. Other participants (P15 in particular) expressed many and varied body image issues. I felt body image truly upset this participant. This participant often contradicted some of her comments. Conclusions made about P15's body image experience were clarified and validated my many comments P15 made (such as body image sucks), then when asked directly about her body image P15 would often say she did not care about body image, it was not important. Other participants often expressed these types of contradictions. This could be explained by sociology theories. The problem appeared to be the women did not like to admit to me (or themselves) that they had body image issues; they had to be thankful to be alive therefore the right to complain was taken away from them. These women do not want to be seen as vain, thinking only of their own person looks and feelings about their looks. They may feel it is selfish to think such thoughts when maybe they should be thinking more about now their illness impacts on others (children and partners). Self-criticism almost launched into self-chastisement for thinking about body image issues as a problem.

Some consequences of breast cancer treatment were responsible for participants body image concerns, these were: lost libido; hair loss; weight change (up or down); disfigurement (specifically loss of breast and other tissue and related scarring); going into early menopause (this made participants feel old); lymphoedema; other scarring (such as radiation and portacath related); and having to use a prosthesis. Table A3.11 provides detail of the impact of damaged/lowered body image had on participants. Table A3.12 provides detail of participants' difficulty with clothing, impacting on their body image.

Table A3.11: The impact of damaged/lowered body image of follow-up participants following breast cancer treatment.

Code	Time 1	Time 2	Time 3
P1 (L)	Always dresses in private. Self-conscious of scar. Body image issues were mostly reported retrospectively and were resolved prior to interview1.	No body image issues reported.	No body image issues reported.
P4 (L)	Felt old. Body image issues were reported retrospectively, all body image issues resolved prior to interview 1.	No body image issues reported.	No body image issues reported.
P8[a] (M)	Covers up; hates the clothes she has to wear.	P8 avoided questions about body image.	P8 is very conscious of her lost breasts (1 ½). Covers up. P8 found this topic very difficult to talk about – P8 has ongoing body image issues. P8 is not sure if she has ever dealt with body image issues.
P9[a*] (L)	Body image issues were reported retrospectively, though weight loss appeared to be an ongoing issue.	No body image issues reported.	No body image issues reported.
P10 (M)	***P10 started reconstruction, expander in; also only 4 months since diagnosis***. Impinges on sex life; wonders if she will ever be the same; not feeling good in herself; does not feel like a whole woman; does not feel feminine; worries partner will not be attracted to her anymore; has not accepted how she looks	***Reconstruction almost complete.*** Still does not feel like a woman	Still some body image issues as new breast is not quite right. P10 is pinning her hopes on corrective surgery. Body image issues are ongoing for P10.

P11 (M)	No major body image issues though would prefer to have 2 breasts.	No body image issues reported.	Always conscious of lost breast. Always dresses in private.
P15[s] (M)	Covers up; feels like a freak; self-conscious; disguises breast loss with prosthesis; body image issues may be have been different if P15 had a partner; taking away a young woman's breast/s and hair is the worst thing you can do to them. P15 will not do anything to further compromise her self-image, such as start a relationship.	Physical appearance is a lessor priority – though P15 also states she hates how she looks. P15 goes on to state body image is not a high priority – however P15 still states her body image 'sucks'. Mastectomy should be worn like a badge, not hidden/disguised with prostheses and non-revealing clothes – howeverP15 is not brave enough to challenge social norms/rules. If P15 went in public without a prosthesis and people reacted badly P15's self-image would be damaged.	Society makes you feel like ½ a woman if you have 1 breast – are we measured as a woman by our breasts. Body image is a hassle to worry about. P15 says her hair loss was worse (for her body image) than her breast loss or uterus loss. Presently her lymphoedema is a big body image issue as P15 cannot get clothes suitable to fit her arm and the rest of her. Weight gain from treatment consequence has also impacted on P15 body image.
P18 (M)	Self-conscious; dresses in a way that does not draw attention to bust line. Scar area is unattractive.	Not pleased with appearance; terrible sex life; does not feel sexy; stopped obsessing over her appearance. P18 is comfortable with her appearance as long as she does not see a photo of herself (weight related).	Not pleased with appearance; P18 is fine with her appearance as long as she does not look in a mirror undressed; looking considerably better comes at a price; the further you get away from treatment the more the bigger the little issues appear – such as appearance problems.
P27 (M)	P27 feels she must have more body image issues than she thought she had as she is undergoing a reconstruction shortly. Self-conscious of prosthesis.	As P27 is feeling so much better about herself since her reconstruction she feels she must have had underlying body image issues she was not aware of.	No longer see breasts as sexual – though feels fine in herself since reconstruction.
P34 (M)	Covers up; felt like a freak in early days	P34 has body image issues though no related to breast cancer.	More self-conscious of breast loss during sex.

Table A3.11: The impact of damaged/lowered body image of follow-up participants following breast cancer treatment. (Clothing/fashion issues are in a separate table below).

Note: L – denotes a participant who had a lumpectomy only
M – denotes a participant who had a mastectomy
[a] – denotes a participant who had advanced disease at interview 1
[a*] - denotes a participant who had advanced disease at interview 2
[s] – denotes a participant who was single throughout all interviews

Code	Issue
P8 (M)	**Time 1:** It is difficult to find age appropriate suitable clothes to wear, have to wear granny clothes. Clothes need to hide prosthesis. **Time 3:** Fashions are cleavage focused. P8 does not what to wear granny clothes. Clothes need to hide prosthesis.
P10 (M)	**Time 1:** *(Started reconstruction)* In summer it is the hardest as fashions are skimpy. **Time 2:** *(Reconstruction almost finished, needs some correction)* Still very conscious in clothes. **Time 3:** *(Reconstruction has not been corrected yet)* P10 is bothered by wearing low cut tops and this affects P10 emotionally.
P11 (M)	**Time 1:** Limited in what she can wear and this is a current issue. P11 felt if she could have had a reconstruction she could wear low cut tops again. P11 says worrying about fashion is petty. **Time 3 :** Body image is a big concern. P11 no longer gets dressed up for bed. After a reconstruction she can wear sexy clothes again.
P15 (M)	**Time 1:** It is difficult to buy suitable clothes. **Time 2:** Lymphoedema creates difficulties when it comes to clothes – have to buy large sizes to accommodate arm, and then the clothes are too big everywhere else – why doesn't someone cater for women with lymphoedema? Always have to wear high neckline clothes (due to mastectomy, radiation and portacath scarring).
P18 (M)	**Time 1:** Have to dress in a way that does not draw attention to myself. Self-conscious in some clothes.
P34 (M)	**Time 2:** Trying to look good in clothes can be a nuisance.

Table A3.12: Clothing/fashion specific issues of follow-up participants.
Note: M – Participant had a mastectomy
Time 1, 2 or 3 indicates the study phase in which data were collected

Sociology Issues Which May Help Explain Findings:

Social Norms/Rules – the participants are aware of unspoken social norms and rules and do not wish to challenge them – though by having breast cancer (and breast loss/disfigurement) they already have.

Self-Preservation – the participants not only disclosed their data in a way that was self-preserving but also stated clearly the things they do, avoid, to self-preserve.

Reinventing Self – some participants discuss who their lives will never be the same and how they must create a new normal – to normalise their experience.

Self-Criticism – often participants spoke relatively freely of how they felt about their body image then reverted quickly to comment of possible greater social acceptance – this was done with comments of self criticism – such as speaking of being vain and how trivial and petty it was to do so.

APPENDIX 3.12: Validation Documents and Response Tables

Validation Document Concerning Reproductive Issues – Regarding Chapter 5 (Results 2)

Please use the following to guide your responses in the boxes provided.
N/A – not applicable; Y – (Yes) if you agree; N – (No) if you do not agree.

Code:

Fertility And Contraception After Breast Cancer Treatment.

☐ Being infertile was a concern for me, as I wanted (more) children in the future.

☐ How I viewed being infertile changed from the time of the first interview (date) to the time of the last interview (Date).

☐ At the time of the last interview (Date), I had not tried to become pregnant therefore I did not know what my fertility status was.

☐ I did not know for sure if I was still fertile.

☐ Changes occurred in my fertility status from the time of the first interview (Date) to the time of the last interview (DATE).

☐ Being fertile was a concern for me as I did not want more children, or at least not in the near future.

☐ As much as I wanted to have a baby, I felt guilty and selfish to do so as I may have a shorter than usual lifespan.

☐ I found out I was fertile by becoming pregnant.

☐ My trust in non-hormonal methods of contraception was minimal.

☐ Suitable safe reliable contraception was an important consideration for me.

☐ Permanent sterilization was an acceptable form of contraception for either my partner or myself.

☐ Permanent sterilization, of either my partner or myself, was *not* an acceptable option for contraception.

Code:

Pregnancy After Breast Cancer.

☐ I feared that a pregnancy could either speed up or cause more cancer activity.

☐ When I became pregnant I was concerned that important breast changes would become difficult to find.

☐ I was concerned that I was unable to undergo usual breast checks and testing while I was pregnant.

☐ I knew how the hormonal changes related to pregnancy make breast cancer difficult to find.

☐ Becoming pregnant helped me to move on from the cancer.

☐ Becoming pregnant gave me something positive to look forward to.

☐ Becoming pregnant helped me to trust my body again.

Code:

Breastfeeding After Breast Cancer

☐ I wanted to breastfeed my infant.

☐ I wanted to breastfeed my infant, as I wanted to be a good mother.

☐ I wanted to breastfeed my infant, as it would be convenient.

☐ I wanted to breastfeed my infant, as I knew the benefits to my infant and myself.

☐ I wanted to breastfeed my infant, as I wanted to experience breastfeeding.

☐ The decision to breastfeed my infant was clear-cut; an easy decision.

☐ The decision to breastfeed my infant was *not* clear-cut; much thought and consideration was necessary to reach the decision.

☐ I did not want to breastfeed my infant from my affected breast.

☐ I did not want my affected breast to lactate.

☐ The original plan to breastfeed my infant changed from when I first told Shirley Connell that I was pregnant to the time of the last interview (date).

☐ My decision to breastfeed (either at all or for a specific time frame) changed from when I first told Shirley Connell that I was pregnant to the time of the last interview, due to my fears that lactation could speed up or cause further cancer activity.

☐ I was concerned that I would not have enough milk supply to feed my infant.

☐ I was/would be relieved when my breast/s was/were back to the non-lactating state so I could continue usual breast checks and testing.

☐ I was concerned that I could not undergo my usual breast checks while my breast was still lactating.

☐ I was aware of, and concerned that, important breast changes were difficult to identify while breastfeeding.

☐ Breastfeeding my infant was considered and/or undertaken within a ‘life after breast cancer’ context, which made this breastfeeding experience different to previous breastfeeding experiences.

☐ I enjoyed breastfeeding even though I did have some concerns.

☐ Breastfeeding my infant helped me to move on from the cancer further.

Code:

☐ I saw breastfeeding as a sign that I am cured.

Please feel free to add any comments you feel are necessary to clarify the issues presented and/or raise any important points that are not covered within this checklist.

Comments Box

Thank you for taking the time to complete this document. Your feedback is greatly appreciated and your views held in high regard.

Validation Responses Regarding Chapter 5 (Results 2) – Reproductive Issues

Response Rate: 100%

Code	Fertility	Contraception	Pregnancy	Breastfeeding
P1	As expected	States permanent sterilization not acceptable, but I think she meant before her last pregnancy	As expected	Decision not clear cut as I assumed; did not see bf as a sign of cure
P4	As expected	As expected	As expected	N/A
P11	Does not wish to continue with study – had relapse			
P15	Contradicted findings – changes to feelings about infertility over time	N/A	N/A	N/A
P18	I think hope prevails – fertility status always unsure	As expected	N/A	N/A
P35	Some confusion, I think over time this changed, as being fertile was a concern until suitable contraception found	Some confusion, I think over time this changed, as P35 did state that she did not trust non-hormonal forms of contraception. Permanent sterilization was not a totally acceptable form of contraception in interview 2	As expected	States did want to breastfeed from affected breast but she stated in interview 2 she did not, then in interview 3 she had tried. Did not see breastfeeding as cured
P38	As expected	As expected	N/A	N/A

Table A3.13: Validation responses; reproductive issues, participant feedback.

Validation Document Concerning Issues of the External Portrayal of Participants' Bodies and Generational Differences – Regarding Chapter 6 (Results 3).

Please use the following to guide your responses in the boxes provided.
N/A – not applicable; Y – (Yes) if you agree; N – (No) if you *do not* agree.

Code:

Social Issues

☐ I am aware of society's expectations of women's bodies in relation to breasts.

☐ In my opinion, society expects women to have 2 whole breasts.

☐ I feel pressure from society to hide or disguise my breast loss/disfigurement.

☐ I feel male sexual views of breasts dominate society's views of breasts in general.

☐ I have experienced stigma from others due to being diagnosed with breast cancer.

☐ I have experienced stigma from others due to my breast loss/disfigurement.

Personal Issues

☐ I feel breasts hold sexual importance.

☐ I feel breasts are a symbol of sex.

☐ I feel breasts are a mark of femininity.

☐ Compared to before I had breast cancer to my current situation, I *do not* feel differently about my breasts.

☐ Compared to before breast cancer to my current situation, I *do* feel differently about my breast/s.

☐ Since having breast cancer, I feel my breast/s is/are a site of potential grief.

☐ Since having breast cancer, I feel my breast/s is/are no longer sexual.

Code:

Prosthesis Use

☐ By wearing a breast prosthesis, I hide or disguise my breast loss/disfigurement.

☐ I would not go out in public without wearing my breast prosthesis.

☐ I wear a breast prosthesis as I do not wish to take the chance of being embarrassed and/or distressed if others treat me differently.

☐ I am not bothered by wearing a breast prosthesis.

☐ In my experience, wearing a breast prosthesis can sometimes be a hassle.

☐ Wearing a breast prosthesis interferes with my preferred lifestyle.

Expectations and Experiences of Breast Reconstruction

☐ My decision to undergo, or not undergo, breast reconstructive surgery was partly influenced by my partner’s views.

☐ Having undergone breast reconstructive surgery, I feel less stigmatised by others regarding my breast loss.

☐ Breast reconstructive surgery has enabled me to disguise my breast loss.

☐ I *am* satisfied with my reconstructed breast.

☐ I *am not* satisfied with my reconstructed breast.

☐ Having breast reconstruction has improved my body image.

☐ I expect that if I had breast reconstructive surgery it would reduce the stigma I experience from others regarding my breast loss.

☐ I expect that if I had breast reconstructive surgery it would help me to feel normal again.

Code:

How young women with breast cancer experience their breast cancer differently to that of older women with breast cancer.

☐ In my opinion, I feel young women experience breast cancer differently to that of older women with breast cancer.

☐ In my opinion, I feel young women experience breast cancer differently to that of older women due to the social expectations placed on younger women to be, and dress, sexier.

☐ In my opinion, I feel young women experience breast cancer differently to that of older women due to being more sensitive to, and therefore more influenced by, media images.

Ongoing body image issues.

☐ I have ongoing body image issues not only as a result of breast loss, but also from other tissue loss and scarring.

Code:

Please feel free to add any comments you feel are necessary to clarify the issues presented and/or raise any important points that are not covered within this checklist.

Comments Box

Thank you for taking the time to complete this document. Your feedback is greatly appreciated and your views are held in high regard.

Validation Responses Regarding Chapter 6 (Results 3) – External Portrayal of Participants' Bodies and Generational Differences.

Response Rate: 62.4%

Code	Social Issues	Personal Issues	Prosthesis Use	Reconstruction	Generational differences	Ongoing BI Issues
P1 (L)	As expected	As expected, though since interview 3 P1 feels very differently about her breasts.	Prosthesis issues remain long after Breastfeeding due to affected loss of tissue in affected breast due to RT.	Since Breastfeeding after breast cancer P1 now wishes to have reconstruct-ion due to ongoing lopsidedness	As expected	As expected
P15 (M)	As expected	As expected	Mostly as expected, though issue of being bothered by wearing a prosthesis – in all interviews it was very much an issue, now P15 says it is not.	Mostly N/A, however when asked in the last interview about hypothetical expectations of reconstruction, P15 responded, but now placed N/A in box.	As expected	As expected
P18 (M)	As expected	As expected	As expected	As expected	As expected	Total contradiction of what was recorded in transcripts and of further comments made on validation document – this suggests P18 was confused by the way I presented this to her.
P27 (M)	As expected	Mostly as expected. P27 now states she does not feel breasts are a symbol of sex.	N/A – has had reconstruction	As expected	As expected	As expected
P34 (M)	As expected	Mixed responses – sexual importance of breasts not confirmed, and breasts as a site of grief also not confirmed. These were clearly stated as such in transcripts.	As expected	Mixed responses – states her decision to not have reconstruction was not influenced by her partner – transcripts suggest otherwise.	As expected	As expected.

Table A3.14: Validation responses; external portrayal of the body issues, participant feedback.

Note: *L – Participant had lumpectomy only*
M – Participant had mastectomy
N/A – Non applicable

APPENDIX 3.13: Final Summary Letter

QUT Letterhead

Participant name
Participant address
Participant address
Participant address

DATE

RE: Summary of Findings of the Young Women with Breast Cancer Study

Dear (Participant's name),

I trust this letter finds you well and in good spirits. I am sorry I have taken so long to get this summary to you. I have completed the first draft of my thesis and have written three manuscripts, to be submitted to journals for publication, from the study findings to date. Below is an overview of these manuscripts.

Manuscript 1

The first manuscript reports on findings of the first phase of the study drawing on the experiences of all 35 participants. The most pressing concerns found were for children and partners. Even participants who did not have children recognised that concerns for children would be paramount for young women with breast cancer. Not only were negative emotional aspects of having breast cancer at a young age reported, with the majority of participants expressing concerns related to recurrence, but also positive emotional experiences, such as feeling more assertive and being able to say no to outside demands. Negative physical consequences of treatment, which included nausea, vomiting, hair loss, disfigurement, early menopause and subsequent sexual problems, reproductive issues such as infertility concerns and concerns related to maintained or regained fertility, i.e., contraception, and pregnancy after breast cancer and more, were also documented. Approximately half of all participants felt there was a shortage of support services for young women with breast cancer.

Subsequent Interviews

As this study sought to explore the experiences of young women with breast cancer over time, a group of 13 participants were interviewed twice more approximately six months apart. Limited resources, together with the relatively tight timeline of a PhD project, only allowed me to interview a small number of participants more than once. In consideration of the various aspects of the study, a logical reason was developed to select these participants. Participants who were selected, and hence interviewed a total of three times, were not told why they were selected, to reduce bias of the study findings. The participants who were selected had stated that their greatest unmet need was support related, either physical or emotional, hence these participants were not selected due to any other criteria, such as disease state or fertility status. This group of participants provided the follow-up portion of the study with a very broad pool of experiences and life circumstances.

Manuscript 2

As reproductive concerns are specific to younger women with breast cancer, manuscript 2 reports on findings related to this area of interest. Infertility issues were a concern for some participants while for others it was not. Some participants reported that how they felt about reproductive issues changed over time. Throughout the study, some participants, who were followed over time, became pregnant. The findings related to reproductive issues brought to light the lack of professional knowledge in this area, together with the lack of relevant information available to young women with breast cancer to make informed choices.

Contraception was found to be an issue, with concerns of which contraception method was the best to use after breast cancer. Permanent sterilization of either partner (of the couple) was not acceptable to some participants for a variety of reasons. Hormonal methods, too, were not acceptable to participants and problems were encountered with non-hormonal methods, hence medical/health professionals need to address the issue of suitable, safe and reliable contraception for young women with breast cancer. Another problem raised was that of uncertainty of fertility status. Many participants who became pregnant throughout the study did not expect to be fertile.

In addition to these above-mentioned concerns was the issue of becoming pregnant after breast cancer, in particular in relation to whether there was an increased risk of further or accelerated cancer activation. Pregnancies after breast cancer were experienced in a different context to prior pregnancies (particularly those experienced prior to breast cancer). Pregnancies after breast cancer then led to issues of breastfeeding after breast cancer. Again participants were concerned of any increased risk of further cancer activation due to lactation. The decision to breastfeed was not an easy one, considering concerns of recurrence, together with social expectations of breastfeeding equating to good mothering. Participants were acutely aware of the difficulty of detecting a cancer in a breast preparing to lactate or already lactating, thus increasing concerns. Participants' focus was again placed on their breasts throughout the pregnancy, in particular after the birth when breastfeeding commenced. Some breastfeeding problems were encountered, such as sore and cracked nipples and low milk supply. Even so, breastfeeding after breast cancer was a positive experience for most participants, although breastfeeding often did not continue for a long period.

Manuscript 3

Young women generally are adversely affected by concerns for body image following breast cancer. Manuscript 3 concentrates on understanding the underlying reasons why young women suffer body image problems. Issues of breast symbolism, both societal and personal, were included in this manuscript. In addition, by understanding how participants perceived their experience to differ from that of older women with breast cancer helped to unravel why young women often experience magnified body image concerns. Breast symbolism was found to be closely linked to male dominated views of breasts. Perceived differences of younger as compared to older women's experiences of breast cancer also reflected male dominated sexual views of women, in general, and breasts specifically. Cultural influences were also explored. The modern consumer culture, including that of the cult of the body to be fit, slim and young, impacted on participants' experiences. Experiences of young women with breast cancer need to be understood to refine current information and educational materials to make them more suitable for this group of young women.

Other Findings:

The above three manuscripts only report on a relatively small portion of this study. Other findings include great concerns of treatment-induced menopause and the lack of relevant information concerning the physical and emotional consequences of this. In particular it was found that sex-related problems were ongoing, sometimes not being experienced until long after treatment had ended. Problems of a sexual nature reported were not only of dry vaginas and painful sex, but also of lowered/lost libido and emotional problems impacting on sex lives. Sexual problems also had the potential to impact on relationships. More readily available, age appropriate, information is needed on the sex-related consequences, both emotional and physical, of cancer treatment. It was also found that participants considered themselves to be more assertive and questioning and more open to discuss intimate matters than older women, hence forum style information sessions and/or support may be appropriate for young women with breast cancer to discuss such matters.

This study found many problems with the information supplied to young women with breast cancer. Information materials given to young women with breast cancer generally need to be updated and made more relevant to this age group. In regards to issues of maintained and regained fertility an almost total lack of relevant information was reported. Issues of contraception, pregnancy and breastfeeding after breast cancer have been largely neglected to date. More research is needed in these areas to provide up to date and relevant information for young women with breast cancer of the future.

Recommendations and Future Research

Within my thesis I have suggested how medical/health professionals can improve educational and information resources and support services for young women with breast cancer. Recommendations are also made regarding the areas of knowledge medical/health professionals need to update, such as contraception, pregnancy and breastfeeding after breast cancer.

More research is needed on the issues and concerns of young women with breast cancer and subsequent survival issues. I have documented many areas of possible further research to explore.

Presentation of Findings

As well as presenting the findings of this study in three manuscripts within my PhD thesis, I also presented findings at two conferences, which were the ‘Research to Reality’ Breast Care Nurses Conference and the 3rd Annual Queensland Health and Medical Scientific Meeting. I plan to present more findings at future conferences. Presenting findings at conferences directly informs relevant medical/health professionals of what is important to young women with breast cancer.

I thank you so much for taking the time to take part in this study. All of the information you have provided to this study has been dealt with in a confidential and respectful manner. Some of the issues I have presented here may not match your personal experience; rather the findings are a general overview of that reported. I wish you luck and good health in the future.

Yours Faithfully

Shirley Connell

Signed:…………………………………………….

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