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Women's Psychosocial Outcomes following Breast Cancer Surgery and Breast Reconstruction and the Associated Interventions

Matthews, Hannah

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Women's Psychosocial Outcomes following Breast Cancer Surgery and Breast Reconstruction and the Associated Interventions

By

Hannah Matthews

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Abstract

Objective: The number of women undergoing mastectomy and the number of women electing for breast reconstruction is increasing. This research is both necessary and timely in order to identify and understand more comprehensively the unmet needs of women following breast reconstruction and breast cancer surgery.

Design: This research is comprised of three inter-related studies: a quantitative questionnaire-based study, a qualitative interview-based study and a systematic review and meta-analysis.

Methods: For study 1, a retrospective cross-sectional study, 148 women who elected for post-mastectomy breast reconstruction completed a questionnaire. Data were analysed using hierarchical multiple regression analyses. For study 2, a qualitative retrospective study, in-depth semi-structured interviews were conducted with 25 women following reconstruction. Data were analysed using template analysis. For study 3, the review, a comprehensive literature search was undertaken using keyword and subject headings within 7 databases. Included studies employed a quantitative methodology and presented empirical findings which focused on interventions for women following breast cancer surgery.

Findings: Study 1 demonstrated psychosocial factors were able to predict a high percentage of the total variance for breast satisfaction (75%) and outcome satisfaction (68%), and a modest percentage for quality of life (46%) following post-mastectomy breast reconstruction. Study 2 established most women were satisfied with their breast appearance and overall reconstructive outcome, and many experienced positive emotional gains and a renewed appreciation for life. However, these gains were often accompanied with substantial deterioration in physical, sexual and social functioning. Study 3 demonstrated that cognitive behavioural therapy based interventions often have ameliorative effects on depression, anxiety and quality of life.

Conclusion: The thesis provides novel findings in relation to post-mastectomy breast reconstruction through the incorporation of psychological, social, clinical and demographic variables. This thesis also defines and distinguishes distinct dimensions of satisfaction and quality of life, as these measures are often conceptually confused and a clear multidimensional definition is rarely applied across research. This thesis also applies template analysis to explore the experiences of women following breast reconstruction. This is a novel application of the qualitative data analysis method, which demonstrates only slight variation in some categories of experience among women. The thesis also identifies outcomes of clinical importance and is the first meta-analysis to evaluate the efficacy of interventions to improve psychosocial outcomes following breast cancer surgery.

Clinical Implications: The findings of this thesis provide a more in-depth understanding of the unmet needs of women following breast reconstruction and could be used to inform women of the likely outcomes of different reconstructive procedures. The findings may also allow clinicians and patients to identify specific areas of focus which may require further surgical or psychological intervention, in order to enhance both satisfaction and quality of life following reconstruction. The thesis recommends the implementation of specialist breast reconstruction nurses, trained in cognitive behavioural therapy to provide educational and psychosocial support throughout the reconstructive process.

Future Research: Future research should consider the experience of post-mastectomy breast reconstruction from a prospective, longitudinal stance. Researchers should also consider the benefit of evaluating objective experience alongside subjective outcomes measures to provide a more meaningful understanding of experience.

Word Count

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Supervisory Team

Professor Andy Turner, Dr Iain Williamson and Dr Wendy Clyne

Ethical Approval

Project Title	Chapter	University/NHS Reference
The PREDICT Project- Psychosocial outcomes following post-mastectomy breast reconstruction.	4	P39039/ GF0095
The ADAPT Project- Psychosocial outcomes following post-mastectomy breast reconstruction	5	P46098
The REVIEW Project- Systematic review and meta-analysis	6	P33731

Declarations

I declare that the content of this thesis is entirely my own work and has not been submitted as part of any degree at another university.

Glossary

Anorgasmia: failure to experience an orgasm, despite adequate stimulation.

Capsular contracture: a response of the immune system to foreign materials in the human body that results in hardening of the implant due to scar tissue compressing the implant.

Cardiac toxicity: is damage to the heart by toxins.

Deep Inferior Epigastric Artery Perforator (DIEP): involves the transfer of the blood vessels, fat and skin from the lower abdomen over the rectus abdominis muscle.

Donor-site morbidity: refers to complications at the donor site as it heals.

Ductal Carcinoma in Situ (DCIS): refers to abnormal changes in the cells lining and these abnormal cells are confined to the milk ducts of the breast.

Dyspareunia: is pain during or after sexual intercourse.

Dyspnoea: sudden shortness of breath or breathing difficulty.

Fear of recurrence: is a type of anxiety or worry that cancer could return in the same breast, opposite breast or metastasis in other parts of the body.

Gluteal Artery Perforator (SGAP): involves the transfer of skin and fat from the superior gluteal artery perforator muscle.

Iatrogenic: relating to illness caused by medical examination or treatment.

Invasive Ductal Carcinoma (IDC): The abnormal cancer cells that began forming in the milk ducts have spread beyond the ducts into other parts of the breast tissue.

Invasive Lobular Carcinoma (ILC): The abnormal cancer cells that began forming in the inner lining of the breast lobules have spread beyond the lobules into other parts of the breast tissue.

Latissimus Dorsi (LD): involves the transfer of the latissimus dorsi muscle, skin and fat from the upper back.

Lobular Carcinoma in Situ (LCIS): refers to abnormal changes contained inside the inner lining of the breast lobules.

Lymphedema: is a condition of localised fluid retention and tissue swelling caused by a compromised lymphatic system.

Molecular biology: the understanding of different cancer subtypes at the molecular level.

Neurotoxicity: is toxicity in the nervous system.

Physiopathology: the branch of medicine that studies how disease disrupts normal body functions.

Psychosocial: involving aspects of social and psychological behaviour.

Ptosis: abnormal lowering or drooping of an organ or a part.

Systemic therapy: treatment using substances that travel through the bloodstream, reaching and affecting cells all over the body including chemotherapy, hormonal therapy, targeted drugs, and immunotherapy.

Thoracodorsal Artery Perforator (TDAP): involves the transfer from the upper back skin and fat.

Tissue Expander (TE): is an inflatable breast implant which stretches the skin and muscle to later allow for a permanent implant.

Transverse Rectus Abdominis Myocutaneous (TRAM): involves the transfer of part of the rectus abdominus muscle, skin and fat from the abdomen.

Transverse Upper Gracilis: involves a section of fat and skin taken from the upper thigh and gracilis muscle.

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List of Figures and Tables

Chapter 1.0: Introduction, Aims and Objectives

1.1 Overview

Chapter one introduces the context, rationale and aims of the research. The chapter situates the reader in the context of the thesis and provides a succinct discussion of breast cancer, mastectomy and breast reconstruction literature (1.2). This chapter also identifies gaps in existing research and subsequently provides a rationale for this thesis (1.3). The chapter states the aims of the research (1.4) and concludes by explaining and justifying the conceptually coherent arrangement of the thesis (1.5), and the content of the following chapters (1.6).

1.2 The Context of the Thesis

Globally breast cancer is the most commonly diagnosed cancer among women (International Agency for Research on Cancer 2013). It is estimated 1.38 million new cases are diagnosed each year and 50,000 new cases are diagnosed in the United Kingdom (Eccles et al. 2013). In the United Kingdom and the United States the estimated lifetime risk of breast cancer is 1 in 8 (Cancer Research UK 2016). These statistics position breast cancer and its subsequent treatments as an international research priority (Eccles et al. 2013). Breast cancer mortality rates have fallen over recent decades due to advances in diagnostics, surgical and radiotherapy techniques, molecular biology and systemic therapy (Manos et al. 2009). These advances have resulted in improved survival rates and a growing cohort of breast cancer survivors (Graham et al. 2014). Today, women with a history of breast cancer constitute the largest group of cancer survivors (Graham et al. 2014). In the United Kingdom, it is estimated that approximately 550,000-570,000 women are living with or after a diagnosis of breast cancer (Maddams et al. 2009). This figure is expected to triple by 2040 due to an ageing population and continued improvements in breast cancer survival (Maddams, Utley and Moller 2012). This places an increased importance on promoting and supporting a high quality of life and optimal psychosocial functioning among women after breast cancer. However, the understanding of psychosocial aspects of breast cancer lags behind the physiopathology understanding. Women experience substantial iatrogenic and psychosocial harms created by diagnosis, disease symptoms and treatment (Fallowfield and Jenkins 2015). As a consequence, identifying and addressing psychosocial needs of women following breast cancer has become a focus of contemporary research (Eccles et al. 2013, Jacobsen et al. 2016).

The primary treatment for breast cancer is surgical (Rowland et al. 2001). Mastectomy with or without reconstruction is the recommended treatment for approximately 25-40% of women (Deppen et al. 2012, Guyomard, Leinster and Wilkinson 2007, Hartmann et al. 1999 and Nano et al. 2005). For many women mastectomy leads to long-term psychosocial concerns (Damen et al. 2008), with 30% of women experiencing both anxiety and depression (Kydd, Reid and Adams 2010). Some women also experience a range of psychosexual issues including body image disturbance, perceived loss of femininity and attractiveness, and decreased sexual desire and/or sexual pleasure (Archibald et al. 2006, Bertero and Wilmoth 2007, Garrusi and Faezee 2008, Maguire 2000, Tykkä Asko-Seljavaara and Hietanen 2002, Wilmoth 2001). Following mastectomy most women are eligible for breast reconstruction to minimise the effects of mastectomy. In the United Kingdom, approximately 21% of women elect for breast reconstruction (The National Mastectomy and Breast Reconstruction Audit 2011), although across all epidemiological studies uptake of breast reconstruction is less than 50% (Alderman, McMahon and Wilkins 2003). This may suggest that despite the assumed psychological benefits (Abu-Nab and Grunfeld 2007), in maintaining and improving body image, self-esteem, sexuality, anxiety and quality of life (Al-Ghazal et al. 2000, Ballard et al. 2015, Harcourt et al. 2003, Howard-McNatt 2013, Nano et al. 2005, Wilkins 2000), the majority of women do not elect for post-mastectomy breast reconstruction. However, the current psychological evidence base following post-mastectomy breast reconstruction is relatively limited and lags behind other integral time points of the disease, such as diagnosis and treatment. Therefore, this mixed methods thesis will allow for a comprehensive understanding of the psychosocial needs of woman following breast cancer surgery. The findings of this study will be used to identify the unmet needs of women following breast reconstruction and aim to strengthen the case for the development of interventions following breast cancer surgery.

1.3 Clinical Importance of the Research Questions

It is well established within the current literature that the psychosocial needs of women following post-mastectomy reconstruction are not fully met in terms of research, theory and practice (Armes et al. 2009, Eccles et al. 2013). Moreover, it is estimated that 30% of women with breast cancer have multiple unmet needs (Armes et al. 2007). The number of women undergoing mastectomy is increasing (Tuttle et al. 2007), and the overall number of breast reconstructions are also steadily increasing (Schmauss, Machens and Harder 2015). As a consequence, this research is both necessary and timely to identify and understand more fully the unmet needs of women following surgical treatment for breast cancer. It is hoped that through identifying outcomes of clinical importance this will positively impact the case for interventional development following breast cancer surgery within clinical practice.

1.4 Aims

This thesis aims to provide a comprehensive understanding of the psychosocial needs of woman following breast cancer surgery and post-mastectomy reconstruction. The thesis comprises of three interrelated studies:

Study	Aim
Study 1	The aim of this study is to identify factors which predict breast satisfaction, outcome satisfaction and quality of life following post-mastectomy breast reconstruction.
Study 2	The aim of this study is to explore breast reconstruction from a qualitative stance in relation to breast satisfaction, outcome satisfaction and quality of life.
Study 3	The aim of this systematic review and meta-analysis is to evaluate the efficacy of interventions on psychosocial outcomes following surgical treatment for breast cancer.

1.5 Thesis Summary

Each study within this thesis was developed in a coherent conceptually linked order. The first study focused on the psychosocial needs of women following post-mastectomy breast reconstruction, via a questionnaire based study. This study established a quantitative understanding of psychosocial factors which predict breast satisfaction, outcome satisfaction and quality of life. This study allowed for the identification of outcomes of clinical importance and informed the decision to explore satisfaction and quality of life from a qualitative stance. The second study allowed for a detailed account of experience to be captured and a greater understanding of the components involved in shaping postoperative outcomes. The third study evaluated the efficacy of interventions on psychosocial outcomes for women following breast cancer surgery with the view that the efficacy of such interventions may also be applicable to post-reconstruction outcomes.

1.6 Overview: Structure of the Thesis

Chapter 2: Research paradigms, epistemological, ontological and methodological considerations

This chapter considers the differing research paradigms, epistemological, ontological and methodological positions. The chapter discusses and provides justification for the use of the mixed methods paradigm and aligns the thesis with the biopsychosocial framework.

Chapter 3: A Review of Relevant Research and Theoretical Concepts

The chapter provides a narrative review of research and theoretical concepts considered in relation to breast cancer. This chapter establishes the unmet needs of cancer and breast cancer survivors and how recognition of these unmet needs led to the emergence of psycho-oncology. The chapter also discusses body image and theories of body image in relation to breast cancer and provides a historical perspective of breast reconstruction and discussion of its assumed benefits.

Chapter 4: Background

This chapter provides an understanding of the clinical aspects of breast cancer, alongside a brief consideration of psychosocial aspects, in order to allow for the discussion of the psychosocial impact of the disease in the following chapters of the thesis. Chapter 3 outlines relevant literature in relation to breast cancer classifications, treatments and breast reconstruction.

Chapter 5: A quantitative analysis of predictors of satisfaction and quality of life following post-mastectomy breast reconstruction

This chapter examines the factors which predict breast satisfaction, outcome satisfaction and quality of life following post-mastectomy breast reconstruction, through a retrospective cross-sectional questionnaire design. The findings of this chapter demonstrate psychosocial factors were able to predict a high percentage of the total variance for satisfaction and a moderate percentage for quality of life.

Chapter 6: A qualitative analysis of satisfaction and quality of life following post-mastectomy breast reconstruction

This chapter explores post-mastectomy breast reconstruction in relation to breast satisfaction, outcome satisfaction and quality of life, through a retrospective interview design and the application of template analysis. The findings of this chapter suggest women positively appraise their breast appearance and are often satisfied with the outcome of their reconstruction. The findings also suggest women's emotional functioning improves following reconstruction, although this is often accompanied with substantial deterioration in physical, sexual and social functioning.

Chapter 7: The efficacy of interventions to improve psychosocial outcomes following surgical treatment for breast cancer

This chapter presents a systematic review and meta-analysis of interventions following breast cancer surgery. The findings of the review demonstrate that cognitive behavioural therapy based interventions typically have ameliorative effects on depression, anxiety and quality of life.

Chapter 8: Discussion and Recommendations

This chapter draws together the findings from each of the three interrelated studies and provides a summary of the main findings. The chapter presents a theoretical framework of breast reconstruction and considers the implication of the findings on policy, practice and research, in order to provide recommendations for future research.

Chapter 2.0: Research Paradigms, Epistemological, Ontological and Methodological Considerations

2.1 Overview

This chapter discusses and evaluates research paradigms, epistemological, ontological and methodological positions of relevance to this thesis. The chapter considers the differing approaches to breast cancer care and aligns the thesis with the biopsychosocial framework (2.1). Chapter 2 discusses quantitative, qualitative and mixed methods paradigms in relation to their philosophical assumptions (2.2) and evaluates each of the research paradigms (2.3). The chapter also establishes a five-point rationale for employing a mixed methods approach (2.4) and provides justification for the epistemological position adopted (2.5). Chapter 2 concludes by providing an overview of the current chapter (2.6).

2.2 The Biopsychosocial Model and Its Application to Breast Cancer Care

The biomedical approach to healthcare has dominated healthcare research and practice (Wade and Halligan 2004). This approach draws upon biochemical components of health and illness and places limited emphasis on psychosocial components (Porter 1997). The biomedical model is derived from the theory of dualism (Engel 1977). Dualism positions the mind and body as separate entities which function independently from one another (Engel 1977). However, Engel (1977) offers a holistic alternative the biopsychosocial model, which assumes biological, psychological and social factors influence health and illness. This framework has become the cornerstone of contemporary health psychology (Adler 2009). The biomedical approach is often implemented in the United Kingdom within the National Health Service (NHS), despite this model placing limited emphasis on the psychosocial aspects of diagnosis and treatment (Porter 1997). This omission leaves a limited, arguably incomplete view of the experience of breast cancer. Furthermore, research examining psychological aspects of breast cancer receives limited funding. Consequently, some patients receive relatively little support in relation to the psychosocial impact of breast cancer and its treatments. This is particularly prevalent in relation to breast reconstruction (National Mastectomy and Breast Reconstruction Audit 2011), highlighting the need for psychology-based research within the biopsychosocial model. Moreover, contemporary literature demonstrates breast cancer patients have unmet psychosocial needs (Eccles et al. 2013, Jacobsen et al. 2016), with one study suggesting 30% of breast cancer patients report multiple unmet needs (Armes et al. 2007). As a consequence, a gradual subspecialty of oncology has emerged, psycho-oncology, with its own body of knowledge and tool-box of research methods which contribute to cancer care (Holland 2002).

This thesis is based on a biopsychosocial approach which considers biological, psychological, and social components and their complex interaction in understanding health, illness and healthcare delivery (Engel 1977, Borrell-Carrio, Suchman and Epstein 2004). This approach is holistic and addresses the complexity of interactions between different domains of functioning (Borrell-Carrio et al. 2004). The biopsychosocial approach is a dynamic, interactional, and a dualistic view of human experience with mutual influence of mind and body. The biopsychosocial approach guided key aspects of this thesis. For example, through the biopsychosocial framework the benefits of evaluating human experience through a mixed methods model and identifying a range of psychological, social, clinical and demographic characteristics was recognised. Moreover, this thesis further establishes the utility of the biopsychosocial framework in breast cancer research, policy and practice.

2.3 Research Paradigms

Research is influenced by underlying philosophical assumptions and these assumptions form a research paradigm. A research paradigm is a basic belief system and is interconnected by three dimensions ontology, epistemology and methodology (Guba 1990). Ontology concerns the nature of reality and is closely related to epistemology which reflects understanding (Dures et al. 2010). Ontology and epistemology both facilitate and constrain the methodological position adopted in this thesis (Dures et al. 2010). Often quantitative and qualitative research approaches are considered separate entities which are underpinned by contrasting epistemological and ontological assumptions (Dures et al. 2010). Typically, quantitative researchers assume a positivist stance and qualitative researchers a constructivist stance (Guo 2015). This thesis will consider the two predominant epistemologies of positivism and constructivism. Positivism assumes that there is one truth determined by objective reality which must be deductive and quantifiable in nature (Guba 1990, Newman 2002). Positivist's ontological assumptions are deeply rooted in direct realism the notion of '*real*' apprehendable reality (Guba 1990). Positivism assumes a dualist and objectivist epistemological stance (Guba 1990) and employs experimental/ manipulative methodology such as surveys and questionnaires in order to verify hypotheses (Aliyu et al. 2014). This epistemological position has been criticised as it presents a rigid belief of reality as a fixed entity (Aliyu et al. 2014). Therefore, a more critical approach emerged within the positivist paradigm, post-positivism (Lincoln & Guba 2003).

Post-positivism adopts a critical realist ontological position which assumes a "*real*" reality which is only imperfectly apprehendable (Guba 1990). Post-positivism ontology is often characterised as critical realism. The theory of critical realism infers reality must be subjected to critical examination in order to consider reality as closely as possible, yet never perfectly (Guba 1990). Post-positivism assumes a modified dualist and objectivist epistemological stance (Guba 1990). Therefore, post-positivism employs modified experimental/ manipulative methodology which includes some qualitative research methods for falsification of hypotheses (Aliyu et al. 2014). Both positivist and post-positivist paradigms seek to accumulate knowledge and provide both generalisations and cause and effect linkages (Guba and Lincoln 1994). Similarly, both paradigms strive for rigour, internal and external validity, reliability and objectivity (Guba and Lincoln 1994). In contrast, most qualitative researchers assume a constructivists stance which considers that there are multiple truths (Aliyu et al. 2014). Constructivists seek to accumulate authentic, informed and sophisticated accounts of experiences of a phenomenon (Guba & Lincoln 1994). Constructivism's ontological assumptions are rooted in relativism which assumes realities are local, specific and constructed (Aliyu et al. 2014). Constructivism also assumes a transactional and subjectivist epistemological stance and employs a hermeneutic and dialectical methodology including observational studies, individual interviews and focus groups (Aliyu et al. 2014, Guba 1990).

Traditionally, researchers assume a singular epistemological and ontological stance, which stipulates the type of approach and signifies that quantitative and qualitative paradigms are distinct entities, which cannot be integrated (Creswell and Plano Clark 2007, Sale, Lohfeld and Brazil 2002). However, today many researchers consider these approaches to run on an epistemological continuum (Creswell and Plano Clark 2007). Therefore, researchers adopt a pragmatic epistemological position as complex research questions require multiple modes of enquiry (Creswell and Plano Clark 2007). Mixed methods research is grounded on the notion that there are multiple ways of making sense of the social world and of what is important and valuable (Greene 2008). A mixed methods paradigm can be identified by distinct characteristics which if carefully considered can include the inclusion of both quantitative and qualitative methods and pragmatism as the philosophical underpinning (Denscombe 2008). This research design also requires researchers to specify the sequencing and priority given to the quantitative and qualitative elements of the research and the need to account for the manner in which the quantitative and qualitative elements are related (Denscombe 2008). This approach offers a logical and practical alternative from the traditionally dichotomised paradigms (Johnson and Onwuegbuzie 2004). Through methodological pluralism (the integration of quantitative and qualitative approaches) researchers are able to bridge the gap between quantitative and qualitative research methods.

2.4 Evaluation of Research Paradigms

Each research paradigm has strengths and weaknesses. The strengths and weakness of quantitative, qualitative and mixed methods research in relation to this thesis are discussed. Strengths of quantitative research methods include (1) the testing and validation of hypotheses and theories; (2) the capacity to make comparisons across groups and examine relationships between variables; (3) the ability to control for extraneous variables which allows for high levels of internal validity and reliability; (4) and the use of large sample sizes which allows for generalisability (Johnson and Onwuegbuzie 2004). However, weaknesses of quantitative research methods include (1) the oversimplification of the complexity of human nature; (2) which may result in detached and decontextualized data; (3) and a decrease in external validity (Janesick 1994). In addition to the potential neglect of important aspects of a phenomenon due to (4) the rigidity of theory or hypothesis testing (Johnson and Onwuegbuzie 2004).

Strengths of qualitative research methods include (1) the generation of rich in-depth data which is based on meanings and experience; (2) the provision of a contextualised approach to understanding a complex phenomenon (Johnson and Onwuegbuzie 2004); (3) which is likely to result in greater insight into healthcare systems and identification of opportunities and challenges within healthcare practice and policy (Guo 2015). Qualitative research is also inductive in nature, (4) which allows for qualitative research to be applied in circumstances when developing a standardised instrument is difficult, as a result of limited knowledge on a phenomenon (Patton 2002). Weaknesses of qualitative research methods include (1) their subjective and idiosyncratic nature, although this can be mitigated with a number of techniques for improving the validity of research including reflexivity, triangulation and transferability (Gough and Deatrick 2015). Other weaknesses include (2) the ability of the findings to be influenced by the personal biases and experience of the researcher, (3) and the limited capacity to generalise findings to other populations (Johnson and Onwuegbuzie 2004).

Strengths of the mixed methods approach include (1) the ability to draw upon the strengths and minimise the weaknesses of individual paradigms; (2) the allowance of shared assumptions; (3) the flexibility of the approach; (4) and the provision of a higher level of understanding and more robust findings through convergence and corroboration (Creswell and Plano Clark 2007, Johnson and Onwuegbuzie 2004). Weakness of the approach include (1) the extensive time, skill and resources required to implement the mixed methods approach; (2) and the challenges associated with the development of a sufficient epistemological '*fit*' between both the qualitative and quantitative components of the research (Creswell and Plano Clark 2007).

2.5 Rationale for a Mixed Methods Approach

Denscombe (2008) asserts the rationale for assuming a mixed methods approach and the manner in which the quantitative and qualitative elements are related should be explicitly stated to ensure transparency and high quality research. Creswell and Plano Clark (2007) suggest there are four major types of mixed methods design: triangulation, embedded, explanatory, and exploratory. Triangulation is used to obtain different but complementary data on the same topic, whereas embedded is used to describe one set of data as supportive and secondary (Creswell and Plano Clark 2007). Both explanatory and exploratory are two-phase designs. Explanatory allows for qualitative data to explain and/or build upon initial quantitative results, whereas exploratory allows for the results of the first qualitative element to develop or inform the second quantitative element (Greene et al.1989). Greene, Caracelli, and Graham (1989) also provide a mixed methods conceptual framework. This thesis adopts this framework in order to provide a clear rationale for the implementation of a mixed methods approach. Caracelli and collegues (1989) conceptual framework advocates five rationales for adopting a mixed methods approach: triangulation, complementarity, development, initiation and expansion. This thesis considers all five of the rationales as appropriate justification for the use of a mixed methods paradigm. Each of the five rationales will be discussed in turn:

Firstly, from a theoretical perspective mixed methods research allows for multiple ways of making sense of the complex world and multiple standpoints on what is important and valuable (Greene 2008). Consequently, **triangulation** of both qualitative and quantitative approaches enables behaviour to be measured and understood through both objective testable reality and subjective multiple realities, maximising the strengths of individual paradigms (Lewin, Glenton and Oxman 2009). This provides a rationale for employing a mixed methods approach, as this thesis provides a comprehensive understanding of the psychosocial needs of women following breast cancer surgery and post-mastectomy reconstruction.

Secondly, through the integration of the different paradigms, **complementarity** can be achieved allowing for clarification, illustration and interpretation of the results from one method with the results from the other, in order to create a more comprehensive view of the phenomenon and provide a subsequent rationale for adopting a mixed methods approach. Moreover, the implementation of a mixed methods approach supports National Service Frameworks (NSFs) policies set by the National Health Service (NHS). The NSFs assert care provided for cancer patients should be patient-centred and healthcare providers should seek to understand the needs and experiences of patients within cancer services (Department of Health 2001). Therefore, this thesis adopts a mixed methods paradigm and assumes a **complementarity** as the methods seek an understanding of different aspects of the same phenomena (Sale, Lohfeld and Brazil 2002).

Thirdly, this thesis assumes both paradigms are of equal status and employs a sequential explanatory design in order for the qualitative element of research to explain and **develop** the initial primary quantitative thesis data (Creswell 2003). Within healthcare research there is increasing recognition that our theoretical understanding of phenomena is dependent on rich in-depth data, which cannot always be derived from quantitative methodology (Al-Busaidi 2008). Moreover, health research funders are slowly welcoming qualitative research in order to give a voice to the patient experience (Gough and Deatrick 2015). However, it was considered important that the primary quantitative research of this thesis informed the aims and design of the qualitative research due to those (policy makers, healthcare professionals and some funders) who rely on medical, scientific and post-positivistic paradigms.

Fourthly, **initiation** refers to the discovery of paradox and contradiction, new perspectives or frameworks, and the recasting of findings from one method to another method. This thesis utilises the results from the primary quantitative research and employs novel qualitative methodology to allow for contradictory findings to be acknowledged and considered in the discussion of this thesis.

Finally, a mixed methods approach also allows for the breadth of the findings to be clarified and **expanded** upon. The utilisation of a mixed methods model enhances the contribution of this thesis by selecting the methods most appropriate for multiple components of inquiry. This thesis employs two quantitative studies to allow for empirical generalisations and a qualitative study to allow for an in-depth insight into experience, therefore providing a sense of both breadth and depth.

2.6 Epistemological Position

This thesis adopts a pragmatic post-positivist mixed methods approach. The post-positivism approach is an appropriate paradigm as this approach assumes "*real*" reality but only based on probable truth and may include qualitative research methods for falsification of hypotheses (Aliyu et al. 2014). This thesis assumes the qualitative and quantitative elements of a mixed methods approach run along a continuum and that certain methods may appear to sit further towards one end of the continuum than the other. This thesis includes a questionnaire study design which utilises standardised validated clinical measures and assumes a positivist approach, as the data collected was considered deductive, quantifiable and analysed by standardised statistical techniques. However, as breast cancer patients operate in a complex social world their responses should not be considered objective but rather interpreted with the consideration of socially constructed factors. This thesis also includes an interview based study which is post-positivist in nature, as it involves multiple representations of reality. Yet, this study also contains elements which lean towards the positivist end of the continuum, as the interview schedule is structured and guides the focus of the narrative in a certain direction. Moreover, the data analysis technique, template analysis involves a hierarchical structured coding system with *a priori codes* (King 2012), which assumes a realist position somewhat similar to mainstream quantitative psychology. Moreover, the suitability of template analysis within a mixed methods model has been well established (King and Brooks 2017), with mixed methods studies implementing this qualitative analytical method across a range of disciplines (Brooks and Youngson 2014, Green et al. 2014, Kelliher and Anderson 2010, Zikic and Richardson 2007). The thesis also includes a systematic review and meta-analysis, a quantitative form of research which is considered objective, replicable and comprehensive and predominately leans towards a positivistic approach to research.

2.7 Conclusion

This chapter sought to identify the different research paradigms and highlight the significant implications of paradigm selection at a practical level. This thesis applies a mixed methods model to examine psychosocial outcomes following post-mastectomy breast reconstruction and breast cancer surgery, as the consideration of multiple perspectives provides a more comprehensive understanding of this complex disease. This chapter also allows for the ontology, epistemology and methodology of the thesis to be explicitly discussed. The thesis assumes a pragmatic post-positivist mixed methods approach. Post-positivism underpins the mixed methods paradigm and acknowledges the benefits of incorporating subjective and objective approaches to portray a valuable interpretation of truth and reality.

Chapter 3.0: A Review of Relevant Research and Theoretical Concepts

3.1 Overview

The chapter provides an overview of research and theoretical concepts considered in relation to breast cancer. This chapter establishes the unmet needs of cancer and breast cancer survivors (2.1), and how recognition of these unmet needs led to the emergence of psycho-oncology (2.2). This chapter also discusses breast cancer in relation to body image and incorporates theories of body image within this discussion (2.3). Chapter 2 also considers the evolution of breast reconstruction and its assumed psychological benefits (2.4). This chapter provides a broad discussion of the history of psycho-oncology and breast reconstruction and considers salient issues and debates within the current field of psycho-oncology, in order to both contextualise and establish a rationale for the three empirical studies discussed later within this thesis. The chapter concludes by providing an overview of the current chapter (2.5).

3.2 The Unmet Needs of Breast Cancer Survivors

The number of people surviving cancer is increasing (International Agency for Research on Cancer 2012). Worldwide, the number of cancer survivors within five years of diagnosis was estimated to be 32.6 million in 2012, up from 28.7 million in 2008 (International Agency for Research on Cancer 2012). Breast cancer is the most common cancer in women worldwide with approximately with 1.67 million new cases diagnosed in 2012 (Ferlay 2014), contributing to approximately 25% of all cancers (International Agency for Research on Cancer 2012). Breast cancer has one of the highest survival rates (Cancer Research UK 2014). In the United Kingdom the number of breast cancer survivors is increasing and is expected to reach approximately 4 million by 2030 (Maddams, Utley and Moller 2012). Mullan (1985) proposed a model of cancer survivorship which establishes three stages of survival: the transition from diagnosis to the end of treatment (acute survival/1), from observation to surveillance (extended survival/3), and towards permanent survival (long term disease free survival/5). Mullan’s (1985) model of the seasons of survival was one of first articles to describe the natural history of cancer survivorship, although in light of the increasing number of cancer survivors and the practical issues of healthcare delivery a relatively recent revision to the model has been proposed. Miller, Ben-Aharon and Haines (2011) proposed the inclusion of two additional stages: the time from treatment completion to return to normal functioning (transitional survival/2) and to the transition to living with cancer (chronic survival/4). Nevertheless, despite the seminal advances in cancer detection and treatment breast cancer survivors still report experiencing physical, social and psychological issues following treatment (Allen, Savadatti and Levy 2009, Armes et al. 2009, Cardy et al. 2015, Corner et al. 2013, Pauwels et al. 2013, Richards, Corner and Maher 2011). This is further demonstrated by research which suggests a greater number of cancer survivors experience poor health and wellbeing in comparison to those who have not had cancer and those who have other serious chronic conditions (Elliott et al. 2011, Khan et al. 2011).

Commonly cited unmet needs of breast cancer survivors include the fear of recurrence (Allen, Savadatti and Levy 2009, Glaser et al. 2013), which may be triggered by physical symptoms and may also lead to anxiety, depression and psychological distress (Ganz et al. 1996, Northouse 1989). Physical symptoms also include fatigue, loss of energy, lymphedema (Coleman 2000, Jack, Davies & Moller 2009, Macleod et al. 2000, National Cancer Intelligence Network 2014), hormonal changes and menopausal symptoms (Cappiello et al. 2007, Cimprich et al. 2005, Oxlad et al. 2008). These difficulties often occur alongside changes in sexual functioning, which include decreased libido (Cappiello et al., 2007, Griggs et al. 2007, Kantsiper et al. 2009, Oxlad et al., 2008), changes in physical appearance and body image difficulties (Cappiello et al. 2007, Cimprich et al. 2005, Griggs et al. 2007, Kantsiper et al. 2009, Oxlad et al. 2008), which may also lead to intimacy and relationship difficulties (Cappiello et al. 2007, Griggs et al. 2007, Kantsiper et al. 2009, Oxlad et al. 2008). The effects of breast cancer and its subsequent treatments are far-reaching and have the ability to impact on a women’s physical, social and psychological wellbeing. Therefore, a broad range care services and support are required to assist women to manage these effects (Carey et al. 2012). However, research demonstrates that approximately 30% of cancer patients have five or more unmet needs at the end of their cancer treatment and 20% of patients continue to have more than five unmet needs six month following treatment completion (Armes et al. 2009). Moreover, a recent analysis suggests breast cancer survivors report more unmet needs than survivors of other types of cancer including prostate, colorectal, bladder, uterine and skin melanoma (Burg et al. 2015). Following breast cancer women report specific concerns in relation to the fear of recurrence and death (Ziner et al. 2012), altered social support (Sammarco 2001), psychological difficulties (Sherman, Rosedale and Haber 2012), work and financial difficulties (Shewbridge, Wiseman and Richardson 2012), body image difficulties (Harcourt and Rumsey 2008), and altered relationships with healthcare professionals (Corner et al. 2013). In recognition of the multiple challenges most people experience around cancer, a gradual subspecialty of oncology has emerged, psycho-oncology with its own body of knowledge and tool-box of research methods which contribute to cancer care (Holland 2002).

3.3 The Emergence of Psycho-Oncology

Psycho-oncology began formally around the mid-1970s and is a multi-disciplinary field of practice which involves the psychological, social and behavioural dimensions of cancer (Bultz 2016, Watson, Dunn and Holland 2014). Psycho-oncology contributes to the clinical care of patients and families, to the training of staff in psychological techniques and to collaborative research that ranges from the behavioural issues in cancer prevention to the management of mental health conditions and the psychosocial difficulties throughout the cancer trajectory (Holland 1998, Watson, Dunn and Holland 2014). The contributions to psycho-oncology from psychiatry, behavioural medicine, health psychology, social work, nursing, oncologists, ethicists and patients have developed a richness and a significant range of information and theoretical models and approaches (Holland 2002). It is important to note that the number and range of disciplines that contributes to psycho-oncology alludes to the breadth of issues involved in understanding and treating the psychosocial difficulties associated with cancer patients and their families (Holland 2002). The emergence of psycho-oncology is interesting because it has produced a model in which the psychological domain has been integrated, as a subspecialty, into the disease specific specialty of oncology. It is important to understand the historical underpinnings of psycho-oncology as this continues to colour contemporary attitudes and beliefs in relation to cancer and the associated psychosocial comorbidity.

In the 1800s, a diagnosis of cancer was unusual and the likelihood of reaching survival or long term disease free survival was limited, as effective treatments were not available (Holland 2002). Subsequently, extension of life was often the sole focus of cancer care (Bultz 2016). During this period cancer was a disease surrounded by the unknown and stigma, and synonymous with death, pain and suffering (Bultz 2016). The stigmatisation of those diagnosed with cancer was particularly prevalent for those with cancer of the sex organs, specifically cancers of the breast and genitalia, as these cancers were thought to be sexually transmitted (Watson, Dunn and Holland 2014). Subsequently, the psychological and emotional implications of cancer were concealed like the cancer itself (Holland 2002). In the 1950's researchers began to consider the psychological reactions to cancer, later in the 1960s and 1970s the development of patient advocacy groups and particularly breast cancer advocacy groups, politicised the cancer agenda as a health, education and equality issue (Watson, Dunn and Holland 2014). This alongside the behavioural medicine movement in the late 1970's promoted an awareness and a research focused approach of the psychological and emotional difficulties associated with cancer (Holland 2002). During this period, health psychologists provided novel and valuable research with the development of theoretical models of coping and the assessment of the effectiveness and efficacy of these models, e.g. cognitive-behavioural models (Watson, Dunn and Holland 2014).

In the United Kingdom, during the 1980's psychological medicine units were established at the Royal Marsden Hospital in London and Sutton and the Christie Hospital in Manchester (Watson, Dunn and Holland 2014). At this time, there was also increased importance placed on developing psycho-oncology as a specialism and this was achieved by the establishment of professional societies, which include the British Psychosocial Oncology Society in 1982, and the American Psycho-Oncology Society and International Psycho-Oncology Society in 1984. There are now approximately 36 societies throughout 30 countries, which in 2007 united to form the Federation of Psychosocial Oncology, with almost 6,000 members (Grassi & Watson, 2012; IPOS, 2010 – 2013). In the 1990's academic journals were established, e.g. Psycho-Oncology and the Journal of Psychosocial Oncology, allowing for dissemination of clinical research in psycho-oncology. The publication of evidenced based research supported the advancement of the field of psycho-oncology and was central in the acceptability of psychological treatment in cancer care (Watson, Dunn and Holland 2014).

In the early 20th century the possibility of a cure for cancer emerged, derived from further innovations in surgery and anaesthesia, and the introduction of effective radiation therapy and chemotherapy (Watson, Dunn and Holland 2014). Therefore, this increased the likelihood of cancer patients achieving long term disease-free survival. However, despite improved survival rates mainstream, oncology care often failed to successfully address patient's psychological and social needs (Bultz 2016). Therefore, patients assumed control of their own care, and eventually this escalated into a high profile, financially resourced self-help movement, through personal donations and a significant number of charities such as Cancer Research UK and Macmillan, focusing on provision of psychosocial care for cancer patients. Subsequently, healthcare providers could no longer overlook patients unmet psychosocial needs (Watson, Dunn and Holland 2014).

Today, cancer care acknowledges the psychological and social implications of the disease and seeks to provide psychosocial support to cancer patients (Bultz 2016). Subsequently, standards for psychosocial care are being established in the developed world (Grassi and Watson, 2012). The World Health Organization declaration that there can be no health without mental health (Chisholm 1950), can be considered as a driver for the endorsement and development of comprehensive whole patient care. However, the inclusion of psycho-oncology into mainstream cancer care remains varied and in many countries limited, with continued adherence to a predominantly biomedical approach in many areas of the world (Bultz 2016). Subsequently, shifting from a biomedical model to a comprehensive biopsychosocial model of care remains a significant challenge within oncology (Bultz 2016). Yet, this relatively new subspecialty of oncology in some regions of the world is gradually growing into a core service, helping to alleviate the symptoms of cancer and enhance quality of life throughout the cancer trajectory (Bultz 2016). Within the field of psycho-oncology future challenges include the need to acknowledge that behavioural and mental health services are significant component in providing comprehensive cancer care and that multi-disciplinary care is the optimal model for ensuring the needs of patients are sufficiently and adequately met (Watson, Dunn and Holland 2014).

3.4 Breast Cancer, Body Image and Theories of Body Image

A distressing but often under-recognised aspect of breast cancer is the associated change in physical appearance (White and Hood 2011). Chemotherapy presents challenges including hair loss, weight fluctuation, skin and fingernail discolouration and hot flushes associated with early-onset menopause (Notari et al. 2017, White and Hood 2011). Radiotherapy which may be administered alone or in combination with chemotherapy, can also cause skin reactions and discolouration and the potential for gradual progression of long-term neurological changes (Lundstedt et al. 2011). Hormone treatments present further difficulties including treatment-induced weight gain and hot flushes (White and Hood 2011). These multifactorial negative bodily changes are often out of the patients' control, particularly in terms of the extent of the severity or the adverse impact (Tacon et al. 2011). In recent years, increasing importance has been placed on understanding body image issues among cancer patients (Silva, Moreira and Canavarro 2012), and particularly among breast cancer patients in relation to surgical intervention and the visible difference this may cause (Harcourt and Rumsey 2008). Surgical intervention is the first line of treatment for nearly all women with breast cancer, achieved by breast conservation surgery or mastectomy (Sivell et al. 2011).

Breast cancer surgery involves the partial or complete loss of one or both breasts and this may result in poorly aligned breasts, breast asymmetry, extensive scarring, alteration to breast and/or nipple sensation, the requirement for a breast prosthesis, possible changes to limb mobility and lymphoedema (Andersen and Johnson 1994, Collins et al. 2011, Crane-Okada et al., 2008, Swenson et al. 2002, Vadivelu, Schreck and Lopez 2008). All of which may contribute to negative connotations of body image following breast cancer surgery.

Body image refers to the mental representation of one's physical appearance (Cash 2004), whereby negative thoughts and feelings related to one's body suggest a disturbance of body image and lead to dissatisfaction with one's self (Stokes and Frederick-Recascino 2003). In accordance to Cash's (2011) conceptualisation of body image is a multidimensional construct that encompasses both perceptual experiences and subjective attitudes toward the body. However, altered body image may occur when unnatural or unexpected changes in self-concept occur (Wassner 1982). There are three main theories in relation to the development of altered body image and these include: the body image care model (Price 1990), the fear avoidance model (Newell 1999) and models with defining stages of adjustment, namely the life transition model (Selder 1994) and grief model (Kubler-Ross 1969).

The body image care model focuses on how we experience our bodies and our reaction to how others regard us (Price 1990). The model identifies three related body image components: *body reality* which refers to the body as it is physically, *body ideal* which refers to our desired body image and *body presentation* which refers to the body as it is presented to others (Price 1986, Price 1990, Price 1995). In accordance to the body image care model when all three components are balanced self-esteem is supported (Price 1986, Price 1990, Price 1995). Moreover, within this model *normal* body image is represented when all three components are balanced through the environment, coping strategies and social support networks (Price 1986, Price 1990, Price 1995). For example, *normal* body image may be maintained through adaptation, where individuals accommodate changes to the body (e.g. breast cancer), to the body ideal (e.g. norms of appearance and aesthetic expectations of others) and to body presentation (e.g. prostheses and surgical reconstruction). However, it is important to note a change (e.g. breast cancer), does not necessarily constitute a state of altered body image, as altered body image only occurs if adaptation is not possible and this is represented as unbalance between the three components (Price 1986, Price 1990, Price 1995). Therefore, as the three components of body image are not balanced self-esteem is not supported and interaction with the environment is dysfunctional (Price 1986, Price 1990, Price 1995). The body image care model assumes that the starting point for body image is satisfactory, although this assumption is problematic as a result of the individual nature of body image (Newell 1999). Subsequently, Newell (1991) proposed an alternative model of altered body image, the fear avoidance model. In accordance to the fear avoidance model altered body image occurs if there is a conflict between fear and avoidance of the altered body area (fear of the changed body) and reassurance-seeking behaviour (fear of the reactions of others) (Newell

1991). The fear avoidance model comprises of a further four components: life events, the history of body image change, personality and body image coping strategies (Newell 1991). These components combine to establish the psychological and social context in which confrontation or avoidance behaviours result (Henderson 2006, Newell 1991).

Theorists have also proposed models with defining stages of adjustment, specifically the life transition model (Selder 1994) and grief model (Kubler-Ross 1969). The life transition model (Selder 1994) describes the restructuring of reality to accommodate and resolve uncertainty during altered body image to allow for the eventual acceptance of body image. This model was further developed by Atkinson (2002) who established three stages of experience; disrupted reality, uncertainty and restricting of reality or acceptance. However, these models are simplistic and do not consider the possible influences of expectations and social support (Henderson 2006). Subsequently, Norris and Stockard-Spelic (2002) developed the reimaging model. This model encompasses three components; body image disruption, wishing for restoration and reimaging of the self (Norris and Stockard-Spelic 2002), although in contrast to Selder's (1994) model, the reimaging model considered social support, individual values and life experience (Henderson 2006). An alternative model with defining stages of adjustment is the grief model (Kubler-Ross 1969). This model defines five stages of grief; denial, anger, bargaining, depression and acceptance. The grief model assumes that those who do not grieve are in denial or engaging in avoidance behaviours (Kubler-Ross 1969). However, a critic of the grief model has argued that grief is a form of natural human resilience, rather than an abnormal response which requires treatment (Bonano 2004). Therefore, as a result of resilience it may be possible to experience altered body image with limited psychosocial implications.

3.5 A History of Breast Reconstruction and its Assumed Psychological Benefits

Altered body image as a result of surgical treatment following breast cancer demonstrates significant emotional and psychological challenges (Rumsey and Harcourt 2005). However, breast reconstruction may minimise the effects of surgical treatment and help patients to recover an acceptable body image and establish psychological wellbeing (Oiz 2005). The benefits of mastectomy has been evident for many years, yet it is only relatively recently that reconstruction has been recognised as an achievable outcome and incorporated into mainstream surgical practice (Rozen et al., 2009). Early attempts of autologous reconstruction were often deemed unsuccessful and were associated with substantial scarring and morbidity (Bostwick 1990, Rozen et al., 2009). Subsequently, this led to an array of prosthetic options and in the early 1960's silicone implants were introduced and revolutionised the field of plastic and reconstructive surgery (Bostwick 1990, Cronin and Gerow 1963). Yet, despite the incorporation of prosthetic techniques reconstruction still involved extensive surgical morbidity and this contributed to poor aesthetic outcomes (Harcourt and Rumsey 2001). As a consequence, in the early 1980's implant reconstructions reduced in popularity in favour of tissue expanders (Radovan 1982). A tissue expander is an inflatable breast implant which stretches the skin and muscle to later allow for a permanent implant. However, there have been significant advances in the design of implants and the availability of different shapes, textures and consistencies (Rozen et al., 2009). There have also been significant advances within plastic and reconstructive surgery which allowed for a revival of autologous techniques (Rozen et al., 2009). Today, it is common practice for implants to be used in conjunction with autologous techniques (Harcourt and Rumsey 2001), in order to provide an acceptable result, low morbidity and a satisfactory aesthetic outcome.

However, regardless of the surgical technique breast reconstruction remains a substantial and complex surgical procedure and may involve a series of operations in order to achieve a satisfactory outcome (Harcourt and Rumsey 2001). Recent advances in plastic and reconstructive surgery are widely publicised and may increase the pressure for those opting for surgical treatment to seek further revisions (Hansen and Clarke 2008, Harcourt and Rumsey 2008). This may be particularly prevalent within the breast cancer population, due to the availability and range of surgical and corrective procedures, including nipple-areolar complex reconstruction and tattooing. In the United Kingdom, care is often constructed around biomedical procedures which are designed to modify appearance, (e.g. breast reconstruction to alleviate the effects of mastectomy), and this based upon the implicit assumption that if aesthetic appearance improves, psychological wellbeing and quality of life will also improve (Harcourt and Rumsey 2008). However, this approach may not account for the multifaceted nature of adjustment following surgical treatment for breast cancer (Harcourt and Rumsey 2008, Moss and Rosser 2008). As a consequence, electing for post-mastectomy breast reconstruction may afford significant physical and psychological benefits, but also the possibility of physical and psychological morbidity (Rumsey and Harcourt 2005). Subsequently, a number of models have been designed to demonstrate the development of body image distress following cancer treatment. Fox and Corbin (1989) advocated that physical self-worth can be divided into four domains; body attractiveness, physical strength, physical conditioning and physical competence. Breast cancer and its subsequent treatments may effect of all the four domains which contribute to the physical self-perception profile (Fox and Corbin 1989).

An alternative model which has also been applied to understand body image distress in relation to cancer is the self-discrepancy theory (Higgins 1987). The self-discrepancy theory suggests that self-concept is a relationship between actual and ideal state representations (Higgins 1987). The self-discrepancy theory proposes that there are three domains of self: the 'actual self', the 'ideal self' and the 'ought self' (Higgins 1987), similar to Price's (1986, 1990, 1995) body image care model. The 'actual self' reflects ones perceptions of attributes and characteristics (Higgins 1987). This is particularly relevant in the context of body image as it is well documented that people often misperceive the shape and size of their own body (Vartanian 2012). In addition to the actual self, Higgins (1987) describes the 'ideal self' which refers to the attributes one would like to possess or aspires to possess and the 'ought self' which reflects the attributes that one believes they are obligated or have a duty to possess. The self-discrepancy theory also proposes that these selves can be conceptualised from one's own perspective and from the perspective of significant others (Higgins 1987). Breast cancer and its subsequent treatments may increase the discrepancy between how one would like to appear and how one actually is (Przezdziecki et al. 2013). A prolonged state of high discrepancy could manifest in body image distress (Higgins 1987).

3.6 Conclusion

This chapter provides a narrative review of current research and theoretical concepts considered in relation to breast cancer. The chapter describes models of cancer survivorship in order to consider common unmet needs of cancer survivors, such as psychological and body image difficulties and the fear of recurrence. This chapter's initial consideration of the unmet needs of breast cancer survivors also allows for the discussion of the emergence of psycho-oncology, which provides a biopsychosocial perspective to cancer care. The chapter also discusses body image and theories of body image in relation to breast cancer, specifically the body image care model, the fear avoidance model, the life transition model and grief model. Finally, the chapter concludes by providing a historical perspective of breast reconstruction and discussion of its assumed psychological benefits.

Chapter 4.0: Background

4.1 Overview

The previous chapter discusses the epistemological, ontological and methodological position of this thesis. This chapter situates the research in the field of oncology with a specific focus on clinical aspects of breast cancer. The discussion of clinical aspects alongside a brief consideration of psychosocial aspects provides the reader with an understanding of the disease and allows for a fuller discussion of the psychosocial impact in the following chapters. Chapter 3 commences by exploring types of breast cancer (3.2) and treatment modalities (3.3). This chapter considers breast reconstruction, specifically the timing of breast reconstruction (3.4) and the types of reconstruction (3.5). The chapter also acknowledges the physical and psychosocial impact of the disease, treatments and reconstructive procedures. The chapter concludes by emphasising the complexity of the disease and its subsequent psychosocial impact (3.6).

4.2 Breast Cancer and Classifications

Breast cancer is an uncontrolled growth of breast cells and is often classified into two types: non-invasive and invasive (World Health Organization 2003). Non-invasive breast cancer refers to an absence of visible cancer cells beyond the basement membrane, therefore cancer cells are confined solely to the lobules and ducts (Narod and Rakovitch 2014). Often non-invasive breast cancer is classified on appearance after examination under the microscope, as either ductal carcinoma in situ (DCIS) or lobular carcinoma in situ (LCIS) (World Health Organization 2003). DCIS refers to abnormal changes in the cells lining the milk ducts of the breast, these abnormal cells are confined to the milk ducts channels (Cancer Research UK 2015). Often DCIS is classified into three groups: low, intermediate and high grade and is based on the resemblance of the cells in the DCIS to the normal cells lining the milk ducts (Dixon 2010). LCIS refers to an abnormality contained inside the inner lining of the breast lobules and this increases a person's risk of developing invasive breast cancer later on in life (Cancer Research UK 2015, Dixon 2010). Invasive breast cancer is cancer that has moved beyond the membrane of the lobule or duct into the surrounding breast tissue. Invasive cancers have the ability to spread locally in the breast, entering lymph channels and spreading to lymph glands. Sometimes, invasive cancer cells may enter the blood stream either from the lymph nodes or by direct growth into blood vessels in the breast. Once invasive cancer has entered the bloodstream they can spread to any part of the body. Approximately 85% of invasive breast cancer cases involve invasive ductal carcinoma (IDC) or invasive lobular carcinoma (ILC). The remaining 15% of cases include rarer forms of breast cancer with specific differentiation and are classified by the type of tumour: tubular, cribriform, mucinous/mucoid, papillary, medullary, and metaplastic (Barquet-Muñoz et al. 2015).

4.3 Breast Cancer Treatment

Breast cancer is not a single disease but composed of distinct subtypes and each subtype is associated with different clinical treatments and outcomes (Polyak 2007). The primary aim of breast cancer treatment is to reduce the risk of premature death by removing or ablating the tumour (The National Mastectomy and Breast Reconstruction Audit 2011). Surgical intervention is the first line of treatment for nearly all women with breast cancer, achieved by breast conservation surgery or mastectomy (Sivell et al. 2011). Breast conservation surgery is the preferred treatment for patients with early stage breast cancer (Cabioglu et al. 2005). This surgery involves removal of the tumour by a lumpectomy or the removal of a quarter of the breast tissue by a quadrantectomy (Cancer Research UK 2015). Mastectomy refers to the removal of the whole breast (Cancer Research UK 2015). Contemporary literature indicates lumpectomy patients report fewer surgical complications (wound complications, bleeding and infections) (Chatterjee et al. 2015), and a higher quality of life than mastectomy patients (Chow et al. 2016). However, breast conservation surgery is not recommended for all patients and is dependent on the size, location and pathological features of the tumour (Contant et al. 2000). Therefore, in some cases mastectomy may be preferable.

In England, approximately 4 in 10 women with breast cancer opt for a mastectomy (The National Mastectomy and Breast Reconstruction Audit 2011). There are different types of mastectomy and each procedure detailed progressively becomes more invasive in nature. A simple mastectomy refers to only the removal of the breast tissue. A modified radical mastectomy involves the removal of the breast tissue and lymph nodes. A radical mastectomy refers to the removal of the breast tissue, lymph nodes and the underlying chest wall muscles. A skin-sparing technique may also be used during a mastectomy in order to preserve as much skin as possible. In addition, a sentinel node biopsy is often performed alongside a mastectomy to allow for the adequacy of surgical treatment to be determined and to test if the cancer cells have metastasised to the lymph nodes or blood vessels (Graham et al. 2014). If metastasis is confirmed this would suggest the need for additional adjuvant treatment (postoperative) to ensure the optimisation of surgical procedures (Graham et al. 2014).

Other cancer treatments include radiation therapy, chemotherapy and endocrine therapy. Radiation therapy is a course of treatment which involves high-energy radiation to destroy cells in the body (Macmillan Cancer Support 2013). This treatment can be used in a preoperative setting as a neoadjuvant treatment and in a postoperative setting as an adjuvant treatment (Cancer Research UK 2015). The primary aim of neoadjuvant therapy is to allow for surgical intervention by reducing the tumour size (Kaufmann et al. 2006), whilst adjuvant therapy aims to reduce the likelihood of recurrence and to prolong disease-free and overall survival (Sainsbury 2003). Radiation therapy is known to reduce the incidence of distant metastases and improve survival through controlling loco-regional recurrence, the reoccurrence of cancer in the same breast (Overgaard, Hansen and Overgaard 1997, Overgaard, Jensen & Overgaard 1999). Many radiation patients experience frequent and debilitating side effects including fatigue (Reidunsdatter et al. 2010), with a third of patients reporting depressive symptoms and more than a quarter demonstrating signs of distress (Luutonen et al. 2011).

Chemotherapy utilises one or more chemotherapeutic agents and is administered either intravenously or orally into the blood stream to disrupt the growth of cancer cells (NCCN Clinical Practice Guidelines in Oncology 2011). Chemotherapy can be used as neoadjuvant and adjuvant treatment (Cancer Research UK 2015). Chemotherapy is known to be efficacious in prolonging survival for individuals with breast cancer (National Institute of Health 1985: 2001). However, long term side effects associated with chemotherapy include cardiac toxicity, secondary leukemia, impaired cognitive function, and neurotoxicity (Azim et al. 2011). Chemotherapy patients also report a range of moderate to severe side-effects including fatigue, anxiety, pain, nausea and vomiting, mood changes, depression, lack of appetite, dyspnoea, changes in skin and nails, oral sores, numbness in the hands and adverse effects on fertility in younger patients (Akin and Durna 2013, Cramarossa et al. 2013, Hutter et al. 2013, de Pedro, Otero and Martín 2015).

Endocrine therapies include ovarian ablation (removal of the ovaries) and ovarian suppression (suppression of the ovaries) (Sawesi, Carpenter and Jones 2014). Endocrine treatments can be used as both neoadjuvant and adjuvant treatment options (Cancer Research UK 2015). However, this treatment is only suitable for tumours which are estrogen receptor positive (ER positive breast cancer) and for pre-menopausal women (Sainsbury 2003). Ovarian ablation allows for an immediate and permanent reduction in ovarian hormone production, which results in menopause (Bines, Oleske and Cobleigh 1996, Goodwin et al. 1999). Ovarian ablation is associated with osteoporosis and an increased risk of heart disease (Bines, Oleske and Cobleigh 1996, Goodwin et al. 1999). Ovarian suppression reduces oestradiol concentrations to postmenopausal levels (Furr 1989), allowing for a reliable and potentially reversible suppression of ovarian estrogen production (Sainsbury 2003). Other endocrine treatments include tamoxifen and aromatase inhibitors. These treatments inhibit either estrogen action (tamoxifen) or the aromatase enzyme (aromatase) and are known to minimise disease recurrence and mortality rates (Mates et al. 2015, Nekhlyudov et al. 2001), in both premenopausal and postmenopausal women (Johnston and Dowsett 2003).

4.4 Breast Reconstruction

The removal of the breast can create a sense of loss and a feeling of dissonance between the self and body image (Rosenblatt 2006), as the breast represents femininity, sexual identity and nurturing obligations (Crompvoets 2006). Breast reconstruction may minimise the effects of mastectomy and help patients to recover an acceptable body image and re-establish psychological wellbeing (Oiz 2005). In the United Kingdom, most women are eligible for breast reconstruction following mastectomy and some women are eligible following breast conservation surgery if a large amount of breast tissue has been removed (Macmillan Cancer Support 2015). Post-mastectomy options to reconstruct the breast mound include using an external prosthesis or undergoing breast reconstruction surgery. An external prosthesis is an artificial breast form which sits inside the bra to create the illusion of the breast (Piot-Ziegler et al. 2010). The prosthesis is held in place by the bra with or without a specially formed pocket or applied directly to the chest with adhesive strips (Wilkins 2016). Many women have reported the use of an external prosthesis as inconvenient and potentially embarrassing, with some women describing the prosthesis as difficult to keep in place, uncomfortable and limiting in terms of both clothing choice and physical activity (Tykkä, Asko-Seljavaara and Hietanen 2002). Moreover, the use of an external prosthesis can act as a daily distressing reminder of the disease (Schain et al. 1985). Breast reconstruction may provide an effective solution to the problems associated with the use of an external prosthesis.

Women may elect for breast reconstruction for a variety of reasons some of which include the desire to improve body image (Al-Ghazal, Fallowfield and Blamey 2000), and to restore feelings of wholeness and personal autonomy (Kocan and Gursoy 2016). Qualitative literature also suggests many women diagnosed with breast cancer feel too young to live without a breast (Gopie et al. 2011). Other reasons may include a reluctance to wear a limiting external prosthesis and the ability to wear a greater variety of clothing

(Korvenoja, Smitten and Asko-Seljavaara1998). The psychological benefits of breast reconstruction in preserving and improving body image, self-esteem, sexuality and quality of life are recognised in both research and practice (Ballard et al. 2015, Howard-McNatt 2013). However, as with all surgical procedures breast reconstruction is not without its risks. Common risks and possible side effects include rupturing or deflation of a breast implant, infection, loss of blood circulation to the transplanted muscle tissue, loss of sensation and movement difficulties (Clayton and Waller 1996, Nano et al. 2005, Roberts, Wells and Walden 1999).

Breast reconstruction may be carried out immediately at the time of mastectomy or delayed. Immediate breast reconstruction is a reconstructive procedure that starts at the same time as the mastectomy (Hu and Alderman 2007). A delayed reconstruction is a post-mastectomy reconstructive procedure which can be started any time after the wound has healed and/or adjuvant therapy administered (Hu and Alderman 2007). Factors which may influence the timing of reconstruction include pre-existing scars, a patient’s age and fitness, the size of the breasts and shape of the body, the stage of the disease, a patient’s personal preference and if adjuvant radiotherapy and/or chemotherapy is expected (Yang, Zhu and Yan 2015). Immediate breast reconstruction is considered a favourable option for women who have ductal carcinoma in situ (DCIS) or early breast cancer (Hu and Alderman 2007). There are multiple advantages to immediate breast reconstruction. Women who elect for immediate breast reconstruction have fewer surgical procedures which subsequently decreases the risks associated with breast reconstruction (Barry et al. 2014, Kontos et al. 2010), and also results in lower healthcare costs (Yang, Zhu and Yan 2015). Immediate breast reconstruction also allows the patient to recover from the mastectomy and breast reconstruction simultaneously, therefore reducing the overall recovery time and patient inconvenience (Yang et al. 2015). Women who elect for immediate breast reconstruction often report superior outcomes including body image, self-esteem, satisfaction and lower levels of distress than women who elect for delayed reconstruction (Al-Ghazal et al. 2000).However, the decision for immediate breast reconstruction is required quickly after diagnosis and this may place additional stress on women during the initial treatment decision making phase (Harcourt et al. 2003).

Disadvantages of immediate breast reconstruction include the potential delay of adjuvant therapy due to post-operative complications such as delayed wound healing and the potential for adverse breast reconstruction outcomes, such as capsular contracture from both neoadjuvant and adjuvant radiotherapy (Hu and Alderman 2007). Therefore, delayed breast reconstruction may be preferable for some women who have advanced breast cancer, medical comorbidities including the use of nicotine, morbid obesity and/or cardiovascular disease and the need for postoperative radiation, although the timing of reconstruction in relation to radiotherapy therapy is disputed (Hu and Alderman 2007). Delayed breast reconstruction also has a number of surgical advantages which include greater healing of the mastectomy site, a shorter operation and typically completion of radiotherapy and/or chemotherapy prior to reconstruction, which allows both surgeons and patients to consider their reconstructive options more accurately (Harcourt and Rumsey 2001). Moreover, women who elect for delayed reconstruction report lower complication rates in comparison with immediate reconstruction (Atisha et al. 2008). Furthermore, the psychological grief perspective proposes women require time to grieve and accept the loss of the breast in order to recover an acceptable body image (Klein, 1971, Winder and Winder 1985). This perspective is supported by The National Mastectomy and Breast Reconstruction Audit which suggests that 33% of women who elected for immediate reconstruction reported feeling disappointed at 12 months in comparison to 22% of women who opted for delayed reconstruction (The National Mastectomy and Breast Reconstruction Audit 2011). This would suggest delayed reconstruction may result in superior aesthetic results and/or psychosocial adjustment in comparison to immediate reconstruction. Disadvantages of delayed reconstruction include prolonging the overall treatment and recovery time, poorer cosmetic results with autologous reconstruction as the skin envelope is not preserved, and higher healthcare costs (Hu and Alderman 2007).

4.5 Types of Breast Reconstruction

Current methods of reconstructive breast surgery include implant reconstruction, autologous reconstruction (the use of skin, blood vessels, fat and sometimes muscle from another part of the body) and a combination of these procedures (Clayton and Waller 1996, Nano et al. 2005). Breast reconstruction can be achieved with the use of implants, tissue expanders and implants or with autologous tissues such as the latissimus dorsi flap (LD), transverse rectus abdominis myocutaneous (TRAM) flap, deep inferior epigastric artery perforator (DIEP) and superior gluteal artery perforator (SGAP). The short and long-term complication rates after implant breast reconstruction range from 18 to 51% (Berry et al. 2010, Delgado et al. 2010, McCarthy et al. 2009, Sullivan et al. 2008, Woerdeman et al. 2007), and after autologous breast reconstruction between 32 and 43% (Sullivan et al. 2008, Woerdeman et al. 2007). Implant reconstruction is considered a simpler surgical procedure with a shorter operative time, and offers no donor site morbidity and fewer scars compared to autologous reconstruction (Ceradini and Levine 2008). Autologous reconstruction is considered to provide a more '*natural breast*' in terms of softness, ptotic nature, texture and appearance (Ceradini and Levine 2008). However, autologous breast reconstruction leads to scarring on the reconstructed breast and donor-site (Stalder et al. 2015), and this may be a source of distress following reconstruction (Abu-Nab and Grunfeld 2007, Stalder et al. 2015). At present, disagreement exists within both research and clinical practice regarding the optimal method of post-mastectomy breast reconstruction (The National Mastectomy and Breast Reconstruction Audit 2011).

Implant reconstruction involves the use of prosthetic implants composed of a silicone elastomer envelope filled with either silicone-gel or saline (Bar-Meir, Eherenfeld and Shoenfeld 2003). Silicone based implants are considered to provide a superior aesthetic result, a more natural feeling and are less likely to rupture than saline filled implants (Bar-Meir, Eherenfeld and Shoenfeld 2003). Reconstruction can also be achieved with the use of tissue expanders and implants. A tissue expander uses an inflatable breast implant to stretch the skin and muscle to later allow for a permanent implant. This method provides donor tissues with a similar colour, texture and minimal scarring (Alani and Balalaa 2013). However, it is associated with a number of problems including infection, extrusion, expander displacement, pain on expansion, chest wall compression and difficulties of breast mound finalisation after expander removal (Eriksen and Stark 2006, Marangi et al. 2010). This method is also time and cost-consuming as several operations are required to achieve a satisfactory symmetrical result (Eriksen and Stark 2006), and the average lifespan of all breast implants is 15 years after which a replacement is required (Dixon 2010).

An alternative method of reconstruction is autologous reconstruction. Autologous breast reconstruction uses the patient's own tissue in two ways either a pedicle flap or free flap reconstruction. Pedicle flap reconstruction involves rotating a flap, comprised of skin, fat and usually muscle, from the patient's back or abdomen to the breast area, while keeping intact a tube of tissue containing its blood supply (The National Mastectomy and Breast Reconstruction Audit 2011). Free flap reconstruction involves a flap being completely detached from the body (usually from the abdomen, buttock or thigh) along with its supplying blood vessels. The flap is then placed at the mastectomy site and the blood supply restored by the joining of the vessels that supply the flap to vessels in the breast area (The National Mastectomy and Breast Reconstruction Audit 2011). The most common reconstructive techniques use tissue from the back (latissimus dorsi flap, LD) or abdomen muscle (transverse rectus abdominis myocutaneous flap, TRAM flap and deep inferior epigastric artery perforator, DIEP).

A LD flap reconstruction involves the transfer of the latissimus dorsi muscle, skin and fat from the upper back to reconstruct the breast mound (Baildam et al. 2007). This is a relatively simple surgical technique which allows for easy closure of the donor site and acceptable donor site function and cosmesis (Eriksen and Stark 2008, Kim, Bullocks and Armenta 2007, Muhilbauer and Olbrisch 1977). This technique has a high success rate and problems are relatively rare (Macmillan Cancer Support 2015). The LD reconstruction is considered a reliable and cost-effective technique (Chang et al. 2002). Nevertheless, there are disadvantages to LD reconstruction including donor site scarring, a contour defect on the back, a difference in skin colour between the back and the breast and the possibility of shoulder impairment (Baildam et al. 2007). An LD reconstruction can also be used with a breast implant to provide a more natural feel than an implant alone (Macmillan Cancer Support 2015).

A TRAM flap reconstruction involves the transfer of part of the rectus abdominus muscle, skin and fat from the abdomen to recreate the breast mound (Sandau 2002). A TRAM flap reconstruction is considered to offer a sizeable and natural breast mound and can produce excellent long term results (Baildam et al. 2007). However, some TRAM procedures may result in hernias and/or abdominal bulges, abdominal weakness, wound infection and delayed healing (Baildam et al. 2007, Clayton and Waller 1996). An alternative to the TRAM procedure is the DIEP procedure, which uses the blood vessels, fat and skin from the lower abdomen over the rectus abdominis muscle, although the DIEP procedure spares all of the abdominal muscle (Rozen and Ashton 2009). DIEP reconstruction is a relatively new technique and is often considered a superior option to other methods of autologous breast reconstruction, due to the preservation of the abdominal and back muscle (Blondeel et al. 1997, Futter et al. 2000, Hamdi, Weiler-Mithoff and Webster 1999). However, this method is inherently technical and complex, requiring a high level of surgical expertise, specialised training in dissection techniques and a significant operating period (Baildam et al. 2007). It is also possible to utilise skin and fat from the superior gluteal artery perforator (SGAP) for reconstruction. However, this type of procedure is extremely demanding and the failure rates are high (Baildam et al. 2007). Therefore, SGAP reconstruction is only used for women who are unsuitable for other types of surgery (Dixon 2010).

Following breast reconstruction nipple reconstruction may be performed as a separate procedure after the breast has stabilised, typically six to eight weeks following reconstruction (Hu and Alderman 2007). Nipple reconstruction involves the rearrangement of local skin flaps to create a projecting nipple (Ceradini and Levine 2008). Nipple projection decreases postoperatively and requires a 50% overcorrection at the time of surgery (Hu and Alderman 2007). The surrounding skin and reconstructed nipple may also be tattooed to match the areolar colour of the contralateral side in order to complete the breast reconstruction (Ceradini and Levine 2008). Satisfaction rates with nipple reconstruction and nipple tattooing are typically high (Clarkson et al. 2006), with one study reporting a satisfaction rate of over 71% (Harcourt et al. 2011). Nevertheless, some women may choose not to reconstruct the nipple or may prefer to use temporary adhesive nipples which allow for reconstruction with no further surgical procedures (Harcourt and Rumsey 2001).

4.6 Conclusion

This chapter provides an outline of the clinical and some of the psychosocial aspects of breast cancer. The chapter describes different types of breast cancer, non-invasive and invasive and also describes treatment options including surgical intervention, radiation therapy, chemotherapy and endocrine therapy. This chapter also discusses immediate and delayed reconstruction and autologous and implant based reconstruction. The chapter sought to situate the reader in the field of breast cancer to allow for the later understanding of the vast and complex psychosocial consequences of the disease and its surgical treatments. This chapter also highlights the need for a mixed methods model situated in the biopsychosocial framework to address the complicated and complex psychosocial nature of breast cancer. The following two chapters will consider psychosocial outcomes in relation to breast reconstruction using quantitative and qualitative methodology.

Chapter 5.0: Predictors of Satisfaction and Quality of Life following Post-Mastectomy Breast Reconstruction

5.1 Overview

The previous chapter situates the reader in the research area of breast cancer and provides an understanding of the disease and treatment modalities. This chapter moves beyond the contextualisation of previous literature and begins to focus on breast reconstruction, through the examination of the predictors of satisfaction and quality of life following post-mastectomy breast reconstruction. Chapter 4 begins introducing the reader to the topic area of breast reconstruction and key patient reported outcomes (4.2). The chapter details methodological considerations, specifically study design (4.3), procedure (4.4), demographic and clinical characteristics (4.5) study measures (4.6), and variable definitions (4.7). This chapter also reports the type of statistical analysis (4.8) and subsequent results (4.9). The chapter concludes with a discussion of the findings (4.10), strengths and limitations (4.11), clinical implications (4.12) and an overall conclusion of the chapter (4.13). A component of this research has been published in *Psycho-Oncology* and is displayed in Appendix 13 (Matthews et al. 2016).

5.2 Background

As noted previously, women with a history of breast cancer constitute the largest group of cancer survivors (Rowland et al. 2001). Improved survival rates have placed increased importance on promoting and supporting a high quality of life and optimal psychosocial adjustment among breast cancer survivors. The primary treatment for breast cancer is surgical (Rowland et al. 2001), consisting of either breast conservation surgery or mastectomy. The number of women electing for breast conservation surgery is increasing, although there is also a steady increase in the number of women electing for mastectomy (McGuire et al. 2009). This may be partially attributed to the incorporation of reconstructive options into mainstream breast cancer surgery. Post-mastectomy options include using an external prosthesis, undergoing breast reconstruction surgery or deciding to have no prosthesis or reconstruction. An external prosthesis is an artificial breast form moulded to imitate the natural shape of a woman's breast (Wilkins 2016). Many women have reported the use of an external prosthesis as relatively inconvenient describing the prosthesis as difficult to keep in place, uncomfortable and limiting in terms of both clothing options and physical activity (Tykkä, Asko-Seljavaara and Hietanen 2002). Breast reconstruction may provide an effective solution to the problems associated with the use of an external prosthesis.

The aim of breast reconstruction is to obtain the best aesthetic outcome and satisfy patients with respect to improvements in their psychosocial functioning (Benditte-Klepetko et al. 2014, Kronowitz et al. 2008). The patient in consultation with the surgeon must decide between the different methods of reconstruction (autologous or implant), and the timing of reconstruction (immediate or delayed). Women may also elect for additional surgery following reconstruction, such as nipple reconstruction, reshaping a flap, removing extra fat from a donor site or repositioning the implant (Begum et al. 2011). A more detailed explanation of the different types of reconstruction (i.e. 3.5) and timing of reconstruction (i.e. 3.4/5.2) is provided in this thesis. In the United Kingdom, the National Institute of Clinical Excellence recommends that breast reconstruction is offered to all women following mastectomy (Mayor 2009). In England and Wales, approximately 21% of women undergo breast reconstruction (The National Mastectomy and Breast Reconstruction Audit 2011). Internationally, breast reconstruction rates vary; the United States report rates between 25-59% (Elmore et al. 2012, Kruper et al. 2011), and Australia and Denmark report rates of 9% and 14%, respectively (Hall and Holman 2003, Hvilsom et al. 2011).

For many women, breast reconstruction is associated with psychological benefits including aesthetic satisfaction, psychological wellbeing, and positive effects on body image and self-esteem (Oiz 2005, Wilkins et al. 2000). Breast reconstruction may also help to strengthen the affective and sexual relationship of couples (Filiberti et al.1989), with one study suggesting breast reconstruction is one of the most important determinants of long-term health and wellbeing following breast cancer (Atisha et al. 2008). Furthermore, the National Mastectomy and Breast Reconstruction Audit (2011) demonstrated the positive effect of breast reconstruction on quality of life following mastectomy. These benefits have been observed for both immediate and delayed reconstructions (Benditte-Klepetko et al. 2014, Nissen et al. 2001) and across a number of procedures (Atisha et al. 2008). However, some studies have reported similar patient outcomes following breast reconstruction compared to breast conservation surgery or mastectomy alone (Parker et al. 2007), with one study reporting poorer psychosocial functioning and increased mood disturbance in patients who elected for reconstruction compared to mastectomy alone (Nissen et al. 2001). Complications with the reconstructed breast and abdominal problems have been identified as causes of dissatisfaction with breast reconstruction (Andrade, Baxter and Semple 2001). The type of breast reconstruction may also influence patient satisfaction, for example autologous reconstruction involves scarring of the breast and donor-site and donor-site morbidity (Contant et al. 2000).

In recent years, the external demands on medical and surgical treatments highlights the importance of patient satisfaction, particularly when patients are presented with more than a single viable surgical option. As the aim of breast reconstruction is to satisfy patients with respect to improvements in the appearance of their breasts and psychosocial functioning (Benditte-Klepetko et al. 2014, Kronowitz et al. 2008), patient satisfaction (which reflects the patient's assessment of the achievement of personal benefits of the procedure) is an important marker of surgical success following reconstruction. Patient satisfaction measures have been reported as a primary and useful source of feedback within healthcare services (Fingeret et al. 2013). Many patients report high levels of satisfaction following breast reconstruction (Fingeret et al. 2013). However, the value of distinguishing between satisfaction with the appearance of the breasts (e.g., size, shape, symmetry, softness and scarring) and satisfaction with the overall outcome (e.g., overall evaluation of surgery, expectations, and decision regret) is under-recognised within the field of psycho-oncology. Moreover, a primary rationale in the majority of healthcare interventions is the improvement in one or more aspects of a patient's quality of life. Yet, beyond the evidence that breast reconstruction is likely to be positively associated with satisfaction and improved quality of life, few studies have attempted to identify the key factors that are involved in determining levels of reported satisfaction and quality of life. For example, one study reported 93% of women were satisfied with their breast reconstruction but the reasons for their satisfaction were not explored (Noone et al. 1982). Satisfaction is often based on a range of factors and few studies distinguish between breast satisfaction and outcome satisfaction. Consequently, methodological issues of uniformly high levels of satisfaction and variability in outcomes have led many researchers to criticise the sensitivity of satisfaction measures and their ability to provide useful information (Avis, Bond and Arthur 1997, Williams, Coyle and Healy 1998).

As a consequence, this thesis employs the patient-reported outcome Breast Q measure (Pusic et al, 2009), and the associated conceptual model of satisfaction and quality of life in breast surgery patients (Klassen et al. 2009). These conceptual models allow researchers and clinicians to facilitate the distinction of breast satisfaction, outcome satisfaction and quality of life. This allows for important information to be obtained in relation to the impact and effectiveness of breast reconstruction from a patient’s perspective and delivers valid and reproducible data (National Mastectomy and Breast Reconstruction Audit 2011). Whilst this thesis employs the work of Pusic and colleagues (2009) and Klassen and colleagues (2009), it is also important to acknowledge other conceptual models of relevance to psychosocial adjustment of breast reconstruction. Rumsey and colleagues

(2008) present a conceptual model of psychosocial factors and processes which contribute to successful adjustment to disfiguring conditions, including cancer. This conceptual model explains the complex and multivariate nature of adjustment and reports that optimism, feelings of social acceptance, social support satisfaction, negative evaluation of others, salience and valence afforded to appearance and social comparisons contribute to predicting adjustment to disfigurement. Rumsey and colleagues (2008) conceptual model is undoubtedly of interest within the breast reconstruction population, however the validity of the Breast Q measure (Pusic et al, 2009) has been established within this population and therefore guides chapters 4 and 5 of this thesis. This study aims to identify the factors which predict breast satisfaction, outcome satisfaction and quality of life following post-mastectomy breast reconstruction.

5.3 Design

The present study used a cross-sectional retrospective questionnaire design, which examined predictors of breast satisfaction, outcome satisfaction, and quality of life following post-mastectomy breast reconstruction.

5.4 Procedure

Ethical approval was granted by a university ethics committee (P39039) and a local NHS trust committee (GF0095). Study eligibility criteria consisted of breast reconstruction following breast cancer patients, who were aged 18 and over with no breast cancer recurrence or palliative treatment. Eligible participants were identified from patient lists of two Consultant Plastic Surgeons based in one teaching hospital. In total, 263 women were identified as eligible. A postal questionnaire was administered to all eligible women, along with information regarding the purpose of the study, a consent form, an opt-out slip, and instructions on how to complete the questionnaire and two stamped addressed envelopes for the return of the questionnaire and consent form/opt-out slip. Two weeks after the initial postal administration, 71 women had responded. A further 192 second questionnaires and reminder letters were sent to those women who had not yet responded. One hundred forty-eight responders completed and returned the questionnaire (response rate: 56%). Responders were asked to provide consent to the release of their demographic details and relevant sections of their medical notes.

5.5 Participants

Cohen's (1992) power primer guidelines were applied to calculate an *a priori* sample size for the multiple regression analyses. In this calculation the anticipated effect size (f^2) =0.35 and the desired statistical power was set at .80, subsequently for a large effect size we aimed to recruit at least 66 participants. This figure was confirmed with G*Power, a tool to compute statistical power analyses (Faul et al. 2009). However, this is a conservative estimate and a larger number of participants were recruited for greater statistical power in order to detect any potential effect. Demographic and clinical characteristics of the sample are displayed in Table 1. Nine women did not provide consent for their details to be released, although did consent for their questionnaire data to be incorporated into the analysis. The mean age of participants was 55 years (SD = 8.70), with women aged between 32 and 76 years old and 84% of participants were White-British.

Table 1. Demographics and Clinical Characteristics of the Patient Group

Characteristics of clinical outcomes	Absolute value (% of women)		
Ethnicity	White British	124	3.8%
	White Other	3	2.0%
	White Irish	1	0.7%
	Black British	1	0.7%
	Indian	2	1.4%
	Other ethnic group	2	1.4%
	Not recorded	6	4.1%
Timing of breast reconstruction	Immediate reconstruction	103	74.1%
	Delayed reconstruction	36	25.9%
Type of surgery	Bilateral mastectomy	18	12.2%
	Left mastectomy	43	29.1%
	Right mastectomy	67	45.1%
	Not recorded	11	7.5%
Type of reconstruction	Dermal sling reconstruction	6	4.1%
	DIEP[1]	103	69.6%
	Implant	9	6.1%
	LD[2]	13	8.8%
	LD Implant	5	3.4%
	TDAP[3]	1	7.0%
	TE[4] and Strattice	1	7.0%
	TUG[5]	1	7.0%

Abbreviations: Deep Inferior Epigastric Perforator Flap (DIEP) [1], Latissimus Dorsi (LD) [2], Thoracodorsal Artery Perforator (TDAP)[3], Tissue Expander (TE)[4], Transverse Upper Gracilis[5]

5.6 Measures

The Breast Q Scale (reconstruction model): a validated patient-report outcome questionnaire which evaluates outcomes among women after breast reconstruction. The scale comprised 57 items divided into 5 modules: (1) satisfaction with breasts, (2) satisfaction with outcome, (3) psychosocial wellbeing, (4) sexual wellbeing, and (5) physical wellbeing. The validity and reliability of the Breast Q has been established within this patient population (Cano et al. 2012, National Mastectomy and Breast Reconstruction Audit 2011). The measure used a 4 point scale ranging from 1 (very dissatisfied/disagree/none of the time) to 4 (very satisfied/agree/all of the time). Scores were transformed using Q Score scoring software (Q Score Version 1.0). This software analyses data based on RUMM 2020, a data analysis program developed by Rasch Unidimensional Measurement Models Laboratory. This software automatically transforms raw data into total score ranging from 0 (very dissatisfied) to 100 (very satisfied).

The European Organisation for Research and Treatment of Cancer (EORTC QLQ-30) measure: a 30 item standardised, self-administered measure, which assessed health-related quality of life of cancer patients. The scale comprised 5 functional scales (physical, role, cognitive, emotional, and social), 3 symptom scales (fatigue, pain, and nausea), a number of single items, which assessed commonly reported symptoms of cancer patients (dyspnoea, loss of appetite, insomnia, constipation, and diarrhoea), and the financial impact of the disease. Items 1 to 28 ranged from 1 (not at all) to 4 (very much). Items 29 and 30 are single items, which assessed global health status and quality of life and ranged from 1 (very poor) to 7 (excellent). High scores on these items represented high global health status and quality of life. A linear transformation was used to standardise the raw scores on a scale of 0 to 100. High scores on the functional scales indicated good functioning, whereas high scores on the symptom scales indicated a greater number of symptoms. The validity and reliability of this measure has been established (Giesinger et al. 2016).

Patient and Observer Scar Assessment Scale (POSAS): is a self-administered scale which measures scar quality of the breast and donor sites from the patients' perspective. This 7 item measure utilised a 10 point scale, which ranged from 10 (worst imaginable scar or sensation) to 1 (as normal skin) on seven scar features including: pain, itching, colour, pliability, thickness, irregularity and overall scar quality. The validity and reliability of the POSAS measure has been established within this patient population (Truong et al. 2007). A total score for each scar feature was obtained by reversing and summing the six specific scar items. Overall scar quality was scored separately, reversed and summed. A higher score indicated greater satisfaction with the scar features and overall scar quality.

A series of visual analogue scales were developed for this study to examine the aesthetic features of the breast in 3 dimensions: symmetry, shape and sensitivity. Each dimension used a 10 cm horizontal visual analogue scale, which ranged from 1 (complete satisfaction) to 10 (complete dissatisfaction). The scores from each dimension were reversed and summed to provide 3 total scores for symmetry, shape, and sensitivity. A higher score indicated greater satisfaction with aesthetic features of the breast.

5.7 Variable Definitions

Variable	Definition	Distinguishing Features
Breast satisfaction	This variable relates to satisfaction with overall breast appearance.	This focuses on perceptions of breast appearance including size, shape, symmetry, softness, scarring and appearance expectations.
Outcome satisfaction	The variable relates to an overall sense of satisfaction with outcomes following breast reconstruction.	This considers the overall evaluation of reconstruction, expectations, life impact and decision regret.
Quality of life	The variable relates to the appraisal and perception of overall health status and quality of life.	This encompasses basic elements of quality of life including physical, psychological, emotional, social, role and sexual functioning.

5.8 Statistical analysis

Three hierarchical multiple regression analyses were performed for 3 dependent variables: breast satisfaction, outcome satisfaction, and quality of life. In the analysis, the appearance related visual analogue measures and the Breast Q measure ("satisfaction with breasts") were entered at stage 1. The POSAS scarring variables were entered at stage 2, and a variable from the Breast Q measure ("satisfaction with outcome") was entered at stage 3. In the final stage of the model, EORTC quality of life variable ("quality of life") and the Breast Q measures ("psychosocial wellbeing and sexual wellbeing") were entered. Predictor variables were selected based on previous literature and variables considered to be of particular importance in predicting the outcome were entered into the model first. A moderator analysis was also performed to determine if age, year of reconstruction, or type of reconstruction moderated the dependent variables.

5.9 Results

Preliminary analyses were performed to test the assumptions of normality and multi-collinearity. The analyses suggested that there was no violation of normality. Histograms were symmetrical and approximately bell-shaped, indicating normal distribution. The normal probability plots also indicated that the residuals were normally distributed. Collinearity statistics guidelines state that if the largest variance inflation factor is greater than 10 and if the average variance inflation factor is substantially greater than 1, the regression may be biased (Bowerman and O'Connell 1990). Tolerance <0.2 also indicates a potential problem (Bowerman and O'Connell 1990). The analyses did not meet any of these criteria for multi-collinearity. Three separate hierarchical multiple regression analyses were performed.

Breast Satisfaction

Hierarchical multiple regression analysis depicted in Figure 1, revealed that at stage 1, appearance variables contributed significantly to the regression model, F (6,98) = 23.87, $P < .001$, and accounted for 59% of the variation in breast satisfaction. The scarring variables explained an additional 8% of variation in breast satisfaction and this change in R^2 was significant, F (7,91) = 3. 12, $P = .005$. Introducing the variable outcome satisfaction to the regression model explained an additional 10% of the variation in breast satisfaction, and this change in R^2 was significant, F (1,90) = 9.57, $P = .003$. Finally, the addition of quality of life measures (psychosocial wellbeing, sexual wellbeing, and quality of life) to the regression model explained an additional 4% of the variation in satisfaction, and this change in R^2 square was significant, F (3,87) = 4.71, $P = .004$). The final model accounted for 75% of variance in breast satisfaction F (17,87) = 14.96, $P = <.001$, $R^2 = 0.745$, R^2 Adjusted = 0.695. In the final model, psychosocial wellbeing was found to be the most important predictor variable of breast satisfaction ($\beta = .322$, $P = .006$). Moderator analysis also demonstrated participant age ($\beta = .011$, $P = .865$) did not significantly moderate breast satisfaction. However, there was a trend between breast satisfaction and type of reconstruction ($\beta = .120$, $P = .073$), with higher levels of satisfaction of breast appearance demonstrated with deep inferior epigastric perforator flap (DIEP) reconstruction compared to other types of reconstruction. The year of reconstruction ($\beta = .148$, $P = .029$) significantly moderated breast satisfaction. A 1 year increase in the year of reconstruction between 2010 and 2016 resulted in a .148 increase in breast satisfaction.

Outcome Satisfaction

Hierarchical multiple regression analysis depicted in Figure 2, revealed that at stage 1, appearance variables contributed significantly to the regression model, F (7,97) = 16.75, $P < .001$, and accounted for 55% of the variation in outcome satisfaction. The scarring variables explained an additional 6% of variation in outcome satisfaction, and this change in R^2 was significant, F (7, 90) = 2.05, $P = .057$. The addition of quality of life measures (psychosocial wellbeing, sexual wellbeing, and quality of life) to the regression model explained an additional 7% of the variation in satisfaction, and this change in R^2 was significant, F (3, 87) = 5.99, $P = .001$.The final model accounted for 67.7% of variance of outcome satisfaction, F (17, 87) = 10.71, $P = <.001$, $R^2 = 0.677$, R^2 Adjusted = 0.613. The factors found to be the most important predictors of outcome satisfaction were breast sensitivity ($\beta = -.169$, $P = .014$), pain ($\beta = -.204$, $P = .018$), scar thickness ($\beta = .369$, $P = .041$), and psychosocial wellbeing ($\beta = .406$, $P = .002$). Moderator analysis demonstrated participant age ($\beta = -.018$, $P = .804$) and year of reconstruction ($\beta = .005$, $P = .950$) did not significantly moderate outcome satisfaction, although type of reconstruction did significantly moderate outcome satisfaction ($\beta = .167$, $P = .026$), with significantly higher levels of outcome satisfaction demonstrated with DIEP reconstruction compared with other types of reconstruction.

Quality of Life

Hierarchical multiple regression analysis depicted in Figure 3, revealed that at stage 1, appearance variables contributed significantly to the regression model, F (7,97) = 5.85, $P < .001$ and accounted for 30% of the variation in quality of life. Introducing the scarring variables explained an additional 11% of variation in quality of life, and this change in R^2 was significant, F (7, 90) = 2.29, $P = .034$). Adding the variable satisfaction of the overall outcome explained an additional 0.6% of the variation in quality of life, and this change in R^2 was non-significant, F (1,89) = 0.950, $P = .332$). The addition of quality of life measures (psychosocial wellbeing and sexual wellbeing) to the regression model explained an additional 5.3% of the variation in quality of life and this change in R^2 was also significant, F (17,87) = 4.25, $P = .017$). Together, all independent variables accounted for 46% of variance in quality of life F (23, 81) = 4.40, $P = <.001$, $R^2 = 0.46.2$, R^2 Adjusted = 0.357. In the final model, no one variable was found to be significantly more important predictor of quality of life than another. Moderator analysis demonstrated participant age ($\beta = .004$, $P = .962$), type of reconstruction ($\beta = -.087$, $P = .371$), and year of reconstruction ($\beta = -.730$, $P = .467$) did not significantly moderate quality of life.

Figure 1. Hierarchical Multiple Regression Analysis of Breast Satisfaction following Breast Reconstruction

Step/predictor	R^2	Adjusted R^2	*F*	*P*-values in the final equation	*B* in the final equation
1.	.594	.569	23.871		
VAS[1]: Breast Shape					
VAS: Breast Symmetry					
VAS: Breast Sensitivity					
2.	.672	.625	14.358		
VAS: Breast Shape					
VAS: Breast Symmetry					
VAS: Breast Sensitivity					
POSAS[2]: Pain					
POSAS: Itch					
POSAS: Scar colour					
POSAS: Pliability					
POSAS: Thickness					
POSAS: Irregularity					
POSAS: Overall Opinion					
3.	.704	.658	15.273		
VAS: Breast Shape					
VAS: Breast Symmetry					
VAS: Breast Sensitivity					
POSAS: Pain					
POSAS: Itch					
POSAS: Scar colour					
POSAS: Stiffness					
POSAS: Thickness					
POSAS: Irregularity					
POSAS: Overall Opinion					
Outcome Satisfaction					
4.	.745	.695	14.963		
VAS: Breast Shape				.105	.238
VAS: Breast Symmetry				.274	.158
VAS: Breast Sensitivity				.562	.036
POSAS: Pain				.208	.098
POSAS: Itch				.403	.063
POSAS: Scar colour				.180	.132
POSAS: Stiffness				.469	.070
POSAS: Thickness				.651	-.073
POSAS: Irregularity				.251	-.188
POSAS: Overall Opinion				.342	.081
Outcome Satisfaction				.315	.096
QOL[3]				.897	.010
Psychosocial Wellbeing				.006	.322
Sexual Wellbeing				.667	.043

Abbreviations: Visual Analogue Scales[1], The Patient and Observer Scar Assessment Scale[2], Quality of Life Scale[3]

Figure 2. Hierarchical Multiple Regression Analysis of Outcome Satisfaction following Breast Reconstruction

Step/predictor	R^2	Adjusted R^2	*F*	*P*-values in the final equation	*B* in the final equation
1.	.547	.515	16.759		
VAS[1]: Breast Shape					
VAS: Breast Symmetry					
VAS: Breast Sensitivity					
Breast Satisfaction					
2.	.610	.549	10.045		
VAS: Breast Shape					
VAS: Breast Symmetry					
VAS: Breast Sensitivity					
Breast Satisfaction					
POSAS[2]: Pain					
POSAS: Itch					
POSAS: Scar colour					
POSAS: Pliability					
POSAS: Thickness					
POSAS: Irregularity					
POSAS: Overall Opinion					
3.	.677	.613	10.709		
VAS: Breast Shape				.078	.291
VAS: Breast Symmetry				.657	-.072
VAS: Breast Sensitivity				.014	-.169
Breast Satisfaction				.315	.121
POSAS: Pain				.018	-.204
POSAS: Itch				.168	.116
POSAS: Scar colour				.285	-.119
POSAS: Stiffness				.954	-.006
POSAS: Thickness				.041	.369
POSAS: Irregularity				.327	-.181
POSAS: Overall Opinion				.984	.002
QOL[3]				.852	-.016
Psychosocial Wellbeing				.002	.406
Sexual Wellbeing				.581	.062

Abbreviations: Visual Analogue Scales[1], The Patient and Observer Scar Assessment Scale[2], Quality of Life Scale[3]

Figure 3. Hierarchical Multiple Regression Analysis of Quality of Life following Breast Reconstruction

Step/predictor	R^2	Adjusted R^2	*F*	*P*-values in the final equation	*B* in the final equation
1.	.297	.246	5.851		
VAS[1]: Breast Shape					
VAS: Breast Symmetry					
VAS: Breast Sensitivity					
Breast Satisfaction					
2.	.403	.311	4.348		
VAS: Breast Shape					
VAS: Breast Symmetry					
VAS: Breast Sensitivity					
Breast Satisfaction					
POSAS[2]: Pain					
POSAS: Itch					
POSAS: Scar colour					
POSAS: Pliability					
POSAS: Thickness					
POSAS: Irregularity					
POSAS: Overall Opinion					
3.	.410	.310	4.119		
VAS: Breast Shape					
VAS: Breast Symmetry					
VAS: Breast Sensitivity					
Breast Satisfaction					
POSAS: Pain					
POSAS: Itch					
POSAS: Scar colour					
POSAS: Stiffness					
POSAS: Thickness					
POSAS: Irregularity					
POSAS: Overall Opinion					
Outcome Satisfaction					
4.	.462	.357	4.402		
VAS: Breast Shape				.512	.140
VAS: Breast Symmetry				.959	-.011
VAS: Breast Sensitivity				.105	-.146
Breast Satisfaction				.897	.020
POSAS: Pain				.723	.040
POSAS: Itch				.516	.071
POSAS: Scar colour				.101	-.233
POSAS: Stiffness				.434	.110
POSAS: Thickness				.199	-.301
POSAS: Irregularity				.124	.366
POSAS: Overall Opinion				.289	.131
Outcome Satisfaction				.852	-.026
Psychosocial Wellbeing				.183	.232
Sexual Wellbeing				.131	.216

Abbreviations: Visual Analogue Scales[1], The Patient and Observer Scar Assessment Scale[2]

5.10 Discussion

This study identified psychosocial factors which predicted breast satisfaction, outcome satisfaction and quality of life following post-mastectomy breast reconstruction. The results of the hierarchical multiple regression analyses revealed that psychosocial factors were able to predict a high percentage of the total variance for both satisfaction with breast appearance and outcome satisfaction, approximately 75% and 68%, respectively. The total variance explained by the model for quality of life was more modest (46%). The findings of this study are consistent with the theoretical framework of breast reconstruction presented by Fingeret and Colleagues (2013) which illustrated the associations of patient satisfaction, body image, and quality of life and also highlighted the importance of distinguishing features of satisfaction with breast appearance and outcome satisfaction. Moreover, psychosocial wellbeing was a key predictor of both satisfaction with breast appearance and outcome satisfaction. Previous literature also indicates that aesthetic satisfaction promotes greater psychological wellbeing (Al-Ghazal, Fallowfield and Blamey 1999). This study demonstrated that women with greater psychological wellbeing are more likely to report greater breast satisfaction and outcome satisfaction. It has also been suggested that there is a possibility of a relationship whereby satisfaction with breast appearance promotes greater psychosocial wellbeing (Harcourt and Rumsey 2008), therefore greater psychosocial wellbeing may also promote breast and outcome satisfaction. This finding has important clinical implications and demonstrates a need to consider psychosocial wellbeing both preoperatively and postoperatively.

Moderator analysis demonstrated that the year of reconstruction was a significant predictor of breast satisfaction. As the year of reconstruction increased, satisfaction with breast appearance increased. This finding could be attributed to the continuously advancing reconstructive techniques offered which may lead to a better cosmetic outcome. Such new and refined approaches to reconstructive surgery may also have an important bearing on other psychosocial outcomes such as sexual functioning. However, it must also be considered if women were less satisfied with earlier reconstructive procedures because of the time lag between use of services and evaluation of satisfaction, as this may indicate that satisfaction with reconstruction decreases over time. This finding will be considered further later in this thesis (i.e.7.7). Moreover, this study also reported as breast sensitivity increased, outcome satisfaction decreased. Breast sensitivity as a predictor of satisfaction has not been explored fully within current literature and warrants further consideration in future studies. Subsequently, this finding was considered in the qualitative element of this thesis and is discussed further in the final chapter (i.e. 7.2).

As expected, as scarring pain increased, outcome satisfaction decreased. However, as scar thickness increased, satisfaction with the overall outcome increased. It could be suggested that some participants may have struggled to provide a precise scar thickness score. Although, these findings are inconsistent with previous qualitative scarring literature (Abu-Nab and Grunfeld 2007), they are undoubtedly of interest and warrant further consideration. A more detailed consideration of this finding is detailed later in this thesis (i.e. 7.2). Moreover, reconstruction type was associated with outcome satisfaction. Deep inferior epigastric perforator patients reported greater satisfaction with the overall outcome compared with other types of reconstruction. Previous literature has reported higher satisfaction rates with autologous tissue-based procedures than implant-based reconstructions (Atisha et al. 2008). However, although greater patient satisfaction and cosmetic outcome is observed with the deep inferior epigastric perforator flap technique compared with other surgical procedures, there is no difference in reported quality of life (Tønseth et al. 2008). This is consistent with the finding of the present study and suggests that procedure type effects both breast and outcome satisfaction but not overall quality of life. It may be that DIEP reconstruction enables women to perceive their reconstructed breasts as a natural part of their own body, which is not the case in implant reconstruction (Damen et al. 2010).

5.11 Strengths and Limitations

The study sought to control for many of the shortcomings identified in previous literature (Fingeret et al. 2013). Consequently, all outcomes were clearly defined and distinguished, standardised measures were validated within the same clinical population, the effect of scarring was considered, and a multiple-surgeon design was applied. Nevertheless, selection bias is possible as participants were identified by 2 plastic surgeons from 1 NHS site, and most participants elected for a DIEP reconstruction. Moreover, the postoperative questionnaire to assess subjective surgical outcomes has both advantages and disadvantages. The primary advantage is women make their own interpretation of how they feel about the reconstructive outcomes. However, the cross-sectional study design does not distinguish the direction of the relationships or account for the changing nature of the outcomes over time. This may be of particular importance as satisfaction is thought to fluctuate during long-term breast cancer recovery. Other limitations include the omission of pre-surgical data, and some clinical characteristics such as treatment types, the number of reconstructive surgeries, and any reconstructive complications. Moreover, only a small sample of women elected for delayed reconstruction, therefore we were unable to examine if the timing of reconstruction moderated the dependent outcomes. Future studies should be prospective, longitudinal, and possibly of a qualitative design to provide a comprehensive understanding of the trajectory of satisfaction and quality of life following breast reconstruction.

5.12 Clinical Implications

This study breaks down the concept of satisfaction and distinguishes between breast satisfaction and outcome satisfaction to provide evidence for key predictors of specific components of satisfaction and quality of life. The findings demonstrate that a number of psychosocial outcomes were able to predict a high percentage of the total variance for breast satisfaction and outcome satisfaction, and a modest percentage for quality of life. These findings could be used to inform both clinicians and patients of the importance of specific psychosocial outcomes (i.e. psychosocial wellbeing/ sexual wellbeing) in relation to satisfaction and quality of life following post-mastectomy breast reconstruction. This will allow for the identification of specific areas of focus, which may require further surgical or psychological intervention to enhance both satisfaction and quality of life. For example, if a clinician has a patient who is deemed to be unsatisfied as rated on the Breast Q measure (Pusic et al. 2009), the findings would suggest this could be derived from a combination of the identified psychosocial outcomes. The findings also demonstrate the need for healthcare providers to consider the psychosocial wellbeing of patients both preoperatively and postoperatively. Both plastic surgeons and/or specialist breast reconstruction nurses may be suitably placed to assess the psychosocial wellbeing of patients. These healthcare professionals have expert knowledge and play a pivotal role in the care of oncology patients. Therefore, future studies should investigate the feasibility for the role of specialist breast reconstruction nurses to provide tailored psychological support. The findings also provide preliminary evidence for the use of the extensive and complex DIEP procedure over other types of reconstructive techniques, although further longitudinal comparison studies are required.

5.13 Reflections

The development of this study presented a number of substantial challenges including ethical restrictions, recruitment difficulties and participant complaints. As a result of ethical restrictions only anonymised NHS data were accessed, resulting in a reliance on NHS staff to extract and anonymise the data. Furthermore, recruitment for this study began over the Christmas period and only 71 participants completed and returned the questionnaires. Therefore, a further 192 questionnaires and reminder letters were sent to participants and eventually 148 questionnaires were returned. However, due to recruitment difficulties study completion took significantly longer than anticipated. Moreover, several participants' submitted complaints specifically in relation to the questionnaire, as participants expressed the questionnaires did not reflect the depth of their experience, thus reinforcing the need for the research to have a significant qualitative component. The questionnaires did not allow for participants to provide additional comments, due to the ethical implications of collecting surplus data. However, future studies could employ a mixed methods design as this may provide a more comprehensive and holistic examination of breast reconstruction.

5.14 Conclusion

This chapter examines the predictors of satisfaction and quality of life following post-mastectomy breast reconstruction. This chapter demonstrated psychosocial factors were able to predict a high percentage of the total variance for satisfaction and a moderate percentage of the total variance for quality of life. The findings enable women to identify the likely outcomes following post-mastectomy breast reconstruction. This is of significant importance given the steadily increasing number of women electing for breast reconstruction. This thesis adopts a mixed methods model in order to develop multiple perspectives and a better understanding of breast reconstruction. Subsequently, the following chapter will assume a qualitative stance and further consider satisfaction and quality of life following post-mastectomy breast reconstruction.

Chapter 6.0: "It's a Silver Lining": A Template Analysis of Satisfaction and Quality of Life following Post-Mastectomy Breast Reconstruction

6.1 Overview

The previous chapter examines satisfaction and quality of life following post-mastectomy breast reconstruction from a quantitative stance. This thesis adopts a sequential explanatory design, therefore this chapter employs a qualitative approach in order to explain and expand primary quantitative data. Chapter 5 commences providing further background information on breast reconstruction and the suitability of qualitative research methods to address the phenomena (5.2). The chapter details methodological considerations including the participant sample and inclusion and exclusion criteria (5.3), the data collection method of interviews (5.4) and the data analysis method of template analysis (5.5). The chapter also discusses the methods employed to attain rigour (5.6), and presents the findings of the analysis (5.7) culminating in a discussion (5.8). Finally, the chapter concludes presenting limitations (5.9), clinical implications (5.10) and an overall conclusion (5.11).

6.2 Background

Breast cancer and breast cancer treatments are, by their very nature, destructive (Boquiren et al. 2013), and this destructive influence often involves the loss of a breast or breasts, scarring, and disfigurement. Subsequently, the universal experience of women with breast cancer is often one of profound loss (Boquiren et al. 2013). However, as noted previously reconstructive surgery may ameliorate the effects of mastectomy. A more detailed explanation of the different types of reconstruction (i.e. 3.5) and timing of reconstruction (i.e. 3.4) is provided elsewhere in this thesis. This is a complex decision for which there is no clearly defined clinically preferable option. As a consequence, the decision is largely influenced by the beliefs and personal values of the patient and surgeon (Charles, Gafni and Whelan 1997), and surgeon expertise as demonstrated in the previous chapter where almost 70% of women from one NHS trust underwent the same procedure (Matthews et al. 2017) (i.e. Chapter 4/ Appendix 13). In recent years, views on the most suitable timing for breast reconstruction have undergone a substantial evolution. Before 1990, the general consensus was that after mastectomy women must grieve the loss of their breast before they can obtain psychological equilibrium (Klein, 1971, Winder and Winder 1985). However, more recently, the literature has shifted in favour of immediate breast reconstruction (The National Mastectomy and Breast Reconstruction Audit, 2011). Advantages of immediate reconstruction include a superior aesthetic result (Al-Ghazal et al. 2000), a lower number of surgical procedures, hospitalisations and recovery periods (Khoo et al. 1998). Immediate breast reconstruction is also significantly more cost-effective than delayed on a direct resource-cost basis (Khoo et al. 1998, Neyt et al. 2005). However, the decision regarding immediate breast reconstruction is often made in haste, as oncology teams must provide the first definitive treatment within 31 days of diagnosis (The National Mastectomy and Breast Reconstruction Audit, 2011). This rapid decision making is thought to subject patients to a substantial amount of stress (Harcourt et al. 2003). Delayed reconstruction allows the patient more time to consider their reconstructive options and for the completion of cancer treatments (Shakespeare and Hobby 2001). A more detailed discussion of the advantages and disadvantages of immediate and delayed reconstruction has been previously discussed within this thesis (i.e.3.4).

Breast reconstruction techniques have been developed and refined over recent years and reconstructive results have improved substantially (Schmauss, Machens and Harder 2015).As noted previously, contemporary reconstructive techniques include a range of distinct surgical procedures and the most common types of reconstructive techniques are: transverse rectus abdominis myocutaneous (TRAM), deep inferior epigastric perforator (DIEP), latissimus dorsi myocutaneous flap (LD) and superior gluteal artery perforator S-GAP (Neyt, Blondeel, Morrison and Albrecht 2005). Controversy exists in relation to the most appropriate type of reconstructive techniques (Dutra et al. 2012). However, there is a growing consensus in plastic surgery literature that autologous-based reconstructions produce higher levels of breast and outcome satisfaction compared with implant-based reconstructions (Alderman et al. 2000). Moreover, we have previously reported DIEP patients at one site experience greater breast and outcome satisfaction compared with other types of reconstruction (Matthews et al. 2017) (i.e. Chapter 4/ Appendix 13). This is in line with previous literature which suggests higher satisfaction rates with autologous tissue based procedures than implant-based reconstructions (Atisha et al. 2008, Yueh et al. 2010).

Contemporary research provides strong support for the notion that post-mastectomy breast reconstruction is an important determinant of health and wellbeing following breast cancer (National Mastectomy and Breast Reconstruction Audit 2011). Moreover, qualitative literature suggests reconstruction allows women to establish a sense of normality following breast cancer treatment (Denford et al. 2011). However, a systematic review reported outcomes of breast reconstruction after mastectomy are similar to outcomes of mastectomy alone (Lee, Sunu and Pignone 2009). This review also included four high-quality studies which reported poorer quality of life, body image and sexual outcomes in women who elected for mastectomy with reconstruction compared to/with mastectomy alone (Arora et al. 2001, Janz et al. 2005, Nissen et al. 2001, Rowland et al. 2000). With a mixed evidence base, understanding the wide-reaching effects of breast reconstruction has become increasingly important for researchers and clinicians, with satisfaction and quality of life deemed as the most important measures of surgical success (Ceradini and Levine 2008). The National Mastectomy and Breast Reconstruction Audit (2011) reports overall reconstruction satisfaction rates are often high. However, within this audit only 59% of women were specifically satisfied, postoperatively, with how they looked in the mirror unclothed and fewer still were satisfied with preoperative preparedness for postoperative experiences of pain, recovery, and scarring (The National Mastectomy and Breast Reconstruction Audit, 2011).

The National Mastectomy and Breast Reconstruction Audit (2011) and Fingeret and Colleagues (2013) theoretical framework of breast reconstruction attempts to identify the key factors that are involved in determining levels of reported satisfaction and quality of life. However, relatively few studies distinguish between breast satisfaction and outcome satisfaction. Previously, this thesis examined satisfaction and quality of life following breast reconstruction from a quantitative stance and a number of participants reported struggling to quantify their experience numerically (Matthews et al. 2017/ Chapter 5/ Appendix 13). This may be because the measures utilised asked women to rate the presence and/or severity of an outcome rather than the impact of the outcome and if it is a problem for which they require or receive support. Qualitative analysis of breast reconstruction specifically exploring satisfaction and quality of life is limited, yet qualitative methods are particularly suitable for looking at patient’s experiences and perceived outcomes of plastic surgery (Shauver and Chung 2010), and may allow for elaboration, nuance and a further depth to understanding. Consequently, this chapter considers breast reconstruction in relation to breast satisfaction, outcome satisfaction and quality of life from a qualitative stance. It is hoped that the utilisation of qualitative methodology will allow for detailed accounts of experience and contribute to the understanding of post-mastectomy breast reconstruction.

6.3 Participants

Women were screened using the inclusion and exclusion criteria. Eligible participants were post-mastectomy breast reconstruction patients, aged 18 or over and English speaking. Women were excluded if they were undergoing active treatment or palliative care for breast cancer. Each participant was assigned a study identification number to protect their confidentiality. Sociodemographic and clinical information of participants is displayed in Table 2. Relative variation was achieved within the sample (e.g., age, type of reconstruction, time since surgery and marital status) in order to facilitate the production of a more encompassing understanding of breast reconstruction than would be possible with a homogenous sample. Representatives from UK-based cancer organisations promoted and distributed postal or email information to potential participants. Word of mouth/ snowball sampling was also adopted to maximise recruitment. The recruitment strategy is illustrated in Figure 4. Enrolment in the study continued until the point of data saturation. King (2012) advised data saturation can be claimed after all data of clear relevance to the research question are coded and the template is clear and well-defined. Data saturation was obtained after 25 interviews.

Figure 4. A Flow Diagram Depicting the Recruitment Process

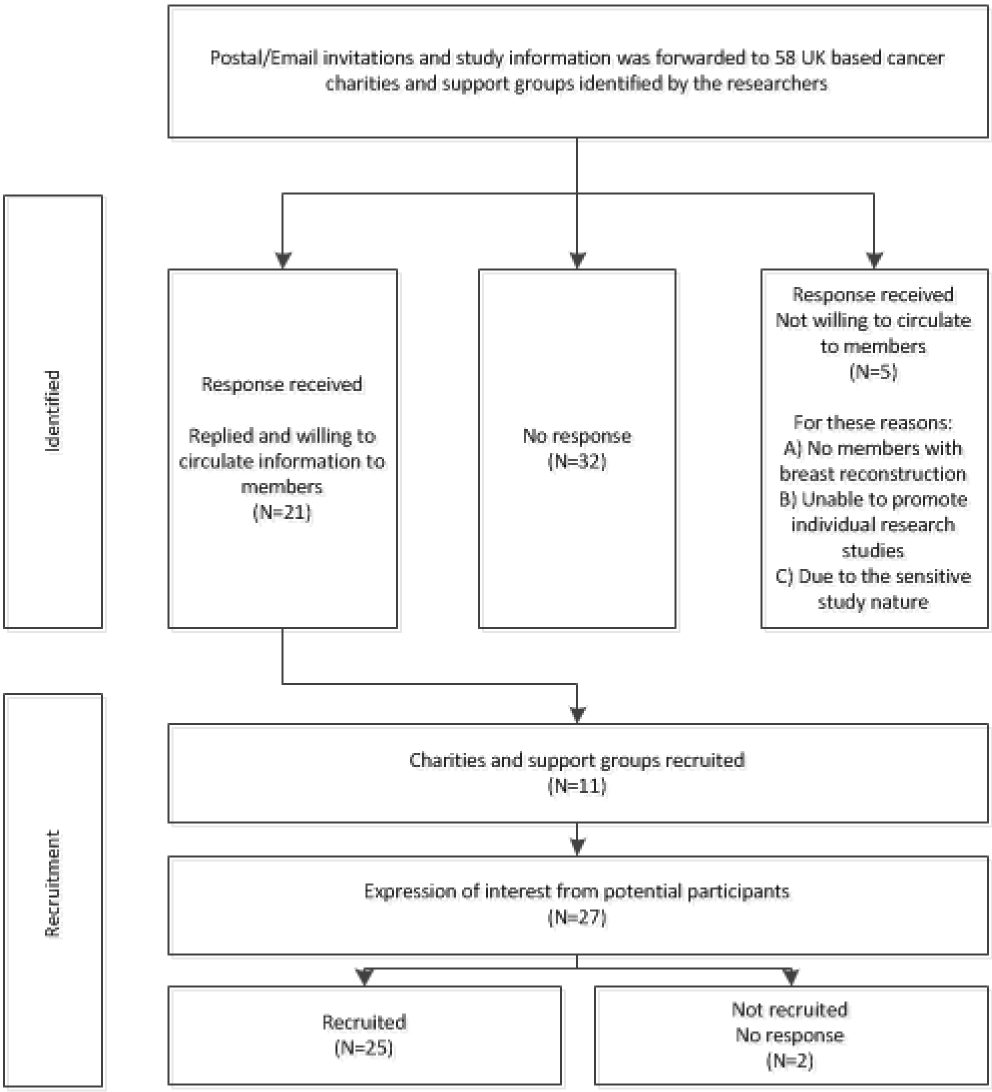


Table 2. Socio-Demographic and Clinical Information of Participants

ID	Age	Marital status	Ethnicity*	Diagnosis Year	Recon** type	Recon** timing	Recon** year	Treatment types	Surgical Complications
1	52	Cohabiting	WB	2014	DIEP Flap	Immediate	2014	UM,C	Hematoma
2	72	Divorced/ Partner	WB	2003	LD Flap	Delayed	2012	C,R,UM,NR	No complications
3	54	Single	WB	2010	TRAM Flap	Delayed	2013	C,R,BM,NR	No complications
4	67	Widow/ Partner	WB	2007	LD Flap & Implant	Immediate	2007	C,R,UM,NR	Bleeding
5	56	Married	WB	2011	LD Flap & Implant	Immediate	2011	UM,NR	No complications
6	48	Divorced/ Partner	WB	2014	DIEP Flap	Immediate	2015	C,R,UM	No complications
7	50	Married	Caucasian	2011	Implant	Immediate	2012	C,R,BM,NR	No complications
8	49	Married	WB	2013	Implant	Immediate	2013	UM	Bleeding
9	47	Married	WB	2013	DIEP Flap	Delayed	2014	C,R,UM,NR	No complications
10	54	Married	Black	2006	TRAM Flap	Delayed	2007	UM	No complications
11	48	Married	WB	2016	Implant	Immediate	2016	C,R,UM	No complications
12	47	Married	WB	2013	Implant	Immediate	2013	C,R,BM	Necrosis
13	51	Divorced	WB	2011	DIEP Flap	Delayed	2015	C,R,UM,NR	No complications
14	50	Married	WB	2014	LD Flap & Implant	Delayed	2016	C,R,UM	No complications
15	60	Divorced	WB	2013	LD Flap & Implant	Delayed	2014	UM,NR	Blood clot
16	51	Married	WB	2016	TRAM Flap	Immediate	2016	UM	No complications
17	62	Single	WB	2001	DIEP & LD Flap	Delayed	2003	C,R,UM,NR	Failed DIEP
18	70	Widowed	WI	2011	LD Flap & Implant	Immediate	2011	UM,NR	Infection
19	51	Married	WB	2014	LD Flap & Implant	Immediate	2014	C,R,UM	Capsular contracture
20	53	Single	WP	2016	Implant	Immediate	2016	C,UM	No complications
21	38	Cohabiting	WB	2015	Implant	Immediate	2015	C,BM	No complications
22	37	Married	WB	2010	TRAM/LD/DIEP	Delayed	2013/15	C,R,UM,NR	Necrosis
23	56	Married	WB	2015	Implant	Immediate	2015	C,R,UM	No complication
24	47	Married	WB	2013	Strattice/Implant	Immediate	2014	C,UM,NR	No complication
25	57	Married	Caucasian	2016	DIEP	Immediate	2016	UM,NR	No complications

WB=White British, WI= White Irish, WP= White Portuguese, Recon= Reconstruction Type, DIEP Flap=Deep Inferior Epigastric Perforators, LD Flap= Latissimus Dorsi, TRAM Flap= Transverse Rectus Abdominis Muscle, C=Chemotherapy, R=Radiotherapy, BM= Bilateral Mastectomy, UM= Unilateral Mastectomy, NR=Nipple Reconstruction. *Self-Identified Ethnicity, **Reconstruction

6.4 Data Collection

Following university ethical approval (P46098), an interview schedule was developed through a review of relevant literature and discussion with two consultant plastic surgeons in relation to breast reconstruction surgery. Some questions were also adapted from interview items used by Klassen and colleagues (2009) to explore both predetermined and emergent issues relevant to the research question. The interview schedule is displayed in Table 3. The interview schedule was piloted for the first three interviews to identify areas requiring more detail and to modify or remove items which did not '*fit*' the scope of the research question. Data were collected through semi-structured interviews and were digitally audio-recorded. All telephone interviews were conducted by the female researcher (BSc & MSc) with experience in qualitative methodologies between November 2016 and March 2017. A professional relationship was established with participants through the recruitment and interview process. Participants were aware that they were contributing to the researcher's doctoral programme of study. Interview length ranged from 30-80 minutes. Interviews were transcribed in verbatim and used an abbreviated form of the Jefferson system of notation (Jefferson 2004). Data were organised for analysis using Nvivo 11 (QRS International, 2015).

Table 3. Interview Schedule

Pre-operative process: reasons for reconstruction; motivations; type of reconstruction chosen; support seeking; information seeking
Pre-operative perceptions: preoperative feelings; expectations of the recovery process; concerns regarding the procedure; concerns regarding complications; quality of life
Post-operative perceptions: feelings immediately after the procedure; complications; the recovery process; quality of life; overall outcome satisfaction
Functional ability and role performance: work and normal activities; interference in social activities; interference with family function; comfort; energy and vitality
Aesthetic outcome: size; shape; appearance; symmetry; nipple/areola complex; breast scarring; donor site scarring; overall aesthetic satisfaction
Psychological wellbeing and self-concept: changes in self; changes in body images; feelings clothed and unclothed; feelings in a social setting; fear of recurrence; overall psychological wellbeing
Sexual life: undressing in front of a partner; satisfaction with sex life; changes in frequency of sex; changes in feelings of sexual attractiveness; breast sensitivity
Support: sources of support; accessing support; satisfaction with informational support; satisfaction with medical support; unmet needs
Expectations: fulfilment of expectations; regrets; satisfaction with decision making; willingness to repeat/ recommend the procedure ; overall outcome better or worse than expected; recovery process better or worse than expected

6.5 Data Analysis

The study assumed a critical realist perspective which acknowledged the subjective nature of the data production and analysis (Madill, Jordan and Shirley 2000). All of the participant's interviews were conceptualised as their own reality at the point of the interview, although the researcher maintained an awareness of the context and beliefs that may underlie such realities. The data were analysed using Template analysis. Template analysis is the process of organising and analysing textual data in accordance to the research question (King 2012). This involves the production of a list of codes or a coding template to represent the themes identified in the data (King 1998). Template analysis allows for the template to be revised iteratively during the analysis process, as some codes may be deemed irrelevant to the research question or too narrow to be included in the template (Miles and Huberman 1994). Moreover, data may also be sorted and sifted to explore possible relationships and trends in the codes (King 2012). Template analysis was deemed appropriate as it affords a clear and systematic yet flexible approach to data analysis (Brooks, McCluskey, Turley & King, 2015). Moreover, the suitability of template analysis within a mixed methods model has been well established (King and Brooks 2017).

Within the template the codes are ordered hierarchically, with the highest level codes representing broad themes in the data and lower level codes indicating narrowly focused themes within these themes. Following standard template analysis methodology, three *a priori* codes were identified based on the BREAST-Q $^{©}$ reconstruction measure: quality of life, breast satisfaction and outcome satisfaction (Klassen et al. 2009). The *a priori* codes were used as a provisional framework for the coding template, although were open to modification throughout the analysis. The researcher conducted the initial analysis through successive readings of four participant's transcripts and identified initial codes guided by the *a priori* codes. Template production at an early stage of the analysis allowed for the researcher to focus on the areas with greatest relevance to the research question and aligned the study with the critical realist perspective (King 1998). These codes were arranged into a preliminary template and refined as the analysis progressed through discussion with supervisors.

The coding of transcripts continued in sets of three for the development of the subsequent templates. The final coding template, template 8 was constructed by the researcher in collaboration with the supervisory team. This was considered the final template as all sections of clear relevance to the research question were coded and the template was deemed well-defined. Refinements to the templates included: inserting themes, deleting themes, changing the scope of themes and changing theme titles, in order to ensure all data of relevance to the research question was captured and that the template was sufficiently supported by the data (Miles and Huberman 1994). Refinements to the final template, template 8 included the removal of five themes: (1) role functioning, (2) returning to work, (3) child-centred decision making, (4) shifting sex life frequency and (5) difficulties transitioning into survivorship. The removal of more generalised cancer-related findings allowed for themes of particular relevance to breast reconstruction to be captured and emphasised within the final template. Refinements to template 8 were also made to the scope and/or organisation of five themes and the subsequent theme titles including: (1) protection of the self, (2) inevitability of scarring, (3) the normal self, (4) changes in confidence and (5) breast sensation.

6.6 Rigour of Analyses

Quality assurance of template analysis was established following the methods recommended by King (2012). At each stage of the analysis each template was subjected to independent scrutiny by the researcher and supervisors. A subject expert also coded a subset of transcripts in order to highlight the similarities and differences within the analyses which were discussed until a consensus was reached. An audit trail was also maintained demonstrating all stages of the analysis from the raw transcripts to the final interpretation of the data. This study was also guided by Meyrick's (2006) review of rigour in qualitative research. Meyrick's (2006) review centred on transparency and systematic negotiation throughout the research process and these principles and processes informed all elements of the qualitative study. More specifically these were addressed by detailing the aims of the study and the focus of analysis; using appropriate methods of data collection and analysis; providing details about sampling; providing details about data collection; providing a clear association between results and conclusions; and providing links to other relevant literature to assist in the identification of implications for practice. This study also adhered to the consolidated criteria for reporting qualitative research guidelines (COREQ) (Tong *et al.* 2007).

6.7 Results

Three first-level, 13 second-level and 19 third-level themes were identified. Figure 5 depicts the first, second and third level themes coded in the final template, with top-level themes in bold, and second and third level themes in plain text. First level themes are described and all sub-themes illustrated with a series of extracts indicative of interview data. Table 4 depicts first, second and third level themes and presents three sample extracts for each theme.

Figure 5. Template 8: First, Second and Third Level Theme Codes

1.0 Quality of life

- 1.1 Emotional functioning
    - 1.1.1 Striving for normality
- 1.2 Physical functioning
    - 1.2.1 Experiencing breast pain
    - 1.2.2 Breast sensation
    - 1.2.3 Donor site discomfort
    - 1.2.4 Prosthesis inconvenience
- 1.3 Sexual functioning
    - 1.3.1 Sense of sexual attractiveness
    - 1.3.2 Breast sensitivity
- 1.4 Social functioning
    - 1.4.1 Protection of the self
    - 1.4.2 Concealing reconstruction

2.0 Breast satisfaction

- 2.1 Satisfied with breast appearance
- 2.2 Unsatisfied with breast appearance
- 2.3 Breast satisfaction over time
- 2.4 Breast appearance expectations
- 2.5 Inevitability of scarring
    - 2.5.1 Acceptance of scarring
    - 2.5.2 Struggling to accept scarring
- 2.6 Nipple reconstruction satisfaction
    - 2.6.1 Satisfaction with nipple reconstruction over time

3.0 Outcome satisfaction

- 3.1 Outcome expectations
  - 3.1.1 Underestimating the surgery
  - 3.1.2 Recovery expectations
- 3.2 Impact on life
  - 3.2.1 Altering outlook on life
  - 3.2.2 Changes in confidence
  - 3.2.3 Fear of recurrence
  - 3.2.4 The normal self
- 3.3 Satisfaction with decision
  - 3.3.1 Regret

6.7 Results Continued

1.0 Quality of life

Throughout the analysis participants described their quality of life and often considered the multidimensional nature of the construct through not only discussing their overall quality of life but their emotional, physical, role, sexual and social functioning. Quality of life was discussed prior to mastectomy and reconstruction, in the period between mastectomy and reconstruction for women who elected for delayed reconstruction and following reconstruction. These time periods became the temporal anchor around which the accounts were discussed and highlighted the complexity of this breast reconstruction population.

1.1 Emotional functioning

> I was going through a grieving process, it was great to know I would wake up cancer free, but there is a lot of your femininity and whole psyche tied up with it (Participant 21).

The participant described mourning the loss of her breasts as she was unable to conceptualise her implants as her own. However, the participant displayed a mixed emotional state, as she was able to seek some solace in the notion that she would be free from disease following surgery. It is well established within the field of psycho-oncology that mastectomy is associated with a sense of loss, loss of the breast and other integral parts of identity including femininity (McKean, Newman and Adair 2013).

> I got home from the surgery and I got really low as it was only at that point I processed what I had been through. I thought you've just gone through a mastectomy and the reason you've had all these ops is because you've got cancer, it was almost like it hit me and then all the tears came. I remember being in bed one day and just crying and crying and crying and crying because I think at that point your head just accepts what you've gone through (Participant 16).

Often, the level of importance attributed to the breasts influences coping following surgery (Marshall and Kiemle 2005). Yet, the participant described acting in a pragmatic and logical manner throughout her breast cancer journey. However, following immediate reconstruction she experienced an emotional battle of acceptance, as the participant attempted to accept the enormity of her experience from the diagnosis, to the loss of a breast, to reconstruction. This may suggest the participant previously experienced elements of denial throughout her cancer journey.

1.1.1 Striving for normality

> Not having breasts did act as a constant reminder of the breast cancer. Now I feel I can sort of move on and feel normal (Participant 3).
>
> I think having the reconstruction was a way of not thinking about breast cancer every day or every time I get undressed (Participant 4).

Participants who were satisfied with their overall breast reconstruction described how the procedure allowed them to move forward and transition from a breast cancer patient to a survivor. Qualitative literature asserts there is an overwhelming need for normality within breast cancer patient populations (Denford et al. 2011). For many participants breast reconstruction afforded a sense of normality and restoration of self-image.

1.2 Physical functioning

> I think you don’t realise how much it knocks out of you physically, although I could get up and move around I had lost the use of the right hand side of my arm, as they had taken the lymph nodes out (Participant 12).

The participant described sudden and intense physical incapacity following reconstruction. The participant suggests this incapacity goes far beyond the breast site, as she describes loss of arm functioning which highlights the extensive and complex nature of breast reconstruction.

> I’m really pleased with the appearance of my breast but it has debilitated me, because I’m not mobile but it is just one of those things (Participant 15).

This participant also described the debilitating nature of breast reconstruction following an LD flap and implant procedure. However, this participant offsets and almost minimises her physical incapacity through trivialising language, as she is satisfied with the appearance of her breasts, and suggests the physical discomfort experienced is simply a side-effect of the procedure.

1.2.1 Experiencing breast pain

> The only thing that bothers me is the constant pain of the implants, where I had my radiotherapy I grew fibrosis everywhere, so the implants are hard like a piece of wood on both sides (Participant 7).
>
> It is with me day in and day out and I go to bed with it and I wake up with it and some days it just doesn't feel too great. I get these feelings and I think that doesn't feel right you know and it doesn't feel good (Participant 8).

Both participants described relentless breast pain following breast reconstruction which placed a considerable physical burden on participants. Fourteen participants described experiencing breast pain and with some participant's donor site pain following reconstruction. Breast pain was particularly prevalent with participants who opted for implant-based reconstruction prior to radiotherapy. However, some literature suggests radiotherapy increases the risk of complications and poor aesthetic outcomes following implant-based reconstruction (Kronowitz 2012).

1.2.2 Breast sensation

> My husband gets a bit freaked out, he feels that the TRAM flap one feels a lot smoother inside, and the other one is a bit lumpy and feels a bit strange. I do not like him playing with them because in my head I know they're not boobs so do not play with them as if they are, being my attitude. I just hang clothes off of them because they're not boobs (Participant 22).
>
> I think he forgets because he touches me and I'm like ok whatever it is just for him really (*laughs*). For me I don't feel anything at all and I just get on with it and actually it bothers me because I know it's just plastic well actually it's not plastic its silicone, so it's not really me there anymore (Participant 7).

Both participants described a sense of disconnect from the ownership of their breasts, as a result of the change of their breast sensation. As a consequence, the participants no longer constituted the caressing of their breasts as means of sexual arousal. Participant 7 described her husbanding embracing her reconstructed breasts during intercourse, although participant 22 described her partner's distress towards the sensation of her new breasts, which may be derived from the connotation of uneven breasts and cancer tumours.

1.2.3 Donor site discomfort

> Well I definitely feel my whole body has changed my tummy button is much higher, so my waist is in a different place and so my hips kind of feel bigger, and all my trousers kind of fit differently and that took quite a lot of getting used to. It is a bit odd really having a healthy area that is damaged and taking a long time to recover (Participant 6).

The participant described her stomach area as almost feeling "*alien*" to her and the rest of her body. This is akin to how some of the participants previously described their breasts earlier in this theme. As a consequence, the participant struggled to psychologically accept the disfigurement and discomfort of a healthy area of the body which was unaffected by the disease.

> It kind of felt like you could have had a skiing accident and like you were incapacitated. With the DIEP reconstruction I had major abdominal surgery, and it wasn't just the breast, which is great because that was like a tummy tuck and that was the real silver lining but that was hugely debilitating (Participant 9).

This participant compares her breast reconstruction to a "*skiing accident*", which suggests an extensive physical impairment at the abdominal donor site. It is well established that autologous breast reconstruction may weaken the abdominal wall as a result of the removal of the donor site tissue from its native location (Ceradini and Levine 2008), although this has not been reported to affect quality of life (Dian et al. 2007). This finding may be derived from the ability of the participant to contextualise the physical impairment as necessary to reconstruct the breast mound and improve the shape of the abdomen.

1.2.4 Prosthesis inconvenience

> I had a really embarrassing situation when I was getting changed out of a swimming costume and my prosthesis dropped out and bounced into the changing room next to me. There was a young lad in there and I do not know who was more embarrassed when I was asking for my boob back (*laughs*), so it was just mainly practicality but in retrospect I wish I had not had it done (Participant 13).

> It [the reconstruction] has made a massive difference as I am quite active and I can just get up and go now. Whereas, before I would drop the bloody thing and felt like throwing it out the window (*laughs*) (Participant 14).

Impracticality surrounding prosthesis utility is a common problem for mastectomy patients (McKean, Newman and Adair 2013). Prior to reconstruction the participant described a number of prosthesis mishaps, the inconvenience of a prosthesis and the distress associated with wearing a prosthesis. The unexpected movement of the prosthesis is a common and distressing complaint from many women following mastectomy (Gallagher et al. 2010). However, participant 13 described a sense of regret due to the physical burden of the surgical reconstruction which failed to offset the inconvenience of the prosthesis, subsequently reducing her quality of life. However, participant 14 emphasised the positive impact of breast reconstruction, allowing the participant to continue with her normal daily functioning without the inconvenience associated with a prosthesis.

1.3 Sexual functioning

> It has gone [my sex drive] because I remember how I felt before and now it is mental when you have sex. I feel like I need to think about something harder, and it is less physical. You really have to try not to think this is hurting (*laughs*) and then there is no sensitivity in the breasts and the menopause as well (Participant 7).

Following reconstruction this participant reported a severe decline in feelings of sexual desire. This decline significantly impacted on her quality of life as she no longer conceptualised herself as a sexual being. The participant attributed this decline to a number of factors including pain, diminished breast sensitivity and treatment side-effects including the menopause. Literature indicates multiple side-effects are associated with a decline in sexual functioning including nausea, hair loss, hot flushes, vaginal dryness and fatigue (Marshall and Kiemle 2005), highlighting the complex nature of breast cancer and its treatments.

> My sex life has probably got better (*laughs*) but that is probably more to do with the mastectomy and all the stuff that went with that really (Participant 14).

The participant described increasing sexual satisfaction following reconstruction. However, she does not attribute this improvement to the breast reconstruction rather to the mastectomy and the belief she is now cancer free. This belief relieves a sense of anxiety and allows the participant to live in the moment and function as fully sexual being.

1.3.1 Sense of sexual attractiveness

> I still feel sexually attractive and strangely, many people have complimented me saying, I look far better now than I did a year ago, I think it is probably a bit more of a zest for life (Participant 16).
>
> I am quite happy to have it [sex] and body confident but it is my husband who is not, he is either not body confident or not confident to look at my body. I don't know so it has not even happened (Participant 16).

Breast reconstruction has allowed the participant to appreciate and fully grasp life which has also enhanced her feelings of sexual attractiveness. However, the participant describes no longer having sex and she attributes this to her spouse's feelings towards her breast reconstruction. This places a psychological burden on the participant as she feels '*body confident',* yet lacks sexual communication with her spouse. Qualitative literature demonstrates reciprocal communication styles are an important coping mechanism following reconstruction (Loaring et al. 2015). Moreover, breast cancer can also affect a spouse's level of desire and arousal and this may be linked to sexual anxiety (Marshall and Kiemle 2005).

1.3.2 Breast sensitivity

> No it is completely numb and it's probably for the best because it has had that many needles and I've had the tattoo and all the rest of it (Participant 9).
>
> No not at all, which is a shame [loss of breast sensitivity] but I would rather not have to worry about still having breast tissue. I mean I still have what 5% of my original breast tissue but that is tiny compared to what I had and it is a small price to pay. Of course, you can lose sensitivity anyway even if you just have a boob job (Participant 21).

Participant 21 described a sense of sadness towards the loss of her breast sensitivity. However, the participant psychologically compensated this loss with the reduced likelihood of local recurrence and further rationalised this by employing the comparison of post-mastectomy breast reconstruction and cosmetic augmentation. Furthermore, Participant 9 embraced the loss of breast sensitivity as the participant elected for a series of operational procedures following her initial reconstructive procedure, therefore having limited or no breast sensitivity ultimately reduced the participant's pain.

1.4 Social functioning

> I always used to sort of feel a bit strange and on show and I was never really out and loud. I was just a bit there quiet in the background (Participant 22).

> Sometimes I feel like a bit remote from things and I do feel differently. I have always loved small talk and I loved going into crowded rooms and chatting to everyone (*laughs*), but I do not feel like doing that now (Participant 23).

Following mastectomy participant 22 described feeling exposed as she worried about the reaction of others towards her flat chest, whilst also struggling to adjust to her altered body image and wearing a prosthesis. However, following reconstruction the participant described feeling able to socialise and this restored her self-esteem and enhanced her quality of life. This is in line with previous qualitative literature which suggests breast reconstruction allows for the reversal of body image changes and reinforces normal appearance (McKean, Newman and Adair 2013). Nevertheless, participant 23 reported a continuing struggle to socialise following reconstruction.

1.4.1 Protection of the self

> I couldn't bear anyone to be near my front and I would always step back if someone came to talk to me. I would make sure there was no one behind me, as it was a very painful operation and recovery (Participant 2).

> I wouldn't say it's an embarrassment but I'm just conscious of needing to be careful, and if I'm in a crowd I don't want to be jostled. I almost feel like I need a bit of a shell around myself (Participant 6).

Both participants described feeling the need to physically protect their bodies in a social setting following breast reconstruction. Participants described feeling physically and psychologically vulnerable throughout the recovery period and for a substantial time following reconstruction. This vulnerability sometimes contributed to psychological problems including anxiety which sometimes forced participants to withdraw from social situations.

1.4.2 Concealing reconstruction

> I am conscious of that and if I am going out trying to find the right clothes to wear, that do not make it obvious so that people do not know, so it does knock your confidence, definitely (Participant 11).
>
> In terms of appearance it gives me self-confidence and people don’t know I’ve had a mastectomy if I’m wearing my normal clothes (Participant 20).

The participants reported concerns regarding the perceptions of others and described concealing their reconstruction from others. Both participants feared that others may perceive them in a narcissistic or superficial manner, due to the negative connotation of routine cosmetic augmentation. Subsequently, participants sought to conceal their breast reconstructions from others. This is consistent with qualitative literature which suggests many women report reduced body confidence following breast reconstruction (Abu-Nab and Grunfeld 2007).

2.0 Breast satisfaction

Breast satisfaction explored perceived body image in terms of satisfaction with breast appearance, appearance expectations and postoperative issues including scarring and nipple reconstruction.

2.1 Satisfied with breast appearance

> The wow factor of how it looked and I was just amazed. When I undressed, the first words my husband said were just wow and I thought well how nice is that. It was a good experience out of bad experience for me because you have to take something good out of it, as you can’t go backwards (Participant 5).
>
> To be honest I have had two kids and I breast-fed them both so I have a new lease of life up top (*laughs*). It is looking great and I am looking 20 years younger, so not only am I not without they are better than they were (Participant 9).

It is well established that cancer and cancer related treatments often have a negative impact on appearance related outcomes (White 2000). However, reconstruction allows women to reverse body image changes and reinforce normal appearance (McKean, Newman and Adair 2013). Both participants described their elation at the appearance of their reconstructions. For participant 5 her feelings of elation were reinforced by the reaction of her spouse and healthcare professionals. This participant describes feeling fortunate that from her negative experience she was able utilise her breast reconstruction as a positive outcome, which allowed for the successful integration and ownership of her new breasts. Moreover, participant 9 described feeling more satisfied with the appearance of her breasts than prior to mastectomy.

2.2 Unsatisfied with breast appearance

> I am not happy with the final product of my breasts (*laughs)*, so I never remove my top half. I cannot look at myself in the mirror and it's just obvious that I have had something going on, like I've been in a war where I had cancer and it's the mutilation. I have to admit even today I am still a bit affected by that and it is a constant reminder of what I have been through (Participant 7).

Participant 7 described feeling strongly unsatisfied and self-conscious following her breast reconstruction in 2012. The participant uses strong thought-provoking terminology, denoted with the terms "*war*" and "*mutilation*" which suggests she feels as if her "*real body*" has been mutilated and further disfigured by the reconstruction. The participant has failed to accept her reconstructed breasts into her body image and this ultimately restricts progression into long-term recovery.

> I am in limbo now [waiting for further reconstructive procedures] but I am happier that I do not have a prosthesis. I am actually more unbalanced though, so for me that is a negative, although I am grateful for what they have been able to achieve and this is where I struggle now (Participant 13).

The participant described feeling in a state of uncertainty following reconstruction, although more content with the reconstruction than the prosthesis. The participant described feeling physically and psychological unbalanced and this may ultimately result in further surgeries. Interestingly, some breast reconstruction patients may take some satisfaction in that their reconstruction has provided them a replacement breast, even if the breast does not match their original breast or expectations (Abu-Nab and Grunfeld 2007).

2.3 Breast satisfaction over time

> When it was all first done yes it was fantastic, scars aside the upright and the perkiness but because the DIEP flap is a natural thing they do droop naturally. Ok we are a couple of years on and they are starting to sag a little bit, and the one on the left that had the lift has started to droop too and I didn't realise that would happen so quickly, but it doesn't matter I mean honestly it doesn't matter (Participant 9).

The participant describes being unaware of the ptotic nature of her autologous breast reconstruction. However, the participant offsets and almost minimises her relative dissatisfaction by repeatedly suggesting the appearance of her breasts does not matter. This may because the participant feels grateful and somewhat to indebted to the oncologists, plastic surgeons and healthcare system which ultimately saved her life.

> Yes, I am but yes it has taken quite a while [to achieve breast satisfaction] to get there but yes, I am more than happy with it (Participant 17).

Multiple studies have reported that following breast reconstruction women often enter an initial period of adjustment where they adjust to their new normality (Hill and White 2008, McKean, Newman and Adair 2013). Participants described undergoing a series of surgical procedure some of which included scar revision, lipofilling, nipple reconstruction, dog-ear removal, DIEP reduction and in the case of unilateral mastectomy augmentation of the other breast. Some of these procedures resulted in gradual improvement in satisfaction with breast appearance over time.

2.4 Breast appearance expectations

> It absolutely amazes me and it completely exceeded my expectations. I never believed I would be able to wear a swimming costume and no one would tell it is not my real breast (Participant 6).

> They don't completely match what I thought they would look like, they aren't bad but they aren't quite as nice as the one in the illustration (Participant 18).

Participant 6 described having relatively low expectations for the appearance of her breasts prior to reconstruction. Yet, following reconstruction the participant described her breast appearance as exceeding expectations. This allowed the participant to adjust to her reconstructed breasts, which subsequently enhanced her overall wellbeing. However, participant 18 described an imbalance of expectations, as the participant compares the appearance of her breasts to reconstructive illustrations.

2.5 Inevitability of scarring

> I just thought that there has to be a scar somewhere for the operation and because it looks so good, the scarring has never bothered me (Participant 8).

The participant described her scarring as visible yet neat. Through the awareness that breast reconstruction would inevitably result in scarring the participant conceptualises her scarring as a foreseeable consequence of major surgery, although major surgery which allowed her to restore her body image. This is aligned to some qualitative literature which suggests women are able to accept their scars as part of the reconstruction process (Abu-Nab and Grunfeld 2007).

> I have a scar that goes underneath and one that comes up to the top of the nipple, but it is the same sort of scar that I would have had if I had a breast reduction essentially, which is the way I see it. It is also a similar scar to if I had implants so just as a breast augmentation, but I tend to heal very well and my scars don't tend to last for very long so I'm sure within twelve months those would have really died down (Participant 21).

The participant aligned her post-mastectomy breast reconstruction with routine reduction mammoplasty and cosmetic breast augmentation. This allowed the participant to minimise the nature of the disease in order to psychologically accept scarring as an inevitable consequence of breast reconstruction and positively consider future healing.

2.5.1 Acceptance of scarring

> They are what they call the war wounds and I am quite proud of them really (Participant 17).

> Scarring is brilliant, lovely and it's fading really lovely. I must admit I have seen some photos on the internet of tummy scars and breast so I just think I have been blessed with the most brilliant surgeons because mine are so neat and lovely (Participant 16).

Literature indicates some women view their scars as symbolic of their survival (McKean, Newman and Adair 2013). Participant 7 referred to her scars as "*war wounds*" suggesting she is proud of her scars as they act as a reminder of her journey, signifying survival and resilience. Moreover, participant 16 compared her scars to others and described feeling grateful for her neat scarring at both the breast and donor site. This comparison allowed the participant to successfully incorporate her scarring into her body image, as she compares herself to others with poorer scarring outcomes.

2.5.2 Struggling with scar acceptance

> I try not to look at them really and my husband never sees me naked on the top anymore. I cannot and he cannot hide it because it is too painful to look at it (Participant 7).
>
> I went on holiday this year and I wore a bikini and it is so cleverly done, it's under your bikini line so that strap that you tie up at the back is underneath it and you can't tell, although I still can't expose it to anyone (Participant 19).

Both participants struggled to accept their scarring and as a consequence the participants failed to successfully incorporate their scars into their post-reconstruction body image. Both participants described concealing their scars due to the psychological distress derived from their appearance. Participant 7 also described her spouse's distress towards the appearance of her scars, which negatively affected her own acceptance. At present, literature surrounding spousal response to surgical scarring is limited.

2.6 Nipple reconstruction satisfaction

> I had the nipple put back on and that is like the cherry on top (Participant 17).
>
> I suppose in my mind I was saying to myself I want to get to five years and if I get to five years and nothing has come back on that side that I'll sign it all off by putting the nipple on, it is almost like my little treat (Participant 19).

Nipple-areolar complex reconstruction allows for the transformation of the reconstructed breast into a more organic form resembling the original breast and in some cases the contralateral breast (Murphy et al. 2010). Participant 17 described her nipple-areolar complex reconstruction using the metaphor "*cherry on top*" which suggest the nipple-areolar complex reconstruction was the finishing touch to her reconstructive journey, providing an accurate breast representation. Participant 19 described perceiving breast reconstruction as a "*treat*" for enduring breast cancer treatment with no recurrence. For both participants having this procedure signified the end of their disease and subsequent suffering. This allowed these participants to both physically and psychological move beyond the disease, although many other participants felt that nipple reconstruction was not necessary.

2.6.1 Satisfaction with nipple reconstruction over time

> The nipple tattoo fades unfortunately but the only other option was to have a permanent tattoo from a tattooist but I am not going to bother with all that (Participant 2).
>
> In the end, it just did not sew in and it ended up falling off in the shower when I was washing one day, and I have never really bothered after that (Participant 22).

Both participants reported declining satisfaction over time with their nipple reconstruction. This was attributed to the fading of the nipple-areolar complex tattoos and failed reconstruction. Satisfaction rates with nipple reconstruction and nipple tattooing are typically high (Clarkson et al. 2006), although nipple-areolar complex tattoos are prone to significant fading and often result in patients seeking revisions (Levites et al. 2017). However, participants did not seem overly concerned with the decline of their nipple reconstructions and only a small proportion of participants sought revisions for their nipple-areolar complex tattoos.

3.0 Outcome satisfaction

The theme outcome satisfaction captured participants overall appraisal of their satisfaction with their breast reconstruction, including if their expectations were met, the impact surgery had upon their lives and satisfaction with the decision to reconstruct.

3.1 Outcome expectations

> I do not think anyone would have it done if they knew what they were going to go through, although there are pros and cons for everything and I am glad now that I had it done (Participant 15).

The participant described a mixture of emotions and expectations towards reconstruction. The participant suggested if other women knew the full extent of the procedure and recovery they would not opt for surgical reconstruction. However, now the participant has successfully completed the process of reconstruction and is satisfied with the breast appearance, she is content with the decision she made.

> They didn’t match my reality but they did match the surgeon’s reality. The surgeon told me healing would be delayed because of the chemotherapy, although you do not really have a concept of that and that is one of the hardest bits as you have to be incredibly patient (Participant 19).

The participant described an imbalance of recovery expectations between herself and her plastic surgeon. Although, the plastic surgeon conveyed the long and complex recovery process associated with a combined autologous and implant procedure, participant 19 struggled to internalise this information and this resulted in frustration and distress in relation to the slow recovery period.

3.1.1 Underestimating the surgery

> Absolutely traumatised [initially following reconstruction] and its different when you’re ill because you’re having a mastectomy and treatment to save your life, but choosing to have cosmetic surgery to improve how you feel is different. I must say, I did not know just how large of an operation it was (Participant 3).
>
> The only thing I wasn’t prepared for was the pain of breast reconstruction, even by looking at what people said online. I think that is because most people have one and not many people have a double reconstruction and I really was not prepared for that pain (*laughs*) (Participant 4).

Some women have unrealistic expectations in relation to the outcomes of reconstruction and underestimate the obstacles breast reconstruction presents (Abu-Nab and Grunfeld 2007, Murry et al. 2015). Participant 4 described underestimating the complexity of breast reconstruction surgery in relation to pain. However, participant 3 considered the removal of her breast as the removal of the cancer and disease. Therefore, the participant interprets the surgical procedure of mastectomy as a positive lifesaving action, although she conceptualises breast reconstruction as purely cosmetic and this heightens the physical and psychological distress experienced following reconstruction.

3.1.2 Recovery expectations

> I made a very good recovery far better than I was expecting, both mentally and physically from the reconstruction (Participant 1).
>
> I knew I was not just going to be bouncing back in a couple of weeks to be honest (Participant 8).

Participant 1 and particularly participants who underwent implant-based reconstructions reported significantly shorter recovery periods than they anticipated. Nevertheless, participant 8 also demonstrated realistic expectations of recovery, through an understanding of the physical and psychological burden of breast reconstruction.

3.2 Impact on life

> I really feel body confidence and strangely more so since the operation. I feel like I have had cancer come through it and WOW so I just feel empowered (Participant 16).

Breast reconstruction for many women signals the final phase of breast cancer treatment (McKean, Newman and Adair 2013), and allows women to evaluate and make sense of their experiences (Murray et al. 2015). Many participants described how breast reconstruction impacted their lives through restoring and in some cases enhancing their confidence. This enabled participants to overcome their role as a cancer patient and adjust to their new identity as a breast cancer survivor.

> We cannot do the long hours we used to but we are still productive. We are not dead and because we are not dead, we want to be part of society. We want people to understand we are not like before and we can’t help that but we still have a lot to offer (Participant 7).

The participant suggested she felt restricted and frustrated by a society that views cancer patients as weak and vulnerable, as she recognises the strength and courage required to accept and treat the disease. Nevertheless, she also recognises the impact cancer has had on her life, yet asserts cancer survivors can be productive and active members of society. Additionally, the participant uses the first person plural “*we*” which suggests she identifies with other women who have also had breast cancer as a collective, sharing similar experiences and an identity following breast reconstruction.

3.2.1 Altering outlook on life

> Life is short and you just have to make the most of it, like when I was in hospital and women were crying because they had lost a breast, I did not say anything but I thought you are still alive and so I just can’t grasp that at all (Participant 5).
>
> If I am out in a social setting and hear someone moaning about crap *(laughs*) or low-level stuff, I do not say get a life but I often look at people. It has really brought home to me how precious life is and you should not moan about crap (Participant 16).

Breast reconstruction is often considered to result in a holistic life-changing experience (Hill and White 2008). Both participants described how breast cancer had forced them to evaluate priorities in their lives, as for these participants breast cancer evoked a premature confrontation with mortality highlighting the transient nature of life. This allowed the participants to feel fortunate that they were able to survive the disease and thankful that they were able to restore their body image through breast reconstruction, subsequently enhancing their outlook on life.

3.2.2 Changes in confidence

> I could put a top on and if my boob shows ok it’s got a little bit of a scar, but it’s absolutely fine, so yes it gives you a little bit more confidence (Participant 2).
>
> I think I am more aware of my body image and I think I lack a bit more confidence regarding my body image (Participant 13).

Whilst, some participants described how breast reconstruction restored their body confidence, other participants, like participant 13 reported a decline in body confidence following reconstruction.

3.2.3 Fear of recurrence

> You could have a recurrence on the chest wall and of course you would not feel it, and you cannot mammogram them so that is a bit of a concern (Participant 4).
>
> I know there are no guarantees about preventing recurrence, but I have been trying to do the things that I am in control of such as diet and exercise (Participant 16).

Participant 4 attributed this fear to not being able to attend routine mammograms. This concern was particularly heightened in older participants who may have been attending routine mammogram appointments every three years for a number of decades. As a consequence, what was a consistent routine and a source of psychological comfort for some participants was also altered following reconstruction. Subsequently, participant 16 actively managed the likelihood of cancer recurrence through maintaining a healthy and active lifestyle.

3.2.4 The normal self

> Now I have had my breasts reconstructed I feel normal, I feel normal. I would feel maimed without it and it is a silver lining (Participant 9).
>
> To me having the breast reconstruction was like the end of the journey that I am very proud of (*laughs*). I forget that I have had breast cancer and I feel privileged that I have gone through all of the bits and pieces (Participant 17).

Participants described reconstruction as providing a sense of closure to the breast cancer journey. As some women conceptualised their breast reconstruction as the completion of cancer treatment or even a symbol of survivorship, as noted previously in references to war wounds (McKean, Newman and Adair 2013). This provides the participants a sense of normality, as they have managed to incorporate their new breast into their body image. The participants described feeling proud at what they have managed to overcome and recognised breast reconstruction as a positive aspect of the cancer experience.

3.3 Satisfaction with decision

> I was 100% happy with the decision I made and that really helped me (Participant 1).

Twenty out of twenty-five women suggested they were satisfied with their decision to elect for reconstruction, despite appearance or surgical discomforts. Participant 1 described how through making an informed decision she was able to gain control over her disease, supporting her physical and psychological recovery. This is in line with previous literature, which conceptualises breast reconstruction as approach women use to gain control over their lives (McKean, Newman and Adair 2013).

> I did not realise I would be left with a series of operational discomforts. I thought I would be better off with the reconstruction because I would not have problems with the prosthesis, but in a lot of ways I would have been better off staying as I was, but being the other side of it now I am glad I did have the reconstruction (Participant 15).

Participant 15 described the pros and cons of her breast reconstruction. Whilst, the participant initially opted for the procedure due to the inconvenience and restrictive nature of the prosthesis, she now struggles with the restrictive nature and discomforts of the reconstruction. However, on balance the participant is satisfied with her decision to surgically reconstruct the breast, due to the appearance of her breasts.

3.3.1 Regret

> I would say slight regret because of the loss of movement, the discomfort and I could have also had something [secondary cancer] on the chest wall. With implants you are a patient of the plastic surgeons for life and the implants will be ten years old shortly, yet I do feel very lucky [to have had reconstruction] (Participant 4).

> When you are told you have cancer you have to make very important decisions straight away and that just messes with your brain (*laughs*) you enter a strange mode thinking I have to save my life and then later you realise once you’ve gone through the whole thing, I wish I had done it differently (*laughs*) (Participant 7).

Both participants suggested slight elements of regret following reconstruction, attributed to restrictive movements, operational discomfort, fear of recurrence, implant longevity and hasty decision making. Yet, despite experiencing procedural regret participant 4 described herself as “*lucky*” as she has not had any problems commonly associated with implant reconstruction. This upward comparison allowed the participant to offset her sense of regret and continually move forward in a positive solution focused manner.

6.8 Discussion

This chapter sought to produce an understanding of the experiences of women following post-mastectomy breast reconstruction, in order to identify key components involved in shaping postoperative satisfaction and quality of life. This is the first study to apply template analysis to explore the experiences of women following breast reconstruction. Template analysis allowed for the combination of established conceptual themes with rich patient data, through coding for specific and distinct predetermined themes together with more inductive driven codes. Furthermore, the use of template analysis highlighted that there was only slight variation in some categories of experience among women, despite a heterogeneous participant sample. This study did not find any substantial variation in the experiences of women in relation to demographic details such as age, ethnicity or marital status. However, the type of reconstruction, timing of reconstruction and treatment types may have influenced experiences of breast reconstruction and this should be examined more systematically in future research. Interestingly, surgical complications did not appear to influence satisfaction or quality of life following breast reconstruction. This is inconsistent with existing literature which suggests complications are a central cause of dissatisfaction with breast reconstruction (Andrade, Baxter and Semple 2001).

The present study indicates breast reconstruction is an extensive and complex procedure, yet to many women the silver-lining of their cancer journey. In relation to *quality of life,* many women reported improved emotional functioning and suggested reconstruction had allowed them to establish a new normality. Previous qualitative literature also indicates breast reconstruction helps to establish a sense of normality by allowing women to adapt to their new bodies and identity (Denford et al. 2011). However, some women reported a sense of disconnect and denounced ownership of their breasts. This is inconsistent with qualitative research which suggests reconstruction restores an embodied sense of self (McKean, Newman and Adair 2013). Moreover, women reported poorer functioning in physical, sexual and social domains of quality of life. Although these findings are consistent with some reconstruction literature (Arora et al. 2001, Janz et al. 2005, Nissen et al. 2001, Rowland et al. 2000), the effect of breast reconstruction on quality of life warrants further consideration, particularly as some women felt well emotionally yet deteriorated in other domains of quality of life. A number of women also reported debilitating physical side effects following reconstruction. This was particularly pertinent with autologous-based reconstructions, specifically TRAM and DIEP flap procedures with women reporting donor site discomfort as a source of physical and psychological distress. This is consistent with literature which suggests the removal of donor site tissue from its native location weakens the abdominal wall (Ceradini and Levine 2008). However, autologous-based reconstructions allow for a more natural breast mound in comparison to implant-based reconstructions. Consequently, many women were able to offset their physical discomfort as they were satisfied with the appearance of their breasts.

Nearly all women experienced a decline in the frequency and satisfaction of their sexual functioning following reconstruction. Multiple components are known to contribute to a decline in sexual functioning including physical illness, anxiety, depression and the physiological changes associated with chemotherapy (Hawton 1991, Kaplan 1992, Speer et al. 2005). Women who described their breasts as an important part of their sexual lives reported a loss of sensitivity negatively affected their sexual functioning. However, only a handful of participants aligned breast sensitivity with sexual enjoyment. Moreover, most women felt their sexual attractiveness returned to their normal levels following reconstruction and some participants felt their sexual attractiveness increased. Consequently, it could be suggested that the reported decline of sexual functioning may be partly attributed to spousal reaction following reconstruction. As research indicates breast cancer can affect a spouse’s level of desire and arousal (Marshall and Kiemle 2005). This may be linked to sexual anxiety in relation to damaging the breasts, inflicting pain and/or causing the cancer to return during sexual intercourse (Marshall and Kiemle 2005). Subsequently, spousal reaction following breast reconstruction requires further research and couples’ needs should be explored in relation to intimate problems following mastectomy and breast reconstruction. In relation to social functioning women’s perspectives were divided with some women reporting improved social functioning following quality of life and others reporting a lack of confidence in social situations following reconstruction. Qualitative literature suggests some women report reduced self-confidence following reconstruction (Abu-Nab and Grunfeld 2007). Moreover, some women described feeling concerned regarding the perception of others, with some women concealing their breast reconstruction due to the fear of appearing vain.

In regards to *breast satisfaction,* most women positively appraised their breast appearance and described realistic appearance expectations. However, three women experienced significant and extended distress due to the appearance of their breasts. This is consistent with previous research which suggests some women have unresolved and ongoing emotional problems following reconstruction (Murry et al. 2015). Additionally, some participants described declining appearance satisfaction over time, due to either ptotic nature of autologous-based reconstruction or the fuller projected breast implant-based reconstruction affords. However, others reported improved satisfaction over time due to gradual acceptance of the reconstructed breast and further corrective and surgical procedures. This is in line with current literature which suggests women enter a period of initial physical and psychological adjustment following delayed and even immediate reconstruction (Hill and White 2008). Many women discussed the inevitability of scarring and nearly all women perceived their scars in a positive manner, as their scars represented their reconstructive journey and signified survival. Similarly, both quantitative and qualitative literature indicates scarring is not a major concern for women following reconstruction (Abu-Nab and Grunfeld 2007, Shakespeare and Hobby 2001), as women view their scars as a symbol of their survival, providing a constant reminder of their strength and journey (McKean, Newman and Adair 2013). Women described nipple-areolar complex reconstruction as representing the final chapter of their journey. Similarly, Marshall and Kiemle (2005) reported nipple-areolar complex reconstruction is often deemed as the ‘‘*finishing touch*’’ to the breast and allows the breast to more closely resemble its natural form. However, nearly all women reported declining satisfaction over time. This is consistent with contemporary evidence which indicates nipple-areolar complex tattoos are prone to significant fading and often result in patients seeking revisions (Levites et al. 2017). However, only a small proportion of women in this study sought revisions and many described fading as unavoidable.

In relation to the theme *outcome satisfaction*, many women were satisfied with the outcome of their breast reconstruction, yet on reflection a number of women would not have opted for reconstruction due to appearance and/or operational discomforts. This is consistent with previous literature which suggests some women underestimate the obstacles reconstruction presents (Murray et al. 2015), and the enormity of the surgical procedure (Loaring et al. 2015). This finding is also reflective of the National Mastectomy and Breast Reconstruction Audit (2011) which reported the need to improve the quality and availability of preoperative information in order to enable women to understand the physical impact of surgery. Many women had realistic expectations of the recovery period, although others described unrealistic recovery expectations in relation to the complexity of the procedure, despite this being emphasised by many of the women’s plastic surgeons. It is suggested that plastic surgeons have a crucial role in setting reconstructive expectations, although during this distressing period further clinical support may be required for women to internalise this information. Many women considered breast reconstruction as positively impacting their lives by restoring and in some cases enhancing their confidence, although others reported a decline in confidence following reconstruction. Around half of the women reported concerns of recurrence and many of the women attributed their fears to no longer being able to have a mammogram on the affected breast(s). This finding is novel and may suggest women undergoing breast reconstruction are increasingly likely to experience the fear of recurrence. This undoubtedly requires further research in order to provide appropriate support to minimise the fear of recurrence following breast reconstruction. Overall, twenty out of twenty-five women defended their decision to elect for breast reconstruction, suggesting reconstruction allowed for a sense of normality, closure and a renewed appreciation for life. However, five women expressed regret following reconstruction and attributed this to restrictive movement, operational discomfort, fear of recurrence, implant longevity and hasty decision making.

6.9 Study Limitations

This study yields valuable insights into post-mastectomy breast reconstruction, although there are methodological limitations. Firstly, template analysis typically affords across case rather than within case analysis, the result of which is slight loss of the holistic nature of individual experiences. Nevertheless, template analysis and the selective use of *a priori* themes allows for the most important measures of surgical success, satisfaction and quality of life to be captured and the breadth of experience to be recognised. Moreover, template analysis emphasises the various dimensions of breast reconstruction, therefore is a useful tool to develop interventional support for women following reconstruction. Secondly, the time since reconstruction varied and it is likely that women’s experiences and outcomes change over time. Thirdly, given the retrospective study design it is possible women may not have recounted all aspects of their experiences. However, literature suggests memories of emotionally salient experiences are enhanced over time (Yonelinas and Ritchey 2015), arguably mitigating this potential limitation. Consequently, future research should consider the experience of post-mastectomy breast reconstruction from a prospective, longitudinal stance.

6.10 Clinical Implications

The findings of this study could be used to inform women of the possible outcomes following post-mastectomy breast reconstruction. Moreover, the findings allow researchers and clinicians to focus on specific dimensions of satisfaction and quality of life which require improvement (e.g. physical, sexual and social functioning), in order to support the unmet needs of women following breast reconstruction. In addition, this study presents two novel findings. Firstly, approximately half of women experienced fear surrounding cancer recurrence and this was attributed to not attending routine mammograms following reconstruction. This finding may suggest women electing to reconstruct the breast are increasingly likely to experience the fear of recurrence. This finding is unique to the breast reconstruction population, although may also apply generally to mastectomized women. This undoubtedly requires further research in order to provide appropriate support to minimise the fear of recurrence following breast reconstruction. Secondly, some women experienced declining appearance satisfaction over time due to either the ptotic nature of autologous-based reconstruction or the fuller projected breast implant-based reconstruction affords. This finding also warrants further longitudinal research to ensure clinicians are guiding patients to the most suitable types of surgical technique for short and long term patient satisfaction.

6.11 Reflections

This study also presented some challenges including recruitment difficulties and timescales. In the design and development stage of this study access to NHS patients was initially discouraged by clinicians due to the risk that patients with negative reconstructive experiences may experience distress recalling details of their reconstructive procedures. This was disappointing as in-depth information of experience from a clinical population could allow for high quality transferable research, although the incorporation of both the clinical and voluntary sector allowed for a comprehensive examination of breast reconstruction within this thesis. Moreover, participants were pleased to be given an opportunity to talk about their experiences holistically, although the recruitment process for this study also took a substantial amount of time. Fifty-eight local and national cancer charities and support groups were contacted of which 21 agreed to participate, and many of these did not have any members who elected for breast reconstruction. As a consequence, the recruitment process took substantially more time than anticipated. However, allowances were accounted for in the initial development of this study and other areas of the thesis were developed during recruitment lulls.

6.12 Conclusion

This thesis assumes the biopsychosocial framework and this framework facilitates the exploration of women’s subjective experience following post-mastectomy breast reconstruction. The findings suggest women positively appraise their breast appearance and are satisfied with the outcome of their reconstruction. However, women also report improved emotional functioning, yet this is often accompanied with a substantial deterioration in physical, sexual and social functioning. As previously acknowledged, this thesis employs a sequential explanatory design which allows the thesis to integrate the strengths of quantitative and qualitative research and minimise their weaknesses. This design also allows for consideration of the previous quantitative findings, in order to develop multiple perspectives and a deeper understanding of the data. Through the collection and analysis of primary data chapters 4 and 5 present an in-depth understanding of the unmet needs of women following post-mastectomy breast reconstruction. The following chapter will identify appropriate interventions and examine the efficacy of these interventions to meet the unmet needs of women.

Chapter 7.0: The Efficacy of Interventions to Improve Psychosocial Outcomes following Surgical Treatment for Breast Cancer: A Systematic Review and Meta-Analysis

7.1 Overview

The previous two chapters have examined satisfaction and quality of life using both quantitative and qualitative methodology, and highlight the unmet needs of women following post-mastectomy breast reconstruction. Consequently, this chapter examines the efficacy of interventions in relation to some of the psychosocial outcomes identified in the previous chapters. The chapter begins introducing the reader to the topic area and defines and evaluates some of the psychosocial outcomes associated with breast conservation, mastectomy and breast reconstruction (6.2). Chapter 6 details the systematic reviews search, selection and review strategy (6.3), the meta-analysis strategy (6.4), and potential sources of bias (6.5). The chapter also reports the systematic review results (6.6), and the meta-analysis results (6.7). The chapter concludes by providing a discussion of the review (6.8), limitations (6.9) and an overall discussion of the chapter (6.10). A component of this research has been published in *Psycho-Oncology* and is displayed in Appendix 14 (Matthews, Grunfeld and Turner 2016).

7.2 Introduction

For many women the period following breast cancer surgery is associated with considerable psychosocial morbidity (Ganz et al. 2003). Evidence indicates following surgical treatment for breast cancer patients experience an increase in psychological distress and a reduction in quality of life (Ganz et al. 2003, Kydd, Reid and Adams 2006). Moreover, body image concerns and sexual difficulties are also significantly higher following surgical treatment (Maguire 2000, Matthews et al. 2017). However, it is often assumed that the distress experienced by women with breast cancer abates after the initial treatment, yet stress-related symptoms may actually increase after surgery as patients leave the “*safety nets*” provided by contact with the oncology teams (Ganz et al. 2003). Furthermore, a meta-analysis reported anxiety after a diagnosis of cancer may persist for up to 10 years or more (Mitchell et al. 2013). Collectively, these findings underscore the need to address the psychosocial wellbeing of breast cancer patients following surgical treatment. Chapter 4 and 5 of this thesis highlighted some of the unmet needs of women following post-mastectomy breast reconstruction. Therefore, the natural progression would be to examine the efficacy of interventions following breast reconstruction. However, due to a paucity of interventional studies examining post-mastectomy breast reconstruction this was not and remains not possible. Subsequently, this chapter examines the efficacy of interventions following breast conservation, mastectomy and breast reconstruction with the view that the efficacy of such interventions may also be applicable to post-reconstruction outcomes alone.

The past decade has seen an increase in the development of interventions to reduce psychosocial morbidity and improve coping and adjustment following breast cancer treatment. Psychosocial interventions are broadly defined as any supportive interaction involving two or more individuals whose purpose is to promote awareness and education, provide emotional support, encouragement and assist with problem solving (Sandgren et al. 2000). Accumulating evidence indicates psychosocial interventions provide a consistent beneficial effect for cancer patients (Meyer and Mark 1995), and specifically breast cancer patients (Burke and Kissane 1998). Psychosocial interventions that have been utilised with breast cancer patients following surgery include group therapy, individual counselling, psychotherapy, and psychoeducational interventions (Burke and Kissane 1998, Newell, Sanson-Fisher and Savolainen 2002). Generally, these interventions have only focused on a limited number of patient outcomes such as anxiety, depression, and quality of life. However, chapters 4 and 5 of this thesis identify a number of other unmet needs including body image, psychological distress and sexual functioning all of which will be examined in relation to interventions in this chapter. Moreover, little is known about which interventions are most effective following breast cancer surgery and evidence in relation to interventions following post-mastectomy reconstruction are extremely limited. Therefore, this systematic review and meta-analysis aims to evaluate the efficacy of interventions on psychosocial outcomes following surgical treatment for breast cancer. Common psychosocial outcomes following surgical treatment and their complex interactions within the context of breast cancer are defined and described below:

Anxiety: Anxiety and depression are the most prevalent comorbidities associated with breast cancer (Baumeister et al. 2010, Härter et al. 2001), with as many as 30% of women reporting to have experienced both anxiety and depression (Kydd, Reid and Adams 2006). Anxiety is the feeling of worry and unease (Lim, Devi and Ang 2001, Mitchell et al. 2013), and is thought to present throughout diagnosis, treatment and even among disease-free survivors (Deshields et al. 2007, Farrell et al. 2005, McGregor and Antoni 2009, Montgomery et al. 2003, Schreier and Williams 2004). Psychosocial factors reported to contribute to postoperative anxiety include body image disturbance (Mosher and Danoff-Burg 2005), sexual dysfunction and a decline in social support (Rustoen et al. 1999). Anxiety is also negatively correlated to treatment outcome (Walker et al. 1999), and may physiological impact on the neuroendocrine and immune system (McGregor and Antoni 2009).

Depression: Depression is a feeling of severe despondency and dejection and is characterised by a sense of sadness, low self-worth, loss of interest, disturbed sleep and appetite, fatigue and poor concentration (World Health Organisation 2016). Depression is associated with poorer adherence to treatment regimens (Ell et al. 2005) and reduced quality of life (Shim et al. 2008). The prevalence of postoperative depression is approximately 33% (Mitchell et al. 2013, Zabora et al. 2001), although is considered underdiagnosed and undertreated in the field of breast cancer (Somerset et al. 2004).

Quality of Life: Quality of life is the appraisal and perception of overall health status and a general sense of wellbeing (Ng et al. 2015). The basic elements of quality of life include the evaluation of physical, physiological, emotional, social and sexual functioning (Aaronson et al. 1993, Hutter et al. 2013, O'Neil et al. 2013). Women experience reduced quality of life following breast cancer surgery (Budden, Hayes and Buettner 2014), and this continues in emotional, social and sexual domains up to five years following surgery (Holzner et al. 2001). Often treatment concerns in relation to quality of life are heightened following surgery as the psychological effects of breast cancer become a reality (Berterö 2002).

Mood Disturbance: Mood disturbance is the fluctuation of affective states (McNair, Lorr and Dropplemann 1992). Mood disturbance is associated with reduced quality of life and has implications for treatment adherence, morbidity and mortality (Bower 2008). However, at present the factors associated with mood disturbance are not clearly understood (Von Ah and Kang 2008). Yet, approximately 20%-39% of women with breast cancer experience mood disturbance (Badger et al. 2004, Bardwell et al. 2006, Fulton 1999, Weitzner et al. 1997), which is thought to persist for years following surgical treatment (Bower 2008).

Psychological Distress: Psychological distress reflects a set of concerns captured by an unpleasant emotional experience of a psychological (cognitive, behavioural and emotional), social or spiritual nature which affects coping ability (National Comprehensive

Cancer Network 2012). The prevalence of distress among women with breast cancer ranges from 20%- 40% (Hewitt, Herdman and Holland 2004). However, there is evidence that rates of psychological distress may be underreported (Pasquini and Biondi 2007), as definitions and measurements of distress vary in research and clinical practice (Hewitt, Herdman and Holland 2004). Psychological distress is associated with the fear of recurrence (Andreu et al. 2012), and is a predictor of poor quality of life (Montazeri 2008).

Body Image: Body image is the mental representation of the body (Cash 2004). Basic elements of body image include the perception of physical appearance, attractiveness, competence, health, wholeness, functioning and sexuality (Carver et al.1998, Cash 2004, Cohen, Kahn and Steeves 1998, Fobair et al. 2006, White 2000). Surgical treatment for breast cancer often affects body image perception due to physical alterations including the removal of a breast or breasts, disfigurement, surgical scars and lymphedema (Helms, O'Hea and Corso 2008, Makari-Judson, Judson and Mertens 2007). Approximately, 50% of women report body image difficulties up to five years after breast cancer surgery (Fobair and Spiegel 2009), and these difficulties are consistently associated with psychological distress, anxiety, sexual dysfunction and impaired quality of life (Carver et al.1998, DeFrank et al. 2007, Falk Dahl et al. 2010, Ganz et al. 1996, Härtl et al. 2010, Soothill et al. 2001). However, due to the subjective nature of the construct it is often conceptually confused and a consistent definition is rarely applied across research (White 2000).

Sleep Disturbance: Sleep disturbance is a severe disorder of sleep patterns which affects physical, mental and emotional functioning (Ancoli-Israel et al. 2006). Sleep disturbance is common in patients with cancer (Davidson et al. 2002, Savard and Morin 2001) and particularly prevalent in breast cancer populations (Davidson et al. 2002, Savard et al. 2001). Patients with breast cancer often report reduced sleep quality and approximately 30% of patients report the use of hypnotics (Davidson et al. 2002, Savard et al. 2001). Sleep disturbance is often considered a side effect of cancer treatment among patients (Budhrani et al. 2015). However, sleep disturbance is also known to persist following treatment with 58% of patients reporting sleep disturbance up to four years after breast cancer surgery (Savard et al. 2005). Sleep disturbance is associated with depression (Ancoli-Israel et al. 2006, Kim et al. 2008) and early mortality among breast cancer survivors (Palesh et al. 2014).

Self-Esteem: Self-esteem refers to the evaluation of the self (Curbow et al. 1990). Self-esteem encompasses the degree of worth, value, respect and love that one possesses (Branden 1994). Reduced self-esteem is a common consequence of cancer and its treatment (Curbow et al. 1990, Quigley 1989), and low self-esteem may persist for several years following mastectomy and with breast reconstruction patients (Berterö 2002). Reduced self-esteem is associated with reduced coping ability and wellbeing and an increase in depressive symptoms (Schroevers, Ranchor and Sanderman 2003).

Sexual Functioning: Sexual functioning is the rate of sexual activity of a cancer patient compared to a healthy age-matched woman (Boehmer et al. 2014). Literature in relation to sexual functioning in breast cancer survivors is relatively comprehensive (Den Oudsten et al. 2010), with between 41%-51% of women experiencing sexual problems (Ganz et al. 2002, Raggio et al. 2014). Common sexual concerns include decreased sexual desire (23%-64%), decreased sexual arousal or vaginal lubrication (20%-48%), anorgasmia (16%-36%) and dyspareunia (35%-38%) (Sadovsky et al. 2010). There is also some evidence to indicate that mood disturbance, quality of life and body image influence sexual functioning (Ganz et al. 1999, Speer et al. 2005), although this evidence base is relatively tentative.

7.3 Methods: Search, Selection and Review Strategies

Following ethical approval (P33731), a review protocol was developed and followed, although is not available to access. A review panel was developed and consisted of two chartered health psychologists, a medical librarian and a consultant plastic surgeon in order to develop an appropriate search strategy. Four methods were used to identify relevant studies: a keyword search, a subject search, a backward search and a forward search. Literature searches were performed using seven electronic databases: PsycINFO (1976-2015), CINAHL (1998-2015), MEDLINE (1975-2015), Academic Search Complete (1980-2015), AMED (1996-2014), Cochrane Library (1975-2015) and EMBASE (1974-2015). The search terms were grouped into three blocks: Block 1 - breast neoplasm*, breast oncol*, breast cancer, breast tumo?/#r; Block 2; mastectom* lumpectom*, prophylactic; Block 3 - family therap* group therap*, psychosocial rehabilitation, anxiety management, relaxation therap*, cognitive therap*, cognitive behavio?/#r* therap*, social support, support groups, counsel*, counsel?/#ing, group counsel*.

The key word search strategy employed a truncation (asterisk) to find singular and plural forms of words and variant endings. For example, the term therap* will retrieve references which contain any of these words: therapy, therapies, therapist or therapists. A wildcard (hashtag) was also used to find variants of key words, specifically in relation to British and American spelling. For example, the term behavio?/#r* uses the question mark symbol or hashtag depending on the database to retrieve references containing behaviour or behavior. The terms relating to the types of surgical procedures (Block 2) were combined with the Boolean operators OR and NOT prophylactic, referring to prophylactic mastectomy. Terms within each block were combined using OR, then the results of each block were combined using the AND function. Duplicates were excluded.

Search results were reviewed by the researcher and supervisory team by reading through study titles to remove any clearly non-relevant articles based on the inclusion and exclusion criteria. The remaining study abstracts were read and judged as either relevant to this review, possibly relevant or definitely not relevant based on the inclusion and exclusion criteria. All studies deemed to be relevant or possibly relevant were read in full and independently judged against the inclusion and exclusion criteria by the researcher and supervisory team. All relevant studies were independently extracted into an excel spreadsheet by the researcher. Inclusion criteria were as follows: (i) female adult breast cancer survivors; (ii) any type of primary breast cancer surgery including mastectomy, breast conservation surgery and reconstruction; (iii) any psychological, psycho-educational and/or psychosocial interventions; (iv) written in English; (v) quantitative methodology; (vi) presenting empirical findings. Studies were excluded if interventions focused on physical rehabilitation, physiological outcomes, and palliative and/or metastatic breast cancer or published as conference abstracts or case studies. Disputes were resolved through consultation between the researcher and supervisory team until a consensus was obtained. A backward (reference) search and a forward (citation) search was also performed. The backwards search involved hand searching the reference list of articles included in the analysis. The forwards (citation) search was performed using Scopus, the abstract and citation database. Review articles were also obtained and examined in order to identify any additional articles.

The researcher and supervisory team independently applied a 14 item quality assessment checklist from a standardised tool to each study (Kmet, Lee and Cook 2004). Discrepancies between the researcher and supervisory team were systematically resolved by consensus or by consultation with a third reviewer. Each item of the quality assessment checklist is a question in relation to how the study was conducted and/or reported, e.g. ‘Design evident and appropriate to answer study question?’. Each item has four possible responses ‘yes’, ‘partial’, ‘no’ or ‘n/a’. Items were given a score of two if the answer is yes, one if the answer is partial and zero if the answer is either ‘no’ or ‘n/a’. A total score was calculated by summing the number of “yes” responses, multiplying this by 2 and adding this to the number of partials. If a criterion was not applicable it was excluded from the score calculation. The total possible score was calculated as 28 minus 2 times the number of not applicable. A summary score (total sum/total possible sum) was also calculated representing the methodological quality of each article. These scores were calculated as a linear score from 0-100 and divided into three categories representing low, moderate or high quality studies. Studies with a score of 75 or more were considered high quality, 50-74 moderate quality and 49 or less low quality. This review was conducted in accordance with the preferred reporting for systematic reviews (PRISMA) guidelines, wherever possible (Moher et al. 2009).

7.4 Meta-Analysis Strategy

We used hedges g as the effect size statistic. Hedges g calculates the difference between intervention and control group means (*d*) divided by the pooled standard deviation (SD) multiplied by factor (*J*) that corrects the underestimation of the population SD (Borestein and Hedges 2009). Through pooling variances, hedges *g* standardises outcomes across studies and allows for comparison among disparate outcome measures. The effect size calculations used a random effects model. This assumes that analysed studies represent a random sample of effect sizes, facilitating the generalisability of results (Borenstein et al. 2009). The heterogeneity between studies was calculated using the Q statistic and the heterogeneity I^2 statistic. The Q statistic was used to test the significance of homogeneity. The Q test is computed by summing the squared deviations of each study’s effect estimate from the overall effect estimate, weighting the contribution of each study by its inverse variance (Cochran 1954). The I^2 statistic calculates what proportion (0-100%) of the observed variance reflects variance in true effect sizes, rather than sampling error. A value of 0% represents no observed heterogeneity, an I^2 value of 25%, 50%, and 75% tentatively signify low, moderate, and high heterogeneity between studies (Higgins et al. 2003). To minimise heterogeneity, when studies reported outcomes at multiple time points, the furthest time point was used to calculate effect size. We used the conventional values of effect size (Cohen 1962) in this analysis. An effect size of 0.2 demonstrated a small effect, 0.5 a moderate effect, and 0.8 a large effect. We used the Comprehensive Meta-Analysis software for all statistical analyses (Borenstein et al. 2005).

7.5 Sources of Bias

Mean effects for each outcome were assessed for the degree of publication bias (the preferential publication of studies with positive effects). Publication bias was assessed using two techniques: the examination of funnel plots and estimates of correction, trim and fill. If the points on the funnel plot are evenly distributed between positive and negative effects, bias is lacking within the meta-analysis. If publication bias exist a disproportionate number of studies will fall to the bottom right of the plot (Duval and Tweedie 2000). The trim and fill method attempts to estimate the number of missing studies that may exist in the meta-analysis and correct for funnel plot asymmetry (Duval and Tweedie 2000). Orwin’s fail-safe N was also calculated to assess the robustness of the overall effect (Orwin 1983). This will determine the number of studies with a null effect size required to reduce the overall effect to non-significance. In this meta-analysis the number of studies is represented by *k*.

7.6 Systematic Review Results

The search strategy identified 3,817 records reduced to 1,455 unique articles following the exclusion of duplicates and to 19 articles following the application of the inclusion and exclusion criteria. The search strategy is depicted in Figure 6. A backwards search identified 8 additional articles and a forward search identified 7 further articles, totalling 34 articles. Twenty-one articles were classified as high quality, eleven as moderate quality and two as low quality. Details of each study included in the systematic review are displayed in Table 5. The two low quality articles were removed from the review. In total, 32 articles were included in the review. Twenty-two studies utilised a randomised controlled trial design, 5 pre and post group evaluations, 2 non-randomised controlled studies, 2 single cohort pre & post evaluations and 1 randomised & comparative study design. The articles were based on data collected in numerous countries spanning 4 continents: Asia, Australia, Europe and North America. Follow-up periods ranged from 1 to 36 months with between two and six data collection points. Participant and design characteristics of the 32 studies included in this review are summarised in Table 5.

Figure 6. A Flow Diagram Depicting the Systematic Review Process

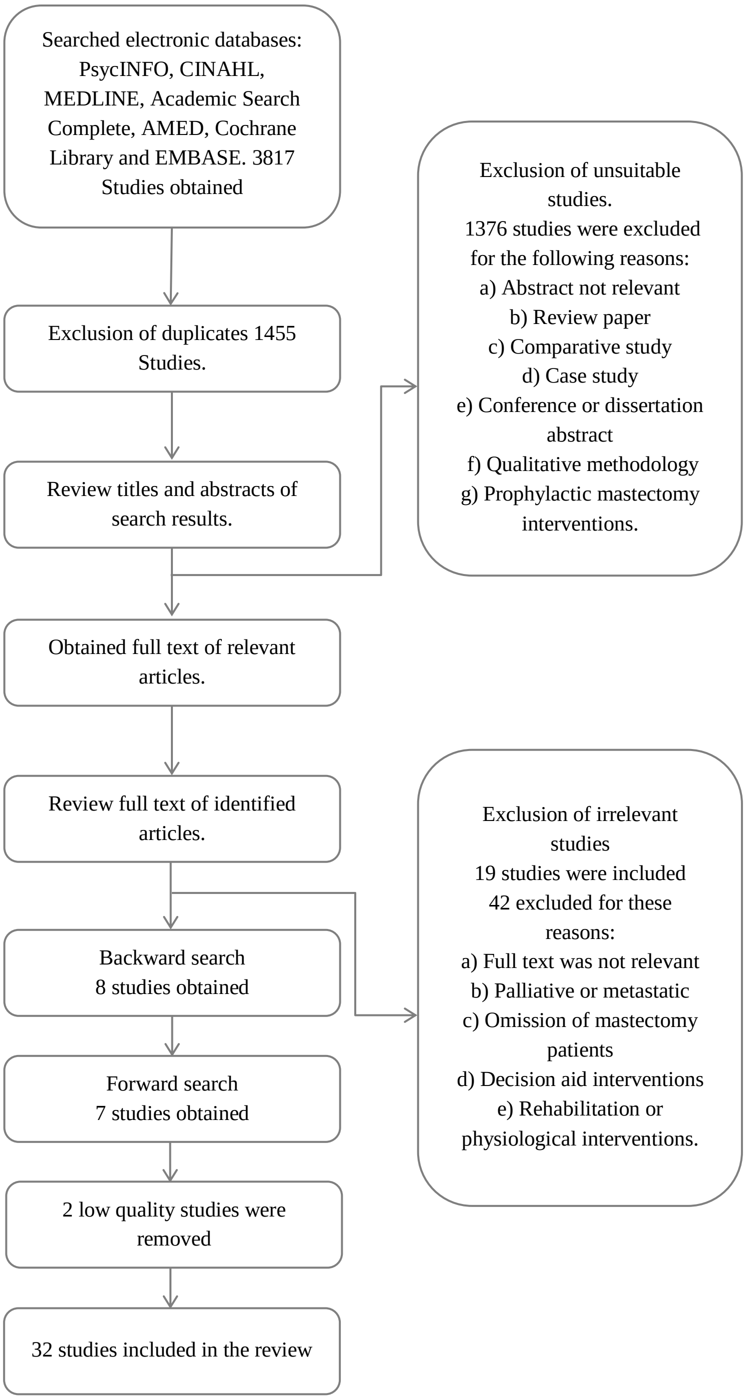


Table 4. Systematic Review of Psychosocial Interventions for Women after Breast Cancer Surgery (*k*=32)

Authors	Study design	Sample size	Intervention	Measures	Outcomes		Quality rating
Antoni et al. 2001 USA	RCT	Int: 46 Comp: 53	Cognitive behavioural therapy	The Profile of Mood States Centre for Epidemiologic Studies Depression Scale Life Orientation Test—Revised	**Distress** **Depression** Optimism	1.77 F=2.33 Int: Q=13.60** Comp: Q=2.67 Int:2.81 Comp=20.15 F=6.96***	High
Antoni et al. 2009 USA	RCT	Int: 63 Comp: 65	Cognitive behavioural therapy	Impact of Event Scale Hamilton rating Scale for Anxiety Affects Balance Scale	**Anxiety** Intrusive thoughts	F = 3.86* F= 3.24*	High
Ashing & Rosales USA	RCT	Int: 100 Comp: 99	Psychoeducational intervention	20 item CES-D	**Depression**	Int: 25.4 ± 17.2*** Comp:14.8 ± 14.1* (CI dif: -5.75 to -0.282)*	High
Charlson et al. USA	Pre & post group evaluation	Int: 46	Contemplative self-healing intervention	The Impact of Events Scale General Functional Assessment of Cancer Therapy Scale + Breast Cancer Subscale FACIT Spirituality Scale	**Quality of life** Spirituality Breast Cancer QoL	4.6 ± 10.9* +1.4±1.0 +4.8± 12.8	High
Cho et al. Asia	Non randomised & comparative	Int: 28 Comp: 27	Psychoeducational intervention & peer support	18-item Psychosocial Adjustment Scale 27-item Quality of Life Scale	Psychosocial adjustment **Quality of life**	Int: 49.1 ± 52.1*** Comp: 50.3 ± 4.73 Int: 6.2 ± 7.0 ** Comp: 6.4 ± 6.3	Moderate
Christensen USA	RCT	Int: 10 Comp: 10	Couples counselling	Locke- Wallace Marital Adjustment Test Sexual Satisfaction Scale Beck Depression Inventory Rosenberg Self-Esteem Scale Spielberger State/Trait Anxiety Inventory (STAI)	Marital happiness **Sexual functioning** **Depression** **Self-esteem** **Anxiety**	Int: 106.15 Comp:99.6 Int: 80.41 Comp: 69.04 F=33.92* Int: 98.18 Comp: 12.02 F=7.53* Int: 17.5 Comp:17.8 Int: 39.9 Comp:40.5	Moderate
Classen et al. USA	RCT	Int: 178 Comp:179	Supportive–expressive group therapy	The Profile of Mood States Questionnaire The Hospital Anxiety and Depression Scale Yale Social Support Index	**Mood** **Anxiety** **Depression** Social support	Int: 13.69 F=4.7* Comp: 9.05 F=6.5*** Int: F=5.4* Comp: F=6.3** Int:F=5.2* Comp: F=5.3* Int:F=6.0* Comp: 5.4*	High
Coleman et al. USA	RCT	Int: 54 Comp: 52	Psychoeducational intervention & social support	Profile of Mood States The visual Analogue Scale–Worry The Relationship Change Scale The 20-item University of California, Los Angeles, Loneliness Scale–Version 3	**Mood** Cancer-Related worry Relationships Loneliness	NS NS NS NS	High

Collie et al. USA	Pre & post group evaluation	Int: 27	Support groups	The Centre for Epidemiologic Studies Depression Scale The Cancer Behaviour Inventory Courtauld Emotional Control Scale	**Depression** Emotional expression Self-efficacy	t=2.44* d=0.51 t=0.44 t=0.71	Moderate
Dow Meneses et al. USA	RCT	Int: 125 Comp: 131	Psychoeducational intervention	Quality of Life-Breast Cancer Survivors	**Quality of life**	Int: -1.687 Comp:-2.909***	High
Esplen et al. USA	RCT	Int: 128 Comp: 65	Support groups	Body Image Scale Objectified Body Consciousness Scale Mental Adjustment to Cancer Scale Female Sexual Function Index Social Support Survey Functional Assessment of Cancer Therapy – Breast	**Body image** Body stigma **Sexual functioning** **Quality of life**	Int:18.3 ± 15.3 Comp:18.5 ± 17.3* Int: 37.5 ± 34.3 Comp: 37.5 ± 37.4*** Int:13.5 ± 15.2 Comp: 12.1 ± 12.7 Int: 91.2 ± 94.8 Comp: 89.8 ± 92.4	High
Fadaei et al. Iran	RCT	Int: 32 Comp: 40	Cognitive behavioural therapy	The body Image Scale (BIS)	**Body image**	Int:16.97 ±9.03 Comp:15.95 ± 17.18 t=-6.07***	Moderate
Fobair et al. USA	Single cohort pre & post evaluation	Int: 20	Supportive–expressive group therapy	The Impact of Event Scale The Profile of Mood States The Hospital Anxiety and Depression Scale The Mini-Mental Adjustment to Cancer The Body Image and Sexuality Scale for Women With Breast Cancer The Family Relations Index The Social Network and Support Assessment The Medical Interaction Scale of the Cancer Rehabilitation Evaluation System The Impact of Illness on Your Life Questionnaire Structured Insomnia Interview	**Mood** **Anxiety** **Depression** Coping **Body image** Relationships Social support Impact of illness on life **Sleep**	t=-2.43* t=-2.52* t=-3.11** t=-3.57** t=0.71 t=-2.78** t=-2.42* t=-1.62 t=2.27*	High
Gunn et al. Australia	Pre & post group evaluation	Int: 44	Support groups	Profile of Mood States The Coopersmith Self-esteem Inventory The Duke UNC Functional Social Support Questionnaire	**Distress** **Self-esteem** Social support	t=3.44*** t=-0.55 t=0.77	Moderate

Hoffman et al. UK	RCT	Int: 103 Comp: 111	Mindfulness based stress reduction	Profile of Mood States Functional Assessment of Cancer Therapy–Breast WHO Five-Item Wellbeing Questionnaire	**Mood** **Quality of life** Well-being	(CI dif:-21.02 to -4.81)*** (CI dif:4.16 to 10.68)*** (CI dif:1.16 to 3.15)***	High
Jones et al. Canada	RCT	Int: 216 Comp: 226	Psychoeducational intervention	Knowledge Questionnaire Perceived Preparedness for Re-entry Scale Self Efficacy for Managing Chronic Disease Profile of Mood States Health Distress Scale	Knowledge Perceived preparedness Self-efficacy **Mood** **Distress**	0.718 (CI dif:0.418 to 1.017)*** 0.409 (CI dif: 0.273 to 0.545)*** -0.221 (CI dif:-0.510 to 0.068) 0.859 (CI dif-2.398 to 4.116) 0.114 CI dif-0.035 to 0.262)	High
Kalaitzi et al. Greece	RCT	Int: 20 Comp: 20	Psychosexual intervention	Speilberger's State Trait Anxiety Inventory (STAI) Centre for Epidemiological Studies-Depression Scale (CES-D) Questionnaire Assessing Sexuality and Body Image	**Depression** **Anxiety**	int: p<0.001*** Comp: p<0.236 int: p<0.006** Comp: p<0.645	Moderate
Kimman et al. Netherlands	RCT	Int: 149 Comp:150	Psychoeducational intervention	The European Organisation for Research and Treatment of Cancer (EORTC QLQ 30) measure State-Trait Anxiety Inventory	**Quality of life** **Anxiety**	NS NS	High
Kionberg et al. Sweden	Non randomised controlled study	Int: 50 Comp: 46	Psychoeducational intervention	The Functional Assessment of Cancer Therapy General Scale (FACT-G) Sense of Coherence Scale	Wellbeing Sense of coherence	NS NS	High
Lengacher et al. USA	RCT	Int: 41 Comp: 43	Mindfulness based stress reduction	30-item Concerns about Recurrence Scale The State-Trait Anxiety Inventory Epidemiological Studies depression Scale 6-item Life Orientation Test 10-item Perceived Stress Scale 19-items Medical Outcomes Social Support Survey	Fear of recurrence **Anxiety** **Depression** Optimism Perceived stress Social support	Int:9.3 Comp:11.6** Int:28.3 Comp:33.0* Int:6.3 Comp:9.6* Int: 46.7 Comp: 44.9 Int: 12.6 Comp:14.4 Int: 12.4 Comp: 12.8	High
Manos et al. Spain	Non randomised controlled study	Int:94 Comp:94	Psychoeducational intervention & cognitive behavioural therapy & social support	The European Organisation for Research and Treatment of Cancer (EORTC QLQ 30) measure Mental Adjustment to Cancer scale.	**Quality of life** Anxious preoccupation Fighting spirit Optimism	F=25.173** F=16.036** F=55.345** F=18.413**	Moderate
Marchioro et al. Italy	RCT	Int: 18 Comp: 18	Cognitive behavioural therapy	Functional Living Index Cancer The Beck Depression Inventory	**Quality of life** **Depression**	Int: 41.17 Comp: 60.28*** Int: 4.83 Comp:8.17***	Moderate

Marcus et al. USA	RCT	Int: 152 Comp: 152	Counselling	Impact of Event Scale Centre for Epidemiologic Studies Depression Scale The Sexual Dysfunction scale	**Distress** **Depression** **Sexual functioning**	p=0.29 r=0.24 p=0.48 r=0.23 p=0.04 r=0.23*	High
Montazeri et al. Iran	Single cohort pre & post evaluation	Int: 56	Support groups	The Hospital Anxiety and Depression Scale	**Anxiety** **Depression**	t=2.21* t=2.75**	Moderate
Qui et al. China	RCT	Int: 31 Comp: 31	Cognitive behavioural therapy	17 item Hamilton Depression Rating Scale Self- Rating Anxiety Scale Functional Assessment of Cancer Therapy- Breast Self-Esteem Scale (SES)	**Depression** **Anxiety** **Self-esteem** **Quality of life**	Int: 7.51 Comp: 14.35 (ES=1.51)*** Int: 37.74 Comp: 43.10 (ES=0.66) Int:28.42 Comp: 27.00 (ES=0.63)* Int: 97.17 Comp: 89.85 (ES=0.53) **	High
Sandgren et al. USA	RCT	Int: 24 Comp: 29	Cognitive behavioural therapy	Coping Response Indices-Revised Profile of Mood States	**Distress** Coping cognitive Coping behavioural Coping avoidant **Anxiety** **Mood**	Int: 8.2 Comp: 7.4 F=4.48* Int:28.9 Comp: 26.7 Int: 31.5 Comp:20.8 Int:11.2 Comp:12.0 Int: 2.9 Comp: 3.6 F=6.29* Int: 2.0 Comp: 3.0 F=3.15*	High
Savard et al. Canada	RCT	Int: 27 Comp: 30	Cognitive behavioural therapy	Insomnia Severity Index Hospital Anxiety and Depression Scale The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire	**Sleep** **Anxiety** **Depression** **Quality of life**	F=11.70*** F=5.19* F=4.14* F=5.69*	High
Sharif et al. Iran	RCT	Int: 49 Comp: 50	Psychoeducational intervention	The European Organisation for Research and Treatment of Cancer (EORTC QLQ 30) Measure	**Quality of life**	Int: 80.0 Comp: 61.66***	High
Stanton et al. USA	RCT	Int:143 Comp: 136	Psychoeducational intervention	Four Item Short Form Vitality Subscale Revised Impact of Events Scale The Centre for Epidemiologic Studies Depression Scale Post-traumatic Growth Inventory Perceived Preparedness for Re-Entry	Vitality **Distress** **Depression** Post-traumatic growth Perceived preparedness	Educ: 7.36 Comp: 6.60 Educ: -0.07 Comp:-0.08 Educ: -0.68 Comp: -1.79 Educ: 5.44 Comp:2.43 B=3.73 (CI:0.95 to 6.52) t=2.64**	High
Watson et al. UK	Pre & post group evaluation	Int: NR Comp: NR	Counselling	Profile of Mood States Speilberger State-Trait Anxiety Inventory	**Mood** **Anxiety**	Int: t=2.98* Comp:t=2.3* Int: 0.5 Comp:4.5	Moderate

Wojtyna et al. Poland	Pre & post group evaluation	Int: 35 Comp:32	Cognitive behavioural therapy	European Organisation for Research and Treatment of Cancer Questionnaire R. Cibor's Self Esteem Scale	**Quality of life** **Self-esteem**	Int: 64.76 Comp:54.86 f=6.33* Int: 27.06 Comp:32.91 f=4.46*	Moderate
Zhou et al. China	RCT	Int: 85 Comp:85	Music therapy & progressive muscle relaxation training	Zung Self-Rating Depression Scale State Anxiety Inventory	**Depression** **Anxiety**	38.29 ± 32.65 F=6.91** 53.98 ± 41.06 F=5.46*	High
p<0.05*	p<0.01**	p<0.001***	**Bold= primary study outcomes**				

7.6 Continued Systematic Review Results

This review comprised of 32 psychosocial interventions with eight studies utilising cognitive behavioural therapy interventions (Antoni et al. 2001, Antoni et al. 2009, Fadaei et al. 2011, Marchioro et al. 1996, Sandgren et al. 2000, Savard et al. 2005, Qiu et al. 2013, Wojtyna, Życińska and Stawiarska 2007), seven psychoeducational interventions (Ashing and Rosales 2014, Dow Meneses et al. 2007, Jones et al. 2013, Kimman et al. 2011, Koinberg et al. 2006, Sharif et al. 2010, Stanton et al. 2005), four support groups (Collie et al. 2007, Esplen et al. 2013, Gunn et al. 2006, Montazeri et al. 2000), and three counselling interventions (Christensen 1983, Marcus et al. 2010, Watson 1989). The review also included two mindfulness based stress reduction interventions (Hoffman et al. 2012, Lengacher et al. 2009), two supportive–expressive group therapy interventions (Classen et al. 2008, Fobair et al. 2002), one psychosexual intervention (Kalaitzi et al. 2007), one music therapy and progressive muscle relaxation training (Zhou et al. 2015) and one contemplative self-healing intervention (Charlson et al. 2005). Two studies also combined psychoeducational interventions and peer and social support interventions (Cho, Yoo and Kim 2006, Coleman et al. 2005), and one intervention which combined cognitive behavioural therapy, social support and psychoeducational elements (Manos et al. 2009). Twenty-five interventions were delivered in-person, six were delivered via telephone and one via videoconferencing. The number of sessions in an intervention ranged from a single session to 30 sessions. The studies reported sample sizes ranging from 20 to 442. The total number of participants across all studies included in this review was 4,148. Twenty-nine of 32 studies reported significant treatment effects in one or more examined outcomes.

Anxiety: Eight studies reported a significant reduction in anxiety following the intervention (Antoni et al. 2009, Classen et al. 2008, Fobair et al. 2002, Kalaitzi et al. 2007, Lengacher et al. 2009, Montazeri et al. 2000, Savard et al. 2009, Zhou et al. 2015). Whilst, two studies demonstrated significant effects with cognitive behavioural therapy on anxiety (Antoni et al. 2009, Savard et al. 2009), two studies reported no significant effects with cognitive behavioural therapy (Qiu et al. 2013, Sandgren et al. 2000). Counselling interventions did not demonstrate significant treatment effects on anxiety (Christensen 1983, Marcus et al. 2010, Watson et al. 1989), and Kimman and colleagues (2011) also reported no significant treatment effects with a telephone educational intervention.

Depression: Thirteen studies reported a significant reduction in depression across a range of interventions including cognitive behavioural therapy (Antoni et al. 2001, Marchioro et al. 1996, Qiu et al. 2013, Savard et al. 2005), a psycho-educational intervention (Ashing and Rosales 2014), a counselling intervention (Christensen 1983), supportive–expressive group therapy (Classen et al. 2008, Fobair et al. 2002), a videoconferencing support group (Collie et al. 2007), a psychosexual intervention (Esplen et al. 2007), mindfulness based stress reduction (Lengacher et al. 2009), a support group (Montazeri et al. 2000), and music therapy & progressive muscle relaxation training (Zhou et al. 2015). No significant treatment effect was reported for telephone counselling (Marcus et al. 2010) or psycho-education with peer modelling on depression (Stanton et al. 2005).

Quality of life: Eleven studies reported improved quality of life across a range of interventions including a contemplative self-healing intervention (Charlson et al. 2005), a psychoeducational intervention (Dow Meneses et al. 2007), mindfulness based stress reduction (Hoffman et al. 2012), cognitive behavioural therapy (Marchioro et al. 1996, Savard et al. 2005, Wojtyna, Życińska and Stawiarska 2007, Qiu et al. 2013), a counselling intervention (Watson et al.1989), a psychoeducational intervention (Sharif et al. 2010), a psychoeducational and peer support intervention (Cho, Yoo and Kim 2006) and combined interventions utilising psychoeducational, cognitive behavioural therapy and social support (Manos et al. 2009). No significant treatment effect was reported for a support group intervention (Esplen et al. 2013), or two psychoeducational interventions (Kimman et al. 2011 and Koinberg et al. 2006).

Mood disturbance: Five studies reported a significant improvement in mood with supportive–expressive group therapy (Classen et al. 2008, Fobair et al. 2002), mindfulness based stress reduction (Hoffman et al. 2012), telephone cognitive behavioural therapy (Sandgren et al. 2000), and counselling (Watson et al. 1989). However, two psychoeducational interventions reported no significant treatment effect on mood disturbance (Coleman et al. 2005, Jones et al. 2013).

Distress: Three studies reported a significant improvement in distress after cognitive behavioural therapy (Antoni et al. 2001), a support group intervention (Gunn et al. 2006), and a relaxation intervention (Fadaei et al. 2011). In contrast, two psycho-educational interventions (Jones et al. 2013, Stanton et al. 2005) and a telephone counselling intervention (Marcus et al. 2010) reported no significant treatment effects.

Body image: Two studies reported significant treatment effects with cognitive behavioural therapy (Fadaei et al. 2011) and support groups (Esplen et al. 2013). No significant treatment effects were observed for supportive expressive group therapy on body image (Fobair et al. 2002).

Sleep disturbance: Two studies reported improved sleep with supportive expressive group therapy (Fobair et al. 2002), and cognitive behavioural therapy (Savard et al. 2005). One study reported a reduction in sleep disturbance was associated with decreased anxiety, depression and improved quality of life (Dow Meneses et al. 2007).

Self-esteem: Two studies reported a significant improvement in self-esteem with Group cognitive behavioural therapy (Qiu et al. 2013, Wojtyna, Życińska and Stawiarska 2007). No significant treatment effects were observed for support groups (Gunn et al. 2006) or couples counselling (Christensen 1983) on self-esteem.

Sexual functioning: Two studies reported significant improvements in sexual functioning through counselling interventions (Christensen 1983, Marcus et al. 2010). However, no significant treatment effects were reported for support groups and sexual functioning (Esplen et al. 2013).

7.7 Meta-Analysis Results

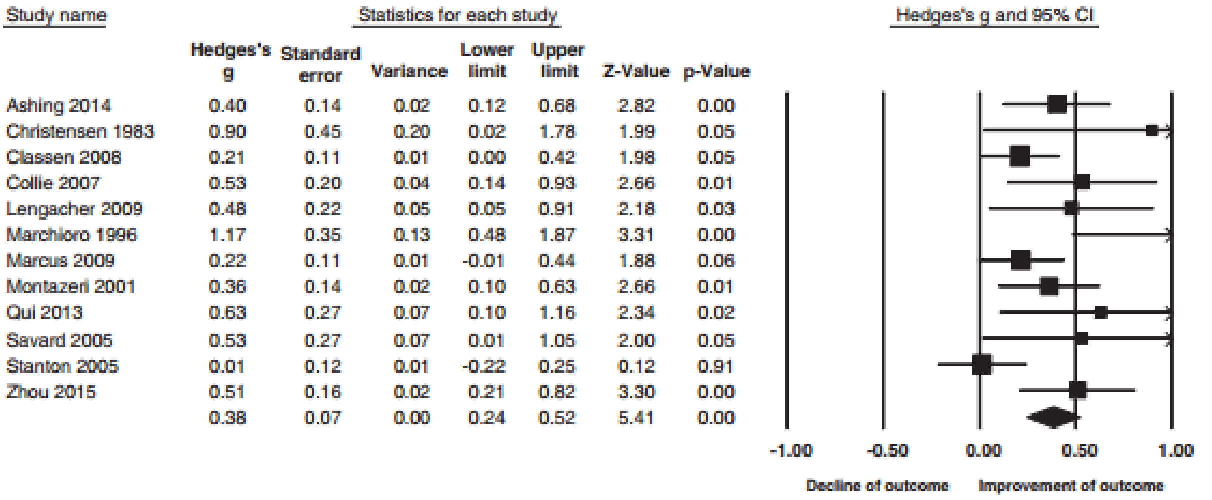
Table 5. Mean Effect Sizes for Psychosocial Outcomes for Review Studies

Psychosocial Outcome	*k*	*Effect size (g)*	*95% CI*	*p-value*	*Heterogeneity*	*Fail-safe N*
Depression	12	0.38	0.24-0.52	0.001	Q=21.52, p=0.04, I^2=44.23	198
Anxiety	10	0.31	0.19-0.43	0.001	Q=12.71 p=0.24, I^2=21.33	81
Quality of Life	12	0.36	0.26-0.45	0.001	Q=20.48 p=0.04, I^2=46.29	189
Body Image	3	0.40	0.16-0.63	0.001	Q=21.68 p=0.33, I^2=7.74	7
Sexual functioning	3	0.22	0.07-0.50	0.14	Q=3.63, p=0.16, I^2= 44.89	2
Sleep disturbance	2	0.67	0.29-1.05	0.001	Q=1.19 p=0.27, I^2=16.52	N/A
Self-esteem	3	0.35	0.00-0.69	0.05	Q=4.14 p=0.12, I^2=51.71	4
Mood disturbance	4	0.31	0.12-0.51	0.001	Q=8.95 p=0.06, I^2=55.33	35
Distress	5	0.27	0.05-0.49	0.02	Q=11.41 p=0.01, I^2=73.72	9

Forest plots displaying the weighted average effect sizes for each psychosocial outcome are displayed in Figure 7. Meta-regression indicated that the number of sessions within an intervention was not a significant moderator of depression (*k*=10: *B*=0.006: *P*=0.49), or quality of life (*k*=11: *B*=-0.016: *P* =0.08). However, the number of sessions was a significant moderator for anxiety (*k*=9: *B*=0.015: *P*=0.04), with the greater number of sessions resulting in a greater reduction in anxiety. In regards to publication bias, all funnel plots displayed a greater number of studies to the right of the mean. However, as a disproportionate number of studies did not fall to the bottom right of the plot this suggests systematic bias does not significantly contribute to the estimate of the efficacy of interventions in relation to psychosocial outcomes. Trim and fill procedures inputted 5 studies for depression, 1 study for anxiety, 4 studies for quality of life, 1 study for sexual functioning, and 2 studies for mood disturbance and distress and no studies were inputted for self-esteem and body image. Orwin's fail-safe N was calculated in order to assess the robustness of the overall effect for each outcome. Orwin's fail-safe N calculated 198 non-significant studies for depression, 81 for anxiety and 189 for quality of life would be required to render the efficacy of the interventions trivial. Orwin's fail-safe N analyses for all outcomes are displayed in Table 6.

Figure 7. Forest Plots displaying the Weighted Average Effect Sizes for Psychosocial Outcomes

Depression

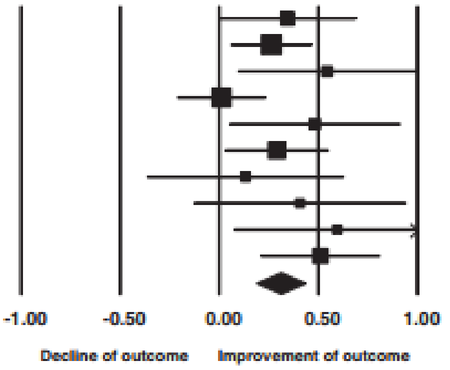


Study name	Hedges's g	Standard error	Variance	Lower limit	Upper limit	Z-Value	p-Value
Ashing 2014	0.40	0.14	0.02	0.12	0.68	2.82	0.00
Christensen 1983	0.90	0.45	0.20	0.02	1.78	1.99	0.05
Classen 2008	0.21	0.11	0.01	0.00	0.42	1.98	0.05
Collie 2007	0.53	0.20	0.04	0.14	0.93	2.66	0.01
Lengacher 2009	0.48	0.22	0.05	0.05	0.91	2.18	0.03
Marchioro 1996	1.17	0.35	0.13	0.48	1.87	3.31	0.00
Marcus 2009	0.22	0.11	0.01	-0.01	0.44	1.88	0.06
Montazeri 2001	0.36	0.14	0.02	0.10	0.63	2.66	0.01
Qui 2013	0.63	0.27	0.07	0.10	1.16	2.34	0.02
Savard 2005	0.53	0.27	0.07	0.01	1.05	2.00	0.05
Stanton 2005	0.01	0.12	0.01	-0.22	0.25	0.12	0.91
Zhou 2015	0.51	0.16	0.02	0.21	0.82	3.30	0.00
	0.38	0.07	0.00	0.24	0.52	5.41	0.00

Anxiety

Study name	Hedges's g	Standard error	Variance	Lower limit	Upper limit	Z-Value	p-Value
	Statistics for each study						
Antoni 2009	0.35	0.18	0.03	-0.00	0.69	1.95	0.05
Classen 2008	0.26	0.11	0.01	0.06	0.47	2.49	0.01
Fobair 2002	0.55	0.23	0.05	0.09	1.00	2.36	0.02
Kimman 2011	0.01	0.12	0.01	-0.21	0.24	0.10	0.92
Lengacher 2009	0.48	0.22	0.05	0.05	0.92	2.18	0.03
Montazeri 2001	0.29	0.13	0.02	0.03	0.56	2.16	0.03
Qui 2013	0.13	0.26	0.07	-0.37	0.63	0.52	0.60
Sandgren 2000	0.41	0.27	0.08	-0.13	0.95	1.48	0.14
Savard 2005	0.60	0.27	0.07	0.07	1.12	2.23	0.03
Zhou 2014	0.51	0.16	0.02	0.21	0.82	3.30	0.00
	0.31	0.06	0.00	0.19	0.43	4.95	0.00

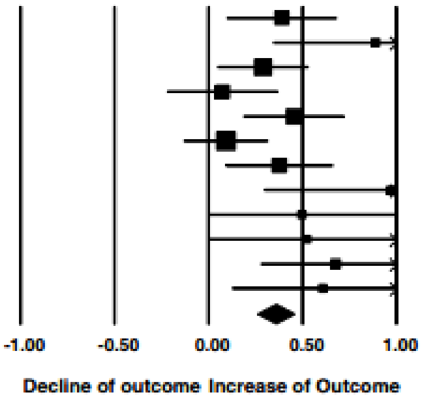
Hedges's g and 95% CI



Quality of Life

Study name	Hedges's g	Standard error	Variance	Lower limit	Upper limit	Z-Value	p-Value
	Statistics for each study						
Charlson 2014	0.39	0.15	0.02	0.09	0.69	2.59	0.01
Cho 2006	0.89	0.28	0.08	0.34	1.44	3.19	0.00
Dow Meneses 2007	0.29	0.13	0.02	0.05	0.54	2.32	0.02
Esplen 2012	0.08	0.15	0.02	-0.22	0.37	0.50	0.62
Hoffman 2012	0.45	0.14	0.02	0.18	0.73	3.29	0.00
Kimman 2011	0.09	0.12	0.01	-0.13	0.32	0.81	0.42
Manos 2008	0.38	0.15	0.02	0.09	0.67	2.58	0.01
Marchioro 1996	0.97	0.35	0.12	0.29	1.65	2.81	0.00
Qui 2013	0.50	0.25	0.06	-0.00	1.00	1.95	0.05
Savard 2005	0.52	0.27	0.07	0.00	1.05	1.97	0.05
Sharif 2006	0.68	0.21	0.04	0.27	1.08	3.30	0.00
Wojtyna 2007	0.61	0.25	0.06	0.12	1.09	2.46	0.01
	0.36	0.05	0.00	0.26	0.45	7.26	0.00

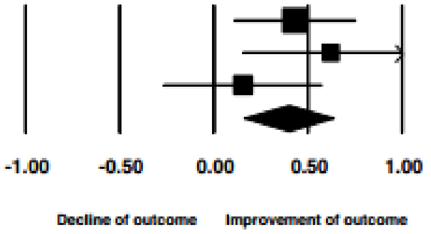
Hedges's g and 95% CI



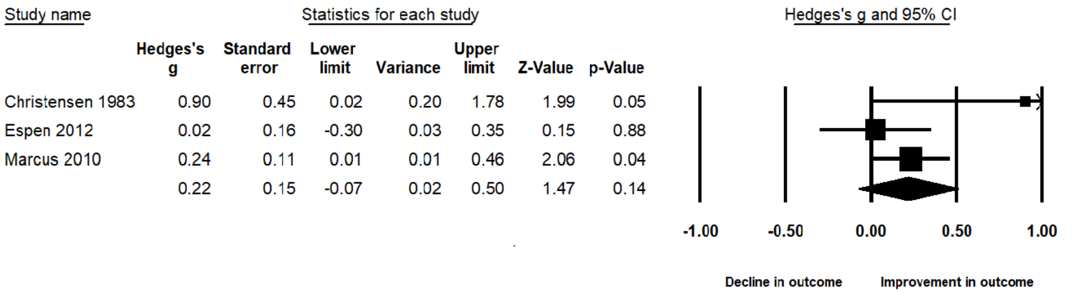
Body Image

Study name	Hedges's g	Standard error	Variance	Lower limit	Upper limit	Z-Value	p-Value
	Statistics for each study						
Esplen 2012	0.43	0.17	0.03	0.10	0.76	2.58	0.01
Fadaei 2010	0.62	0.24	0.06	0.15	1.09	2.59	0.01
Fobair 2002	0.15	0.22	0.05	-0.27	0.58	0.72	0.47
	0.40	0.12	0.01	0.16	0.63	3.26	0.00

Hedges's g and 95% CI

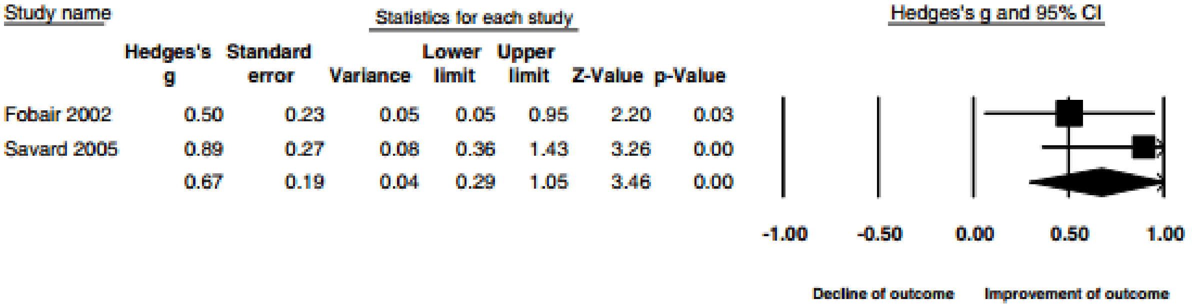


Sexual Functioning



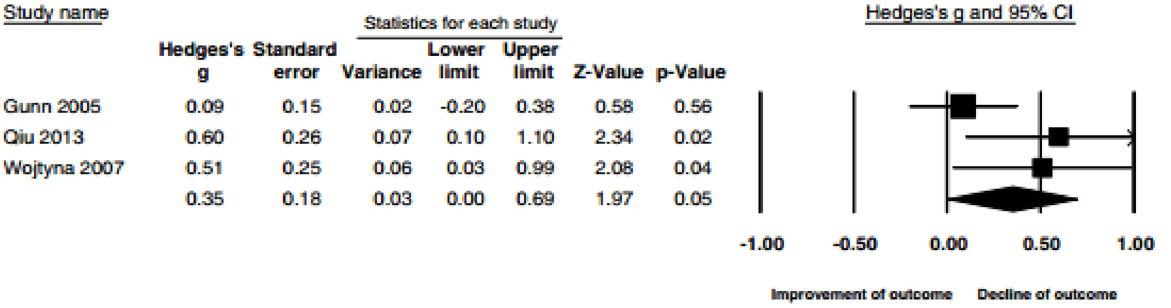
Study name	Hedges's g	Standard error	Lower limit	Variance	Upper limit	Z-Value	p-Value
	Statistics for each study						
Christensen 1983	0.90	0.45	0.02	0.20	1.78	1.99	0.05
Espen 2012	0.02	0.16	-0.30	0.03	0.35	0.15	0.88
Marcus 2010	0.24	0.11	0.01	0.01	0.46	2.06	0.04
	0.22	0.15	-0.07	0.02	0.50	1.47	0.14

Sleep Disturbance



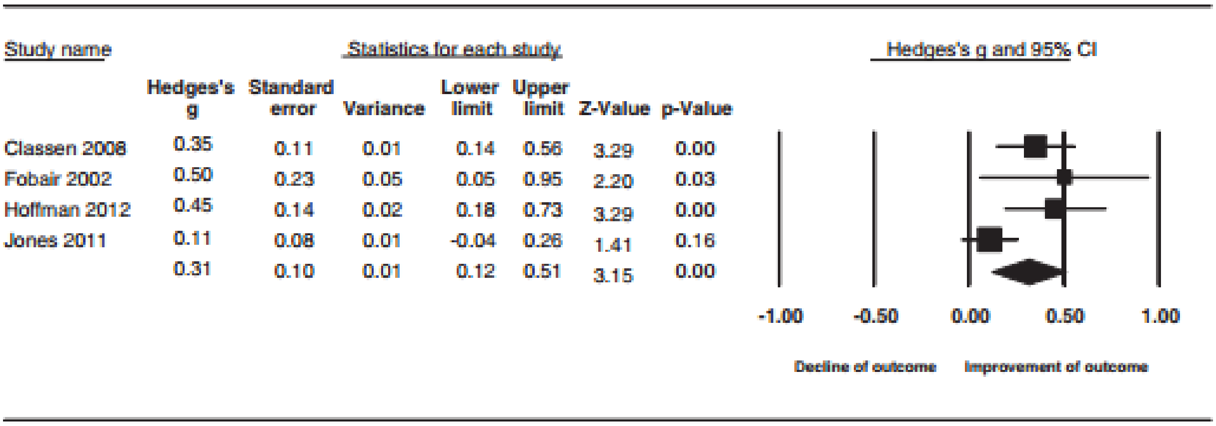
Study name	Hedges's g	Standard error	Variance	Lower limit	Upper limit	Z-Value	p-Value
	Statistics for each study						
Fobair 2002	0.50	0.23	0.05	0.05	0.95	2.20	0.03
Savard 2005	0.89	0.27	0.08	0.36	1.43	3.26	0.00
	0.67	0.19	0.04	0.29	1.05	3.46	0.00

Self-Esteem



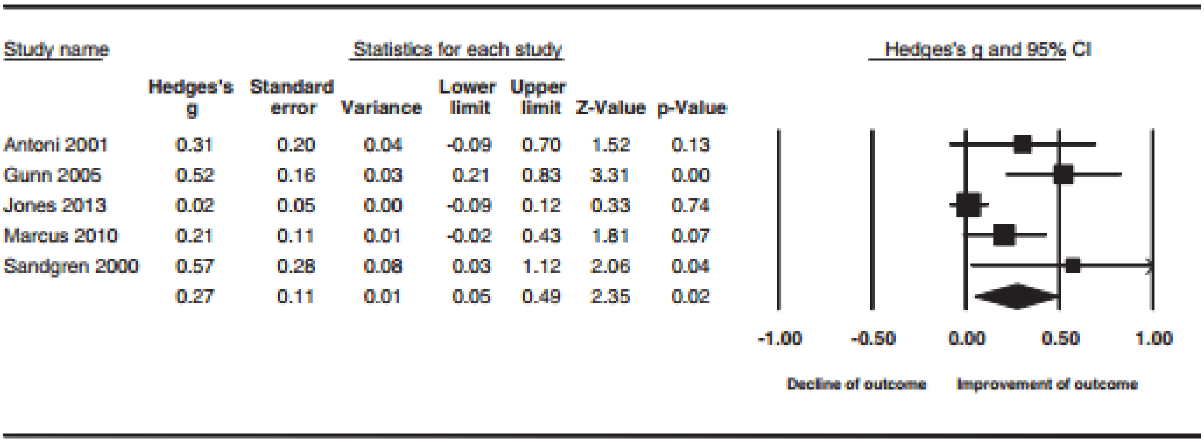
Study name	Hedges's g	Standard error	Variance	Lower limit	Upper limit	Z-Value	p-Value
	Statistics for each study						
Gunn 2005	0.09	0.15	0.02	-0.20	0.38	0.58	0.56
Qiu 2013	0.60	0.26	0.07	0.10	1.10	2.34	0.02
Wojtyna 2007	0.51	0.25	0.06	0.03	0.99	2.08	0.04
	0.35	0.18	0.03	0.00	0.69	1.97	0.05

Mood Disturbance



Study name	Hedges's g	Standard error	Variance	Lower limit	Upper limit	Z-Value	p-Value
Classen 2008	0.35	0.11	0.01	0.14	0.56	3.29	0.00
Fobair 2002	0.50	0.23	0.05	0.05	0.95	2.20	0.03
Hoffman 2012	0.45	0.14	0.02	0.18	0.73	3.29	0.00
Jones 2011	0.11	0.08	0.01	-0.04	0.26	1.41	0.16
	0.31	0.10	0.01	0.12	0.51	3.15	0.00

Distress



Study name	Hedges's g	Standard error	Variance	Lower limit	Upper limit	Z-Value	p-Value
Antoni 2001	0.31	0.20	0.04	-0.09	0.70	1.52	0.13
Gunn 2005	0.52	0.16	0.03	0.21	0.83	3.31	0.00
Jones 2013	0.02	0.05	0.00	-0.09	0.12	0.33	0.74
Marcus 2010	0.21	0.11	0.01	-0.02	0.43	1.81	0.07
Sandgren 2000	0.57	0.28	0.08	0.03	1.12	2.06	0.04
	0.27	0.11	0.01	0.05	0.49	2.35	0.02

7.8 Discussion

To my knowledge, this is the first meta-analysis to evaluate the efficacy of interventions on psychosocial outcomes in breast cancer patients following surgical treatment. The meta-analysis demonstrated small effect sizes on eight psychosocial outcomes: anxiety, depression, quality of life, mood disturbance, distress, body image, self-esteem and sexual functioning. A moderate to large effect size was detected on sleep disturbance. Within this meta-analysis anxiety (*k*=10), depression (*k*=12) and quality of life (*k*=12) were the most commonly reported outcomes. This is not surprising given the high incidence of anxiety and depression after surgical treatment for breast cancer, with 30% of women reporting to experience both anxiety and depression (Kydd, Reid and Adams 2010), and the recognised impact on quality of life (Ganz et al. 2003). Moreover, cognitive behavioural therapy was the most common intervention for anxiety, depression and quality of life often reporting significant treatment effects (Antoni et al. 2001, Antoni et al. 2009, Marchioro et al. 1996, Qiu et al. 2013, Savard et al. 2005, Wojtyna, Życińska and Stawiarska 2007).This meta-analysis provides clear evidence for the efficacy of cognitive behavioural therapy in improving outcomes in relation to anxiety (Antoni et al. 2009, Esplen et al. 2013, Montazeri et al. 2000, Sandgren et al. 2000), depression (Antoni et al. 2001, Esplen et al. 2013, Marchioro et al. 1996, Qiu et al. 2013) and quality of life (Marchioro et al. 1996, Qiu et al. 2013, Savard et al. 2005, Wojtyna, Życińska and Stawiarska 2007). Meta-regression indicated the number of sessions was not a significant moderator of depression or quality of life, although the number of sessions is related to the effect size for anxiety. However, it cannot be concluded if the length of the sessions moderated the effect size, nor the timing of the intervention or who delivered the intervention as a large proportion of the studies did not report these important intervention details. This should be addressed in future research in order to develop effective evidence based interventions to enhance breast cancer care following surgical treatment.

Previous literature indicates cognitive behavioural therapy reduces sleep disturbance (Gielissen, Verhagen and Bleijenberg 2007), insomnia (Ritterband et al. 2012), improves physical activity and quality of life (Armes et al. 2007) following breast cancer. The efficacy of cognitive behavioural therapy has also been demonstrated with adult cancer survivors, with the authors reporting large effect sizes (g=1.99) on anxiety, depression and quality of life based on four studies (Osborn, Demoncada and Feuerstein 2006). Moreover, the efficacy of cognitive behavioural therapy has also been reported within the breast cancer population on anxiety, depression, and quality of life (Naaman et al. 2009). Furthermore, research suggests cognitive behavioural therapy may be effective at all stages of the breast cancer trajectory (Eccles et al. 2013). The findings of this meta-analysis are conservative yet consistent with previous literature. To my knowledge, this meta-analysis is the first to demonstrate the efficacy of interventions on psychosocial outcomes following breast cancer surgery. Previous literature has predominately focused on anxiety, depression and quality of life (Osborn, Demoncada and Feuerstein 2006). These are undoubtedly important outcomes, although this meta-analysis goes beyond this and considers less explored yet emerging research outcomes. However, this meta-analysis cannot conclude if the time period following breast cancer surgery is optimal to provide support for breast cancer patients and this warrants further investigation. Moreover, it is not clear for the other psychosocial outcomes which intervention would be most effective and this should be addressed in future studies. Consequently, robust conclusions cannot be drawn surrounding which intervention would be most effective for specific psychosocial outcomes, with the exception of cognitive behavioural therapy improving outcomes in relation to anxiety, depression and quality of life.

7.9 Limitations

The quality of both the systematic review and meta-analysis is dependent on the quality of studies analysed. One review suggests the more rigorous the review the less likely it is to conclude there is evidence psychosocial interventions in oncology are effective (Lepore and Coyne 2006). Consequently, the design of the studies included must be considered. Whilst the majority of studies utilised a randomised controlled trial study design, a number of studies employed a pre and post-test design. Therefore, in relation to the studies which employed a pre and post-test design the findings may be attributed to changes which occurred independently to the intervention. A number of studies acknowledge an absence in randomisation and/or the process of randomisation did not result in equity between groups. Therefore, further evidence with randomised controlled trials may be required to confirm significant treatment effects are not linked to weaker study design. This meta-analysis did not include unpublished studies, as we considered published peer-reviewed studies would provide the strongest evidence regarding the efficacy of psychosocial interventions. However, the effect sizes may be overestimated with the absence of publication of null findings. This review also reported both primary and secondary outcomes of studies within the meta-analysis. Therefore, there is a possibility of reporting small effect sizes for secondary outcomes. Four studies were excluded because the published data were not suitable for meta-analysis and the required data could not be obtained from the authors (Coleman et al. 2005, Kalaitzi et al. 2007, Koinberg et al. 2006, Watson et al. 1989).

The studies included in this meta-analysis also present a number of limitations. The majority of the studies recruited a sample of highly educated, middle class white women who may be more likely to be motivated to participate in health research. Furthermore, three studies (Ashing & Rosales 2014, Classen et al. 2008, Qiu et al. 2013) utilised samples with clinically depressed and highly distressed participants and one study included women experiencing chronic insomnia (Savard et al. 2005). Consequently, a significant improvement is more likely, as participants who experience considerable psychological symptoms may be more likely to fully engage in interventions. Therefore, participants may benefit more from the intervention and this enhances the likelihood of detecting significant treatment effects (Goodwin et al. 2001).We recommend that researchers should be aware of the sample when assessing the findings. Future studies may want to consider screening for psychological symptoms and including only those participants with elevated scores. This would allow for resources to be targeted at those who would benefit most from the intervention and reduce the likelihood of bias from the ceiling/ floor effects. Seven studies acknowledged limited generalisability from small sample sizes (n<50), and were therefore underpowered to evaluate changes in the multiple outcomes that were measured (Charlson et al. 2005, Christensen 1983, Collie et al. 2007, Fobair et al. 2002, Gunn et al. 2006, Kalaitzi et al. 2007, Marchioro et al. 1996). Notably, studies with low statistical power have a reduced chance of detecting a true effect (Button et al. 2013).

A number of studies also reported limited generalisability from single centre trials and due to the use of a single highly trained therapist within the interventions. Furthermore, many of the interventions included multiple components and subsequently on occasions it was not possible to determine which component an improvement is attributable to. As Czaja and colleagues (2003) acknowledged the decomposition of psychosocial interventions to identify effective components is an important goal within the field of psycho-oncology and should be addressed in future studies. Moreover, no studies included in this meta-analysis evaluated the cost effectiveness of interventions. However, there is a pressing need for studies to address cost issues for breast cancer interventions to determine if the initial intervention cost becomes cost effective over time (Button et al. 2013). For example a reduction in the number of GP visits may result in overall cost-effectiveness of an intervention (Badr and Krebs 2013). We recommend future investigators to consider the cost-effectiveness of interventions, particularly considering different modes of administration (i.e. in-person or over the phone) in order to provide efficient and cost effective support.

7.10 Reflections

Initially, this review sought to examine the efficacy of interventions following breast reconstruction, although due to a lack of literature this was not possible. This was frustrating, although it was at this point it became entirely evident that the literature within this field was complex and the experiences of women were intertwined from diagnosis, treatment and reconstruction. The complexity of the breast cancer experience highlighted the importance of identifying the most clinically relevant outcomes of breast reconstruction and employing well-constructed and validated measures. Future research recommendations are consider in-depth in chapter 8, specifically sections 8.8 and 8.9 of this thesis.

7.11 Conclusion

This chapter evaluates the efficacy of interventions following breast cancer surgery and the findings of the review confirm that cognitive behavioural therapy based interventions typically have ameliorative effects on anxiety, depression and quality of life. Future research priorities should focus on strengthening studies both conceptually and methodologically to meaningfully pool data, in order to determine which interventional components are required to enhance breast cancer survivorship. This chapter provides a methodical, novel and secure evidence base for the efficacy of cognitive behavioural therapy. This is of significant importance given the potential for widespread integration of evidenced-based psychosocial interventions in clinical cancer care. The final chapter of the thesis will draw together the findings from each interrelated study to provide an overall conclusion and a platform to discuss the implications of this thesis.

Chapter 8.0: Discussion and Recommendations

8.1 Overview

The previous chapter sought to examine the efficacy of interventions following surgical treatment for breast cancer. This chapter brings together the key findings from the thesis to provide an overview of psychosocial outcomes following post-mastectomy breast reconstruction and breast cancer surgery. The chapter begins summarising the key findings of the current thesis and situates these findings within the context of existing literature (7.2). The chapter also discusses findings in relation to the development of a theoretical model of psychosocial outcomes following post-mastectomy breast reconstruction (7.3). Chapter 7 considers the key research findings (7.4) and strengths and limitations of the research (7.5). The chapter concludes with implications for policy (7.6), practice (7.7) and research (7.8) and identifies future research directions and proposes an appropriate intervention for the psychosocial problems identified (7.9).

8.2 Results and Consistency of Findings

This thesis contributes to existing literature and advances the knowledge within the field of psycho-oncology. The thesis commenced by examining satisfaction and quality of life following post-mastectomy breast reconstruction. Clinical evidence deemed satisfaction and quality of life as the most important measures of surgical success following breast reconstruction (Ceradini and Levine 2008), although these measures are often conceptually confused and a clear multidimensional definition is rarely applied across research. Therefore, this thesis provides a clear definition of each of the outcomes (i.e. 4.7), increasing the reliability and validity of the findings of the research described in the thesis. Furthermore, the value of distinguishing between satisfaction with the appearance of the breasts (eg, size, shape, symmetry and scarring) and satisfaction with the overall outcome (eg, overall evaluation of surgery, expectations and decision regret) is under-recognised within the field of psycho-oncology. As a consequence this thesis was heavily influenced by the work of Pusic and Colleagues (2009) and Klassen and Colleagues (2009) who also provide clear definitions of outcome measures and distinguish between the types of satisfaction within the Breast Q measure.

The findings from study 1 demonstrate that psychosocial factors were able to predict a high percentage of the total variance for breast satisfaction (75%), outcome satisfaction (68%) and a modest percentage for quality of life (46%). Psychosocial wellbeing was also a predictor of both breast and outcome satisfaction. This is consistent with previous literature which indicates aesthetic satisfaction promotes greater psychological wellbeing (Al-Ghazal, Fallowfield and Blamey 1999). Furthermore, the year of reconstruction was a predictor of breast satisfaction and scarring pain was associated with a decline in outcome satisfaction. This study also revealed two unexpected findings as breast sensitivity increases outcome satisfaction decreases, and as scar thickness increases satisfaction with the overall outcome increases. These findings are inconsistent with some previous qualitative scarring literature (Abu-Nab and Grunfeld 2007), and subsequently warrants further consideration in this section of chapter 7. The type of breast reconstruction also affects both breast and outcome satisfaction, with DIEP patients reporting greater outcome satisfaction compared to other types of reconstruction. This may be because DIEP reconstruction enables women to perceive their reconstructed breasts as a natural part of their own body (Damen et al. 2010), which results in greater acceptance of the reconstructed breast. However, the degree of a plastic surgeons' specialisation may also affect patient satisfaction (Waljee et al. 2007). In this study, the two consultant plastic surgeons specialised in DIEP reconstructions, therefore this finding may not be generalisable to other NHS trusts or independent sites. Nevertheless, this preliminary finding combined with existing research may allow plastic surgeons to make more informed recommendations to women between different types of procedures, which ultimately have the same goal.

The findings from study 1 report that as breast sensitivity increases, outcome satisfaction decreases. This finding was further explored in the qualitative element of this thesis, study 2 which reported that although women who describe their breasts as an important part of their sexual lives report sensitivity loss negatively affecting their sexual functioning, only a handful of participants align breast sensitivity with sexual enjoyment. Therefore, it is suggested that many women accept the loss of breast sensitivity as it ultimately reduces the likelihood of experiencing breast pain in further operational procedures, which are often required. Moreover, study 1 reports that as scar thickness increases, satisfaction with the overall outcome increases and this was also explored in study 2. In chapter 5, many women discuss the inevitability of scarring and nearly all women perceive their scars in a primarily positive manner. This would suggest scars represent women's reconstructive journeys. Therefore, a visually prominent scar may provide an increased sense of wellbeing and thicker scars may provide a more prominent visual representation of survival and resilience. Moreover, often women who elected for nipple-areolar complex reconstruction describe this phase as representing the final chapter of their journey. However, women often report declining satisfaction over time in relation to the fading of nipple-areolar complex tattoos and gradual reconstruction failure.

The findings from study 2 demonstrate that breast reconstruction is an extensive and complex procedure, yet to many women it represents the silver-lining of their cancer experience. This thesis reports most women experience positive emotional gains and a renewed appreciation for life, although these gains are often accompanied with substantial deterioration in physical, sexual and social functioning. This finding highlights the power of emotional functioning in the quality of life domain as some women felt well emotionally, yet deteriorated in other domains of quality of life. Therefore, further research is required to understand the complexities of the interactions of the quality of life domain, particularly as reconstructive surgery attempts to improve both appearance and psychosocial wellbeing (Benditte-Klepetko et al. 2014). The findings also discuss the debilitating physical side effects following breast reconstruction. This was particularly pertinent with autologous-based reconstructions and specifically with TRAM and DIEP flap procedures. However, most women were able to offset their physical discomfort as they were satisfied with the aesthetic appearance that autologous-based reconstructions afforded. Generally, most women were satisfied with their breast appearance. Some women describe improved satisfaction with breast appearance over time, while others report declining appearance satisfaction due to either the ptotic nature of autologous-based reconstruction or the fuller projected breasts implant-based reconstruction affords. Previous research demonstrates the failure of implant-based reconstruction to naturally ptosis as the patient ages as an area of dissatisfaction (Dutra et al. 2012). However, declining satisfaction due to the ptotic nature of autologous-based reconstruction is a unique finding to this study. Therefore, this finding warrants further longitudinal research to ensure clinicians are guiding patients to the most suitable types of surgical technique for both short and long term patient satisfaction.

The findings from study 2 also demonstrate that most women were satisfied with the outcome of their breast reconstruction, although on reflection a number of women would not have elected for reconstruction due to appearance and/or operational discomforts. This is consistent with qualitative literature which suggests women may underestimate the obstacles reconstruction presents (Murray et al. 2015). Most women had realistic expectations of the recovery period, although some described unrealistic recovery expectations in relation to the complexity of the procedure. Moreover, some women conceptualise breast reconstruction as providing closure to their cancer experience and a sense of normality. However, approximately half of the women experienced fear surrounding cancer recurrence. This finding is consistent with previous research which suggests fear of cancer recurrence is a substantial challenge following breast cancer (Pinto & Azambuja 2011, Saquib et al. 2011); however it is inconsistent with breast reconstruction literature, which suggests reconstruction may lessen fear of recurrence (Harcourt et al. 2003, Wilkins 2000). This study attributed fear of recurrence to no longer being able to have a mammogram on the affected breast(s). To my knowledge, this is a novel finding and may suggest women who elect for breast reconstruction are more than likely to experience fear of recurrence. This is also somewhat inconsistent with other literature which suggests the fear of cancer recurrence may be heightened around annual appointments and check-ups (Gill et al. 2004). Therefore, this undoubtedly requires further research to investigate the appropriateness of interventions and support mechanisms to minimise the fear of recurrence following breast reconstruction.

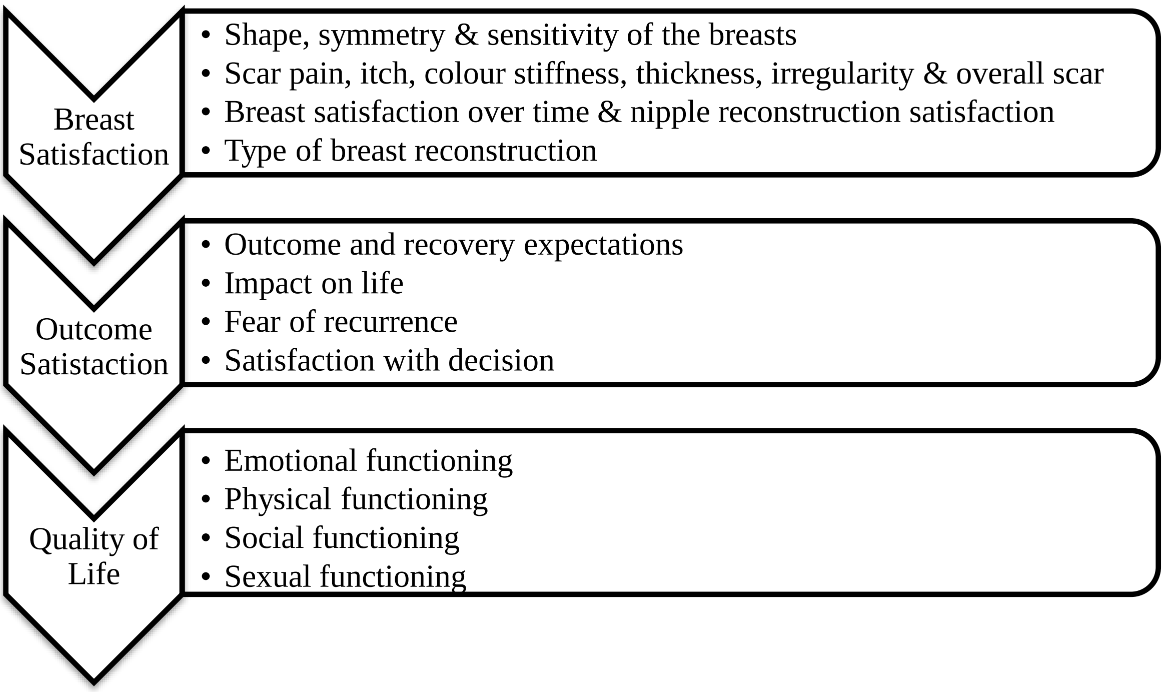
The systematic review and meta-analysis, study 3, examines the efficacy of interventions to improve psychosocial outcomes following surgical treatment for breast cancer. This review identifies psychosocial outcomes of clinical importance following surgical treatment for breast cancer including anxiety, depression, quality of life, mood disturbance, distress, body image, sleep disturbance, self-esteem and sexual functioning. Previous reviews have predominately focused on anxiety, depression and quality of life, therefore this study sought to extend existing knowledge within the field of psycho-oncology. To my knowledge, this is the first systematic review and meta-analysis to demonstrate the efficacy of interventions following surgical treatment for breast cancer. Consistent with previous literature (Naaman et al. 2009, Osborn, Demoncada and Feuerstein 2006), the findings of the review confirm that cognitive behavioural therapy based interventions typically have ameliorative effects on anxiety, depression and quality of life. The literature was and remains insufficient to provide a synthesis of interventions on post-reconstruction outcomes alone, although it is recommended that the efficacy of such interventions is likely to be applicable to post-reconstruction outcomes. Moreover, the findings of this thesis may help to inform more specific forms of cognitive behavioural therapy for women following reconstruction. For example, the findings demonstrate that a suitable target for interventional development may be to address sexual functioning through the use of cognitive restructuring following breast reconstruction. Moreover, the findings of this thesis also identify the need to provide interventional support to address the fear of recurrence and this could be achieved through the provision of risk information and a focus of managing symptoms following reconstruction.

8.3 A Theoretical Model of Breast Reconstruction

This thesis demonstrates the complexity of the breast reconstruction population and highlights the complex interplay of components of breast cancer from the diagnosis of the disease to its complex treatment regimens and surgical treatments. This thesis demonstrates originality as it provides novel findings in relation to post-mastectomy breast reconstruction and examines the efficacy of interventions on psychosocial outcomes following surgical treatment for breast cancer. The thesis draws together the outcomes of breast satisfaction, outcome satisfaction and quality of life with a wide range of additional outcomes including psychological, social, clinical and demographic variables which influence a woman's perspective of breast reconstruction. The research design and analysis of chapters 4 and 5 were guided by Pusic and Colleagues (2009) and Klassen and Colleagues (2009) conceptual models of satisfaction and quality of life in breast surgery patients. This conceptual model defines and examines the most clinically important outcomes (breast satisfaction, outcome satisfaction and quality of life) of breast reconstruction. Moreover, the Breast Q (Pusic et al. 2009) provides a Q score which allows for oncologists, plastic surgeons and breast care nurses to obtain feedback on outcomes of breast reconstruction from the patient's viewpoint. However, this measure has been criticised in relation to the generality of the 0-100 Q score (Swanson 2014), particularly as the usefulness of overall indices has not been established within plastic surgery. This thesis also establishes that although some elements of the Breast Q were accepted by participants others were not. This is demonstrated in Chapter 4 as women raised concerns in relation to the Breast Q measure and suggested this measure did not adequately reflect the depth of their experience. Therefore, it is recommended that the Breast Q measure may be most suitably placed in studies of mixed methodology which would allow for both depth and breadth of the research findings.

However, this thesis identifies the need for researchers and clinicians to be more aware of psychosocial aspects following post-mastectomy breast reconstruction and the importance of satisfaction and quality of life measurements in plastic surgery. The thesis provides clear and concise definitions of each outcome and demonstrates the valuable and unique role of the outcomes in evaluating breast reconstruction. This thesis presents a preliminary theoretical model of breast reconstruction based on previous conceptual models, theoretical frameworks (Fingeret et al. 2013, Klassen et al. 2009, Pusic et al. 2009) and the findings of this thesis. The theoretical model of breast reconstruction is displayed in Figure 8. This model is aligned with the biopsychosocial model which acknowledges the association between mental and physical health is complex and emphasises the importance of a women's perspective. The model was developed in a holistically coherent nature. As the central aim of breast reconstruction is to obtain the best aesthetic outcome, this theoretical model is designed so that breast satisfaction influences outcome satisfaction which both influence quality of life. The model could be used to strengthen existing literature through empirical research in order to establish the degree to which each psychosocial outcome contributes to evaluating the key measures of breast reconstruction. This model and findings of this thesis could also be used to facilitate interventions for the psychosocial adjustment to breast reconstruction.

Figure 8. A Theoretical Model of Breast Reconstruction



There are also considerable opportunities to expand and improve this theoretical model and provide further support for the findings of this study. For example, this thesis acknowledges clinical treatment factors may affect clinical outcomes as the type of breast reconstruction is associated with breast and outcome satisfaction. Demographic variables such as the year of reconstruction are also associated with breast satisfaction. Moreover, this thesis did not report age to be associated with satisfaction or quality of life or any association with demographic factors. However, this is inconsistent with previous literature as other studies acknowledge an association between satisfaction, quality of life and demographic factors (Fingeret et al. 2013). Therefore, it is clear that a myriad of psychological, social and clinical outcomes influence women's perceptions of breast reconstruction. However, further research is required to demonstrate causal relationships between clinical (for example, cancer treatment and reconstruction type) and demographic data (for example, age and marital status). This framework has important clinical implications for developing and delivering psychosocial interventions to provide optimal satisfaction and quality of life. Future research would benefit from utilising a mixed methods model in order provide a real-life contextual understanding and multi-level perspective of this complex health problem.

8.4 Key Research Findings

Study 1

- The identification of three fundamental outcome measures of breast reconstruction: breast satisfaction, outcome satisfaction and quality of life.
- Psychosocial factors were able to predict a high percentage of the total variance for breast satisfaction (75%) and outcome satisfaction (68%), and a modest percentage for quality of life (46%).
- The type of breast reconstruction was found to effect both breast and outcome satisfaction. DIEP patients reported greater outcome satisfaction compared with other types of reconstruction.
- The year of reconstruction was a significant predictor of breast satisfaction.
- Scarring pain was a significant predictor of a decline in outcome satisfaction.
- Psychosocial wellbeing was a significant predictor of breast and outcome satisfaction.

Study 2

- Nearly all women reported improved emotional functioning, although this was often accompanied by substantial deterioration in physical, sexual and social functioning following breast reconstruction.
- Some women reported debilitating physical side effects, specifically with TRAM and DIEP flap procedures.
- Most women embraced the loss of breast sensitivity as it ultimately reduced the likelihood of experiencing breast pain in further operational procedures.

- Many women discussed the inevitability of scarring and nearly all women perceived their scars in a positive manner.
- Nipple-areolar complex reconstruction represented the final chapter of the breast reconstruction journey, although women often reported declining satisfaction over time.
- Twenty out of twenty-five women suggested they were satisfied with their decision to elect for reconstruction, despite appearance or surgical discomforts.
- Approximately, half of the women in this study experienced fear of cancer recurrence. Many women attributed this fear to no longer being able to have a mammogram on the affected breast(s).
- Some women experienced declining appearance satisfaction over time due to either the ptotic nature of autologous-based reconstruction or the fuller projected breast implant-based reconstruction affords.

Study 3

- Psychosocial outcomes of clinical importance following surgical treatment for breast cancer were identified including anxiety, depression, quality of life, mood disturbance, distress, body image, sleep disturbance, self-esteem and sexual functioning.
- Cognitive behavioural therapy promoted improvements in anxiety, depression and quality of life.
- The number of interventional sessions was a significant moderator for anxiety (k=9:B=0.015: P=0.04), as the greater number of sessions promoted a greater reduction in anxiety.

8.5 Strengths and Limitations

This section considers additional strengths and limitations of the research described in chapters 4, 5 and 6, and of the overall thesis. This thesis sought to recruit participants from the NHS and voluntary sector in order to recruit a varied sample, which represented both clinical and support group service users. Recruitment from both sectors proposed unique challenges. The study described in chapter 4 of the thesis recruited women from an NHS site. At this site the researcher worked directly with two consultant plastic surgeons and only had access to the information provided by the surgeons. As a consequence, some clinical characteristics including the type of breast cancer, other treatment types such as chemotherapy, the number of reconstructive surgeries and details in relation to reconstructive complications could not be obtained. This limitation may be of particular importance as such factors may affect satisfaction and quality of life following post-mastectomy breast reconstruction. A further problem with clinical research is the researcher must have an association with clinicians to obtain access to participants and demonstrate the approval of research. This association conflicts with the researchers need to appear neutral and detached from the medical model of breast reconstruction. Therefore, there is a possibility that women who were dissatisfied with aspects of their reconstruction may not have participated or failed to complete the full assessment of the questionnaire.

The qualitative component of this thesis, the study outlined in chapter 5 sought to recruit women from the voluntary sector, specifically from local and national support groups. This recruitment strategy allowed for a more comprehensive account of women's demographic characteristics such as marital status and ethnicity. Furthermore, this recruitment method enabled the collection of more comprehensive clinical characteristics than in chapter 4, including reconstructive complications and treatment types, obtained via the self-report method. This method allowed for unique information in relation to women and their reconstructive experience, although there may be an element of recall bias as some women could not recall the exact medical terms for their complications. However, literature suggests memories of emotionally salient experiences are often enhanced over time (Yonelinas and Ritchey 2015), arguably mitigating this potential limitation. Moreover, some women recruited from the voluntary sector may have a more holistic and formed understanding of their experience through attending support groups. Consequently, this may potentially limit the transferability of the findings. Nevertheless, the methodological design of chapter 5 allowed for an in-depth exploration of the experiences of women following breast reconstruction. Through this research design, the researcher was able to consider how much importance or value women placed upon the outcomes under consideration. For example, some women reported being unsatisfied with their nipple reconstruction over time, yet for most women this was not an important issue and was not associated with their quality of life. The provision of such in-depth information highlights the strengths of qualitative research, as information of this depth would be unobtainable using quantitative methodology.

A limitation of both chapters 4 and 5 of this thesis is the reliance on self-report data. Whilst there are numerous indisputable advantages to the self-report method, the disadvantages of self-report data are widely acknowledged within the literature. Advantages include the ability to extract comprehensive and unique information in relation to experience, the ability of the method to tap directly into women's self-perceived personality and the clarity of communication and ease of administration (Paulhus and Vazire 2007). However, disadvantages of self-report measures include socially desirability bias and a lack of flexibility due to the fixed choice questions (Paulhus and Vazire 2007). Therefore, this somewhat limits the reliability of the findings of chapter 4 and 5 of the thesis. However, Paulhus and Vazire (2007) advocate researchers planning to use self-report measures would benefit from choosing a well-established instrument in order to allow researchers to build on cumulative evidence. Therefore, this thesis applied the Breast Q measure (Pusic et al. 2009) and the conceptual model of satisfaction and quality of life in breast surgery patients (Klassen et al. 2009), as in accordance to the National Mastectomy and Breast Reconstruction Audit (2011) this is the highest standard of methodology and analysis available. As a consequence, this thesis provides valid and reproducible data and allows for the '*benching marking*' of breast reconstruction outcomes in the United Kingdom and internationally (National Mastectomy and Breast Reconstruction Audit 2011).

Chapter 6, the systematic review and meta-analysis used a relatively large number of articles which provided an in-depth examination into the existing interventional literature following breast cancer surgery. However, the studies included in the review used an extensive range of measures to assess each outcome, depicted in Appendix 12. This makes it relatively difficult to provide valid comparisons between studies. Therefore, to enable comprehensive psychological intervention development, researchers must agree which outcomes are of clinical importance and the most appropriate measures to test each outcome. Moreover, this review employed Kmet and Colleagues (2004) 14 item quality assessment checklist and this checklist assumes equal importance for all of the 14 items. However, this review could have also considered the individual importance of each of the 14 items through consolation with an expert in methodology. For example, studies which scored 0 (lowest score) on items such as sample size or items which did not score 2 (highest score) in relation to appropriate outcome measures, conducting appropriate analyses and being able to support conclusions within the data could potentially have been considered as moderate quality. This may have resulted in the inclusion of the two low quality studies excluded from this review. Therefore, future studies may consider assessing the importance of items from standardised assessment measures.

A limitation of this thesis is the omission of pre-surgical data and the retrospective, cross-sectional design. Chapters 4 and 5 employ a retrospective cross-sectional design and this design does not distinguish the direction of relationships or account for the changing nature of outcomes over time. This limitation may be of particular importance as satisfaction and quality of life are thought to fluctuate during long-term survivorship. The design is also problematic as it does not examine changes between pre-surgical and post-surgical functioning. Moreover, this thesis employed a mixed methods design and the studies presented in chapters 4 and 5 assumed triangulation. This type of design is used to obtain different but complementary data on the same topic (Creswell and Plano Clark 2007). However, triangulation may not be fully achieved due to the variation in participant samples in chapters 4 and 5, particularly in relation to the proportions of reconstruction types.

8.6 Implications for Policy

The Oncoplastic Breast Reconstruction Guidelines for Best Practice (2012) called for healthcare providers to consider the psychological wellbeing of breast reconstruction patients. The report recommends women should be informed of the potential emotional and psychological impact before breast reconstruction and have continuous access to support and advice from plastic surgeons and/or specialists breast care nurses. The report also acknowledges that some patients may require further psychological support following discharge. However, The National Mastectomy and Breast Reconstruction Audit (2011) suggests there are only a relatively small number of specialist breast care nurses employed in the English NHS. Therefore, this strengthens the suggestion for the role of specialist breast reconstruction nurses to provide educational and psychosocial support throughout the reconstructive process. This recommendation is consistent with The Oncoplastic Breast Reconstruction Guidelines for Best Practice (2012) for specialist breast care nurses with expert knowledge of breast reconstruction. This thesis also identifies cognitive behavioural therapy as an appropriate and effective source of psychological support for women following breast cancer surgery. Subsequently, specialist breast reconstruction nurses trained in cognitive behavioural therapy techniques would be suitably placed to provide psychological support to those patients who require further support. Moreover, it is of importance that specialist breast reconstruction nurses are aware of some of the common issues highlighted in the research presented. For example, the findings of chapter 5 revealed a number of cognitions that women hold about themselves, their partners, their bodies and particularly their reconstructed breast. Therefore, it is essential that specialist breast reconstruction nurses are appropriately trained. This could be achieved through a professional workshop in order for nurses to support the complex care needs of breast reconstruction patients.

The National Mastectomy and Breast Reconstruction Audit (2011) reported the mean score for sexual wellbeing was substantially lower than the score for other scales included in the report, such as physical wellbeing, emotional wellbeing and satisfaction. This is consistent with the findings of this thesis which suggest that while most women are satisfied with their reconstruction many experienced poorer physical, sexual and social functioning and a decline in overall quality of life. Interestingly, The National Mastectomy and Breast Reconstruction Audit (2011) advised sexual wellbeing is likely to reflect many issues that cannot be dealt with by the surgical team, and therefore do not make any specific recommendations. However, this thesis recommends that specialist breast reconstruction nurses could also be trained to provide psychosexual support. This would position the role of a breast reconstruction nurse to be highly specialised in order to provide coherent and inclusive support for the unmet needs of women following post-mastectomy breast reconstruction. Future research may also consider the feasibility of providing support to spouses, as social support plays an important role in the adjustment to and ability to cope with breast cancer. Subsequently, there remains a need to develop effective interventions to support and educate spouses in relation to breast cancer surgery and the impact this may have on themselves and their partners.

8.7 Implications for Practice

Policy makers should be aware of the findings of this research, although the implementation of these recommendations is likely to remain with clinical staff and most probably breast care nurses. It is suggested that the findings presented in the current research are disseminated to oncologists, plastic surgeons and breast care nurses in a professional healthcare seminar. This thesis demonstrates that women are generally satisfied with the outcomes attained following post-mastectomy breast reconstruction, and this finding is reflective of the National Mastectomy and Breast Reconstruction Audit (2011). The findings of this thesis demonstrate the need for healthcare providers to consider the wellbeing of patients both preoperatively and postoperatively, as predictors of satisfaction and quality of life include breast characteristics (i.e. size, shape and symmetry) and scarring characteristics (i.e. pain, itch and thickness) (i.e. 4.9). Therefore, it could be suggested that if women have realistic aesthetic expectations prior to reconstruction, breast satisfaction rates are likely to be higher following reconstruction. The findings of this thesis should also be used to inform women of the likely outcomes of breast reconstruction and what to expect in relation to different types of reconstructive procedures. This information should augment existing information provided by oncologists, plastic surgeons and breast care nurses to help women make informed choices in relation to breast reconstruction. This would also fulfil one of The Oncoplastic Breast Reconstruction Guidelines for Best Practice (2012) recommendations for women to be informed of the potential emotional and psychological impact of reconstruction prior to the procedure. The findings may also allow clinicians and patients to identify specific areas of focus, which may require further surgical or psychological intervention to enhance both satisfaction and quality of life following surgery. This would allow for resources to be targeted at those who would benefit most and reduce the likelihood of bias from the ceiling/ floor effects within psycho-oncology research.

8.8 Implications for Research

This thesis reports an association between the year of reconstruction and breast satisfaction, specifically, as the year of reconstruction increases satisfaction with breast appearance increases. This finding was attributed to the continuously advancing reconstructive techniques offered which may have led to better cosmetic outcomes and/or the time lag between use of services and evaluation of satisfaction. This would indicate that satisfaction with reconstruction increases over time (i.e. 4.9). However, chapter 5 reported declining appearance satisfaction over time, due to either ptotic nature of autologous-based reconstruction or the fuller projected breast implant-based reconstruction affords (i.e. 5.7). The inconsistency of findings between chapters 4 and 5 of this thesis demonstrate the need for longitudinal breast reconstruction research. Moreover, it is recommended that a breast surgery gallery of before and after photographs is developed, implemented and updated prior to and following post-mastectomy breast reconstruction. Images of women’s breast reconstruction should be taken preoperatively, postoperatively, at 3 months, 6 months and then yearly for approximately 10 years following reconstruction. This would allow for the process of breast reconstruction to be captured longitudinally and enable women to make informed surgical decisions with an understanding of the long-term appearance implications. It is recommended that the breast surgery gallery is a computer program of digital photographs depicting real-life, de-identified breast surgery images. The gallery should contain a range of images and should be surgery specific, and matched by age, size and ethnicity in order for women to be able to relate to the images. A specialist breast reconstruction nurse would be well placed to guide and support women accessing the breast surgery gallery and managing reconstructive expectations. This would also support the recommendation of the National Mastectomy and Breast Reconstruction Audit (2011) which asserts the need to improve the quality and availability of preoperative information to enable women to fully understand the likely aesthetic outcome of breast reconstruction.

8.9 Future Research Directions

Prospective and Longitudinal Study Design: This thesis focused exclusively on post-surgical outcomes, as comprehensive psychosocial evidence is relatively limited and lags behind preoperative and perioperative evidence. However, satisfaction and quality of life with reconstructive surgery stems from a combination of events experienced during preoperative, perioperative and postoperative phases, along with the final aesthetic outcome. Therefore, a prospective, longitudinal questionnaire-based study design would allow for satisfaction and quality of life to be measured over time. Research on long-term outcomes of breast reconstruction is important because reconstructive results appear to evolve over time. This type of design would allow the needs of women to be considered throughout the cancer trajectory and identify long-term issues that may arise as a result of post-mastectomy breast reconstruction. Moreover, this would also allow for the identification of appropriate time-points for the implementation of clinical support. Future research should continue to use the Breast Q measure (Pusic et al. 2009) along with well-chosen supplementary measures in order to produce valid and reproducible data. Future studies should also consider incorporating other scales of the Breast Q measure (Pusic et al. 2009) such as satisfaction with care to provide a more comprehensive examination of the breast reconstruction population. A comprehensive understanding of breast reconstruction may allow for researchers to pinpoint which preoperative and perioperative factors lead to poorer postoperative outcomes. This would allow for policy to be designed to reduce the likelihood of poorer postoperative outcomes and enable optimum use of NHS and independent hospitals resources.

Objective Measures of Breast Reconstruction: This thesis is contextualised within the biopsychosocial model. The biopsychosocial approach is a dynamic, interactional and a dualistic view of human experience with mutual influence of mind and body (Engel 1977). The biopsychosocial approach broadens the scope with which health and illness can be examined in clinical practice. Subsequently, the complex relationship between mental and physical aspects of health and illness can be examined by evaluating the patient's subjective experience alongside objective biomedical data (Borrell-Carrio, Suchman and Epstein 2004). Multiple studies have reported patients assessments of aesthetic outcomes following reconstruction differ significantly from clinician's assessments (Kim et al. 2008, Thomson et al. 2008). Objective methods include physical measurements, laser scanning, MRI, mammography, ultrasound, photography and digital images (Potter et al. 2011). Whilst, such measures have provided some acceptable results there is substantial variability among quantitative outcome measures (Kim et al. 2008). However, 3D imaging technology has been developed which has the potential to allow for consistent and objective assessment of breast reconstruction (Henseler, 2011). Within the field of breast reconstruction evaluating perspectives of reconstructive outcomes is of paramount importance, although evaluating objective experience could allow for inconsistencies in research findings to be further explored. For example, chapter 4 reported that as scar thickness increased, satisfaction with the overall outcome increased. This finding was attributed to the difficulties associated with calculating a precise scar thickness score (i.e. 4.9). However, chapter 5 attributed this finding to the visual prominence of the scar providing women with a greater sense of wellbeing and subsequently greater satisfaction with the overall reconstructive outcome (i.e. 5.7). Therefore, whilst it is widely acknowledged that patients provide a valid and reliable perspective (Black and Jenkinson 2009), future research should also consider evaluating subjective experience alongside objective outcomes to provide a more meaningful understanding of experience.

Cognitive Behavioural Therapy Intervention: This thesis suggests breast reconstruction can offer positive and rewarding outcomes for many women, although for others can be an upsetting and traumatic experience. The efficacy of cognitive behaviour therapy in promoting improvements in anxiety, depression and quality of life following surgical treatment for breast cancer has been demonstrated within this thesis (i.e. 6.8). This finding combined with existing literature suggests that the efficacy of cognitive behavioural therapy may be applicable to post-reconstruction outcomes alone. Eccles and Colleagues (2013) analysis of critical research gaps and translational priorities for the prevention and treatment of breast cancer acknowledged the efficacy of cognitive behavioural therapy within clinical practice. However, the analysis stressed the need to provide a clear understanding of the components of interventions, adherence and long-term benefit, and suggested novel interventions must be developed and validated using methods based upon sound theoretical principles (Eccles et al. 2013). This is consistent with the findings of chapter 6 which highlighted the need for researchers to report a comprehensive account of intervention components and significant details of interventions, such as who delivers the intervention. Therefore, we suggest the implementation of a two phase research and evaluation project which would include a systematic review and a mixed-methods feasibility study.

The systematic review would examine quantitative studies of cognitive behavioural therapy interventions for breast cancer survivors. A review of the literature would allow for the identification of important clinical outcomes of cognitive behavioural therapy, the content of existing interventions, and examination of different modes of delivery to assess the overall efficacy of interventions. This will enable the provision of a consolidated evidence base that will inform the implementation of a feasibility study of a cognitive behavioural therapy for the breast reconstruction population. To my knowledge, there are no existing studies examining cognitive behavioural therapy specifically for the breast reconstruction population, therefore a feasibility study is warranted. The mixed methods study would utilise a pre-test, post-test design with nested qualitative interviews. This would allow for the assessment of the study design and the acceptability of the intervention to patients and clinicians. Moreover, chapter 6 highlights the pressing need for researchers to address cost issues for breast cancer interventions, to determine if the initial intervention cost becomes cost-effective over time (i.e. 6.9). Therefore, future research must evaluate the cost effectiveness of interventions and may consider implementing cognitive behavioural therapy within a group setting, for both cost-effectiveness and practicality.

The intervention should be situated within cognitive behavioural models. Cognitive behavioural models assume that as individuals we are continually processing information and that the nature and results of this processing can be used to understand psychological dimensions of human experience (White 2000). Cognitive behavioural therapy emphasises the importance of identifying predominant processes, beliefs and thoughts that mediate psychological problems to modify and facilitate change in related outcomes (White 2000). Future researchers should utilise a predetermined, highly structured and reproducible cognitive behavioural therapy treatment manual. It is recommended that researchers use the cognitive behavioural therapy five area assessment model (Williams 2001). This model was developed as part of an NHS commission to provide a jargon-free and accessible model of cognitive behavioural therapy for use in clinical settings. The model provides a clear structure to summarise the range of problems and difficulties within each of the five domains: 1) life situation, relationships, practical problems and difficulties, 2) altered thinking, 3) altered feelings, 4) altered physical feelings/symptoms in the body and 5) altered behaviour or activity levels. The findings from this study would determine if recruitment to a full trial is feasible and provide an estimate of the acceptability of a cognitive behavioural therapy intervention for the breast reconstruction population.

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Appendices

Appendix 1: Chapter 4- Consent Form

CONSENT FORM

The PREDICT project: Predictors of satisfaction and quality of life following breast reconstruction.

Lead Researcher: Hannah Matthews

	Initial here
I confirm that I have read and understood the Information Sheet *(PIS PREDICT)* **for the PREDICT study** *(Version 1.1 27/01/2016).* I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my medical care being affected.	
I agree to complete questionnaires.	
I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals within a research team at Coventry University, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records, once my records have been anonymised.	
I agree to take part in the above study.	

Signature of participant Date

Print Name in **CAPTIAL LETTERS** please.

Appendix 2: Chapter 4-Information Sheet

INFORMATION SHEET (PREDICT) (Version 1.1 27/ 01/ 16)

The PREDICT project: Predictors of satisfaction and quality of life following breast reconstruction

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please read through the information sheet carefully and please feel free to contact the researcher (contact details stated below) regarding any questions that you have or if you would like more information. Take time to decide whether or not you wish to take part. Talk to others about the study if you wish.

What is the study about?

Breast cancer remains the most common malignancy among women with over 40,000 cases diagnosed each year in the United Kingdom. The primary treatment for breast cancer is surgical. Whilst any surgical treatment for breast cancer is an emotional experience, mastectomy can be especially difficult, since women face the distress and disfigurement caused by the loss of the breast, in addition to the fear of a potentially life threatening disease. Following mastectomy approximately one third of women choose to undergo breast reconstruction surgery, to reconstruct or reshape the breast. The aim of this study is to identify the factors which predict satisfaction and quality of life among breast cancer patients following breast reconstruction.

Why have I been asked?

You have been contacted by Hannah Matthews (lead researcher), as you have undergone breast reconstruction after breast cancer at University Hospitals Coventry. Coventry University aims to identify the factors which predict satisfaction and quality of life among breast cancer patients following reconstruction. We would like your views and opinions on how to do this.

What am I being asked to do?

We would like you to complete the questionnaire provided in this pack, regarding your satisfaction with your breast reconstruction and quality of life. Questionnaire completion will take around 30 to 45 minutes. The questionnaire will also ask if you are willing to have specific demographic details released: (1) date of breast reconstruction, (2) timing of reconstruction (immediate or delayed), (3) type of reconstruction, (4) age, (5) ethnicity and (6) marital status. Importantly, if you agree to release these details all of your information will be fully anonymised, before it is released to the lead researcher (Hannah Matthews). Your demographic details will be matched with your completed questionnaires by Mr Park’s secretary. The research team from Coventry University will only ever have access to your anonymised data.

Do I have to take part?

No. Participation is entirely voluntary and will not affect your treatment. If you change your mind about taking part in any aspect of the study you can withdraw at any point without having to provide a reason for your withdrawal. There are no consequences to deciding that you no longer wish to participate in the study. If you do decide to withdraw your data you have provided up to that point will be used in an anonymised form for research purposes.

What are the possible disadvantages and risks of taking part?

We are not aware of any risks to you in taking part. We are however aware that there is the possibility that some people may feel upset when answering questions about breast cancer and the reconstruction process. However, we will provide you with a useful contact number for the Cancer Centre, an organisation you can speak to if you require further support.

What are the possible benefits of taking part?

It is hoped that your answers from this questionnaire, will guide us to understand what questions we need to ask ladies in the future, prior to and during breast reconstruction. To ensure that we can understand if we are meeting ladies needs during this time.

What if something goes wrong?

If you change your mind about taking part in the programme you can withdraw at any point. You can email or write to me (see Hannah Matthews contact details). If you have a concern about any aspect of this research, you should ask to speak to the researchers who will do their best to answer your questions (see Hannah Matthews contact details). Coventry University has comprehensive public liability insurance to cover negligent harm. Coventry University's insurers do not automatically provide non-negligent indemnity cover. In those circumstances where non-negligent cover is advised or is essential, cover will be sought on a case to case basis. You can also contact Professor Beth Grunfeld (see contact details).

Will my taking part in this study be kept confidential?

Yes. This study will comply with the Data Protection Act 1998 and your participation will be kept confidential. Only members of the research team will have access to the data. All the consent forms will be stored in a separate, secure (locked) location from the data itself. Any data which may identify you will be locked in a secure filing cabinet and no identifiable information will be included in any report or publication relating to this study.

What will happen to the results of the research study?

The research will be used to highlight the implications of undergoing breast reconstruction, in order to recommend appropriate support for breast reconstruction patients.

Who is organising the research?

The research is being organised by Hannah Matthews (PhD researcher), Professor Beth Grunfeld and Dr Andy Turner, all of whom are based in the Centre for Technology Enabled Health Research (CTEHR) at Coventry University.

Who has reviewed the study?

The study has been approved by Coventry University ethics committee and has gained local NHS trust approval.

Contact for further information

Hannah Matthews
Centre for Technology Enabled Health Research
Faculty of Health and Life Sciences
Richard Crossman Building (4th Floor)
Coventry University
Priory Street
Coventry CV1 5FB
Email: matthe94@uni.coventry.ac.uk

Professor Beth Grunfeld
Centre for Technology Enabled Health Research
Faculty of Health and Life Sciences
Richard Crossman Building (4th Floor)
Coventry University
Priory Street
Coventry CV1 5FB
Email: ab7505@coventry.ac.uk

The Cancer Centre
Macmillan Cancer Information and Support Manager
Deborah Smith
Tel: 024 7696 6052
Email: deborah.smith3@uhcw.nhs.uk

Appendix 3: Chapter 4- Invitation Letter

INVITATION (PREDICT) (Version 1. 29/02/16)

Dear

My name is Hannah Matthews and I am a PhD student at Coventry University. For my PhD, I am aiming to identify which factors predict satisfaction and quality of life among breast cancer patients following reconstruction. We would like your views and opinions on how to do this.

You have been contacted as you have undergone breast reconstruction after breast cancer with Mr Park or Ms Skillman at University Hospitals Coventry. I am inviting you to participate in this research study by completing the attached questionnaire.

The questionnaire will take approximately 30 minutes to complete. It is hoped that your answers from this questionnaire, will guide us to understand what questions we need to ask women in the future, prior to and during breast reconstruction. To ensure that we can understand if we are meeting women's needs during this time.

For more detailed information please refer to the participant information sheet. If you would like to participate in this study please complete the questionnaire and return in the large freepost envelope. Please also return the consent form (orange) in the smaller freepost envelope. If you **do not** wish to take part in the study, please complete the opt-out slip below and return in the smaller freepost envelope.

If you require additional information or have questions, please contact me via the details listed below. Thank you for your consideration in taking part in this research study.

Sincerely,

Hannah Matthews
Centre for Technology Enabled Health Research
Faculty of Health and Life Sciences
Richard Crossman Building (4th Floor)
Coventry University
Priory Street
Coventry CV1 5FB
Email: matthe94@uni.coventry.ac.uk

Participant number

I do NOT wish to participate in the PREDICT research project.
Thank you for your consideration, you will not receive any future correspondence.

Appendix 4: Chapter 4- Postal Questionnaire

THE PREDICT PROJECT QUESTIONNAIRE

SECTION 1: Satisfaction with Breast Reconstruction

The following questions are about your breasts and breast reconstruction surgery. Please **CIRCLE** the number which best describes your situation. If you are unsure how to answer a question, choose the answer that comes closest to how you feel. Please answer all questions. With your breasts in mind in the past two weeks, how satisfied or dissatisfied do you feel with:

	Very dissatisfied	Somewhat dissatisfied	Somewhat satisfied	Very satisfied
1. How you look in the mirror clothed?	1	2	3	4
2. The shape of your reconstructed breast (s) when you are wearing a bra?	1	2	3	4
3. How normal you feel in your clothes?	1	2	3	4
4. The size of your reconstructed breast (s)?	1	2	3	4
5. Being able to wear clothing that is more fitted?	1	2	3	4
6. How your breasts are lined up in relation to each other?	1	2	3	4
7. How comfortably your bras fit?	1	2	3	4
8. The softness of your reconstructed breast(s) ?	1	2	3	4
9. How equal in size your breasts are to each other?	1	2	3	4
10. How natural your reconstructed breast (s) looks?	1	2	3	4
11. How naturally your reconstructed breast (s) sits/hangs?	1	2	3	4
12. How naturally your reconstructed breast (s) feels to touch?	1	2	3	4
13. How much your reconstructed breast (s) feels like a natural part of your body?	1	2	3	4
14. How closely matched your breasts are to each other?	1	2	3	4
15. How your reconstructed breast (s) look now compared to before you had any breast surgery?	1	2	3	4
16. How you look in the mirror unclothed?	1	2	3	4

This question is about breast reconstruction using IMPLANTS. If you do not have an implant (s) please move on to the next box of questions. If you do have an implant (s), please answer the 2 questions below. In the past two weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat satisfied	Very Satisfied
17. The amount of rippling (wrinkling) of your implant (s) that you can see?	1	2	3	4
18. The amount of rippling (wrinkling) of your implant (s) that you can feel?	1	2	3	4

We would like to know how you feel about the outcome of your breast reconstruction surgery. Please indicate with a circle how much you agree or disagree with each statement:

	Disagree	Somewhat agree	Definitely Agree
19. Having reconstruction is much better than the alternative of having no breast (s).	1	2	3
20. I would encourage other women in my situation to have breast reconstruction surgery.	1	2	3
21. I would do it again.	1	2	3
22. I have no regrets about having the surgery.	1		3
23. Having this surgery changed my life for the better.	1	2	3
24. The outcome perfectly matched my expectations.	1	2	3
25. It turned out exactly as I had planned.	1	2	3

With your breast area in mind, in the past two weeks how often have you felt:

	None of the time	A little of the time	Some of the time	Most of the time	All of the Time
26. Confident in a social setting?	1	2	3	4	5
27. Emotionally able to do things that you want to do?	1	2	3	4	5
28. Emotionally healthy?	1	2	3	4	5
29. Of equal worth to other women?	1	2	3	4	5
30. Self-confident?	1	2	3	4	5
31. Feminine in your clothes?	1	2	3	4	5
32. Accepting of your body?	1	2	3	4	5
33. Normal?	1	2	3	4	5
34. Like other women?	1	2	3	4	5
35. Attractive?	1	2	3	4	5

Thinking of your sexuality, how often do you generally feel:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not applicable
36. Sexually attractive in your clothes?	1	2	3	4	5	N/A

37. Comfortable/ at ease during sexual activity?	1	2	3	4	5	N/A
38. Confident sexually?	1	2	3	4	5	N/A
39. Satisfied with your sex-life?	1	2	3	4	5	N/A
40. Confident sexually about how your breast area looks when unclothed?	1	2	3	4	5	N/A
41. Sexually attractive when unclothed?	1	2	3	4	5	N/A

In the past two weeks how often have you experienced:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
42. Neck pain?	1	2	3	4	5
43. Upper back pain?	1	2	3	4	5
44. Shoulder pain?	1	2	3	4	5
45. Arm pain?	1	2	3	4	5
46. Rib pain?	1	2	3	4	5
47. Pain in the muscles of your chest?	1	2	3	4	5
48. Difficulty lifting or moving your arms?	1	2	3	4	5
49. Difficulty sleeping because of discomfort in your breast area?	1	2	3	4	5
50. Tightness in your breast area?	1	2	3	4	5
51. Pulling in your breast area?		2	3	4	5
52. Niggling feeling in your breast area?	1	2	3	4	5
53. Tenderness in your breast area?	1	2	3	4	5
54. Sharp pains in your breast area?	1	2	3	4	5
55. Shooting pains in your breast area?	1	2	3	4	5
56. Aching feeling in your breast area?	1	2	3	4	5
57. Throbbing feeling in your breast area?	1	2	3	4	5

SECTION 2: European Organisation for Research and Treatment of Cancer (EORTC QLQ-30)

	Not at all	**A little**	**Quite a bit**	**Very much**
1. Do you have any trouble doing strenuous activities? For example, lifting a shopping bag.	1	2	3	4
2. Do you have any trouble taking a long walk?	1	2	3	4
3. Do you have any trouble taking a short walk outside of the	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself?	1	2	3	4
During the past week:				
6. Were you limited in doing either your work or activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you lacked appetite?	1	2	3	4
12. Have you felt nauseated?	1	2	3	4
13. Have you vomited?	1	2	3	4
14. Have you been constipated?	1	2	3	4
15. Have you had diarrhea?	1	2	3	4
16. Have you had trouble sleeping?	1	2	3	4
17. Have you felt weak?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things? For example, reading or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered With your life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you any difficulties?	1	2	3	4

Please circle the number between 1 and 7 that best applies to you:

29. How would you rate your overall health_during the last week?									
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Very Poor					Excellent				

30. How would you rate your overall quality of life during the past week?									
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Very Poor					Excellent				

SECTION 3: Breast Shape, Symmetry and Sensitivity

	Very dissatisfied				Very satisfied
Breast shape	1	2	3	4	5
Breast symmetry	1	2	3	4	5

How similar in shape do you feel your two breasts are?									
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Totally Similar					Not Similar At All				

How symmetrical do you feel your two breasts are?									
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Totally Symmetrical					Not Symmetrical At All				

How do you feel that your reconstruction has healed to date?									
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Healed Well					Healed Poorly				

How sensitive do you feel that your reconstructed breast is?									
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
More Sensitive Than Other Breast					Less Sensitive Than Other Breast				

SECTION 4: Scarring

Has the scar been painful the past few weeks?									
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Not At All					Yes Very Much So				

Has the scar been itching the past few weeks?									
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Not At All					Yes Very Much So				

Is the scarring a different colour from the skin at present?									
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No					Yes				

Is the stiffness of the scar different from your normal skin at present?									
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No					Yes				

Is the thickness of the scar different from your normal skin at present?									
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No					Yes				

Is the scar more irregular than your normal skin at present?									
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No					Yes				

What is your overall opinion of the scar compared to normal skin?									
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
As Normal Skin					Very Different				

Appendix 5: Chapter 4- Reminder Letter

REMINDER LETTER (Version 1, 18/11/2015)

Dear

It has now been two weeks since you have received a letter from Mr Park and Ms Skillman introducing a researcher based at Coventry University (Hannah Matthews) and were asked to take part in the PREDICT research project.

At this point we have not received an opt-out slip or completed questionnaire, so we are sending you a duplicate questionnaire in case you may have misplaced the original questionnaire. Please feel free to contact me (Hannah Matthews) if you have any questions or concerns regarding the PREDICT project on matthe94@uni.coventry.ac.uk or alternatively via post (address listed below).

Please ignore this letter if you have recently returned either an opt-out slip or completed questionnaire. If we do not receive an opt-out slip or completed questionnaire, we will assume you do not wish to take part in the PREDICT project and you will not be contacted again. We thank you for your time and consideration.

If taking part in this study has raised any issues or concerns and you require further support please contact:

The Cancer Centre
Macmillan Cancer Information and Support Manager
Deborah Smith
Tel: 024 7696 6052
Email: deborah.smith3@uhcw.nhs.uk

Hannah Matthews
Centre for Technology Enabled Health Research
Faculty of Health and Life Sciences
Richard Crossman Building (4th Floor)
Coventry University
Priory Street
Coventry CV1 5FB
Email: matthe94@uni.coventry.ac.uk

Appendix 6: Chapter 5- Participant Invitation Letter

To whom it may concern,

My name is Hannah Matthews and I am a PhD student based at Coventry University and I wanted to get in touch regarding some research I am currently undertaking.

My PhD focuses on exploring the psychological and social impact of breast reconstruction following mastectomy and for the final year of my PhD, I am running a telephone interview-based study. During each interview women who have undergone breast reconstruction following mastectomy will be asked about their experiences of breast reconstruction. The purpose of the study is to gain an understanding of how people feel after breast reconstruction surgery, as we can then use this information to develop resources and provide support for women making decisions regarding breast reconstruction.

I am writing to ask if you think any suitable members of your group may be willing to take part in a telephone interview (average duration 40 minutes). If you think this may be a possibility, I would be very happy to meet or attend your next meeting to discuss this further or alternatively talk over email or the telephone. My telephone number is 07891180822.

I have attached an information sheet and a consent form which if you feel appropriate could be circulated to members of your group.

I hope to hear from you and thank you for your time.

Best Wishes,

Hannah Matthews
PhD Student

BSc (Hons), MSc (Health Psychology)
Centre for Technology Enabled Health Research
Faculty of Health and Life Sciences
Richard Crossman Building (4th Floor)
Coventry University
Priory Street
Coventry CV1 5FB

Appendix 7: Chapter 5- Information Sheet and Consent Form

Information Sheet for Participants
Version 1.1 (27/10/2016)

The ADAPT Project- Exploring psychosocial outcomes following post-mastectomy breast reconstruction.

We would like to invite you to take part in a research study. Before you give your consent to participate in the research it is important that you understand why the research is being conducted and what you will be asked to do. Please take time to read the following information sheet and discuss it with others if you wish. **You are under no obligation to participate in the study and it is entirely up to you whether you decide to take part in the study or not.**

What is the purpose of the study?
The purpose of the study is to gain an understanding of how people feel after breast reconstruction surgery. The aim of the ADAPT project is to explore how satisfied women are with the appearance of their reconstructed breast(s) and the overall reconstruction process. The study also aims to explore women's wellbeing and quality of life after breast reconstruction surgery. We hope that the information we gain will help us to improve how satisfied women are with their breast reconstruction, as we can then use this information to develop resources and provide support for women making decisions regarding breast reconstruction.

Why have I been chosen?
You have been contacted as you have undergone breast reconstruction after breast cancer and currently attend a support group.

What are you asking of me?
We would like you to take part in a telephone interview to discuss your experience of breast cancer, breast cancer treatment and breast reconstruction. Interviews will last approximately 45-60 minutes. The interviews will be audio taped for the purpose of producing a verbatim (word-for-word) transcript. All information provided will be anonymised and kept confidential so your responses will be unidentifiable.

Who will have access to the recording and transcript of the interview?
Only the researcher (Hannah Matthews) will have access to the recording. The sound file will be stored on a password protected computer at Coventry University and deleted in January 2019. The researcher, supervisors and assessors will have access to fully transcribed anonymised interviews. The transcripts will be stored in a locked filing cabinet at the Coventry University and only the study researchers will have access to this information.

How will you protect my anonymity and that of other people I might mention?
You will be asked to pick a pseudonym (a false name) for yourself and any patients, colleagues or significant others (e.g. friends) that you mention during the interview. This means that your identity will remain fully anonymous. Only the researcher will know your identity.

Will my taking part in this study be kept confidential?

Yes. This study will comply with the Data Protection Act 1998 and your participation will be kept confidential. Only members of the research team will have access to the data. All the consent forms will be stored in a separate, secure (locked) location from the data itself. You will only be identified by your participant code number. Any data which may identify you will be locked in a secure filing cabinet and no identifiable information will be included in any report or publication relating to this study.

What are the possible disadvantages and risks of taking part?

We are not aware of any risks to you in taking part. We are however aware that there is the possibility that some people may feel upset discussing breast cancer, breast cancer treatment and the reconstruction process. However, we will provide you with a useful contact number for Macmillan Cancer Support, an organisation you can speak to if you require further support (see contact details).

What if something goes wrong?

If you change your mind about taking part in the programme you can withdraw at any point. You can email, telephone or write to me (see Hannah Matthews contact details). If you have a concern about any aspect of this research, please speak to the researchers at Coventry University who will do their best to answer your questions (See Hannah Matthews contact details). You can also contact Professor Andrew Turner (see contact details). Coventry University has comprehensive public liability insurance to cover negligent harm. Coventry University's insurers do not automatically provide non-negligent indemnity cover. In those circumstances where non-negligent cover is advised or is essential, cover will be sought on a case to case basis.

What will happen to the results of the study?

The anonymised input to the research will be used for research purposes (publications and conferences) and will inform future research, and the development of resources, to provide support for women following breast reconstruction.

What happens if I have any further questions or concerns?

If you have any further questions or concerns about your participation in this research you can contact Hannah Matthews by telephone 07891180822 or email matthe94@uni.coventry.ac.uk. You can also contact Professor Andrew Turner by email hsx116@coventry.ac.uk or by post at 4th Floor, Richard Crossman Building, Centre for Technology Enabled Health Research (CTEHR), Faculty of Health & Life Sciences, Coventry University, Priory Street, CV1 5FB.

Who is involved in this study?

Primary Researcher
Hannah Matthews
CTEHR/HLS
RC Building
Coventry University
Priory Street
Coventry CV1 5FB
07891180822
matthe94@uni.coventry.ac.uk

Supervisor
Professor Andrew Turner
CTEHR/HLS
RC Building
Coventry University
Priory Street
Coventry CV1 5FB
hsx116@coventry.ac.uk

For Support
Macmillan Cancer Support
0808 808 00 00
http://www.macmillan.org.uk

The ADAPT Project- Exploring psychosocial outcomes following post-mastectomy breast reconstruction.

Consent Form for Participants
Version 1.1 (27/10/2016)

Please tick each statement to indicate agreement:

☐ I have read and understood the information sheet for the above study (Version 1.1 dated 27/10/2016) and have been given the opportunity to ask questions.

☐ I understand that my participation is voluntary and that I am free to withdraw from the study without having to give any reason and without me being affected or this having any negative consequences on my circumstances.

☐ I agree to provide information that will be used for research purposes only. I understand that all the information relating to myself obtained as part of the study will be strictly confidential, and that I will not be personally identified in any write-up of the results. I understand my name and any personal details will be anonymised.

☐ I understand that information will be stored in secured manual and electronic files and is subject to the provisions of the Data Protection Act.

☐ I understand that I am being asked to participate in an interview (approximately 60 minutes in duration) and discuss a series of points relevant to the study. I understand that the whole interview will be recorded.

☐ I wish to participate in this study under the conditions set out here and in the Information Sheet for Participants.

____________________	________________	_______________
Print Name of Participant	Date	Signature
______________________	_________________	________________
Researcher	Date	Signature

Appendix 8: The Development of Coding Templates

Template 1: *A priori* theme codes

1.0 Quality of life

2.0 Breast satisfaction

3.0 Outcome satisfaction

Template 2: First, second and third level theme codes

1.0 Quality of life
- 1.1 Cognitive functioning
- 1.2 Emotional functioning
- 1.3 Physical functioning
- 1.4 Role functioning
- 1.5 Sexual functioning
- 1.6 Social functioning

2.0 Breast satisfaction
- 2.1 Breast aesthetics
  - 2.2.1 Breast aesthetics clothed or unclothed

3.0 Outcome satisfaction
- 3.1 Expectations
- 3.2 Impact on life
- 3.3 Satisfaction with decision

Template 3: First, second and third level theme codes

1.0 Quality of life
- 1.1 Emotional functioning
- 1.2 Physical functioning
- 1.3 Role functioning
- 1.4 Sexual functioning
  - 1.4.1 Breast sensitivity
- 1.5 Social functioning

2.0 Breast satisfaction
- 2.1 Breast aesthetics
  - 2.1.1 Breast aesthetics clothed or unclothed
  - 2.1.2 Breast appearance expectations
  - 2.1.3 Scarring
- 2.2 Nipple reconstruction satisfaction

3.0 Outcome satisfaction
- 3.1 Surgical complications

- 3.2 Outcome expectations
- 3.3 Impact on life
    - 3.3.1 Fear of recurrence
- 3.4 Satisfaction with decision

Template 4: First, second and third level theme codes

1.0 Quality of life
- 1.1 Emotional functioning
- 1.2 Physical functioning
- 1.3 Role functioning
    - 1.3.1 Returning to work
    - 1.3.2 Child centred decision making
- 1.4 Sexual functioning
    - 1.4.1 Undressing
    - 1.4.2 Sexual attractiveness
    - 1.4.3 Frequency of sex life
    - 1.4.4 Breast sensitivity
- 1.5 Social functioning

2.0 Breast satisfaction
- 2.1 Breast aesthetics
    - 2.1.1 Breast appearance expectations
    - 2.1.2 Scarring
- 2.2 Nipple reconstruction satisfaction

3.0 Outcome satisfaction
- 3.1 Surgical complications
- 3.2 Outcome expectations
- 3.3 Impact on life
    - 3.3.1 Fear of recurrence
- 3.4 Satisfaction with decision
    - 3.4.1 Regret

Template 5: First, second and third level theme codes

1.0 Quality of life
- 1.1 Emotional functioning
    - 1.1.1 Striving for normality
- 1.2 Physical functioning
    - 1.2.1 Experiencing breast pain
    - 1.2.2 Donor site discomfort
    - 1.2.3 Prosthesis inconvenience
- 1.3 Role functioning
    - 1.3.1 Returning to work
    - 1.3.2 Child centred decision making
- 1.4 Sexual functioning
    - 1.4.1 Shifting sex life frequency
    - 1.4.2 Sense of sexual attractiveness

    - 1.4.3 Breast sensitivity
- 1.5 Social functioning
    - 1.5.1 Active self-protection following surgery
    - 1.5.2 Social comparisons

2.0 Breast satisfaction

- 2.1 Breast appearance expectations
- 2.2 Breast satisfaction over time
- 2.3 Scarring
- 2.4 Nipple reconstruction satisfaction
    - 2.4.1 Satisfaction with nipple reconstruction over time

3.0 Outcome satisfaction

- 3.1 A sense of overcoming
- 3.2 Surgical complications
- 3.3 Outcome expectations
    - 3.3.1 Underestimating the surgery
    - 3.3.2 Recovery expectations
- 3.4 Impact on life
    - 3.4.1 Altering outlook on life
    - 3.4.2 Fluctuating confidence
    - 3.4.3 Fear of recurrence
    - 3.4.4 Difficulties transitioning to survivorship
- 3.5 Breast sensitivity
- 3.6 Satisfaction with decision
    - 3.6.1. Questioning decision making
    - 3.6.2 Regret

Template 6: First, second and third level theme codes

1.0 Quality of life

- 1.1 Emotional functioning
    - 1.1.1 Striving for normality
- 1.2 Physical functioning
    - 1.2.1 Experiencing breast pain
    - 1.2.2 Donor site discomfort
    - 1.2.3 Prosthesis inconvenience
- 1.3 Role functioning
    - 1.3.1 Returning to work
    - 1.3.2 Child centred decision making
- 1.4 Sexual functioning
    - 1.4.1 Shifting sex life frequency
    - 1.4.2 Sense of sexual attractiveness
    - 1.4.3 Breast sensitivity
- 1.5 Social functioning
    - 1.5.1 Active self-protection following surgery
    - 1.5.2 Concealing reconstruction

2.0 Breast satisfaction

- 2.1 Satisfied with breast appearance
- 2.2 Unsatisfied with breast appearance
- 2.3 Breast satisfaction over time
- 2.4 Breast appearance expectations
- 2.5 Scarring
    - 2.5.1 Acceptance of scarring
    - 2.5.2 Struggling to accept scarring
- 2.6 Nipple reconstruction satisfaction
    - 2.6.1 Satisfaction with nipple reconstruction over time

3.0 Outcome satisfaction

- 3.1 A sense of overcoming
- 3.2 Surgical complications
- 3.3 Outcome expectations
    - 3.3.1 Underestimating the surgery
    - 3.3.2 Recovery expectations
- 3.4 Impact on life
    - 3.4.1 Altering outlook on life
    - 3.4.2 Fluctuating confidence
    - 3.4.3 Fear of recurrence
    - 3.4.4 Difficulties transitioning to survivorship
- 3.5 Breast sensitivity
- 3.6 Satisfaction with decision
    - 3.6.1 Questioning decision making
    - 3.6.2 Regret

Template 7: First, second and third level theme codes*

1.0 Quality of life

- 1.1 Emotional functioning
    - 1.1.1 Striving for normality
- 1.2 Physical functioning
    - 1.2.1 Experiencing breast pain
    - 1.2.2 Donor site discomfort
    - 1.2.3 Prosthesis inconvenience
- 1.3 Role functioning
    - 1.3.1 Returning to work
    - 1.3.2 Child centred decision making
- 1.4 Sexual functioning
    - 1.4.1 Shifting sex life frequency
    - 1.4.2 Sense of sexual attractiveness
    - 1.4.3 Breast sensitivity
- 1.5 Social functioning
    - 1.5.1 Active self-protection following surgery
    - 1.5.2 Concealing reconstruction

2.0 Breast satisfaction

- 2.1 Satisfied with breast appearance
- 2.2 Unsatisfied with breast appearance

- 2.3 Breast satisfaction over time
- 2.4 Breast appearance expectations
- 2.5 Scarring
  - 2.5.1 Acceptance of scarring
  - 2.5.2 Struggling to accept scarring
- 2.6 Nipple reconstruction satisfaction
  - 2.6.1 Satisfaction with nipple reconstruction over time

3.0 Outcome satisfaction

- 3.1 A sense of overcoming
- 3.2 Outcome expectations
  - 3.2.1 Underestimating the surgery
  - 3.2.2 Recovery expectations
- 3.3 Impact on life
  - 3.3.1 Altering outlook on life
  - 3.3.2 Fluctuating confidence
  - 3.3.3 Fear of recurrence
  - 3.3.4 Difficulties transitioning to survivorship
- 3.4 Breast sensitivity
- 3.5 Satisfaction with decision
  - 3.5.1 Regret

***Removal of surgical complications and questioning decision making themes.**

Template 8: First, second and third level theme codes

1.0 Quality of life

- 1.1 Emotional functioning
  - 1.1.1 Striving for normality
- 1.2 Physical functioning
  - 1.2.1 Experiencing breast pain
  - 1.2.2 Breast sensation
  - 1.2.3 Donor site discomfort
  - 1.2.4 Prosthesis inconvenience
- 1.3 Sexual functioning
  - 1.3.1 Sense of sexual attractiveness
  - 1.3.2 Breast sensitivity
- 1.4 Social functioning
  - 1.4.1 Protection of the self
  - 1.4.2 Concealing reconstruction

2.0 Breast satisfaction

- 2.1 Satisfied with breast appearance
- 2.2 Unsatisfied with breast appearance
- 2.3 Breast satisfaction over time
- 2.4 Breast appearance expectations
- 2.5 Inevitability of scarring
  - 2.5.1 Acceptance of scarring
  - 2.5.2 Struggling to accept scarring
- 2.6 Nipple reconstruction satisfaction

        - 2.6.1 Satisfaction with nipple reconstruction over time

3.0 Outcome satisfaction

- 3.1 Outcome expectations
    - 3.1.1 Underestimating the surgery
    - 3.1.2 Recovery expectations
- 3.2 Impact on life
    - 3.2.1 Altering outlook on life
    - 3.2.2 Changes in confidence
    - 3.2.3 Fear of recurrence
    - 3.2.4 The normal self
- 3.3 Satisfaction with decision
    - 3.3.1 Regret

Appendix 9. First, Second and Third Level Themes and Sample Quotations

Themes	Sample quotations
1.0 Quality of life	
1.1 Emotional functioning	To be honest I do have mixed emotions only in the sense of how the breast feels sometimes but I think it may be a bit more mind over matter (Participant 8). I got home from the surgery and I got really low as it was only at that point I processed what I had been through. I thought you've just gone through a mastectomy and the reason you've had all these ops is because you've got cancer, it was almost like it hit me and then all the tears came. I remember being in bed one day and just crying and crying and crying and crying because I think at that point your head just accepts what you've gone through (Participant 16). I was going through a grieving process, it was great to know I would wake up cancer free, but there is a lot of your femininity and whole psyche tied up with it (Participant 21).
1.1.1 Striving for normality	Not having breasts did act as a constant reminder of the breast cancer. Now I feel I can sort of move on and feel normal (Participant 3). I think having the reconstruction was a way of not thinking about breast cancer every day or every time I get undressed (Participant 4). I wanted to feel normal but it never defined me (Participant 22).
1.2 Physical functioning	I am now 8 years down the line and physically I am still hampered by the reconstruction, as there are still things that I cannot do because of having the back muscle removed (Participant 4). I think you don't realise how much it knocks out of you physically, although I could get up and move around I had lost the use of the right hand side of my arm, as they had taken the lymph nodes out (Participant 12). I'm really pleased with the appearance of my breast but it has debilitated me, because I'm not mobile but it is just one of those things (Participant 15).
1.2.1 Experiencing breast pain	The only thing that bothers me is the constant pain of the implants, where I had my radiotherapy I grew fibrosis everywhere, so the implants are hard like a piece of wood on both sides (Participant 7). It is with me day in and day out and I go to bed with it and I wake up with it and some days it just doesn't feel too great. I get these feelings and I think that doesn't feel right you know and it doesn't feel good (Participant 8).

	You do get ghost pain or some sort of prickling, so yes sometimes there is some sort of discomfort (Participant 18).
1.2.2 Breast Sensation	I think he forgets because he touches me and I'm like ok whatever it is just for him really (*laughs*). For me I don't feel anything at all and I just get on with it and actually it bothers me because I know it's just plastic well actually it's not plastic its silicone, so it's not really me there anymore (Participant 7). My husband gets a bit freaked out well (*laughs*) not freaked out, he feels that the TRAM flap one feels a lot smoother inside, and the other one is a bit lumpy and feels a bit strange. I do not like him playing with them because in my head I know there not boobs so do not play with them as if they are, being my attitude. I just hang clothes of off them because there not boobs (Participant 22). I am not very happy with the feel of it and it is not pain because that would be an exaggeration but it feels uncomfortable. It has left me feeling a bit wounded but I don't want to make a great fuss about it (Participant 23).
1.2.3 Donor site discomfort	That kind of surgery took a lot to get through and it is like being taken apart and then stuck back together again. My stomach muscles were so sore and tight and you could barely stand up (Participant 3). Well I definitely feel my whole body has changed my tummy button is much higher, so my waist is in a different place and so my hips kind of feel bigger, and all my trousers kind of fit differently and that took quite a lot of getting used to. It is a bit odd really having a healthy area that is damaged and taking a long time to recover (Participant 6). It kind of felt like you could have had a skiing accident and like you were incapacitated. With the DIEP reconstruction I had major abdominal surgery, and it wasn't just the breast, which is great because that was like a tummy tuck and that was the real silver lining but that was hugely debilitating (Participant 9).
1.2.4 Prosthesis inconvenience	It was the inconvenience of having to put this thing in all the time and having to check if it was showing, but now I haven't got that problem anymore, so yes it has improved my quality of life (Participant 2). I had a really embarrassing situation when I was getting changed out of a swimming costume and my prosthesis dropped out and bounced into the changing room next to me. There was a young lad in there and I do not know who was more embarrassed when I was asking for my boob back (*laughs*), so it was just mainly practicality but in retrospect I wish I had not had it done (Participant 13). It has made a massive difference, as I am quite active and I can just get up and go now. Whereas, before I would drop the bloody thing and felt like throwing it out the window (*laughs*) (Participant 14).
1.3 Sexual functioning	I don't have the same sense of desire or lust. It is a shame but I don't feel any libido and it is a bit disappointing really (Participant 6).

	It has gone, because I remember how I felt before and now it is mental when you have sex. I feel like I need to think about something harder, and it is less physically. You really have to try not to think this is hurting (*laughs*) and then there is no sensitivity in the breasts and the menopause as well (Participant 7). My sex life has probably got better (*laughs*) but that is probably more to do with the mastectomy and all the stuff that went with that really (Participant 14).
1.3.1 Sense of sexual attractiveness	I still feel sexually attractive and strangely, many people have complimented me saying, I look far better now than I did a year ago, I think it is probably a bit more of a zest for life (Participant 16). I am quite happy to have it and body confident but it is my husband who is not. Whether he is not body confident or confident to look at my body, I don't know so it has not even happened (Participant 16). I've got worse (*laughs*) I have a perv at everyone I see now (Participant 22).
1.3.2 Breast sensitivity	I knew that part of my sexuality had kind of gone. I thought to myself that I'm going to miss the feeling of my breasts and I still do. I think it is a big chunk of my endogenous zones and now it has gone I just feel less now (Participant 7). No it is completely numb and it's probably for the best because it has had that many needles and I've had the tattoo and all the rest of it (Participant 9). No not at all, which is a shame but I would rather not have to worry about still having breast tissue. I mean I still have what 5% of my original breast tissue but that is tiny compared to what I had, and it is a small price to pay. Of course, you can lose sensitivity anyway even if you just have a boob job (Participant 21).
1.4 Social functioning	I was always a little bit sensitive and when I had a mastectomy one of the mothers said "how are you getting on lopsided?" and that was like someone cutting a knife through you, so immediately my confident hit the floor and I avoided people and situations for a while (Participant 14). I always used to sort of feel a bit strange and on show and I was never really out and loud. I was just a bit there quiet in the background (Participant 22). Sometimes I feel like a bit remote from things and I do feel differently. I have always loved small talk, and I loved going into crowded rooms and chatting to everyone (*laughs*) but I do not feel like I do feel like doing that now (Participant 23).
1.4.1 Protection of the self	I couldn't bear anyone to be near my front and I'd always step back if someone came to talk to me. I would make sure there was no one behind me, as it was a very painful operation and recovery (Participant 2).

	I wouldn't say it's an embarrassment but I'm just conscious of needing to be careful, and if I'm in a crowd I don't want to be jostled. I almost feel like I need a bit of a shell around myself (Participant 6). After the operation it is so tender and you are frightened of getting it knocked (Participant 8).
1.4.2 Concealing reconstruction	I am conscious of that and if I am going out trying to find the right clothes to wear, that do not make it obvious so that people do not know, so it does knock your confidence, definitely (Participant 11). In terms of appearance it gives me self-confidence and people don't know I've had a mastectomy, if I'm wearing my normal clothes (Participant 20). Obviously, no-one would know if I didn't tell anyone because when you have a bra on or a bikini they look exactly the same (Participant 24).
2.0 Breast satisfaction	
2.1 Satisfied with breast appearance	The wow factor of how it looked and I was just amazed. When I undressed the first words my husband said were just wow and I thought well how nice is that. It was a good experience out of bad experience for me because you have to take something good out of it, as you can't go backwards (Participant 5). To be honest I have had two kids and I breast-fed them both so I have a new lease of life up top (*laughs*). It is looking great and I am looking 20 years younger, so not only am I not without they are better than they were (Participant 9). It is really amazing and without a bra there are no tucks or dents or anything. It is brilliant and I look like I have never had children (*laughs*) and they have done a superb job and they look fabulous (Participant 15).
2.2 Unsatisfied with breast appearance	I am not happy with the final product of my breasts (*laughs),* so I never remove my top half. I cannot look at myself in the mirror and it's just obvious that I have had something going on, like I've been in a war where I had cancer and it's the mutilation. I have to admit even today I am still a bit affected by that, and it is a constant reminder of what I have been through (Participant 7). The implants are very small and not a great shape, and on one side it is very wrinkly (Participant 12). I am in limbo now but I am happier that I do not have a prosthesis. I am actually more unbalanced so for me that is a negative, although I am grateful for what they have been able to achieve and this is where I struggle now (Participant 13).
2.3 Breast satisfaction over time	When it was all first done yes it was fantastic, scars aside the upright and the perkiness but because the DIEP flap is a natural thing they do droop naturally. Ok we are a couple of years on and they are starting to sag a little bit, and the one on the left that had the lift has started to droop too and I didn't realise that would happen so quickly, but it doesn't matter I mean honestly it doesn't matter (Participant 9).

	Yes, I am but yes it has taken quite a while to get there but yes, I am more than happy with it (Participant 17). The implant was pressing into the flesh underneath so I had to have the implant redone. It was simple and straightforward but hard mentally because it was like here I go again (Participant 19).
2.4 Breast appearance expectations	It absolutely amazes me and it completely exceeded my expectations. I never believed I would be able to wear a swimming costume, and no one would tell it is not my real breast (Participant 6). I just remember thinking (*sobbing*) it was emotional because it just looked so good and I just wasn't expecting it to and it totally exceeded my expectations (Participant 8). They don't completely match what I thought they would look like they aren't bad but they aren't quite as nice as the one in the illustration (Participant 18).
2.5 Inevitability of scarring	Obviously with the latissimus dorsi procedure you get a great big scar at the back but that sits underneath the bra, so actually my scar is lovely (Participant 4). I just thought that there has to be a scar somewhere for the operation and because it looks so good, the scarring has never bothered me (Participant 8). I have a scar that goes underneath and one that comes up to the top of the nipple, but it is the same sort of scar that I would have had if I had a breast reduction essentially, which is the way I see it. It is also a similar scar to if I had implants so just as a breast augmentation, but I tend to heal very well and my scars don't tend to last for very long so I'm sure within twelve months those would have really died down (Participant 21).
2.5.1 Acceptance of scarring	I do have the mastectomy scar and the scar on my tummy but you can barely see them and they have healed very well, I actually forget I ever had anything done (Participant 3). Scarring is brilliant, lovely and it's fading really lovely. I must admit I have seen some photos on the internet of tummy scars and breast so I just think I have been blessed with the most brilliant surgeons because mine are so neat and lovely (Participant 16). They are what they call the war wounds and I am quite proud of them really (Participant 17).
2.5.2 Struggling with scar acceptance	I try not to look at them really and my husband never sees me naked on the top anymore. I cannot and he cannot hide it because it is too painful to look at it (Participant 7).

	I do have some bumpy areas across my back and I am having difficulty with the last site where I was cut underneath the arm that is quite thick and red at the moment (Participant 15). I went on holiday this year and I wore a bikini and it is so cleverly done, it's under your bikini line so that strap that you tie up at the back is underneath it and you can't tell, although I still can't expose it to anyone (Participant 19).
2.6 Nipple reconstruction satisfaction	I had the nipple put back on and that is like the cherry on top (Participant 17). I suppose in my mind I was saying to myself I want to get to five years, and if I get to five years and nothing has come back on that side that I'll sign it all off by putting the nipple on, it is almost like my little treat (Participant 19). It doesn't look anything like a nipple as its flat compared to the other one, and so they are uneven but I just keep thinking I'm still here, so so what (Participant 24).
2.6.1 Satisfaction with nipple reconstruction over time	The nipple tattoo fades unfortunately but the only other option was to have a permanent tattoo from a tattooist, but I am not going to bother with all that (Participant 2). In the end, it just did not sew in and it ended up falling off in the shower when I was washing one day, and I have never really bothered after that (Participant 22). I didn't bother to go back but if the nipple had stayed up I think I would have carried on with the tattooing but it sank down and was just kind of a little bump, so I brought some stick on nipples instead just to alter the shape (Participant 4).
3.0 Outcome satisfaction	
3.1 Outcome expectations	I do not think anyone would have it done if they knew what they were going to go through, although there are pros and cons for everything and I am glad now that I had it done (Participant 15). They didn't match my reality but they did match the surgeon's reality. The surgeon told me healing would be delayed because of the chemotherapy, although you do not really have a concept of that, and that is one of the hardest bits as you have to be incredibly patient (Participant 19). After a couple of months he said you can start doing sit ups now but just because you can do 20 one day don't expect to be doing 20 the next day, and if your sore at 10 stop. The surgeon was always very honest with me about how it would hurt (Participant 22).
3.1.1 Underestimating the surgery	Absolutely traumatised and its different when your ill because you're having a mastectomy and treatment to save your life, but choosing to have cosmetic surgery to improve how you feel is different. I must say I did not know just how large of an operation it was (Participant 3).

	The only thing I wasn’t prepared for was the pain of breast reconstruction, even by looking at what people said online. I think that is because most people have one and not many people have a double reconstruction, and I really was not prepared for that pain (*laughs*) (Participant 4). I had a big operation and you didn’t know what was coming (*laughs*) and it was horrendous (*laughs*) but there you go (Participant 15).
3.1.2 Recovery expectations	I made a very good recovery far better than I was expecting, both mentally and physically from the reconstruction (Participant 1). I knew I was not just going to be bouncing back in a couple of weeks to be honest (Participant 8). I was expecting a lot of pain and not being able to move like I did. I was expecting lots of stuff really that just did not happen (Participant 16).
3.2 Impact on life	We cannot do the long hours we used to but we are still productive. We are not dead and because we are not dead, we want to be part of society. We want people to understand we are not like before and we can’t help that but we still have a lot to offer (Participant 7). I would not say my life has been enhanced in the sense that it is great having one breast like this and one normal one, but it is life changing (Participant 8). I really feel body confidence and strangely more so since the operation. I feel like I have had cancer come through it and WOW so I just feel empowered (Participant 16).
3.2.1 Altering outlook on life	Life is short and you just have to make the most of it, like when I was in hospital and women were crying because they had lost a breast, I did not say anything but I thought you are still alive, and so I just can’t grasp that at all (Participant 5). Just because I have a reconstructed breast after having cancer does not mean I cannot achieve but cancer does change you (Participant 8). If I am out in a social setting and hear someone moaning about crap *(laughs*) or low-level stuff, I do not say get a life but I often look at people. It has really brought home to me how precious life is and you should not moan about crap (Participant 16).
3.2.2 Changes in confidence	I could put a top on and if my boob shows ok it’s got a little bit of a scar, but it’s absolutely fine, so yes it gives you a little bit more confidence (Participant 2). I used to go to the gym a lot beforehand and I am trying to get back into it very gently now, I am quite conscious laying down because my boobs look totally different and obviously one sticks up and one out (Participant 11). I think I am more aware of my body image and I think I lack a bit more confidence regarding my body image (Participant 13).
3.2.3 Fear of recurrence	You could have a recurrence on the chest wall and of course you would not feel it, and you cannot mammogram them so that is a bit of a concern (Participant 4).

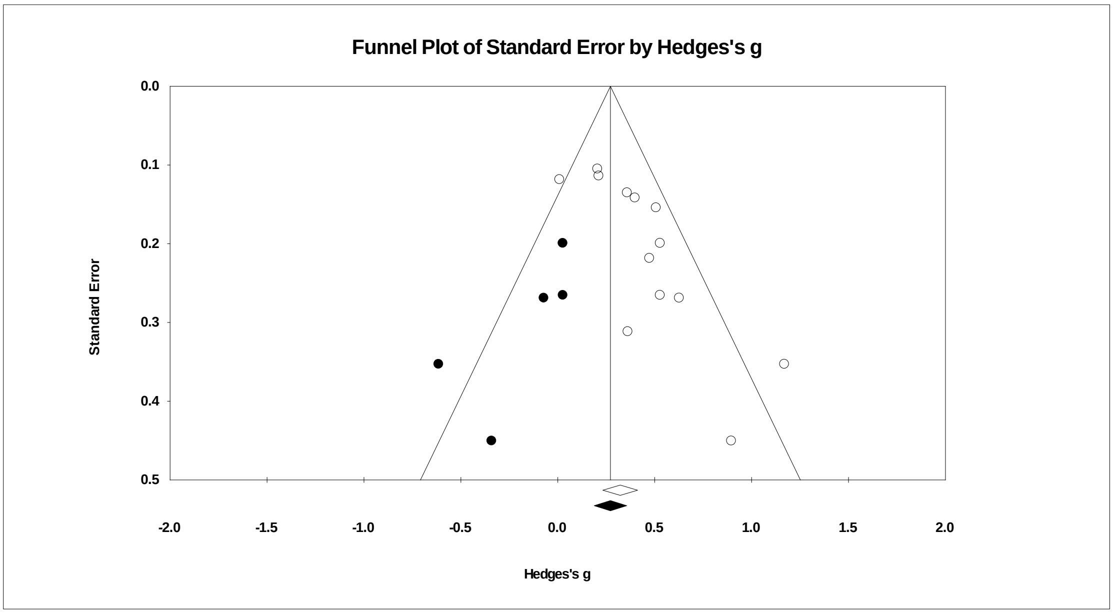
	I know there are no guarantees about preventing recurrence, but I have been trying to do the things that I am in control of such as diet and exercise (Participant 16). You obviously prey it does not come back because you cannot have a mammogram on it but to me that is a risk you take (Participant 17).
3.2.4 The normal self	Now I have had my breasts reconstructed I feel normal, I feel normal. I would feel maimed without it and it is a silver lining (Participant 9). To me having the breast reconstruction was like the end of the journey that I am very proud of (*laughs*). I forget that I have had breast cancer and I feel privileged that I have gone through all of the bits and pieces (Participant 17). I feel like I have even breasts and I'm normal (Participant 19).
3.3 Satisfaction with decision	I was 100% happy with the decision I had made and that really helped me (Participant 1). I'm glad I waited for the reconstruction and did my research because I was aware of what was going to happen and what it would look like and I have not looked back (Participant 14). I did not realise I would be left with a series of operational discomforts. I thought I would be better off with the reconstruction because I would not have problems with the prosthesis, but in a lot of ways I would have been better off staying as I was, but being the other side of it now, I am glad I did have the reconstruction (Participant 15).
3.3.1 Regret	I would say slight regret because of the loss of movement, the discomfort and I could have something in the chest wall. With implants, you are patient of the plastic surgeon for life and the implants will be ten years old shortly, yet I do feel very lucky (Participant 4). I mean it was (*deep breath*) you know (*deep breath*) kind of a big, long surgery and I do still wonder if I should have just gone for the implant (Participant 6). When you are told you have cancer you have to make very important decisions straight away and that just messes with your brain (*laughs*) you enter a strange mode thinking I have to save my life, and then later you realise once you've gone through the whole thing I wish I had done it differently (*laughs*) (Participant 7).

Appendix 10: Consolidated Criteria for Reporting Qualitative Studies (COREQ): 32-Item Checklist

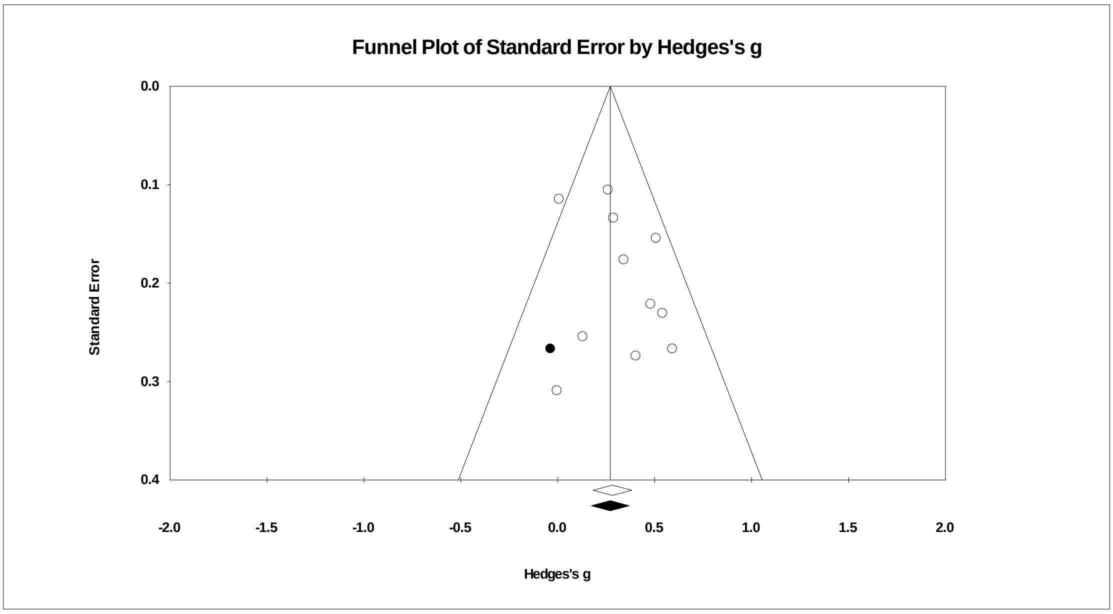
No. Item	**Guide questions/description**	**Reported on Page #**
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	61
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	61
3. Occupation	What was their occupation at the time of the study?	61
4. Gender	Was the researcher male or female?	61
5. Experience and training	What experience or training did the researcher have?	61
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	61
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	61
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	194
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	62
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	58
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	58
12. Sample size	How many participants were in the study?	58-59
13. Non-participation	How many people refused to participate or dropped out? Reasons?	59
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	61
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	61

16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	60
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	61
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	61
20. Field notes	Were field notes made during and/or after the interview or focus group?	63
21. Duration	What was the duration of the interviews or focus group?	61
22. Data saturation	Was data saturation discussed?	58
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	62
25. Description of the coding tree	Did authors provide a description of the coding tree?	64
26. Derivation of themes	Were themes identified in advance or derived from the data?	62
27. Software	What software, if applicable, was used to manage the data?	61
28. Participant checking	Did participants provide feedback on the findings?	N/A
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	66-73
30. Data and findings consistent	Was there consistency between the data presented and the findings?	74-95
31. Clarity of major themes	Were major themes clearly presented in the findings?	91-95
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	91-95

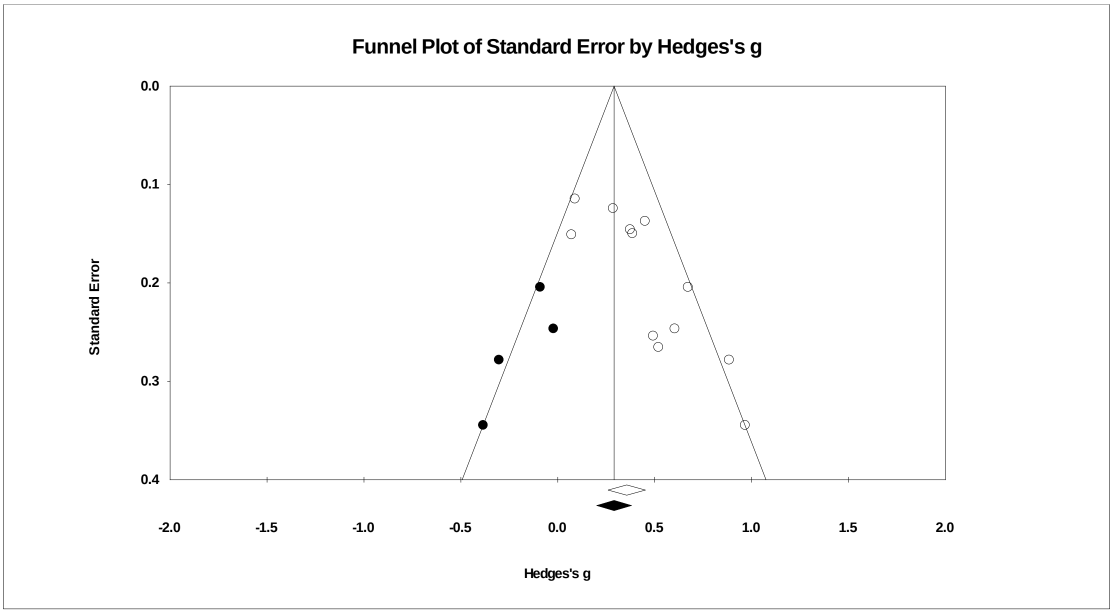
Appendix 11: Chapter 6- Funnel Plots of Psychosocial Outcomes in the Meta-Analysis



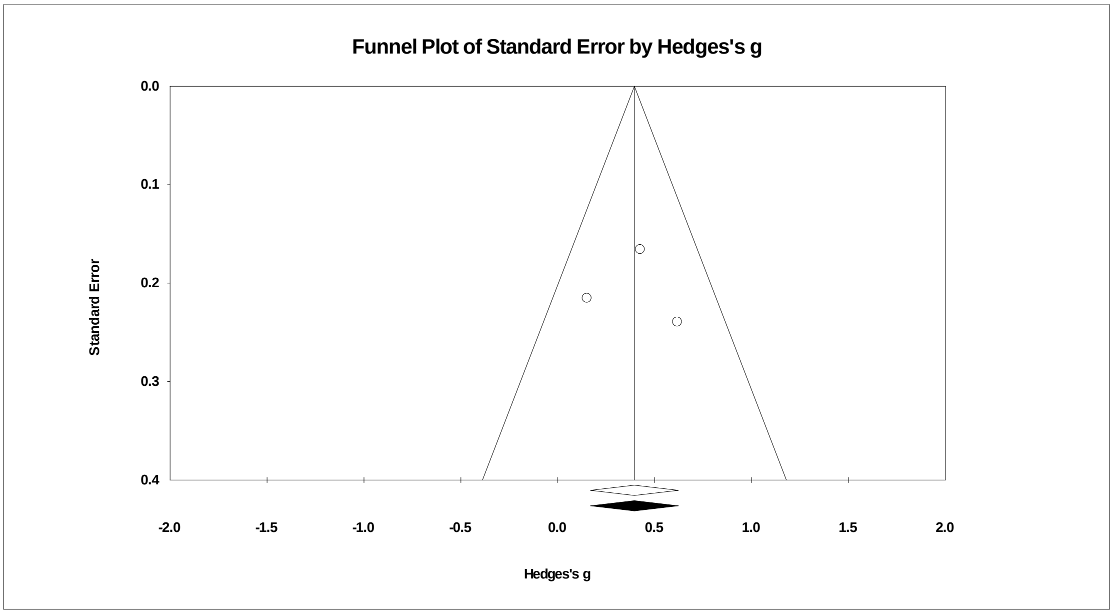
Funnel Plot 1. Depression



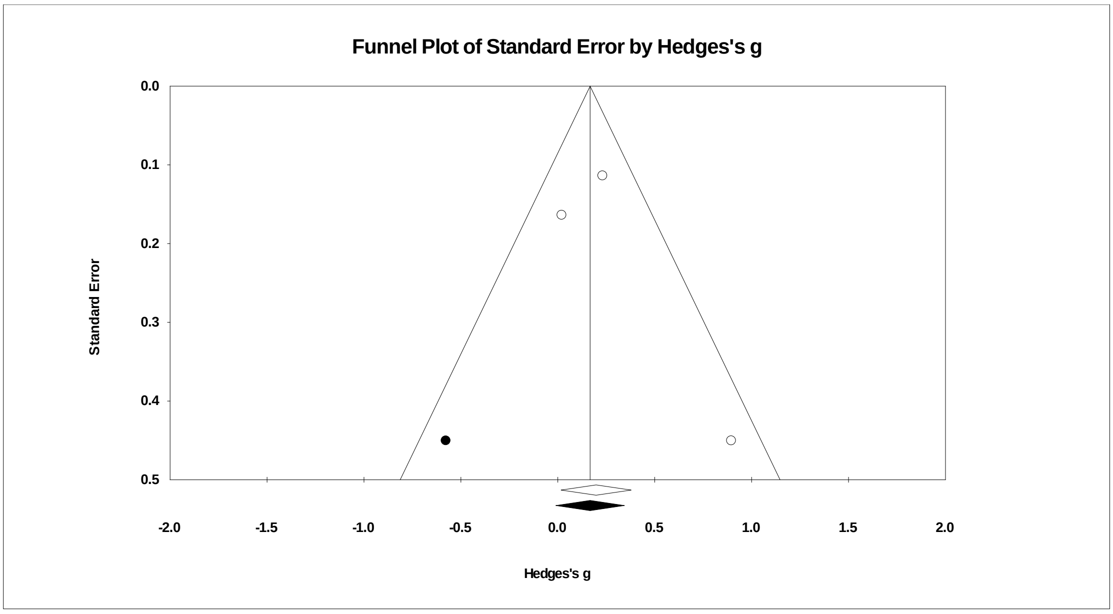
Funnel Plot 2. Anxiety



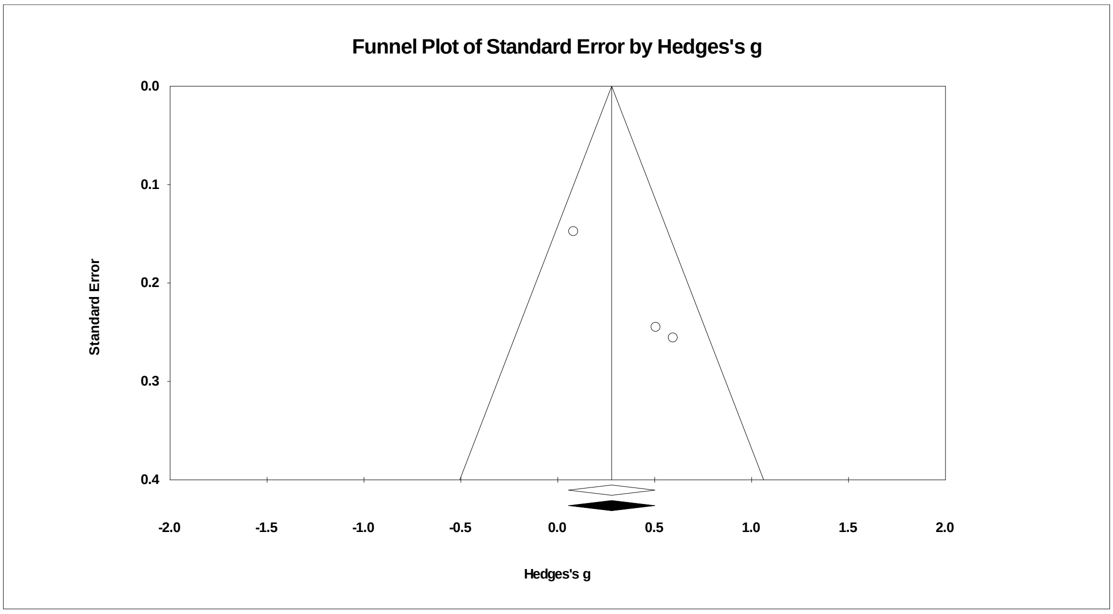
Funnel Plot 3. Quality of Life



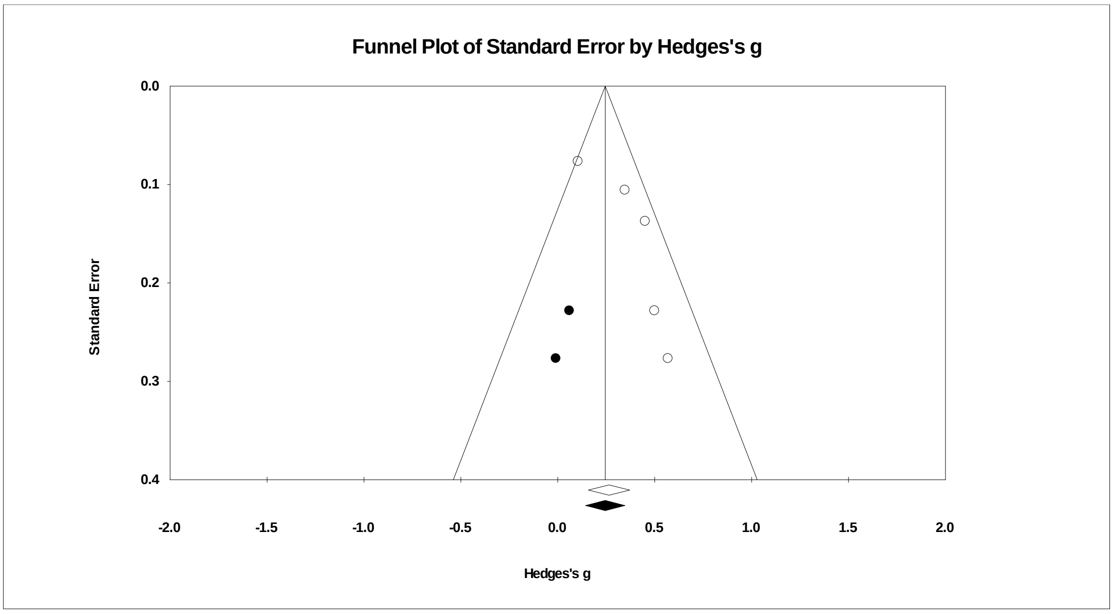
Funnel Plot 4. Body image



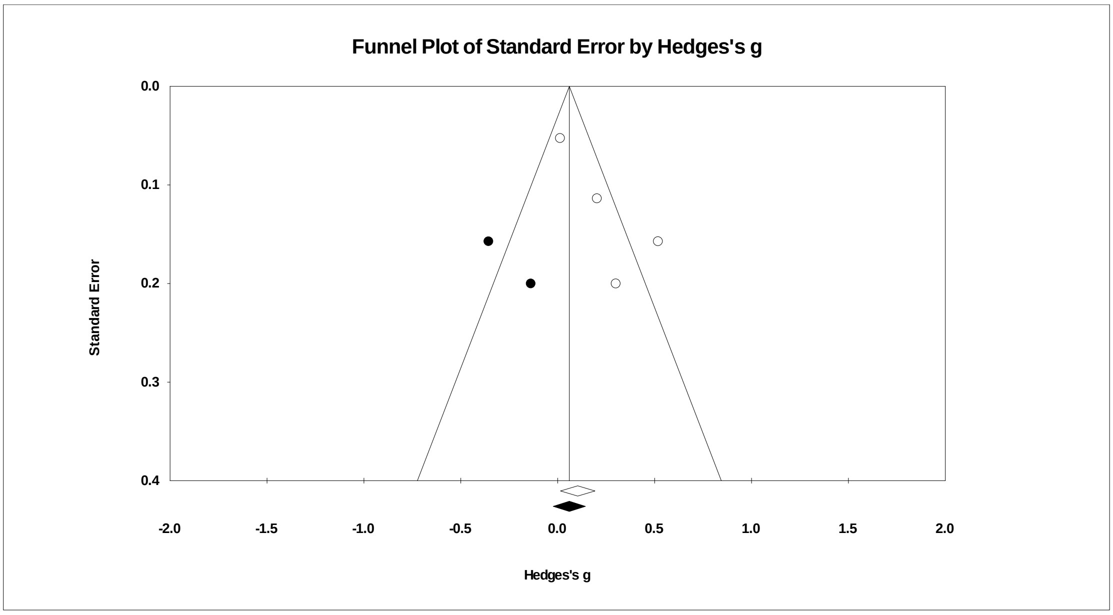
Funnel Plot 5. Sexual functioning



Funnel Plot 6. Self-esteem



Funnel Plot 7. Mood disturbance



Funnel Plot 8: Distress

Appendix 12: PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	97
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	179
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	98
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	98/102
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	101
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	101/102
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	101
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	101
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	102/103
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	102
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	112-114

Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	102-103
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	103
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	103

Section/topic	**#**	**Checklist item**	**Reported on page #**
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	104
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	114
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	105
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	106-110
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	114
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	115-117
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	114
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	114
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	114
DISCUSSION			

Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	114/117
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	119-120
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	117-121
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	192

Appendix 13: Psychosocial Outcomes and Assessment Measures

Outcome	Assessment Measures
Body image	Body Image Scale (BIS) The Body Image and Sexuality Scale for Women With Breast Cancer (BISS)
Anxiety	Hamilton rating scale for anxiety Hospital Anxiety and Depression Scale (HADS) Spielberger's State Trait Anxiety Inventory (STAI) The State-Trait Anxiety Inventory Self- Rating Anxiety Scale (SAS) State anxiety inventory (SAI)
Depression	The Center for Epidemiologic Studies Depression Scale (CES-D) Beck Depression Inventory (BDI) The Hospital Anxiety and Depression Scale (HADS) 17 item Hamilton Depression Rating Scale (17-HAMD) Zung self-rating depression scale (SDS)
Mood disturbance	The Profile of Mood States Questionnaire (POMS-TMD)
Quality of life	General Functional Assessment of Cancer Therapy Scale (FACT-G) Functional Assessment of Cancer Therapy-Breast (FACT-B) Quality of Life-Breast Cancer Survivors The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Functional Living Index Cancer (FLIC)
Distress	The Impact of Events Scale (IBS) Revised Impact of Events Scale (IES-R)
Sleep disturbance	Structured Insomnia Interview (Stanford Sleep Disorders Clinic)
Self-esteem	The Coopersmith Self-esteem Inventory R. Cibor's Self Esteem Scale Self-Esteem Scale (SES)
Sexual functioning	Sexual Satisfaction Scale (SSS) Female Sexual Function Index (FSFI) The Sexual Dysfunction scale

Appendix 16: Ethical Approval

Coventry University

Certificate of Ethical Approval

Applicant:

Hannah Matthews

Project Title:

The PREDICT project: Predictors of outcome and reconstruction satisfaction and quality of life following breast reconstruction

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

18 December 2015

Project Reference Number:

P39039

Coventry University

Certificate of Ethical Approval

Applicant:

Hannah Matthews

Project Title:

The ADAPT Project- Exploring psychosocial outcomes following post-mastectomy breast reconstruction.

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

10 November 2016

Project Reference Number:

P46098

Certificate of Ethical Approval

Applicant:

Hannah Matthews

Project Title:

The effectiveness of existing breast cancer interventions for women who are experiencing or have experienced mastectomy.

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low Risk

Date of approval:

15 June 2015

Project Reference Number:

P33731