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Masters By Research Psychology Thesis

Longitudinal Psychosocial Functioning Following Mastectomy With or Without Breast Reconstruction.

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Overall Abstract for thesis

Objective

Each year in the United Kingdom 48,000 women receive a diagnosis of breast cancer (Desantis et al., 2014). Most women opt to have a mastectomy with or without reconstruction (Mortenson et al., 2004). The aim of this thesis was to assess the longitudinal psychosocial functioning following mastectomy with or without breast reconstruction.

Methods:

Study 1: a systematic review to identify the longterm psychosocial outcomes following post- mastectomy breast reconstruction.

Study 2: a longitudinal qualitative study to explore psychosocial function, following mastectomy with or without breast reconstruction.

Results :

Study 1

The systematic review suggested women undergoing breast reconstruction demonstrate improvement over time in certain aspects of quality of life when comparing their scores pre surgery with their scores at follow up. Only one article showed women's sexual functioning / wellbeing improved over time (Eltahir et al., 2013). Women were better on quality of life for physical role/activity and concerning quality of life pain women experienced less pain over time. Several articles reported non – significant findings on QOL meaning the outcome may not be significantly strong. In terms of body image/ stigma only two articles suggested a difference between the two types of reconstruction; delayed reconstruction showed an improvement over time and immediate reconstruction a decline over time (Metcalfe et al.,2012) and (Gournay et al.,2010). As the issue of body image/stigma was only addressed by two articles more research is needed to replicate the finding. Two articles reported differences in terms of aesthetic satisfaction; (Gui et al., 2007) showed a decline in aesthetic satisfaction over time in contrast to (Eltahir et al., 2013) which reported aesthetic satisfaction was higher over time. However more research is needed to replicate the finding for aesthetic satisfaction. Concerning breast reconstruction and breast conserving surgery there was little difference in terms of the long term psychosocial outcomes however two articles found that breast reconstruction was worse in relation to body image/ stigma (Min et al.,2010) and (Han et al ., 2010). The comparison for healthy women at follow up showed there was some significant differences in terms of the evidence; one article by (Wehrens et al., 2005) reported that those in the breast reconstruction group were more self-conscious about their appearance (body image /stigma) and less mobile (able to carry out daily tasks like washing etc) in relation to physical/role activity. One article by (Rubino et al., 2007) found women were better in the following psychosocial outcomes; QOL general, QOL social function/adaptation and sexual functioning/well-being and poorer in terms of depression. These findings do need to be replicated in order to draw casual conclusions.

Study 2

The main themes found in the qualitative study were body image the disfigured breast, the need for normality cancer is not the boss and physical functioning. Women showed a strong desire to return to normality. The desire to fight, live and survive was evident amongst the women. Women experienced problems with physical functioning in terms of carrying out everyday tasks (cleaning, bathing etc).

Conclusion:In conclusion there was little evidence that breast reconstruction was linked to the long term psychosocial outcomes in the review. Women who have a reconstruction have a strong desire to return to normality and their concepts of what returning to normality is are similar. Research should look into this further in order to help cancer patients in dealing with a reconstruction and cancer treatment.

Chapter 1:Breast Cancer : Background Information

This chapter will focus on breast cancer in general and provide information on the epidemiology, the treatments and breast reconstruction.

Epidemiology

In the United Kingdom, breast cancer is the most common disease in women andin 2011 breast cancer accounted for 31% of diagnosed cancers in women (Office For National Statistics, 2011).Since 1971, the survival rate for breast cancer has doubled by 50% and is steadily increasing. In the year 2011, 9,700 females deceased due to breast cancer. Survival is significantly lower in younger women aged 15-39 years (84%) in comparison to women aged 40-69 years (89-90%), which is significantly higher.

Breast cancer accounts for 31% of all cancers in women in the United Kingdom (Office ForNational Statistics, 2011). The incidence rates in 2011 per 100,000 women were 125; this is an increase of 89% between the years of 1971-2011 (Office For National Statistics, 2011). Survival rates for the disease have risen from 1971 to 84% in 2011(Office For National Statistics,2011).In relation to worldwide statistics cancer is responsible for most deaths in economically developed countries and is the second reason for deaths in developing countries (Jemal et al.,2011). Worldwide statistics predict that 50% of breast cancer incidences and 60% of deaths will be present in economically developed countries (Jemal et al.,2011). It is considered that an unhealthy lifestyle, drinking excessive alcohol and smoking could be the causes of most cancers (Jemal et al., 2011). Since improved treatment, due to more new research, 85% of women who are diagnosed with breast cancer survive for 5 years or more (Office for National Statistics, 2011).

In England and Wales,40,500 women are diagnosed every year with breast cancer (NICE , The National Institute For Health and Care Excellence, 2014). Breast cancer is diagnosed when a patient visits their GP, and if their GP feels their symptoms are related to cancer the patient is then referred to a breast cancer clinic in their local hospital (NICE , 2014). The first initial symptoms patients normally report are a lump in the area of the breast, itching or burning in the affected site (Dye et al., 2012). The diagnosis is then carried out in the clinic in several stages, 1.Clinical assessment ,2. Mammography or ultrasound imaging, 3. biopsy or fine needle aspiration cytology (NICE, 2014).

Treatments for Breast Cancer

The main treatments for breast cancer aresurgery, radiotherapy, chemotherapy, hormone therapy and biological therapy (known as targeted therapy) (NICE, 2014).

Surgery

Clinicians (surgeons) are vital to the process of conducting a mastectomy with or without reconstruction and have an important position in the breast cancer treatment process (Thomas,Movat& King, 2012). Surgery involves having a mastectomy, lumpectomy or a reconstruction (NICE ,2014). New developments in the way in which mastectomies are designed and carried out have been devised especially concerning one new method which eradicates the lateral dog ear (Thomas et al., 2012). When a patient undergoes a mastectomy, a lateral dog ear can occur following the operation. The lateral dog ear mainly occurs in women who are overweight. Lateral dog ears can be aesthetically displeasing and can cause irritation. A lateral dog ear is formed by excess adipose tissue (fat tissue) which is lateral to the breast. A proposed method to eliminate the dog ear involves re-draping the excessive skin over the chest area, this eradicates the dog ear. (Thomas et al., 2012).

The side effects of having surgery are; infection in the surgical wounds when fluid collated in the surgical site. Women can also experience tingling, numbness and swelling. Patients can experience death of the tissue which is used to form the new breast. Women can be at risk of hernias in the long term (Cancer.org).

Radiotherapy

Radiotherapy was first used in 1949 (Cuzick, 2005) and it has been shown to decrease the risk of cancer returning by 70%, but radiotherapy does not reduce the mortality rate (10 years onwards). Radiotherapy is a treatment which uses radiation. Radiotherapy is given following breast cancer surgery to lower the risk of the cancer returning (Cuzick, 2005). Radiotherapy can cause certain side effects, these includecardiac problems, soreness, reddening, swelling, discomfort and tiredness (Cuzick, 2005).In the past trials have reported cardiac problems from using radiotherapy (Cuzick, 2005). However, Giordano et al. (2005) devised a method of avoiding this by conducting a comparison study on cardiac mortality to identify what was causing the cardiac problems. It was found in the research that increased cardiac mortality was due to the dose received on a left - sided tumour where the heart is (Cuzick, 2005). If a patient has radiotherapy, it may mean that they cannot have some forms of reconstructive surgery as radiotherapy may restrict blood flow to the breast tissue. Certain breast reconstruction operations require adequate blood flow to the reconstructed breast (Cuzick, 2005).

Chemotherapy

Chemotherapy is a cancer treatment which involves the use of drugs to eradicate cancer cells. The patient is normally given three drugs to consume (Barcenas et al.,2014) Chemotherapy is used to reduce the size of a cancerous tumour pre-operation, following surgery to reduce the risk of the cancer spreading or returning and for second- line cancer (where the cancer has returned). The side effects of having chemotherapy are reduction in white blood cells (neutropenia), low red blood cells and platelets however it can mean a person is at high risk of infections. Patients can have the following infections, bacterialinfections, viruses and fungal infections (Burstein, 2000).Other side effects from having chemotherapy treatment include, fatigue, sickness, hair loss, diarrhoea, constipation and the menstrual cycle can also be affected. The long-term side effects from chemotherapy are, fatigue, women may have no menstrual cycle, have difficulty getting pregnant and early menopause (Burstein, 2000). There have been issues with chemotherapy concerning patients having to be hospitalized due to the extreme side effects of certain doses in association with TAC and AC + T (T= Taxotere known as Docetaxel, A = Adriamyein known as Doxorubicin, C = Cytoxan known as Cyclophosphamide) (Barcenas et al.,2014).

Hormone therapy

Hormone therapy can be given before or after surgery. It involves lowering the level of oestrogen and progesterone in the female body. It is thought that certain hormones like oestrogen and progesterone can activate the growth of cancerous cells. Hormone therapy is shown to reduce the likelihood of oestrogen receptor positive breast cancer returning (Gelmon& Kim Sing, 2001). The side effects of hormone therapy are, nausea, period problems which include early onset of menopause resulting in no periods , lowered libido, hot flushes, vaginal dryness, aching joints, mood changes and fatigue. There are some long- term side effects from hormone therapy, including thinning of the bones from taking aromatase inhibitors. Women can take Tamoxifen for five years (NICE, 2014).Patients taking Tamoxifen are at risk of developing womb cancer and abnormal bleeding (Gelmon& Kim Sing, 2001). However, hormone therapy can increase the risk of breast cancer in post-menopausal women (Gelmon& Kim Sing, 2001). Research suggests that women should be prescribed lower levels of the hormone,oestrogen to alleviate symptoms and reduce the risk of cancer due to hormone therapies (Gelmon& Kim Sing, 2001).

Tamoxifen

Developments in new methods to reduce the side effects of cancer drugs are on the increase. A research trial conducted by Lee et al. (2014) aimed to decrease the systemic effects when using Tamoxifen. (Lee et al.,2014) found that using Tamoxifen in gel form instead of administering the oral Tamoxifen was beneficial. It was also found that the effects on endocrine and coagulation parameters were decreased. Therefore demonstrating that using Tamoxifen in gel form may be of benefit to women who take the oral form of Tamoxifen and who suffer significantly with long – term effects (Lee et al., 2014). The long- term effects can consist of the following, risk of womb cancer, eye problems, for example,cataracts, irregular periods, blockages in veins in the lungs or brain (Lee et al.,2014).

In the NICE (2014) guideline it suggests that the National Health Service should prescribe the following drugs Tamoxifen and Raloxifene to women who are significantly prone to developing breast cancer. The two medicines could potentially prevent women from developing breast cancer if taken for five years (NICE, 2014). NICE recommends that women who are at a significantly higher risk of developing cancer should receive more of the following; breast screening, genetic testing for the cancer mutation gene, the drugs, Tamoxifen and Raloxifene as preventative medicines (NICE, 2014). Due to the drugs Tamoxifen and Raloxifenenot been classed as preventative medicines for breast cancer in the United Kingdom compared to in the USA (United States of America). The patient's doctor would have to ask for written documented consent from a patient to take the drugs as preventative medicines against developing breast cancer NICE (2014).

Biological therapy

Biological therapy is a form of cancer treatment that alters the way cancerous cells communicate by blocking the effects of certain proteins. The most common drug used for biological therapy is Herceptin (Trastuzumab) (Arteaga,Sliwkowski& Osborne,2012).Women who have large quantities of a protein termed HER2, which is known to stimulate the growth of some cancers, may be prescribed this drug. The role of Herceptin is to block signals sent out by the cancer cells which help the cells to divide and grow. Herceptin also aides the effect of chemotherapy on cancer cells. Another biological therapy is Lapatinib (Tyverb) used with Capecitabine (Xeloda) which is used when a patient has advanced cancer cells which have receptors for Lapatinib on the cancerous cells. The side effects of biological therapies are; swelling, skin rashes, fatigue, diarrhoea, loss of appetite and a decrease in blood counts (white blood cells, platelets) (Arteaga et al., 2012).

The Psychosocial Impact of Breast Cancer

Sexual functioning is a difficulty following breast cancer treatment(Panjari,Bell& Davis, 2011). Following chemotherapy,women are at more risk of sexual dysfunction in comparison to those who have not had chemotherapy (Emilee,Ussher&Perz, 2010). Women who have had chemotherapy are more at risk because chemotherapy chemically activates the menopause (Emilee et al .,2010).In Panjari et al.(2011) study it was found that out of 1,011 patients, 70% of the patients had difficulties with sexual function and 77% experienced vasomotor symptoms (menopause symptoms). It was also found that the sexual function difficulties found in breast cancer patients was linked to aromatase inhibitors (Panjari et al., 2011). Emilee et al. (2010) found that sexual functioning difficulties can last for years following breast cancer, this included problems with arousal, orgasm,lubrication, vaginal dryness and induced menopause due to the cancer treatments. The article by Emilee et al. (2010) also highlighted that sexual functioning may contribute to several psychosocial outcomes including,anxiety, decrease in how the person feels about their femininity, depression and anxiety over fertility loss. Other studies have also provided evidence of the wider impact of the alterations in fertility, body image and sexual functioning. For example, research conducted by(Fingeret,Nipomnick,Crosby& Reece,2013) demonstrated women experienced difficulties with body image and this affected the patient’s ability to return to work due to a lack of confidence.

Breast Reconstruction

Women can opt to have breast reconstruction following a mastectomy. There are two options for reconstruction either immediate or delayed (D’Souza,Darmanin&Fedorowicz, 2011).Immediate breast reconstruction is when the reconstruction is carried out at the same time as the mastectomy. A delayed reconstruction is carried out several months following a mastectomy. According to the NHS (National Health Service) National Mastectomy and Breast Reconstruction Audit conducted in 2011, 16,485 women had a mastectomy, 3,389 had immediate reconstruction and 1,731 had a delayed reconstruction. The data showed 31% (5120) had a reconstruction and 69% (11365) did not have a reconstruction.

Women who have a breast reconstruction suffer physically with lifting objects, hairloss, fatigue, healing of scars and problems with menstruation due to the cancer drugs (Nice, 2014). Following reconstruction patients can experience wound infections, build-up of fluids in the operation site, numbness, tingling in the upper arm and swelling of the arm or hand Nice (2014). Patients can suffer from death of the tissue which can result in smaller reconstructed breasts (Cancer research 2016).

Chapter 2: A Systematic Review of Long Term Psychosocial Outcomes Following Post – Mastectomy Breast Reconstruction

Abstract

Objective

Long - term psychosocial outcomes are an issue following breast reconstruction. The aim of the review was to identify the long – term, 12- month psychosocial outcomes following post –mastectomy breast reconstruction.

Method

A literature search covering the years 2000-2014 was conducted using key cancer search terms with three databases, PsycINFO,EMBASE, Medline. Then organic backward and forward searches were conducted to identify additional inclusion criteria for the systematic review.The forward citation search involved examining references that were cited in the articles found from the search on the databases. The backwards citation search involved examining the list of references from any new articles found in the reference lists from the forward citation search. The inclusion criteria were articles had to be quantitative and the articles had to have assessed thelong term psychosocial outcomes following breast reconstruction. Articles were rated using a quality framework.

Results

Thirteenarticles met the criteria for inclusion and are included in this review. The results suggested that women who undergo breast reconstruction initially show improvement following a reconstruction. The key findings were women showed signs of improvement at baseline in terms of body image. Delayed reconstruction had a

decrease in stigma. Immediate reconstruction had an increase in stigma. When compared to breast conserving surgery women had poorer body image/stigma and when compared to healthy women they were more self-conscious.

Conclusion

This systematic review suggests women who undergo breast reconstruction show improvement over time on certain aspects of quality of life when comparing their scores pre sugergy at follow up. Only one article showed women's sexual functioning / wellbeing improved over time (Eltahir et al., 2013). Women were better on quality of life for physical role/activity and concerning quality of life pain women experienced less pain over time. Several articles reported non – significant findings on QOL meaning the outcome may not be significantly strong. In terms of body image/ stigma only two articles suggested a difference between the two types of reconstruction; delayed reconstruction showed an improvement over time and immediate reconstruction a decline over time (Metcalfe et al.,2012) and (Gournay et al.,2010). As the issue of body image/stigma was only addressed by two articles more research is needed to replicate the finding. Two articles reported differences in terms of aesthetic satisfaction; (Gui et al., 2007) showed a decline in aesthetic satisfaction over time in contrast to (Eltahir et al., 2013) which reported aesthetic satisfaction was higher over time. However more research is needed to replicate the finding for aesthetic satisfaction. Concerning breast reconstruction and breast conserving surgery there was little difference in terms of the long term psychosocial outcomes however two articles found that breast reconstruction was worse in relation to body image/ stigma (Min et al.,2010) and (Han et al ., 2010). The comparison for healthy women at follow up showed there was some significant differences in terms of the evidence; one article by (Wehrens et al., 2005) reported that those in the breast reconstruction group were more self-conscious about their appearance (body image /stigma) and less mobile (able to carry out daily tasks like washing etc) in relation to physical/role activity. One article by (Rubino et al., 2007) found women were better in the following psychosocial outcomes; QOL general, QOL social function/adaptation and sexual functioning/well-being and poorer in terms of depression. These findings do need to be replicated in order to draw causal conclusions.

Introduction

The systematic review was carried out to examine the long -term psychosocial outcomes following post – mastectomy breast reconstruction. Women can opt to have a breast reconstruction following cancer treatment. Breast reconstruction procedures began in the 1980s (Lee et al.,2014).The two types of reconstruction are immediate and delayed reconstruction (D'Souza ,Darmanin, Redorowicz ,2011). In the United Kingdom in 2011, 16,485 women had a mastectomy, 3389 women had an immediate reconstruction and 1,731 had delayed reconstruction (NHS audit 2011). The differences were 31% (5,120) women had a reconstruction and 69% (11,365) women had no reconstruction. A woman's decision to have an immediate reconstruction or delayed reconstruction can depend upon the following factors ; the stage of the cancer, lifestyle and personal preference, radiation, additional therapies and the individual's medical condition. Immediate and delayed reconstructions are conducted by an autologous tissue procedure which involves using the patient's own tissue to substitute the breast tissue which has been removed. Immediate breast reconstruction is when the operation is conducted at the same time as the mastectomy (D'Souza et al., 2011). Delayed reconstruction is when the autologous procedure is carried out any time following the mastectomy. It is common for the procedure to be conducted two months after the mastectomy depending on how rapidly the patient's scar has healed (D'Souza et al., 2011).

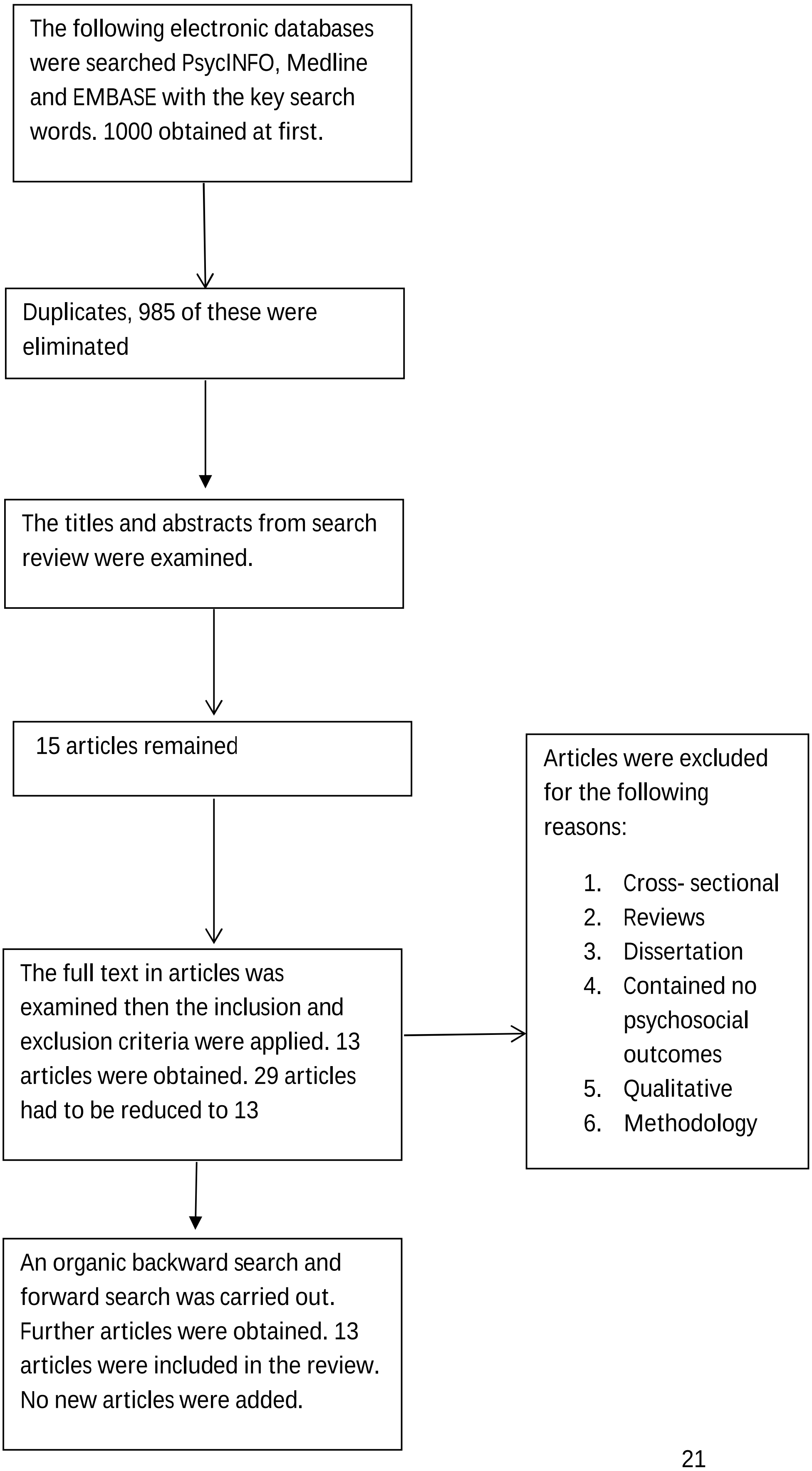
The three main types of autologous flaps which can be performed by using tissue from the abdomen are TRAM flap, DIEP flap and SIEP flap (Breast cancer.org). The TRAM flap (transverse rectus abdominis muscle) the muscle is located between the waist and pubic bone area. The TRAM flap is carried out by using a flap of skin which contains fat to reconstruct the new breast. The DIEP flap (Deep inferior epigastric perforator artery) is located in the abdomen. The DIEP is carried out by removing tissue from the wall of the abdomen to reconstruct the new breast. The SIEP flap (superficial inferior epigastric perforator) is located in the lower abdomen. The SIEP flap is carried out by using blood vessels, fat, nerves and tissue from the lower abdomen to reconstruct the new breast. There are other more advanced flaps which can be carried out including latissimus dorsi flap using tissue from the back. GAPflap (Gluteal artery perforator)involves extracting tissue from the buttocks. TUG (Transverse upper gracilis) and PAP flaps (Profunda artery perforator)involve using tissue from the thighs and fat grafting which involves using fat tissue from the abdomen, buttocks or thighs via liposuction (D'Souza et al., 2011) and Breastcancer.org). According to the NHS National Information Centre National Mastectomy and Breast Reconstruction Audit (2011), 21,605 females had breast reconstruction operations. Breast reconstruction can be associated with a number of psychosocial outcomes (Stagl et al., 2015) and NHS Audit (2011).

Women who have breast reconstruction can experience significant psychological distress. Women can suffer from long term psychosocial outcomes for instance,body image, sexual functioning, social functioning and physical functioning. This review aims to identify the long term psychosocial outcomes associated with greater than 12- months, post – mastectomy surgery following breast reconstruction.

Method

The data bases, EMBASE,Medline and PsycINFO, were searched between the years 2000-2013. The search terms used were quality of life, body image, depression, sexual functioning, post mastectomy, tumour, breast reconstruction, anxiety, neoplasm, and oncology. The terms linked to cancer were then grouped using AND/OR. Any duplicates were eliminated. A backwards organic search was then conducted which entailed searching through the reference lists in the articles to select any further relevant articles. A forward citation was then carried out on Web of Science .The inclusion criteria were females only, quantitative articles, and articles which reported outcomes on psychosocial measures12 months or more following reconstruction, published in English and focused on post – mastectomy breast reconstruction. The exclusion criteria were qualitative data, thesis or dissertation and reviews. Figure 1 outlines the search strategy. For each article, the following data was extracted, author, year of publication and demographic data which included sample size and reconstruction type.

Figure 1: Flow diagram of search strategy



The following electronic databases were searched PsycINFO, Medline and EMBASE with the key search words. 1000 obtained at first.

Duplicates, 985 of these were eliminated

The titles and abstracts from search review were examined.

15 articles remained

The full text in articles was examined then the inclusion and exclusion criteria were applied. 13 articles were obtained. 29 articles had to be reduced to 13

Articles were excluded for the following reasons:

1. Cross- sectional
2. Reviews
3. Dissertation
4. Contained no psychosocial outcomes
5. Qualitative
6. Methodology

An organic backward search and forward search was carried out. Further articles were obtained. 13 articles were included in the review. No new articles were added.

Quality Rating Assessment

Information about the methodology of each of the 13 articles is summarised in Table 1. The articles were also evaluated using a quality rating assessment which consisted of 11 items. These 11 items were extracted from an approved quality assessment method (Kmet,Lee & Cook, 2004).The scores were calculated by calculating a total score for each paper by adding up the entire score obtained across applicable items and dividing by the total possible score, for instance, 25-(Number of “yes” x 2.Three items were excluded from the assessment, these items were ,1. “Method of subject / comparison group selection or source of information/input variables described and appropriate”, 2. If interventional and random allocation was possible, was it described”, and 3. “If interventional and blinding of investigators was possible, was it reported? /If interventional and blinding of subjects was possible ,was it reported?”. The first criterion, number one, was excluded because the studies were observational and not experimental.The participants were in their groups and the studies did not have selection processes for allocating participants into groups. The second criterion was excluded because the studies were observational and not experimental in nature. The women were not randomly allocated to the healthy group, the breast- reconstruction or the breast -conserving surgery group. The women were in one of these three groups because of their health status and too the specific treatment they had chosen i.e. breast reconstruction. The third criterion was excluded because none of the studies were randomized control trials of medicines, therefore, you cannot blind participants in terms of whether they have had treatment for breast reconstruction or breast conserving surgery. The assessment was conducted by one researcher.Then, from

Table 1: Summary of method and quality ratings

Study and location	Study Design	Sample Size	Type Of Reconstruction	Comparison Group	Time Since Breast reconstruction at follow up	Quality Rating
Elder et al 2005 Sweden	Longitudinal	76	Delayed reconstruction	Healthy women 920	1 year	1.8
Metcalfe et al 2012 Canada	Longitudinal	190	Immediate breast reconstruction Delayed breast reconstruction	Three groups: Mastectomy alone N = 109; mastectomy, with immediate reconstruction N= 24; delayed reconstruction N = 57	1 year	1.9
Wehrens et al 2005 Netherlands	Longitudinal	49 reconstruction	Mastectomy	59 No reconstruction	7.5 mean years	1.9
Rubino et al 2007 Italy	Comparative Analysis	33 breast reconstruction	Beckers Permanent expander / Implants or TRAM flaps (pedicled or free)	33 mastectomy alone 33 healthy women	1 year	1.7
Guiet et al 2007 United Kingdom	Longitudinal	40 completed follow up	Sub muscular implant breast reconstruction or implant assisted latissimus dorsi flap	Two groups: Sub-muscular implant breast reconstruction N = 46; Implant-assisted latissimus dorsi flap N = 64	5 years	2
Gournay et al 2010 France	Retrospective longitudinal	160 reconstruction	Mastectomy then 6 months on Immediate or deferred reconstruction	Without reconstruction N = 86	3.6 years range 6 months to 17 years	2
Min et al 2010 Korea	Longitudinal	52	Mastectomy with immediate latissimus dorsimyocutaneousflap	Breast conserving surgery N = 104	39 months	2
Heneghan et al 2011 Ireland	Longitudinal	255	Immediate breast reconstruction	Breast conserving surgery N = 160	5 years	1.7

Han et al 2010 Germany	Retrospective study	16	Immediate breast reconstruction	Breast conserving therapy N = 76	1 year	1.6
Eltahir et al 2013 Netherlands	Cross sectional /cohort longitudinal	92	Mastectomy with immediate breast reconstruction	Mastectomy Alone N = 45	4 years	1.8
Fung et al 2001 Hong Kong	Longitudinal	17	Mastectomy with immediate breast reconstruction	Three groups Breast conserving treatment N = 17 Mastectomy N = 15	16 months	2
Shi et al 2011 Taiwan	Longitudinal	32	Immediate breast reconstruction	Breast conserving surgery N = 57 Modified radical mastectomy N = 83	2 years	1.6
Mullan et al 2007 USA and Sweden	Longitudinal	226 tram flap	TRAM FLAP	None	1 year	1.5

these scores, they were classified as high, moderate or low in quality rating. Scores ranging from 0-6 were classed as low or moderate, scores 7-9 were classed as high. The total scores for this evaluation are given in Table 1.Most of the articles had low quality ratings.

Results

Thirteenarticles were included in the review. The results have been organised into separate subheadings which explain the results of each psychosocial outcome. The results are summarised in Table 2.

Mood – Anxiety and depression

The articles had inconsistent results for anxiety and depression. Several articles found that anxiety and depression was non-significant when compared to baseline, breast conserving surgery and healthy women (Metcalfe et al.,2012), (Eltahir et al.,2013) , (Min et al.,2010). One article by (Rubino,Figus, Lorettu&Serchi, 2007) found non- significant results for anxiety and found that depression was poorer following reconstruction when compared to healthy women.

Aesthetic Satisfaction (Patient Satisfaction)

The results for aesthetic satisfaction were mixed. Two papers reported that aesthetic satisfaction was either reduced or higher following breast reconstruction. Two articles found mixed results for aesthetic satisfaction. One article by Gui et al. (2007) highlighted reduced aesthetic satisfaction when compared to baseline and (Eltahir et al., 2013) found higher aesthetic satisfaction when compared to baseline.

Table 2: Summary of findings

Author	**Follow-up post reconstruction (mean)**	**Anxiety**	**Depression**	**Cancer distress/FCR**	**Body image/stigma**	**Sexual functioning/ wellbeing**	**QoL - vitality**	**QoL- Physical role / activity**	**QoL- pain**	**QoL- General**	**QoL- Spiritual**	**QoL- physical symptoms**	**QoL- social function/ adaptation**	**QoL - emotion function**	**QoL – Cognitive function**	**QoL- mental health**	**Beliefs about future**	**Aesthetic satisfaction**
Comparison within group – follow-up scores when compared to baseline																		
Elder et al, 2005	1 year	~	~	~	~	~	Improved*	ns	ns	ns	~	ns	Improved***	Improved*	~	Improved***	~	~
Metcalfe et al 2012	1 year	ns	ns	ns	DRG decrease stigma*** IRG increase stigma***	ns	~	~	~	ns	ns	ns	ns	~	~	~	~	~
Mullan et al 2007	1 year	~	~	~	~	~	Improved**	Poorer*	ns	Improved***	~	ns	Improved***	Improved***	~	Improved***	~	~
Shi et al 2011	2 years	~	~	~	ns	ns	~	Improved**	~	Improved**	~	~	Improved*	Improved*	Improved**	~	Improved**	~
Gui et al 2007	6 years	~	~	~	~	~	~	~	ns	~	~	~	~	~	~	~	ns	Reduced**
Gournay et al 2010	3.6 years	~	~	~	Better *	~	ns	ns	ns	ns	ns	ns	ns	ns	~	ns	~	~
Eltahir et al 2013	4 years?	ns	ns	ns	~	Higher **	ns	Better*	Less pain**	Better**	~	~	ns	ns	~	ns	~	Higher **

*<0.05; **<0.01; *<0.001 ns=not significant; ~ = not examined in study DRG = Delayed reconstruction group IRG = Immediate reconstruction group

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Comparison across groups – results for reconstruction group when compared to group receiving breast conserving surgery																		
Heneghan et al 2011	3 years	~	~	~	~	~	~	ns	~	ns	~	ns	~	~	~	~	~	~
Min et al 2010	39 mths	~	ns	~	Poorer **	ns	~	~	~	~	~	~	~	~	~	~	Poorer*	~
Fung et al 2001	16 mths	~	~	~	ns	ns	~	~	~	ns	~	~	~	~	~	~	~	~
Han et al 2010	12 months	~	~	~	Poorer **	ns	~	ns	ns	ns	~	ns	ns	ns	ns	~	Better*	~
Comparison across groups – results for reconstruction group when compared to healthy women																		
Rubino et al 2007	1 year	ns	Poorer **	~	~	Better ***	~	~	~	Better ***		~	Better **	~	~	~	~	~
Wehrens et al 2005	7.5 years	ns	ns	ns	More self conscious *	~	ns	Less mobile*	ns	ns	ns	ns	ns	ns	~	ns	~	~

*<0.05; **<0.01; *<0.001 ns=not significant; ~ = not examined in study DRG = Delayed reconstruction group IRG = Immediate reconstruction group

Quality of life

Quality of life was measured in general and then in the following subscores; vitality , physical / role activity, pain, spiritual, physical symptoms, social function /adaptation, emotional function, cognitive function and mental health.

Quality of life in general

The articles reported consistent results. The results for quality of life in general reported an improvement following breast reconstruction when compared to baseline, breast - conserving surgery and healthy women (Elder et al., 2005), (Shi et al., 2011) and (Rubino et al., 2007).

QOL – Vitality

The results for vitality were inconsistent. Quality of life concerning vitality found an improvement in two articles when compared to baseline (Elder et al., 2005) and (Mullan et al., 2007). The following other articles reported non- significant results when compared to baseline (Gournay et al., 2010) and (Eltahir et al., 2013).

Vitality when compared to healthy women showed a non- significant result for (Wehrens, Cuypers, Boeckx& Van der Hulst, 2005).

QOL – Physical Role/Activity

The articles reported inconsistent results concerning physical activity and role activity. Women were found to be less mobile and poorer in physical/role activity in the following articles (Mullan et al., 2007) (when compared to baseline) and (Wehrens et al., 2005) (when compared to healthy women). However, two articles found the opposite in both (Shi et al., 2011) and (Eltahir et al., 2013). It was found that women showed signs of improvement when compared to baseline. Four articles found non –significant results for physical/role activity,(Elder et al., 2005),(Gournay et al., 2010) (when compared to baseline),(Heneghan et al., 2011) and(Han et al., 2010) (when compared to breast conserving- surgery).

QOL – Pain

The results for pain were mixed. The articles reported women had no problems with pain and a majority of the articles found non –significant results. The following papers had non – significant results,(Elder et al., 2005), (Mullan et al., 2007), (Gui et al., 2007),(Gournay et al.,2010) (when compared to baseline). There were non-significant results for (Han et al., 2010) when compared to breast- conserving surgery. There werenon – significant results for (Wehrens et al., 2005) when compared to healthy women. However, one article found the opposite; (Eltahir et al., 2013)found women had less pain.

QOL – Spiritual

The articles found women did not experience any problems with spirituality concerning quality of life. It was highlighted that non – significant results were found for (Metcalfe et al., 2012) and (Gournay et al., 2010) when compared to baseline.

QOL- Physical Symptoms

Quality of life physical symptoms were measured using the following: SF36 health survey questionnaire, Quality of life index, the Michigan breast reconstruction outcome study and the European Organization for Research and Treatment of Cancer Quality of Life. The results were non -significant and consistent across all three comparisons for quality of life physical symptoms. The articles found women did not experience problems with physical symptoms. The following articles found non – significant results when compared to baseline, (Elder et al., 2005), (Metcalfe et al., 2012),(Mullan et al., 2007) and (Gournay et al., 2010). Two papers found non – significant results when compared to breast- conserving surgery, (Heneghan et al., 2011) and(Han et al., 2010). One article found non – significant results when compared to healthy women, (Wehrens et al., 2005).

QOL – Social Function / Adaptation

Social function was measured using the SF36 health survey questionnaire, European Organization for Research and Treatment of Cancer Quality of Life, the Michigan Breast Reconstruction Outcome Study, Quality of Life Index and the SASS Social Adaptation Self- Evaluation Scale. The results for quality of life social function/adaptation were inconsistent. Several papers found an improvement for social function when compared to baseline (Elder et al., 2005),(Mullan et al., 2007) and (Shi et al., 2011). One paper found social function got better when compared to healthy women (Rubino et al., 2007). Three papers found non-significant results for social function when compared to baseline (Metcalfe et al., 2011),(Gournay et al.,2010) and (Eltahir et al., 2013). One paper found non-significant results when compared to breast conserving surgery (Han et al., 2010).Wehrenset al. (2005) found non-significant results when compared to healthy women.

QOL – Emotional Function

Emotional function was measured using the following questionnaires in the articles, Michigan Breast Reconstruction Outcome Study, Breast –Q, EORTC QLQ C30 European Organization for Research and Treatment of Cancer Quality of Life Questionnaire , Nottingham Health profile questionnaire and Euro QOL EQ-5D

European Quality of Life Questionnaire . The results for emotional function were mixed. Two papers when compared to baseline showed non-significant results (Gournay et al., 2010) and (Eltahir et al., 2013).

One paper highlighted a non-significant result when compared to breast - conserving surgery (Han et al., 2010). When compared to healthy women one paper showed a non – significant result (Wehrens et al., 2005).

However, three articles found the opposite, three papers found an improvement for emotional function when compared to baseline (Elder et al., 2005),(Mullan et al., 2007) and (Shi et al., 2011).

QOL – Cognitive function

The results for quality of life cognitive function were inconsistent. When compared to baseline, one paper found an improvement for cognitive function (Shi et al., 2011). However, the opposite was reported in the following two articles, when compared to breast -conserving surgery, one paper showed a non – significant result (Han et al., 2010) The following article found a non-significant result for cognitive function (Wehrens et al., 2005)(when compared to healthy women).

QOL – Mental Health

Mental health was measured using the following questionnaires , Michigan Breast Reconstruction Outcome Study , Breast – Q , Nottingham Health Profile, Euro QOL EQ-5D European Quality of Life Questionnaire and the SF -36 Health Survey. The results reported inconsistent results for mental health. Two articles highlighted non – significant results (Gournay et al., 2010) and(Eltahir et al., 2013) when compared to baseline. The following article was found to have a non-significant result when compared to healthy women (Wehrens et al., 2005). The opposite was found for two articles which showed an improvement for mental health (Elder et al., 2005) and(Mullan et al., 2007) when compared to baseline.

Cancer Distress /FCR

The results for cancer distress were consistent for all three comparisons. Cancer distress showed non-significant results in two papers when compared to baseline (Metcalfe et al., 2012) and(Eltahir et al., 2013).When compared to healthy women, one article found non-significant results (Wehrens et al., 2005).

Body Image /Stigma

The results for body image / stigma were inconsistent. Body image/stigma, when compared to baseline, reported mixed results. One article found body image improved (Gournay et al., 2010) and another article found a decrease in stigma (DRG) and an increase in stigma (IRG) (Metcalfe et al., 2012). One paper had a non-significant result (Shi et al., 2011) when compared to baseline.

When compared to breast- conserving surgery body image/stigma was found to be poorer in two papers (Min et al., 2010) and (Han et al., 2010).When compared to healthy women , one article found women were more self-conscious(Wehrens et al., 2005).

However, two articles reported the opposite; one paper had a non-significant result (Shi et al., 2011) when compared to baselineand (Fung, Lau, Fielding &Yip, 2001) reported non-significant results when compared to breast conserving surgery.

Sexual Functioning/ Well-being

Sexual functioning was measured using the following questionnaires, Quality of Life Index, European Organization for Research and Treatment of Cancer Quality of Life and the Chinese Health Questionnaire. The results for sexual functioning/ well-being were mixed.When compared to baseline, two papers had non-significant results (Metcalfe et al., 2012) and (Shi et al., 2011). When compared to breast- conserving surgery, the results were non–significant (Min et al., 2010; Fung et al., 2001; Han et al., 2010). However, Eltahir et al. (2013) reported higher sexual function/well-being when compared to baseline. When compared to healthy women,(Rubino et al. , 2007) found an improvement.

Beliefs about Future

The results for beliefs about future were mixed when compared to baseline. One article showed improvement (Shi et al., 2011) and another article found non-significant results (Gui et al., 2007).

When compared to breast conserving- surgery the results were mixed. One article highlighted poorer beliefs about the future (Min et al., 2010) and another article showed improved beliefs (Han et al., 2010).

Discussion

The aim of this review was to identify the long- term 12 months, psychosocial outcomes following post – mastectomy breast reconstruction. A key findings table (Table 3) has been included to demonstrate the key findings found within the systematic review.

Table 3: Key findings

Key findings for the systematic review. A systematic review of long -term psychosocial outcomes following post – mastectomy breast reconstruction.	Description of the key findings
Body image/stigma	Women showed signs of improvement when compared to baseline.
Body image/stigma	Delayed reconstruction had a decrease in stigma and immediate reconstruction had an increase in stigma
Body image/stigma	Women had poorer body image/stigma when compared to breast- conserving surgery
Body image/stigma	When compared to healthy women , women were self-conscious
Other variables	There was no strong evidence for the other measures. Mood : Anxiety and depression, Cancer distress, sexual functioning /well-being, QOL- vitality , QOL physical role / activity , QOL pain, QOL spiritual , QOL general , QOL physical symptoms , QOL social function / adaptation , QOL emotional function, QOL cognitive function, QOL mental health, beliefs about future and aesthetic satisfaction.

Mood – Anxiety /Depression

There was no strong evidence for an association between breast reconstruction and anxiety/depression. Only two papers provided a comparison between pre-surgery and follow-up on anxiety and depression(Metcalfe et al., 2012) and (Eltahir et al., 2013) and they reported no significant difference on either variable anxiety or depression. Only one paper compared breast reconstruction and breast conservation surgery (Min et al., 2010) and it found no significant difference in terms of depression (anxiety was not investigated). In comparison to healthy women, Rubino et al. (2007) did find that those who had breast reconstruction were significantly more depressed. However, they did not find any difference in terms ofanxiety, and two other papers (Eltahir et al., 2013; Wehrens et al., 2005) found no difference between anxiety and depression.

Aesthetic Satisfaction

There was no strong, significant evidence for an association between aesthetic satisfaction and breast reconstruction. There were only two papers which found that satisfaction was reduced or higher when compared to baseline (Gui et al., 2007) and (Eltahir et al., 2013).

Quality of Life in General

There was no strong, significant evidence for an association between quality of life in general and breast reconstruction. Six papers provided a comparison for pre – surgery (baseline) and follow – up,(Elder et al., 2005; Metcalfe et al., 2012; Mullan et al., 2007; Shi et al., 2011;Gournay et al., 2010 ; Eltahir et al., 2013). Three of these papers reported non-significant results (Elder et al., 2005; Metcalfe et al.,2012; Gournay et al.,2010) and three reported improvements (Mullan et al. 2007; Shi et al., 2011; Eltahir et al., 2013). Three papers provided a comparison for breast-conserving surgery (Heneghan et al., 2011; Fung et al., 2001; Han et al., 2010) and they reported non-significantresults in relation to breast reconstruction. Two papers provided a comparison for healthy women (Rubino et al., 2007; Wehrens et al., 2005); one paper reported an improvement (Rubino et al.,2007) and the other paper found a non-significant result in terms of breast reconstruction (Wehrens et al.,2005).

Quality of Life: Vitality

There was no strong,significant evidence for a link between breast reconstruction and vitality. Only four papers had a comparison between pre – surgery (baseline) and follow- up (Elder et al., 2005; Mullan et al., 2007; Gournay et al., 2010; Eltahir et al.,2013); two of these papers reported an improvement (Elder et al., 2005; Mullan et al., 2007) and two papers reported non-significant results (Gournay et al., 2010; Eltahir et al., 2013). Only one paper provided a comparison for healthy women (Wehrens et al., 2005) and it reported a non-significant result in relation to breast reconstruction.

Quality of Life Physical /Role Activity

There was strong evidence for a link between breast reconstruction and physical/role activity. Five papers provided a comparison between pre- surgery (baseline) and follow- up:(Elder et al.,2005; Mullan et al., 2007; Shi et al.,2011; Gournay et al.,2010 ; Eltahir et al.,2013). Two of the papers showed improvement (Shi et al., 2011; Eltahir et al., 2013). One paper showed poorer physical/role activity and two reported non-significant findings (Elder et al., 2005; Gournay et al., 2010). Two papers had comparisons for breast- conserving surgery and these reported non-significant findings (Heneghan et al., 2011; Han et al., 2010). One paper provided a comparison for healthy women and found that women were less mobile following the reconstruction (Wehrens et al., 2005).

Quality of Life: Pain

There was no strong evidence for a link between pain and breast reconstruction. Five papers provided a comparison between pre – surgery and follow- up:(Elder et al., 2005; Mullan et al., 2007; Gui et al., 2007; Gournay et al., 2010; Eltahir et al., 2013) and four of these papers reported non-significant results (Elder et al., 2005; Mullan et al., 2007; Gui et al., 2007; Gournay et al., 2010) except one paper in which women experienced less pain (Eltahir et al., 2013). One paper provided a comparison for breast- conserving surgery (Han et al., 2010) and this reported a non-significant finding. For healthy women,only one paper had a comparison (Wehrens et al., 2005) and this reported a non-significant result.

Quality of Life: Spiritual

There was no strong evidence for an association between quality of life: spiritual and breast reconstruction. Two papers provided a comparison between pre-surgery and follow - up (Metcalfe et al., 2012; Gournay et al., 2010) and these papers reported non-significant results. No comparisons were reported for breast conserving surgery. Only one paper provided a comparison for healthy women (Wehrens et al., 2005) and this reported a non-significant result.

Quality of Life Physical Symptoms

There was no strong evidence for a link between quality of life: physical symptoms and breast reconstruction. Five papers provided a comparison between pre-surgery and follow- up (Elder et al., 2005; Metcalfe et al.,2012; Mullan et al., 2007; Gournay et al., 2010; Eltahir et al.,2013) and the papers reported non-significant results for physical symptoms. Only two papers provided a comparison for breast- conserving surgery (Heneghan et al., 2011; Han et al., 2010) and these papers reported non-significant results. One paper provided one comparison for healthy women (Wehrens et al., 2005) and this reported a non-significant result.

Quality of Life Social Function/Adaptation

There was no strong evidence for an association between quality of life: social function and adaptation. Six papers provided comparisons for pre-surgery and follow- up:(Elder et al., 2005; Metcalfe et al., 2012; Mullan et al., 2007; Shi et al.,2011; Gournay et al. , 2010; Eltahir et al.,2013). Three of these papers reported improvements in social function and adaptation (Elder et al.,2005; Mullan et al., 2007; Shi et al.,2011) and three of the papers reported non-significant results (Metcalfe et al.,2012; Gournay et al.,2010; Eltahir et al.,2013). One paper provided a comparison for breast - conserving surgery (Han et al., 2010) and this paper reported a non-significant result. However, for healthy women, two papers provided two different comparisons; one paper by (Rubino et al., 2007) reported improvements in social function/adaptation and (Wehrens et al.,2005) reported a non-significant result.

Quality of Life: Emotional Function

There was no strong evidence to link emotional function and breast reconstruction. Five papers provided comparisons for pre- surgery and follow- up:(Elder et al., 2005; Mullan et al., 2007; Shi et al., 2011; Gournay et al., 2010; Eltahir et al., 2013) . Three of the papers showed women’s emotional function improved following reconstruction (Elder et al., 2005; Mullan et al.,2007; Shi et al., 2011) and two papers reported non-significant results (Gournay et al.,2010; Eltahir et al.,2013). Only one comparison was provided for breast - conserving surgery (Han et al., 2010) and this paper reported a non-significant result. For healthy women, only one paper provided a comparison (Wehrens et al., 2005) and this reported a non-significant result.

Quality of Life Cognitive Function

There was no strong evidence for an association between cognitive function and breast reconstruction. Only one paper provided a comparison for pre-surgery and follow- up (Shi et al., 2011) and this paper showed an improvement in cognitive function. For breast - conserving surgery, there was also one comparison provided

(Han et al., 2010) and this paper reported a non-significant result. No comparisons were reported for healthy women.

Quality of Life Mental Health

There was no strong evidence for a link between mental health and breast reconstruction. Four papers provided comparisons for pre-surgery and follow-up:(Elder et al., 2005; Mullan et al., 2007; Gournay et al., 2010; Eltahir et al., 2013). Two of these papers showed women improved following reconstruction in terms of mental health (Elder et al.,2005; Mullan et al., 2007) and two other papers reported non-significant results (Gournay et al., 2010; Eltahir et al.,2013). No comparisons were reported for breast - conserving surgery and only one paper provided a comparison for healthy women (Wehrens et al., 2005) which reported a non-significant result.

Cancer Distress/FCR

There was no strong evidence for an association between cancer distress and breast reconstruction. Only two papers provided comparisons for pre-surgery and follow- up (Metcalfe et al., 2012; Eltahir et al., 2013) these reported non-significant results. No comparisons were provided for breast - conserving surgery. Only one paper provided a comparison for healthy women which showed a non-significant result (Wehrens et al., 2005).

Body Image/Stigma

There was strong evidence for an association between body image/stigma and breast reconstruction. Three papers provided comparisons for pre-surgery and follow- up:(Metcalfe et al., 2012; Shi et al., 2011; Gournay et al., 2010). One of the papers showed women improved in terms of body image (Gournay et al., 2010; Metcalfe et al., 2012) showed women who had a delayed reconstruction (DRG) had a decrease in stigma and those who had an immediate reconstruction (IRG) had an increase in stigma. One paper reported a non-significant result (Shi et al., 2011). Three papers provided comparisons for breast - conserving surgery (Min et al., 2010; Fung et al., 2001; Han et al., 2010). Two of the papers reported women were poorer in body image/stigma (Min et al., 2010; Han et al., 2010). One of the papers Fung et al. (2001) reported a non-significant result in terms of body image/stigma. Only one paper provided a comparison for healthy women (Wehrens et al., 2005) and this paper reported women were more self-conscious in terms of body image/stigma.

Sexual Function/Well-being

There was no strong evidence for an association between sexual function/wellbeing and breast reconstruction. Three papers provided comparisons for pre-surgery and follow- up:(Metcalfe et al., 2012; Shi et al., 2011; Eltahir et al., 2013). Two of the papers reported non-significant results (Metcalfe et al., 2012; Shi et al., 2011) and only one paper reported higher sexual function/well-being (Eltahir et al., 2013). For breast - conserving surgery there were three comparisons and all showed non-significant results (Min et al., 2010; Fung et al., 2001; Han et al.,2010). For healthy women, only one paper provided a comparison (Rubino et al., 2007) and this reported an improvement in sexual function/well-being.

Beliefs about the Future

There was no strong evidence for a link between beliefs about the future and breast reconstruction. Only two papers provided comparisons for pre – surgery and follow - up (Shi et al., 2011; Gui et al., 2007). One paper reported an improvement (Shi et al.,

2011) and another paper reported a non-significant result(Gui et al., 2007). For breast - conserving surgery only two papers provided comparisons. One paper reported women were poorer (Min et al., 2010) and the other paper reported women improved (Han et al., 2010). There were no comparisons for healthy women in terms of beliefs about the future.

Limitations of the Reviewed Evidence

The quality framework highlighted partial weaknesses within the studies reviewed. Two articles did not clearly define the outcome or exposure measure (s) (Elder et al., 2005; Mullanet al., 2007). Concerning sample size, several articles had low sample sizes (Metcalfe et al., 2012; Shi et al., 2011; Eltahir et al., 2013;Fung et al.,2001; Rubinoet al.,2007). The limitation with smaller sample sizes is that a small sample size decreases the power of the statistical test and therefore non–significant results have little meaning. Other partial weaknesses found within the studies were not explaining clearly the input variable or method of subject for the comparison group, not explaining clearly the characteristics for the comparison group, estimate variance not being reported in the main results or the standard deviation, the study design was not always evident or suitable, the analytic methods not being clearly described and the results not being reported in-depth (Han et al., 2010; Rubino et al., 2007; Heneghan et al., 2011; Eltahir et al., 2013; Shi et al., 2011; Mullan et al., 2007; Wehrens et al.,2005). One weakness which stood out from the other weaknesses was found in relation to a conclusion not matching a finding in the results section (Elder et al., 2005).

The studies reviewed in this systematic review were not experimental; therefore, no causal conclusions can be drawn from the review. The articles reviewed usedconvenience sampling which could have resulted in an unrepresentative sample. Some of the articles did not report demographic information such as the age or ethnicity of the participants. The measures used in the articles tended to focus on single items or focus on one aspect instead of investigating different psychosocial outcomes.

Limitations of the Systematic Review

Limitations to this review are the 29 articles originally sourced had to be reduced to 13 because they did not fit the inclusion criteria. The search terms were restricted and one could have included expectations pre-operative to breast reconstructive surgery to widen the literature review. Further limitations were, articles which used quantitative methods were used, and one could have considered qualitative articles to widen the evidence in terms of gaining more detailed insights into individual experiences (Banister,Bunn,Burman&Daniels, 2011). The search terms were restricted and there were only three databases used to search for articles.

The Implications of the Findings

From the findings, there was evidence that women undergoing breast reconstruction demonstrate improvement over a time period in some aspects of quality of life, when comparing their scores pre - surgery with their scores at follow – up. One article Eltahiret al. (2013) reported sexual functioning/well-being was higher over time, women were better on QOL for physical role/activity and women experienced less pain over time concerning QOL pain. However, several articles reported non – significant findings on QOL, therefore, the outcome may not be predominantly strong. In terms of other psychosocial outcomes, two studies (Metcalfe et al.,2012; Gournay et al., 2010) suggested a difference between delayed and immediate reconstruction in relation to body image/stigma (appearance of the reconstructed breast) ,with delayed reconstruction showing an improvement over time and immediate reconstruction a decline over time. In Metcalfe et al.(2012) and in (Gournay et al., 2010) it was found to be better, however, this was an issue that only two articles addressed.Therefore more research is needed before strong conclusions can be drawn. Gui et al. (2007) reported a decline in aesthetic satisfaction over time in contrast to (Eltahir et al., 2013) who reported aesthetic was higher over time. However, more research is needed to replicate the finding.

In terms of breast reconstruction and breast - conserving surgery, there was little evidence of any difference in relation to the long - term psychosocial outcomes, except that two studies (Min et al., 2010; Han et al., 2010) found that breast reconstruction was worse in terms of body image/stigma.

For the comparison for healthy women at follow - up there were some significant differences in terms of the evidence. One article Wehrens et al. (2005) did report that the breast reconstruction group were more self – conscious about their appearance and were less mobile (less able to carry out daily tasks like washing, taking the kids to school) in terms of physical/ role activity. However, Rubino et al. (2007) reported women were better in the following outcomes; QOL general, QOL social function/adaptation and sexual functioning/well - being and poorer in terms of depression.

Future Research

The systematic review found that, in general, on all QOL measures, women improved over time at pre- surgery and follow –up. Women who had immediate reconstruction experienced difficulties with body image/stigma and those who had delayed reconstruction declined, as reported in one paper by (Metcalfe et al.,2012) and improved on body image/stigma in another paper by (Gournay et al., 2010). At pre – surgery and follow - up women had reduced aesthetic satisfaction (Gui et al., 2007) and then it was reported higher in one paper by (Eltahir et al., 2013). There was no strong , significant evidence for the comparison concerning breast - conserving surgery, however, two studies did find that body image/stigma was poorer (Min et al., 2010 ;Han et al .,2010). In relation to healthy women at follow– up (Wehrens et al., 2005) reported women were more self-conscious about their appearance , less mobile concerning physical role/activity and it was found in (Rubino et al., 2007) women were poorer in terms of depression. One article Rubino et al. (2007) reported women improved on three measures; sexual functioning/well-being, QOL-general and QOL social function/ adaptation, when compared to healthy women. The findings in this review need to be replicated and investigated further as causal conclusions cannot be drawn from these findings.

Chapter 3: ALongitudinal Qualitative Study of Psychosocial Function Following Mastectomy with or without Breast Reconstruction

Abstract:

Objective

Women who have breast cancer can opt to have a mastectomy with or without reconstruction. However, there is a growing issue with women who have reconstruction suffering long - term mental health issues like anxiety and depression. This could be due to a lack of support following reconstruction. The aim of this study is to assess the longitudinal psychosocial functioning following mastectomy with or without breast reconstruction.

Method

Fourteen participants were interviewed at several time points. The time points were no - reconstruction baseline and no - reconstruction 12 months, reconstruction baseline and reconstruction 12 months.The participants who had breast cancer were extracted from a large data set containing different types of cancer.The fourteen participants were split into two groups of 7, no - reconstruction and reconstruction. The interviews were transcribed using framework analysis.

Results

The main themes found in the study were, body image the disfigured breast, the need for normality cancer is not the boss and physical functioning. Women showed a strong desire to return to normality. The desire to fight, live and survive was evident amongst the women. This desire to return to normality was similar across the participants and their concepts of normality were also similar. It was similar in terms

of returning to work, getting back to their daily routines and getting back to full health. Both groups had difficulties with hair loss. Women experienced problems with physical functioning in terms of carrying out everyday tasks (cleaning, bathing, taking the kids to school).

Clinical Implications

The desire to fight, live and survive was evident. Women showed a strong desire to return to normality. Health professionals should look into this further to help cancer patients in dealing with a reconstruction/cancer treatment.

Conclusion: This qualitative study demonstrates that women want to fight and live through cancer and return to normality.

Introduction

Breast cancer is the most common disease in women (Office for National Statistics, 2011). Women who have a mastectomy can opt to have one with or without a reconstruction (Roostaeian& Crisera ,2011). The two types of reconstructive surgery patients can opt to have are implant - based reconstruction or autogenous tissue - based reconstruction (Roostaeian & Crisera ,2011).The purpose of a reconstruction is to provide patients with improved quality of life in terms of physical functioning, general QOL andpsychological wellness(Roostaeian & Crisera ,2011). The physical purpose of a reconstruction is to ensure patients breasts are restored in terms of shape, size, fullness, sense of self and sexual function (Roostaeian & Crisera , 2011). The reconstruction should be tailored to the individual patient's needs to ensure a successful reconstruction (Roostaeian & Crisera, 2011). Being newly diagnosed with breast cancer can be a traumatic time for a woman and having to cope with an operation whilst dealing with the notion that one may not survive can be very distressing for the patient and family (Landmark, Strandmark&Wahl, 2001). Some qualitative studies have demonstrated that, in the early diagnosis of cancer, women can experience mild emotional reactions (Arroyo & Lopez, 2011). Fear of recurrence has also been linked to the distress of fearing they may not recover (Grunfeld & Crist, 2013). Breast reconstruction in relation to mastectomy (no reconstruction) has been shown to challenge women's body image before and after the mastectomy in terms of how their breast appears visually before and after (Piot, Sassi, Raffoul&Delaloye, 2010). Immediate breast reconstructionin a study by (Al-Ghazal,Sully,Fallowfield& Blamey, 2000) was shown to cause less distress than delayed reconstruction and it improved women's psychosocial well – being. The aim of this study is to assess the longitudinal psychosocial functioning following mastectomy with or without breast reconstruction.

Method

Participants

Fourteen participants were interviewed at several time points. The participant sample was taken from another study which included women with breast cancer who had a breast reconstruction and the study examined returning to work following a breast reconstruction. The time points were no - reconstruction baseline 12 months before mastectomy and 12 months after no - reconstruction, reconstruction baseline 12 months before reconstruction and 12 months following reconstruction. Seven women had reconstruction and seven had no - reconstruction.

Procedure

The study was approved by the Guy's Hospital Research Ethics Committee. The participants were not paid, it was voluntary. The patients were recruited from Guy's Hospital, St Thomas Hospital and Charing Cross Hospital. The interviews wereon average 42 minutes and ranged from 28-63 minutes. The interviews were conducted by the person who carried out the study initially. The interviews had already been carried out and transcribed. For this qualitative study the interviews were analysed.

Interview Schedule, Data Collection and Framework Analysis

Participants were invited to speak openly about their breast reconstruction experience to gain an in-depth insight into their experiences. All the interviews were analysed using framework analysis.Its purpose is to identify themes which are common across participants. Each participant’s interviews were carefully analysed and main themes and subthemes were identified. The interview questions were based on returning to work,but the analysing of data was focused on the main psychosocial factors long-term. One did not have full access to the interview schedule.Here are some examples of the questions asked; *what were the main reasons for returning to work*? *Are there any particular tasks or duties at work you might sort of struggle with more than others*? *Would you say there have been any sort of difficulties getting back to work over the last year*?.

Framework Analysis

Framework analysis has been used specifically in health research and began in the 1980s (Gale, 2013). Framework analysis has seven stages. The stages are as follows. Stage 1, transcript of the interviews took place where the researcher listened to the recordings of the interviews and typed at the same time. Stage 2, familiarisation with the interviews. The researcher listened to the interviews again and made any further notes. Stage 3,Coding the researcher read the transcripts in-depth and assigned codes/labels to the transcripts whilst also using open coding where notes of any further relevant information were written down. Stage 4, developing a working analytical framework: the researcher met with their supervisor to discuss codes and compare codes/labels. The codes were then grouped into specific categories using tables. Stage 5, applying the analytical framework: transcripts were indexed using codes/labels. Stage 6, charting data into the framework matrix: tables were devised with the codes found and quotes from the transcripts were used to highlight the codes. Stage 7, interpreting the data: any further notes were made of any information which stood out or ideas/concepts which highlighted themselves. Differences between participants were identified. Frame work analysis was used because it is widely used in health research.It is a method which can be flexible and easily adapted, and it is the best suited method for analysing interview data (Gale, 2013). It is crucial when conducting qualitative research that one can compare and contrast the data.In terms of framework analysis, comparing and contrasting is well imbedded into the construction and method of framework analysis (Gale, 2013).

Results

Sample Characteristics

Fourteen participants participated in the study. Demographic details are provided in Table 4. All participants had either undergone a mastectomy without reconstruction or a mastectomy with reconstruction. Seven had reconstruction and seven had no - reconstruction. Common themes were extracted for both groups reconstruction and no- reconstruction, the material for both groups has been presented separately. How the experience changed over time for the women in terms of baseline and 12 months was not mentioned in the main results; however, two case studies were included to show the changes over time in greater detail. Detailed case studies were included for both groups no reconstruction and reconstruction. The case studies were included to show an in-depth examination into the cancer experience. The two participants (BR53 no - reconstruction and BR51 reconstruction) stood out in terms of their experiences being distressing. I included the case studies in order to highlight how distressing a reconstruction and no - reconstruction can be.

Table 4: Demographic and other characteristics of the sample

	Reconstruction (N=7)	No reconstruction (N=7)
Age at end of treatment	Mean = 42.9 Range = 35 to 54	Mean = 44.9 Range = 31 to 52
Civil status	1 single 5 married/cohabiting 1 divorced/separated	1 single 4 married/cohabiting 2 divorced/separated
Highest educational achievement	1 GCSE/equivalent 3 A'level/equivalent 3 Degree or higher	4 GCSE/equivalent 1 A'level/equivalent 1 Degree or higher 1 missing data
Race/ethnicity	5 White 1 Black African 1 Other	6 White 1 Black Caribbean
Number of financially dependent children	5 None 0 One 2 Two	3 None 4 One 0 None
Occupation	2 Professional 3 Managerial/technical 0 Non-manual skilled 1 Manual skilled 1 Partly skilled	4 Professional 2 Managerial/technical 1 Non-manual skilled 0 Manual skilled 0 Partly skilled
Weeks off sick due to cancer	Mean = 32.4 Range = 8 to 56 (N= 6: One participant not yet returned to work)	Mean = 22 Range = 1 to 55
Type of breast cancer	4 IDCA 1 ILCA 2 Multifocal IDCA 0 Mixed IDCA / ILCA	5 IDCA 0 ILCA 1 Multifocal IDCA 1 Mixed IDCA / ILCA
Type of breast surgery	5 Mastectomy & immediate reconstruction 1 Mastectomy & delayed reconstruction 1 WLE & ANC	5 WLE & ANC 2 WLE & SNB
Stage of cancer	2 Stage one 4 Stage two 1 Stage three	5 Stage one 2 Stage two 0 Stage three
Type of chemotherapy	2 None 3 FEC 2 FEC & Docetaxel 0 AC & Docetaxel	2 None 3 FEC 1 FEC & Docetaxel 1 AC & Docetaxel
Radiotherapy	2 Not received 5 Received	0 Not received 7 Received
Endocrine therapy	2 Not received 5 Tamoxifen	3 Not received 4 Tamoxifen

IDCA=InflitratingDoctal Carcinoma ; ILCA= Invasive Lobular Carcinoma ; WLE=White light Endoscopy ; ANC= Absolute Neutrophil Count ; SNB=Sentinel Node Biopsy ; FEC= Fluorouracil Epirubicin Cyclophosphamide ; AC= Adjuvant Chemotherapy

Findings

The themes in the appendices are physical functioning, social functioning, humour, fatigue functioning, body image, lack of support from NHS and employers, physical functioning the cruel pain of cancer and role functioning faced with daily difficulties.The main themes found within the interviews were body image the disfigured breast, the need for normality cancer is not the boss and physical functioning. Participants demonstrated issues with their body image in terms of how their appearance was concerning hair and weight. The need for normality came out as strong, coherent evidence and a strong desire to gain normality ran throughout the data. This desire to return to normality was similar across the participant's and their concepts of normality were also similar. It was similar in terms of returning to work, getting back to their daily routines and getting back to full health. Physical functioning was a difficulty and was involved in every aspect of the participant's daily lives. The physical functioning affected the participants in terms of returning to work, taking their children to school, having a shower/bath and carrying out the housework.

No Reconstruction Group

Body Image: The Disfigured Breast

The participants in the no -reconstruction showed signs of body image issues following a mastectomy. The women discussed how having breast cancer and having to have a mastectomy has impacted on their perception of their bodies in terms of the women feeling more negative. The participants spoke about how they fear other people in society might perceive them.

“I put on loads of weight so there’s that aswell so it’s all , you know double, edge sort of really” (BR08 is the code given to the participant in the original study, no - reconstruction , aged 50.

“I think generally people are a bit apprehensive because they don’t know what this person’s going to be like when they come back. People’s idea of cancer. There is still that stigma attached to it.”(BR14, no – reconstruction, aged 50).

The Need for Normality : Cancer is Not the Boss

The need for normality was a significant theme which ran across the data in the no - reconstruction group. Women strongly spoke about how they wanted to get back to normality and have their lives back in order.

One participant had as little time off as possible in order to get back to normality. One could describe this as desperation to want to live her life too how it was before the cancer diagnosis.

“I felt I had a good three weeks off and I think I just thought it was time to go back and get a sense of normality”(BR08,no – reconstruction,aged 50).

Normality signifies the women being positive about the future and returning to normal and their activities demonstrate a sign of overcoming cancer.

“I actually said to somebody last night, I’m looking forward to a little bit normality, I’m going to go back part time first of all.”(BR24, no– reconstruction, aged 49).

“I’m rushing around doing my own thing again. And I feel like I’m back on top. I’m alive. Yeah I feel much better now I’m back into it.” (BR27, no – reconstruction,aged 52).

The participants showed signs of boredom and their need for normality and effort to work stemmed from this. Normality for some participants demonstrated that the cancer had gone and they were, in a sense, in control of their lives following cancer. The participants evidently demonstrated that they longed for a work/ social life as the cancer had prevented them from participating in social events.

“Just ready to go back, I was just bored. During my chemotherapy there were some days I made it to the bus stop, but at least I tried, sort of thing, It was important to me to try to get back to work and try being normal”.(BR22, no – reconstruction, aged 31).

“I was very glad to get back to work when I did. I don’t think I could have been any earlier. I get bored at home. Yeah,I was glad to get back to normality. It symbolises normality. An end to all the cancer business. I felt very happy to be back at work”.(BR08, no - reconstruction, aged 50).

“It’s such a long time and you can feel sort of like really umm isolated”.(BR14, no – reconstruction,aged 50).

“I’m not one of these people, cus I’m never normally ill. I don’t even get colds so having breast cancer that was a shock”.(BR27,no – reconstruction,aged 52).

Physical Functioning

The participants experienced difficulties with their physical functioning concerning all aspects of their daily lives including their daily cancer treatment, visits to the hospital, general routines and working. Lymph nodes had been removed in some of the participants and it was a particular medical problem for participants as it prevented them from carrying out their work duties. The treatment affected their physical functioning at work.

*“September last year and I’ve not been back since. I intend going back last week in june”,*the lady also spoke about how the treatment has resulted in further health problems,*“ Developed an abscess ,so I’m in the second week of antibiotics and trying to, I’ve had it drained an all sorts so”.*

“The problem is with swimming I haven’t been able to go in the pool. With chemo you can’t go in because of the germs”. (BR38,no - reconstruction,aged 44).

“They’ve taken my lymph glands away under my left arm and I’m left - handed, unfortunately, but the lifting of files and stuff, I won’t be able to do that and I don’t intend doing that, because I’ve got lymphedema and it’s manageable and I know I have to look after it. So somebody else will be running around with the files”. (BR24 , no – reconstruction,aged 49).

“I used to maybe lift the children and things like that which I won’t be able to do”.

(BR38,no – reconstruction,aged 44).

Participants spoke about how the cancer and treatment increased their tiredness and this caused them to take more time off work. Participants even pre-empted that they would experience symptoms of exhaustion when returning to work. However,there was positivity amongst the participants in terms of wanting to recover quickly and making a conscious effort to regain control of their bodies.

“I know I’m going to be absolutely exhausted”, “Put on loads of weight”. (BR14, no – reconstruction, aged 50).

“First of all, it was for shorter hours, I’ve always made a conscious effort, because of cost”. (BR24,no – reconstruction,aged 49).

*“I was just so tired all the time”. (BR27, no –reconstruction,aged 52),*the participant spoke about how the radiotherapy affected her work and that a month was required for her to be back to normal health *“That did affect work, cus it is, it takes a lot out of you. It’s like , I went there about 3 o clock , 4 o clock in the afternoon after I’d finished work. By the time I got home I just went to bed; I had a bath and went to bed and everything. I was just too tired”. “It took a month to actually get back into it full speed”.*The women stated when she felt better she felt alive,*“you start being alive again and once you start being alive it’s brilliant, it’s just brilliant. It is. I feel terrific, I really do”.* (BR27, no – reconstruction,aged 38).

Participantshad difficulties with their physical functioning (daily routines) in terms of conducting everyday tasks such as cleaning, cooking, taking the children to school. Participants showed signs of a lack of confidence in carrying out everyday tasks and demonstrated signs of vulnerability.

“I was a little bit slower when I first back but that’s understandable”. (BR27,no – reconstruction,aged 52).

“I do need to get back to work because I need to get sort out my life back together again. And I just went in and told people and sort of said I’ve got breast cancer and I’m fine with it”. (BR14,no – reconstruction, aged 50).

“It’s such a long time and you can feel sort of like,really, umm, isolated”. (BR14 no – reconstruction, aged 50).

The simplest of tasks which involved carrying a handbag was not possible for one participant.

"I eased off, certainly in the first week, I felt quite vulnerable. I made sure I wasn't carrying heavy bags around".(BR08, no – reconstruction,aged 50).

"I think the hardest things are, umm, making the first step to actually go in and visit. Because, umm, with the treatment and time off, I mean I had ten months off".(BR14,no – reconstruction,aged 50).

Justification for Including Case Studies

The case studies were included to show an in-depth examination into the cancer experience. The two participants stood out in terms of their experiences being quite distressing. I included the case studies in order to highlight how distressing a reconstruction and non-reconstruction can be. This case study has been included because it also shows the difference between the two time points.

Methodology for Analysing the Case Studies

The tables were used from the main analysis to collate the material for presenting the case studies.

Case Study BR53 (BR53 is the code given to the participant in the original study) No - Reconstruction

The patient was aged 38. The patient had a son. She was of African ethnicity and worked as a personal assistant. The patient resided in Surrey and her husband had a professional job. The patient mentioned that she had a private oncologist. At no - reconstruction baseline, the patient experienced difficulties with her physical functioning, specifically fatigue. The patient had to work from home due to the anti-sickness medication which caused the following symptoms, excessive acid and constipation. The medications appeared to be causing more physical difficulties than the cancer itself. The patient has experienced breathlessness during a routine that she normally conducts with no issues. The patient only managed to do four hours a day of work. Due to the physical functioning difficulties the patient cannot work full time. Due to the physical functioning difficulties with the cancer, the patient had been a month delayed before returning to work. In relation to body image, the patient was particularly concerned about the appearance of her hair more than any other aspect of her body. The patient worried about society's stereotypes about what women's appearances were like following cancer. However, the patient presented some form of positivity concerning her appearance that if she makes herself look good she will feel good. The patient mentioned about the unrealistic outcomes the media portrays regarding cancer. However, since having cancer, the patient had made some lifestyle changes (eating healthier foods and exercising more frequently). The cancer made the patient think about the work/life balance and too focus on the more important aspects of life e.g. family and relationships.

BR53 (BR53 is the code given to the participant in the original study), No – reconstruction, 12 months onwards.The patient continued to have physical functioning issues following no reconstruction 12 months onwards. The patient experienced issues with her hair and felt restless on antibiotics given for an infection. The patient has also had an allergic rash to the antibiotics. The participant continued to experience tiredness and her sleeping pattern was disruptive. Concerning body image, the patient has continued to have difficulties with her hair loss which has been the main issue throughout her cancer treatment. The participant experienced a lack of social confidence, in terms of worrying that people are staring,when out socialising. The patient's social functioning had been affected, as she now prefers to be in her home environment. The patient talks about her stereotype,*"you just see I've got cancer and I'm going to die and that is just what you feel no matter what anyone says to you, and it does take a good year or so to change attitude".* She goes on to say that people just see doom and gloom when you mention cancer. However, the patient does demonstrate signs of positivity *"life does go on"* and the patient wanted to gain some normality in her life by returning to work. Throughout her treatment, the patient had developed a coping mechanism,*" I'm very matter of fact like that , I'm the sort of person who I can't change what is going to happen so what can I do to soften the blow to make it better for me, and that is kind of my outlook on what I do on most things" .*

Reconstruction Group

Participants in the reconstruction group also experienced psychological issues concerning all the themes identified across the participants. Participants suffered with physical affects (i.e. fatigue,nausea) in the reconstruction group.

Body Image: The Disfigured Breast

Participants had particular concerns with the appearance of their hair, eyelashes, in terms of having no hair visible in these areas on their bodies. For participants, this made it difficult to attend social and work events due to a lack of confidence. It seemed that participants had difficulties with disclosing the cancer, so they avoided social events. This, therefore, signifies that the participants are suffering from low self – esteem which in turn will affect their personal relationships and those who are around them every day.

“When you’re first diagnosed, you’ve just sort of think,well,of course, I’ll go ahead with surgery, I just want to get rid of it and all of that. But then you don’t think about how you’re going to feel about what you look like afterwards and all of those things, until you’ve gone through it at the time. I think, you know, I’m slowly coming to terms with that”.(BR01, Reconstruction, no age reported).

“I just want to relax, get a little bit of colour, just make myself feel a bit more attractive” When you think about going for meetings and dealing with staff and clients and colleagues then suddenly you’re aware you haven’t got much hair, you haven’t got any eyelashes and look awful and those sort of things. So that’s another mental barrier really to overcome”.(BR02, Reconstruction, aged 40).

For one participant, an avoidance strategy was in place and this meant they did not attend work. This was the participant’s approach to coping with having no hair or eyelashes and low self – esteem.

“I was just exhausted I was, you know, I was wearing a wig, I had my eyebrows painted and I was really glad to not have to go in and feel that pressure, I mean, I was doing that until September so and then when I really didn’t have the energy I just went, no, I’m going to leave it”.(BR07, Reconstruction, aged 38).

When her hair started to grow, she then started to build up her confidence and to attend work.

“I’ve got more used to it, I feel more comfortable, I think I will manage to make it in this week”.(BR07,Reconstruction, aged 38).

Need for Normality: Cancer is not the boss

Participants in the reconstruction group spoke about their need for normality and to gain control over their lives following cancer. Participants took on a positive approach to gaining normality. The need for socialising was crucial to gaining normality within their lives.

One participant spoke about how they wanted to return to normality because of boredom, over - thinking, over - consumption of food and to gain a social life. The participant felt that returning to work helped them feel healthier in the long run. This signifies the participant’s perception and beliefs that carrying out more physical exercise prevented them from feeling ill due to the cancer treatment.

“I was bored at home, fed up with my own company, and then the other things as well are I found that, if you stay at home I was eating more. I was thinking more about what was going on in my life. Whereas, I found by being at work I could concentrate on other things, and I actually felt healthier for it in the long run. And I honestly believe that I didn’t feel the full effects of the chemo because I was back at work, I felt quite isolated at home”.(BR17, Reconstruction, aged 35).

For other participants, participating in natural therapies was a coping strategy to deal with having cancer and receiving treatment. This helped the patients in terms of relaxation and taking their mind off the cancer diagnosis.

“I went swimming every day and did some yoga. I was going to relaxation and meditation at my local hospital, and they had a really nice yoga class for cancer patients. And I was making sure I went there every week because I found it very

therapeutic and very comforting to be in that atmosphere and be with other people". (BR02, Reconstruction, aged 40).

Physical Functioning

Participants in the reconstruction group experienced difficulties with their physical functioning in everyday life. One of the main difficulties women had with their physical functioning was extreme fatigue and side effects from their treatment made it difficult to physically function well.

"I think it's going to be very tiring for me. The only thing I'm slightly concerned about, as I say, is fatigue and I don't think that I am mentally on the ball yet as I was". (BR02, Reconstruction, aged 40).

For two participants, chemotherapy and the treatments caused extreme physical functioning problems. It was evident that participants werestruggling physically. There was more evidence of disclosure issues here concerning returning to work and talking to people about the cancer.

"But now I've started with Tamoxifen and that's made me feel really sick. I think also, like the chemotherapy, I think you can kind of compare it in people's understanding to depression or something. It feels like all my insides have been sucked out and replace with lead. Some days I couldn't even get out of the bath to my bed. I would have to get on the floor for a bit because I couldn't physically move my body". (BR02, Reconstruction, aged 40).

"I would go once a week. I did it from home and I actually found myself avoiding going in during normal work times. I'd go in later when everyone would have gone home. Because I just prefer to just go in and not have, umm, you know, and also

because it’s a lot quieter and also because I’m on Tamoxifen. I just get really hot flushes I find it quite claustrophobic”. (BR07,Reconstruction, aged 38).

The participants,physical functioning was also affected in terms of been able to work and carry out duties. These duties were carrying out work at their place of employment, reading and writing. Due to certain participants not been able to return to work promptly,this meant losing valuable finances.

“Because that’s very physical and, umm, I mean I know my therapy work is, but it’s standing all day, and you’ve got to kind of try and fit in lunch breaks and all of that”. (BR01, Reconstruction, no age reported).

“But I had to cancel a lot of work and I did tell them the reason”

(BR03,Reconstruction, aged 48).

“Building up clients. Umm, I think I think it was just very difficult for me because of the physical work that I do. You know, I’ve done hairdressing for years and I still do one day a week. I couldn’t rush back so I didn’t really feel like I had much choice about it. Trying to do treatments on my partner or, umm, you know just trying to have a busier day then seeing how I felt lifting my table”.(BR01 Reconstruction, no age, reported).

It was also evident, however, that the treatments were affecting the participant’s brain function. Reading and writing was a difficulty.

“ I’ve been given all the steroids, really, I felt messed with my mind, making me quite forgetful and at some points like when I just had them, when I just had my chemo for a couple of days, I could forget how to open a window”.(BR02,Reconstruction, aged 40).

“I found the chemotherapy made my brain quite, I found it very hard to concentrate on anything, um, difficult to read and stuff my work is all translating and reading and so that was, I did actually stop for about a couple of months like November and December I didn’t”. (BR07, Reconstruction, aged 38).

“Physically couldn’t clean the house, couldn’t do any of that because I’d get too tired too easily”. (BR17, Reconstruction, aged 35).

Justification for Including Case Studies

The case studies were included to show an in-depth examination into the cancer experience. The two participants stood out in terms of their experiences being quite distressing. I included the case studies in order to highlight how distressing a reconstruction and non-reconstruction can be. This case study has been included because it also shows the difference between the two time points.

Methodology for Analysing the Case Studies

The tables were used from the main analysis to collate the material for presenting the case studies.

Case Study, BR51, Reconstruction

The patient is aged 43. The patient works as a road safety manager and is in charge of a team of people. The job involves a considerable amount of responsibility. At reconstruction baseline, the patient has experienced physical functioning issues concerning tiredness and difficulty with her concentration levels. The patient has had to ease gradually back into work by devising a plan with the occupational health team. The patient has joined the gym in order to build the muscle tone back up in her knees and joints as these caused her pain. In order to achieve this, theparticipant hired a personal trainer. The participant has been worried about using public transport as she has to use her hands to lift herself up onto a bus and standing for a long time is impossible. The participant also mentioned that she was going to take up horse riding in order to build her back strength and abdominal area. The participant is trying to get one day off work so she only has to work four days a week. The only body image issue the participant presented in baseline was concerning her hair loss when returning to work. The cancer has made the participant revaluate her life and maybe be less concerned about work. However, work was still an important aspect of the patient's life and she wants to achieve a higher status in management.

At reconstruction, 12 months onwards, the patient was still experiencing difficulties with tiredness at the end of the working week. The participant, 12 months on is experiencing a lack of motivation, however, she has changed her perception of work/life. The participant is working fewer hours but also was glad to gain a sense of normality.

Discussion

The aim of this qualitative study was to assess the longitudinal psychosocial functioning following mastectomy with or without reconstruction. The study was a secondary analysis of an existing data set from another study. Both groups of women had difficulties with coping with hair loss and carrying out everyday tasks. For instance cleaning, bathing and taking the kids to school. Both groups experienced equal distress.

Participants demonstrated a strong desire to return to normality. Normality was similar across participants and their concepts of normality were similar.It was similar in terms of returning to work, getting back to their daily routines and getting back to full health. The fight to live and survive was evident in both groups and qualitative research by Landmark and Wahl (2002) suggested that this is related to the fight for existence.When the patients were in the vigorous stages of their cancer treatment, their fight for life deepened. Landmark and Wahl (2002) also highlighted that participants, fight for life was linked to a fear of death and losing contact with close family members.

Concerns about body image, specifically hair loss and weight gain, were evident in both groups. For certain participants it was difficult losing their hair as their jobs required them to be in charge and on the frontline, especially in the case of two participants where one was in the beauty industry and the other owned her own company. A qualitative study by Arroyo and Lopez (2011) stated that those who are in charge have a strong desire to present the perfect “physical ideal” and women find this perfection impossible to show their employees resulting in low self-esteem. Arroyo and Lopez (2011) found, when breast cancer patients are in hospital, they will avoid any contact with a mirror. Arroyo and Lopez (2011) described this as “direct conflict” and patients avoided viewing the mutilation to their breasts as this infringed on the women’s sense of self, “real of the body” as (Arroyo & Lopez, 2011) described. This could be because the feelings of low self-esteem from trying to achieve the “physical ideal” can stay long-term and this was shown in (Arroyo & Lopez, 2011).

Women could be experiencing body image issues in the long – term because they are in a state of bereavement too the loss of the original breast. In a study by Piot et al. (2010) they found women felt their bodies had been destroyed, termed “body destruction” and that the loss of the original breast resulted in a loss of their identity, which resulted in long term grieving.

There was evidence of a strong impact on qualitative data for physical functioning in both groups.Physical functioning appeared across numerous participants.This resulted in difficulties conducting everyday tasks, for instance, cleaning, personal hygiene washing and taking the children to school. Studies have reported that women can suffer with physical functioning issues, and, in both groups fatigue seemed to be the main issue. (Grunfeld, Low & Cooper, 2010; Piot et al., 2010).

The impact of cancer on the participants was great. It affected their ability to carry out activities in relation to daily living. This included activities such as leisure activities, bathing and looking after oneself. Treatment affected the participant's greatly causing nausea, fatigue and hair loss. Participants also struggled to lift heavy objects.

In relation to employment, work was affected. Numerous participants had to take a considerable amount of time off work. This was because the cancer treatments, for example, Tamoxifen, would cause extreme tiredness and this hindered their abilities to function normally.

The Limitations of the Study

There are disadvantages with using qualitative methods when conducting research. Qualitative research is time - consuming this results in small sample sizes, due to qualitative research using small sample sizes the results cannot be generalised. It is difficult to conduct systematic comparisons and qualitative research relies on the skills of the researcher in order to carry out interviews. One disadvantage was that participants were not asked about the impact of breast cancer on sexual functioning, as mentioned in the first chapter as a major consequence of breast cancer. There are advantages with using qualitative research. Qualitative research can provide an in - depth analysis of data and can examine participants experiences, emotions and behaviour. Qualitative research can create unrestricted access concerning individual's answers to questions.Qualitative methods can give a researcher opportunities to explore new topics and qualitative research aims to prevent pre-judgement which can occur in quantitative data (Berg &Lune, 2004). However, this study has provided an insight into the difficulties patients have when undergoing a reconstruction.

Implications of the Findings

Both reconstruction groups suffered equal distress and both groups of women struggled with carrying out everyday tasks. The main themes found in the qualitative study were body image the disfigured breast, the need for normality cancer is not the boss and physical functioning. Women showed a strong desire to return to normality. The desire to fight, live and survive was evident amongst the women. This desire to return to normality was similar across the participants and their concepts of normality were also similar. It was similar in terms of returning to work, getting back to their daily routines and getting back to full health. Women experienced problems with physical functioning in terms of carrying out everyday tasks (cleaning and bathing).

Findings of other research

It is known in research that social isolation can cause mental health problems, http://www.esrc.ac.uk/. A research survey conducted by the Mental Health Foundation, http://www.mentalhealth.org.uk/,highlighted that 42% of individuals (from the general population) have felt lonely and depressed due to isolation. Research has shown that individuals who lost contact with their daily work colleagues, similar to the participants in this study can experience depression http://www.mentalhealth.org.uk/ . Research has shown if individuals are in isolation which seemed to be an issue for some of the participants in this study http://www.mentalhealth.org.uk/Patients who are lonely can find it then difficult to seek support for psychological problems, http://www.mentalhealth.org.uk/ . In terms of the recovery time following an operation, if the patients are experiencing isolation, this can hinder the recovery process. Research has shown individuals do not recover well in isolation (not socialising) (Shepherd,Boardman&Slade, 2007). According to Shepherd et al. (2007) the recovery process is the symbolization of recovering from the illness or disability and to gaining good health. There are five stages to the recovery process. The first stage is moratorium which is classed as a period of withdrawal which is linked to feelings of loss and hopelessness. The second stage is awareness the feeling that one can recover from this illness and that leading a good life is possible. The third stage is preparation identifying your strengths and weaknesses in terms of recovery and to devise recovery skills. The fourth stage is rebuilding, where the patient aims to achieve a positive self, set goals and aims to gain control of their life. The final stage is growth where the patient aims to live a significant life and to manage their illness alone and create a sense of self (Shepherd et al., 2007).

Future Research

This desire to return to normality was similar across the participants and their concepts of normality were also similar. It was similar in terms of returning to work, getting back to their daily routines and getting back to full health. A study by Denford, Harcourt, Rubin and Pusic (2011) had similar findings in terms of participants desire to return to normality. However, this study found participants had different concepts of normality and there were individual differences. In conclusion, health professionals need to look into patient’s normality and their concepts of normality in order to help patients deal with their reconstruction and cancer treatment.

Chapter 4: Overall Discussion for Thesis

The systematic review demonstrated there was evidence that women undergoing breast reconstruction show improvement over a time period, concerning some aspects of quality of life, when their scores were compared to pre-surgery and follow – up. Several articles found non-significant findings in terms of quality of life. Delayed reconstruction showed an improvement and immediate reconstruction showed a decline over time (Metcalfe et al., 2012; Gournay et al., 2010). There was a decline in aesthetic satisfaction and an increase in satisfaction over time (Gui et al., 2007; Eltahir et al., 2013). There was very little evidence of any difference between breast reconstruction and breast - conserving surgery in relation to psychosocial outcomes. Two studies found breast reconstruction was worse in terms of body image/stigma (Min et al., 2010; Han et al., 2010). For the comparison for healthy women, there were some differences; the breast reconstruction group were more self-conscious in terms of their appearance and less mobile in terms of physical/role activity. One article showed women were better in the following psychosocial outcomes, QOL general, QOL social function/adaptation and sexual functioning/well-being (Rubino et al ., 2007). It was also found women were poorer in terms of depression (Rubino et al., 2007).

The qualitative study found the following main themes, body image the disfigured breast, the need for normality cancer is not the boss and physical functioning. Women showed a strong desire to return to normality. Normality was similar across participants and the participant's concepts of normality were similar. The participants had similar ideas about the concepts in terms of returning to work, getting back to their daily routine and back to full health.

Limitations of My Research

The findings for the systematic review and the qualitative study were complex. It was, therefore, difficult to draw out clear conclusions, as the evidence was varied for both reconstruction groups.

There were methodological weaknesses in my studies. The systematic review used a small number of articles which only provided a small insight into the literature. The search terms for the systematic review were restrictive,it would have been useful to have made the search terms more flexible. The exclusions for the search terms were no qualitative data, thesis, dissertation or reviews.

I used qualitative methods for my study instead of quantitative methods. Using statistics would have provided a more reliable and solid conclusion, as the data would have shown significant or non-significant results. However, qualitative data does provide a more in - depth insight into the women's lives. Interpretation of qualitative data may differ from one researcher to another; therefore, this can present difficulties in terms of providing clear conclusions. The qualitative study data was from a secondary data set; therefore, I had not met the participants personally or carried out the study. I was not present when the interviews took place nor did I transcribe the interviews. This, therefore, limited my ability to fully understand what experiences the women had gone through.

The Implications of the Findings

The systematic review suggested women undergoing breast reconstruction demonstrate improvement over time in certain aspects of quality of life, when comparing their scores pre - surgery with their scores at follow - up. Only one article showed women's sexual functioning / well - being improved over time (Eltahir et al., 2013). Women were better on quality of life for physical role/activity and, concerning quality of life pain, women experienced less pain over time. Several articles reported non – significant findings on QOL, meaning the outcome may not be significantly strong. In terms of body image/ stigma, only two articles suggested a difference between the two types of reconstruction; delayed reconstruction showed an improvement over time and immediate reconstruction a decline over time (Metcalfe et al., 2012; Gournay et al., 2010). As the issue of body image/stigma was only addressed by two articles, more research is needed to replicate the finding. Two articles reported differences in terms of aesthetic satisfaction; (Gui et al., 2007) showed a decline in aesthetic satisfaction over time, in contrast to (Eltahir et al.,2013) reported aesthetic satisfaction was higher over time. However, more research is needed to replicate the finding for aesthetic satisfaction. Concerning breast reconstruction and breast - conserving surgery, there was little difference in terms of the long - term psychosocial outcomes. However, two articles found that breast reconstruction was worse in relation to body image/ stigma (Min et al., 2010; Han et al., 2010). The comparison for healthy women at follow - up showed there was some significant differences in terms of the evidence; one article by (Wehrens et al., 2005) reported that those in the breast - reconstruction group were more self-conscious about their appearance (body image /stigma) and less mobile (able to carry out daily tasks like washing etc.) in relation to physical/role activity. One article by Rubino et al. (2007) found women were better in the following psychosocial outcomes, QOL general, QOL social function/adaptation and sexual functioning/well-being and poorer in terms of depression. These findings do need to be replicated in order to draw causal conclusions.

The qualitative study found the following main themes; body image the disfigured breast, the need for normality cancer is not the boss and physical functioning. Women showed a strong desire to return to normality. Normality was similar across participants and the participant’s concepts of normality were similar. The participants had similar ideas about the concepts in terms of returning to work, getting back to their daily routine and back to full health. A study by (Denford , Harcourt , Rubin & Pusic , 2010) had similar findings in terms of participants desire to return to normality. However, this study by (Denford , Harcourt , Rubin & Pusic ,2010) found participants had different concepts of normality and there were individual differences.

Future Research

Future research would need to replicate the findings from the systematic review, as there was little evidence that breast reconstruction was linked to the long - term psychosocial outcomes. In terms of the qualitative study, normality was similar across participants and participant’s concepts of normality were similar. The participants had similar ideas about the concepts in terms of returning to work, getting back to their daily routine and back to full health. Health professionals should look into this further to help cancer patients in dealing with a reconstruction and cancer treatment.

In conclusion, there was little evidence that breast reconstruction was linked to the long - term psychosocial outcomes in the review. Women who have a reconstruction have a strong desire to return to normality and their concepts of what returning to normality are similar. Research should look into this further in order to help cancer patients in dealing with a reconstruction and cancer treatment.

Dedications

I dedicate this thesis to my Auntie who sadly passed away from secondary breast cancer.

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