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DOI:

[10.1037/hea0000195](https://doi.org/10.1037/hea0000195)

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*Document Version*

Peer reviewed version

*Citation for published version (Harvard):*

Loaring, JM, Larkin, M, Shaw, R & Flowers, P 2015, 'Renegotiating sexual intimacy in the context of altered embodiment: the experiences of women with breast cancer and their male partners following mastectomy and reconstruction', *Health Psychology*, vol. 34, no. 4, pp. 426-36. <https://doi.org/10.1037/hea0000195>

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# **Renegotiating sexual intimacy in the context of altered embodiment: the experiences of women with breast cancer and their male partners following mastectomy and reconstruction.**

Jessica Loaring, Michael Larkin, Rachel Shaw, and Paul Flowers.

*Pre-publication accepted version of paper for Health Psychology.*

## **Abstract**

**OBJECTIVE:** Breast cancer diagnosis and treatments can have a profound impact upon women's wellbeing, body image and sexual functioning, but less is known about the relational context of their coping, and the impact upon their intimate partners. Our study focuses upon couples' experiences of breast cancer surgery, and its impact on body image and sexual intimacy.

**METHOD:** Utilising a dyadic design, we conducted 8 semi-structured individual interviews, with four long-term heterosexual couples, after the women had undergone mastectomy with reconstruction. Interviews explored both partners' experiences of diagnosis, decision-making, and experiences of body image and sexual intimacy. Interpretative phenomenological analysis (IPA) was adopted; this is a qualitative research approach characterised by in-depth analysis of the personal meaning of experiences.

**RESULTS:** Findings illustrate the positive acceptance which partners may express towards their wives' post-surgical bodies. They illuminate ways in which gendered coping styles and normative sexual scripts may shape couples' negotiations of intimacy around 'altered embodiment.' Reciprocal communication styles were

important for couples' coping. The management of expectations regarding breast reconstruction may also be helpful.

CONCLUSIONS: The insights from the dyadic, multiple perspective design suggest that psychologists must situate the meaning of supportive relationships and other protective factors in the context of complex life events and histories, in order to understand and support people's developing responses to distress.

### **Introduction.**

Treatment and recovery in relation to breast cancer is varied and complex. Breast cancer treatment typically involves surgery to remove the cancerous tissue, which can include the whole breast area (mastectomy) or part of the breast (lumpectomy). Adjuvant treatment such as chemotherapy or radiotherapy can also be an option to reduce the tumour prior to surgery or prevent its reoccurrence.

Psychosocial consequences of breast cancer and its treatment can be wide-ranging (Baucom, Porter, Kiby, Gremore & Keefe 2006) with threats to embodied, gendered and sexual identity. One surgical response to these threats is the increasing range of reconstruction options which are available to women. Reconstructive surgery is often an option for those who undergo a mastectomy, either at the time of the mastectomy itself (immediate reconstruction) or at a later date (immediate-delayed or delayed reconstruction). Reconstruction can take place with the woman's own healthy body tissue, an implant to replace all or some of the breast tissue, or a combination of both. The scope for decision-making on this issue is growing, and is affected by factors such as fear of reoccurrence (Molenaar et al., 2004) and perceptions of cosmetic results (Temple et al., 2006). Previous research has

demonstrated that outcome satisfaction can be improved, and psychological morbidity reduced, if clinicians discuss treatment options with women (including reconstruction options), thus involving patients in the decision-making process (Ananian et al., 2004; Heller, Parker, Youssef, & Miller, 2008; Keating, Guadagnoli, Landrum, Borbas, & Weeks, 2002). Overall satisfaction rates with treatment are often high, as illustrated in a large UK audit of mastectomy and reconstruction outcomes (e.g. NHS Information Centre, 2010). However, within this survey, only 59% of women were specifically satisfied, post-operatively, with how they looked in the mirror unclothed – and fewer still with how well-prepared they were for their post-operative experiences of pain, recovery, and scarring. Such concerns may set a difficult context for physical intimacy, and there have been calls for further work “in order to elucidate the complex and multi-faceted consequences of breast cancer on sexuality, for both women and their partners” (Gilbert, Ussher & Perz, 2010, p. 406).

In addition to this, the desire for physical intimacy is likely to be affected by issues such as body image (Rowland et al., 2000); reduced feelings of desirability (Carver et al. 1998); changes to relational dynamics after diagnosis and treatment; treatment side effects (e.g. hair loss, fatigue, weight gain, nausea, dryness of the vagina and loss of libido; Yurek, Farrar and Andersen , 2000); and effects on the ovaries which may in turn affect libido (Burwell, Case, Kaelin & Avis, 2006).

Moreover, there is some evidence that women’s perceptions of partner beliefs have an impact on both sexual functioning and body image (Wimberly, Carver, Laurenceau, Harris, & Antoni , 2005; Anllo, 2000; Bukovic et al. 2005; Holmberg, Scott, Alexy & Fife, 2001; Sheppard & Ely, 2008). In this literature, partners’

emotional involvement is reported to be a strong predictor for a woman's sexual, marital, and emotional adjustment after breast cancer.

Within the growing literature on couples' experiences of diagnosis and treatment for breast cancer, few studies have included both partners' views of post-treatment sexuality and body image. Within this literature, cancer is typically characterised as a crisis (Antoine et al., 2013; Chung Hwang, 2012, Fergus & Gray, 2009), and understood within the wider context of other stressors upon the couple (Holmberg et al., 2001; Kayser et al., 2007). It has identified insights into the importance and vulnerability of good communication in couples' ability to support each other. However, most previous studies have not focused specifically on couples' experiences of post-operative sexuality, or on their shared and negotiated perceptions of body image (e.g. see Fitch & Allard, 2007; Harrow, Wells, Barbour, & Cable, 2008; Kadmon, DeKeyser-Ganz, Rom & Woloski-Wruble, 2008). Examining the experience of diagnosis and treatment as a couple also affords the opportunity to determine whether the couple develop coping strategies as a dyad, or whether there are interpersonal differences in their ways of coping. The threat to a couple's intimacy constitutes a stressor that is personally significant to both members of the couple, but it may be that their appraisal of that threat is different (Lazarus & Folkman 1984; Cohen & Lazarus 1979). Therapeutic approaches which foster a reflective environment may help participants to articulate their appraisals of the threat, and to consolidate effective coping strategies. A key issue for this population, especially if information provision regarding treatment is insufficient, is that couples may not feel they have the resources to deal with the stressors of diagnosis

and treatment, leading to feelings of being overwhelmed (Smyth & Filipkowski, 2010) and to poor post-operative outcomes overall.

## **Rationale**

Breast cancer treatment can have a profound impact on women's body image and sexual functioning. Furthermore, the impact extends to intimate partners, who also have to adjust to a diagnosis of breast cancer and the effects of treatment. Previous research presents a mixed picture of the body image and sexual intimacy outcomes for women who undergo a mastectomy with immediate reconstruction (e.g. see reviews by Adams, et al., 2011; Gilbert, Ussher, & Perz, 2010; Schover, 1994). As these reviews demonstrate, there is extensive quantitative research on the clinical outcomes of differing surgery types, but there are fewer studies on how a woman experiences and understands her body in the context of sexual relationships, following a mastectomy and immediate reconstruction. Even less is known about how male partners experience and make sense of this process, or how the couple's views fit together. Such gaps within the existing literature give grounds for employing a qualitative approach to the topic. In particular, experiential research is required, in order to explore accounts of personal and relational processes during breast cancer surgery and recovery. As a consequence, our study adopts a phenomenological approach, and aims to explore and understand couples' lived experiences of their embodied selves and intimate relationships.

## **METHOD**

## **Approach**

Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) is an approach to qualitative research which has been used widely in clinical, health, counselling, educational, forensic, occupational and social psychology (e.g. see Reid, Flowers & Larkin, 2005). It is phenomenological in the sense that it is concerned with understanding how people make sense of their experiences – i.e. how they relate to the things which are important to them. It is interpretative in the dual sense that, firstly, it views all phenomenological work as inevitably interpretative (all observations are made from somewhere), and secondly, that it views analysis as a systematic attempt at making sense (e.g. via synthesising, abstracting, contextualising, analogising or illuminating meaning) of the experiential claims and concerns of participants. There is thus a ‘double hermeneutic,’ (two layers of interpretation), with the participant interpreting their own experience, and the researcher(s) then interpreting the participant’s account.

## **Design**

IPA studies often involve interviews with a single, homogenous sample group (Smith et al., 2009); that is, a group of people who share a mutual perspective on an experience. Increasingly, IPA researchers have also begun to use more complex designs which explore a shared experience from more than one perspective (e.g. Dancyger Smith, Jacobs Wallace, & Michie, 2010; Rostill, Larkin, Toms, Churchman, 2011). This study employs a dyadic form (e.g. see Clare, 2002; Wane,

Larkin, Earl-Grey, Smith, 2009) of such 'multi-perspectival designs' (Smith et al., 2009, p. 52).

Our interest in multiple-perspectival designs for IPA research draws upon a number of key concepts, but two which are particularly important are *profiles* and *systems*. The perspectival nature of our relationship to reality is foreshadowed in Husserl's work (e.g. see Moran, 2000). Husserl describes how the 'outer world' of things and events is perceived via a series of profiles, adumbrations, or aspects. Thus perception has a partial and perspectival quality, and this is a function of our spatial or relational place in the world. This sense of the person as a being always 'in-relation-to the world' was ultimately given an even stronger emphasis – and a rather different language – in the later work of Heidegger (e.g. see Larkin, Clifton & Watts, 2006). This connects, in turn, with an important idea underpinning many family therapy and human systems theories: that events and processes are best understood by exploring what happens *in between* the individuals involved, whether in terms of their interactions with one another, or the stories and language which constitute their realities (e.g. see Andersen, 1987, p. 415). Both systemic theory and IPA draw upon interest in the functions of language, but neither are primarily defined or constrained by that interest. Both may also be implemented with the view that differing personal perspectives on the world can be reconciled by a third party focusing on patterns of meaning-making, provided that the analyst begins from the position that each perspective illuminates an important aspect of a shared experience.

### **Setting and recruitment**

Ethical approval for this study was granted by a National Health Service Research Ethics Committee. Our research took place in the Cancer Service of a large general hospital in the Midlands region of the UK. Nurse Specialists identified and approached women and their partners to ask whether they might be interested in the research. The women they approached had all undergone a mastectomy with immediate reconstruction, either using their own tissue or synthetic implants. Interested couples were then recruited by the first author, based on the inclusion criteria in Table 1. No individuals declined to take part or were excluded from the study for not meeting the inclusion criteria.

TABLE 1 HERE

### **Sample characteristics**

The sample size (n=8) in this study is within the average range for an IPA study (Reid et al, 2005). Names of participants have been changed for external anonymity<sup>i</sup>. The four couples were: Jennifer and John, Gemma and George, Nina and Neil, and Sadie and Sam.

The participants were aged between 37 and 55 years. Two couples described themselves as White British, one as Asian British and one as African British. The women had all been diagnosed with breast cancer; three had been diagnosed with invasive breast cancer (lobular, ductal, or a mix of both) and the fourth had an early

form of breast cancer (ductal carcinoma in situ, DCIS). All women had undergone a mastectomy with immediate reconstruction on one breast. Of these, three had reconstructions using their own tissue and one using implants plus own tissue. All women were between seven months and three years post-surgery, and all less than four years since diagnosis. The couples had been in their relationships from between 10 years and 26 years; all had children (2-4 per couple, ranging in age from 2-24 years).

The women had different reconstructive surgery types: two received TRAM (transverse rectus abdominis muscle) flaps; one a free DIEP (deep inferior epigastric perforator) flap, and one a LD (latissimus dorsi) flap. Each woman had one surgical procedure, and each was treated by a plastic surgeon. They were all offered tattoos (as a form of nipple reconstruction) but, at the time of the interview, had not pursued this.

### **Data Collection**

Each interview followed a semi-structured interview format. The questions were developed by the first author in accordance with recommended conventions (Smith, 1995; Willig, 2008) then reviewed by two other members of the research team, and amended accordingly. The interview schedule consisted of broad questions relating to the time of cancer diagnosis and participants' experiences of treatment, surgery and body image. This helped to set the scene and enabled participants to tell their story (see Table 2). As is typical in IPA interviewing, the schedule was used flexibly - with open prompting and probing from the interviewer - rather than as a fixed

agenda. The interviews were conducted by the first author, a female clinical psychologist (in training at the time of the study). She had worked at the cancer service for 6 months. The first author and second author met regularly during the interview phase, to reflect on issues arising for the interviewer, to monitor interview quality, and to discuss any emergent ethical issues.

TABLE TWO HERE

Phenomenological approaches often emphasise the ‘perspectival’ quality of experience (Larkin, 2014), and in this study we were keen to understand the perspective of each partner in each couple. Each participant was interviewed individually, in an attempt to ensure that they felt comfortable and able to talk openly about their experiences, thoughts and feelings. Interviews took place within the hospital in a sound-proofed room and were undertaken at a time convenient to the participants. The interviews lasted between 30 minutes and two hours (mean 49 minutes). Each was audio-recorded, transcribed verbatim, and pseudonymised.

### **Data Analysis**

The data were analyzed using IPA. The principles underlining this process are described in detail in Smith et al. (2009), and summarised here in Figure 2. The steps are intended to be flexible and iterative, rather than rigid and linear. In this study, individual transcripts were analysed first, and then developed pair-by-pair. The coded transcripts were then reviewed for potential themes within couples, across

couples, and by gender. The final analytic structure (see next section) reflects all of these strategies.

TABLE THREE HERE

The early stages of the analysis were led by the first author, with the second author involved in discussing each stage of the work, and providing feedback and triangulation on the developing interpretations of each pair of transcripts. The third and fourth authors reviewed the analysis at the later stages, and provided insights into the credibility, coherence and structure of the analysis as a whole.

## ANALYSIS

Our analysis identified three major themes relating to: *threat, the body, and communication*. Underpinning these major themes were eight minor themes. This structure is presented in Table 4. The final themes were chosen both for their prevalence and for the weight placed on them by participants.

TABLE FOUR HERE

### **Theme 1: Cancer as a threat**

This theme explores how couples described and understood their journey from diagnosis to breast surgery. There was a sense of "being together" and having a shared understanding of cancer as a central threat. The women were seen by men as strong, and as decision-makers. The women saw themselves as overwhelmed with information, but also as doing their best to navigate some tough decisions.

Although the men wanted to be part of decision-making processes, they were also mindful of putting their wives' needs or preferences first and supporting whatever decision was made by them. During the time of diagnosis and considering treatment, men saw themselves, and were described by their wives, in *practical* terms (as 'do-ers'). Men took on the roles of gatekeeping, looking after their wives, attempting to maintain 'normality,' and portraying a united front for other family members and for people outside of the family. These different coping roles were reminiscent of gender differences within coping styles in the wider literature on cancer survivorship (e.g. Cho, Park & Blank, 2013), but it was not clear here whether they were best understood in terms of these generic gender role conventions, or more specifically as aspects of the reciprocal nature of 'coupled' coping. Due to our design, our analysis largely explores the latter possibility. This highlights that, even though cancer may only directly affect one person, couples' responses can be understood as dyadic and dynamic.

**1a. Being together.** The process of having to make decisions about surgery was described in the context of the couple, with information being received and digested together. It appeared that for both the women and their partners, the diagnosis and the decisions regarding treatment could be overwhelming. Husbands were active and involved in this process; all couples described a primary focus on "banishing the cancer". For example, Neil emphasised how the first priority for them was to deal with the cancer. Understandably, survival was the main concern:

"Uh, my primary thought, um, was about get rid of the cancer, you know, come what may. I wasn't sort of bothered as to whether she, um, had, um,

you know, the mastectomy, as long as her overall health was sort of fine”

**(Neil)**

Prioritising the wife’s needs was a common theme amongst the male partners.

This understanding and acceptance was evident in the partners’ understanding of their wives’ reasons for wanting a mastectomy with reconstruction, even if personally they placed less importance on whether or not the breast was reconstructed. As Sam says:

“From Sadie’s point of view and perhaps from the outside world [immediate reconstruction is] more aesthetically pleasing, erm, and also, I guess she...felt it was worth doing, you know.” **(Sam)**

Sam demonstrated his support of Sadie's decision, but was careful not to present it as his own. In the above quote, he acknowledged that the aesthetic appearance of the breast was important for Sadie, particularly in the context of wider cultural expectations, whilst implying that it was of less significance to him. This kind of reciprocal perspective-taking typified couples’ accounts of the diagnosis and of the difficult period when decisions were made about treatment. Couples recalled presenting a united front against cancer. However, as the following theme shows, a more complex, dynamic and divergent trajectory followed.

## **Theme 2: The body as a primary concern.**

This theme encompasses a divergence in the accounts of the husbands and wives in our study. During diagnosis and decision-making, the struggle against cancer was

the central focus. After surgery, the focus shifted to the recovering body. For some of the women, this was an uncomfortable shift:

“It’s because it’s something that I’ve never really discussed with [partner] and I’ve chosen not to discuss. I’ve never, ever been body confident, never. Never felt, um, I’ve never felt attractive. I’ve never felt, um... I don’t know. I think ((sighs)), I don’t know; it’s quite, it’s quite strange. I never felt sexy. I felt more so when I was younger. Facially and hair, I felt sexy; bodily not<sup>ii</sup>.”

**2a. Surgical threats to the ‘normal body.’** Women’s concerns regarding their bodies were the predominant experiential features of their accounts. This somatic concern seemed to be a direct result of their treatment. The three major issues for the women were complications during recovery, disappointment with the end result of the breast surgery, and distress at the amount of weight gained as a result of chemotherapy and medication. These issues all tapped into the women’s sense of the body as transformed through treatment. As Nina explained:

“There’s this sort of in your head and this option that when you have a reconstruction you’re just going to have a normal looking breast. And so it’s so, it’s so not like that because he gave me a set of websites to come back and look at. And breast reconstructions yeah they give you, they give you a mass there so that you’re not flat chested on the one side, but, but really they look nothing like what I wanted and was used to looking like. So it was, it was very, very distressing.” (Nina)

Nina’s account is representative of the feelings described by the women in our study: the reconstructed breast came as a shock., partly due to prior expectations, and partly due to the scale of the change. The effects of adjuvant treatments (such as hormone treatments) added to this, with women complaining of “*joint pain, lethargy, tiredness, lack of interest*” (Jennifer) and “*loss of libido [and] hot flushes*” (Nina) during

this time. Gendered expectations concerning the body began to emerge during this recovery period: as above, much of the women's anxiety about the body was underpinned by an implicit, normative image of the appearance of the female body and breasts. However, as we will discuss below, the men's experiences were different.

**2b. The body re-encountered.** The presence of surgeons haunted the women's accounts; this flowed through the cancer narrative, from diagnosis and decision-making to surgery and recovery. The women described being told that an immediate reconstruction would not only be reparative but would also give them a new aesthetically-enhanced breast and stomach. This promise of repair was not always met. Nina's account illustrates the different perspectives of the women and their surgeons:

“They get so excited about ((laughing)), their work and what a breast looks like and how fantastic they can make you look and ‘You'll be pleased with it, and it won't be as droopy as your other one’. And, you know, what... it, it almost makes it that I think they're trained to make you think they're giving you a treat after all you've been through.” (Nina)

Here, the body is an object to be repaired or beautified here (‘You'll be pleased with it’). In the context of treatment for life-threatening illness, women were also encouraged to re-encounter their bodies in aesthetic forms, as something ‘to-be-looked-at’. The perceived artistry of the surgeons resonated throughout the women's accounts, and at times the doctor-patient relationship could almost be compared to that of artist and muse. This relationship was fragile and subject to rupture and crisis. In the women's accounts, there was a sense of bewilderment

about the events surrounding surgery. Jennifer, for example, described finding out, in recovery, that the surgeon had created a new belly button<sup>iii</sup>:

“I didn’t know. As far as I was concerned I was having mastectomy, reconstruction, stomach muscles; that was all I was told; that was all I was led to believe. I was not told, ‘Look at this website, look at this piece of paper, cosmetically this is what you’re going to have, you’re going to have a new belly button’. It was as if I’d had more done, which I did, to what I’d expected. And at that point it was I had to readjust to it all in my head. And it was quite strange to have to readjust to so much of the body area being touched and being... it wasn’t the fact – I can’t explain it – it wasn’t the fact that they’d invaded the body as such – that’s the only thing... ((laughs))”

**(Jennifer)**

The extract from Jennifer’s interview illustrates her distress at a palpable sense of bodily violation. Cancer emphasises the body-subject’s vulnerability, but for Jennifer, this vulnerability seemed to be extended when her body became part of the surgeon’s work. The objectification of Jennifer’s body was even perpetuated in her own words: she described it as ‘the’ body rather than ‘my’ body. The surgeon ‘owned’ his work and took action (to work on the belly button) against Jennifer’s presurgical expectations. Although it was ‘invaded,’ we can see that she struggled to identify the source of her discomfort (i.e. it was not the ‘fact’ of the invasion ‘as such’). One could infer that her discomfort arose because her body was re-encountered as a newly vulnerable location (‘I had to *readjust* to it all ... strange to have to *readjust*’ – our emphasis).

The body is not merely changed in these accounts; it is very clearly ‘altered’ (made other). The experiences above appear to reflect a renewed sense of one’s

embodied self, but they do so in the context of the inevitably invasive actions of surgeons. This is compounded, in the next theme, by the anticipated gaze of partners.

**2c. The anticipated gaze as a threat to sexual intimacy.** For the women, various aspects of breast cancer surgery and treatment presented barriers to physical intimacy. Although the women differed in their acceptance of their physical appearance, they shared a concern with wanting to feel physically at ease with their partners. Increased awareness of one's body as both subject (me) and object (it) is often encountered in the experience of ill-health, but for the women in our study, it emerged as a central aspect of their sexual relationships. All four women talked of wanting to 'cover up' in front of their partners and of losing confidence in being naked with them. Their first sexual intimacies following surgery were recalled as difficult times; feelings of fear and discomfort were common. For example, Gemma said:

"After surgery, I was...it like...I was not really in the mood, but, I thought, I'll make the mood, I said to him, I don't want him to be angry, but it's like, 'I'm not complete, well you have...probably seen something else...but this is not what you saw before'. So he told me that he's not really bothered that I'm ok the way I am, as long as I'm...he's with me and ok. But I am not complete I don't want him to see me like this" (**Gemma**)

Gemma's account described her doubts and discomfort about sexual intimacy, but it also included a description of her husband's attempts to reassure her. This was common a theme across all of our participants' accounts. In each case, the couples' positions were polarised. The women expressed disbelief that their

husbands could find them attractive, while the men asserted that they did indeed find their wives attractive, and just as much as before breast cancer was diagnosed. All four women described their initial resistance to their husbands' compliments or reassurance about their bodies. The focus of Gemma's concern (above) was visual: the body is represented as an object 'to be seen' by her husband. For Gemma, this focus on the visual was linked to a feeling of incompleteness, and of herself as changed ("*this is not what you saw before*"). Sadie too experienced difficulties resuming a sexual relationship following surgery because her body was different. Like Gemma, Sadie felt insecure in herself and in her intimacy with her husband, because of her changed body:

"I struggled to do...struggled to think about anything other than what Sam was seeing. So for me it wasn't possible to relax, enjoy, e...a...it. I was just conscious of what, you know, what was there...the fact that it was different" (Sadie)

For the women then, feelings about the body (and particularly its attractiveness) were linked to their experiences of themselves as sexual beings. The men tended to emphasise their sustained sexual interest in their partners, in the context of their feelings for them and shared history. So for example, John described how Jennifer had "*always had a nice body like, you know [...] Obviously because we've known each other for so long she's, um, I've just, not just her body, her, everything about her really, you know... and I still do, you know.*" Even though it is not easy to name the positive feeling (love, attraction, desire) in this extract, the fact that it *is* positive is clear.

As we have seen (e.g. with Gemma, above), the women were aware of the men's positions, but found it difficult to accept their reassurances. Similarly, the men were aware of the women's ("*I think Jennifer will say, 'I don't think he'd find me attractive,' which she knows I do because I've told her like, you know.*" - John). The polarised views of the men and women were re-united when it came to discussing the caution involved in renewing their sexual relationships. For both the women and the men, there was awareness that sexual intimacy had taken on a new dimension, which required careful negotiation, and re-learning of scripts. Nina described how, due to reduced sensitivity in her breast, "*the whole, whole experience [was] awkward and different and something to get past until you get used to [...] both of you.*" This sense of unease was captured in the following pair of mirrored quotations from Gemma and George, who both discussed their reciprocal sensitivities about resuming their sexual relationship after surgery:

"Yeah, the first time was really, a bit of er, new experience really you know because I wasn't really sure to touch it or not, you know, cos I didn't know how she could now feel, you know." **(George)**

"He will just...he would feel it, sometimes he would feel it but say... 'Is it hurting, are you feeling pain?'" **(Gemma)**

**2d. Relief at survival & the holistic view.** All four husbands spoke of their priorities, and expressed relief that their wives had survived surgery. The men grappled with the enormity of surgery and spoke of wanting to offer support and help to their wives. The husbands recalled their reactions to their wives' bodies,

post-surgery. All four men expressed satisfaction with the reconstructive surgery, although they were mindful of their wives' dissatisfaction and feelings. Here, Sam describes his expectations of surgery and his way of coping with uncertainty:

"I think I was expecting it to be much worse than it was...the scarring and everything was far better than I probably anticipated but then I think perhaps part of that is, you fear the worst, and therefore if the end result's better than that's...that's a good result [.....] I think she's looking great now, erm. she's...sure I suppose she'll say she's put on a fair bit of weight, she was a fair bit slimmer before erm, and I think she's probably more concerned about that than I am but, er, you know, that's perhaps understandable" **(Sam)**

It is notable that the men's expectations of surgery appeared to be met, whereas the women's expectations were not. Sam's acceptance of Sadie's altered body was reiterated through his interview; a pattern seen in all the husbands' accounts. Each of them described how they enjoyed looking at their wives, from an aesthetic perspective:

"When she used to get out of the shower and things and, um, get changed in front of me. And, um, uh, and I used to enjoy looking at her body in, uh, you know, bras and [under]pants and, um and even now when she does that [...] I still enjoy doing that. Um, and I'm not doing it from just to say, 'Oh look, does it look any different' or anything; I'm just, you know, I'm just enjoying the whole, you know, visualisation of her and her body. Um, and I do compliment her on it, sort of saying, 'You're looking particularly... this morning'. I don't know whether she feels I genuinely mean that or I'm just constantly sort of saying that as a reassurance; but I do genuinely mean it. So, so to me I don't think that I've changed my sort of view as to how, how good she looks, you know, naked or otherwise" **(Neil)**

Neil was uncertain whether Nina believed his compliments or understood his appreciation of her body. It is notable that in one sense that the women's anxieties were corroborated: their husbands' sexual appraisals *do* have a strong visual component. What was striking, however, was the holistic nature of these appraising views: for these men, the changes to the female body were accommodated into a continuous narrative of positive aesthetics. The men recognised the sensitivities involved in seeing the body this way, while their partners felt differently - perhaps even to the extent that the women over-emphasised the visual element of sexual intimacy to the detriment of the relational and visceral. In the men's accounts, there was talk of needing to consider their wives' feelings during sex and whether they were experiencing pain or discomfort. There was also an acknowledgement that adjustment would take time and consideration. Communication was thus a central concern. Participants talked about thoughts which they had kept to themselves, and had not yet shared with their partners.

### **Theme 3: The importance of communication**

Throughout the couples' accounts there were references to the couple as a unit, describing how they negotiated their way through concerns about body image and sexuality following breast cancer treatment. However, there were times when this was not directly communicated - as we have seen in the example at the beginning of Theme 2. The women's accounts suggested a pattern of 'avoidance' - consciously or unconsciously - and of not wanting to directly discuss concerns at some points. The men described attempting to read their partners' non-verbal cues in situations

that involved affection or sexual intimacy. However, the wives and husbands came together in their accounts in terms of thinking about the future and the need to communicate more clearly in order to build a relationship with their bodies and with each other.

**3a. Not talking about It.** Within this theme, the four women described wanting or feeling the need to communicate with their partners about how they felt about their bodies and sexual relationships. In the extract below, Sadie reflected on *not* discussing issues she felt were present in her sexual relationship, and described her fears of raising them:

“Cos we just didn’t talk about it, when actually we probably should have done. Erm, because what you end up doing is thinking...me thinking that he doesn’t find me attractive any more...and then...him probably thinking the same, in hindsight. I haven’t discussed it, probably because I don’t want him to say that he does find me unattractive, or that you know, he doesn’t love me enough anymore...I don’t...and I’m sure he does, but...but then...I’m sure...I’m sure...I mean I’m sure...I’m sure...I bloody hope he does.” (Sadie)

Sometimes the women felt they could be honest about their feelings, but there were also times when they recalled feeling uncomfortable about this, or found ways to avoid situations which merited disclosure. For some of the women, there was a sense that they should not have to tell their partner what they were thinking, feeling or expecting - that the partner should know. For example, Nina believed that her reconstructed breast “*feels odd to me so it must feel odd to him*”, and when asked if she had discussed this with Neil, she said “*I’ve just told him I don’t like it*”. Nina’s

possible avoidance of asking Neil for his thoughts could imply a fear that Neil would confirm her beliefs about her breast.

**3b. Treading on eggshells.** When talking about their experiences of body image and sexuality, the men described being mindful of their wives' feelings, and trying to read non-verbal cues. On occasions this led to being particularly tentative and a sense of "treading on eggshells" when interacting with their wives. In the extract below, Neil described a long period of stress for Nina and himself, and how it had been difficult to share his own emotions:

"In the last, um, two years, uh, in terms of, you know, work, Nina's health, um, uh, have been quite challenging I must say, I suppose on both of us. And, um, uh, when I've felt like having a bit of a sort of breakdown it's almost like you're not allowed to have one, you know, because you're supposed to be the one that holds all the shit together. Um, and, uh, you do have your moments, you're talking heads conversation in the mirror about, you know: okay, how do I get through this next bit, how do I get through, uh, the next day without actually upsetting the other person or being more sensitive to what they have to say, or staying out of the way, treading on eggshells or what have you." **(Neil)**

The tentative tone, and the direct content of this extract, both captured a conflict for some of the men, regarding the priority of their own needs. Because they were both male and 'well,' they perceived a societal or self-imposed expectation that they must '*hold the shit together*' and be stoic in the face of emotional distress. All the husbands described difficulties in trying to understand their wives, often because neither partner was openly communicating their concerns. Difficulties were

discussed and concerns were raised in the accounts of each couple, but there was an abundance of talk about hope and change, too. This will be discussed in the final sub-ordinate theme 'building communication'.

**3c. Building communication.** This theme represents accounts from both the women and the men that described moving forward in the relationship, and how communication was a part of the process of 'coming back together'. Sadie described the need for shared understanding of each partner's feelings and needs:

"Erm, I think from a...from a man's perspective...I ...I ...I think from both to know that it could be...it might be different...it might feel different and certainly for the first few times, that from the women's perspective her mind is not going to be on...fully on the making love cos her mind is gonna be thinking does...this is different, I'm different, erm, that's not gonna help in any kind of intimate situation. Erm, and so the man needs to understand that, so maybe needs to take longer, maybe...maybe there is almost this erm, you know, kind of this relationship getting back together that you... where you actually don't go for ...don't go for broke the first few times. Get confidence back in the...in your body and for your partner to get confidence back as well. So for me, to get the confidence was more about knowing that you know, the confidence that I'm still loved and my partner would have still wanted to be intimate with me, but that doesn't necessarily mean that you have to...that could just be touching...that...that could just be the kissing and the hugging and the cuddles and hugs, whatever it is but...but give yourself time and...talk about it...and don't put yourself under pressure you know." (**Sadie**)

Here Sadie described her need to build a new relationship with her body, in addition to building intimacy with her husband. This sense of coming to terms with

changed bodies was common in the women's accounts. Talking to each person, there was a sense that this was the first time they had been able to think through and reflect upon their experiences of body image and sexuality and its impact on the couple. Although each couple were at differing stages in their acceptance of bodily and relationship changes, each couple expressed hope for the future and a relief that the 'worst seemed to be over'.

## **DISCUSSION.**

The aim of this study was to use a phenomenological approach to explore how women with breast cancer and their male partners experience and understand sexual intimacy and body image following surgery and reconstruction. The analysis has provided an insight into the process for the couples, as they negotiated the cancer treatment process and made sense of the altered body and its implications for their sexual intimacy and communication. The most striking aspect is the shifting, dynamic nature of people's experiences and roles, within each of the couples, during this process.

In 'the body becomes a central concern,' the women expressed strong beliefs that their partners would not find them attractive as a result of the changes to their bodies. The breast and body were constructed as objects, initially through the diagnosis of cancer, but then particularly through the women's reflections upon their interactions with surgeons, and through their anticipation of their husbands' perspectives upon their altered, post-surgical bodies. These perceptions were

inconsistent with the husbands' accounts. The men's perceptions of their wives' bodies were favourable, situated in an ongoing relational context, and did not impact negatively on their desire to be intimate. We might consider these particular four couples to be coping well – and note the difficulty of expressing negative views - but these findings are consistent with those from other studies with regard to men's production of positive accounts (Hilton , Crawford & Tarko, 2000; Wimberley et al., 2005; Carver et al., 1998).

The couples gave accounts of struggling to adapt to sexual intimacy, after surgery. These were consistent with previous research (Carver et al., 1998; Rowland et al., 2000; Yurek et al., 2000, Anllo, 2000; Sheppard & Ely, 2008), but it is important to stress that the altered body was a matter of *personal* adjustment, as well as *relational* adaptation: the women described their feelings about their bodies, and we noted their struggle to come to terms with the shift in the embodied self. These struggles echo broader concerns with societal understandings of the body (e.g. Diprose, 1994).

Our study also provides insights into women's expectations about immediate breast reconstruction, and its post-operative effects on body image and sexual intimacy. In 'the body re-encountered', the women described their experiences of being given the opportunity to remove the cancer, whilst also 'receiving' a new, aesthetically-enhanced breast by means of cosmetic surgery. The women all talked of how they underestimated the enormity of the surgical procedure, the recovery process and the acceptability of the end results. All women felt discomfort with the breast, the scars, or the weight gain associated with further treatment. Women's

accounts focused on their *changed* body. Our analysis highlighted the centrality of normative expectations of female bodies and illustrated the power of gendered sexual scripts (Gagnon & Simon, 1973). These are patterns of sexual relating, influenced by our personal, relational and cultural contexts (including traditional gender roles). Such scripts shape the expectation, understanding, and enactment of sexual desire. The results add to previous findings relating to information provision and expectations pre- and post-surgery (Adams et al., 2011; Harcourt & Rumsey, 2001), by enriching our view of women's experience of unanticipated results post-surgery.

We also saw in this study how the plastic surgeon can have a crucial role in setting expectations for reconstructive surgery. Nissen, Swenson and Kind (2002) similarly found that although women felt well informed about breast surgery, they wished they had been more informed about recovery issues; following surgery they also had concerns about cosmetic outcome. More recent studies (Lee et al., 2011; Lee, Hultman & Sepucha, 2010) have reported an information deficit for women, in their knowledge of reconstruction facts, and for surgeons, in their knowledge of the personal preferences of women making decisions about mastectomy and reconstruction. We note that *expectations* of an immediate reconstruction may play a major role in outcomes for body image and sexual intimacy. When women were offered a 'new breast and free tummy tuck' through cosmetic surgery, they appeared to expect that this surgery would restore the appearance and function of their breast. Surgeon-patient communication is critically important during breast cancer diagnosis and treatment, because the woman (with her partner) is

simultaneously attempting to make sense of a potentially life-threatening illness, the loss of a breast, changes in physical appearance, decisions around unfamiliar procedures and treatment options, and the threat of potential transformations of sexual intimacy.

The dynamic process for couples in this study began at the point of diagnosis and continued through the decision-making process about the type of surgical procedure to undergo; at this point a sense of 'togetherness' was clear in their narratives. The couples later talked of difficulties discussing body image and sexual intimacy with their partners, despite strong supportive relationships. This created a sense of 'pulling away,' post-surgery, where couples' accounts suggested less emotional or verbal intimacy. There was discrepancy between some couples about the usefulness or appropriateness of discussing these intimate issues. Couples with similar views on the utility of open communication have been shown to communicate more effectively. However, in couples where views are not shared, difficulties in communicating have been demonstrated (Hilton, 1994). Reciprocity appears to be particularly important in negotiating the changing dynamics of breast cancer treatment as a couple.

As 'the centrality of communication' shows, when discussing their present circumstances, it appeared to be helpful to subscribe to a joint narrative of moving forward and building ties through communication with each other. Throughout the interviews, the couples described various communication styles. This issue requires further investigation: previous research shows that different dyadic styles can affect relationship functioning and distress (Manne et al., 2006). Other areas in need of

development in future research include information provision and the setting up of expectations of surgery within the surgeon-couple encounter. Awareness of wider systemic perspectives in the family would also be a helpful addition. There is a growing evidence-base for the use of systemic approaches across range of areas, and within the field, there is increasing awareness of the usefulness of systemic perspectives for understanding the relational context of severe and chronic physical illnesses, particularly in couples and families (e.g. see Carr, 2009; Stratton, 2011). Systemic approaches include a focus on language and communication, and also on reciprocity and balance within relationships, and both of these aspects resonate strongly with issues raised in our study.

### **Methodological Considerations.**

A strength of this study was the use of a multi-perspectival IPA approach that allowed in-depth exploration of participants' experiences. Data were collected and initially analysed at the idiographic level. Our findings also illustrate that careful consideration is required when deciding between joint and separate interviews for dyadic studies. In our study, participants were able to articulate the gendered aspects of their experiences within the safe space of the one-to-one interviews. For topics where researchers are interested in the shared and co-constructed aspects of couple's accounts, joint interviews will be attractive, but for exploring perspectival aspects of sensitive experiences encountered within a relationship, as in our study, separate interviews work well. de Visser and MacDonald's (2007) study provides an example of a situation where joint interviews may be more appropriate; their

analysis suggests that 'jealousy' is a relational experience, or performative emotion, which is best made visible to researchers in the context of an interaction between both parties.

Each individual account was analysed carefully and comprehensively to ensure that participants' experiences were captured, and to enable a good level of interpretative engagement with the narratives. The small sample size allowed time for depth of analysis and the prioritising of participants' voices, therefore meeting the idiographic commitment of IPA (Smith et al., 2009). However, the sample cannot be viewed as representative of all women and their partners who have undergone a mastectomy with reconstruction and therefore it cannot be assumed that emergent themes are *directly* applicable to other couples in the same situation. Representative sampling is not the aim IPA, which challenges the traditional linear relationship between the number of participants and the value of research (Reid et al., 2005). A degree of homogeneity, contextualisation, and depth are prioritised instead, and estimates of the transferability of findings to other contexts are entrusted to the research user. Homogeneity is grounded in certain sample characteristics which are held to be central to the phenomenon under study (in this case, cohabiting heterosexual couples in long-term relationships, living in the same geographical region, with access to similar health services) and in a shared experience of the phenomenon itself (living as a couple through treatment for breast cancer, which included reconstructive surgery). In other respects, partly through the sample (age, ethnicity) and partly through the dyadic design (involving both patients and partners), our sampling inevitably accommodates a degree of variability.

## **Clinical Implications**

This study demonstrates the importance of understanding how couples negotiate a breast cancer diagnosis and treatment, particularly in relation to reconstructive surgery and its impact on body image and sexuality within the couple. Although the findings of IPA studies should only be generalised with caution, the findings discussed here elaborate upon previous research and thus provide additional insight into the following clinical practices.

Firstly, this research has highlighted the dynamic process of couples' coping, during the period following diagnosis and surgery. In this context, we have seen the importance of clear and reciprocal communication (between patients and doctors, and between patients and partners). Receiving a diagnosis of breast cancer is often overwhelming. This research suggests that couples have an information deficit in terms of what, when and how they receive information about surgery, and how this information is digested and understood. This information deficit had implications for the couples in this study and may have contributed to difficulties, for the women particularly, in adjusting to their post-surgery physical identity and resulting body image. Therefore, there is a need to improve the preparation phase for women and their families to gain an understanding of the enormity of surgery and what to expect immediately following surgery. For example using a 'breast gallery' (an image bank designed to help with visualising a range of surgical outcomes - see Kydd, Reid & Adams, 2010) with couples, may help to manage expectations for women. In our study we have seen not only that women experience feelings of loss

in relation to removal of a breast, but also that these feelings *may* be exacerbated by disappointment when high expectations for the reconstructed breast are set, but not met.

Secondly, this research has added to the literature on understanding couples' experiences of body image and sexuality following breast cancer (Wimberly et al., 2005; Holmberg et al., 2001; Hilton et al., 2000). This is useful in demonstrating to couples that partners' acceptance of the post-surgery female body is more positive than anticipated by many women. In addition, it has provided new insights into the changing and dynamic nature of communication within relationships.

During the conduct of this study, women and their partners were given the opportunity to discuss their concerns around body image and sexual intimacy. The depth and complexity of these conversations show the necessity of offering psychological support for both women and their partners throughout the cancer process, particularly around sexual intimacy and body image. Access to therapeutic support, and where necessary to specialist psychosexual therapy, will help to maintain a physical, verbal, and relational dialogue between the woman and her body, as well as between the woman, her body, and her partner (Piot-Ziegler, Sassi, Raffoul & Delaloye, 2010). Awareness of the couple as a dynamic and reciprocal system is likely to be helpful for professionals at all stages of cancer care.

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**Table 1. Sample inclusion criteria.**

- Heterosexual couples between the ages of 18 and 65 where the woman has been diagnosed with breast cancer and has undergone a mastectomy with reconstruction
- Couples who are currently married or cohabiting
- Women who, at their last consultation with the breast cancer specialist, were considered to be in remission from breast cancer. Participants who are at least 6 months post treatment
- Participants who were not currently receiving psychological therapy from the psychology team
- Individuals who are competent to give informed consent
- Individuals with a clear and demonstrated understanding of spoken English

**Table 2. Interview questions for female and male participants**

<b>Female interviewees</b>	<b>Male interviewees</b>
Please can you tell me about the type of breast cancer you were diagnosed with and the surgery you underwent?	Please can you tell me about the type of breast cancer your partner was diagnosed with and the surgery your partner underwent?
Can you describe your feelings towards your body prior to surgery?	Can you describe your feelings towards your partner's body prior to surgery?
Can you tell me about your feelings towards your body shortly after surgery?	Can you tell me about your feelings towards your partner's body shortly after surgery?
How do you feel about your body now?	How do you feel about your partner's body now?
Can you describe your sexual intimacy with your partner prior to your diagnosis?	Can you describe your sexual intimacy with your partner prior to your diagnosis?
Can you tell me about sex with your partner since your diagnosis and then surgery for breast cancer?	Can you tell me about sex with your partner since your partner's diagnosis and then surgery for breast cancer?
How would you describe your experiences of sexuality and body image to couples at the beginning of the breast cancer process now that you have lived this experience?	How would you describe your experiences of sexuality and body image to couples at the beginning of the breast cancer process now that you have lived this experience?

**Table 3. Analytic process.**

1. Open and free coding to identify both initial areas of interest and possible preconceptions ( <i>i.e. incorporating reflexive commentary</i> ).
2. IPA analysis 'proper' begins at the level of the individual case, with close, line-by-line analysis ( <i>i.e. coding</i> ) of the experiential claims, concerns, and understandings of each participant (e.g. see Larkin, Watts & Clifton, 2006).
3. Identification of the emergent patterns ( <i>i.e. themes</i> ) within this experiential material emphasizing both convergence and divergence, commonality and nuance (e.g. see Eatough & Smith, 2008); usually first for single cases, and then subsequently across multiple cases ( <i>the process is iterative rather than linear, but typically all interviews are coded individually before shifting to cross-case analysis; in our case we worked with individual scripts, then pairs of scripts (couples), then patterns across the individuals and couples</i> ).
4. Development of a 'dialogue' between the researchers, their coded data, and their psychological knowledge, about what it might <i>mean</i> for participants to have these concerns, in this context (e.g. see Larkin, Watts & Clifton, 2006; Smith, 2004), leading in turn to the development of a more <i>interpretative account</i> .
5. Development of a <i>structure</i> , frame or gestalt which illustrates the relationships between themes.
6. <i>Organisation</i> of all of this material in a format which allows for coded data to be traced right through the analysis - from initial codes on the transcript, through initial clustering and thematic development, into the final structure of themes.
7. Use of <i>supervision or collaboration, to audit</i> , to help test and develop the coherence and plausibility of the interpretation and explore reflexivity.
8. Development of a <i>narrative</i> , evidenced by detailed commentary on data extracts, which takes the reader through this interpretation, usually theme-by-theme, and often supported by some form of <i>visual guide</i> (simple heuristic, diagram or table).
<i>(adapted from Smith, Flowers &amp; Larkin, 2009, p.79-80).</i>

**Table 4. Structure of analysis.**

<b>Super-ordinate</b>	<b>Sub-ordinate</b>
<b>1. Cancer as <i>threat</i></b>	
<b>Across couples</b>	<ul style="list-style-type: none"><li>• Togetherness – facing the threat to survival</li></ul>
<b>2. The <i>body</i> as a primary concern</b>	
<b>Women</b>	<ul style="list-style-type: none"><li>• Surgical threats to the ‘normal body’</li><li>• The body re-encountered</li><li>• The anticipated gaze as a threat to sexual intimacy</li></ul>
<b>Men</b>	<ul style="list-style-type: none"><li>• Relief at survival &amp; the holistic view</li></ul>
<b>3. Importance of <i>communication</i></b>	
<b>Women</b>	<ul style="list-style-type: none"><li>• Not talking about It</li></ul>
<b>Men</b>	<ul style="list-style-type: none"><li>• Treading on eggshells</li></ul>
<b>Across couples</b>	<ul style="list-style-type: none"><li>• Building communication</li></ul>

## **Acknowledgments**

With thanks to: Dr Darja Brandenburg, for her support during the early stages of this study; the Nurse Specialists who assisted with recruitment to the study; and the four couples who so kindly participated.

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<sup>i</sup> We have chosen not to link demographic details to individual participants’ pseudonyms, in order to protect participants’ identities.

<sup>ii</sup> Due to the participant’s disclosure that this was not a topic for discussion with her partner, we have chosen not to link this quote to the participant’s pseudonym.

<sup>iii</sup> This is not typical practice, but we do not have access to the clinical reasoning underlying it.