



# “I don't know if I understood the whole process from the beginning”: A photo-elicitation exploration of the experience of mastectomy and breast reconstruction decision making

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## ABSTRACT

**Objectives:** Policy and guidance assume that reconstruction following mastectomy will have physical and psychological benefits, however research has disputed whether this is always the case. This study aimed to explore mastectomy experiences and reconstruction decision making.

**Methods:** Semi-structured interviews about self-curated participant photographs of the breast cancer experience were analysed using interpretative phenomenological analysis (IPA).

**Results:** Three themes were developed: ‘Life before mastectomy’; ‘I don't know if I understood the whole process from the beginning’; and getting back to ‘normal’.

**Conclusions:** Decisions regarding reconstruction were influenced by needs of others, and surgeons' communication and behaviour and negative experiences were prominent. Over time participants came to terms with physical and psychological impacts of mastectomy reporting re-finding themselves alongside acceptance of their post mastectomy bodies. However, many participants were living with the fear that their cancer may one day return. Communication skills training for healthcare professionals should be a priority to ensure decisions made result in the best possible outcomes for patients.

**Innovation:** Photo-elicitation is a novel research method enabling rich investigation of mastectomy experiences. Self-curation of images enables patient-led discussions about mastectomy experience and illustrates the importance of life context. Photographs may have value within clinical training to facilitate understanding of patient experiences.

## 1. Introduction

Breast cancer is the most prevalent cancer in the UK [1] and around 43% of those who undergo surgical treatment have mastectomy [2]. The decision-making process relating to breast conserving surgery or mastectomy is complex, influenced by a range of factors including body image, sexuality, and concerns about cancer reoccurrence [3]. While there is an assumption in guidance and policy that reconstruction will be beneficial qualitative research suggests that for some, mastectomy without reconstruction can be viewed positively. For example, women can report body positivity and confidence, rejection of mainstream body shape ideals, and acceptance of and pride in their scars [4]. Detailed understanding of these experiences is needed to inform future policy and guidance for supporting mastectomy care and reconstruction decision making.

Photo-elicitation uses images as tools to unearth rich data from the participant's experience [5,6] and has been used to explore experiences of breast cancer and chemotherapy [7] and breast cancer and sexual dysfunction [8]. The approach helps participants to overcome barriers to conveying feelings verbally when discussing emotionally charged or traumatic events, to make

sense of their experiences and overcome reduced reflective capacity to find a voice and share the unsayable [9,10]. Photo-elicitation also empowers participants to lead discussions about their experiences and facilitates discussion of health-related phenomena over time including the exploration of past experiences [7,9]. To date, photo-elicitation has not been employed to explore women's experiences of mastectomy and reflections on treatment decisions related to breast reconstruction. This study set out to explore the experiences of women who had undergone mastectomy and to illuminate their decision-making experiences regarding breast reconstruction.

The research questions explored were: (1) What is it like to experience breast cancer diagnosis followed by mastectomy? and (2) What factors influence decisions regarding breast reconstruction?

## 2. Method

### 2.1. Design

Photo-elicitation using participant-selected images was employed during interviews to facilitate reflection on past events and empower

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participants to discuss issues of importance to them. To facilitate in-depth exploration of individual experiences data were subjected to Interpretative Phenomenological Analysis [11].

2.2. Recruitment

Participants were invited from United Kingdom (UK) based Facebook breast cancer and mastectomy support groups. Permissions were secured from group administrators prior to advertisements being placed. To be included in the sample participants had to be female, aged 18+, have had a mastectomy, and to be 12 months post final treatment to give sufficient time to reflect on the experience.

2.3. Participants

Interpretative Phenomenological Analysis (IPA) is an idiographic approach facilitating detailed examination of individual cases, therefore necessitating small samples [11,12]. In line with this we used convenience sampling and recruited the first five participants who came forward for interview. Participants were aged between 39 and 66 years at diagnosis (mean: 51) and all white British. Three had been diagnosed following a routine mammogram (Sky, Hattie, Rose) and two had found a lump (Sassy, Kazz). The participants represented a range of mastectomy experiences (See Table 1 for further details).

2.4. Materials

Interviews were guided by participants self-selected photographs from their own personal collections (Table 2). These images were therefore not created explicitly for the purpose of this research. Participants were free to select any image they felt would help to illustrate and explain their experiences. An interview schedule was created based on prior photo-elicitation research [5,13] to explore the participant's chosen images and was made up of the following questions: 1) Why did you choose this photograph? 2) How does this image represent your mastectomy experience? 3) How did you feel when taking this photograph? 4) How do you feel now looking back on this photograph? 5) Is there anything else that you feel it is important to say about this photograph and your mastectomy experience? At the end of the interview participants were invited to share anything else they felt was important regarding their mastectomy experience.

2.5. Procedure

Ethical approval was gained through Staffordshire University Psychology Departmental Ethics Committee. Participants contacted the researcher by email to express an interest in participation. The researcher then arranged a telephone conversation to answer questions, complete the written consent process, and agree a date for interview. During this conversation participants were invited to share up to five photographs with the researcher via email. These photographs could be from any time-point across their entire mastectomy experience from diagnosis to end of treatment.

Interviews were conducted via Microsoft Teams. Participants were invited to choose the order in which to discuss the photographs. Interviews

Table 1 Participant characteristics.

Pseudonym	Age	Age at diagnosis	Mastectomy circumstances
Rose	55*	52	Immediate reconstruction later reversed to flat
Sky	66	63	Immediate reconstruction followed by later DIEP flap reconstruction
Hattie	55	51	Immediate reconstruction
Kazz	63	46	Flat
Sassy	41	39	Flat

\* Age estimated based on interview discussion around the wait for reversal surgery.

Table 2 Descriptions of participant images.

Participant	Image description and context
Rose	<ol style="list-style-type: none"> <li>Rose immediately after surgery, her breast is swollen and purple</li> <li>Rose sat in her garden with post-surgery drains</li> <li>Rose with dressings removed after her second reconstruction surgery</li> <li>Rose on the ward after surgery to reverse the reconstruction</li> <li>Rose after her reconstruction reversal</li> </ol>
Sky	<ol style="list-style-type: none"> <li>Sky's breasts immediately prior to surgery, the left breast is larger</li> <li>Sky post-surgery with surgical drains and scar visible</li> <li>Sky's breasts after reconstruction. Reconstructed breast is swollen and infected</li> <li>Sky's scar following implant removal</li> </ol>
Hattie	<ol style="list-style-type: none"> <li>Hattie on a night out pre-diagnosis</li> <li>Hattie with her son at a family barbeque soon after diagnosis</li> <li>A rainbow Hattie saw when she was undergoing chemotherapy</li> <li>Hattie being kissed by strangers on a night out post-treatment</li> <li>Hattie and her best friend who had previously experienced cancer</li> </ol>
Kazz	<ol style="list-style-type: none"> <li>Kazz on holiday with her children pre-diagnosis</li> <li>Kazz with a bunch of flowers from work sent after diagnosis</li> <li>Kazz with no hair when she was undergoing chemotherapy</li> <li>Kazz's daughter's 10th birthday</li> <li>Kazz in fancy dress and a prothesis for a party</li> </ol>
Sassy	<ol style="list-style-type: none"> <li>Sassy wearing her favourite bra on the morning of surgery</li> <li>Sassy with black marks on her body ready for surgery</li> <li>Sassy standing in front of a mirror after drains had been removed</li> <li>Sassy wearing a black bra and prosthetic breast</li> <li>Sassy on the beach without her prosthetic</li> </ol>

were scheduled for one hour; however, participants were encouraged to talk about their experiences for as long as they wished to. The interviews were guided by the interview schedule and further detail was elicited through the use of active listening techniques, such as nodding, or using small verbal encouragement statements such as 'yes'. Following interviews participants were provided with a written debrief which included contact details for sources of further support. Interviews were transcribed verbatim with all identifying information removed. Participants chose their own pseudonyms. Participation was voluntary and no incentive was offered.

2.6. The interviewer and analyst

Prior to interview participants were made aware that the interviewer (JR), had previously experienced a breast cancer diagnosis and had been offered a mastectomy by her surgeon but had chosen not to take this course of treatment. The interviewer therefore had some shared and some contrasting experience with the participants. Reflections on the conduct of the interviews were recorded in a reflexive diary and discussed in depth with the second author (AB).

2.7. Data analysis

Data were analysed using Interpretative Phenomenological Analysis [11]. Grounded in phenomenology and the exploration of individual meaning-making this approach is well suited to detailed exploration of health-related phenomena. IPA is a critical realist approach that acknowledges the researcher's role in analysis and interpretation through a double hermeneutic process [11]. IPA is an idiographic method allowing for detailed analysis of individual accounts before cross examination of cases to identify common themes or patterns across the participant sample.

In commitment to the idiographic focus of the analysis each transcript was analysed individually before moving on to comparison across the data set. Starting with the first transcript the first author produced unfocused notes, reflecting initial thoughts and observations on the text such as questions, summaries, descriptive, conceptual, and linguistic suggestions, in the left margin of the transcript. Initial notations were then reviewed, organised, and clustered, with the assistance of printed transcripts and post-it notes to form tentative emergent themes. Emergent themes were reviewed and questioned in collaboration with the second author before being collated within a theme table. Quotes were placed within

the table in chronological order to enable the participant's individual experience to be viewed sequentially. This process was repeated for all transcripts before tables were reviewed across the sample to identify common patterns through the production of a master table of themes. Both authors collaboratively produced the final theme narrative.

### 3. Results

Three themes were developed from the data: *'Life before mastectomy'*; *'I don't know if I understood the whole process from the beginning'*; and getting back to *'normal'*. These themes illustrate the stories of the participants and the way in which early healthcare communication and decision-making regarding mastectomy influenced their journey from diagnosis to recovery. In-depth example quotes from the participants can be found in Table 3.

#### 3.1. *'Life before mastectomy'*

The participants depicted an identity transition from life before diagnosis and mastectomy to post-surgery. For some this transition was focused on the loss of a carefree and happy self and for others the changes to their physical appearance. Participants described being happy and healthy before diagnosis which caused a loss of identity both psychologically and physically. Experiences of diagnosis were a shock and while struggling to process their diagnosis many felt the need to conceal it, or the impact it was having on them, by putting on a brave face for those around them.

##### 3.1.1. *'When life was fun'*

Both Kazz and Hattie chose images from before diagnosis to illustrate their pre-cancer identities. They described themselves as *'happy'* and *'care-free'*. Kazz used an image of herself on holiday with her family before diagnosis to explain that she had been *'really fit and healthy'*. For Kazz, this image was *'a reminder that before any of that, I was quite a normal, happy, healthy person'*. Similarly, Hattie chose an image of herself out with friends soon before she was diagnosed (Example 1). Like Kazz, Hattie described a fundamental change following diagnosis. Her *'old self'* had been lost and replaced by someone new.

Other participants reflected on their pre-surgery bodies to illustrate life before mastectomy. Sky and Sassy had both chosen a photograph of their bodies on the morning before their first surgery. Sassy became visibly upset when she explained an image of herself in her favourite bra before surgery representing *'the start of the end of that part of me and the start of a new part'* (Example 2). For Sassy this loss of self was grounded in her potential changes to her physical appearance. Like Kazz and Hattie, the account depicts this as a loss of self and a transition to a new post-diagnosis identity.

##### 3.1.2. *'Putting on a brave face'*

Participants highlighted a need to put on a brave face. The time between diagnosis and mastectomy was depicted as one in which their external presentation was incongruent with the shock, fear, and uncertainty they were experiencing within. For many, putting on a brave face was enacted to protect their children from exposure to their suffering. Participants described the time between diagnosis and treatment as filled with sadness and uncertainty. The diagnosis had been shocking and overwhelming, but they felt the need to protect those around them from this, particularly their children. Referring to an image of herself with flowers from colleagues at work Kazz explained *'I felt I was trying to put on a brave face'* (Example 3). Kazz wanted to remain grateful for the support from others and felt the need to acknowledge this and be thankful through the way she presented herself and acted while protecting her children from the reality of her diagnosis. Similarly, Hattie explained how an image of herself smiling with her son at a family barbeque captured how her exterior presentation was incongruent with how she was feeling internally (Example 4).

#### 3.2. *'I don't know if I understood the whole process from the beginning'*

This theme highlights the ways in which the participants felt uncertain about their decision making. All indicated that the decision to remove the breast was beyond their control and accepted this as a requirement of their recovery. The decision whether to reconstruct was more complex and influenced by several factors including healthcare professional guidance or pressure, personal preference, and past experiences.

Sassy had needed to delay reconstruction for nine months due to radiotherapy and had become happy with being flat in the interim: *'I'd got so used to, that I wasn't going to be, it just wasn't even a question for me then, I was like 'we're done''* (Example 5). However, other participants did not have this opportunity to live with being flat before a reconstruction decision needed to be made. Sky had researched her options and spoken to others including breast cancer support organisations. Ultimately it was the knowledge of her husband's experience with his first wife, who had died of breast cancer following a choice to remain flat, that informed the choice of a reconstruction: *'after that day he never saw her you know? naked or ... again, never and so he was really worried that if I had a mastectomy with no reconstruction, that that would be similar with me'*. Sky was led by her husbands' concerns but also felt remaining flat would be a constant reminder of her experience that would prevent her returning to normality: *'I wasn't happy going flat [...] you just want to move on really, in life you want your normality back, and, it [not having a breast] was a constant reminder'*.

Sky had initially been happy with the reconstruction but experienced pain and infection soon after. It led her to question the guidance she had been given and whether she had been pressured to agree to a procedure that was not what she ultimately wanted and highlighted a growing distrust in her surgeon: *'My surgeon lied to me at the beginning'* (Example 6). Reflecting on an image of her *'reconstruction gone wrong'* Sky explained her fear and helplessness: *'I couldn't force the surgeon to do it, you know? I was just, I had to wait for them, you know? To be ready and all that...but I was desperate to get it out'*.

Rose also felt pressured to undergo reconstruction as her surgeon was a specialist. She later regretted and reversed the decision but felt she had to fight to do this. Rose had chosen an image of herself immediately after her first surgery to explain her experience of feeling pressured and *'bulldozed'* by her surgeon into going along with the reconstruction (Example, 7). Viewing her body after her second surgery was the catalyst for Rose to push for change. Talking about an image of herself following her second surgery Rose explained that *'this was the day, I decided that things needed to change'* but Rose felt that she continued to be met by reluctance from her surgeon: *'My consultant wouldn't agree to it initially, he said, 'I've never heard of anyone wanting to do this before, have it all reversed'*. While the initial decision for reconstruction was accepted unquestioningly a decision to remain flat, something that was framed as a decision no woman would want to make, was met with resistance. Rather than her decision being accepted Rose was referred for psychological support *'he said, 'well you'll need to have some counselling with a health psychologist to make sure that you're making the right decision for yourself'*. After having a painful lumpectomy Kazz was happy with her decision to remain flat. However, several years later Kazz also felt pressured by a surgeon who repeatedly asked her about reconstruction (Example 8).

#### 3.3. *'Getting back to 'normal'*

All described a journey of re-finding themselves and returning to some sense of normality. For some this was through making their way through mastectomy and treatments and being accepting of prosthetics, while others were happy with their body following reconstruction (or deconstruction). Getting back to normal for these participants was therefore about achieving a sense of happiness and acceptance of their bodies. However, despite this the fear of recurrence was ever present preventing them from fully returning to their carefree pre-diagnosis selves.

**Table 3**  
Example quotes from participants for each theme.

Theme	Sub Theme	Participant Quotes
'Life before mastectomy'	'When life was fun'	<p><b>Example 1:</b> When life was fun...before things happened, and my world turned upside down [...] I was probably going to have the mammogram the week later just a routine one [...] I was out with my friends, it was a girly afternoon, and we were just having a really good time [...] there wasn't any worries then, you know? Not any big, major worries [...] when I look back at that, that photo, there was absolutely no, you know? It was just absolutely fabulous, and life was just ticking along without worrying...the constant...worry...you get, after a mastectomy, and all the treatment. So, I do feel like I've lost a little bit of my old self, and that was my old self (Hattie)</p> <p><b>Example 2:</b> [This photograph is] the last one taken before I went, it was taken in the morning, of the day I had surgery. I chose it because (voice wobbles)...it's my favourite bra (brief laugh) and it's just (nearly crying) the old me[...] [when the photograph was taken] I felt terrified actually, I felt really scared about the physical appearance of how I was going to look. I think that was probably the scariest part the whole way through actually, was how, how I was going to look without a breast how I was going to look without hair, how I was going to look, you know, every part of it [...] It's just the start of the end of that part of me and the start of the new part (Sassy)</p>
	'Putting on a brave face'	<p><b>Example 3:</b> [The photograph] represents the sadness that I felt. I mean, I can see it in my face [...] I felt I was trying to put a brave face on it and smile because I'd got some flowers, and I felt I needed to...well, not look negative...because I'd got, you know, a nine year old and a 13 year old and they don't want to see their mum looking miserable and crying all the time (Kazz)</p> <p><b>Example 4:</b> I think you can see in my face, that I'm not 100%. [...] trying to put on a brave face for people that did know, but obviously, as I say, my boys didn't, not at that stage, so trying to be normal, trying to act like normal, but not feeling like normal (Hattie)</p> <p><b>Example 5:</b> I don't know if I understood the whole process from the beginning, but that's probably because there was just so much information [...] I knew I was going to be flat from, for a period of time anyway, and then when she said, it was about 9 months later, she said, 'would you?' you know? 'We're here to talk about your reconstruction' (laughs) and I was like 'oh!'. In that nine months I'd got so used to, that I wasn't going to be, it just wasn't even a question for me then, I was like, 'we're done' (Sassy)</p> <p><b>Example 6:</b> 'My surgeon lied to me at the beginning' [...] I'd got the book there on reconstruction, and I said, well, 'could I be considered for this DIEP?', 'no' she said [...] She said something like there's a two-year waiting list and I thought 'well that's, that can't be right, I can't wait two years, I've got cancer' but 'cause you're in such a state at that time, you don't really question it, so I just accepted it. But I now know, with hindsight that I could have insisted (Sky).</p> <p><b>Example 7:</b> I went along with [the reconstruction] because that's what I thought was best, and I completely put what I wanted to one side [...] this image, is when I first came round, after my operation, it was a five-hour operation and I knew immediately I'd made the wrong decision, because I hated the way it looked. I hated the way it felt. [...] I was like, bulldozed into it. So he's like, 'nobody wants to be flat on one side', you know? 'you're a woman', you know? 'Why would you want to be flat on one side?', and I was never given that opportunity to speak, and I think, because there's so much going on at that time of diagnosis, there's so much to take in, so much to understand, you know? I didn't really have a voice at all, because everything was, a big blur (Rose)</p> <p><b>Example 8:</b> What I wasn't happy about, was constantly being asked, every time I went, to see that next surgeon, was being asked if I wanted reconstruction [...] It was quite a long time afterwards, probably eight years afterwards when the, there was a new consultant, and he obviously likes doing reconstructions [...] every time I saw him, he would, was sort of asking me and [...] I was definitely confident that I don't want that (Kazz)</p>
Reconstruction decision making: 'I don't know if I understood the whole process from the beginning'		<p><b>Example 9:</b> It was like, it's all over now, you know, it's all over. I can move on now, and that feeling was immediate. Literally, as soon as I came round from the anaesthetic [...] [I chose the photograph] because it was the day I turned the corner completely, it was the day, you know? everything I'd fought for I'd got done, and so I knew I was, I was going to turn a corner and I was going to get over this and I was going to be back to being me. (Rose)</p> <p><b>Example 10:</b> That [photograph] was taken after, I'd finished treatment, in April, and in June, me and the girls had gone to, it was a 'Let's Rock', you know like from the 80s [...] we were there, pitched up, and I just looked, and there were these three gorgeous men [...] I just thought, I want a bit of that (laughs). So, I just went up to them and, 'can I have my picture taken with you please?' and of course, they let me and everybody was just sat there, all my friends were sat there, looking as if to say, 'what's she doing, what's she doing?' and I wouldn't have dreamed of doing that prior. [...] it's given me a bit, I wouldn't say that I don't care less, because I do, but it's given me a little bit of not caring, not mattering so much about the small stuff. You know, and if I want to do something, let's do it. [...] (Hattie)</p> <p><b>Example 11:</b> "I've got tissue removed on one side and in the upper part and, I was very pleased with that [dress] because, I didn't wear a heavy prosthesis in it, it's just [...] a light thing with stuffing in it, in, and I thought well that actually doesn't look too bad (Kazz)</p> <p><b>Example 12:</b> We'd gone to the beach for the day and I'd forgotten to take my beach boob [...] but the photo was because, who cares?! (Laughs) I, just, I, yeah, that's me, I am now this person, and I'm okay with that [...] The photo represents that I think it's an absolute triumph [...] If you have a good surgeon and you end up, you grow to re-like yourself and re-accept your body and, yeah, maybe it takes a little while, but not as long as I thought it would [...] I think when we actually took the photo, I was just sat there enjoying this glorious day, at the beach, and, not in the slightest bit bothered that I was having a photo taken and that I was wonky (laughs) [...] it was such a great day, we had such fun, it was, hot, hot, hot, we swam in the sea for hours, it summed up my internal feelings of just being normal (laughs). Which was nice and also, it's only one year afterwards, and I felt pretty, I don't know? It's not a competition in life is it? but I felt really, like I'd come through it, winning rather than struggling (Sassy)</p> <p><b>Example 13:</b> I wanted that risk to be taken away. I wanted to take the other one away, because, you know, I was still paranoid about getting cancer again and you know, even though I was on hormone therapy, and all of that, I wanted that risk to be taken away, and with that constant fear, I check every day, every day (Rose)</p> <p><b>Example 14:</b> I'll never know if the chemo worked, as in, I know it works, but I never had any shrinking the tumours, or killing the cancer that was there, another lady I met, she had the same cancer as me and she had chemo first and then surgery and then there was nothing left, which is like, Yay! So, I just pretend that we're the same because she had the same diagnosis (Sassy)</p>
Getting back to 'normal'	'I was going to be back to being me'	
	'You never stop worrying'	



### 3.3.1. 'I was going to be back to being me'

Rose had chosen a photograph of herself on the day of 'deconstruction', when her implant had been removed, to illustrate the sense of 'relief' and 'calmness' this gave her 'literally, as soon as I came round from the anaesthetic' (Example 9). Pushing for the surgery illustrated to Rose that she was still the strong confident woman she had been prior to diagnoses. Despite doubts from others she knew her own mind, and the image of her body after this final surgery helped her to feel 'normal' again. Following mastectomy and the end of treatment Hattie had also felt confidence returning. For Hattie the experience had pushed her to make the most of life, becoming more extroverted and determined to enjoy the opportunities life offered her (Example 10).

Kazz and Sassy described turning points in which they had accepted their new body. For Kazz this was explained in an image of her in a dress for a fancy-dress party illustrating how she had grown to accept her appearance and her confidence to wear a prosthetic (Example 11). For Sassy confidence in wearing a prosthetic had also grown. In a chance incident at the beach where she had forgotten her prosthetic Sassy was able to enjoy her day out without constant concern about her appearance 'I was just sat there enjoying this glorious day, at the beach, and, not in the slightest bit bothered that I was having a photo taken and that I was wonky' (Example 12).

### 3.3.2. 'You never stop worrying'

Despite evidence of acceptance thoughts of the cancer remained a constant. All participants expressed fear that their cancer might return with several specifically stating that they would have preferred their healthy breast be removed to reduce their risk. Hattie and Rose had wanted bi-lateral mastectomy to ensure the cancer could not return. Hattie explained: 'I knew what I wanted to happen [...] I knew I wanted...them both off...I just wanted it gone, completely gone'. However, neither had been able to convince their surgeon to remove their healthy breast (Example 13).

Kazz reflected on a photograph representing the time between being diagnosed and having her mastectomy as a time of great worry and anxiety. Kazz could never completely escape that worry as she felt she could not trust her body and be sure that the cancer would not return: 'I think, once you've had cancer, you never stop worrying, that the next symptom is going to be indicative of recurrent cancer, so.

yes, I suppose you don't ever think, you know? you can't be too sure of anything'.

Sassy also highlighted the fear of recurrence when comparing herself to another patient whose cancer she perceived to have been 'killed' completely by chemotherapy before having the mastectomy. Her own treatment plan was to have chemotherapy after the mastectomy, and this left her with a worry that she would never be certain that the cancer had gone: 'I'll never know if the chemo worked' (Example 14).

## 4. Discussion and conclusion

### 4.1. Discussion

This study explored the experience of mastectomy and reconstruction decision making through the innovative method of photo-elicitation interviews. Three themes were developed from the data: 'Life before mastectomy'; 'I don't know if I understood the whole process from the beginning'; and getting back to 'normal'.

Past research has suggested the loss of a breast can be likened to bereavement and result in lost identity [14], for these participants changes in appearance, while initially distressing, were eventually accepted and satisfaction with appearance expressed. This supports past research indicating that mastectomy can lead to positive body image evaluations [4] and that reconstructive surgery can be a positive experience for some women [15]. However, fear of recurrence of cancer prevented participants from completely returning to their carefree pre-diagnosis identity. The trade-off hypothesis proposes that the choice to have full mastectomy rather than lumpectomy should reduce the fear of recurrence, however evidence suggests that experiencing multiple operations increases fear of recurrence

and results in worsened body image perceptions [16]. Rose's experience confirms this, having had the greatest number of surgeries and the strongest expression of dissatisfaction with her appearance throughout her journey. While Rose's reconstruction reversal had led to bodily acceptance the surgeon's refusal to remove the healthy breast had left her with, in her words, 'constant fear' of recurrence.

These accounts affirm that desire for bi-lateral mastectomy stems from a fear of recurrence [17]. Bi-lateral mastectomy is not recommended for women with no familial history of breast cancer and those who are deemed high risk must under-go preoperative genetic counselling prior to a decision being made [18]. Therefore, the rejection of bi-lateral mastectomy requests is in line with current recommendations. However, the expressions of ongoing fear by participants illustrate a threat to wellbeing and suggest that the rationale for these decisions is not being effectively communicated by healthcare professionals.

Diagnosis was experienced as a shock with participants discussing information overload and rushed decisions regarding treatment and reconstruction, with Rose describing this period as a 'blur'. While some report positive experiences research has suggested that around 27% of women experience mild regret and 20% moderate or strong regret regarding their reconstruction choices [19]. This is concerning as evidence comparing breast conservation and double or single mastectomy for unilateral breast cancer suggests that regardless of surgical decision, patients who feel confident and informed before surgery experience lower anxiety, reduced fear of recurrence, better psychological well-being, and breast satisfaction at 15 months post-surgery [20]. The participant's accounts highlighted that they did not feel confident or informed.

The central role of the surgeon in guiding decisions regarding reconstruction was evident with several of the participants feeling that they were pressured into a decision which was not right for them. Rose's powerful account of being 'bulldozed', Sky's traumatic battle for the type of surgery she had wanted, and Kazz's account of being pressured regarding reconstruction 8 years after surgery all point to failings in healthcare professional-patient communication at the time of diagnosis, decision making and beyond. This finding is in line with evidence that suggests surgeons' perceptions of breast cancer patient preferences are often at odds with those expressed by the patient themselves [21,22] and that there continues to be deficits in the decision-making process regarding surgical treatment of breast cancer [3]. The experience of reconstruction regret points to poor pre-operative communication, however even when well informed there is no way for a patient to know how they will feel and experience their bodies following mastectomy [23]. There is a clear need to improve communication between healthcare professionals and breast cancer patients, this should involve both improved training for healthcare professionals and better implementation of tools to support decision making. Breast cancer decision aids are available, and evidence suggests they can improve decision related outcomes for patients by reducing decisional conflict and increasing knowledge and satisfaction [24]. The barriers and facilitators to embedding the use of decision aids in patient care need to be better understood to support their successful implementation.

Very little research has explored the disclosure of breast cancer diagnosis to children, however research in England [25,26] has indicated discussions with children can be difficult for parents and more help should be offered by healthcare professionals. The participant accounts illustrated that the concealment of diagnosis to protect children can occur at a time of extreme stress and anxiety and may contribute to psychological distress for the patient. More research is needed to explore this phenomenon and develop guidelines and resources to support with the disclosure of breast cancer diagnosis to children.

While 'looking normal' may be perceived to be an aim following reconstructive surgery [27] for these participants normality was less about aesthetics and more about psychological wellbeing. Three of the participants had made the decision to remain flat following mastectomy, with one returning to flat after an initial reconstruction. The women spoke about the use of prosthetics in replacement of reconstruction. However, they also expressed an acceptance of being flat with Sassy explaining her

newfound confidence to enjoy time on the beach without her prosthetic and Rose expressing a sense of relief and calm with the reversal of her breast reconstruction. This variation in experience confirms that patient needs and preferences are individual and no one recommendation or option is superior for facilitating quality of life post mastectomy [28].

It is important to note that the interviewer and first author has lived through breast cancer. This may have influenced issues discussed during the interviews. To mitigate this the first and second author regularly met to discuss and reflect on the developing analysis to ensure coherence with the transcripts and acknowledge any personal influence in line with the double hermeneutic process within Interpretative Phenomenological Analysis. In addition, participants were all recruited from online support groups and selected self-curated images of their mastectomy experience showing willingness to share these as part of the research process. Therefore, these accounts may not represent the experiences of individuals who avoided documentation of their experience, or who have not pro-actively sought breast cancer support. While the sample were homogenous in terms of diagnosis and mastectomy experience there were differences regarding the treatment options pursued. Only those who had immediate or no reconstruction volunteered and further research focused on breast reconstruction reversal or delayed reconstruction would be of value. Additionally, the sample lacked ethnic diversity which may play a role in breast cancer diagnosis and treatment and warrants further investigation.

#### 4.2. Innovation

This study makes an important contribution to the innovation of healthcare through illustrating the novel value of photo-elicitation as a research method for exploring breast cancer experiences. This approach has allowed a rich investigation of mastectomy experiences led by participant priorities which is not possible in researcher-led interview research. Through enabling self-curation of images participants were uniquely able to lead and guide discussions about their mastectomy experience. This enabled freedom to lead the research towards issues of particular importance for them, highlighting how context such as their life and identity pre-diagnosis and their responsibilities to their children has influenced their experiences, perceptions, and decision-making.

This study also makes an important contribution to the evidence for the need for enhanced empathy within healthcare interactions with patients with breast cancer. Empathy in healthcare interactions can improve patient health outcomes [29] and has been shown to improve information recall [30] and reduce decision-making regret [31] in breast cancer patients. Participants in the study reported negative experiences of healthcare interaction illustrating a need to improve patient-practitioner communication. The findings show how photography has a powerful ability to illustrate patient experience and suffering and may therefore be a valuable addition to healthcare communication training for enhancing healthcare professional empathy.

Finally, our work has provided novel insight into the challenges of communicating breast cancer diagnosis to children, particularly in the time between initial diagnosis and first surgery. While it has already been established that these conversations can be difficult [25,26] these participant stories have given unique insight into how a drive to conceal diagnosis to protect children can exacerbate psychological distress for the patient. This is an area in urgent need of future intervention.

#### 4.3. Conclusion

The ongoing fear of cancer recurrence in breast cancer patients illustrates a need for further psychological support at the point of mastectomy decision-making and enhanced communication training for healthcare professionals. This is also evidenced in the accounts of reconstruction regret suggesting ineffective pre-operative communication. There is a clear need for improved communication training for practitioners working with breast cancer patients and better use of decision aids within patient care to ensure that decisions are made that are aligned with patient

needs and preferences where possible. To acknowledge the variation of experience in patient needs and preferences the central aim of all support for breast cancer patients should be to provide psychological assessment and support, educate about options, and ensure that decision making is collaborative.

Currently the information provision and support provided at diagnosis can be poor with patients left anxious, uncertain, and sometimes experiencing uncertainty and regret regarding reconstruction decisions. Surgeons play an important role in this decision making with the wrong decision having devastating consequences for patients. Communication skills training and the creation and evaluation of decision making aids for surgeons should be a priority to ensure that the options are understood, patients are satisfied with healthcare encounters, and decisions made result in the best possible physical and psychological outcomes for patients.

#### Ethical statement

Ethical approval was obtained from Staffordshire University Psychology Departmental Ethics Committee (UG 18/11/2020 JT/AB). All participants provided written informed consent prior to enrollment in the study.

#### Participant permissions

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

#### CRediT authorship contribution statement

**Janette Renshaw:** Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing – original draft, Writing – review & editing, Project administration. **Amy E. Burton:** Conceptualization, Methodology, Formal analysis, Data curation, Writing – original draft, Writing – review & editing, Supervision.

#### Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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