

Title:

First look: A Mixed Methods Study Exploring Women's Initial Experiences Of Their Appearance After Mastectomy And/Or Breast Reconstruction.

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Presentations

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Abstract:

Objectives: Increasing numbers of women are undergoing appearance-altering surgery for the treatment and/or prevention of breast cancer. However, women's experiences of seeing the results of their breast surgery for the first time, and the support available to them, are currently omitted from the research literature. This study aimed to explore women's initial experiences of seeing their appearance after mastectomy and/or breast reconstruction.

Design: An online mixed methods survey explored participants' feelings and expectations before seeing their breast surgery for the first time, their experiences of looking at the results of their surgery, and the support they received.

Methods: Women ($n = 128$) who had undergone mastectomy and/or breast reconstruction following a diagnosis of invasive breast cancer, DCIS or increased risk of breast cancer took part. Data was analysed using descriptive statistics and qualitative content analysis.

Results: Most respondents had worried about looking at their breast/breast area for the first time, with 75% concerned about what they would see. Women found the experience moderately distressing, and younger women were particularly concerned about other people's reactions to their altered appearance. Approximately half of the women (51%) felt they received enough support, while 29% thought this aspect of care could be improved. Areas for improvement were suggested, including increased preparation, privacy and support.

Conclusion: Women's experiences of looking at their breast/breast area and any donor site after surgery vary considerably. The results indicate important implications for provision of care and further research.

Keywords

Breast reconstruction, appearance, mastectomy, surgery, breast cancer, donor site

Introduction

Women's initial reactions to the post-operative aesthetic outcome of breast cancer treatment and the support available to them when seeing their breast area for the first time after surgery have been omitted from the research literature. This is surprising, given the increasing numbers of women undergoing invasive surgical treatments (including mastectomy and breast reconstruction) following a diagnosis of cancer, Ductal Carcinoma in Situ (DCIS) or because they are at a high risk of disease (1,2).

An altered appearance after diagnosis and treatment for breast cancer can have a severe and long lasting impact, including feeling mutilated, unattractive, inadequate and less feminine (3,4). Body image disturbance amongst this group is often associated with poor quality of life, sexual/intimacy concerns, depression and anxiety (3,5). However, some women perceive changes to their appearance (e.g., surgical scars) as a symbol of strength, triumph and survivorship (6).

Although research has explored women's experiences of their appearance after breast cancer treatment, the focus has been on longer-term outcomes rather than their initial post-surgical experiences. Qualitative studies have reported interviewees describing themselves as '*walking around feeling like an absolute monster*' (p. 85) (7), and '*this one-breasted creature*' (p.88) (8).

Guidelines for best practice in oncoplastic breast surgery (9) specify that information about scarring (e.g., the probable length and position of scarring on the breast and, if applicable, the donor site) should be discussed with patients prior to breast cancer surgery, yet many women report dissatisfaction, regret and negative consequences of surgery (10,11). These findings emphasise the importance of effective support and pre-surgical preparation (10,12). Support from health providers, for example by providing appropriate pre-operative information, can

help inform and empower patients. Although the impact of support such as the use of decision aids and pre-surgical information has been examined at various points throughout a patient's pathway, little is known about the support women receive or require when they see their post-surgical appearance for the first time.

Research in other fields where trauma or surgery impacts individuals' appearance (for example burns) suggests that patients' first experiences of seeing their altered appearance may have implications for their subsequent adjustment when leaving hospital and reintegrating into society (13). Given the current lack of information on this topic within the breast cancer literature, coupled with the potential **short and** longer-term consequences, research focusing on this point in the patient pathway is urgently needed.

This study therefore aimed to address this previously neglected time point. We conducted an exploratory online mixed method survey with women who had undergone mastectomy (with or without immediate or delayed breast reconstruction). We aimed to explore: (a) their thoughts, behaviours and expectations prior to looking at surgical sites (breast area and any donor site) for the first time; (b) whether these varied by demographic or treatment characteristics, (c) their experiences of doing so and (d) their opinions on the support provided at this time.

Methods

Participants and procedure

A total of 128 women completed an online survey into their initial experiences of their appearance after mastectomy and/or breast reconstruction. Ethics approval was obtained from the authors' institution. Participants ranged in age from 31-74 years (mean = 51.60; *SD*: 10.68) and all received treatment in the UK. Table 1 displays participants' characteristics and

treatment details. Women were recruited through breast cancer charities and support organisations' online forums, newsletters, and social media, in addition to the social networking sites and website of the authors' research group. Participants completed the questionnaire unsupervised.

Design and measures

The study design and survey questions were based on previous burns research (13), adapted to the patient group. Specifically, questions about any donor site and additional free-response questions were added. Feedback on the survey was sought from two patient representatives and some questions were reworded following their advice. Participants were asked to respond in relation to their first surgical procedure, rather than follow up, revisional or contralateral procedures.

Six questions enquired about their thoughts, expectations and behaviours *before* looking at the results of their surgery for the first time (for example '*I initially avoided looking*').

Participants responded to each statement using a Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree).

Three questions explored the extent to which participants felt ready/prepared, distressed and relieved at looking at their breast/breast area for the first time, using a Likert scale ranging from 0 (not at all) to 10 (extremely). Two questions with a choice of responses asked participants how their experience compared to: (1) how they had expected it to be, and (2) any images they had in their mind before they looked. A free-text response box asked participants to describe their feelings or emotions when they saw their breast/breast area for the first time. Participants who indicated that their reconstruction involved an autologous procedure were asked the same questions again with reference to seeing the donor site.

Participants used a Likert scale from 1 (strongly agree) to 5 (strongly disagree) to respond to four items exploring their opinions about the support provided by their breast care service at this specific point in time; (1) *I received enough help looking at my breast/breast area for the first time*; (2) *I would have valued more support when looking at the result of my breast surgery*; (3) *I believe my experience in this aspect of my breast care could have been improved*; (4) *I was happy with the support I received looking at my breast/breast area for the first time*. Finally, participants were provided with a free-text box to respond to two open-ended questions; (1) please describe what help, if any, you were offered when looking at your breast/breast area and (2) what, if anything, could have been done differently by the breast care service to improve your experience of looking at your breast surgery for the first time?

Analysis

Analysis consisted of statistical analysis (Descriptive analyses, Spearman's rank-order correlation, Kruskal-Wallis test) and a qualitative content analysis. Qualitative content analysis is an inductive approach which involves a descriptive analysis, rather than an in-depth interpretation of the data (14).

Results

(a) Thoughts, expectations and behaviours before seeing their appearance for the first time

Eighty-nine respondents (71%) were worried about looking at their breast/breast area for the first time and 75% (n = 94) were concerned about what they would see. Thirty-seven (30%) initially avoided looking at their breast area, whilst 27% (n = 34) looked forward to seeing the results of surgery. Fifty-four (43%) had negative or unpleasant images in their mind about what their breast(s)/breast area might look like and 60% (n = 75) were worried about how other people might react.

(b) Reactions at seeing their appearance for the first time

The majority of women first saw the results of surgery whilst on the hospital ward, approximately half were alone, and none had a psychosocial specialist with them (see Table 2). Most reported that they had chosen when to look for the first time.

Eight women (6.3%) felt 'not at all ready' and 35 (28%) felt 'completely ready' (mean=7.69; SD=3.03) to see their breast/breast area for the first time after surgery. On scales ranging from 0 (not at all) to 10 (extremely), women reported moderate levels of distress (mean = 5.60; SD = 3.13) and relief (mean = 7.02; SD = 2.83). Seventeen (13%) reported that the experience was not at all distressing, and fifteen (12%) found it extremely distressing. Eight (6.3%) did not feel at all relieved, while 17% (n = 22) felt extremely relieved. Fifty-three women (42%) reported that seeing their breast/breast area for the first time was not as distressing as they had anticipated, 58 (46%) felt it was as distressing as they had expected, and 16 (13%) found it more so.

Around one-third (36%) reported that what they saw was better/not as unpleasant as the image(s) they had in their mind beforehand. A similar proportion (35%) considered it was like the image they had in their mind, and 22 (17%) thought that what they saw was worse/more unpleasant than what they had imagined. Fifteen women (12%) responded that they did not have any image(s) in their mind before looking at their breast/breast area.

Participants also responded to an open-ended question about their feelings or emotions when they saw their breast/breast area for the first time. The results of a qualitative content analysis of this data are displayed in Table 3. The emotions reported varied considerably, with the largest numbers of participants reporting feelings of relief (relief that the cancer had been removed, and relief at the appearance/outcome of the surgery), powerlessness, loss, distress and pleasure.

Forty (31%) participants responded to questions regarding a donor site, including the back (40%, n=16), abdomen (55%, n=22), and thighs (5%, n=2). Women felt relatively well prepared for seeing the donor site for the first time (mean = 7.77; SD=3.45) on a scale of 0 (not at all prepared) to 10 (completely prepared). Four (10%) felt 'not at all ready', whilst 36% (n=14) felt 'completely ready'. Women reported moderate levels of distress when looking at the donor site for the first time (mean = 5.03; SD=3.46), on a scale from 0 (not at all) to 10 (extremely). Compared with how they had expected seeing the donor site to be, 18% (n=7) reported that it was not as distressing as they had envisaged, 49% (n=19) thought it had been as they had anticipated, 33% (n=13) considered it had been more distressing than expected. The analysis of women's comments about seeing the donor site (see Table 4), found that the majority commented on the appearance of the scar, whilst others described their emotional reaction, the process of looking, and feeling pleased or unprepared.

(c) Demographic differences

Further statistical analyses were conducted to explore the relationship between women's thoughts, expectations and behaviours regarding seeing her breast(s)/breast area for the first time, and age, marital status and surgery type.

No statistically significant difference was found between participant's age and the extent to which they were concerned about seeing their breast for the first time ($r=.053$, $p=.558$), avoided seeing their breast for the first time ($r=.044$, $p=.629$), were ready and prepared ($r=-.104$, $p=.250$), or found the experience distressing ($r=-.019$, $p=.832$). A statistically significant relationship was found between age and concern regarding other people's reactions to the appearance of the breast ($r=.250$, $p=.005$), with older women expressing less concern.

No statistically significant relationship was found between marital status and the extent to which they were concerned about seeing their breast for the first time ($H(5)=4.176$, $p=.524$), avoided seeing their breast for the first time ($H(5)=1.897$, $p=.863$), were ready and prepared ($H(5)=6.123$, $p=.294$), found the experience of seeing their breast distressing ($H(5)=1.026$, $p=.960$), or concern regarding other people's reactions ($H(5)=2.385$, $p=.794$).

No statistically significant relationship was found between surgical procedure and the extent to which they were concerned about seeing their breast for the first time ($H(2)=1.250$, $p=.535$), avoided seeing their breast for the first time ($H(2)=.288$, $p=.866$), were ready and prepared ($H(2)=1.043$, $p=.594$), found the experience distressing ($H(5)=1.002$, $p=.606$), or were concerned regarding other people's reactions ($H(5)=4.216$, $p=.121$).

(c) Support available

The majority of the women who responded to an open-ended question about the support available to them (see Table 5) had not been offered any specific help around looking at their surgical site/s for the first time. Approximately half of participants (51%; $n=62$) felt they had received enough support at this time, whilst 29% ($n=35$) commented that this aspect of care could be improved. A similar proportion (30%; $n=36$) would have valued more support.

Women suggested several ways to improve the experience (see Table 6), including additional information, greater privacy, and more psychological/emotional support.

Discussion

This research explored women's thoughts, expectations and behaviours prior to looking at the initial results of their mastectomy and/or breast reconstruction for the first time, their reactions to the appearance of their breast(s)/breast area and donor site, and their opinions on the support available at this time. To the best of our knowledge, this is the first study to

specifically explore women's experiences of this key point in their treatment pathway. The results provide an important insight into women's post-surgical experiences and suggest ways in which breast care teams might be able to meet their patients' needs through appropriate supportive care and intervention.

The majority of women were worried and concerned about looking at their breast(s)/breast area for the first time, and several had initially avoided looking. However, experiences varied considerably and some women looked forward to seeing their surgical results. The variation in women's experiences at this time mirror findings from a sample of burn patients (13) suggesting that, across patient/surgical groups, some individuals are more vulnerable than others. These findings highlight the need to consider patients' concerns and behaviours (e.g. avoidance) at this time.

Participants' reactions to seeing their post-surgical breast/breast area for the first time were characterised by relief, powerlessness, and distress. Many reported being pleased with their appearance or relieved that the cancer had been removed, and over two thirds reported that their appearance was better or about the same as they had imagined it would be. However, participants also described negative feelings; less than a third felt 'completely ready' to look at the surgical site for the first time, and a small (but important) proportion reported that the experience was more distressing than anticipated. In line with previous research, our findings highlight the variation in women's expectations, reactions and emotions at this particular point in their treatment (15,16), and reinforce the importance of emotional support and preparation (10).

When specifically asked about the donor site, the majority of respondents commented on the size and location of scarring, whilst several mentioned feeling unprepared and shocked.

Almost one third of those who had a donor site reported that seeing it was more distressing

than expected. These concerns echo research suggesting that some women had unrealistic expectations regarding the outcome of breast reconstruction, including donor-site scarring (17). Managing patients' expectations of the donor site in addition to the breast area itself is therefore crucial, particularly as research suggests pre-surgical expectations are associated with post-operative outcomes and quality of life (18). This may involve reiterating what the surgery involves, the possible outcomes and providing opportunities to discuss it with other women who have previously undergone the same procedure.

Women's thoughts, feelings and behaviours regarding seeing their appearance for the first time were not found to differ according to age, marital status or surgery type, with the exception of a statistically significant relationship between age and concern about other people's reactions to their appearance. This finding suggests that younger women are more concerned about other's reactions after surgery and may require additional psychosocial support around this element of the experience.

Both the qualitative and quantitative results of this mixed-methods study suggest that many women were generally happy with the support they had received. Many indicated that they were well prepared and gave examples of explicit advice, preparation (e.g., photos) and support. Our findings reinforce the importance of the recommendations within best practice guidelines, which state 'patients should be supported and prepared for seeing the results of surgery for the first time' (p.25) (9). However, over a third of women felt this aspect of care could have been improved and would have valued more support, with many commenting that no help was offered. Further, several women suggested there was a need for improved information, discussion of what to expect, privacy when seeing their appearance for the first time and more psychological/emotional support.

These findings indicate the importance of ensuring patients have access to support that meets their individual preferences and level of need when looking at the results of surgery for the first time. Support may take the form of a preparatory discussion (facilitated by photos or written information, and including information concerning when and where they are likely to see the results of their surgery), a private space (ideally not on a busy ward, even if curtains can be drawn around the bed), and a supportive presence (staff and/or family member/partner). This is particularly important given that almost half of women who completed this survey reported being alone when they saw their appearance for the first time. Future research could survey breast care services regarding their practice and protocol (if one is in place), for when women first see the results of their surgery. Additionally, exploring health professionals' confidence in supporting this aspect of care would be beneficial, with possible implications for staff training if necessary.

Several limitations of this study must be acknowledged. Firstly, the data are retrospective and risk recollection bias. **Furthermore, the study employed a cross sectional design. Prospective, longitudinal research is needed to a) fully understand women's initial experiences of their post-surgical appearance, and b) examine its potential longer-term impact on quality of life, surgical regret, adjustment and body image. Given that research has shown that unmet expectations and a lack of preoperative information provision predict postsurgical outcomes including decisional regret and post-operative dissatisfaction (10,18,19), it would be interesting to explore whether women's first impressions (i.e., feeling prepared and supported, expectations being met) are associated with long term postoperative outcomes including quality of life.**

Secondly, the vast majority of participants were White British and thus may not represent the experiences of women with different ethnic and cultural backgrounds. Future research would benefit from recruiting a more diverse sample.

Conclusion

This study has highlighted an aspect of breast cancer care previously overlooked by researchers, namely women's experiences of seeing their breast/breast area and any donor site for the first time after mastectomy and/or breast reconstruction. Our findings identified considerable variation in women's experiences. Whilst many reported positive experiences (especially those who felt prepared, whose expectations had been met and who considered that thought had been given to this element of their treatment), others described negative experiences and suggested ways to improve the support provided at this time. We believe this study has highlighted important areas for further research and practice that could improve the provision of care for women at this potentially difficult time.

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Conflict of interest statement

None

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Tables

Table 1 Sample characteristics and treatment variables

Characteristic		n	%
Ethnicity (n=127)	White	117	92
	Mixed background	4	3.1
	Black/Black British	2	1.6
	Other	3	2.4
	Prefer not to say	1	0.8
Marital Status (n=128)	Single	12	9.4
	Married	94	73
	In a relationship	10	7.8
	Divorced	8	6.3
	Separated	3	2.3
	Widowed	1	0.8
Surgical procedure (n=128)	Mastectomy	49	38
	Mastectomy and immediate breast reconstruction	47	37
	Mastectomy and delayed breast reconstruction	24	19
		8	6.3

		Other	
Time since surgery (n=128)	6 - 12 months	32	25
	1 – 2 years	32	25
	3 – 4 years	27	21
	5 – 6 years	13	10
	7 – 8 years	7	5.5
	9 – 10 years	10	7.8
	11 + years	7	5.5
Reason for surgery (n=128)	Diagnosed with invasive breast cancer	91	71
	Diagnosed with Ductal carcinoma in situ	26	20
	To reduce risk of developing breast cancer in the future	2	1.6
	Other	9	7
Specific reconstructive procedure undergone (n=69)	TRAM Flap	3	4.3
	DIEP Flap	18	26
	Latissimus Doris Flap	15	22
	Implant	25	36
	Other	6	8.7
	Unsure	2	2.9

Currently	Yes	52	41
undergoing	No	76	59
treatment			
(n=128)			
Treatment	Hormonal	39	75
currently	Chemotherapy	5	9.6
undergoing	Radiotherapy	3	5.8
(n=52)	Other	5	9.6

Table 2 Participants' responses regarding who suggested looking at their breast(s)/breast area for the first time after surgery, who they were with and where this took place

In relation to seeing their			
appearance for the first		n	%
time:			
Where were you? (n=127)	On the ward	80	63
	At home	32	25
	In a hospital clinic (outpatient)	12	9.45
	Other	3	2.36
Who was with you? (n=126)	Doctor	21	17
	General ward nurse	21	17
	Specialist breast care nurse	22	17
	Psychologist	0	0
	Family/friend/partner	17	13
	No-one – I was alone	67	53
	Other	5	3.97
Whose idea was it to look? (n=127)	My own idea	97	76
	A member of the breast care team	19	15
	Family/friend/partner	2	1.57
	Other	11	8.66

Table 3: Responses to the question ‘please describe the feelings or emotions you had when you saw your breasts/breast area for the first time after surgery’. (n=119)

Category	Sub-category	Frequency	Example
Relief	Feelings of general relief	15	‘Relief’
	Relief to have had the operation	5	‘relieved to have had the operation’
	Relief at appearance	4	‘Relief that I still had shape and in clothes would look normal’
	Relieved cancer had been removed	18	‘relief that the cancer was gone’
	Relieved with surgical outcome	4	‘Relieved that I still had a recognisable breast form’
(Dis)satisfaction	Pleased with appearance	23	‘I was pleased the scar was as neat as it is’
	Pleased with surgical outcome	9	‘I was pleased that the reconstruction had taken place’

	Better than expected	2	‘not as bad as I had thought’
	Unhappy with appearance	4	‘a bit upset with the symmetry’
Fear	Anxiety	7	‘anxious about the thought of seeing it ’
	Wounded	1	‘I looked and felt like I had been assaulted’
	Scared	5	‘Frightened’
	Vulnerable	1	‘nervous and vulnerable.’
	Unable to cope	1	‘I had no idea how I would cope with looking at myself everyday’
Loss	Feeling and looking different	5	‘Felt incomplete as nipple missing and large area of different colour skin’
	Grief	13	‘I think it's like mourning your old self.’
Distress	Anger	3	‘Hated people.’
	Change in femininity	2	‘I hated it, did not feel at all feminine’
	Disappointed	3	‘I was disappointed that I was left with a dent close to my breast bone.’

	Lonely	1	‘Lonely’
	Sadness	15	‘Sadness at having surgery ‘
	Shame	2	‘Felt ashamed of my appearance’
	Shock and despair	13	‘I was devastated when I looked at myself that first time’
	Stress	1	‘Stress’
	Tearful	4	‘I did cry.’
	Upset	7	‘very upset’
Acceptance/	Acceptance of illness	1	‘Made me accept I had (had) a life-threatening illness’
Non-acceptance	Acceptance of treatment outcome	1	‘Acceptance that my breast had gone’
	Difficulty with acceptance	1	‘I struggled with accepting that this was a good thing. That the cancer had been cut away’
Negative thoughts	Self-doubt	1	‘Did I really want this? Why did I do it? ‘
	Guilt	1	‘There was guilt and tears’

Reflection	Surviving	2	‘at least I’m still alive’
	Wished the whole thing had not been necessary	1	‘wished the whole thing had not been necessary’
	Grateful for location of cancer	1	‘grateful that if I had to have cancer it was in a part of my body that I didn’t actually “need”’
Concerns about reaction of others		3	‘apprehension as to what my husband's reaction would be’
Curiosity		4	‘I wasn't upset, just intrigued by how it looked’
Hopeful		1	‘hopeful that the scar will fade’
Disconnected/Unemotional		14	‘I wasn’t really emotional, I had already gone through so much’

Table 4: Experiences of seeing the donor site for the first time (n=26)

Category	Sub-category	Frequency	Example quote(s)
Appearance of scar	Inconspicuous	3	“Given the scar is on my back it’s not something I see regularly, but in any case it’s not very visible – just a fine line.”
	Size	9	“It was a huge scar from one side to another”
	Changes over time	2	“When I first saw my donor site, I was delighted with the smooth and flat looking tummy, despite the extensive scar. Unfortunately, as it healed, it got a lot worse to look at, with the scar puckering quite badly and the tummy bulging in some areas”
	Comparison with breast scar	2	“The scar was in a really good location but the scar was puckered and nowhere near as neat as the breast scar.”
Emotional reaction	Shock	5	“I really was shocked at what I saw. I was expecting a scar that would hide easily under a bra strap. What I saw was much bigger than anything I was anticipating.”
	Sadness	2	“Sad that my ‘perfect’ back now had a huge wound”

Process	Delay	3	“I was some time before I saw the scar on my back. I think I first saw it when getting out of the bath at home about 10 days after surgery.”
	After-care	3	“I had a problem with healing and following the surgery it didn’t heal for 8 months and required dressings and special care from plastic surgery unit. I didn’t see it during this time”
Satisfied with outcome		5	“I was pleased to see the back of the ‘extra’ tummy I had after two caesarean births and felt pleased that it had been put to good use. It felt like my precious children had a hand in me being able to use my own tissue to create breasts”
Unprepared		6	“I was not at all prepared for looking at the donor site, especially my belly button wound”
Other concerns		1	“My biggest concern was that I would have pain in my back – this did not happen.”

Table 5: Responses to the question ‘describe what help, if any, were you offered with regards to looking at your breast/breast area?’ (n=111)

Category	Sub-category	Frequency	Example
Nothing		60	“I was not offered any help or support...very matter of fact and no questions or discussion”
Preparation	Explicit advice	5	“the nurse also explained how it may look”
	Images	3	“I was shown photographs pre-op”
Emotional support		15	“Discussion as to whether or not I was really ready. Nurses encouraged looking at it in own time scale”
Supportive physical presence		7	“immediately asked if I wanted her to be with me”

Table 6: Responses to the question ‘could anything have been done differently by the breast care service that may have improved your experience of looking at your breast surgery for the first time?’ (n=100)

Category	Sub-category	Frequency	Example
Nothing		42	<p>“No think you have to do it when you are ready yourself”</p> <p>“No I was happy to do it alone”</p> <p>“Not really”</p>
Anything		1	“Anything would have been more helpful than what I received”
More privacy		4	“Perhaps a treatment room rather than on the ward”
Emotional support	General emotional support	11	“more support. I felt so overwhelmed at the time I had nowhere to turn”
	Supportive presence	6	“offering to be with me”
	A breast care nurse	10	“a specialist nurse available if requested”
	Remote support	2	“offering phone support”

	Peer support	2	“Maybe having a group session with other patients on the ward. Making you not feel so isolated and alone”
Information	Expectations	6	“A bit more warning of what I could be looking at”
& advice	Photographs	7	“look at images with the breast care nurses beforehand”
	Scarring	1	“more info about scar and physical appearance”
	Healing process	1	“advice that how the breast looked initially is not how it looks once healed”
	When to look	1	“perhaps more information on when would be a good time to look for the first time”
