

# Patient perceptions of physical rehabilitation education and treatment after breast cancer surgery: A mixed methods study

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## Research Article

**Keywords:** breast cancer, physical rehabilitation, physical side-effects, patient perceptions, physical recovery.

**Posted Date:** April 5th, 2021

**DOI:** <https://doi.org/10.21203/rs.3.rs-265448/v1>

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# Abstract

**Purpose** To investigate the content and delivery of physical rehabilitation education and treatment received by women following breast cancer surgery and to establish patient perceptions of this physical rehabilitation.

**Methods** 509 Australian women (55 years SD 6.5) who previously had breast cancer surgery retrospectively completed an online survey about the content, delivery, satisfaction with and perceptions of the physical rehabilitation they received for six physical side-effects. The percentage of respondents who received each delivery format for the six physical side-effects and their satisfaction levels were tabulated. A thematic analysis was conducted on patients' perceptions of the physical rehabilitation they received.

**Results** Pamphlets were the most common delivery format of physical rehabilitation following breast cancer surgery. Common physical side-effects, however, were not included in the content and at less than 50% of women were satisfied with their physical rehabilitation. Three major themes emerged: Women perceived (i) they were unaware of and unprepared for the physical side-effects of their surgery/treatment, (ii) information delivery was unsuitable in terms of the timing, delivery format and cognisance of patient needs, and (iii) follow-up was insufficient at critical time points of recovery.

**Conclusion** The physical rehabilitation received by women after all types of breast cancer surgery is perceived to be poor in terms of its content, delivery format and follow-up and women perceive that their needs at various stages of recovery are not being met. Physical rehabilitation needs to improve after all types of breast cancer surgery.

## Introduction

Cancer survivorship can be divided into two distinct periods: the rehabilitation period, which immediately follows primary treatment, and the disease prevention/health promotion period, which involves longer term survival [1]. The primary goal of the rehabilitation period is to address the acute side-effects of treatment and facilitate a return to pre-treatment health [1, 2]. This period continues until any major loss of function is restored, consequently, its duration is highly variable [1]. Maximising physical recovery during the rehabilitation period is vital to enable women to be physically capable of maximising their disease prevention and health promotion, which have become a priority because of the high 10-year survival rate of the 2 million women world-wide diagnosed breast cancer [3]. Unfortunately, a high percentage of women have been found to suffer from frequent and severe physical side-effects following breast cancer surgery, which they perceive to limit them from living a physically active lifestyle and restrict their ability to resume sport, paid work and daily tasks [4–8].

The physical side-effects following breast cancer surgery are responsive to physical rehabilitation education and treatment provided within research studies [9, 10] [2, 11–14]. There appears, however, to be limited translation of such physical rehabilitation into clinical practice, with only a minority of women

reporting they receive physical rehabilitation education or treatment after their breast cancer surgery [10, 15–21], even women who have a higher risk of developing more frequent and severe physical side-effects [22].

The content of physical rehabilitation provided within research studies has only covered some of the commonly experienced physical side-effects, such as shoulder issues and lymphoedema [9, 16, 23–28]. After breast cancer surgery women also commonly report scar, torso and breast support issues and physical discomfort disturbing sleep [7, 29–32]. The delivery format of physical rehabilitation has ranged from education only, where women are given a pamphlet, to small group or individual follow-up sessions where exercises are checked and progressed by a physiotherapist [10, 14, 23, 33, 34]. Research investigating patient perceptions on these delivery formats or their perceived efficacy has been limited, as has research into the translation of physical rehabilitation recommendations into clinical practice. It is therefore unknown whether research recommendations are being implemented. For example, researchers have recommended that early intervention for lymphoedema should include physical measurements, post-operative exercises and education about lymphoedema before surgery [25, 27, 28], although whether this occurs in clinical practice is unknown.

Patient perceptions on physical rehabilitation have only previously been investigated in focus group studies, where dissatisfaction with physical rehabilitation has been reported [10, 11, 17]. Further research is therefore required to quantify the content and delivery format of the physical rehabilitation provided to a large cohort of women within clinical practice, in conjunction with patient perceptions on this physical rehabilitation. This could determine whether the needs of patients at the various stages of recovery are being met and facilitate improvements in the physical rehabilitation provided within clinical practice [10–12]. This is, in turn, could limit the duration, progression and impact of the physical side-effects of breast cancer surgery and maximise the long-term health and quality of life of women *surviving* breast cancer [22].

The aim of this study was therefore to investigate the content and delivery format of physical rehabilitation education and treatment received by women following breast cancer surgery and to establish patient perceptions of this physical rehabilitation. It was hypothesised that: (i) the content of physical rehabilitation education and treatment for shoulder issues and lymphoedema would be received by a higher percentage of respondents compared to scar, torso and breast support issues or physical discomfort disturbing sleep; (ii) that a high percentage of respondents would receive no physical rehabilitation; and (iii) that a high percentage of women would be dissatisfied with the physical rehabilitation they received.

## Patients And Methods

### 1.1 Participants

Women who previously had breast cancer surgery were invited to complete an anonymous online survey advertised on breast cancer specific websites across Australia (Breast Cancer Network Australia,

Register4, Reclaim Your Curves, breast cancer support groups).

Consent was granted by clicking an “I agree” button after the participant information sheet.

The University Human Research Ethics Committee approved all data collection procedures (HE15/453).

## **2.2 On-line survey**

The content of the survey was developed based on previous education/exercise intervention studies for women after breast cancer surgery [2, 9, 13, 14, 25, 28], research on the common physical side-effects following breast cancer surgery [4, 5, 30, 32, 35, 36]; and semi-structured interviews with physiotherapists involved in treating women with breast cancer women (n = 6). Based on this information, categories of physical rehabilitation delivery formats were classified for six physical side-effects (scars, shoulder and torso (i.e., pain, decreased range-of-motion or muscle strength), lymphoedema, sleep discomfort and breast support and bra fit issues). Respondents were asked to report the physical rehabilitation delivery format they received for each side-effect and rank their level of satisfaction. Respondents who had an autologous breast reconstruction were also asked to report on the physical rehabilitation delivery format and level of satisfaction for any donor site issues. The survey concluded with an open-ended question to explore the respondents’ perceptions around physical rehabilitation education and treatment and recommendations on how they could be improved.

The respondents were also asked to provide their age, residential location, cancer surgery/treatments and whether they had lymph nodes removed, post-operative complications or pre-existing musculoskeletal issues.

Face validity of the survey was conducted by representatives from Breast Cancer Network Australia, Register4, regional breast cancer support groups, three clinicians and three women with breast cancer. The survey took approximately 10 minutes to complete and was open for 10 months (July 2017 to April 2018). It was published on Qualtrics (v0217; Provo, UT) and of the 729 women who visited the link to the site, 625 completed the survey (85.7% completion rate).

## **2.3 Statistics**

The percentage of respondents who received each rehabilitation delivery format for each physical side-effect and their level of satisfaction was tabulated. A thematic analysis was conducted on the open-ended question to identify, analyze and report on the main themes in the data set [37]. To achieve this, the open-ended responses were extracted and entered into a Microsoft Excel spreadsheet. Iterative coding of the dataset was initially conducted, which included familiarisation with the data by reading and rereading of the extracted data and generating initial codes by the primary researcher (DM). The themes were then reviewed, defined and final themes were agreed through consensus with a secondary researcher (AM). Exemplary quotes to authenticate the themes were extracted from participants’ quotes and agreed with the secondary researcher. All statistical tests were conducted using SPSS Statistics v26.0 for Windows (IBM® Inc., Armonk, USA) with the alpha level set at  $P < 0.05$ .

# Results

## Participants

Of the 625 respondents who completed the survey, 509 (81%) had their surgery within 10 years of survey completion and were included in the analysis considering the greater in focus to survivorship during the last 10 years (see Table 1).

## Content and delivery format of physical rehabilitation education and treatment

The highest percentage of respondents reported receiving no physical rehabilitation education or treatment for the physical side-effects of scars, torso and breast support issues and physical discomfort disturbing sleep (Fig. 1). Where some form of physical rehabilitation was received, the most common delivery formats were verbal instructions or a pamphlet. The least common delivery format was follow-up sessions where exercises/scar massage or breast support were checked and/or progressed by a health professional (Fig. 1). For the physical side-effect lymphoedema, less than 30% of the respondents received any physical assessment and ~ 25% received either no education at all about lymphoedema or only after they had developed the condition (Fig. 1).

For the physical side-effects of breast support and bra fit issues, ~ 70% of respondents received no specific guidelines or education from a health professional (Fig.

1) and more than one in two reported that they were not able to find a comfortable, well-fitting bra following their breast cancer surgery (Fig. 2). For each physical side-effect, less than 50% of respondents were satisfied with the physical rehabilitation education or treatment they received (Fig. 3); the percentage was highest for the side-effects of lymphoedema and shoulder issues and lowest for physical discomfort disturbing sleep.

## Patient Perceptions Of Physical Rehabilitation

Three major themes emerged from analysis of the qualitative data. Women perceived: (i) they were unaware of and unprepared for the physical side-effects of their surgery/treatment; (ii) information delivery was unsuitable in terms of the timing, delivery method and cognisance of patient needs; and (iii) follow-up was insufficient at critical time points of recovery (Fig. 4).

### Theme 1: Unaware of and unprepared for the physical side-effects

Respondents consistently reported they were unaware of and unprepared for the physical side-effects, which made the physical side-effects more distressing and debilitating.

*"My breast lymphoedema became apparent 8 months after radiation finished. It frightened the hell out of me because I thought the lumpiness was the cancer returning. Huge scare!" (P444).*

*"I would have liked more information about the side effects of each treatment stage, so I could have been more prepared mentally "(P554).*

*"Providing more information about what is likely to happen after the surgery. I think I was in shock for about 2 weeks and I didn't really take in what I was being told immediately after the surgery. I didn't even understand what I needed to know (because you don't know what you don't know)" (P622).*

*"..finding a bra to fit me was two years of hell" (P 282).*

**Theme 2:** Information delivery was perceived to be unsuitable

The timing of delivery meant that the content of physical rehabilitation education and treatment resources was not commonly connected to patient needs at the various stages of recovery or when women were in a cognitive or emotional state to allow them to understand or retain information.

*"I had visits post-surgery in hospital and I was very affected by pain killers. I don't remember much about their advice then" (P309).*

*"...follow up when relevant rather than convenient to health care.*

*e.g. information about bras etc doesn't sink in while you are waiting for pathology results" (P704).*

The delivery format of pamphlets or verbal instructions were perceived to be ineffective.

*"I was inundated with pamphlets, most of which I did not read" (P599).*

*"...make info available in different forms e.g. verbal, written pamphlet, online and video (P98).*

**Theme 3:** Follow-up was insufficient

Respondents consistently reported the need and desire for more follow-up with health professionals to help them to manage physical side-effects associated with their surgery. Respondents lacked the knowledge to self-manage their side-effects and how to access appropriate professional help.

Respondents from rural/regional areas perceived they were particularly disadvantaged by limited local access to cancer-specific expertise and difficulty and expense of travelling to venues that offered exercise programs.

Respondents who had their surgery in private hospitals reported that breast care nurses were not necessarily employed in private hospitals, which limited any follow up.

*"Often problems/questions can occur later but without good background knowledge a person isn't quite sure what is normal or not normal" (P242).*

*"More physio intervention whilst in hospital rather than saying; "lift your arms - oh you will be fine". Cording and truncal and lymphoedema prevention should be discussed. As should scar management and sleeping with specialist in field rather than surgeon saying: "you will need to massage the scar for the rest of your life", and surgeon dismissing pain on sleeping" (P604).*

*"I found the most useful help came from physiotherapists (strength/flexion and lymphoedema). I would like to see surgeons and oncologists work more closely with physios. Patients should be referred to appropriate practitioners ASAP" (P408).*

*"Private patient - I needed to source a lot of information myself...Developed lymphoedema - didn't have info regarding assessment prior to surgery - this should be a must" (P685).*

*"A rehab program is available but at a venue approx. 60 km from where I live" (P281).*

"The availability of a breast care nurse in my regional area would have been a great help, plus GP's support and advice could have been better.

*I sourced my own private Lymphedema specialist who I had to travel 3 hours to see" (P541).*

Perceptions of physical rehabilitation after breast cancer surgery could be improved.

Physical rehabilitation was perceived to be "...disjointed, unsupportive and not patient centred (P619)".

Recommendations to improve physical rehabilitation included:

*"In a perfect world there would be big speciality allied services centres near every cancer care centre that could support physical health during and after cancer treatment" (P48).*

*"More initial information and then actually following up on patients to see how they are coping would go a long way" (P58).*

## **Discussion**

This is first study to systematically investigate the physical rehabilitation education and treatment received by a large cohort of women after breast cancer surgery in terms of the content, delivery format, level of satisfaction and patient perceptions. Of concern was that a high percentage of respondents received no form of physical rehabilitation for most of their physical side-effects such that they were unaware of and unprepared for the physical side-effects of their surgery/treatment. The most common delivery formats were either verbal instructions or pamphlets and both the format and timing of these resources were perceived to be unsuitable. Only a minority of respondents received any form of follow-up where their physical side-effects or exercises were checked or progressed, such that the respondents perceived follow-up as insufficient. The implications of these findings and patient perceptions of how physical rehabilitation could be improved are discussed below.

The perceptions of respondents regarding their physical rehabilitation were consistent with previous research [10–12], as was the percentage of respondents who received some form of physical rehabilitation education and treatment for shoulder issues and lymphoedema [17, 33]. Physical side-effects being more distressing and debilitating because women were unaware and unprepared (Fig. 4) was also consistent with previous research [11, 12, 38, 39].

The results of this study suggest there is an urgent need to improve the physical rehabilitation provided to women following all types of breast cancer surgery because inadequate physical rehabilitation can be a barrier to effective patient management.

Early intervention for lymphoedema, for example [14, 27, 28, 33], would not have been possible for the 25% of respondents who received no information at all about lymphoedema or only received information once they had developed the condition (Fig. 1). A lack of awareness about breast lymphoedema was specifically highlighted to be a problem by the respondents, consistent with previous research [40]. The translation of research recommendations about lymphoedema into clinical practice was also limited, with only 8% of respondents reporting to have received a physical assessment or education about lymphoedema before surgery (Fig. 1). In order for women to take a proactive approach to their physical recovery, they need to be aware of strategies to self-manage any side-effects, such as lymphoedema, and cues to signal when they need professional help. Clinicians also need to be aware of the characteristics that increase the risk of more severe side-effects (e.g., post seroma, post-operative infection) and conduct post-operative assessments to allow for early referral and intervention [7]. This could limit the progression of physical side-effects into secondary issues from disuse or misuse of the musculoskeletal system [25] and enable women to maximise their potential within their disease prevention/health promotion phase so they can live well with breast cancer.

The respondents' perceptions on the delivery format and timing of when they received physical rehabilitation education and treatment (Fig. 4) also highlight the need to review how and when physical rehabilitation is delivered to women after breast cancer surgery within clinical practice. The respondents perceived pamphlets to be ineffective and, instead, recommended more diverse delivery formats such as videos, podcasts, and telehealth. Timing was also perceived by respondents to be inconsistent with their needs and their ability to understand and retain new information at different stages of treatment and recovery (Fig. 4). A staged approach was recommended so that education is delivered using a patient-centre approach.

The need and desire for more follow-up with health professionals to help women manage their physical side-effects was a consistent theme and those who had received physiotherapy reported it to be extremely beneficial [10, 14]. Researchers have previously recommended a surveillance model of care [25, 27, 41], although such a model might not be economically feasible within all health care systems.

An alternative approach could be a two-level model of care, which involves a public health self-management mode of care for most women and a professional treatment mode of care for women who were not able to self-manage.

The public health mode would require free, evidence-based, on-line resources to be developed, incorporating various delivery modalities (e.g. videos, podcast, written information). These resources would provide foundation information to empower women to self-manage their side-effects following breast cancer surgery, together with clear milestones for progressing exercises and cues to determine whether women needed to seek professional assistance. Such a resource would allow consistent information to be delivered to all women irrespective of where they live or had their surgery.

It would also allow women to better control when they access physical rehabilitation education according to their needs at different stages of recovery and cognitive capacity.

Such a resource would particularly benefit women from rural and regional areas, as well as women who have their surgery in private hospitals.

The professional treatment mode of care acknowledges that a percentage of women will require professional support to manage their side-effects, including women with more severe and frequent side-effects over multiple body regions or with specific side-effects such as lymphoedema.

This professional support could include a variety of delivery formats such as telehealth, group classes and individual sessions, together with the up-skilling of clinicians in rural/remote areas, linking them with cancer-specific experts.

Greater awareness and inclusion of physical recovery in the post-operative care managed by breast care nurses and doctors could also ensure early identification and referral of women that need professional support and a proactive approach of all women to their physical recovery.

Gaps in the content of physical rehabilitation education and treatment for commonly experienced physical side-effects were also identified[22]. Less than one in two respondents received any form of physical rehabilitation education or treatment for scars, torso or donor site physical side-effects or comfortable and safe sleeping positions (Fig. 1). Furthermore, less than 50% of respondents were satisfied with the physical rehabilitation they received for every physical side-effect (Fig. 3). This suggests that the content of physical rehabilitation resources needs to include more information about commonly experienced physical side-effects. Education on breast support, bra fit and external breast prosthesis, for example [32, 42], should be an essential component of any physical rehabilitation resource following breast cancer surgery because breast support and external breast prostheses are known barriers to women participating in physical activity [43, 44]. Indeed ~ 50% of respondents reported ongoing difficulties with breast support, such that 16% were unable to wear a bra (Fig. 2).

Breast care nurses and physiotherapists therefore require greater education about breast support issues specific to women following breast cancer surgery/treatment.

This could enable these clinicians to problem solve issues related to breast asymmetry, scar sensitivity and torso deformity and educate and empower women to make more informed choices about breast support following surgery. Education and follow-up to enable women to find a safe and comfortable sleeping position, particularly in the acute post-operative period is vital considering the high percentage (~ 60%) of women who report suffering from physical discomfort disturbing their sleep after their surgery [7] and the negative impact poor sleep has on tissue healing, mental and physical health. Yet only 25% of respondents received any form of education about sleep issues and only 17% were satisfied with this education.

## Limitations

Although this study provides a unique insight into the content, delivery format and patient perceptions on physical rehabilitation following different types of breast cancer surgery, there are several limitations. The

data were collected retrospectively and up to 10-years post-surgery, which could have affected respondent recall accuracy. The physical rehabilitation delivered, surgery techniques and, in turn, physical side-effects could also have changed over this 10-year period.

It is also possible the physical rehabilitation differed according to the types of breast cancer surgery, which were grouped together.

Further research is therefore recommended to prospectively investigate the content of physical rehabilitation education and treatment over a more limited time-period.

## Conclusion

The physical rehabilitation received by women after all types of breast cancer surgery is poor in terms of its content, delivery format and follow-up. A high percentage of women are dissatisfied and perceive that the physical rehabilitation education and treatment they received did not meet their needs at various stages of recovery. Physical rehabilitation needs to improve after all types of breast cancer surgery to enable women to live an active lifestyle and resume their sport, paid work and daily tasks.

## Declarations

The authors (Deirdre McGhee, Anne McMahon and Julie Steele) have nothing to declare.

## Funding

The study was funded by the University of Wollongong, Faculty of Science, Medicine and Health.

## Conflicts of interest/Competing interests (include appropriate disclosures)

The authors have no conflicts of interest or competing interests.

**Availability of data and material:** The data can be made available on request.

**Code availability:** N/A

**Authors' contributions:** Deirdre McGhee and Julie Steele contributed to the study conception and design. Material preparation, data collection and analysis were performed by Deirdre McGhee. Anne McMahon and Deirdre McGhee analysed the qualitative data. The first draft of the manuscript was written by Deirdre McGhee and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

**Ethics approval:** The University Human Research Ethics Committee approved all data collection procedures (HE15/453).

**Consent to participate:** Informed consent was obtained from all individual participants included in the study.

**Consent for publication:** Authors are responsible for correctness of the statements provided in the manuscript.

## Acknowledgements.

The authors would like to thank Breast Cancer Network Australia, Register4, and breast cancer support groups (including Reclaim Your Curves) for their support of this project. We also thank Jodi Steel for her invaluable contribution as a consumer advocate.

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## Table 1

**Table 1:** Participant characteristics (n = 509).

<b>Characteristic</b>	<b>N (%)</b>
<b>Age<sup>†</sup></b>	
<50 years	83 (16.3)
50+ years	425 (83.7)
Missing data	1
<b>Postcode</b>	
Regional	158 (31.3)
Metropolitan	346 (68.7)
Missing data	5
<b>Health System Type</b>	
Public	132 (26.2)
Private	372 (73.8)
Missing data	5
<b>Laterality of Surgery</b>	
Unilateral	379 (74.5)
Bilateral	130 (25.5)
<b>Lymph nodes removed</b>	
Yes	395 (77.6)
No	114 (22.4)
<b>Radiation Treatment</b>	
Yes	337 (66.5)
No	170 (33.5)
Missing data	2
<b>Pre-existing musculoskeletal issue*</b>	
Yes	62 (12.2)
No	447 (87.8)
<b>Post-operative complication<sup>†</sup></b>	
Yes	261 (51.3)
No	339 (48.7)
Missing data	1

\* Pre-existing shoulder or torso injury reported

† Includes infections, seromas, necrosis and other identified complications.

# Figures

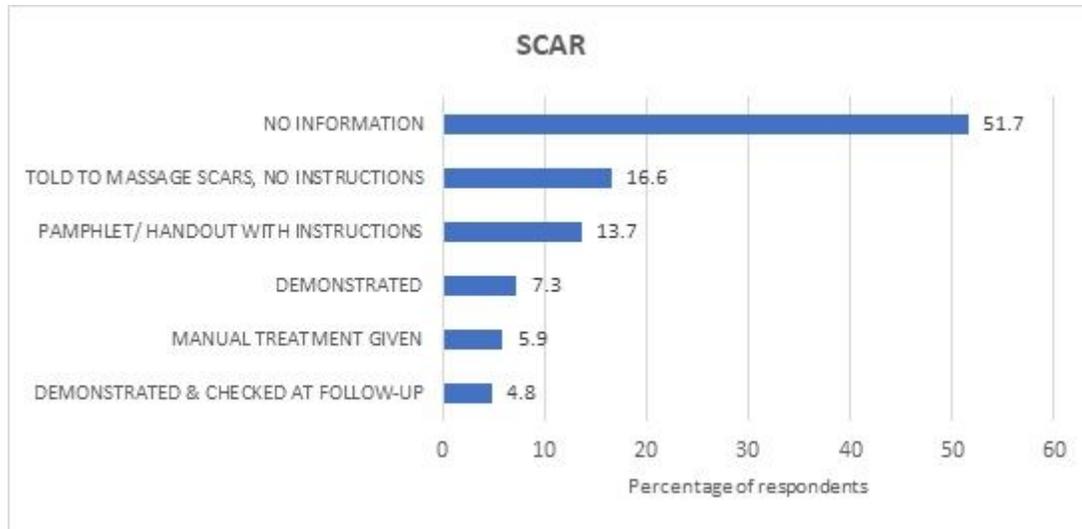


Figure 1

Format of physical rehabilitation education and treatment received for each physical side effects (N=509).

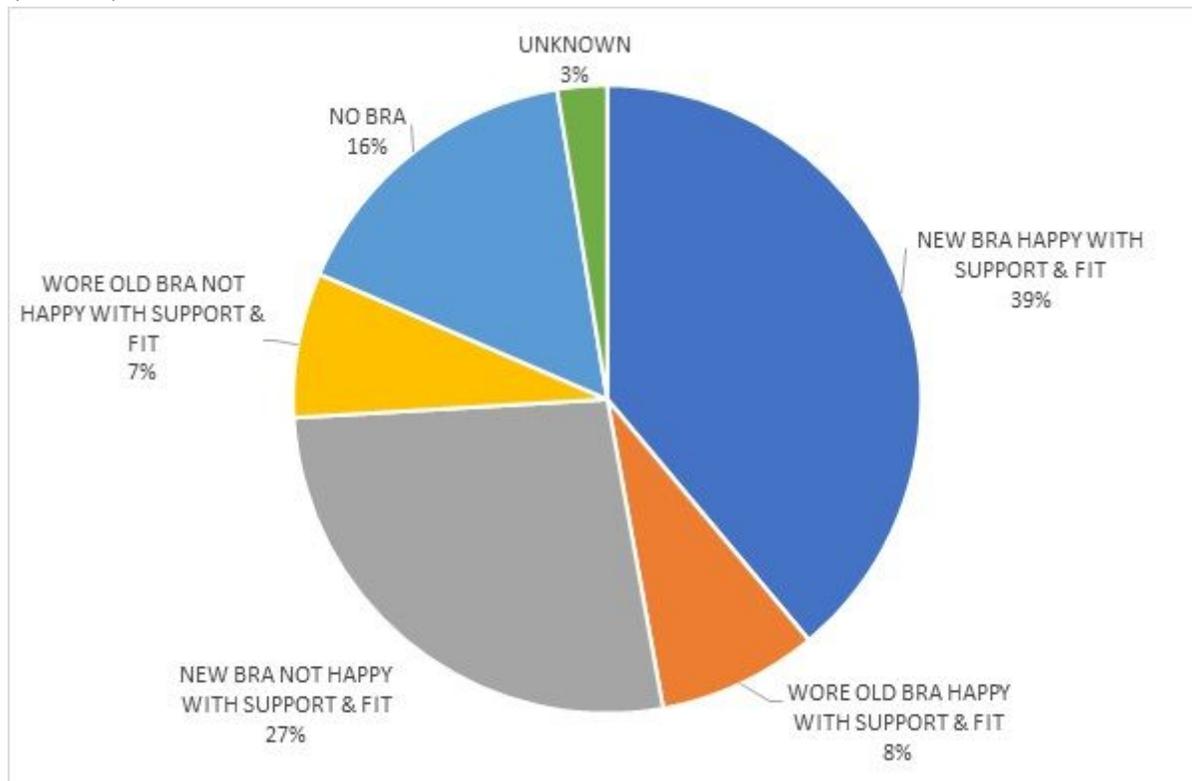


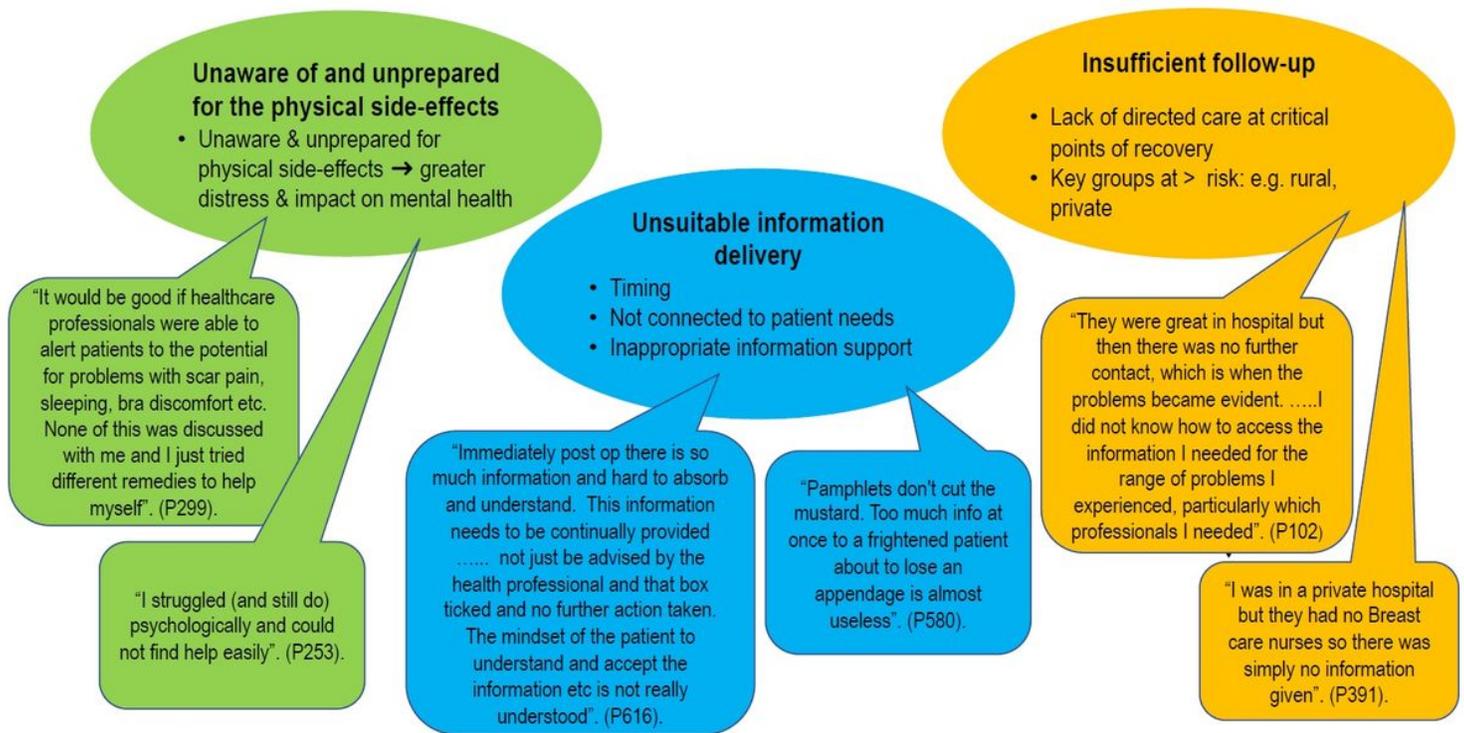
Figure 2

Ongoing self-reported breast support and bra fit issues (N = 509).



**Figure 3**

Percentage of respondents satisfied, dissatisfied or neutral regarding the physical rehabilitation received for each physical side-effect.



**Figure 4**

Summary of respondents' perceptions of the physical rehabilitation education/treatment they received after breast cancer surgery.