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Response to reviewers

Reviewer and associate editor	Comment	Revision
Reviewer 1	1.Lack of specific approach women wanted or desired in each stage or what specific care they perceived as important	Clarification within results/discussion section
Reviewer 1 & Associate editor	2.Discussion really short without any scientific value	Discussion re-written following comments
Reviewer 1	3.Not sure what specific patient-centred holistic approach has been implemented	Definition added see lines 115-117
Reviewer 1	4.Misconception with title	Title amended: see title page
Reviewer 1 & 2 & Associate editor	5.Did you have appropriate ethical approval and gain consent? When was consent gained? Consent should be gained for both the interviewing and physical examination	See lines 87-91 re ethical approval See lines 54-55 re consent. No physical examination was carried out during this study therefore not stated
Reviewer 1	6.Confusion with use of names rather than subjects	See line 109 for clarification. Pseudonyms used in line with good practice in qualitative research and realist/personal style
Reviewer 1	7.Page 6, line 138: who is 'her' here	Line removed as results/discussion re-written
Reviewer 1	8.Line 139: too many 'hers' in sentence	Line removed as results/discussion re-written
Reviewer 1	9.Conclusion missing	Lines 285-291
Reviewer 1	10.I am not quite sure why and how they wrote the participant's interview section	Results/discussion section re-written
Reviewer 2 & Associate editor	11.Confused with regards to the aims and methods, would encourage different way of presenting results. Aims not clearly presented, need to be clear whether exploring the experience of physio in general or comparing general physio with specialist service	Clarification re aims lines 43-46
Reviewer 2 & Associate editor	12.Stratification strange as aim would suggest authors are trying to explore the breadth of physio services for breast	Clarification re stratification lines 60-61

	cancer, rather than compare specialist vs non specialised service. If the aim is to compare specialist vs general then I do not think the authors have asked the right questions to participants. Not made clear why participants divided into 3 groups – if aims clearer then perhaps methodology may be clearer	
Reviewer 2	13.How many patients in each group	Clarification re group numbers lines 95-96
Reviewer 2	14.How many of the patients from each group volunteered for phase 2? Which group did Laura, Pamela and Chris belong to?	All participants volunteered for phase two. For clarity and due to limitation of word count phase one has been excluded from the account reported in this paper, this is referenced 'as part of a larger study' line 75
Reviewer 2	15.Dual role clinician-researcher big confounding factor and should be elaborated on. The results should be interpreted with care	Clarification re dual role clinician-researcher lines 233-244
Reviewer 2	16.I feel the researcher-interviewer role should also be clearly stated in the methods	See lines 83-84
Reviewer 2 & Associate editor	17.Results should be described in terms of common themes identified in Phase one. Table 1 and figures 1-3 not adequate in explaining what themes mean. Some of the themes from phase 1 should be discussed.	Following serious consideration of the reviewer feedback it has been decided to exclude discussion of "phase one" in order to focus on the main aim of the study which was to explore patient experience of the value of physiotherapy in more depth. Therefore table one has been removed.
Reviewer 2	18.Often combined results and discussion section, as it makes sense to discuss the themes and support them with quotes as they are presented	See newly restructured results/discussion section
Reviewer 2	19.If the authors wish to present table 1 in relation to each of the 3 groups, an explanation should be given as to why they think certain themes were not mentioned by certain groups	As "phase one" has been removed from this report, the paper is now more sharply focused on reporting and analysis of the interviews
Reviewer 2	20.No need to present data in this manner, as no difference between	As above and stated lines 103-106

	the groups because the numbers in some groups were so small	
Reviewer 2	21.Encourage to provide phase one demographics	As explained above, “phase one” now omitted from discussion
Reviewer 2	22.The authors should examine phase 1 demographic data and see if there are any trends between themes and patients who have different types of treatment, or perhaps patients of different ages, or patients who may have lymphoedema, compared to those who do not	The aim of the study was to explore in-depth the experience of physiotherapy care received by a small purposive sample of patients with breast cancer. The research design was not planned to explore trends between different treatments; that would need to be addressed in other study designs.
Reviewer 2	23.An unexplored area is timing of physio, how does this impact on the patient? Would the patient have remembered the info given at a time of great stress? Further discuss encouraged	See lines 203-207
Associate editor	24.Themes identified from each group in phase one (not just in table form) and then these expanded and discussed	As explained above “phase one” now omitted from the discussion
Associate editor	25.One stated aim was to better understand the impact of specialist service, but results from phase 2 do not address this	Results/discussion re-written to address this
Associate editor	26.A lot of detail on the individual participant interviews – perhaps this detail could go in appendix and summary presented in results and comparison between experiences of three women discussed in discussion section	Results/discussion re-written to address this
Associate editor	27.It is not clear to which sub group each of the 3 participants belonged and this should be made clear and form part of the discussion	See lines 110-111
Associate editor	Needs to be discussion around comparison of general with specialist physio from results of phase 1 and 2.	This was not the aim of the study, discussion re-written for clarification

*Title Page (with authors and addresses)

Exploring aspects of physiotherapy care valued by breast cancer patients

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Word count: 2989

Exploring aspects of physiotherapy care valued by breast cancer patients

Introduction:

Breast cancer has been the most common cancer in the United Kingdom since 1997 and accounts for 31% of all new cases of cancer in females [1]. The rate of new diagnoses increases rapidly amongst those aged 40 years, rising from about 1 per 100,000 in young adults to just over 400 per 100,000 in those aged over 85 years [2]. Although much progress has been made in combating breast cancer, women endure multiple assaults to the body from both the disease and treatments. For some of the nearly three million people diagnosed annually [3], the life-prolonging surgical and adjuvant therapies are associated with complications and side effects, can lead to functional limitations, disability and have a negative impact on quality of life.

As acknowledged in the National Cancer Survivorship Initiative (NCSI) Vision [4], the next challenge is to ‘’understand the needs of those living with breast cancer today and to develop models of care which meet their needs’’ (page 4). It also acknowledges the need for services which are responsive to individual needs and access to specialist care when needed.

It is recognised that breast cancer patients have specific support needs and if these remain unmet, they are likely to have implications for long term rehabilitation outcomes. Hence there is an urgent need for physiotherapists to develop effective and high quality rehabilitation protocols for breast cancer patients, to support their functioning and to prevent permanent disabilities [5, 6].

Exploring aspects of physiotherapy care valued by breast cancer patients

The Specialist Breast Care Physiotherapy Service was first established as a pilot service in 2010, in accordance with National Institute for Health and Clinical Excellence guidelines (2004) [7] and the National Cancer Action Team 'Breast Cancer Rehabilitation Pathway' (2009) [8]. As outlined in the NCSI document (2010) [4] the Service has been designed to accommodate the increasing numbers of breast cancer survivors in the future and to optimise the use of NHS resources.

The Service has been developed to support patients at all stages of their breast cancer treatment pathway, with the provision of a Specialist Outpatient Service for treatment related problems; including shoulder dysfunction, arm and breast lymphoedema, reduced arm strength, scar tightness, myofascial dysfunction, axillary web syndrome, donor site morbidity following reconstruction and pain. The Service is delivered by a physiotherapist who specialises in the treatment of breast cancer patients and has extensive clinical experience working with this patient group. The need to evaluate the impact of the new Service was identified as a priority. Hence, the study aimed to explore the value of physiotherapy care received by patients who had accessed the new Specialist Breast Care Physiotherapy Service.

The study objectives were to:

- identify which aspects of care patients valued most and least
- gain insights into why these aspects were liked or disliked
- make recommendations for clinical care pathways based on outcomes

Method:

Participants were recruited from a sampling frame of patients who had been referred to the Specialist Service and discharged within the last six months. The researcher accessed patient records to identify potential participants who met the inclusion criteria. Consent forms were sent by post with invitation to participate and an information sheet. Written consent was gained prior to taking part in the study.

In order to draw a representative sample from the population, a stratified purposeful sampling technique [9] was used; with the patients being stratified into one of three subgroups dependant on their previous physiotherapy experience. The researcher was interested to see whether the previous physiotherapy affected participant's experience of the Specialist Service. Group One patients had accessed the Specialist Service only, Group Two patients had accessed the Specialist Service and had previous experience of physiotherapy locally and Group Three patients had accessed the Specialist Service and had previous experience of physiotherapy outside this locality. Those selected were contacted by post and asked to telephone the Physiotherapy Department if they agreed to take part.

The inclusion criteria were any patients who had been referred to the Specialist Service following a diagnosis of breast cancer, since June 2010. Any patients identified as requiring full-time cognitive or physical care, those unable to participate in a group setting or requiring a translator or a family member to communicate were excluded.

This paper reports the results of in-depth one to one interviews which were conducted as part of the larger study involving three groups described above. One participant from each subgroup was selected using a random number table. The order of the interviews was also generated via this method. Items developed from the earlier part of the larger study were used to guide the interview schedule of open-ended questions. A consistent scripted protocol was followed for each interview, which was audio-recorded then transcribed and lasted between 30-45 minutes. The researcher conducted the interviews in a dual role alongside being the physiotherapist who had delivered care as part of the Specialist Service. The implications of this dual clinician-researcher role are further discussed in the 'limitations' section below. A thematic network analysis approach was adopted to interpret the data [10].

An application for full NHS ethical approval (Ref 12/NW/0009) was submitted, the committee decision was that the study was a service evaluation and therefore did not require any NHS ethics approvals. Governance approval was obtained from the host NHS Trust R&D Department (Ref 2011/266can) and ethical approval was obtained from the University ethics panel (Ref BuSH 041).

Results & discussion:

Nineteen female participants were recruited. Due to the stratification dependant on previous physiotherapy experience, the numbers in each group varied; in group one there were seven participants two in group two, and ten in group three.

As stated above one participant was randomly selected to take part in an in-depth interview from each subgroup. It is beyond the remit of this paper to fully present the findings from each of the interviews, and as the participants were stratified into sub-groups related to previous experience of physiotherapy, the findings cannot be combined together as one set of outcomes. However within this small sample, previous experience of physiotherapy had not affected the perceived value of experience of the Specialist Service; therefore comparisons between findings can be made.

The results are presented as an analysis of themes generated from each interview (see Figures One, Two and Three), followed by a discussion of themes below. The names quoted are pseudonyms to protect the identity of the participants. Laura was selected from Group One, Pamela from Group Two and Chris from Group Three.

All three interviews highlighted the theme of the importance of a patient-centred holistic approach to care. As defined by McEvoy and Duffy (2008) [11] in their concept analysis study, holistic care embraces the mind, body and spirit of the patient, in a culture that supports a therapeutic relationship, resulting in wholeness, harmony and healing. In their qualitative study in 2011, Kidd et al [12] found that patients insisted that the physiotherapist should locate the patient at the centre of the therapeutic encounter, and make them feel understood and respected.

The value of receiving specialist physiotherapy from an experienced clinician was also consistent throughout the three interviews, which fulfils the recommendations of the NCSI document [4] as discussed in the introduction, in providing access to a Specialist Service. Participants talked about the confidence they felt in being treated by a therapist who specialised in treating breast cancer patients and had experience in the management of post treatment dysfunction.

The participants felt the Service had met their physiotherapy needs; emotionally and psychosocially, as well as physically. This perceived value of both physical and psychological support is very similar to the findings of Lattanzi et al (2010) [13] where participants acknowledged the importance of the therapist providing this support, especially for those who may not have anyone else with whom to share their struggles. Their study in 2010 was methodologically very similar to this study; with a similar sampling technique, inclusion criteria, overall findings and subsequent recommendations.

The impact of physical improvement was stated in all three interviews. In the 'Individualised care' theme in Figure one, Laura reported *'it was motivation, even in the space of 2 days I could see a difference'* (line 50). Pamela stated *'my god it helped. I think it was within a couple of weeks I was able to move my arm. And it was brilliant'* (lines 178-179) in the 'Physiotherapy experience' theme in Figure Two. In the 'Self-awareness' theme in Figure Three, Chris states *'I didn't realise how restricted my arm was till I met you'* (Line 57) and *'you could actually see physically the progression of it which was fantastic'* (Lines 59-60).

The general consensus was that the participants reported an overall positive experience. All three participants expressed gratitude at being able to access the Specialist Service. As stated in the 'Physiotherapy experience' theme in Figure Two Pamela talked about the therapist taking a personalised approach, stating '*it was just as though you had just time for me, like I was the only one who mattered*' (lines 238-239).

The value of individualised care, goal setting and seeing continuous improvement was consistent for both Laura and Chris. Laura talked about the importance of goal setting and the value of monitoring her progress with her physiotherapist, stating '*It had a big impact in that I had something to work towards. It stopped my stressing about what else was going on; I had something to focus on'* (line 45). As this empowered her and built her confidence, her therapy was delivered using a more 'hands-off' approach.

Participants talked about valuing the therapist's knowledge regarding the impact of a breast cancer diagnosis and subsequent treatment physically, emotionally and psychologically. All three participants focused strongly on the value of the provision of emotional support, specifically motivation, positivity and encouragement. As stated within the 'Support' theme in Figure Three, Chris described the emotional support provided by her therapist as giving her a kind of 'mental stability' and stated '*It gave me a lot of reassurance that I wasn't on my own and that I was coping with it as well as could be expected'* (line 223).

Chris talked about the value of seeing the same therapist throughout her treatment, and the impact this had on being able to form a therapeutic relationship. She reflected that the support provided by her therapist gave her the confidence to utilise other support and services and also played a key part of enabling her return to work, which was also valued by Laura.

The importance of educational support and effective communication was recognised by Pamela and Chris. Chris valued the early identification and referral onwards with regards to her lymphoedema. She also found her experience gave her a better self-awareness in terms of her physical limitations and she felt empowered by this.

When describing the physiotherapy experience as a whole, Pamela compared her previous experience of physiotherapy, where she struggled to get the help she needed, to the positive experience and relationship she developed with her therapist. She talked about the improvement in both physical functioning and the impact this subsequently had on her confidence and family role. She discussed the impact of having to rely on others to help her do the tasks at home she previously carried out and through improvement in movement and function and reduction in pain, stated '*Well I felt as though I'd got my life back again. So now I don't have to ask anybody for anything'* (line 202).

When Laura described her physiotherapy experience, she valued the importance of early intervention post diagnosis and a flexible, easily accessible service. Laura did feel however that the service could be improved by the availability of online access. This service development has been discussed with the Physiotherapy Manager, as a

way to enhance communication with patients. She also liked the multi- disciplinary approach to her care. She specifically reflected that she felt well supported with the awareness that her care was being provided by a team who regularly communicated with each other, thus creating a holistic approach and facilitating referral onto other disciplines.

Chris described her referral to the Specialist Service happened 'by chance' as she hadn't retained the information received on the ward post-operatively regarding self-referral. This confirms findings of Larsson et al (2008) [14] who acknowledge the fact that women may still be in a state of shock when they go through surgery and cannot be expected to be receptive to information. Chris felt that the Service would be improved by the introduction of a pre-operative assessment and routine follow-up with the physiotherapist.

The theme of body image was explored in Chris's interview, when she talked about when her therapist began treating her mastectomy scar. Her 'hands-on' physiotherapy approach enabled patient-clinician exploration of how her mastectomy had impacted on her self-image. Chris reflected that the impact of her therapist treating her mastectomy scar affected her both emotionally and also physically, as she was able to touch her scar and massage it, stating '*It would have been something I would have blocked out completely and I wouldn't have even wanted to look at it and now when I have a shower I do go through the massage and things like that'* (line 446). Talking about this actually made Chris cry, demonstrating how powerful and meaningful the experience was to her. This demonstrates the need for

therapist's to develop the ability to deal with sensitive issues and communicate effectively.

Interestingly, the environment of the physiotherapy service provision, that takes place in the Outpatient Physiotherapy Department, usually in a cubicle surrounded by curtains, was not raised as an issue. It had been felt by the therapist that this environment may not be as conducive to patient satisfaction as a more private clinical area, but in fact Chris stated she preferred the therapy taking place here as it was easier to access than the main outpatient area of the hospital.

Limitations:

This study comprised a relatively small sample size from one geographical site, which limits the direct transferability of the findings. However the in-depth analysis of these data has generated important issues related to the patient experience of care. The potential bias of the lead investigator's dual clinician-researcher role is acknowledged. As described by Yanos and Ziedonis (2006) [15], the dual role of clinician-researcher can facilitate the development of clinically relevant research. However, there is a risk that this can pose both ethical and role conflicts for the researcher. They conclude that the establishment of an 'integrated identity' is ultimately the most comprehensive means of balancing and prioritising ethical issues.

The complexity of clinical research does not permit a clean cut between therapeutic and non-therapeutic studies, therefore alternating between a clinical or research orientation would not prove satisfactory. The clinician-researcher aimed to maintain a conception of moral identity that integrated the roles of the clinician and researcher, without giving predominance to one or the other [16].

Implications for future research:

The importance of an effective therapeutic relationship that can develop between patient and therapist has been demonstrated. Further studies to explore the concept of therapeutic relationships are needed to obtain a more conclusive understanding of the influence of the alliance and its effects on treatment outcomes [12, 17, 18].

The impact of the development of lymphoedema was briefly touched upon in both phases of the study. Further exploration of this area was beyond the scope of this study, but the need for evaluation of patient experience of this chronic condition [19] is highlighted.

Within the sample of participants that took part in the study, previous experience of physiotherapy did not affect the perceived value of the experience of a Specialist Service. This suggests that the stratification of participants into sub-groups dependant on their previous experience of physiotherapy may not have been necessary. This has implications for future research in terms of research design with this patient population.

Implications for practice:

As the role of the physiotherapist in providing rehabilitation for breast cancer patients emerges, so does the need to evaluate interventions, demonstrate effectiveness and review current service provision, in order to establish best practice and to secure future service provision. The Specialist Service that has been evaluated in this study was developed in response to the identification of need and aims to deliver a holistic and individualised approach to care and support patients to return to function and optimise quality of life, following a diagnosis of breast cancer. The outcomes of this study will be used to make recommendations for future clinical care pathways and support continued service provision.

This study supports the need for physiotherapy at all stages of the treatment pathway, following a diagnosis of breast cancer. What has emerged from this study is the importance of treating a patient ‘as a whole’; incorporating both the physical and the psychological and emotional impact of receiving a diagnosis of breast cancer and its subsequent treatment. The importance of the therapeutic relationship between patient and therapist has been identified, and the positive impact this can have on overall satisfaction and treatment outcomes.

Breast cancer patients often have unmet information needs and the importance of educational support and effective communication has been demonstrated. The recommendation of the introduction of a pre-operative assessment and routine follow-up with the physiotherapist is also supported in previous literature [13, 20, 21, 22] and therefore has implications for clinical practice.

Conclusion:

These findings highlight the importance of a patient-centred holistic approach to care. The importance of the physiotherapist locating the patient at the centre of the therapeutic encounter confirms previous findings [12, 23].The value of receiving specialist physiotherapy from an experienced clinician was also consistent throughout the three groups, which is in line with current government recommendations [4].

Key messages:

- Participants value a patient-centred holistic approach to care and access to a Specialist Service with an experienced clinician.
- Alongside the value of physical improvement, the importance of the therapeutic alliance and the value of psychological, emotional and educational support helped the participants to feel more empowered in their own recovery.

Acknowledgements:

The authors are grateful to the participants and for the support of employers who made this study possible.

Ethical approval:

NRES Research Ethics Committee Reference: 12/NW/0009

Salford Research and Development Number: 2011/266can

University of Central Lancashire Reference Number: BuSH 041

Funding: Nil

Conflict of interest statement: Nil

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Exploring aspects of physiotherapy care valued by breast cancer patients

Figure One: Laura's interview

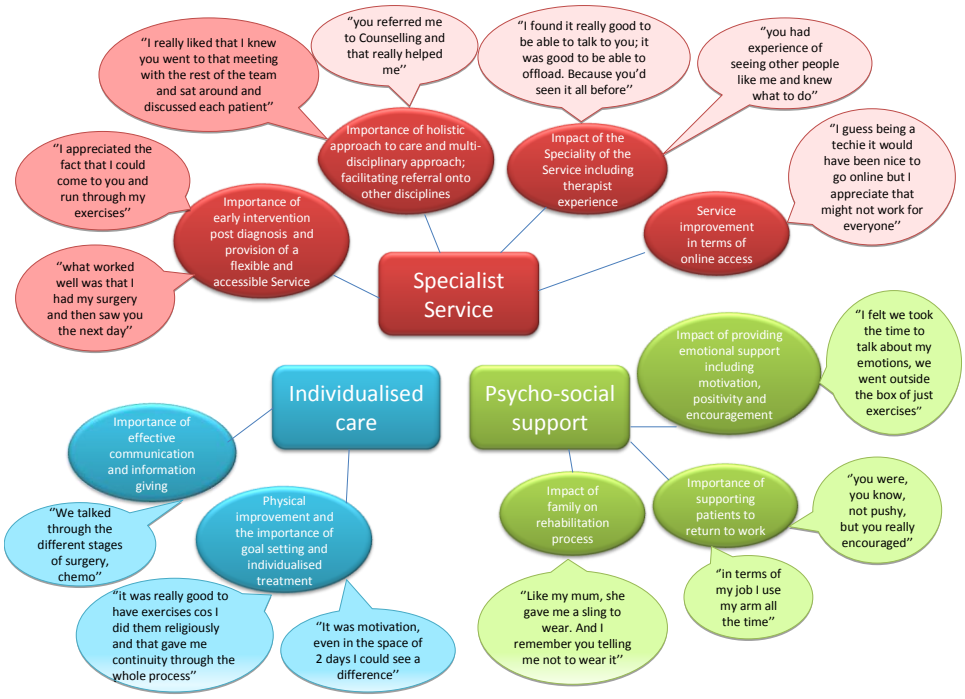

Figure Two: Pamela's interview

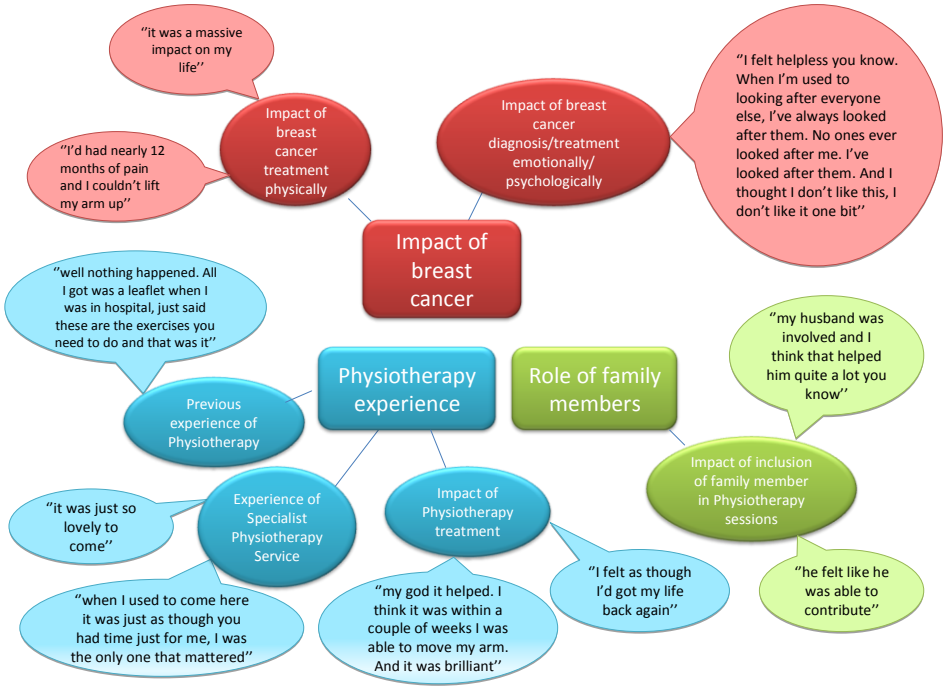

Figure Three: Chris' interview

Exploring aspects of physiotherapy care valued by breast cancer patients

Abstract

Objective: To explore the reported value of physiotherapy care received by patients who had accessed a Specialist Breast Care Physiotherapy Service.

Design: Exploratory qualitative study using in-depth interviews to explore aspects of physiotherapy care valued by breast cancer patients. Thematic network analysis was used to interpret the data and bring together the different experiences of the participants and identify common themes.

Setting: Physiotherapy Department at a NHS Foundation Trust Teaching Hospital.

Participants: Nineteen participants were recruited and three were selected to take part in the in-depth interviews. All participants had received physiotherapy care from a Specialist Breast Care Physiotherapy Service and had been discharged within the last six months.

Results: Participants valued a patient-centred holistic approach to care and access to a Specialist Service with an experienced clinician. In particular the importance of the therapeutic alliance and the value of psychological, emotional and educational support emerged, with the participants feeling empowered in their recovery.

Conclusion and clinical implications:

Participants reported an overall positive experience of their physiotherapy care. This study supports the need for service providers to evaluate their current physiotherapy provision and subsequently develop Specialised Services to meet the physiotherapy needs of breast cancer patients throughout all stages of their treatment pathway from the delivery of pre-operative care through to post-treatment follow-up.

Keywords: Patient care; Physiotherapy; Breast Cancer; Patient experience; Rehabilitation

Cover letter

03.03.14

Please find attached our paper submission entitled “Exploring aspects of physiotherapy care valued by breast cancer patients”.

I can confirm that this is original research which has not been submitted elsewhere for publication.

I will be pleased to hear from you in due course about the review progress.

Yours sincerely,

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