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Title: Exploring aspects of physiotherapy care valued by breast cancer patients

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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

	<p>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</p>	
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

Exploring aspects of physiotherapy care valued by breast cancer patients

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1 **Introduction:**

2 Breast cancer has been the most common cancer in the United Kingdom since 1997
3 and accounts for 31% of all new cases of cancer in females [1]. The rate of new
4 diagnoses increases rapidly amongst those aged 40 years, rising from about 1 per
5 100,000 in young adults to just over 400 per 100,000 in those aged over 85 years
6 [2]. Although much progress has been made in combating breast cancer, women
7 endure multiple assaults to the body from both the disease and treatments. For
8 some of the nearly three million people diagnosed annually [3], the life-prolonging
9 surgical and adjuvant therapies are associated with complications and side effects,
10 can lead to functional limitations, disability and have a negative impact on quality of
11 life.

12
13 As acknowledged in the National Cancer Survivorship Initiative (NCSI) Vision [4], the
14 next challenge is to “understand the needs of those living with breast cancer today
15 and to develop models of care which meet their needs” (page 4). It also
16 acknowledges the need for services which are responsive to individual needs and
17 access to specialist care when needed.

18
19 It is recognised that breast cancer patients have specific support needs and if these
20 remain unmet, they are likely to have implications for long term rehabilitation
21 outcomes. Hence there is an urgent need for physiotherapists to develop effective
22 and high quality rehabilitation protocols for breast cancer patients, to support their
23 functioning and to prevent permanent disabilities [5, 6].

24

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25 The Specialist Breast Care Physiotherapy Service was first established as a pilot
26 service in 2010, in accordance with National Institute for Health and Clinical
27 Excellence guidelines (2004) [7] and the National Cancer Action Team 'Breast
28 Cancer Rehabilitation Pathway' (2009) [8]. As outlined in the NCSI document (2010)
29 [4] the Service has been designed to accommodate the increasing numbers of
30 breast cancer survivors in the future and to optimise the use of NHS resources.

31

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

42

43 The study objectives were to:

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

47

48

49

50 **Method:**

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

56

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

67

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

73

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

86

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

92

93 **Results & discussion:**

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

97

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

106

107 The results are presented as an analysis of themes generated from each interview
108 (see Figures One, Two and Three), followed by a discussion of themes below.

109 The names quoted are pseudonyms to protect the identity of the participants. Laura
110 was selected from Group One, Pamela from Group Two and Chris from Group
111 Three.

112

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

120

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

127
128 The participants felt the Service had met their physiotherapy needs; emotionally and
129 psychosocially, as well as physically. This perceived value of both physical and
130 psychological support is very similar to the findings of Lattanzi et al (2010) [13]
131 where participants acknowledged the importance of the therapist providing this
132 support, especially for those who may not have anyone else with whom to share
133 their struggles. Their study in 2010 was methodologically very similar to this study;
134 with a similar sampling technique, inclusion criteria, overall findings and subsequent
135 recommendations.

136
137 The impact of physical improvement was stated in all three interviews. In the
138 'Individualised care' theme in Figure one, Laura reported *'it was motivation, even in*
139 *the space of 2 days I could see a difference'* (line 50). Pamela stated *'my god it*
140 *helped. I think it was within a couple of weeks I was able to move my arm. And it was*
141 *brilliant'* (lines 178-179) in the 'Physiotherapy experience' theme in Figure Two. In
142 the 'Self-awareness' theme in Figure Three, Chris states *'I didn't realise how*
143 *restricted my arm was till I met you'* (Line 57) and *'you could actually see physically*
144 *the progression of it which was fantastic'* (Lines 59-60).

145

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146 The general consensus was that the participants reported an overall positive
147 experience. All three participants expressed gratitude at being able to access the
148 Specialist Service. As stated in the 'Physiotherapy experience' theme in Figure Two
149 Pamela talked about the therapist taking a personalised approach, stating '*it was just*
150 *as though you had just time for me, like I was the only one who mattered*' (lines 238-
151 239).

152

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

160

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

169

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

175

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

180

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

190

191 When Laura described her physiotherapy experience, she valued the importance of
192 early intervention post diagnosis and a flexible, easily accessible service. Laura did
193 feel however that the service could be improved by the availability of online access.

194 This service development has been discussed with the Physiotherapy Manager, as a

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

200

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

208

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

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

221

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

228

229 **Limitations:**

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

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

245

246 **Implications for future research:**

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

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

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

261

262 **Implications for practice:**

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

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

279 Breast cancer patients often have unmet information needs and the importance of
280 educational support and effective communication has been demonstrated. The
281 recommendation of the introduction of a pre-operative assessment and routine
282 follow-up with the physiotherapist is also supported in previous literature [13, 20, 21,
283 22] and therefore has implications for clinical practice.

284

285 **Conclusion:**

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

292

293 **Key messages:**

- 294
- Participants value a patient-centred holistic approach to care and access to a
295 Specialist Service with an experienced clinician.
 - Alongside the value of physical improvement, the importance of the
296 therapeutic alliance and the value of psychological, emotional and educational
297 support helped the participants to feel more empowered in their own recovery.
298

299

300 **Acknowledgements:**

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

303

304 **Ethical approval:**

305 NRES Research Ethics Committee Reference: 12/NW/0009

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307 University of Central Lancashire Reference Number: BuSH 041

308

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310 **Conflict of interest statement:** Nil

311

312 **References:**

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Exploring aspects of physiotherapy care valued by breast cancer patients

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Figure One: Laura's interview

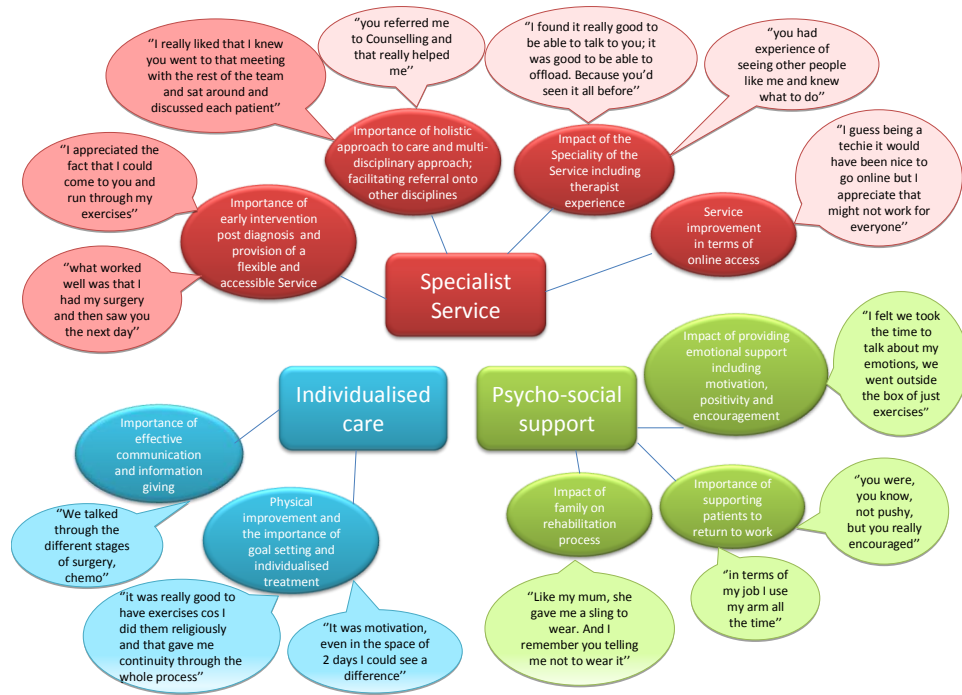
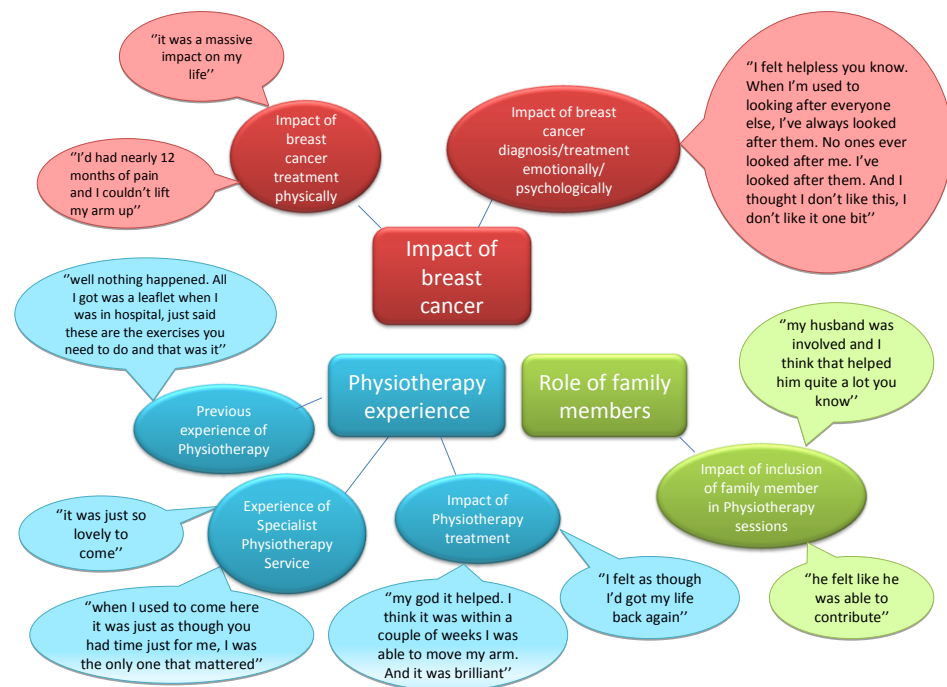
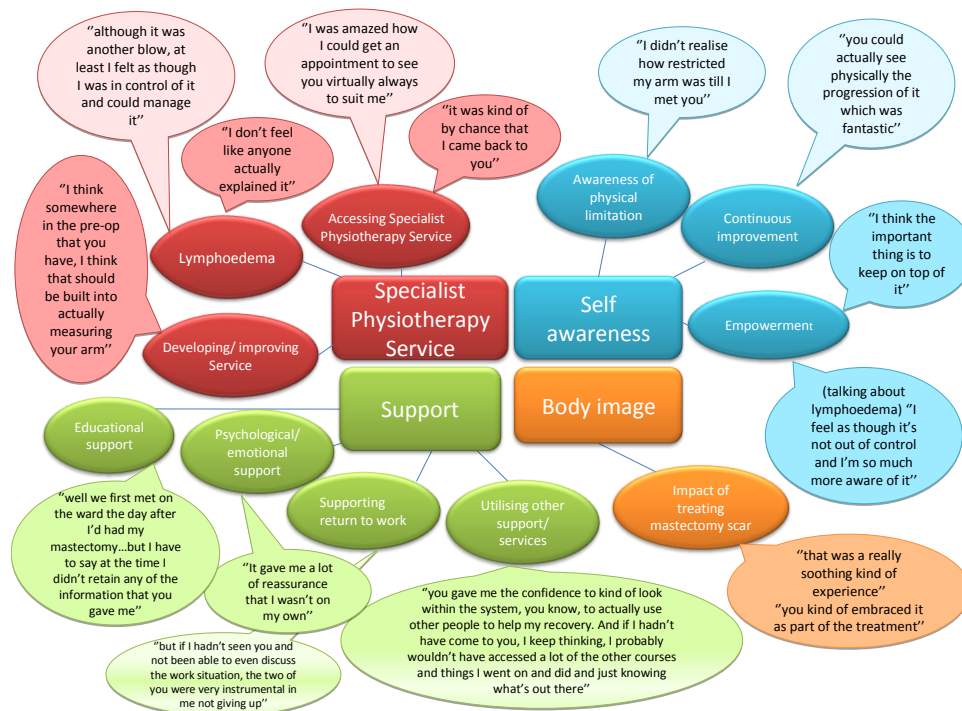


Figure Two: Pamela's interview



Exploring aspects of physiotherapy care valued by breast cancer patients

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.

Exploring aspects of physiotherapy care valued by breast cancer patients

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

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,

A handwritten signature in black ink, appearing to read 'Hazel Roddam', with a long horizontal flourish extending to the right.

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