

## The Breast Cancer Specific Patient Concerns Inventory [PCI] As a Means to Assist the Identification of Body Image Concerns in Routine Follow Up Clinics

A Kanatas<sup>1\*</sup>, D Lowe<sup>2</sup>, G Velikova<sup>3</sup>, B Roe<sup>4</sup>, J P White<sup>5</sup>, RJ Shaw<sup>6</sup> and SN Rogers<sup>7</sup>

<sup>1</sup>Specialty Registrar, Leeds Teaching Hospitals and St James Institute of Oncology, UK

<sup>2</sup>Evidence-Based Practice Research Centre [EPRC], Faculty of Health, Edge Hill University, St Helens Road, Ormskirk, L39 4QP, UK

<sup>3</sup>Department of Oncology, Honorary Consultant, St. James's Institute of Oncology, Leeds LS9 7TF, UK

<sup>4</sup>Department of Health Research, Edge Hill University, St Helens Road, Ormskirk, L39 4QP, UK

<sup>5</sup>Leeds Teaching Hospitals, Clinical Specialist in breast oncology, Breast Surgery Department, St James's University Hospital, Leeds. LS9 7TF, UK

<sup>6</sup>Department of Head & Neck Surgery, Liverpool CR-UK Centre, Department of Molecular & Clinical Cancer Medicine, Duncan Building, Daulby Street, Liverpool, L69 3GA, UK

<sup>7</sup>Evidence-Based Practice Research Centre (EPRC), Faculty of Health, Edge Hill University, St Helens Road, Ormskirk, L39 4QP and Consultant Regional Maxillofacial Unit, University Hospital Aintree, Liverpool, L9 1AE, UK

### Abstract

**Introduction:** The aim of this work is to assess the role of the breast cancer (BC) specific Patient Concerns Inventory (PCI) in the identification of body image concerns in breast cancer patients.

**Materials and methods:** A cross-sectional survey, using the BC specific PCI with an established breast cancer HRQOL measure (EORTC C30 with BR23).

**Results:** Survey responses were obtained from 80% (200/249) of participants. There was significant correlation between the number of body image related items selected and the number of PCI items selected in other PCI domains, the total number of other PCI items selected and the total number of health professionals selected.

**Conclusions:** The breast cancer specific PCI can be use as a screening tool for body image as well as for a range of other issues in order to identify a subgroup of patients that would benefit from focus interventions.

**Keywords:** Patient concerns inventory; Body image; Breast cancer; Quality of life

**Corresponding author:** Anastasios Kanatas, Specialty Registrar in Oral and Maxillofacial Surgery, Leeds Teaching Hospitals and St James Institute of Oncology, Leeds General Infirmary, LS1 3EX, UK, Tel: 00447956603118; E-mail: [a.kanatas@doctors.org.uk](mailto:a.kanatas@doctors.org.uk)

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### Introduction

Many changes to our appearance may occur through life. These may be planned or unplanned, desired or not<sup>[1]</sup>. There are several definitions of body image in the literature based on body size estimation, evaluation of body attractiveness, feelings associated with body size and shape<sup>[2]</sup>. The definition we use relates body image to a person's perceptions, feelings and thoughts about his or her body<sup>[2,3]</sup>.

Women treated for breast cancer endure scars and disfigurement of the breast, skin changes related to radiotherapy and/or hair loss due to chemotherapy<sup>[4,5]</sup>. These effects from the disease and its treatment are life changing and can lead to a significant alteration in body image<sup>[5,6]</sup>. In turn this effect on body image can result in undesirable Health-Related-Quality-of-Life (HRQOL) changes that affect the transition from patient to breast cancer survivor<sup>[7-12]</sup>. Younger patients may be more susceptible to stress related to change in body image and report greater changes in HRQOL scores<sup>[11-16]</sup>. Brunet et al.<sup>[17]</sup> reported that women with breast cancer experienced various physical changes that negatively affected, their perceptions, thoughts, attitudes, feelings, and beliefs about their bodies. Based on these findings they highlighted the need to recognise body image concerns that could have a long lasting effect on the HRQOL.

The link between body image disturbance, lower self-compassion and an increase level of distress has been recognised by Przedziecki et al.<sup>[18]</sup>. Specific treatment options such as mastectomy may adversely affect specific aspects of body image such as problems related to sexual intimacy<sup>[19]</sup>. Mastectomy may alter body image so much that can obliterate sexual relationships for a period of time<sup>[20]</sup>. Support in relation to sexuality and body image could improve relationships by modifying perceptions with a direct improvement in patient's and spouse's HRQOL<sup>[21]</sup>. Clinicians do not always elicit such concerns from patients. One way of improving recognition of these problems is to develop tools to improve clinicians' communication with patients. Cohen et al.<sup>[22]</sup> suggested that patients want honesty, openness, and directness from their physicians during the discussion of breast-related body image issues. Breast cancer patients rate the information on physical changes, sexual response and body image as very important. However, Ussher et al.<sup>[23]</sup> reported that only 41% of their patients obtained such information, hence only 34% of patients claimed to be satisfied with this aspect of their consultation.

Body image can affect a woman's treatment decisions with respect to surgical options such as mastectomy versus breast conserving surgery<sup>[24]</sup>. A multidisciplinary approach to address the impact of body image, with specific medical and psychosocial interventions has been analysed<sup>[25]</sup>. Younger patients take longer to make treatment decisions and require enhanced levels of support compared to older adults. The availability of breast reconstruction only partially ameliorates this effect<sup>[26]</sup>.

Body image changes associated with mastectomy, chemotherapy and radiotherapy are well recognised<sup>[27-29]</sup>. Up to a third of women report moderate or marked breast, arm, and shoulder symptoms over 5 years of follow-up after radiotherapy, and skin changes related to radiotherapy are well document in the literature<sup>[30]</sup>. However, these appear to have little impact on body image. As expected, adjuvant treatments [chemotherapy and radiotherapy] are associated with decrease in overall HRQOL, an increase in physical problems and adverse effects on the body image<sup>[31]</sup>.

Tools to evaluate changes in body image following breast cancer exist and may be used in both research and clinical settings<sup>[32]</sup>. A number of HRQOL instruments in use in breast oncology have incorporated body image questions<sup>[32-40]</sup> (Table 1).

During the past week have you lost any hair [Sprangers et al] [35]
During the past week have you felt physically less attractive as a result of your disease or treatment [Sprangers et al] [35]
During the past week have you been feeling less feminine as a result of your disease or treatment [Sprangers et al] [35]
During the past week did you find it difficult to look at yourself naked [Sprangers et al] [35]
During the past week have you been dissatisfied with your body [Sprangers et al] [35]
I avoid looking at my scars from breast surgery [Baxter et al] [36]
I am satisfied with the shape of my body [Baxter et al] [36]
I feel less feminine since cancer [Baxter et al] [36]
I Like my body [Baxter et al] [36]
I feel comfortable about the way I look when exercise [Baxter et al] [36]
I would feel comfortable changing in a public change-room [Baxter et al] [36]
I feel my body has been invaded [Baxter et al] [36]
I am satisfied with the appearance of my arm [Baxter et al] [36]
I am satisfied with the appearance of my hips [Baxter et al] [36]
I am satisfied with the shape of my buttocks [Baxter et al] [36]
I feel comfortable looking at my mastectomy [Baxter et al] [36]
I am happy with the position of my nipple [Baxter et al] [36]
I feel satisfied with the size of my breast [Baxter et al] [36]
I feel comfortable when other see my breasts [Baxter et al] [36]
The appearance of my breasts could disturb others [Baxter et al] [36]
I feel that people are looking at my breasts [Baxter et al] [36]
How satisfied are you with the way your breast looks [Polivy J] [37]
Have you been feeling self-conscious about your appearance [Hopwood et al] [32]
Have you felt less physically attractive as a result of your disease or treatment [Hopwood et al] [32]
Have you been dissatisfied with your appearance when dressed [Hopwood et al] [32]
Did you find it difficult to look at your self naked [Hopwood et al] [32]
Did you avoid people because of the way you felt about your appearance [Hopwood et al] [32]
Have you been feeling the treatment has left your body less whole [Hopwood et al] [32]
Have you been dissatisfied with your body [Hopwood et al] [32]
Have you been dissatisfied with the appearance of your scar [Hopwood et al] [32]
Is there a difference between the treated and untreated areas in terms of Breast size [Stanton et al] [38]
Is there a difference between the treated and untreated areas in terms of breast texture [hardening] [Stanton et al] [38]
Is there a difference between the treated and untreated areas in terms of nipple appearance [Stanton et al] [38]
Is there a difference between the treated and untreated areas in terms of breast shape [Stanton et al] [38]
Is there a difference between the treated and untreated areas in terms of breast elevation [Stanton et al] [38]
Is there a difference between the treated and untreated areas in terms of scar tissue [Stanton et al] [38]
I am self-conscious about the way I dress [Brady et al] [39]
I am bothered by hair loss [Brady et al] [39]
How satisfied or dissatisfied have you been with how you look in the mirror clothed [Pusic et al] [40]
How satisfied or dissatisfied have you been with the shape of your reconstructed breasts when you are wearing a bra [Pusic et al] [40]
How satisfied or dissatisfied have you been with how normal you feel in your clothes [Pusic et al] [40]
How satisfied or dissatisfied have you been with the size of your reconstructed breasts [Pusic et al] [40]
How satisfied or dissatisfied have you been with being able to wear clothing that is more fitted [Pusic et al] [40]

How satisfied or dissatisfied have you been with how your breasts are lined up in relation to each other [Pusic et al] [40]
How satisfied or dissatisfied have you been with how comfortably your bras fit [Pusic et al] [40]
How satisfied or dissatisfied have you been with the softness of your reconstructed breasts [Pusic et al] [40]
How satisfied or dissatisfied have you been with how equal in size your breasts are to each other [Pusic et al] [40]
How satisfied or dissatisfied have you been with how natural your reconstructed breast looks [Pusic et al] [40]
How satisfied or dissatisfied have you been with how natural your reconstructed breast sits/hangs [Pusic et al] [40]
How satisfied or dissatisfied have you been with how your reconstructed breast feels to touch [Pusic et al] [40]
How satisfied or dissatisfied have you been with how much your reconstructed breast feels like a natural part of your body [Pusic et al] [40]
How satisfied or dissatisfied have you been with how closely matched your breasts are to each other [Pusic et al] [40]
How satisfied or dissatisfied have you been with how your reconstructed breast look now compared to before you had any surgery [Pusic et al] [40]
How satisfied or dissatisfied have you been with how you look in the mirror unclothed [Pusic et al] [40]

**Table 1:** Body image –related domain

In other types of cancer, HRQOL tools have been used as a trigger for discussion of patients' problems of appearance<sup>[41]</sup>. HRQOL tools can help focus the consultation and are a suitable means of screening for appearance issues<sup>[42]</sup>. In head and neck cancer the Patient Concerns Inventory [PCI] has been used with HRQOL tool and its role has been defined<sup>[43]</sup>.

The PCI enables holistic evaluation of body image concerns in the breast cancer outpatient clinic<sup>[44]</sup>. The aim of this work is to assess the role of the breast cancer specific Patient Concerns Inventory (PCI) in the identification of body image concerns in breast cancer patients and compare this against an established HRQOL such as the European Organization for Research and Treatment of Cancer breast cancer-specific quality of life questionnaire module (BR23).

## Materials and Methods

We have performed a cross-sectional survey, using the BC specific PCI with an established breast cancer HRQOL measure [EORTC C30 (European Organisation for Research and Treatment of Cancer) with BR23]. A convenience sample of 249 breast cancer patients was recruited prospectively from February to July 2012. The patients had completed their initial treatments and were attending an outpatient clinic for review. All patients were recruited by the clinical team but participants completed the questionnaires at home. Prospective study participants received a study information pack containing details about the study and the BC specific PCI. The BC specific PCI<sup>[44]</sup> has two parts and includes 55 items that are divided into six groups. In the first part the groups include general information, body image-related, physical functioning and health-related, psychological state and emotional well being, sexual functioning and social functioning / family-related. In the second part there is a list of the members of the breast cancer MDT that the patients are given the option to consult, either in the clinic or by referral. The Body image -specific domains include overall physical appearance, arm appearance, breast appearance, breast prosthesis / padding, hair loss, hair replacement (wig), mastectomy appearance, weight and wound healing (scar appearance).

Also the pack included a consent form and a reply slip. Study participants also gave consent for the chief investigator to collect social and treatment-related data from their clinical files. Approval for this study was granted by the Leeds Central Ethics Committee.

Statistical analysis was performed using SPSS version 19. the distribution of PCI body image related items (range 0-9) was analysed using the Mann-Whitney test. Patient/clinical subgroups was compared by the number of body image related items selected using the Kruskal-Wallis or Mann-Whitney test as appropriate. the association of number of PCI Body image related items with number of other PCI items selected overall or within domain and with number of health professionals selected, and with EORTC scores was assessed using Spearman rank correlation methods. In view of the multiple tests performed, statistical significance was taken as  $P < 0.01$ .

## Results

Survey responses were obtained from 80% (200/249) of participants. Response was lowest from patients aged  $\geq 75$  (63%), with primary local disease (72%), having anti-oestrogen therapy (72%), without radiotherapy (70%), and was higher after reconstructive surgery (96%). Median (IQR) age of responders was 59 (52-68) years, and the overwhelming majority were female (198), only two were male. The most recent breast cancer diagnosis was 2009/2010 for 54% (108), 2011/2012 for 31% (61), unknown 16% (31). Patients with all stages of disease were represented: 51% (101) primary local, 2% (3) local recurrent, 5% (9) metastatic and 4% (8) living with cancer (includes patients with hormonal or biological treatment as the only modality). The multimodal nature of breast cancer management was reflected in the range of treatments received by participants: 47% (93) chemotherapy, 63% (126) radiotherapy, 47% (93) wide local excision / lumpectomy, 44% (88) mastectomy, 13% (25) reconstructive surgery, 41% (82) anti-oestrogen therapy. Responders were mainly from Leeds 57% (113), or Wakefield 32% (64), and 17% (30/178) lived in one of the 20% most IMD deprived areas.

Two-thirds (68%, 136) of patients selected one or more of the nine PCI items within the Body-image-related domain, with 28% (56) selecting 1 item, 27% (54) selecting 2-3 items and 13% (26) selecting 4-8 items (Table 2). In descending order of frequency the items selected were breast appearance 30%, weight- unable to control weight 28%, mastectomy appearance 19%, overall physical appearance 17%, wound healing – scar appearance 17%, breast prosthesis/padding 15%, hair loss 14%, arm appearance 13% and hair replacement-wig 6%. Those who selected hair replacement-wig were a subset of those who selected hair-loss. Nearly half (26/56) of those selecting just one item selected weight.

**Table 2:** Body image related items selected on the PCI

Body table gives % [n] of column totals	Number of body Image related items					
	0	1	2	3	4-8	ALL
	N=64	N=56	N=37	N=17	N=26	N=200
BODY IMAGE RELATED items:						
B21 Appearance [Overall physical appearance]	0	4 [2]	22 [8]	47 [8]	62 [16]	17 [34]
B22 Arm appearance	0	5 [3]	22 [8]	29 [5]	35 [9]	13 [25]
B23 Breast appearance	0	18 [10]	43 [16]	59 [10]	88 [23]	30 [59]
B24 Breast Prosthesis / Padding	0	4 [2]	22 [8]	18 [3]	65 [17]	15 [30]
B25 Hair loss	0	7 [4]	19 [7]	24 [4]	46 [12]	14 [27]
B26 Hair replacement [wig]	0	0	3 [1]	12 [2]	31 [8]	6 [11]
B27 Weight [Unable to control my weight]	0	46 [26]	30 [11]	24 [4]	58 [15]	28 [56]
B28 Wound healing [Scar appearance]	0	9 [5]	16 [6]	47 [8]	54 [14]	17 [33]
B29 Mastectomy appearance	0	7 [4]	24 [9]	41 [7]	69 [18]	19 [38]

There was significant correlation between the number of body image related items selected and the number of PCI items selected in other PCI domains, the total number of other PCI items selected and the total number of health professionals selected (Table 3). Those selecting four or more body image related items also selected a median [IQR] of 17 (10-23) other items and there was a clear gradient in the increase in numbers of other items across the PCI and in the number of health professionals selected as the number of body image related items increased. This is reflected also in the analysis of specific PCI items (Table 4) and there were associations at  $P < 0.01$  for 37 of the 46 non-body image related items. There were associations at  $P < 0.001$  with wanting to discuss activity, arm swelling, breast texture, breast sensitivity/pain, indigestion, memory/concentration, nausea, pain in arm or shoulder, sleeping, taste, vomiting/sickness, anger, anxiety, fear of cancer spreading, mood, self-esteem, fear about the future, and with wanting to see the plastic surgeon, medical oncologist, radiation oncologist, breast care nurse, lymphoedema specialist, hair prosthesis advisor/ breast prosthesis expert and nurse practitioner.

**Table 3:** Median [IQR] and total number of items selected on the PCI, by number of body image related items selected.

Body table gives median [IQR], total number of items in other domains	N of body Image related items*			
	0	1	2-3	4-8
	N=64	N=56	N=54	N=26
General information [6 items]	0 [0-0], 19	1 [0-1], 37	1 [0-1], 48	1 [1-2], 38
Physical functioning and health-related [20 items]	2 [0-4], 155	3 [2-4], 166	5 [3-7], 279	7 [5-11], 216
Psychological state and emotional wellbeing [10 items]	1 [1-2], 101	1 [1-2], 88	3 [2-4], 159	5 [3-6], 124
Sexual functioning [3 items]	0 [0-0], 10	0 [0-0], 11	0 [0-1], 28	1 [0-1], 22
Social functioning / family related [8 items]	0 [0-0], 16	0 [0-1], 21	0 [0-2], 52	2 [1-3], 49
Total number of other PCI items [range 0-47 after excluding the 9 body image related items]	4 [2-6], 301	6 [4-7], 323	10 [5-14], 566	17 [10-23], 449
Health professionals [15 staff]	1 [1-2], 92	2 [1-3], 110	3 [2-4], 174	5 [3-6], 132

\*Spearman correlation was significant at  $P < 0.001$  between the number of body image related items [range 0-9] and the number of items in each other domain, and also with total number of other items and with the number of health professionals selected.

**Table 4:** Percentage selecting other specific PCI items and health professionals, by number of PCI body image related items selected

Body table gives % of column totals	N of body Image related items	P			
Value*					
	0	1	2-3	4-8	
	N=64	N=56	N=54	N=26	
GENERAL INFORMATION					
B11 Activity	9	29	31	54	<0.001
B12 Information about Breast Cancer [Unable to get or unable to understand]	9	14	15	38	0.005

B13 Information about personal hygiene [Maybe related to breast prosthesis/wig]	0	2	0	15	0.007
B14 Lifestyle [Smoking/ alcohol-started or unable to stop]	6	11	13	15	0.10
B15 Complementary /Homeopathic Medicines [information about]	3	11	26	23	0.001
B16 Fertility issues following treatment [information about]	2	0	4	0	0.93
PHYSICAL FUNCTIONING AND HEALTH RELATED					
B31 Appetite	8	16	19	42	0.001
B32 Arm swelling [Lymphoedema]	6	5	24	38	<0.001
B33 Diarrhoea	6	7	11	19	0.06
B34 Constipation	9	5	20	35	0.002
B35 Breast texture	0	12	20	27	<0.001
B36 Breast sensitivity /Breast pain	28	39	61	69	<0.001
B37 Cancer Treatment	16	4	22	42	0.004
B38 Sore mouth / Dry Mouth	13	13	19	42	0.004
B39 Fatigue / Tiredness [Low energy levels overall]	33	43	50	73	0.001
B310 Indigestion	3	4	20	23	<0.001
B311 Memory/ Concentration	16	23	35	50	<0.001
B312 Nausea	2	4	11	31	<0.001
B313 Pain in the Breast	17	25	37	46	0.001
B314 Pain in the arm or shoulder	17	11	35	54	<0.001
B315 Pain elsewhere	19	13	15	31	0.36
B316 Sleeping	17	21	52	62	<0.001
B317 Swallowing	0	2	4	8	0.03
B318 Taste	2	2	9	38	<0.001
B319 Vomiting / Sickness	3	2	6	31	<0.001
B320 Hot Flushes	28	46	46	69	0.001
PSYCHOLOGICAL STATE AND EMOTIONAL WELLBEING					
B41 Angry [why me?, why this treatment]	2	4	7	27	<0.001
B42 Anxiety [Related to the diagnosis or treatment]	8	13	30	50	<0.001
B43 Coping [coping with the disease, the treatment or the side effects of treatment]	16	9	28	42	0.005
B44 Depression	11	11	19	38	0.006
B45 Fear of Cancer coming back	55	57	67	81	0.02
B46 Fear of Cancer spreading	25	27	52	73	<0.001
B47 Mood	8	7	20	38	<0.001
B48 Self esteem	8	4	17	42	<0.001
B49 Temperament and personality	6	5	13	27	0.004
B410 Fear about the future	20	21	43	58	<0.001
SEXUAL FUNCTIONING					
B51 Intimacy	5	5	19	31	<0.001
B52 Relationships	3	2	17	27	<0.001
B53 Sex	8	12	17	27	0.01
SOCIAL FUNCTIONING / FAMILY RELATED					
B61 Financial issues	8	16	30	35	<0.001
B62 Home care / district nurse support	0	0	11	23	<0.001
B63 Mobility	5	2	15	19	0.008
B64 Spiritual / Religious aspects	2	2	4	4	0.38
B65 Support for my family	0	5	11	46	<0.001
B66 Worried about the future of my children	5	5	15	19	0.01
B67 Unable to go out and enjoy my family	5	4	7	19	0.04
B68 Unable to go to go to work	2	4	4	23	0.002
HEALTH PROFESSIONALS					
R1 Breast surgeon	50	41	41	58	0.99
R2 Plastic surgeon	0	2	24	38	<0.001
R3 Medical oncologist	14	23	35	54	<0.001



R4 Radiation oncologist	5	7	17	31	<0.001
R5 Breast Care Nurse	30	39	65	69	<0.001
R6 Chaplain	0	2	2	8	0.04
R7 Psychologist	13	13	26	42	0.002
R8 Dietician	9	18	15	27	0.08
R9 Lymphoedema specialist /clinic	0	9	17	23	<0.001
R10 Hair prosthesis [wig advisor] / Breast prosthesis expert	0	4	9	38	<0.001
R11 Nurse Practitioner	0	0	8	15	<0.001
R12 Pain specialist	5	7	17	31	0.001
R13 District Nurse	0	0	7	4	0.03
R14 My own doctor [General Practitioner]	11	16	15	12	0.70
R15 Complementary therapies	8	16	26	35	0.001

\*Mann-Whitney test comparing the full distribution [range 0-9] of body image related items for specific PCI items being selected Vs. not selected.

The number of body image related items was significantly associated with treatment by chemotherapy, wide local excision/lumpectomy, mastectomy and reconstructive surgery (Table 5), with an increase in items related to chemotherapy and mastectomy and reconstructive surgery and the absence of wide local excision/lumpectomy. There was also a tendency for fewer items to be selected by older patients aged 65 years and over, but no notable differences in regard to the IMD deprivation measure and time of most recent diagnosis. A fuller stratification by treatment combination is shown in Table 6.

**Table 5:** Clinical/personal characteristics and selection of PCI body image related items

Body table gives % [n] of row totals		Patients	Number of Body image related items selected				P value*
			0	1	2-3	4-8	
	ALL	200	32 [64]	28 [56]	27 [54]	13 [26]	-
Age	<55	69	28 [19]	23 [16]	36 [25]	13 [9]	0.04**
	55-64	59	25 [15]	34 [20]	24 [14]	17 [10]	
	65-74	52	42 [22]	31 [16]	15 [8]	12 [6]	
	75+	19	42 [8]	16 [3]	37 [7]	5 [1]	
Gender	Female	198	32 [64]	28 [56]	27 [53]	13 [25]	-
	Male	2	0	0	50 [1]	50 [1]	
IMD deprivation: living in area that is one of the 20% most deprived	No	148	28 [42]	30 [44]	28 [41]	14 [21]	0.38 excl NK
	Yes	30	37 [11]	27 [8]	23 [7]	13 [4]	
	Not known	22	50 [11]	18 [4]	27 [6]	5 [1]	
Year of most recent diagnosis	2009/2010	108	34 [37]	26 [28]	26 [28]	14 [15]	0.84 excl NK
	2011/2012	61	30 [18]	31 [19]	28 [17]	11 [7]	
	Not known	31	29 [9]	29 [9]	29 [9]	13 [4]	
Location	Leeds	113	29 [33]	26 [29]	31 [35]	14 [16]	0.21
	Wakefield	64	33 [21]	34 [22]	17 [11]	16 [10]	
	Other	23	43 [10]	22 [5]	35 [8]	0	
Extent of disease: Primary Local	No	99	31 [31]	24 [24]	30 [30]	14 [14]	0.48
	Yes	101	33 [33]	32 [32]	24 [24]	12 [12]	
Extent of disease: Local recurrent	No	197	32 [64]	28 [55]	27 [53]	13 [25]	-
	Yes	3	0	33 [1]	33 [1]	33 [1]	
Extent of disease: Metastatic	No	191	32 [61]	28 [54]	27 [52]	13 [24]	0.84
	Yes	9	33 [3]	22 [2]	22 [2]	22 [2]	
Extent of disease: Living with cancer	No	192	32 [61]	28 [53]	28 [53]	13 [25]	0.55
	Yes	8	38 [3]	38 [3]	13 [1]	13 [1]	
Treatment [known for 193/200]							
Chemotherapy	No	100	40 [40]	30 [30]	21 [21]	9 [9]	0.002
	Yes	93	23 [21]	28 [26]	31 [29]	18 [17]	
Radiotherapy	No	67	27 [18]	28 [19]	28 [19]	16 [11]	0.24
	Yes	126	34 [43]	29 [37]	25 [31]	12 [15]	

Wide local excision /lumpectomy	No	100	23 [23]	30 [30]	30 [30]	17 [17]	0.005
	Yes	93	41 [38]	28 [26]	22 [20]	10 [9]	
Mastectomy	No	105	44 [46]	30 [31]	22 [23]	5 [5]	<0.001
	Yes	88	17 [15]	28 [25]	31 [27]	24 [21]	
Reconstructive surgery	No	168	34 [57]	31 [52]	23 [38]	13 [21]	0.006
	Yes	25	16 [4]	16 [4]	48 [12]	20 [5]	
Anti-oestrogen therapy***	No/NK	111	32 [35]	23 [25]	28 [31]	18 [20]	0.08
	Yes	82	32 [26]	38 [31]	23 [19]	7 [6]	
Other treatment: ***	No/NK	176	31 [54]	30 [53]	27 [47]	13 [22]	0.92
	Yes	17	41 [7]	18 [3]	18 [3]	24 [4]	

\* Mann-Whitney [2 group comparison] or Kruskal-Wallis test [>2 group comparison] as appropriate using the number of body image related items selected [range 0-9]

\*\* Spearman correlation between age in years and number of body image related items [range 0-9]

\*\*\* Anti-oestrogen therapy included: tamoxifen, letrozole, anastrozole, aromasin, arimidex, exemestane;

Other treatment included :Herceptin, lepatinib, trastuzumab, neratinib.

**Table 6:** Number of body image related items by treatment

Wide local excision or lumpectomy surgery	Reconstructive surgery	Chemotherapy	Mastectomy	Number of Body image-related items				Total
				0	1	2-3	4-8	
				No	No	No	No	
No	No	No	Yes	1	6	7	4	18
No	No	Yes	No	1	4	3	-	8
No	No	Yes	Yes	10	14	7	10	41
No	Yes	No	Yes	-	2	4	-	6
No	Yes	Yes	Yes	3	2	6	3	14
Yes	No	No	No	31	19	6	2	58
Yes	No	No	Yes	-	1	1	2	4
Yes	No	Yes	No	6	6	10	3	25
Yes	No	Yes	Yes	-	-	1	-	1
Yes	Yes	No	Yes	-	-	-	1	1
Yes	Yes	Yes	No	-	-	1	-	1
Yes	Yes	Yes	Yes	1	-	1	1	3
Treatment not known			4	3	-	4	-	7

Correlations between the numbers of PCI body image related items and summary scores from the EORTC QLQ-C30 and the EORTC breast cancer QLQ-BR23 are summarised in Table 7. These correlations were generally quite weak, the strongest of these being with the QLQ-BR23 Body image score and the QLQ BR23 systemic therapy side effects score.

**Table 7:** Number of PCI Body image related items and summary scores from the EORTC QLQ-C30 and EORTC breast cancer module QLQ-BR23

EORTC	Spearman correlation*			Number of PCI body image related items			
	Correlation coefficient	P value	Patients	0	1	2-3	4-8
				Mean [SE]	Mean [SE]	Mean [SE]	Mean [SE]
C30 Physical functioning	-0.23	0.001	199	85.3 [2.4]	81.3 [2.7]	77.5 [3.2]	76.8 [3.5]
C30 Role functioning	-0.18	0.01	200	82.6 [3.0]	77.1 [3.9]	70.7 [4.2]	69.9 [6.0]
C30 Emotional functioning	-0.13	0.08	195	73.8 [2.8]	75.3 [2.7]	66.2 [3.5]	62.7 [6.0]
C30 Cognitive functioning	-0.25	<0.001	196	84.1 [2.5]	77.8 [3.2]	65.4 [3.8]	69.2 [6.2]
C30 Social functioning	-0.25	<0.001	195	86.6 [2.9]	76.2 [3.7]	70.1 [3.9]	70.5 [6.2]
C30 Fatigue	0.29	<0.001	200	22.6 [3.1]	32.1 [2.7]	38.5 [3.3]	41.0 [5.5]
C30 Nausea and vomiting	0.18	0.01	200	3.4 [1.0]	5.4 [2.1]	10.2 [2.4]	11.5 [4.4]
C30 Pain	0.17	0.02	199	19.3 [2.6]	23.3 [3.4]	34.3 [4.4]	30.8 [6.0]
C30 Global health status / QOL	-0.06	0.39	196	67.2 [2.6]	66.2 [2.5]	61.7 [3.1]	63.5 [4.6]
C30 Dyspnoea	0.22	0.002	200	9.4 [2.6]	16.7 [3.3]	14.2 [3.2]	26.9 [5.2]
C30 Insomnia	0.26	<0.001	200	22.9 [3.3]	37.5 [4.7]	54.3 [4.9]	37.2 [7.0]

C30 Appetite loss	0.09	0.23	200	8.9 [2.7]	8.9 [2.8]	18.5 [4.3]	10.3 [4.8]
C30 Constipation	0.11	0.13	200	14.6 [3.4]	13.1 [2.9]	17.9 [3.7]	19.2 [5.0]
C30 Diarrhoea	0.22	0.002	193	2.8 [1.4]	8.6 [3.2]	10.7 [2.8]	14.1 [5.3]
C30 Financial difficulties	0.15	0.03	196	12.0 [3.0]	15.8 [3.4]	25.3 [4.4]	21.8 [7.1]
BR23 Body image	-0.34	<0.001	195	78.8 [3.3]	74.4 [3.3]	53.8 [4.4]	60.3 [5.5]
BR23 Sexual functioning	-0.01	0.87	177	21.5 [3.2]	15.4 [2.4]	18.8 [3.2]	24.3 [5.9]
BR23 Sexual enjoyment	-0.05	0.69	68	57.3 [5.3]	47.1 [5.8]	47.1 [7.6]	59.3 [10.8]
BR23 Future perspective	0.01	0.95	195	41.9 [4.1]	51.2 [4.5]	43.4 [4.7]	42.3 [6.6]
BR23 Systemic therapy side effects	0.32	<0.001	197	14.0 [1.6]	18.7 [1.7]	23.8 [2.2]	30.8 [4.8]
BR23 Breast symptoms	0.19	0.007	197	15.8 [1.9]	20.9 [2.4]	29.6 [3.2]	21.5 [3.8]
BR23 Arm symptoms	0.26	<0.001	197	13.1 [2.0]	16.9 [2.4]	23.5 [3.8]	32.9 [5.5]
BR23 Upset by hair loss	0.41	0.001	62	15.8 [5.3]	64.4 [10.0]	62.2 [9.1]	56.4 [8.8]

\* Spearman correlation coefficient between the number of PCI Body image related items selected [range 0-9] and the EORTC scores  
 SE: Standard Error of mean

## Discussion

To our knowledge this is the first study in which the BR23 questionnaire and the PCI have been used in combination to screen for body image problems in patients with breast cancer. Although several important points have been raised we must recognise that there are limitations to this study. The study involved a limited number of patients from one area in the United Kingdom, and the results may reflect the beliefs and practice of this group. The present study is limited by the cross-sectional nature of the data. More longitudinal studies need to focus on body image and need to examine whether body image state will eventually return to values similar to those before the breast cancer diagnosis. Body image should not be seen in isolation. There is a need to examine any possible associations with sexual function and quality of life. In this study there were weak correlations between the number of PCI body image items and the EORTC tool. A limitation of this study is that a specific body image scale would have been appropriate<sup>[4]</sup>. Items such as change in self-consciousness with appearance, less sexually attractive, less feminine, dissatisfaction with appearance when dressed, body feeling less whole that are present in the QOL BR23 were not assessed in our study.

The body can be viewed as a symbol of social expression<sup>[45]</sup>. Breast cancer diagnosis and treatment can result in a sustained disturbance of that view at 12 months post -diagnosis and beyond<sup>[46]</sup>. This is reflected in this study since 54% of patients had their diagnosis at least two years ago. Body image is clearly an issue since 68% of patients selected an item from the body-image domain. In this study the number of body image related items was significantly associated with chemotherapy and mastectomy and reconstructive surgery. Some studies showed that chemotherapy, hormonal therapy and radiotherapy did not have a negative effect on body image<sup>[47]</sup>. The findings from this study are consistent with , Schover et al.<sup>[48]</sup> who concluded that chemotherapy did have a negative impact on body image, while hormonal and radiation therapy did not. Breast appearance was the item most frequently selected followed by weight and mastectomy appearance. This is not unexpected since the physical effects of cancer on the body is a personal reminder of the disease but in addition is an 'announcement' to others<sup>[49]</sup>. Yurek et al.<sup>[50]</sup> reported that those patients who underwent a lumpectomy faced less body change stress than women with a modified radical mastectomy with breast reconstruction or just a modified radical mastectomy.

In this work only 14% of patients selected hair loss. This may seem low at first instance. This may be explained, because most patients in this study did complete the PCI several months after their chemotherapy when their hair were almost back to the pre-treatment state.

As it can be seen on table 3 those patients selecting body image related items selected a median of 17 other items. The effect of breast cancer on body image should not be under-estimated, and this is reflected by others. Fallow field et al.<sup>[51]</sup> found that the incidence of anxiety and/or depression was as high as 38% in patients with a surgical intervention. Age seem to have a negative correlation with the items detected.

In this study fewer times were selected by older patients and this is consistent with other published work. Al-Ghazal et al.<sup>[52]</sup> compared the psychological outcome and satisfaction of patients whom underwent wide local excision, mastectomy alone and mastectomy with breast reconstruction. This study reported that women of different ages face body image issues after breast cancer surgery, with women between 40 and 59 years of age appearing to have the greatest body image issues after breast cancer surgery.

The head and neck PCI has been used before as a tool to identify appearance-related concerns<sup>[53]</sup>. Appearance was raised on the PCI at 9% (42/454) of clinics, and at 10% (47/454) it was indicated as a serious problem on the UW-QoL questionnaire. Concerns about appearance were raised on the inventory or were shown to be a serious problem on the UW-QoL in 14% (64/454) of patients. Comparison with that work requires caution since appearance was related to face, involved male patients and patients with



different socio-economic characteristics.

The routine use of the PCI in breast cancer patients could facilitate a holistic approach to management. It can identify the need for interventions; this can have a bearing in resource allocation and can provide a direction for future research. It is recommended however that the instrument regarding body image be completed before and after treatment as many women have a distorted self image preceding therapy and then adaptive therapeutic intervention could then be applied. The role of interventions such as body beauty treatments to body image<sup>[54]</sup> and exercise need<sup>[55]</sup> in breast cancer patients needs to be evaluated further.

## Conclusions

More research is essential in order to evaluate further the role of the breast cancer specific PCI in the identification of body image issues. A larger patient cohort and a longitudinal approach with qualitative input with a link to possible interventions will give more details around body image concerns and would facilitate successful management.

The breast cancer specific PCI can empower women to engage in an honest conversation about their cancer related body image issues. It can be used as a screening tool for body image as well as for a range of other issues in order to identify a subgroup of patients that would benefit from focus interventions.

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