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Validation of a measurement tool to assess awareness of breast cancer

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ABSTRACT

Aim: Until now, there has been no universally accepted and validated measure of breast cancer awareness. This study aimed to validate the new Breast Cancer Awareness Measure (BCAM) which assesses, using a self-complete questionnaire, knowledge of breast cancer symptoms and age-related risk, and frequency of breast checking.

Methods: We measured the psychometric properties of the BCAM in 1035 women attending the NHS Breast Screening Programme: acceptability was assessed using a feedback questionnaire ($n = 292$); sensitivity to change after an intervention promoting breast cancer awareness ($n = 576$), and test–retest reliability ($n = 167$). We also assessed readability, and construct validity using the 'known-groups' method.

Results: The readability of the BCAM was high. Over 90% of women found it acceptable. The BCAM was sensitive to change: there was an increase in the proportion of women obtaining the full score for breast cancer awareness one month after receiving the intervention promoting breast cancer awareness; this was greater among those who received a more intensive version (less intensive version (booklet): 9.3%, 95% confidence interval (CI): 4.5–14.1%; more intensive version (interaction with health professional plus booklet): 30%, 95% CI: 23.4–36.6%). Test–retest reliability of the BCAM was moderate to good for most items. Cancer experts had higher levels of cancer awareness than non-medical academics (50% versus 6%, $p = 0.001$), indicating good construct validity.

Conclusions: The BCAM is a valid and robust measure of breast cancer awareness suitable for use in surveys of breast cancer awareness in the general population and to evaluate the impact of awareness-raising interventions.

1. Introduction

Breast cancer is the most common cancer among women in the United Kingdom (UK); over 45,000 women are diagnosed with breast cancer each year.[1] In 2007, breast cancer caused nearly 12,000 deaths in British women.[2] Women with breast cancer in the UK tend to present with more advanced disease and have poorer survival rates than their European counterparts.[3]

Delays in diagnosis are associated with poorer survival in breast cancer[4] and may be responsible for worse survival rates in the UK than other parts of Europe.[5] Delayed diagnosis is likely to be due, at least partly, to low breast cancer awareness; certainly low awareness of the early warning signs of

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breast cancer is a risk factor for delayed presentation.[6] Women belonging to populations most likely to have delayed diagnosis of breast cancer also have lower cancer awareness, including older women, women of lower socioeconomic status and black women.[7–9] Research in the UK has consistently shown low public awareness of the early warning signs of breast cancer and limited knowledge of the risk factors,[7,10–13] particularly among older women.[8]

In recognition of the likely contribution of low cancer awareness to poor survival rates, there is a drive to improve and standardise the measurement of cancer awareness in the UK, supported by the Cancer Reform Strategy.[14] Standardised, valid measurement is essential for monitoring levels of cancer awareness, examining its risk factors and consequences, and evaluating interventions to promote it. The Cancer Research UK Cancer Awareness Measure, which uses a face-to-face interview technique, has been designed and used to assess levels of cancer awareness in Britain recently,[15,16] but it does not focus on awareness of particular cancers.

We have developed a measure of breast cancer awareness (the Breast Cancer Awareness Measure (BCAM)) which can be self-completed using a questionnaire in a few minutes. It consists of the three items relating to: knowledge of breast cancer symptoms, knowledge of age-related risk and reported frequency of breast checking (Appendix 1 provides details of the questions and response categories). We report the results from a series of studies evaluating the psychometric properties of the BCAM.

2. Materials and methods

2.1. Generating items

We developed a pool of possible questionnaire items based on a review of the literature on the existing breast cancer awareness measures, a review of the 'grey' literature (i.e. unpublished surveys carried out by cancer charities and other organisations) and our experience during previous research with breast cancer patients.[7] Following the rationale that the main purpose of increasing breast cancer awareness is to reduce delay in presentation in the event of developing symptoms, we decided to include items relating to the minimum awareness women need to be able present promptly: what to look for (the range of symptoms), why to look for symptoms (magnitude of risk), and the minimum skills (how to look for symptoms and signs). Possible items were excluded from the pool if they were poorly worded or employed terminology not frequently used in the UK. In addition, we generated several items specifically for the instrument that had not been used in previous questionnaires. Once we reached consensus over the generated items, we circulated a first version of the BCAM to a panel of experts including academic researchers, cancer charity representatives, oncologists and experts in the field of questionnaire design. We then carried out cognitive interviews based on the BCAM in 20 older women known to the researchers. As a result, we identified ambiguous, upsetting or difficult-to-understand items and refined the phrasing.

2.2. Piloting the BCAM

We piloted the BCAM with 82 women aged 67–70 attending for their final breast screening appointment on the National Health Service (NHS) Breast Screening Programme and experimented with different formats of the items. For the knowledge of symptoms item, we tested closed versus open formats (recall versus recognition), presented a scattered list of breast cancer symptoms (versus a straight list), and included dummy symptoms. We also tested various graphical and text presentations for the items measuring women's understanding of the risk of developing breast cancer and the increase in risk with age. We used the next version of the BCAM, which closely resembles the current version, in a national UK survey of 712 women aged 67–73 and used these data to assess readability, acceptability and test–retest reliability.[8,17]

The final version of the BCAM consists of the three items relating to: knowledge of breast cancer symptoms, knowledge of age-related risk and reported frequency of breast checking (Appendix 1). We considered a woman to be aware of breast cancer if she identified five or more non-lump symptoms from the list of nine provided; identified that a 70-year old woman was most likely to get breast cancer in the next year compared to a younger woman or a woman of any age; and reported checking her breasts at least once a week or once a month. We used the current version of the BCAM as an outcome measure in a randomised controlled trial of an intervention to raise breast cancer awareness and promote early symptomatic presentation in older women.[18]

2.3. Validating the BCAM

We evaluated the psychometric properties of the BCAM in three samples of women (total $n = 1035$) attending the NHS Breast Screening Programme in South East London. All statistical analyses were conducted using Stata statistical software (version 10).

2.4. Readability

We calculated the readability score of the BCAM using the Flesch Reading Ease formula,[19] which ranges from 1 to 100, using Microsoft Word 2003 Professional Edition. A higher score indicates easier reading and a score of 60–70 is considered the normal range of readability.

2.5. Acceptability

Acceptability was assessed in 292 women aged 67–73 in the NHS Breast Screening Programme in South East London who were participating in a preliminary evaluation of an intervention to increase breast cancer awareness and early symptomatic presentation among older women.[20] They were asked to complete an 18 item questionnaire including the three items of the BCAM before and after receiving the intervention. An additional section at the end of the baseline questionnaire asked the women if any of the questions were difficult-to-understand or upsetting, how long it took them to complete, and whether they had any comments about

the look of the questionnaire items, for example, the size of the writing or the layout.

2.6. Sensitivity to change

Sensitivity to change of the BCAM was assessed in 576 women aged 67–73 participating in a randomised controlled trial of two versions of the intervention aimed at older women (10-min interaction with a health professional supported by a booklet versus booklet alone).[18] We evaluated the sensitivity of the BCAM to detect an increase in breast cancer awareness before and one month after receiving either version of the intervention; it should be greatest among those receiving the interaction plus booklet, as this is likely to be more potent compared to the booklet alone. We calculated the increase in the percentage of women who were breast cancer aware at one month compared to baseline for each version of the intervention and present 95% confidence intervals.

2.7. Test–retest reliability

To test the extent to which the measure was repeatable, we recruited 167 women aged 50 and above attending for a routine mammogram in two breast screening units in South East London. The women were asked to complete the BCAM questionnaire at the screening unit on the day of their appointment prior to being screened, and were sent a follow-up questionnaire two weeks later. Test–retest reliability was assessed separately for each item using the unweighted kappa statistic. We also calculated the proportion of exact agreements as the kappa statistic can sometimes be misleading if there is a large proportion of responses in one particular category, or a large number of categories.

2.8. Construct validity

The degree to which the items measure the construct of breast cancer awareness was assessed using the 'known-groups' method.[21] The validity of the measure is supported if the scores of two groups known to differ in levels of cancer awareness are significantly different in the expected direction. We posted the BCAM questionnaire to 30 female cancer specialists and 66 female non-medical senior academics and compared their responses. We tested the difference in the proportion responding correctly between groups using Fisher's Exact Test.

3. Results

3.1. Readability

The Flesch Reading Ease score for the BCAM was 87.9, indicating that the measure is easier to read than standard adult reading material.

3.2. Acceptability

The sociodemographic characteristics of the 292 women taking part in assessment of acceptability of the BCAM are shown in Table 1. Half the women belonged to non-white ethnic groups and many women lived in more deprived areas than the English average (Index of Multiple Deprivation median 38; English median 17).

Eighty seven percent (253/292) answered the questionnaire feedback questions: 231 (91%) found the questions easy to understand, and 244 (96%) reported that they did not find the questions upsetting. Twenty two (9%) women had

Table 1 – Socio-demographic characteristics of the three samples of women (n = 1035) recruited in the NHS Breast Screening Programme and participating in validation studies of the Breast Cancer Awareness Measure.

	Acceptability sample (n = 292)	Sensitivity to change sample (n = 576)		Test–retest reliability sample (n = 167)
		Booklet (n = 292)	Interaction plus booklet (n = 284)	
Age at attendance for mammogram, median (range)	68 (66–71)	68 (66–71)	68 (66–71)	53 (43–82)
Relationship status, n (%)				
Married or cohabiting	121 (44)	151 (53)	174 (62)	120 (73)
Widowed	63 (23)	61 (22)	50 (18)	11 (7)
Single	45 (16)	28 (10)	17 (6)	17(10)
Divorced or separated	48 (17)	43 (15)	41 (15)	17 (10)
Education, n (%)				
None	142 (59)	109 (41)	116 (44)	31 (19)
O level or school certificate	41 (17)	81 (30)	77 (29)	63 (39)
A level or higher school certificate	23 (10)	31 (12)	29 (11)	31 (19)
Degree or above	35 (15)	48 (18)	41 (16)	36 (23)
Ethnic group, n (%)				
White British	140 (51)	196 (69)	186 (66)	143 (87)
Other ethnic group	137 (49)	88 (31)	94 (34)	22 (13)
Index of multiple deprivation, median (range)				
0 (least deprived) to 100 (most deprived)	38 (12–54)	17 (2–54)	18 (2–54)	9 (2–45)

additional comments about the look of the questionnaire items, most of which were positive.

3.3. Distribution of responses to the BCAM and individual BCAM items in a sample of older women

Table 1 shows the sociodemographic characteristics of the 576 women who received the BCAM before and after receiving an intervention to raise breast cancer awareness and promote early symptomatic presentation as part of a randomised controlled trial. Just over 30% belonged to non-white ethnic groups, and their median Index of Multiple Deprivation of area of residence was similar to the English median. At recruitment, 566 (98%) answered the question about breast cancer symptoms, 558 (97%) answered the question about age-related risk, and 572 (99%) answered the question about frequency of breast checking. We were able to calculate a breast cancer awareness score for 547 (95%) women who completed all three questions.

Table 2 shows how these women responded to the individual questions prior to receiving the intervention. Most of the women recognised lumps in the breast or armpit as being warning signs of breast cancer but few recognised nipple rash and redness of skin as possible symptoms. Nearly 90% of women did not know that a 70-year old woman was at greatest risk of breast cancer; most thought that the risk did not vary by age. Around half of women reported checking their breasts at least once a month, but around one quarter reported rarely or never checking their breasts.

Among the 547 women completing all three questions for the breast cancer awareness measure, only 13 (2%) gave answers indicating breast cancer awareness by answering all three questions appropriately prior to receiving the intervention. One hundred and fifty (27%) achieved a score of 2, 239 (44%) achieved a score of 1 and 145 (27%) achieved a score of 0. Of the 150 women who achieved a score of 2, 16 answered both the symptoms and the age-related risk question appropriately, 118 answered both the symptoms and breast-checking question appropriately, and 16 answered both the age-related risk and breast-checking question appropriately. Of the 239 women who achieved a score of 1, 90 answered only the symptoms question appropriately, 19 answered only the age-related risk question appropriately, and 130 reported only the breast-checking question appropriately.

3.4. Sensitivity to change

In the randomised controlled trial of the intervention to raise cancer awareness and promote symptomatic presentation, 508 (88%) women responded to the BCAM questionnaire at one month. Four hundred and sixty six (92%) of these gave answers to all three questions. The level of missing data for the three component items was low: 6% for knowledge of symptoms; 6% for knowledge of age-related risk and 1% for breast checking.

Both the interaction plus booklet and the booklet alone significantly increased the proportion of women answering all three questions appropriately, and all the individual questions appropriately, after one month (Table 3). The increase was greatest in women who received the interaction plus booklet followed by those who received the booklet alone.

3.5. Test–retest reliability

Table 1 shows the sociodemographic characteristics of the women who took part in the test–retest reliability study. These women lived in less deprived areas that the English median. Thirteen per cent belonged to non-white ethnic groups. One hundred and twenty seven of the 167 women (76%) who completed the first questionnaire responded to the second questionnaire. Results of the analyses of test–retest reliability of the BCAM are shown in Table 4. Most of the kappa statistics were in the range moderate to good

Table 2 – Distribution of responses to the Breast Cancer Awareness Measure at recruitment in the randomised controlled trial.

Question	Response	Number (%)
Breast cancer symptoms (n = 566)	Change in nipple position	282 (50)
	Pulling in of nipple	255 (45)
	Pain in breast/armpit	322 (57)
	Puckering/dimpling	253 (45)
	Discharge from nipple	356 (63)
	Lump in breast	465 (82)
	Nipple rash	77 (14)
	Redness of skin	103 (18)
	Lump under armpit	402 (71)
	Change in size	250 (44)
	Change in shape	323 (57)
Age-related risk (n = 558)	A 30 year old woman	29 (5)
	A 50 year old woman	114 (20)
	A 70 year old woman	64 (11)
	A woman of any age	351 (63)
Breast checking (n = 572)	At least once a week	88 (15)
	At least once a month	205 (36)
	At least once every six months	129 (23)
	Rarely or never	150 (26)

Table 3 – Sensitivity to change of the Breast Cancer Awareness Measure.

		n	Baseline	One month	Difference in percentages (95% confidence interval)
Breast cancer awareness (% of women who were breast cancer aware[a])	Booklet	226	2.7	11.9	9.3 (4.5–14.1)
	Interaction	220	1.8	31.8	30.0 (23.4–36.6)
Knowledge of breast cancer symptoms (% of women identifying more than five non-lump symptoms)	Booklet	242	45.0	62.0	16.9 (9.8–24.0)
	Interaction	235	46.0	78.7	32.8 (25.9–39.6)
Knowledge of age-related risk (% of women identifying a 70 year old woman as most likely to get breast cancer)	Booklet	243	12.3	24.7	12.3 (6.0–18.7)
	Interaction	237	9.7	43.9	34.2 (27.1–41.3)
Breast checking (% of women reporting breast checking at least once a month)	Booklet	254	47.2	61.4	14.2 (8.3–20.1)
	Interaction	247	53.8	77.7	23.9 (17.5–30.3)

[a] We considered a woman to be breast cancer aware if she circled five or more non-lump symptoms; answered 'A 70 year old woman' to the question about age-related risk; and either 'Once a month' or 'Once a week' to the question about frequency of breast checking.

Table 4 – Test–retest reliability of the Breast Cancer Awareness Measure.

	Kappa statistic (sd)	% of exact agreements
Breast cancer awareness total score (score 0–3)	0.44 (0.06)	64
Knowledge of breast cancer symptoms		
Can identify more than five non-lump symptoms (yes/no)	0.56 (0.09)	78
Know if the following are warning signs: (yes/no)		
Change in nipple position	0.56 (0.09)	78
Pulling in of nipple	0.58 (0.09)	79
Pain in breast/armpit	0.42 (0.09)	71
Puckering/dimpling	0.67 (0.09)	84
Discharge from nipple	0.68 (0.09)	87
Lump in breast	0.28 (0.09)	90
Nipple rash	0.49 (0.08)	87
Redness of skin	0.42 (0.08)	84
Lump under armpit	0.47 (0.09)	82
Change in size	0.45 (0.09)	72
Change in shape	0.45 (0.09)	75
Knowledge of age-related risk (A 30 year old/50 year old/70 year old woman/a woman of any age)	0.61 (0.07)	79
Breast checking (Rarely or never/at least every six months/once a month/once a week)	0.70 (0.05)	79

(0.42–0.70). For the item which asks if a lump in the breast is a warning sign of breast cancer kappa was less than moderate (0.28), but this was due to a large proportion of women responding 'yes' in the first and second questionnaire; the percentage agreement between the two questionnaires was very high (90%) for this item.

3.6. *Construct validity*

Eighteen of the thirty cancer specialists (60%) and 33 of the 66 non-medical academics (50%) responded to the postal questionnaire. The age distribution of the cancer consultants was: 41% aged 35–44 years; 47% aged 45–54 years and 12% aged over 55 years. The non-medical academics were older: 45% aged 35–44 years; 6% aged 45–54 years and 48% aged over 55 years.

There was clear discrimination between the group of cancer specialists and non-medical academics in the knowledge of breast cancer symptoms ($p < 0.001$) and age-related risk ($p < 0.001$) (Table 5). The cancer specialists were more able to identify the breast cancer symptoms in the list provided; the only symptoms where there were no significant differences in symptom knowledge were for the two lump symptoms and pain in the breasts or armpit. Although a greater proportion of cancer specialists reported checking their breasts regularly, there was only a marginal statistical difference between the two groups ($p = 0.08$).

To explore whether the age difference between the cancer specialists and non-medical academics was a possible explanation for the difference we found in breast cancer awareness, we examined the responses of the oldest and youngest age group among the non-medical academics. Sparse data did not permit a full age-stratified analysis and only two non-medical academics were in the middle age group, hence this group was omitted. For every item (except for the pain in breast symptom), the non-medical academics aged over 55 years scored more highly than those aged 35–44 years. This implies that the differences between the two groups of experts in this sample would have been even greater if the non-medical academics had the same age distribution as the cancer experts.

4. Discussion

This series of studies demonstrated that the BCAM, which is quick and simple to complete, is a valid and acceptable

Table 5 – Construct validity of the Breast Cancer Awareness Measure.

	Cancer specialists (n = 18)	Non-medical academics (n = 33)	p-Value
Breast cancer awareness			
Number (%) breast cancer aware[a]	9 (50)	2 (6)	0.001
Knowledge of breast cancer symptoms			
Number (%) identifying more than five non-lump symptoms	17 (94)	11 (33)	<0.001
Know if the following are warning signs			
Change in nipple position	17 (94)	13 (39)	<0.001
Pulling in of nipple	18 (100)	11 (33)	<0.001
Pain in breast/armpit	6 (33)	16 (48)	0.38
Puckering/dimpling	18 (100)	16 (48)	<0.001
Discharge from nipple	17 (94)	17 (52)	0.002
Lump in breast	18 (100)	31 (94)	0.53
Nipple rash	13 (72)	3 (9)	<0.001
Redness of skin	12 (67)	5 (15)	<0.001
Lump under armpit	18 (100)	29 (88)	0.28
Change in size	16 (89)	16 (48)	0.006
Change in shape	17 (94)	18 (55)	0.004
Knowledge of age-related risk			
Number (%) identifying a 70 year old woman as most likely to get breast cancer	17 (94)	10 (30)	<0.001
Breast checking			
Number (%) reporting breast checking at least once a month	11 (61)	11 (33)	0.08

[a] We considered a woman to be breast cancer aware if she circled five or more non-lump symptoms; answered 'A 70 year old woman' to the question about age-related risk; and either 'Once a month' or 'Once a week' to the question about frequency of breast checking.

measure of breast cancer awareness, and achieves high response rates, even in populations of older women.

The BCAM showed sensitivity to change following a psycho-educational intervention. In addition, the change was greater in the more intensive version of the intervention. The only individual breast symptoms that were not sensitive to change were the two lump symptoms; most women recognised these as symptoms prior to receiving the intervention, providing less scope for change. For this reason, we only include knowledge of non-lump symptoms to measure breast cancer symptom awareness; however, we believe it is important to retain the lump symptoms in the list of symptoms in the questionnaire as their absence might convey a misleading message.

Test–retest reliability of the BCAM was moderate to good and the percentage of exact agreements was high for most of the items; discrepancies were mainly due to an improvement in score in the second questionnaire. This is most likely due to a 'mere measurement' effect; simply completing questionnaire items may increase knowledge and change behaviour.[22]

The BCAM discriminated well between a group of cancer experts and non-experts with similar levels of education; knowledge of non-lump symptoms, age-related risk and breast checking were all greater in the expert group. The only symptoms where they did not differ were the two lump symptoms as these are symptoms which women are generally already highly aware of, and pain in the breasts or armpit, which is likely to reflect the cancer experts' knowledge that this is a very common symptom in benign disease. The non-experts were older than the cancer experts which may have accounted for the differences between groups, however, we found the oldest non-medical experts scored consistently more highly than their younger counterparts, hence we might have expected greater discriminatory power had the age distribution in the two groups been similar.

Breast cancer awareness was very low in the women participating in the validation studies. Most of this was due to lack of knowledge of the increase in risk of breast cancer with age, which may reflect frequent media reporting about younger women with breast cancer.

We have validated the BCAM in a population of older women who were ethnically and socioeconomically diverse compared to the general UK population. These women completed the questions with ease, suggesting that it is suitable for use in non-white women and those of lower socioeconomic status. We also anticipate that it would work well among a younger population of adult women.

In conclusion, we have demonstrated that the BCAM is a reliable and valid measure of breast cancer awareness, and is easy to complete. We recommend its use in the evaluation of interventions to increase breast cancer awareness, in surveys to establish and monitor levels of breast cancer awareness and in studies examining risk factors and consequences of different levels of breast cancer awareness. The format could also be adapted for other cancers. In future, we plan to broaden the concept and measurement of breast cancer awareness to include health beliefs, and the motivation, confidence and skills to check breasts and to seek help promptly in the event of symptom discovery, adding additional domains to the current BCAM. Broadening the concept in this way will allow us to develop a

measure that will go beyond 'awareness' alone and may be better predictor of early presentation of symptomatic breast cancer.

Ethics approval

King's College Hospital Research Ethics Committee 2007 (Ref No: 05/Q0703/51).

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Conflict of interest statement

None declared.

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Appendix 1. The Breast Cancer Awareness Measure

1. Do you know any of the warning signs of breast cancer?

Yes ☐ No ☐

If yes, please circle the signs you know below:

Change in the position of your nipple

Pulling in of your nipple

Pain in one of your breasts or armpit

Puckering or dimpling of your breast skin

Discharge or bleeding from your nipple

A lump or thickening in your breast

Nipple rash

Redness of your breast skin

A lump or thickening under your armpit

Changes in the size of your breast or nipple

Changes in the shape of your breast or nipple

2. In the next year, who is most likely to get breast cancer? Please tick one answer only

A 30 year old woman ☐
A 50 year old woman ☐
A 70 year old woman ☐
A woman of any age ☐

3. How often do you check your breasts?

Rarely or never ☐ At least once a month ☐
At least once every 6 months ☐ At least once a week ☐

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