

# Are depressive symptoms more common among British South Asian patients compared with British White patients with cancer? A cross-sectional survey

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## ABSTRACT

**Objectives:** This cross-sectional survey investigated whether there were ethnic differences in depressive symptoms among British South Asian (BSA) patients with cancer compared with British White (BW) patients during 9 months following presentation at a UK Cancer Centre. We examined associations between depressed mood, coping strategies and the burden of symptoms.

**Design:** Questionnaires were administered to 94 BSA and 185 BW recently diagnosed patients with cancer at baseline and at 3 and 9 months. In total, 53.8% of the BSA samples were born in the Indian subcontinent, 33% in Africa and 12.9% in the UK. Three screening tools for depression were used to counter concerns about ethnic bias and validity in linguistic translation. The Hospital Anxiety and Depression Scale (HADS-D), Patient Health Questionnaire-9 (both validated in Gujarati), Emotion Thermometers (including the Distress Thermometer (DT), Mini-MAC and the newly developed Cancer Insight and Denial questionnaire (CIDQ) were completed.

**Setting:** Leicestershire Cancer Centre, UK.

**Participants:** 94 BSA and 185 BW recently diagnosed patients with cancer.

**Results:** BSA self-reported significantly higher rates of depressive symptoms compared with BW patients longitudinally (HADS-D  $\geq 8$ : baseline: BSA 35.1% vs BW 16.8%,  $p=0.001$ ; 3 months BSA 45.6% vs BW 20.8%,  $p=0.001$ ; 9 months BSA 40.6% vs BW 15.3%,  $p=0.004$ ). BSA patients used potentially maladaptive coping strategies more frequently than BW patients at baseline (hopelessness/helplessness  $p=0.005$ , fatalism  $p=0.0005$ , avoidance  $p=0.005$ ; the CIDQ denial statement 'I do not really believe I have cancer'  $p=0.0005$ ). BSA patients experienced more physical symptoms (DT checklist), which correlated with ethnic differences in depressive symptoms especially at 3 months.

**Conclusions:** Health professionals need to be aware of a greater probability of depressive symptomatology (including somatic symptoms) and how this may present clinically in the first 9 months after diagnosis if this ethnic disparity in mental well-being is to be addressed.

## ARTICLE SUMMARY

### Article focus

- We investigated whether there were differences in depressive symptoms among British South Asian (BSA) patients with cancer compared with British White (BW) patients over a 9-month period.
- To limit cultural bias, we used multiple questionnaires including the Hospital Anxiety and Depression Scale and a version of the Patient Health Questionnaire-9 developed for India.
- We considered how coping strategies were used and whether physical symptoms affected mood.

### Key messages

- BSA patients had twice the self-reported rate of depressive symptoms as BW patients and five times the incidence of severe depression.
- Differences persist for 9 months after baseline assessment.
- BSA patients used potentially maladaptive coping strategies far more than BW patients did at baseline assessment.
- BSA patients appear to experience a heavier physical symptom burden than BW patients.

## INTRODUCTION

Depression is one of the strongest determinants of health-related quality of life and it can influence medical care and participation in treatment.<sup>1 2</sup> It may also be linked with other serious outcomes including mortality.<sup>3</sup> The point prevalence of major depression at any time in the first 2 years following a cancer diagnosis is 14.9% by DSMIV criteria.<sup>4</sup> This is 2–4 times that observed in the general population using equivalent criteria.<sup>5</sup> An under-researched area is the incidence of depression in ethnic minority patients. Some research suggests that UK ethnic minorities may be more vulnerable to mental illness within the general population than the majority host population,<sup>6</sup> leaving the largely

ARTICLE SUMMARY

Strengths and limitations of this study

- This is the first comparison of how BSA and BW patients cope with cancer.
- We have used multiple assessment tools.
- We have demonstrated highly statistically significant differences in the rate of depressive symptoms between the two groups and marked differences in coping style.
- BSA clinical staff were involved in the study. In spite of this, we had difficulty recruiting and retaining BSA patients, especially by 9 months.
- Any variations in mood, which may have occurred between the three data collection points, are not represented.
- It is most likely that the rates of depressive symptoms are under-reported since anecdotally those who were most distressed often did not feel able to participate in this study.
- Self-reported questionnaires indicate the presence of depressive symptoms, but given the absence of psychiatric interviews, this is not diagnostic of a depressive disorder.

unproven impression that they also suffer more distress when diagnosed with cancer. However, ethnic minorities may be less likely to receive high quality care.<sup>7 8</sup> Inequalities in access to care, receipt of treatment and mortality are particularly striking among ethnic minorities, the elderly and those with mental ill health in both the UK<sup>9-11</sup> and the USA,<sup>12-14</sup> where it is a governmental aspiration to remove such disparities.

People originating from the Indian subcontinent account for the largest ethnic minority group in England and Wales (total population 56.1 million). Specifically those classified as Indian are in the majority accounting for 1 412 958, followed by Pakistanis 1 124 511 and Bangladeshis 447 201.<sup>15</sup> Most of the Indians born in Africa either sought sanctuary from or were expelled by leaders such as Idi Amin in East African states.

The city of Leicester has one of the highest concentrations of this population (total population 329 836: Indian 93 000, Pakistani 8000, Bangladeshi 3600), which contrasts with the surrounding county (total population 650 489: Indian 54 000, Pakistani 2100, Bangladeshi 2300).<sup>15</sup> We define 'British South Asian (BSA)' as a person whose ancestry originates in the Indian subcontinent, and who identifies with, or is identified with, their host country.<sup>16</sup> A previous pilot study showed a significantly higher incidence in symptoms of depression among BSA patients in Leicester and the local county compared with British White (BW) patients via the Hospital Anxiety and Depression Scale (HADS-D)  $\geq 10$  (BSA 20.7%; BW 10.4%  $p=0.001$ ).<sup>17</sup> Depressive symptoms were associated with potentially maladaptive coping strategies among both ethnic groups but were employed statistically significantly more frequently by BSA patients. For example, fatalism  $p=0.0001$ ; denial  $p=0.019$ ; hopelessness and helplessness,  $p=0.007$ .

The findings of our pilot study<sup>17</sup> were consistent with the few publications reporting the incidence of

depression or distress in ethnic minority patients with cancer. The largest is a meta-analysis of 21 papers which found that US Hispanic patients were significantly more distressed ( $p=0.0001$ ) and depressed ( $p=0.04$ ) than the majority population.<sup>18</sup>

Similar findings were reported from Canada with more distress among ethnic minorities (E and SE Asia, South Asian, First Nation) compared with the majority population (European, Canadian, British  $p=0.0001$ ). Greater distress was also found among those with lower income ( $p=0.001$ ).<sup>19</sup>

Our study addressed how the UK's largest ethnic minority population (BSA) coped with cancer, compared with the host population, by analysing data from a sample of those attending the Leicestershire Cancer Centre.

Feeling distressed or low in mood is an initial emotional response to a diagnosis of cancer, and is part of normal adjustment, if of short duration. If, however, distress persists, it can have a harmful effect on the mental well-being of the individual leading to a risk of depressive symptoms<sup>17 20</sup> and a reduction in their quality of life.<sup>21-23</sup>

This study was designed in reference to the Transactional Model of Stress and Coping, which requires an assessment of personality traits within the context of the individual's environment.<sup>24</sup> For patients with cancer, this environment includes beliefs about cancer, level of social support, proficiency in host languages, level of literacy, degree of disability, comorbidities, spiritual beliefs, cultural background and economic circumstances.<sup>25</sup>

The symptom burden on patients with cancer can have a close inter-relationship with psychological well-being. Fatigue and 'disabilities' independently predicted depression among patients with lung cancer starting treatment<sup>26</sup> and have been observed in prechemotherapy patients with curative cancer.<sup>27</sup> A high-symptom burden can persist over time. One in four patients ( $n=4903$ ) had a high symptom burden 1 year postdiagnosis with depression, fatigue and pain having the greatest impact on their quality of life.<sup>28</sup> Similarly, a high-symptom burden at 12 months was reported among patients referred for control of pain and depression ( $n=405$ ).<sup>29</sup> Among Chinese patients with breast cancer ( $n=285$ ), less distress from physical symptoms immediately after surgery predicted psychological resilience. The study suggested that ineffective symptom control during treatment increased a woman's risk of persistent psychological distress longitudinally. The value of pre-operative interventions was highlighted.<sup>30</sup>

Of particular concern are reports of a higher symptom burden among ethnic minorities, for example, among Hispanic women postchemotherapy for breast cancer.<sup>31</sup> A greater 'unmet need' for symptom control was implicated among Black and Spanish speaking Hispanic women with breast cancer than White women.<sup>32</sup>

We report the longitudinal incidence of depressive symptoms among a sample of BSA and BW patients. Selected demographics, coping styles and the burden of

patient problems were examined to determine if they were associated with depressive symptoms.

## HYPOTHESES

On the basis of our literature review and pilot studies, we hypothesised that more BSA patients with cancer would self-report depressive symptoms than BW patients over time. We further hypothesised that a greater use of potentially maladaptive coping strategies and a heavier symptom burden would reflect higher rates of depressive symptoms.

## METHODS

### Study procedures

In total, 279 patients who were aware that they had cancer were recruited at the Leicestershire Cancer Centre between September 2007 and January 2010 at their first or second appointment. Patients were recruited by either an English-speaking clinical nurse specialist or one of two radiographers, who between them spoke English, Gujarati and Hindi and Urdu. None were involved in the clinical care of the patients and all received training in 'Good Clinical Practice' and in the principles of informed consent. The Leicestershire, Northamptonshire and Rutland Ethics Committee approved the study.

Eligible patients were aged 18–85 with a confirmed diagnosis of cancer with evidence of being informed of the diagnosis. Eligible patients were identified by the nurse specialist via the cancer registry with ethnicity confirmed by their surname and by hospital records.

Prior to their attendance, a 'convenient' sample of eligible patients were sent an introductory letter outlining the study and inviting them to participate. All correspondence and questionnaires were available in English, Gujarati and Hindi. Consent was sought requesting

patients to complete three sets of questionnaires in writing, the first immediately, and then at 3-month and 9-month intervals (table 1).

### Questionnaires

Patients completed the HADS-D<sup>33</sup> and The Emotion Thermometers (ETs),<sup>34</sup> which include the Depression and Distress Thermometers (DTs)<sup>35</sup> and Depression Thermometer (Dep T). The DT problem checklist identified the patient's symptom burden. All are validated but were not initially available in Gujarati or Hindi. A commercial company undertook an iterative back-translation process.<sup>36</sup> A version of the Patient Health Questionnaire (PHQ-9), which was already validated into Gujarati and Hindi, having been adapted for use in India, was the third questionnaire used.<sup>37</sup> Several tools were used to address the concern that some were ethnically biased.

An adaptive coping strategy (fighting spirit) and potentially maladaptive strategies (hopelessness/helplessness, fatalism, anxiety preoccupation and cognitive avoidance) were assessed via the Mini-MAC scale.<sup>38</sup> The locally developed Cancer Insight and Denial questionnaire (CIDQ) included question 38 from the original MAC questionnaire to assess the use of denial. The vast majority of participants chose to complete the first questionnaires at home, returning them by post. Subsequent questionnaires were posted to participants.

Personal statements illustrating how patients coped were generated by two qualitative questions, 'How would you describe your current illness?' and 'What does having cancer mean to you?'

### Statistical analysis

Depressive symptoms were assessed by HADS-D, ET Thermometers and PHQ-9.

**Table 1** Recruitment and retention

	BSA	BW	Total
Patient participation			
Total consented	179	329	508
Consented/completed Q1	94	185	279
Completed Q2	56	144	200
Completed Q3	32	117	149
Retained in study from consent until completion of study (%)	34	63	53.4
Reasons for withdrawal from study			
Consented but did not complete a questionnaires	85	51	136
Died	5	3	8
Returned to country of origin	5	0	5
Family member reversed consent of patient	8	0	8
Patient verbally withdrew	12 (14.1%)	12 (23.5%)	24
Avoidant behaviour	55 (64%)	0 (0%)	55
Lost to follow-up (excluding travel abroad)	0	29	29
Not interested in research subject	0	2	2
Already involved in another study	0	5	5

BSA, British South Asian; BW, British White.

The revised classification of the original HADS-D identified the severity of depressive symptoms (normal 0–7, mild 8–10, moderate 11–14 and severe 15–21).<sup>39</sup> A threshold of  $\geq 11$  identified patients with moderate symptoms. However, following the recommendation to have a lower threshold for patients with cancer than in general practice,  $\geq 8$  was selected for HADS-D.<sup>40</sup> This is supported by a review of 747 papers using HADS-D, where the best balance between sensitivity and specificity was achieved most often when using the cut-off  $\geq 8$  (Cronbach's  $\alpha$  coefficient 0.80).<sup>41</sup> Threshold scores of  $\geq 10$ ,  $\geq 15$ ,  $\geq 20$  for PHQ-9 were in accordance with the original recommended scores.<sup>42</sup> The current recommended threshold for the DT is  $\geq 4$  and this was retained in the ET<sup>43</sup> and for this analysis. A prior power calculation determined that a sample size of 86 participants was required for each ethnic group.

Graphs denote 95% CIs. Summary scores for selected coping strategies were from the Mini-MAC and the denial indicators in the CIDQ. Reference was made to individual indicators. Longitudinal data at baseline and at 3 and 9 months are reported.

Computation of frequencies, percentages and arithmetic median was conducted to identify patterns in the data. Mann-Whitney tests for continuous variables detected differences between the ethnic groups and the direction of these relationships. Spearman's Rank Order Tests ( $\rho$ ) explored correlations between depressive symptoms (HADS-D as a continuous variable) and deprivation.<sup>44</sup> We report analysis by age, gender, deprivation, tumour site, place of birth and ethnicity.

$\chi^2$  describes the relationship between categorical variables. The extent to which patients used each coping strategy and how their use changed longitudinally are described. Associations between each strategy and depressive symptoms are reported. Qualitative data were recorded verbatim and when they were in Gujarati, they were translated to English. Analysis was performed via SPSS V.18.

## RESULTS

Ninety-four BSA patients were recruited. The BSA sample largely represents patients with cancer within the Leicester Indian population and although of interest to other BSA populations with cancer, these findings may not be representative. In total, 53.8% were born in the Indian subcontinent, 33% in Africa of Indian descent and 12.9% in the UK. Hindus accounted for 53.2%, Muslims for 25.5% and Sikh for 17%. All 185 BW patients were recruited. Several cancer sites are represented. The largest was 114 patients with breast cancer. The educational attainment, religion and place of birth were self-reported by participants. The demographic characteristics of this sample showed significant differences between ethnic groups in terms of their socioeconomic status and educational attainment. These details and the patients' sex, age, cancer site and treatment intent are listed in [table 2](#).

## Demographics and depressive symptoms

Age was not associated with depression among BSA patients ( $r$ : HADS-D,  $p=0.62$ ). Older BW patients were less likely to be depressed ( $r$ : HADS-D,  $p=0.03$ ). There was no statistical differences based on gender, with women having a higher mean depression score than men at baseline (HADS-D; women 4 (range 0–18) IQR 1.7; men 3 (range 0–20) IQR 1.6)  $p=0.46$ .

Of these, 67.4% patients received radical treatment with the aim of cure or long-term control of disease and 32.6% received palliative treatment given with no expectation of cure. Unexpectedly, there was no evidence that receiving palliative as opposed to radical (curative intent) treatment influenced a difference in depressive symptoms (HADS-D  $\geq 8$  baseline  $p=0.088$ , 3 months  $p=0.588$  9 months  $p=1.0$ ). Those with lung cancer, who generally have a poor prognosis, had the highest median depression score via HADS-D of 5 (IQR 3.7, scale 0–21). The lowest score was attributed to people with prostate cancer (Md 1 (IQR 0.5); (see online supplementary table S1).

Data on educational attainment were recoded into two groups with those patients reaching an educational level of 15/16 being removed. This represented groups at either end of educational attainment. Those educated at the highest level had notably less depressive symptoms than those with either no formal education or only up to the age of 11 (HADS-D  $\geq 8$ , Lowest Ed. 14/30 (46.7%); Highest Ed. 18/97 (18.6%)  $p=0.004$ ). However, these results should be treated with caution, given that the educational systems of India and the UK are different. For example, some patients listing no formal education spoke up to five languages fluently. Individual results in patients who reported little formal education were consistent across assessment tools, suggesting adequate comprehension.

There was no significant difference in depressive symptoms between those BSA patients originating from Africa compared with those from the Indian subcontinent at baseline (MW: Africa 31/80 Md 4 (2.9) Indian subcontinent Md 5.5 (2.11)  $Z=-1.184$   $p=0.23$ ). Neither was there a significant difference in the experience of symptoms frequently associated with depression such as pain ( $p=0.23$ ), sleep disturbances ( $p=0.91$ ) and fatigue ( $p=0.52$ ).

Since socioeconomic deprivation is closely associated with being a member of an ethnic minority, we considered the extent to which deprivation influenced the strength of the relationship between ethnicity and depressive symptoms. Although there was a strong association between ethnicity and deprivation (MW  $r=0.503$ ,  $p=0.0005$ ), deprivation had minimal influence on the strength of the relationship between ethnicity and depression when comparing Pearson product-moment correlations with partial correlation calculations ([table 3](#)).

## Depressive symptoms at baseline

All three assessment tools showed approximately double the incidence of depression in BSA patients compared

**Table 2** Demographics

	Total (%)	British South Asian (BSA)	British White (BW)	p Value
Number	279	94	185	
Male	88 (31.5)	25 (26.6%)	64 (34.6%)	$\chi^2$ p=0.223
Female	190 (68)	69 (73.4%)	121 (65.4%)	
Age				WRST
Median (IQR)		57.1 (19)	61 (14)	Z=-14.480 p=0.0005
IMDS (1–20)*		6.5 (IQR 4.10)	16 (11.18)	WRST
Median (IQR)				Z=-14.435 p=0.0005
Educational attainment				
No formal education	30 (10.7)	27 (29.7%)	3 (1.7%)	$\chi^2$ p=0.0005
Junior school (up to 11)	8 (2.8)	4 (4.4%)	4 (2.2%)	
Senior school (15–16)	97 (34.7)	16 (17.8%)	81 (44.8%)	
Sixth form (17–18)	22 (7.8)	11 (12.1%)	11 (6.1%)	
University or college	115 (41.2)	33 (36.3%)	82 (45.3%)	
272 pts†				
Religion				
Christian	148 (53)	Nil	148 (80%)	
Muslim	24 (9)	24 (25.5%)	Nil	
Hindu	50 (18)	50 (53.2%)	Nil	
Sikh	16 (6)	16 (17%)	Nil	
Other	4 (1)	1 (1.06%)	3 (1.6%)	
None	37 (13)	Nil	34 (18.4%)	
Questionnaire language				
English	267 (96)			
Gujarati	11 (4)			
Urdu (verbal translation)	1 (0.3)			
Place of birth				
UK	195 (70)	13 (14%)	182 (98.4%)	
British forces overseas	2 (0.7)	Nil	2 (1.08%)	
The USA	1 (0.3)	Nil	1 (0.52%)	
Africa	31 (11.1)	31 (33%)	Nil	
Indian subcontinent	50 (17.9)	50 (53%)	Nil	
Diagnosis				
Breast	114 (41)	34 (36.2%)	80 (43.2%)	
Colorectal	45 (16)	15 (16%)	30 (16.2%)	
Gynaecological	33 (12)	19 (20.2%)	15 (8.1%)	
Prostate	23 (8)	3 (3.2%)	20 (10.8%)	
Lung	19 (7)	6 (6.4%)	13 (7.0%)	
Other	43 (15)	17 (18%)	26 (14.6%)	
Type of treatment				$\chi^2$
Radical (curative intent)	188 (67.4)	64 (68.1%)	124 (67.4%)	p=0.966
Palliative	91 (32.6)	30 (31.9%)	61 (33%)	
Time from diagnosis to first interview (weeks)				WRST
Median (IQR)	7 (3)	8 (3)	6 (3)	Z=-14.506 p=0.0005

\*Index Multiple Deprivation Scale (Office National Statistics, 2007).

†Number of patients who provided their educational attainment.

WRST, Wilcoxon rank sum test.

with BW patients (figure 1A–D and see online supplementary table S2). Severe depression was also more common in the BSA groups as demonstrated using a higher HADS-D score  $\geq 11$  (BSA 23/94 (24.5%) BW 11/185 (5.9%) p=0.001). A similar trend was seen using a higher PHQ-9 threshold  $\geq 15$  (BSA 13/85 (15%) BW 10/173 (5%) p=0.04).

### Longitudinal trends in depressive symptoms

All tools indicated how BSA patients were more vulnerable to depressive symptoms in contrast to BW patients. HADS-D  $\geq 8$  suggested significantly higher rates of depressive symptoms among BSA patients longitudinally than BW patients (figure 1B). All three assessment tools indicated a slight decrease in depressive

**Table 3** Influence of deprivation

Ethnicity and depressive symptoms corrected for deprivation	N	Pearson product-moment correlation	p Value	N	Correlation corrected for deprivation	p Value
HADS-D	277	-0.274	0.0005	276	-0.235	0.0005
PHQ-9	256	-0.257	0.0005	255	-0.208	0.001
Dep T	262	-0.131	0.033	261	-0.118	0.057

Dep T, Depression Thermometer; HADS-D, Hospital Anxiety and Depression Scale; PHQ-9, Patient Health Questionnaire-9.

symptoms among BSA patients at 3 months. Depression rates had not fallen lower than those at baseline by 9 months, although the ethnic difference remained (figure 1C,D).

**Coping strategies**

BSA patients used coping strategies differently from BW patients particularly at baseline when greater use of potentially maladaptive strategies was associated with higher rates of depressive symptoms (see online supplementary tables S3–S5).

**Hopelessness/helplessness (Mini-MAC)**

its an awful thing to happen...feeling hopeless  
BSA patient No.16 at baseline

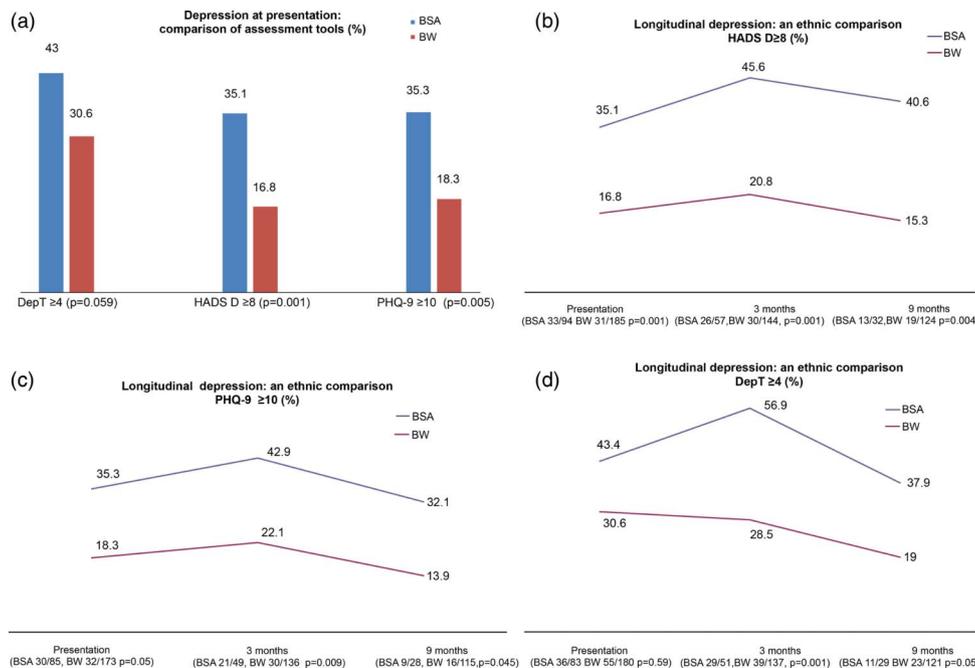
Although initially the majority of patients did not express helplessness or hopelessness, BSA patients were far more likely to do so (p=0.0005). For example, more BSA patients than BW patients agreed with the statement ‘I feel completely at a loss about what to do’ (BSA 31 (33%); BW 23 (12.4%) p=0.0005). Across the

study period, BSA patients had higher helplessness/hopelessness scores than BW patients, although use decreased over time for both groups (figure 2A). Helplessness/hopelessness is sometimes considered to be a substitute for depression, so it was not surprising that over time more patients (BSA and BW combined) felt helplessness/hopelessness and also acknowledged depressive symptoms (MW: PHQ-9 ≥11/HADS-D ≥8 p=0.0005).

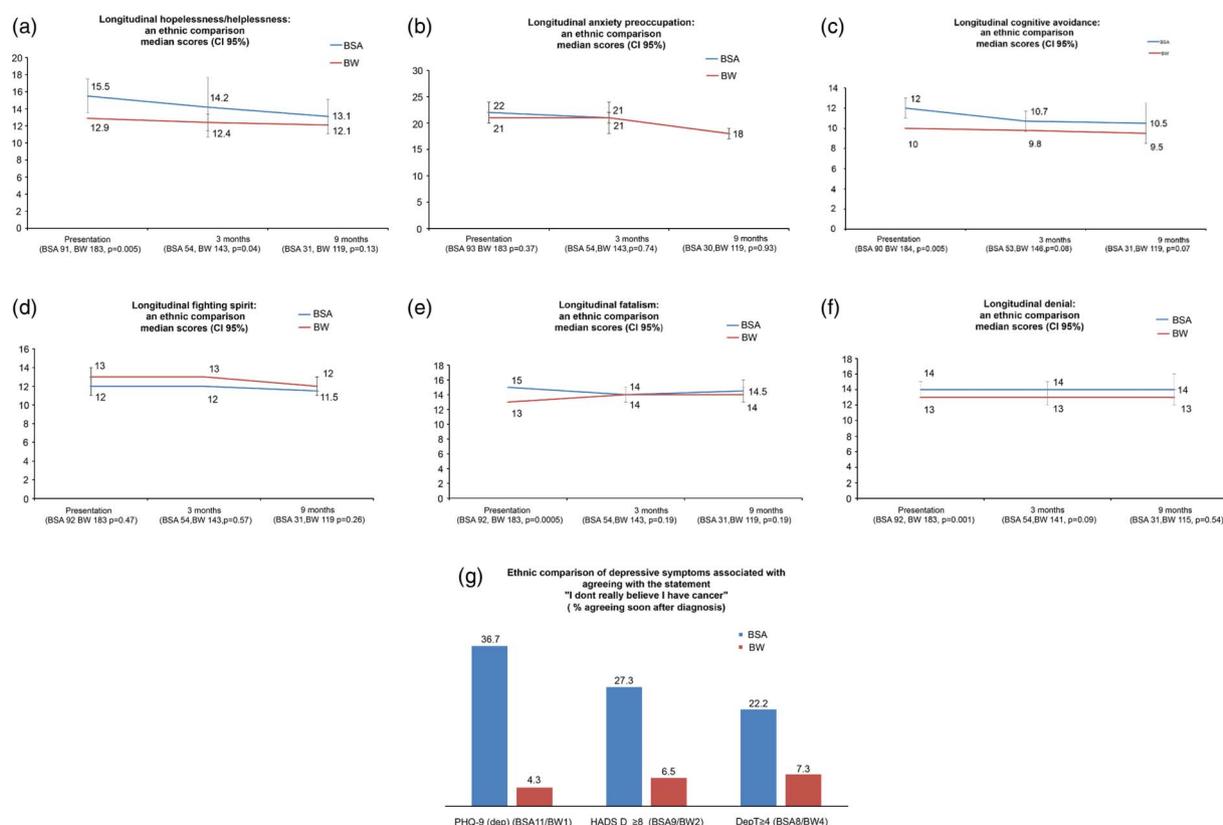
**Anxiety preoccupation**

Cancer has totally changed my life. I am worried, anxious about my treatment and what lies ahead as this is the second occasion I am going through this. BSA No.103.

There was a negligible ethnic difference in the use of anxiety preoccupation. Over time this strategy was used less (figure 2B). It was strongly associated with depression (HADS-D and PHQ-9, p=0.0005). These patients were more likely to report depressive symptoms longitudinally (PHQ-9: baseline p=0.0005, 3 months p=0.0005, 9 months p=0.0005).



**Figure 1** Longitudinal depressive symptoms by HADS, PHQ-9 and Dep T. Dep T, Depression Thermometer; HADS-D, Hospital Anxiety and Depression Scale; PHQ-9, Patient Health Questionnaire-9.



**Figure 2** Longitudinal coping strategies.

### Cognitive avoidance

Cancer is "...something that I put to the back of my mind and don't let it interfere with my day to day life"  
BW No.118.

Initially, BSA patients used cognitive avoidance to cope more than BW patients (MW:  $p=0.0005$ ; figure 2C). For example, 'I deliberately push all thoughts of cancer out of my mind' (BSA 61/93 (65.6%); BW 63/185 (34.4%),  $p=0.0005$ ). Over time, this ethnic difference continued but was only statistically significant at baseline, as illustrated by a comparison of median scores (figure 2C). At baseline, as one sample, those who used cognitive avoidance were more likely to have symptoms of depression (MW: PHQ-9  $p=0.007$ ; HADS-D  $\geq 8$   $p=0.001$ ; Dep.T  $\geq 4$   $p=0.002$ ). Over time, avoidant patients did not continue to be depressed (HADS-D; 3 months,  $p=0.2$ ; 9 months, 0.14).

### Fighting spirit

(I see cancer) as a challenge...a temporary state....a hurdle to get over  
BW patient No.172.  
It means I have a fight on my hands but I'm determined to get better  
BW No.354.

A large number of patients in both ethnic groups approached their illness with an 'adaptive' coping strategy of 'fighting spirit' (figure 2D). For example, 'I am

determined to beat this disease' (BSA 85/93 (91.4%); BW 170/185 (91.9%)  $p=1.0$ ). There was little ethnic difference in the extent to which patients used this coping strategy (MW baseline  $p=0.47$ , 3 months  $p=0.57$ , 9 months  $p=0.2$ ).

### Fatalism

It's horrible. Why me? My mum died from cancer. My sisters have cancer. Why is this happening? I wish I'd never woken up after my operation  
BSA No.125

More BSA patients were fatalistic when diagnosed with cancer than BW patients at baseline assessment (MW:  $p=0.0005$ ). However, this was largely based on one of five Mini MAC indicators, 'I've put myself in the hands of God' (BSA 71/94 (75.5%); BW 60/185 (32.4%)  $p=0.0005$ ). There was a gradual decrease in fatalism in both ethnic groups by 9 months, although it persisted among BSA patients (figure 2E). Those who were fatalistic were more likely to experience depressive symptoms (MW: HADS-D  $\geq 8$   $p=0.024$ ; PHQ-9,  $p=0.003$ ) but not by the Dep T  $\geq 4$  ( $p=0.101$ ).

### Insight and denial (CIDQ)

I'm not ill

**Table 4** Ethnic differences in reporting of physical symptoms

Problem		n	No	Per cent	Yes	Per cent	$\chi^2$
Pain	Baseline	BSA	88	37	42	51	58
		BW	180	121	67	59	32.8
	3 months	BSA	53	14	26.4	39	73.6
		BW	141	92	65.2	49	34.8
	9 months	BSA	31	12	38.7	19	61.3
		BW	121	80	66.1	41	33.9
Nausea	Baseline	BSA	83	56	68	27	32.5
		BW	178	141	79	37	20.8
	3 months	BSA	54	29	53.7	25	46.3
		BW	140	91	65	49	35
	9 months	BSA	29	22	75.9	7	24.1
		BW	121	104	86	17	14
Getting around	Baseline	BSA	85	59	69	26	30.6
		BW	177	155	88	22	12.4
	3 months	BSA	55	33	60	22	40
		BW	140	112	80	28	20
	9 months	BSA	31	23	74.2	8	25.8
		BW	120	95	79.2	25	20.8
Bathing and dressing	Baseline	BSA	86	62	72	24	27.9
		BW	178	167	94	11	6.2
	3 months	BSA	55	42	76.4	13	23.6
		BW	140	129	92.1	11	7.9
	9 months	BSA	31	25	80.6	6	19.4
		BW	120	104	86.7	16	13.3
Mouth sores	Baseline	BSA	87	66	76	21	24.1
		BW	179	167	93	12	6.7
	3 months	BSA	55	37	67.3	18	32.7
		BW	140	114	81.4	26	18.6
	9 months	BSA	31	25	80.6	6	19.4
		BW	121	109	90.1	12	9.9
Fevers	Baseline	BSA	87	69	79	18	20.7
		BW	177	172	97	5	2.8
	3 months	BSA	54	42	77.8	12	22.2
		BW	139	127	91.4	12	8.6
	9 months	BSA	31	26	83.9	5	16.1
		BW	119	108	90.8	11	9.2
Skin	Baseline	BSA	84	42	50	42	50
		BW	179	156	87	23	12.8
	3 months	BSA	56	26	46.4	30	53.6
		BW	142	96	67.8	46	32.4
	9 months	BSA	31	16	51.6	15	48.4
		BW	121	86	71.1	35	28.9

BSA, British South Asian; BW, British White.

Written at the top of an uncompleted questionnaire by a patient having chemotherapy for breast cancer following surgery. BW No.127 at baseline.

...part of me still feels there is nothing wrong with me and this is happening to someone else. This is presumably my way of handling it all. BW No.311 at 9 months

Of those who used denial, potentially a maladaptive coping strategy,<sup>45</sup> BSA patients were over-represented, most notably at baseline assessments ( $p=0.001$ ). The ethnic gap remained longitudinally (figure 2F). Of the three tools assessing depression, only PHQ-9 indicated

an association between denial and depression, albeit weakly (MW:  $p=0.039$ ).

To facilitate comparisons with Roy's 2005 study,<sup>17</sup> analysis of the single indicator 'I don't really believe I have cancer' originating from the MAC questionnaire was repeated. At baseline, 229/278 patients (82%) accepted the reality of their diagnosis by disagreeing with the statement. Of the 27 patients who did not believe that they had cancer, more were BSA (BSA 19/93 (20.2%); BW 8/185 (4.3%),  $p=0.0001$ ). Of interest, 23 patients agreed with this statement 'sometimes' (BSA 12 (52.2%); BW 11 (47.8%)). There was a strong trend towards BSA patients, who denied their diagnosis, to be

more depressed at baseline, but the sample numbers were too low to warrant analysis at 9 months (figure 2G).

We considered whether causes of distress listed in the distress thermometer checklist explained ethnic differences in depressive symptoms. Cancer treatments offered to both groups were similar, so they did not influence findings. Critically BSA patients experienced more distress from physical symptoms of illness and treatment than BW patients. There were 17 physical symptoms listed in the DT checklist. In 13 categories, BSA had statistically significantly increased symptoms compared with BW patients. For example, pain (BSA 51/83 (58%), BW 59/180 (32.8%)  $p=0.0001$ ), mouth sores (BSA 21/88 (24.1%), BW 12/179 (6.7%)  $p=0.0001$ ) and fevers (BSA 18/87 (20.7%), BW 5/177 (2.8%)  $p=0.0001$ ). At 3 months, significantly higher percentages of BSA patients reported problems with pain, mouth sores, nausea, skin, washing and dressing and getting around as causes for distress, which were not reflected in BW patients. By 9 months, the differences had narrowed with the exception of pain (BSA 19/31 (61.3%) vs BW 41/121 (33.9%)  $p=0.009$ ; table 4).

## DISCUSSION

With the exception of our pilot study,<sup>17</sup> we are not aware of another comparison of how BSA and BW patients cope with cancer. It should be of major concern to healthcare policymakers in the UK that this study provides evidence that there is a higher prevalence of depressive symptoms among BSA patients soon after the cancer diagnosis than BW patients. The percentages vary depending on the assessment tool used but all showed the same trend. The BSA rates for depression were twice that for BW patients using two tools. Of these, 35.1% of BSA compared with 16.8% of BW patients ( $p=0.001$ ) had depressive symptoms measured on HADS-D ( $\geq 8$ ). This was confirmed on a version of PHQ-9  $\geq 10$  developed for India (35.3% BSA vs 18.3% BW  $p=0.05$ ). This is a critical finding since this is almost six times higher than reported within the UK general population using the same assessment tool (6%).<sup>46</sup> Depression rates for BW patients (HADS-D  $\geq 8$ , 16.8%; PHQ-9 18.3%) were similar to those reported in a recent meta-analysis of patients with cancer (16.3%), being approximately 2.5 times higher than in the general population.<sup>4</sup> What is disturbing is the incidence of more severe depression in BSA patients, which is reflected in their HAD-D score  $\geq 11$  (BSA 24.5% vs BW 5.9%  $p=0.0001$ ). These findings supported trends in other studies, notably our pilot study. Using the threshold HADS-D  $\geq 10$ , Roy<sup>17</sup> reported that BSA 20.7% vs BW 10.4% ( $p=0.001$ ) had moderate depressive symptoms. These concur with other reports, which suggest that ethnic minority patients with cancer experience more psychological distress than patients from host populations.<sup>16 17 47 48</sup> However, the BSA population is heterogeneous. It would be grossly simplistic to assume that all

BSA patients respond psychologically in the same way, given the breadth and diversity of their religious and cultural influences. However, Indian Hindus comprised the majority of our BSA sample and our findings may be of particular relevance to this subgroup.

What is very interesting is that HADS-D, PHQ-9 and Dep.T showed higher levels of depressive symptoms in both ethnic groups at 3 months after baseline, this being steeper among BSA patients. Although the symptoms decreased, BSA consistently reported higher rates of depression than BW patients longitudinally. These findings confirmed our first hypothesis.

A counter-intuitive finding in this study is the similarity of depressive symptoms in patients being treated with curative intent (radical) and palliative patients. Although there were fewer questionnaires returned at 3 and 9 months, the ratio of radical and palliative patients remained the same (HADS-D  $\geq 8$  baseline  $p=0.08$ , 3 months  $p=0.58$ , 9 months  $p=1.0$ ). In fact, this finding is consistent with a recent meta-analysis.<sup>4</sup>

At baseline, the rates of fatalism/helplessness/hopelessness and domains of denial were far higher among BSA patients and there was a strong correlation between these potentially maladaptive coping strategies and the incidence of depression in both ethnic groups. Helplessness/hopelessness is strongly associated with depression,<sup>20 49 50-54</sup> as we found in this study. A similar pattern was seen in the use of cognitive avoidance. Fatalism too was associated with higher levels of depressive symptoms, as demonstrated on both the PHQ-9 and HADS-D, which supports research from India<sup>55 56</sup> and the UK<sup>57 58</sup> into the use of potentially maladaptive behaviours.

In our previous study,<sup>17</sup> denial was significantly related to depression in both BW and BSA patients. BSA patients were far more likely to agree with the statement in the MAC questionnaire (Question 38) 'I don't really believe I have cancer'. In this study, a minority of patients denied their diagnosis, but again it was more common among BSA patients using the same indicator until 9 months (MW baseline  $p=0.0005$ , 3 months  $p=0.001$ , 9 months  $p=0.2$ ). Initially, this was strongly associated with depression; however, the sample numbers were too small to consider longitudinal associations.

What is puzzling is that although BSA patients remained more depressed than BW patients longitudinally, by 3 and 9 months the use of coping strategies did not explain this. At 3 months, the only difference was in the helplessness/hopelessness scores ( $p=0.043$ ) and by 9 months, the ethnic differences in the use of coping strategies were insignificant. Interestingly, by 9 months, the trend towards higher depression among BSA patients remained. Even taking into account a lag time for the alleviation of depressive symptoms after less use of maladaptive coping, there remains an incomplete explanation as to why more BSA patients in particular remain so distressed. Our hypothesis that a greater use of maladaptive coping strategies would reflect higher rates of depressive symptoms was therefore only partially

confirmed. A retrospective audit into referral to psycho-oncology or prescribing patterns of psychotropic medication in the two groups did not suggest a difference that could account for this.

We considered whether the burden of physical symptoms explained this ethnic gap. BSA patients were more likely to report physical symptoms at baseline and at 3 months. This was particularly true for pain, nausea, skin concerns, mouth sores, tingling and feeling swollen. These symptoms peaked at 3 months, but there was no statistically significant difference in symptomatology between the two groups by 9 months with the exception of pain. However, the ethnic differences in depressive symptoms persisted up to 9 months. Possible explanations include the somatisation of physical symptoms being undetected, inadequate symptom management, non-compliance due to a lack of literacy and language skills or patient's preference for traditional medicines for symptom control purposes. Our findings reflect the greater symptom burden found in other ethnic minority patients with cancer, such as among the Chinese and Hispanic populations.<sup>31 32</sup> This study supports the original hypothesis that more BSA patients with cancer would self-report depressive symptoms than BW patients over time. Our hypothesis that a greater use of potentially maladaptive coping strategies would reflect higher rates of depression among BSA patients was supported but only until the 3 month point. A heavier symptom burden among BSA patients does appear to contribute to depression rates among this ethnic minority compared with the host population.

### Limitations

Limitations to the study are acknowledged. The BSA sample largely represents patients with cancer within the Leicester Indian population and, although of interest to other BSA cancer populations, these findings may not represent them. In addition, there was a large sample of patients with breast cancer, which risks under-representation of those patients with other body site cancers.

Difficulties in recruiting and retaining BSA participants by 9 months reduced the sample size.<sup>59</sup> Self-reported questionnaires indicate the presence of depressive symptoms, but given the absence of psychiatric interviews, this is not diagnostic of a depressive disorder.

Modulations in patient mood between the three data collection points are not represented. It is also likely that depressive symptoms are under-reported since anecdotally those who were most distressed often did not feel able to participate in the study.

### Recommendations

The decreased use of maladaptive coping strategies among BSA patients in the first few months after diagnosis requires investigation, the aim being to reduce the associated distress earlier along the cancer trajectory. Evidence of greater distress among BSA patients caused

by a heavier symptom burden than among BW patients also needs further study since several potential causes are reversible by proactive patient assessments during cancer treatment and follow-up.

### CONCLUSION

Health professionals need to be aware of a greater probability of depressive symptomatology and how this may present clinically, including somatic symptoms, in the first 9 months after diagnosis if this ethnic disparity in mental well-being is to be addressed.

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