



**Increased anxiety and depression among British South Asian compared to British White cancer patients: a longitudinal study**

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# Increased anxiety and depression among British South Asian compared to British White cancer patients: a longitudinal study.

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## **Abstract**

### **Objectives**

We investigated whether there were ethnic differences in anxiety and depression among British South Asian (BSA) cancer patients compared to British White (BW) patients in Leicestershire. We considered how coping strategies were used and whether physical symptoms affected mood.

### **Design**

Questionnaire-based study of newly diagnosed cancer patients interviewed soon after diagnosis and at 3 and 9 month intervals. The Hospital Anxiety and Depression Scale (HADS), Patient Health Questionnaire (PHQ9), Mini-MAC and Emotion Thermometers (inc distress thermometer) were used. Patients also completed the newly developed Cancer Insight and Denial questionnaire, and Cancer Beliefs/ Physician/Patient Trust questionnaire.

### **Setting**

Leicestershire Cancer Centre, UK.

### **Participants**

94 BSA and 185 BW newly diagnosed cancer patients.

### **Results**

BSA self reported significantly higher rates of depression compared to BW patients longitudinally e.g. (HADS D $\geq$ 8: presentation: BSA 35.1% v BW 16.8% p=0.001; 3 months BSA 45.6% v BW 20.8% p=0.001; 9 months BSA 40.6% v BW 15.3% p=0.004). A similar ethnic difference was detected in rates of anxiety until 9 months (HADS  $\geq$ 8 at presentation BSA 54.3% v BW 36.2% p=0.006; 3 months BSA 47.4% v BW 32.6%; 9 months BSA 40.6% v BW 28.2% p=0.25). BSA patients used maladaptive coping strategies far more than BW patients. In particular hopelessness/helplessness p=0.005, fatalism p=0.0005, avoidance p=0.005 and agreement with the denial statement 'I do not

1 really believe I have cancer'  $p=0.0005$ ) were all more common in BSA patients. An  
2  
3 increase in cancer burden or treatment associated symptoms may have contributed to a  
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5 peak in depression at 3 months.  
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### 8 **Conclusion**

9  
10 High rates of anxiety and depression were present longitudinally among BSA cancer  
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12 patients when compared to BW patients.  
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## Article summary

### Article Focus

- We investigated whether there were differences in anxiety and depression among British South Asian (BSA) cancer patients compared to British White (BW) longitudinally over a 9 month period.
- To try to avoid cultural bias we used 8 questionnaires including HADS and a version of the PHQ-9 developed for India.
- We considered how coping strategies were used and whether physical symptoms affected mood.

### Key Messages

- BSA have twice the self-reported rates of anxiety and depression than BW patients and 5 times the incidence of severe depression.
- These differences persist for 9 months after presentation.
- BSA patients used maladaptive coping strategies far more than BW patients.

### Strengths and Limitations

This is the first comparison of how BSA and BW patients cope with cancer. We have used multiple assessment tools including a version of the PHQ-9 developed for India. We have demonstrated statistically very significant differences in the rates of anxiety and depression 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 BSA patients and retention, especially by 9 months was low. Changes in mood between the 3 data collection points are not represented. It is also likely that the rates of anxiety and depression are under-reported since anecdotally those who were most distressed often did not feel able to participate in this study.

## Introduction

Depression is one of the strongest determinants of health related quality of life and it also influences medical care and participation in treatment.[1, 2] It may also be linked with other serious outcomes including mortality.[3] The point prevalence of major depression at any time in the first two years following a cancer diagnosis is 14.9% via DSMIV criteria.[4] This is two to four times that observed in the general population using equivalent criteria.[5] An under researched area is the incidence of psychological distress including anxiety and 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[6] leaving the largely unproven implication that they also suffer more distress when diagnosed with cancer. However ethnic minorities may be less likely to receive high quality care.[7, 8] Inequalities in access to care, receipt of treatment and mortality are particularly striking among ethnic minorities, the elderly and those with mental ill health on both sides of the Atlantic.[9-11] Removing such disparities is a priority both of UK [12, 13] and US government.[14]

The UK British South Asian (BSA) population is a large ethnic minority. The city of Leicester has one of the highest concentrations of this population accounting for approximately 33%, predominantly of Gujarati decent originally from western India. A previous pilot study showed a significantly higher incidence in symptoms of depression amongst BSA patients in Leicester and local counties compared to British White (BW) patients via HADS D  $\geq 10$  (BSA 20.7%; BW 10.4%  $p=0.001$ ).[15] Anxiety and depression were associated with certain coping styles particularly the use of denial in both BSA and BW patients but was employed more frequently by BSA patients.

1 The findings of our pilot study were consistent with the few publications reporting the  
2 incidence of depression or distress in ethnic minority cancer patients. The largest is a  
3 meta-analysis of 21 papers which found that US Hispanic patients were significantly more  
4 distressed ( $p=0.0001$ ) and depressed ( $p=0.04$ ) than the majority population.[16]  
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12 Similar findings were reported from Canada with more distress amongst ethnic minorities  
13 (E and SE Asia, South Asian, Aboriginals) compared to the majority population  
14 (European, Canadian, British  $p=0.0001$ ). Greater distress was also found among those  
15 with lower income ( $p=0.001$ ).[17]  
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23 Here we aimed to address how the UK's largest ethnic minority population (BSA) cope  
24 with cancer in comparison to the host population by analysing data from a sample of  
25 those attending the Leicestershire Cancer Centre. We report the longitudinal incidence of  
26 anxiety and depression in both groups. Initial assessment took place as soon as possible  
27 after diagnosis and 3 and 9 months later. Coping styles were also examined to determine  
28 if patterns of maladaptive coping changed with time. Greater understanding of how  
29 patients from ethnic minorities cope with cancer is a pre-requisite to eliminating  
30 inequalities.  
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## 43 **Methods**

### 44 **Hypotheses**

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48 On the basis of our literature review and pilot studies we hypothesized that longitudinally  
49 more BSA cancer patients would self report symptoms of anxiety and depression than  
50 BW patients. We further hypothesized that a greater use of maladaptive coping  
51 strategies would reflect higher rates of anxiety and depression.  
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### Study procedures

279 patients, who were aware they had cancer, were recruited at the Leicestershire Cancer Centre between September 2007 and January 2010 at their first or second appointment. Prior to their attendance eligible patients were sent a letter outlining the study and inviting them to participate. Consent was sought requesting patients complete three sets of questionnaires in writing, the first as soon as possible, then at 3 months and 9 month intervals. Patients were recruited by either an English speaking clinical nurse specialist or one of two radiographers, who between them spoke English, Gujarati and Hindi.

### Questionnaires

Patients completed the Hospital Anxiety and Depression Scale (HADS) [18] and The Emotion Thermometers [19] which incorporates the Distress Thermometer [20] alongside thermometers for anxiety (Anx T) and depression (Dep T). All are validated but were not initially available in Gujarati or Hindi. Therefore we undertook a translation via the back to back method.[21] 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.[22] Several tools were used to address the concern that some tools are ethnically biased.

Coping strategies were assessed via the Mini-MAC scale [23] and the locally developed Cancer Insight and Denial questionnaire (CIDQ). The CIDQ included question 38 from the original MAC questionnaire to elicit the use of denial. The Brief Illness Perception Questionnaire [24] and the Physician/Patient Trust/ Cancer Beliefs Questionnaire [25] considered how patients interpreted cancer. The vast majority of participants chose to



1 complete the first questionnaires at home, returning them by post. Subsequent  
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3 questionnaires were posted to participants.  
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### 8 **Statistical analysis**

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10 We used the following scales and cut-off thresholds. HADS-A and HADS D 7v8, ET  
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12 Thermometers 3v4 and PHQ-9 9v10. In addition cut-off scores of HADS  $\geq 11$  and PHQ-9  
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14  $\geq 15$  and  $\geq 20$  were used to indicate high severity for depressive symptoms. Graphs  
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16 denote 95% confidence intervals. Summary scores for selected coping strategies were  
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18 from the Mini-MAC and the denial indicators in the CIDQ questionnaire. Reference was  
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20 made to individual indicators. Longitudinal data at presentation and at 3 and 9 months is  
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22 reported.  
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28 Computation of frequencies, percentages and arithmetic median was conducted to  
29  
30 identify patterns in the data. Mann Whitney tests for continuous variables detected  
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32 differences between the ethnic groups and the direction of these relationships. Chi<sup>2</sup>  
33  
34 described the relationship between categorical variables. The extent to which patients  
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36 used each coping strategy and how its use changed longitudinally is described.  
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38 Associations between each strategy and anxiety and depression are reported. Analysis  
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40 was performed via SPSS v 18.  
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### 46 **Results**

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48 94 BSA patients were recruited with approximately 33% born in Africa. 185 BW patients  
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50 were recruited. Several cancer sites are represented. The largest cohort was 114 breast  
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52 cancer patients. The educational attainment, religion and place of birth record were self  
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54 reported by participants. The demographic characteristics of this sample showed  
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56 significant differences between ethnic groups in terms of their socio-economic status and  
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educational attainment. These details and the patient’s sex, age, cancer site and treatment intent are listed in Table 1.

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**Table 1: Demographics**  
 \* Index Multiple Deprivation Scale (Office National Statistics,2007)

|   | Total (%)   | British South Asian (BSA) | British White (BW) | p value   |
|---|-------------|---------------------------|--------------------|---|
| <b>Number</b>   | 279         | 94                        | 185                |   |
| Male  | 88 (31.5%)  | 25 (26.6%)                | 64 (34.6%)         | Chi <sup>2</sup><br>p=0.223                                 |
| Female  | 190 (68%)   | 69 (73.4%)                | 121 (65.4%)        |   |
| <b>Age</b><br>median (Inter Quartile Range)                         |             | 57.1 (19)                 | 61 (14)            | Wilcoxon<br>rank sum<br>test(WRST)<br>Z=-14.480<br>p=0.0005 |
| <b>IMDS (1-20)*</b><br>Median (IQR)                                 |             | 6.5 ( IQR 4,10)           | 16(11,18)          | WRST<br>Z=-14.435<br>p=0.0005                               |
| <b>Educational Attainment</b>                                       |             |                           |                    | Chi <sup>2</sup><br>p=0.0005                                |
| No formal education   | 30 (10.7%)  | 27 (29.7%)                | 3 (1.7%)           |   |
| 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%)         |   |
| <b>Religion</b>   |             |                           |                    |   |
| 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%)         |   |
| <b>Interview Language</b>   |             |                           |                    |   |
| English   | 267 (96%)   |                           |                    |   |
| Gujarati  | 11 (4%)     |                           |                    |   |
| Urdu  | 1 (0.3%)    |                           |                    |   |
| <b>Place of birth</b>   |             |                           |                    |   |
| UK  | 195 (70%)   | 13 (14%)                  | 182 (98.4%)        |   |
| British Forces overseas   | 2 (0.7%)    | nil                       | 2 (1.08%)          |   |
| USA   | 1 (0.3%)    | nil                       | 1 (0.52%)          |   |
| Africa  | 31 (11.1%)  | 31 (33%)                  | nil                |   |
| Indian sub continent  | 50 (17.9%)  | 50 (53%)                  | nil                |   |
| <b>Diagnosis</b>  |             |                           |                    |   |
| Breast  | 41%         | 34 (36.2%)                | 80 (43.2%)         |   |
| Colorectal  | 16%         | 15 (16%)                  | 30 (16.2%)         |   |
| Gynaecological  | 12%         | 19 (20.2%)                | 15 (8.1%)          |   |
| Prostate  | 8%          | 3 (3.2%)                  | 20 (10.8%)         |   |
| Lung  | 7.0%        | 6 (6.4%)                  | 13 (7.0%)          |   |
| Other   | 15%         | 17 (18%)                  | 26 (14.6%)         |   |
| <b>Type of treatment</b>  |             |                           |                    | Chi <sup>2</sup><br>p=0.966                                 |
| Radical   | 188 (67.4%) | 64 (68.1%)                | 124 (67.4%)        |   |
| Palliative  | 91(32.6%)   | 30 (31.9%)                | 61 (33%)           |   |
| <b>Time from diagnosis to first interview (wks)</b><br>Median (IQR) | 7(3)        | 8(3)                      | 6(3)               | WRST<br>Z=-14.506<br>P=0.0005                               |

### **Anxiety and depression early after diagnosis**

All three assessment tools showed approximately double the incidence of depression in BSA patients compared to BW patients (Fig 1a). Severe depression was also more common in the BSA groups as demonstrated using a higher HADS 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 cut-off score ( $\geq 15$ ) BSA 13/85 (15%) BW 10/173 (5%)  $p=0.04$ . Again significantly higher levels of anxiety were seen in BSA patients (HADS-A  $\geq 8$  BSA 54.3% v BW 36.2%  $p=0.006$ ) especially severe anxiety (HADS-A  $\geq 11$  BSA 34% v BW 18.9%  $p=0.008$ ). The ethnic difference was reproduced via the AnxT $\geq 4$  albeit inclusive of more patients (BSA 67.5% v BW 52.2%  $p=0.02$ ) (Fig 1b).

### **Longitudinal trends in anxiety and depression**

All tools indicated how more vulnerable BSA patients were in contrast to BW patients. HADS D  $\geq 8$  suggested significantly higher rates of depressive symptoms among BSA patients longitudinally than BW patients (Fig 1c). All three assessment tools indicated a slight decrease in depressive symptoms among BSA patients at 3 months. Depression rates had not fallen lower than those at presentation by 9 months although the ethnic difference remained (Fig 1d). Rates of anxiety appeared to subside for both ethnic groups over time although more BSA patients remained anxious than BW patients at 3 months (HADS A  $\geq 8$   $p=0.04$ ) (Fig 1e). The difference had gone by 9 months ( $p=0.254$ ). The Anxiety Thermometer  $\geq 4$  echoed this trend (3 months ( $p=0.13$ ), 9 months ( $p=0.17$ )) (Fig 1f).

### **Influence of deprivation**

Since socio-economic 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 anxiety and depression.

Although there was a strong association between ethnicity and deprivation (MW  $r=0.503$ ,  $p=0.0005$ ), the latter had minimal influence on the strength of the relationship between ethnicity and depression when comparing Pearson product-moment correlations (PCC) with partial correlation calculations. (HADS D:  $-.274$ ;  $p=.0005$ ) partial correlation ( $-.235$ ,  $p=0.001$ ) and via PHQ-9 (PCC  $-.257$ ,  $p=0.0005$ ) partial correlation ( $-.208$ ,  $p=0.001$ ). There was a weak association between ethnicity and anxiety (HADS A  $-.147$   $p=0.014$ ). Although deprivation did influence the strength of that relationship to the extent that it became insignificant ( $-.093$   $p=0.123$ ), the difference between the correlations was minimal, results supported by findings via Anx-T (PCC  $-.087$   $p=0.158$ ) partial correlation ( $-.083$ ,  $p=0.179$ ).

### **Coping Strategies**

BSA patients used maladaptive coping strategies more than BW patients particularly early after diagnosis when they were associated with higher rates of anxiety and depression.

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

*"its an awful thing to happen....feeling hopeless"*

## BSA patient soon after diagnosis No.16

Although initially the majority of patients did not express helplessness nor 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 its use decreased over time for both groups (Fig 2a). Helplessness/hopelessness is sometimes considered to be a substitute for depression so it was not surprising that over time as one sample more patients who felt helplessness/hopelessness, acknowledged depressive symptoms (MW: PHQ-9 10v11/HADS D 7v8  $p=0.0005$ ). Helplessness/hopelessness was also associated with a higher incidence of anxiety (MW: HADS A 7v8,  $p=0.0005$ ).

**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 (Fig 2b). Individual indicators suggested that BW patients appeared far more apprehensive than BSA patients (BSA 47/93 (50.5%); BW 135/185 (73%)  $p=0.0005$ ), more upset about having cancer

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2  
3 (BSA 58/94 (61.7%); BW 149/185 (80.5%)  $p=0.001$ ) and more likely to describe  
4  
5 themselves as a 'little frightened' (BSA 65/94 (69.1%), BW 149/185 (80.5%)  
6  
7  $p=0.048$ . It appears paradoxical therefore that BSA patients self reported  
8  
9 greater anxiety via a single indicator (BSA 46/94 (48.9%) BW 60/185 (32.4%)  
10  
11  $\text{Chi}^2 p=0.011$ ). Longitudinally there remained little ethnic difference in patients  
12  
13 who were preoccupied with anxiety (3 months  $p=0.751$ , 9 months  $p=0.926$ ).  
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16  
17  
18 Anxiety preoccupation was strongly associated with depression (HADS D and  
19  
20 PHQ-9  $p=0.0005$ ). Given the overlap of phenomena between anxiety  
21  
22 preoccupation (the strategy) and anxiety (the outcome) there was predictably a  
23  
24 strong association between them (HADS A  $r=0.63$ ,  $p=0.0005$ ). These patients  
25  
26 were also at greater risk of becoming depressed longitudinally (PHQ-9:  
27  
28 presentation  $p=0.0005$ , 3 months  $p=0.0005$ , 9 months  $p=0.0005$ ).  
29  
30  
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### 32 33 34 **Cognitive avoidance**

35  
36 Cancer is "*...something that I put to the back of my mind and don't let it*  
37  
38 *interfere with my day to day life*" BW No.118  
39  
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43 Initially BSA patients used cognitive avoidance to cope more than BW patients  
44  
45 (MW:  $p=0.0005$ ) (Fig 2c). For example, 'I deliberately push all thoughts of  
46  
47 cancer out of my mind' (BSA 61/93 (65.6%); BW 63/185 (34.4%),  $p=0.0005$ ).  
48

49  
50 Over time this ethnic difference continued but was only notable at presentation  
51  
52 as illustrated by a comparison of median scores (Fig 2c). Soon after diagnosis,  
53  
54 as one sample those who used cognitive avoidance were more likely to have  
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56 symptoms of depression (MW: PHQ-9  $p=0.007$ ; HADS D  $\geq 8$   $p=0.001$ ; Dep.T  $\geq 4$   
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3 p=0.002) and anxiety (HADS A  $\geq 8$  p=0.0005/ Anx.T.  $\geq 4$  p= 0.002). Over time  
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5 avoidant patients continued to be anxious (HADS A 3 months p=0.016, 9  
6  
7 months p=0.026) but not depressed (HADS D 3 months p=0.2, 9 months 0.14).  
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### 10 11 12 **Fighting Spirit**

13  
14 (I see cancer) *“as a challenge...a temporary state....a hurdle to get over”*

15  
16 BW patient No.172

17  
18 *“It means I have a fight on my hands but I’m determined to get better”*

19  
20  
21 BW No.354

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25 A large number of patients in both ethnic groups approached their illness with a  
26  
27 ‘fighting spirit’ (Fig 2d). For example, ‘I am determined to beat this disease’  
28  
29 (BSA 85/93 (91.4%) (n=93); BW 170/185 (91.9%) (n=185) p=1.0). There was  
30  
31 little ethnic difference in the extent to which patients used this coping strategy  
32  
33 (MW presentation p=0.47, 3 months p=0.57, 9 months p=0.2). Furthermore  
34  
35 there was no consistent association with anxiety (HADS A p=0.8, 3 months  
36  
37 p=0.4, 9 months p=0.6) or depression as one sample for example (PHQ-9  
38  
39 presentation p=0.3, 3 months p=0.2, 9 months p=0.7).  
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### 45 46 **Fatalism**

47  
48 *“It’s horrible. Why me? My mum died from cancer. My sisters have cancer. Why*  
49  
50 *is this happening? I wish I’d never woken up after my operation”* BSA No.125  
51

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54 At presentation more BSA patients were fatalistic when diagnosed with cancer  
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56 than BW patients (MW: p=0.0005) however this was largely based on one of 5  
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3 Mini MAC indicators, 'I've put myself in the hands of God' (BSA 71/94 (75.5%);  
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5 BW 60/185(32.4%)  $p=0.0005$ ). There was a gradual decrease in fatalism in  
6  
7 both ethnic groups by 9 months although it persisted among BSA patients (Fig  
8  
9 2e). Those who were fatalistic were more likely to experience depressive  
10  
11 symptoms via two tools (MW PHQ-9  $p= 0.003$ ; HADS D $\geq$ 8  $p= 0.024$ ) but not by  
12  
13 the Dep T.  $\geq$ 4 ( $p=0.101$ ). Anxiety too was associated with fatalism (HADS A  
14  
15 MW;  $p=0.011$ ). Again AnxT did not support these findings ( $p= 0.164$ ).  
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### 20 21 **Insight and Denial (CIDQ)**

22  
23 *"I'm not ill"*

24  
25 Written at the top of an uncompleted BIPQ by a patient having chemotherapy  
26  
27 for breast cancer following surgery. BW No.127 at presentation  
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29

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32 *"...part of me still feels there is nothing wrong with me and this is happening to*  
33  
34 *someone else. This is presumably my way of handling it all."* BW No.311 at 9  
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36 months  
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40 Of those who used denial as a means of coping BSA patients were  
41  
42 overrepresented, most notably soon after diagnosis ( $p=0.001$ ). The ethnic gap  
43  
44 remained longitudinally (Fig 2f). Of the three tools assessing depression only  
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46 PHQ-9 indicated an association between denial and depression albeit weakly  
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48 (MW:  $p= 0.039$ ). There was a similar difficulty in generating firm conclusions  
49  
50 about the relationship between denial and anxiety. The median scores using  
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52 HADS A and AnxT suggested a tendency towards being more anxious when  
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54 using denial.  
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5 To facilitate comparisons with Roy's 2005 [15] study, analysis of the single  
6 indicator 'I don't really believe I have cancer' originating from the MAC  
7 questionnaire was repeated. At presentation 229/278 patients (82%) accepted  
8 the reality of their diagnosis by disagreeing with the statement. Of the 27  
9 patients who didn't believe that they had cancer, more were BSA (BSA 19/93  
10 (20.2%); BW 8/185 (4.3%),  $p=0.0001$ ). Of interest is that 23 patients agreed  
11 with this statement 'sometimes' (BSA 12 (52.2%); BW 11 (47.8%)). There was  
12 a strong trend towards BSA patients who denied their diagnosis to be more  
13 anxious and depressed but sample numbers were too low to assess statistically  
14 at 9 months (Fig 2g).  
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29 We considered whether causes of distress via the distress thermometer  
30 checklist explained ethnic differences in anxiety and depression. Cancer  
31 treatments offered to both groups were similar so did not influence findings.  
32 Critically BSA patients experienced more distress from physical symptoms of  
33 illness and treatment than BW patients. In 13 out of 17 symptoms BSA patients  
34 returned higher scores than BW patients at presentation. For example, pain  
35 (BSA 51/83 (58%); BW 59/180 (32.8%)  $p=0.0001$ ), mouth sores (BSA 21/88  
36 (24.1%) BW 12/179 (6.7%)  $p=0.0001$  and fevers (BSA 18/87 (20.7%); BW  
37 5/177(2.8%)  $p=0.0001$ ). At 3 months significantly higher percentages of BSA  
38 patients reported pain, mouth sores, nausea, skin, washing and dressing and  
39 getting around as causes for distress which were not reflected in BW patients.  
40 By 9 months differences had narrowed with the exception of pain (BSA 19/31  
41 61.3% v BW 41/121 (33.9%)  $p=0.009$ ).  
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## **Discussion**

To our knowledge a comparison of how BSA and BW patients cope with cancer has not previously been reported. It should be of major concern to health care policy makers in the UK that this study provides evidence that there is a higher prevalence of anxiety and depression 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. BSA rates for depression were twice that of BW patients. For example on the HADS-D scale 35.1% of BSA compared to 16.8% of BW patients ( $p=0.001$ ) had at least moderate depression (score  $\geq 8$ ). This is a critical finding since this is almost 6 times higher than reported within the UK general population (6%).<sup>[26]</sup> Depression rates for BW patients (PHQ-9 18.3%, HADS D $\geq 8$  16.8%) were similar to those reported in a recent meta-analysis of cancer patients (16.3%), being approximately 2.5 times higher than in the general population.<sup>[4]</sup> What is most striking is the incidence of severe depression in BSA patients which is reflected in their HAD-D score  $\geq 11$  (BSA 24.5% v BW 5.9%  $p=0.0001$ ). This was confirmed on a version of the PHQ-9 $\geq 10$  developed for India (35.3% BSA v 18.3% BW  $p=0.05$ ). However differences were not just confined to depression. Significantly higher levels of anxiety were seen in BSA patients (HADS A $\geq 8$  BSA 54.3% v 36.2% BW  $p=0.006$ ) including severe anxiety (HADS A  $\geq 11$  BSA 34%v18.9%  $p=0.008$ ). Patients also exhibited more anxiety with rates far higher than in the general population (DSMIV 5-15%).<sup>[27]</sup>

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3 These findings supported trends in other studies, notably a pilot study. Using  
4 the cut-off (HADS  $\geq 10$ ), Roy [15] reported BSA 20.7% v BW 10.4% ( $p=0.001$ )  
5 had severe depressive symptoms. With a slightly higher cut-off ( $\geq 11$ ) our study  
6 findings at presentation again pointed to a significant difference (BSA 34% v  
7 BW 18.9%  $p=0.008$ ). [15] These concur with other reports which suggest that  
8 ethnic minority cancer patients experience more psychological distress than  
9 patients from host populations. [16, 17, 28, 29] Ethnic minorities are however  
10 not heterogeneous. There are for example variations in baseline common  
11 mental disorders in the UK among some BSA groups. [6] However over 50% of  
12 our BSA sample were Indian Hindus.  
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27 What is very interesting is that the HADS-D, PHQ-9 and DepT showed higher  
28 levels of depression in both ethnic groups at 3 months after presentation, this  
29 being steeper among BSA patients. Although rates fell back, BSA consistently  
30 reported higher rates of depression than BW patients longitudinally. The  
31 decline in the prevalence of anxiety was consistent in both groups over time but  
32 the ethnic difference persisted. These findings confirmed our first hypothesis.  
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43 A counter intuitive finding in this study is the similarity of anxiety and depression  
44 in patients being treated with curative intent (radical) and palliative patients.  
45 Although there was a poorer rate of return of questionnaires at 3 and 9 months  
46 the ratio of radical and palliative patients remained the same (HADS D 7v8  
47 presentation  $p=0.08$ , 3 months  $p=0.58$ , 9 months  $p=1.0$ ). In fact this finding is  
48 consistent with a recent meta-analysis. [4]  
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3 Previously we had considered whether there were differences in knowledge  
4 about cancer and levels of trust in doctors between BSA and BW patients. High  
5 levels of trust were found in both groups and differences in knowledge about  
6 cancer did not explain the increased psychological morbidity.[25, 30] However  
7 of particular interest were the marked differences in coping styles between the  
8 two groups of patients.  
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18 At presentation the rates of fatalism helplessness/hopelessness and domains of  
19 denial were far higher among BSA patients and there was a strong correlation  
20 between these coping strategies and the incidence of anxiety and depression in  
21 both ethnic groups. Helplessness/hopelessness is strongly associated with  
22 anxiety and depression globally, findings replicated in this study.[31-37] A  
23 similar pattern was seen in the use of cognitive avoidance. Fatalism too was  
24 associated with higher levels of anxiety and depression as demonstrated on  
25 both the PHQ-9 and HADS which supports research from India [38, 39] and  
26 maladaptive behaviours in the UK.[40, 41]  
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40 In our previous study [15] denial was significantly related to depression in both  
41 BW and BSA patients. BSA patients were far more likely to agree with the  
42 statement in the MAC questionnaire (Question 38) 'I don't really believe I have  
43 cancer'. In this study a minority of patients denied their diagnosis but again it  
44 was more common among BSA patients via the same indicator until 9 months  
45 (MW presentation p=0.0005, 3 months p=0.001, 9 months p=0.2). Initially this  
46 was strongly associated with anxiety and depression however the sample  
47 numbers were too small to consider longitudinal associations.  
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What is puzzling is that although BSA patients remained more depressed and anxious than BW patients longitudinally, by 3 and 9 months the use of coping strategies did not explain this. With the exception of helplessness/hopelessness at 3 months ( $p=0.043$ ) the ethnic differences in use of coping strategies are insignificant but the trend towards higher anxiety and depression among BSA patients remained. Even taking into account a lag time for the alleviation of symptoms of anxiety and depression after less use of maladaptive coping, there remains an incomplete explanation as to why more BSA patients in particular remain so distressed. Our second hypothesis was therefore only partially confirmed. A retrospective audit into referral to psycho oncology or prescribing patterns in the two groups did not suggest a difference that could account for this.

We considered whether physical symptoms explained this ethnic gap. BSA patients experienced significantly more pain, nausea, skin concerns, mouth sores, tingling and feeling swollen at 3 months, which may account for the peak in depression particularly among BSA patients at that time but the ethnic difference in anxiety and depression persisted with only one symptom (pain) indicating an ethnic difference at 9 months. The somatisation of physical symptoms notwithstanding, this is insufficient evidence to explain the difference.

We wonder whether greater involvement of the General Practitioner (GP) at a very early stage may reduce anxiety and depression in BSA patients given the difference between BW and BSA patients' preferences for the source of

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3 information about their cancer. In an earlier study 66.2% of BSA compared to  
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5 5.1% BW wrote that they would prefer to receive their cancer diagnosis from  
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7 their GP ( $p=0.001$ ).<sup>[42]</sup> In this study 49.5% of BSA patients' preferred source of  
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9 sensitive information was their GP compared to 16.9% of BW patients  
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11 ( $p=0.0001$ ). The main reason why the GP is the preferred source of information  
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13 is that the majority of BSA patients prefer to discuss their illness in their mother  
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15 tongue.<sup>[42]</sup> Of note is that 89% of BSA patients in this series were registered  
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17 with a BSA GP.  
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### 23 **Recommendations**

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27 The nature of coping strategies among BSA patients in the first few months after  
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29 diagnosis requires investigation, the aim being to reduce the associated distress  
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31 as early as possible along the cancer trajectory. Further investigation into the  
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33 role of the GP in partnership to support patients, particularly for BSA patients, is  
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35 advised.  
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41 This study provides evidence of worryingly high levels of anxiety and depression  
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43 among the largest ethnic minority in the UK. Further investigation is required if  
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45 this disparity is to be reduced.  
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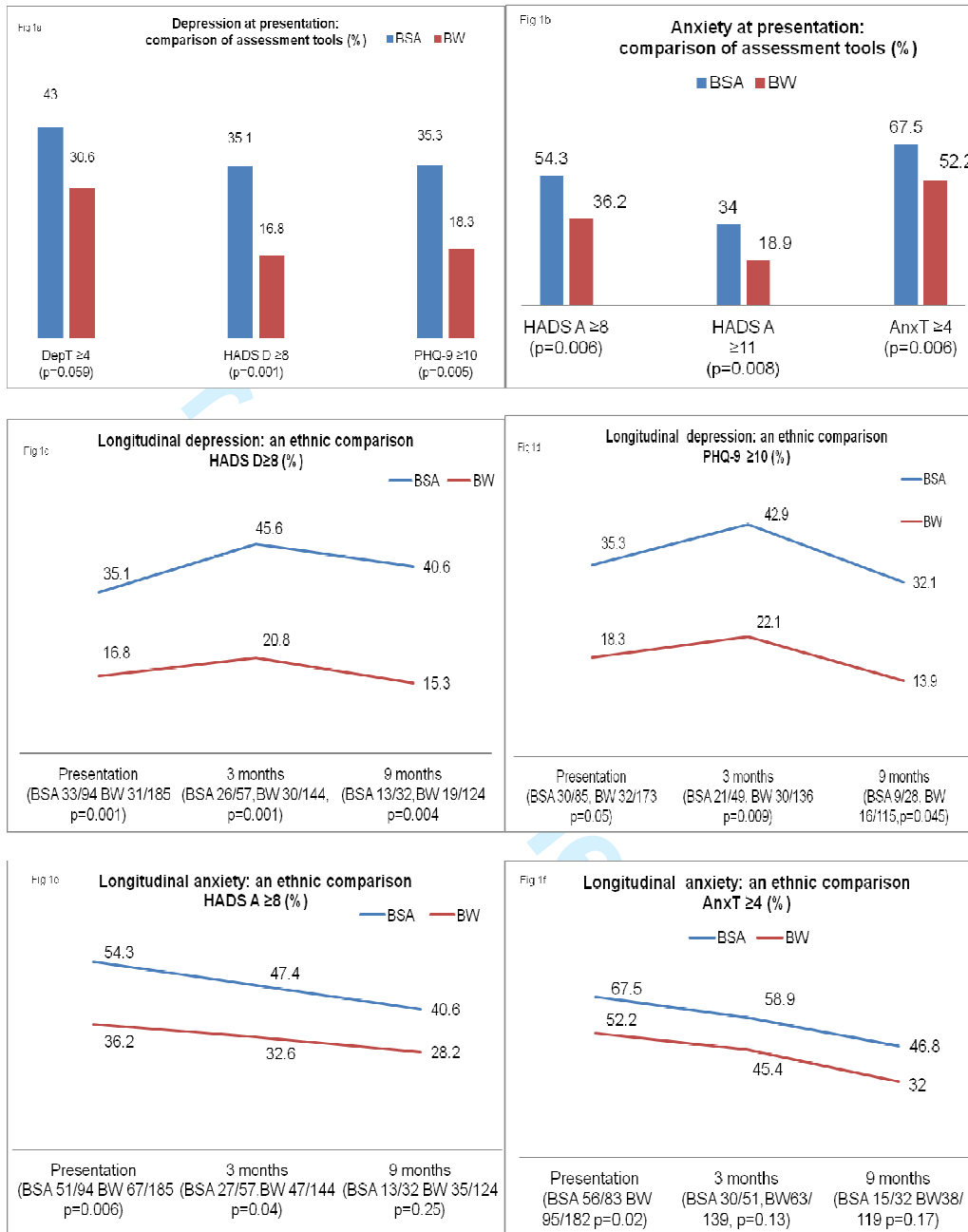
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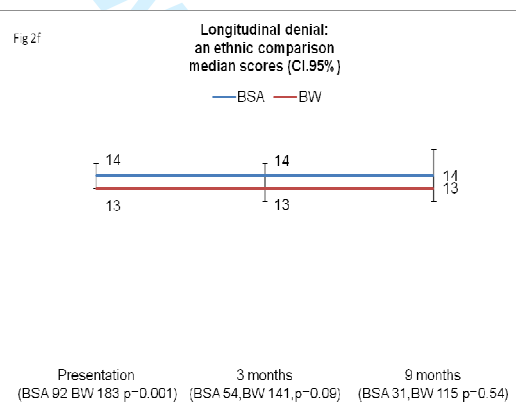
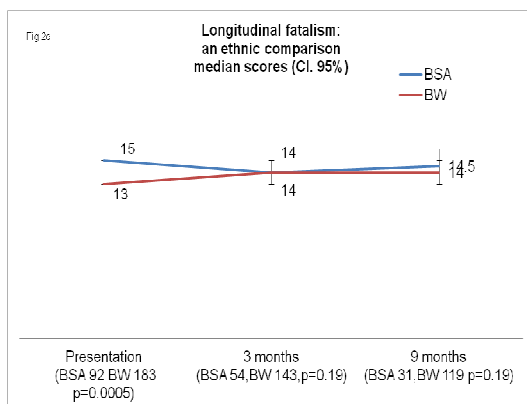
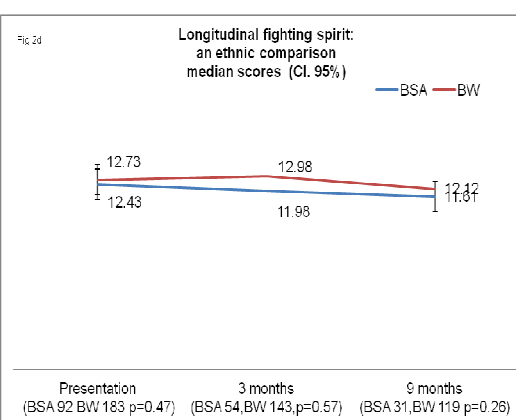
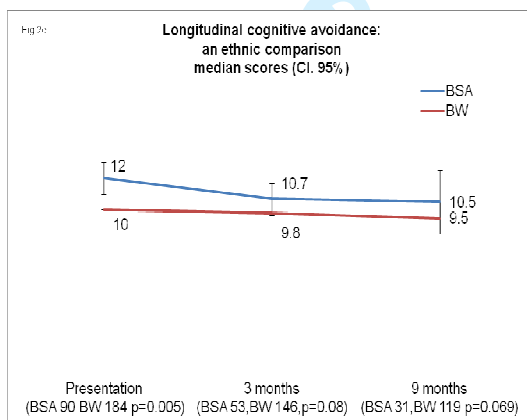
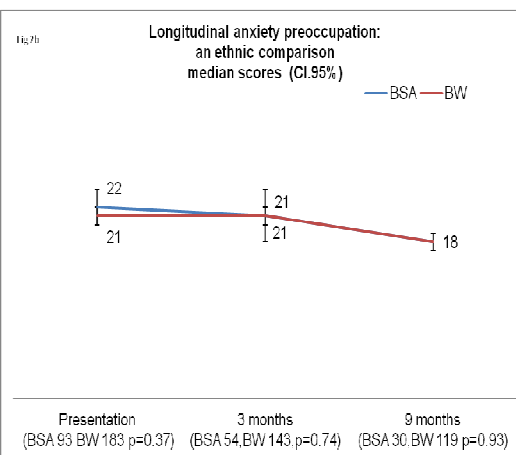
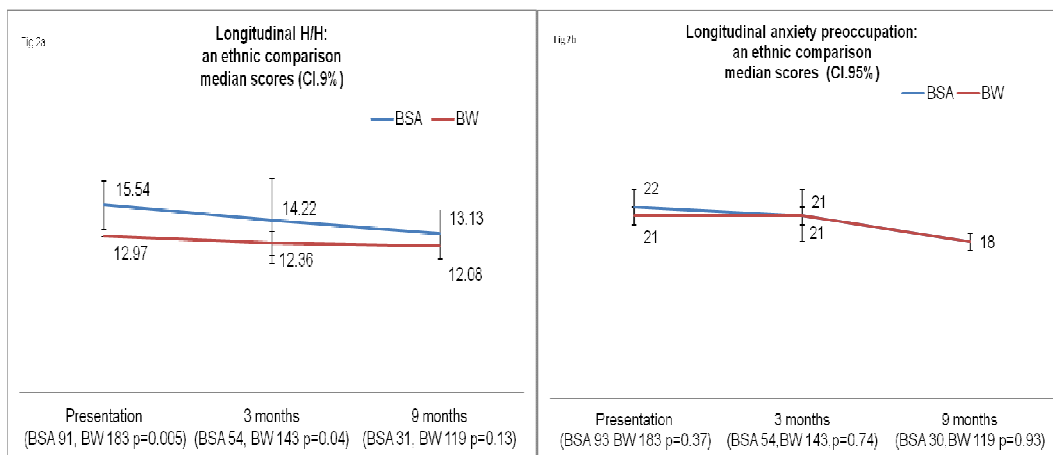
## Longitudinal comparison of anxiety and depression in BSA and BW patients



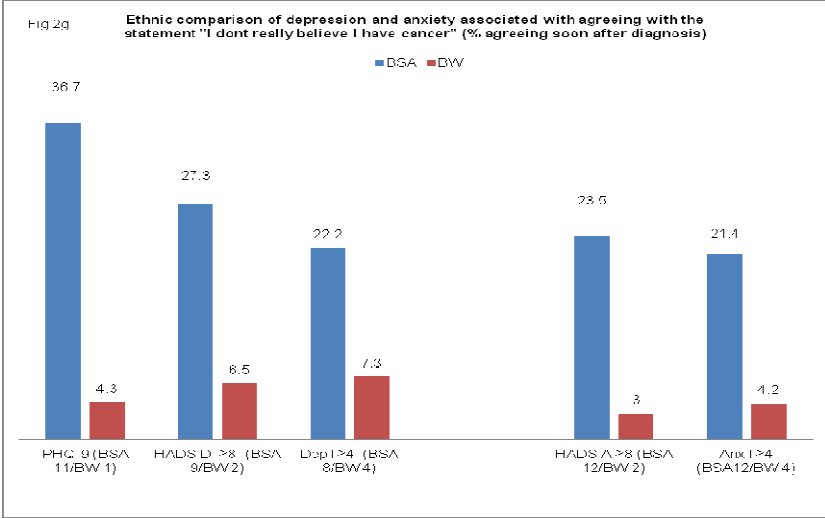


**Longitudinal comparison of coping strategies in BSA and BW patients: median scores with 95% CI. (where absent CI=0)**

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peer review only

Longitudinal associations  
between coping strategies and  
depression via PHQ9

| Mann Whitney<br>U Test (PHQ-9 9v10) |      |    | n=  | Mean Rank<br>Score (MRS) | Median (IQR) | U      | Z      | r     | p-value |
|-------------------------------------|------|----|-----|--------------------------|--------------|--------|--------|-------|---------|
|                                     | Pres | ND | 193 | 112.38                   | 12(10:15.5)  |        |        |       |         |
|                                     |      | D  | 62  | 176.61                   | 17(13:21)    | 2969   | -5.987 | 0.37  | 0.0005  |
|                                     | 3m   | ND | 134 | 76.02                    | 11(8:14)     |        |        |       |         |
|                                     |      | D  | 49  | 135.69                   | 17(16:19)    | 1142   | -6.808 | 0.5   | 0.0005  |
|                                     | 9m   | ND | 116 | 63.98                    | 11(9:15.5)   |        |        |       |         |
|                                     |      | D  | 23  | 100.37                   | 16.5(11:19)  | 635.5  | -3.998 | 0.34  | 0.0005  |
| Cog. Avoidance                      | Pres | ND | 192 | 120.03                   | 10(9:12)     |        |        |       |         |
|                                     |      | D  | 61  | 148.93                   | 11(10:13)    | 4518.5 | -2.712 | 0.16  | 0.007   |
|                                     | 3m   | ND | 134 | 90.10                    | 10(8:12)     |        |        |       |         |
|                                     |      | D  | 49  | 97.20                    | 11(10:12)    | 3028   | -.810  | 0.06  | 0.418   |
|                                     | 9m   | ND | 116 | 67.15                    | 10(8:12)     |        |        |       |         |
|                                     |      | D  | 23  | 84.37                    | 11(10:13)    | 1003.5 | -1.886 | 0.16  | 0.059   |
| Fatalism                            | Pres | ND | 205 | 123.64                   | 14(12:16)    |        |        |       |         |
|                                     |      | D  | 53  | 152.18                   | 15(13:17)    | 4740.5 | -2.474 | 0.15  | 0.013   |
|                                     | 3m   | ND | 134 | 88.95                    | 14(12:16)    |        |        |       |         |
|                                     |      | D  | 49  | 100.35                   | 14(13:16)    | 2874   | -1.297 | 0.09  | 0.15    |
|                                     | 9m   | ND | 116 | 67.81                    | 14(12:15)    |        |        |       |         |
|                                     |      | D  | 23  | 81.07                    | 15(13:19)    | 1079.5 | -1.451 | 0.12  | 0.147   |
| Anx. Preoccup.                      | Pres | ND | 194 | 113.58                   | 20(17:23)    |        |        |       |         |
|                                     |      | D  | 62  | 175.19                   | 24.5 (21:27) | 3119   | -5.987 | 0.37  | 0.0005  |
|                                     | 3m   | ND | 134 | 78.86                    | 19(16:23)    |        |        |       |         |
|                                     |      | D  | 49  | 127.94                   | 24(21:27)    | 1522   | -5.559 | 0.4   | 0.0005  |
|                                     | 9m   | ND | 116 | 62.86                    | 18(15:20.5)  |        |        |       |         |
|                                     |      | D  | 23  | 106                      | 24(22:26)    | 506    | -4.704 | 0.4   | 0.0005  |
| Fight. Spirit                       | Pres | ND | 194 | 130.87                   | 13(12:14)    |        |        |       |         |
|                                     |      | D  | 62  | 121.08                   | 13(11:14)    | 5554   | -.916  | -0.05 | 0.359   |
|                                     | 3m   | ND | 134 | 94.60                    | 12(11:14)    |        |        |       |         |
|                                     |      | D  | 49  | 84.90                    | 12(11:13)    | 2935   | -1.109 | 0.08  | 0.268   |
|                                     | 9m   | ND | 116 | 70.43                    | 12(10:14)    |        |        |       |         |
|                                     |      | D  | 23  | 67.85                    | 13(11:13)    | 1284.5 | -.283  | 0.02  | 0.777   |
| Denial                              | Pres | ND | 194 | 124.49                   | 14 (12:15)   |        |        |       |         |
|                                     |      | D  | 62  | 141.05                   | 14.5 (12:17) | 5236   | -1.542 | -0.09 | 0.123   |
|                                     | 3m   | ND | 130 | 87.52                    | 13(12:15)    |        |        |       |         |
|                                     |      | D  | 49  | 96.58                    | 14(12:15)    | 2862.5 | -1.051 | 0.07  | 0.293   |
|                                     | 9m   | ND | 114 | 68.82                    | 12(11.50:15) |        |        |       |         |
|                                     |      | D  | 23  | 69.89                    | 13(11:16)    | 1290.5 | -.119  | 0.01  | 0.905   |

Longitudinal associations between coping strategies and depression via DepT

| Mann Whitney    |      |      | n=  | Mean Rank Score (MRS) | Md(IQR)     | U        | Z      | r      | p-value |
|-----------------|------|------|-----|-----------------------|-------------|----------|--------|--------|---------|
| <b>DepT 3v4</b> | H/H  | Pres | ND  | 170                   | 108.52      | 12(9:15) |        |        |         |
|                 |      | D    | 92  | 173.96                | 16.5(13:19) | 3913.5   | -6.698 | 0.41   | 0.0005  |
|                 | 3m   | ND   | 118 | 81.49                 | 12(9:16)    |          |        |        |         |
|                 |      | D    | 68  | 114.34                | 15(12:19)   | 2595     | -4.022 | 0.29   | 0.0005  |
|                 | 9m   | ND   | 113 | 66.51                 | 11.5(9:15)  |          |        |        |         |
|                 |      | D    | 34  | 98.88                 | 15(12:17)   | 1075     | -3.905 | 0.32   | 0.0005  |
| Cog. Avoid.     | Pres | ND   | 169 | 120.10                | 10(8:12)    |          |        |        |         |
|                 |      | D    | 91  | 149.81                | 11(10:12)   | 5932.5   | -3.067 | 0.19   | 0.002   |
|                 | 3m   | ND   | 117 | 90.51                 | 10(9:15)    |          |        |        |         |
|                 |      | D    | 68  | 97.29                 | 11(9:12)    | 3686.5   | -.838  | 0.06   | 0.402   |
|                 | 9m   | ND   | 113 | 73.92                 | 10(8:12)    |          |        |        |         |
|                 |      | D    | 34  | 74.26                 | 10(8:12)    | 1912     | -.042  | 0.0003 | 0.967   |
| Fatalism        | Pres | ND   | 170 | 125.88                | 14(12:16)   |          |        |        |         |
|                 |      | D    | 92  | 141.88                | 14(13:16)   | 6865     | -1.641 | 0.1    | 0.101   |
|                 | 3m   | ND   | 118 | 88.49                 | 13(12:15)   |          |        |        |         |
|                 |      | D    | 68  | 102.19                | 14(12.5:16) | 3421     | -1.684 | 0.12   | 0.092   |
|                 | 9m   | ND   | 113 | 72.94                 | 13(12:16)   |          |        |        |         |
|                 |      | D    | 34  | 77.53                 | 14(13:16)   | 1801     | -.555  | 0.04   | 0.579   |
| Anx. Preocc.    | Pres | ND   | 171 | 103.12                | 20(17:22)   |          |        |        |         |
|                 |      | D    | 92  | 185.68                | 24(22:27)   | 2927.5   | -8.412 | 0.52   | 0.0005  |
|                 | 3m   | ND   | 119 | 75.85                 | 19(17:22)   |          |        |        |         |
|                 |      | D    | 68  | 125.76                | 24(21:27)   | 1886     | -6.079 | 0.44   | 0.0005  |
|                 | 9m   | ND   | 114 | 66.54                 | 20(17:23)   |          |        |        |         |
|                 |      | D    | 34  | 101.19                | 24(21:27)   | 1030.5   | -4.145 | 0.34   | 0.0005  |
| Fighting Spirit | Pres | ND   | 171 | 132.79                | 13(11:14)   |          |        |        |         |

|               |      |    |     |        |             |        |        |       |       |
|---------------|------|----|-----|--------|-------------|--------|--------|-------|-------|
|               |      | D  | 92  | 130.53 | 13(11.5:14) | 7731   | -0.232 | 0.01  | 0.817 |
|               | 3m   | ND | 119 | 93.64  | 13(11:14.5) |        |        |       |       |
|               |      | D  | 68  | 94.63  | 13(11:14)   | 4003   | -.122  | 0.008 | 0.903 |
|               | 9m   | ND | 114 | 77.39  | 13(11:15)   |        |        |       |       |
|               |      | D  | 34  | 64.81  | 12(11:14)   | 1608.5 | -1.518 | 0.12  | 0.129 |
| Denial (CIDQ) | Pres | ND | 172 | 132.44 | 14(12:15)   |        |        |       |       |
|               |      | D  | 92  | 132.61 | 13.5(12:16) | 7901.5 | -0.018 | 0.001 | 0.986 |
|               | 3m   | ND | 119 | 90.95  | 13(12:15)   |        |        |       |       |
|               |      | D  | 68  | 99.34  | 13(12:16)   | 3683   | -1.026 | 0.06  | 0.305 |
|               | 9m   | ND | 115 | 76.65  | 13(12:15)   |        |        |       |       |
|               |      | D  | 34  | 69.41  | 13(11:15)   | 1765   | -.865  | 0.07  | 0.387 |

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**Longitudinal associations between coping strategies and anxiety via HADS A**

| Mann<br>Whitney<br>U Test HADS A 7v8 |      |    | n=  | Mean<br>Rank<br>Score | Median<br>(IQR) | U      | Z       | r    | p-value |
|--------------------------------------|------|----|-----|-----------------------|-----------------|--------|---------|------|---------|
| H/H                                  | Pres | NA | 158 | 107.85                | 12(9:15)        |        |         |      |         |
|                                      |      | A  | 116 | 177.89                | 16(13:19)       | 4479   | -7.255  | 0.43 | 0.0005  |
|                                      | 3m   | NA | 127 | 82.14                 | 11(8:14)        |        |         |      |         |
|                                      |      | A  | 70  | 129.59                | 16(12:18.5)     | 2303.5 | -5.636  | 0.4  | 0.0005  |
|                                      | 9m   | NA | 103 | 63.25                 | 11(8:14)        |        |         |      |         |
|                                      |      | A  | 45  | 100.26                | 15(13:16)       | 1158.5 | -4.875  | 0.4  | 0.0005  |
| Cog. Avoidance                       | Pres | NA | 157 | 121.87                | 10(8:12)        |        |         |      |         |
|                                      |      | A  | 115 | 156.47                | 11(10:14)       | 6731   | -3.618  | 0.22 | 0.0005  |
|                                      | 3m   | NA | 126 | 91.30                 | 10(8:11)        |        |         |      |         |
|                                      |      | A  | 70  | 111.46                | 11(9.5:12)      | 3503   | -2.402  | 0.17 | 0.016   |
|                                      | 9m   | NA | 103 | 69.35                 | 10(8:12)        |        |         |      |         |
|                                      |      | A  | 45  | 86.28                 | 11(9:12)        | 1787.5 | -2.226  | 0.18 | 0.026   |
| Fatalism                             | Pres | NA | 158 | 127.62                | 14(12:15.5)     |        |         |      |         |
|                                      |      | A  | 117 | 152.02                | 15(12:15)       | 7603   | -2.530  | 0.15 | 0.011   |
|                                      | 3m   | NA | 127 | 93.93                 | 14(13:16)       |        |         |      |         |
|                                      |      | A  | 70  | 108.21                | 14(12:16)       | 3800   | -1.693  | 0.12 | 0.090   |
|                                      | 9m   | NA | 103 | 74.87                 | 14(12:16)       |        |         |      |         |
|                                      |      | A  | 44  | 71.97                 | 13(12:15)       | 2176.5 | -.381   | 0.03 | 0.703   |
| Anx .Preoccup.                       | Pres | NA | 159 | 96.14                 | 19(16:21)       |        |         |      |         |
|                                      |      | A  | 117 | 196.06                | 24(22:27)       | 2566.5 | -10.374 | 0.63 | 0.0005  |
|                                      | 3m   | NA | 127 | 74.33                 | 18(16:21)       |        |         |      |         |
|                                      |      | A  | 70  | 143.76                | 24(22:27)       | 1312   | -8.195  | 0.58 | 0.0005  |
|                                      | 9m   | NA | 103 | 58.83                 | 17(15:20)       |        |         |      |         |
|                                      |      | A  | 44  | 109.52                | 23(21:25)       | 703    | -6.627  | 0.54 | 0.0005  |
| Fighting Spirit                      | Pres | NA | 159 | 138.95                | 13(11:14)       |        |         |      |         |
|                                      |      | A  | 116 | 136.70                | 13(11:14)       | 9071.5 | -0.234  | 0.01 | 0.815   |

|               |      |    |     |        |               |        |        |      |       |
|---------------|------|----|-----|--------|---------------|--------|--------|------|-------|
|               | 3m   | NA | 127 | 101.14 | 12(11:14)     |        |        |      |       |
|               |      | A  | 70  | 95.11  | 12 (11:14)    | 4173   | -.718  | 0.05 | 0.473 |
|               | 9m   | NA | 103 | 75.50  | 12(10:14)     |        |        |      |       |
|               |      | A  | 45  | 72.21  | 12(11:13)     | 2214.5 | -.433  | 0.03 | 0.665 |
| Denial (CIDQ) | Pres | NA | 160 | 135.80 | 13(12:15)     |        |        |      |       |
|               |      | A  | 115 | 141.06 | 14(12:16)     | 884.5  | -0.544 | 0.03 | 0.587 |
|               | 3m   | NA | 125 | 93.54  | 13(12:15)     |        |        |      |       |
|               |      | A  | 70  | 105.96 | 13.5(12:15.5) | 3818   | -1.484 | 0.1  | 0.138 |
|               | 9m   | NA | 98  | 72.10  | 13(11:15)     |        |        |      |       |
|               |      | A  | 45  | 73.36  | 13(12:15)     | 2214.5 | -.170  | 0.01 | 0.865 |

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**Longitudinal associations between coping strategies and depression (HADS D)**

| <b>Mann<br/>Whitney<br/>U Test HADS D 7v8</b> |      |    | <b>n=</b> | <b>Mean<br/>Rank<br/>Score</b> | <b>Median (IQR)</b> | <b>U</b> | <b>Z</b> | <b>r</b> | <b>p-value</b> |
|---|------|----|-----------|--------------------------------|---------------------|----------|----------|----------|----------------|
| H/H   | Pres | ND | 211       | 119.09                         | 12(10:15)           |          |          |          |                |
|   |      | D  | 63        | 199.17                         | 17.5(14:21.5)       | 2761.5   | -7.065   | 0.42     | 0.0005         |
|   | 3m   | ND | 145       | 83.79                          | 11(9:15.5)          |          |          |          |                |
|   |      | D  | 52        | 141.41                         | 16.5(11:19)         | 1564.5   | -6.303   | 0.4      | 0.0005         |
|   | 9m   | ND | 117       | 65.87                          | 11(9:15)            |          |          |          |                |
|   |      | D  | 31        | 107.08                         | 16(14:18)           | 803.5    | -4.802   | 0.39     | 0.0005         |
| Cog. Avoid                                    | Pres | ND | 210       | 128.22                         | 10(9:12)            |          |          |          |                |
|   |      | D  | 62        | 164.56                         | 11(10:13)           | 4770.5   | -3.227   | 0.19     | 0.001          |
|   | 3m   | ND | 144       | 95.41                          | 10(8:12)            |          |          |          |                |
|   |      | D  | 52        | 107.05                         | 11(10:13)           | 3299.5   | -1.278   | 0.09     | 0.201          |
|   | 9m   | ND | 117       | 71.86                          | 10(8:12)            |          |          |          |                |
|   |      | D  | 31        | 84.45                          | 11(9:12)            | 1505     | -1.464   | 0.12     | 0.143          |
| Fatalism                                      | Pres | ND | 211       | 132.59                         | 14(12:16)           |          |          |          |                |
|   |      | D  | 64        | 155.85                         | 15.5(13:17)         | 5609.5   | -2.062   | 0.12     | 0.039          |
|   | 3m   | ND | 145       | 96.07                          | 14(12:15)           |          |          |          |                |
|   |      | D  | 52        | 107.16                         | 14(13:17)           | 3345.5   | -1.211   | 0.08     | 0.226          |
|   | 9m   | ND | 117       | 73.19                          | 14(12:15)           |          |          |          |                |
|   |      | D  | 30        | 77.17                          | 14(13:16)           | 1660     | -.459    | 0.03     | 0.646          |
| Anx. Peocc                                    | Pres | ND | 212       | 121.09                         | 20(17:23)           |          |          |          |                |
|   |      | D  | 64        | 196.18                         | 25(22.5:27.5)       | 3092.5   | -6.610   | 0.39     | 0.0005         |
|   | 3m   | ND | 145       | 83.76                          | 18(15:20.5)         |          |          |          |                |
|   |      | D  | 52        | 141.41                         | 24(22:26)           | 1559.5   | -6.278   | 0.44     | 0.0005         |
|   | 9m   | ND | 117       | 76.65                          | 18(15:21)           |          |          |          |                |
|   |      | D  | 30        | 103.08                         | 23(18:26)           | 882.5    | -4.203   | 0.34     | 0.0005         |
| Fighting Spirit                               | Pres | ND | 212       | 138.95                         | 13(12:14)           |          |          |          |                |



|        |      |    |     |        |              |        |        |      |       |
|--------|------|----|-----|--------|--------------|--------|--------|------|-------|
|        |      | D  | 63  | 134.80 | 13(11:14)    | 6476.5 | -.368  | 0.02 | 0.713 |
|        | 3m   | ND | 145 | 104.56 | 13(10:14)    |        |        |      |       |
|        |      | D  | 52  | 83.51  | 12(11:13)    | 2964.5 | -2.309 | 0.16 | 0.021 |
|        | 9m   | ND | 117 | 76.65  | 12(11:14)    |        |        |      |       |
|        |      | D  | 31  | 66.40  | 12(10:13)    | 1562.5 | -1.192 | 0.09 | 0.233 |
| Denial | Pres | ND | 211 | 138.33 | 13 (12:15)   |        |        |      |       |
|        |      | D  | 64  | 136.90 | 14 (12:16)   | 6681.5 | -.127  | 0.07 | 0.899 |
|        | 3m   | ND | 141 | 94.36  | 13(11.50:15) |        |        |      |       |
|        |      | D  | 54  | 107.5  | 14(11:16)    | 3294   | -1.466 | 0.10 | 0.143 |
|        | 9m   | ND | 114 | 75.29  | 13(12:16)    |        |        |      |       |
|        |      | D  | 30  | 61.92  | 13(10:14)    | 1392.5 | -1.573 | 0.13 | 0.116 |

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Longitudinal associations between coping strategies and depression via PHQ-9

| Mann Whitney U Test (PHQ-9 9v10) |      |    | n=  | Mean Rank Score (MRS) | Median (IQR) | U      | Z      | r    | p-value |
|----------------------------------|------|----|-----|-----------------------|--------------|--------|--------|------|---------|
|                                  | Pres | ND | 193 | 112.38                | 12(10:15.5)  |        |        |      |         |
|                                  |      | D  | 62  | 176.61                | 17(13:21)    | 2969   | -5.987 | 0.37 | 0.0005  |
|                                  | 3m   | ND | 134 | 76.02                 | 11(8:14)     |        |        |      |         |
|                                  |      | D  | 49  | 135.69                | 17(16:19)    | 1142   | -6.808 | 0.5  | 0.0005  |
|                                  | 9m   | ND | 116 | 63.98                 | 11(9:15.5)   |        |        |      |         |
|                                  |      | D  | 23  | 100.37                | 16.5(11:19)  | 635.5  | -3.998 | 0.34 | 0.0005  |
| Cog. Avoidance                   | Pres | ND | 192 | 120.03                | 10(9:12)     |        |        |      |         |
|                                  |      | D  | 61  | 148.93                | 11(10:13)    | 4518.5 | -2.712 | 0.16 | 0.007   |
|                                  | 3m   | ND | 134 | 90.10                 | 10(8:12)     |        |        |      |         |
|                                  |      | D  | 49  | 97.20                 | 11(10:12)    | 3028   | -.810  | 0.06 | 0.418   |
|                                  | 9m   | ND | 116 | 67.15                 | 10(8:12)     |        |        |      |         |
|                                  |      | D  | 23  | 84.37                 | 11(10:13)    | 1003.5 | -1.886 | 0.16 | 0.059   |
| Fatalism                         | Pres | ND | 205 | 123.64                | 14(12:16)    |        |        |      |         |
|                                  |      | D  | 53  | 152.18                | 15(13:17)    | 4740.5 | -2.474 | 0.15 | 0.013   |
|                                  | 3m   | ND | 134 | 88.95                 | 14(12:16)    |        |        |      |         |
|                                  |      | D  | 49  | 100.35                | 14(13:16)    | 2874   | -1.297 | 0.09 | 0.15    |
|                                  | 9m   | ND | 116 | 67.81                 | 14(12:15)    |        |        |      |         |
|                                  |      | D  | 23  | 81.07                 | 15(13:19)    | 1079.5 | -1.451 | 0.12 | 0.147   |
| Anx. Preoccup.                   | Pres | ND | 194 | 113.58                | 20(17:23)    |        |        |      |         |
|                                  |      | D  | 62  | 175.19                | 24.5 (21:27) | 3119   | -5.987 | 0.37 | 0.0005  |
|                                  | 3m   | ND | 134 | 78.86                 | 19(16:23)    |        |        |      |         |
|                                  |      | D  | 49  | 127.94                | 24(21:27)    | 1522   | -5.559 | 0.4  | 0.0005  |
|                                  | 9m   | ND | 116 | 62.86                 | 18(15:20.5)  |        |        |      |         |
|                                  |      | D  | 23  | 106                   | 24(22:26)    | 506    | -4.704 | 0.4  | 0.0005  |
| Fight. Spirit                    | Pres | ND | 194 | 130.87                | 13(12:14)    |        |        |      |         |

|        |      |    |     |        |              |        |        |       |       |
|--------|------|----|-----|--------|--------------|--------|--------|-------|-------|
|        |      | D  | 62  | 121.08 | 13(11:14)    | 5554   | -0.916 | -0.05 | 0.359 |
|        | 3m   | ND | 134 | 94.60  | 12(11:14)    |        |        |       |       |
|        |      | D  | 49  | 84.90  | 12(11:13)    | 2935   | -1.109 | 0.08  | 0.268 |
|        | 9m   | ND | 116 | 70.43  | 12(10:14)    |        |        |       |       |
|        |      | D  | 23  | 67.85  | 13(11:13)    | 1284.5 | -0.283 | 0.02  | 0.777 |
| Denial | Pres | ND | 194 | 124.49 | 14 (12:15)   |        |        |       |       |
|        |      | D  | 62  | 141.05 | 14.5 (12:17) | 5236   | -1.542 | -0.09 | 0.123 |
|        | 3m   | ND | 130 | 87.52  | 13(12:15)    |        |        |       |       |
|        |      | D  | 49  | 96.58  | 14(12:15)    | 2862.5 | -1.051 | 0.07  | 0.293 |
|        | 9m   | ND | 114 | 68.82  | 12(11.50:15) |        |        |       |       |
|        |      |    | 23  | 69.89  | 13(11:16)    | 1290.5 | -0.119 | 0.01  | 0.905 |

### Longitudinal associations between treatment intent and depression

| HADS<br>D 7v8 |              |      | n=  | ≤7  | %    | ≥8 | %    | p value |
|---------------|--------------|------|-----|-----|------|----|------|---------|
|               | Presentation | Rad  | 188 | 151 | 80.3 | 37 | 19.7 |         |
|               |              | Pall | 91  | 64  | 70.3 | 27 | 29.7 | 0.088   |
|               | 3 months     | Rad  | 136 | 96  | 70.6 | 40 | 29.4 |         |
|               |              | Pall | 65  | 49  | 75.4 | 16 | 24.6 | 0.588   |
|               | 9 months     | Rad  | 111 | 88  | 79.3 | 23 | 20.7 |         |
|               |              | Pall | 45  | 36  | 80   | 9  | 20   | 1.0     |

### Longitudinal associations between treatment intent and anxiety

| HADS<br>A 7v8 |              |      | n=  | ≤7  | %    | ≥8 | %    | p value |
|---------------|--------------|------|-----|-----|------|----|------|---------|
|               | Presentation | Rad  | 188 | 112 | 59.6 | 76 | 40.4 |         |
|               |              | Pall | 91  | 49  | 53.8 | 42 | 46.2 | 0.436   |
|               | 3 months     | Rad  | 136 | 88  | 64.7 | 48 | 35.3 |         |
|               |              | Pall | 65  | 39  | 60   | 26 | 40   | 0.624   |
|               | 9 months     | Rad  | 111 | 71  | 64   | 40 | 36   |         |
|               |              | Pall | 45  | 37  | 82.2 | 8  | 17.8 | 0.041   |

**Supplementary Table 1: Influence of deprivation**

| Ethnicity and anx/ dep corrected for deprivation | No. | Pearson product-moment correlation | p-value | No. | Correlation corrected for deprivation | p-value |
|--|-----|------------------------------------|---------|-----|---------------------------------------|---------|
| HADS D   | 277 | -.274                              | 0.0005  | 276 | -.235                                 | 0.0005  |
| PHQ-9  | 256 | -.257                              | 0.0005  | 255 | -.208                                 | 0.001   |
| DepT   | 262 | -.131                              | 0.033   | 261 | -.118                                 | 0.057   |
| AnxT   | 263 | -.087                              | .158    | 262 | -0.083                                | .179    |
| HADS A   | 277 | -.147                              | 0.014   | 276 | -.093                                 | .123    |

Supplementary Table 2: Ethnic differences in anxiety and depression

| Mann Whitney U Test |          |     | n=  | Mean Rank Score | Md(IQR)   | U      | Z      | r     | Sig.   |
|---------------------|----------|-----|-----|-----------------|-----------|--------|--------|-------|--------|
| PHQ-9               | Present. | BSA | 85  | 156.95          | 7(3:12)   |        |        |       |        |
|                     |          | BW  | 173 | 116.01          | 4(2:8)    | 5019   | -4.158 | -0.29 | 0.0005 |
|                     | 3m       | BSA | 49  | 112.64          | 9(5:12)   |        |        |       |        |
|                     |          | BW  | 136 | 85.92           | 5(2:8)    | 2369   | -3.003 | 0-.22 | 0.003  |
|                     | 9 m      | BSA | 28  | 84.32           | 4 (2:10)  |        |        |       |        |
|                     |          | BW  | 115 | 69.00           | 3(1:7.5)  | 1265   | -1.767 | -0.14 | 0.077  |
| HADS D              | Present. | BSA | 94  | 166.43          | 5(2:10)   |        |        |       |        |
|                     |          | BW  | 185 | 126.57          | 3(1:6)    | 6211   | -3.919 | -0.23 | 0.0005 |
|                     | 3m       | BSA | 57  | 125.31          | 6.5(4:10) |        |        |       |        |
|                     |          | BW  | 144 | 91.38           | 4(2:7)    | 2718.5 | -3.742 | -0.26 | 0.0005 |
|                     | 9 m      | BSA | 32  | 98.47           | 6(2:9)    |        |        |       |        |
|                     |          | BW  | 124 | 73.35           | 3(1:7.5)  | 1345   | -2.825 | -0.25 | 0.005  |
| DepT                | Present. | BSA | 84  | 147.51          | 3(0:6)    |        |        |       |        |
|                     |          | BW  | 180 | 125.50          | 1(0:4)    | 6299.5 | -2.249 | -0.13 | 0.024  |
|                     | 3m       | BSA | 51  | 119.72          | 4.5(1:6)  |        |        |       |        |
|                     |          | BW  | 138 | 85.87           | 1(0:3)    | 2258.5 | -3.877 | -0.30 | 0.0005 |
|                     | 9 m      | BSA | 30  | 90.35           | 1(0:5)    |        |        |       |        |
|                     |          | BW  | 120 | 71.85           | 0(0:2)    | 1354.5 | -2.237 | -0.18 | 0.025  |
| AnxT                | Present. | BSA | 83  | 141.80          | 5(2:8)    |        |        |       |        |
|                     |          | BW  | 182 | 128.99          | 3.5:7)    | 6823   | -1.268 | -0.07 | 0.205  |
|                     | 3m       | BSA | 51  | 112.34          | 5(2:7.5)  |        |        |       |        |
|                     |          | BW  | 139 | 89.32           | 3(1:5)    | 2685.5 | -2.573 | -0.20 | 0.010  |
|                     | 9m       | BSA | 31  | 90.63           | 3(2:5)    |        |        |       |        |
|                     |          | BW  | 120 | 72.22           | 2(0:4.5)  | 1406.5 | -2.123 | -0.17 | 0.034  |
| HADS A              | Present. | BSA | 94  | 155.83          | 8(4:12)   |        |        |       |        |
|                     |          | BW  | 185 | 131.96          | 6(3:9)    | 7207   | -2.342 | -0.14 | 0.019  |
|                     | 3m       | BSA | 57  | 117.46          | 7.5(5:12) |        |        |       |        |
|                     |          | BW  | 144 | 94.38           | 5(3:9)    | 3165.5 | -2.531 | -0.21 | 0.011  |
|                     | 9 m      | BSA | 33  | 87.06           | 6(2:9)    |        |        |       |        |
|                     |          | BW  | 124 | 76.85           | 5(2:8)    | 1780   | -1.150 | -0.09 | 0.250  |

**Supplementary Table 3 Ethnic differences in reporting of physical symptoms**

| Problem              |              |     | n=  | No  | %    | Yes | %    | X <sup>2</sup> |
|----------------------|--------------|-----|-----|-----|------|-----|------|----------------|
| Pain                 | Presentation | BSA | 88  | 37  | 42   | 51  | 58   |                |
|                      |              | BW  | 180 | 121 | 67   | 59  | 32.8 | 0.0001         |
|                      | 3 months     | BSA | 53  | 14  | 26.4 | 39  | 73.6 |                |
|                      |              | BW  | 141 | 92  | 65.2 | 49  | 34.8 | 0.0001         |
|                      |              | BSA | 31  | 12  | 38.7 | 19  | 61.3 |                |
|                      |              | BW  | 121 | 80  | 66.1 | 41  | 33.9 | 0.009          |
| Nausea               | Presentation | BSA | 83  | 56  | 68   | 27  | 32.5 |                |
|                      |              | BW  | 178 | 141 | 79   | 37  | 20.8 | 0.058          |
|                      | 3 months     | BSA | 54  | 29  | 53.7 | 25  | 46.3 |                |
|                      |              | BW  | 140 | 91  | 65   | 49  | 35   | 0.198          |
|                      |              | BSA | 29  | 22  | 75.9 | 7   | 24.1 |                |
|                      |              | BW  | 121 | 104 | 86   | 17  | 14   | 0.574          |
| Getting around       | Presentation | BSA | 85  | 59  | 69   | 26  | 30.6 |                |
|                      |              | BW  | 177 | 155 | 88   | 22  | 12.4 | 0.001          |
|                      | 3 months     | BSA | 55  | 33  | 60   | 22  | 40   |                |
|                      |              | BW  | 140 | 112 | 80   | 28  | 20   | 0.007          |
|                      |              | BSA | 31  | 23  | 74.2 | 8   | 25.8 |                |
|                      |              | BW  | 120 | 95  | 79.2 | 25  | 20.8 | 0.724          |
| Bathing and dressing | Presentation | BSA | 86  | 62  | 72   | 24  | 27.9 |                |
|                      |              | BW  | 178 | 167 | 94   | 11  | 6.2  | 0.0001         |
|                      | 3 months     | BSA | 55  | 42  | 76.4 | 13  | 23.6 |                |
|                      |              | BW  | 140 | 129 | 92.1 | 11  | 7.9  | 0.006          |
|                      |              | BSA | 31  | 25  | 80.6 | 6   | 19.4 |                |
|                      |              | BW  | 120 | 104 | 86.7 | 16  | 13.3 | 0.574          |
| Mouth sores          | Presentation | BSA | 87  | 66  | 76   | 21  | 24.1 |                |
|                      |              | BW  | 179 | 167 | 93   | 12  | 6.7  | 0.0001         |
|                      | 3 months     | BSA | 55  | 37  | 67.3 | 18  | 32.7 |                |
|                      |              | BW  | 140 | 114 | 81.4 | 26  | 18.6 | 0.053          |
|                      |              | BSA | 31  | 25  | 80.6 | 6   | 19.4 |                |
|                      |              | BW  | 121 | 109 | 90.1 | 12  | 9.9  | 0.255          |
| Fevers               | Presentation | BSA | 87  | 69  | 79   | 18  | 20.7 |                |
|                      |              | BW  | 177 | 172 | 97   | 5   | 2.8  | 0.0001         |
|                      | 3 months     | BSA | 54  | 42  | 77.8 | 12  | 22.2 |                |
|                      |              | BW  | 139 | 127 | 91.4 | 12  | 8.6  | 0.020          |
|                      |              | BSA | 31  | 26  | 83.9 | 5   | 16.1 |                |
|                      |              | BW  | 119 | 108 | 90.8 | 11  | 9.2  | 0.436          |
| Skin                 | Presentation | BSA | 84  | 42  | 50   | 42  | 50   |                |
|                      |              | BW  | 179 | 156 | 87   | 23  | 12.8 | 0.0001         |
|                      | 3 months     | BSA | 56  | 26  | 46.4 | 30  | 53.6 |                |
|                      |              | BW  | 142 | 96  | 67.8 | 46  | 32.4 | 0.009          |
|                      |              | BSA | 31  | 16  | 51.6 | 15  | 48.4 |                |
|                      |              | BW  | 121 | 86  | 71.1 | 35  | 28.9 | 0.065          |



**Are depressive symptoms more common among British South Asian compared to British White cancer patients?: a cross sectional survey.**

|                                    |  |
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3 **Are depressive symptoms more common among British**  
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## **Abstract**

### **Objectives**

This cross sectional survey investigated whether there were ethnic differences in depressive symptoms among British South Asian (BSA) cancer patients compared to British White (BW) patients during nine 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 cancer patients at baseline at three and nine months. 53.8% of the BSA sample 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), Patient Health Questionnaire (PHQ9) (both validated in Gujarati), Emotion Thermometers (including the Distress Thermometer and checklist), Mini-MAC and the newly developed Cancer Insight and Denial questionnaire were completed.

### **Setting**

Leicestershire Cancer Centre, UK.

### **Participants**

94 BSA and 185 BW recently diagnosed cancer patients.

### **Results**

BSA self reported significantly higher rates of depressive symptoms compared to BW patients longitudinally (HADS  $D \geq 8$ : presentation: BSA 35.1% v BW 16.8%  $p=0.001$ ; 3 months BSA 45.6% v BW 20.8%  $p=0.001$ ; 9 months BSA

1  
2  
3 40.6% v BW 15.3% p=0.004). BSA patients used potentially maladaptive  
4 coping strategies more frequently than BW patients at baseline  
5  
6  
7 (hopelessness/helplessness p=0.005, fatalism p=0.0005, avoidance p=0.005;  
8  
9 the CIDQ denial statement 'I do not really believe I have cancer' p=0.0005).  
10  
11 BSA patients experienced more physical symptoms (DT checklist) which  
12  
13 correlated with ethnic differences in depressive symptoms especially at three  
14  
15 months.  
16  
17

### 18 **Conclusion**

19  
20 Health professionals need to be aware of a greater probability of depressive  
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22 symptomatology and how this may present clinically, including somatic  
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24 symptoms, in the first nine months after diagnosis if this ethnic disparity in  
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26 mental wellbeing is to be addressed.  
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## Article summary

### Article Focus

- We investigated whether there were differences in depressive symptoms among British South Asian (BSA) cancer patients compared to British White (BW) over a nine month period.
- To limit cultural bias we used multiple questionnaires including HADS and a version of the PHQ-9 developed for India.
- We considered how coping strategies were used and whether physical symptoms affected mood.

### Key Messages

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

### Strengths and Limitations

This is the first comparison of how BSA and BW patients cope with cancer. We have used multiple assessment tools. We have demonstrated statistically very 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 nine months. Changes in

1  
2  
3 mood between the three data collection points are not represented. It is also  
4  
5 likely that the rates of depressive symptoms are under-reported since  
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7 anecdotally those who were most distressed often did not feel able to participate  
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9 in this study. Self-reported questionnaires indicate the presence of depressive  
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11 symptoms but given the absence of psychiatric interviews this is not diagnostic  
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13 of a depressive disorder.  
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## **Introduction**

Depression is one of the strongest determinants of health related quality of life and it also influences medical care and participation in treatment.[1, 2] It may also be linked with other serious outcomes including mortality.[3] The point prevalence of major depression at any time in the first two years following a cancer diagnosis is 14.9% by DSMIV criteria.[4] This is two to four times that observed in the general population using equivalent criteria.[5] 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[6] leaving the largely unproven impression that they also suffer more distress when diagnosed with cancer. However ethnic minorities may be less likely to receive high quality care.[7, 8] 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 [9, 10, 11] and the USA [12, 13, 14] where it is a governmental aspiration to remove such disparities. In England and Wales (total population 56.1 million) those classified as Indians [15] are in the majority accounting for 1,412,958, Pakistan 1,124,511 and Bangladesh 447,201.[16] Most of the Indians born in Africa became refugees, being expelled by Idi Amin and others 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, 8,000, Bangladeshi, 3,600) which contrast with the surrounding county (total population: 650,489: Indian 54,000, Pakistani, 2,100, Bangladeshi, 2,300).[16] We define 'British South

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2  
3 Asian (BSA)' as a person whose ancestry is in the Indian subcontinent, and who  
4 identifies with, or is identified with, their host country, Britain. A previous pilot  
5 study showed a significantly higher incidence in symptoms of depression among  
6 BSA patients in Leicester and local county compared to British White (BW)  
7 patients via HADS D  $\geq 10$  (BSA 20.7%; BW 10.4%  $p=0.001$ ).<sup>[17]</sup> Depression  
8 was associated with certain coping styles, particularly the use of denial in both  
9 BSA and BW patients but was employed more frequently by BSA patients.  
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20 The findings of our pilot study <sup>[17]</sup> 16 were consistent with the few publications  
21 reporting the incidence of depression or distress in ethnic minority cancer  
22 patients. The largest is a meta-analysis of 21 papers which found that US  
23 Hispanic patients were significantly more distressed ( $p=0.0001$ ) and depressed  
24 ( $p=0.04$ ) than the majority population.<sup>[18]</sup>  
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34 Similar findings were reported from Canada with more distress amongst ethnic  
35 minorities (E and SE Asia, South Asian, First Nation) compared to the majority  
36 population (European, Canadian, British  $p=0.0001$ ). Greater distress was also  
37 found among those with lower income ( $p=0.001$ ).<sup>[19]</sup>  
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45 This study addressed how the UK's largest ethnic minority population (BSA)  
46 cope with cancer, in comparison to the host population, by analysing data from  
47 a sample of those attending the Leicestershire Cancer Centre.  
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53 Feeling distressed or low in mood are initial emotional responses to a diagnosis  
54 of cancer, and is part of normal adjustment, if of short duration. If, however  
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3 distress persists it can have a harmful effect on the mental wellbeing of the  
4  
5 individual risking depressive symptoms [17, 20] and reduction in quality of  
6  
7 life.[21, 22, 23]  
8  
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10  
11 The Transactional Model of Stress and Coping requires an assessment of  
12  
13 personality traits within the context of their environment.[24] For cancer patients  
14  
15 this environment includes their beliefs about cancer, their level of social support,  
16  
17 proficiency in host languages, level of literacy, degree of disability, co-  
18  
19 morbidities, spiritual beliefs, cultural background and economic  
20  
21 circumstances.[25]  
22  
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26  
27 The symptom burden on cancer patients can influence coping with a close  
28  
29 interrelationship with psychological wellbeing. Fatigue and disabilities  
30  
31 independently predicted depression among lung cancer patients commencing  
32  
33 treatment [26] and has been observed in pre-chemotherapy patients with  
34  
35 curative cancer.[27] A high symptom burden can persist over time. 1 in 4  
36  
37 patients (n=4903) had a high symptom burden 1 year post diagnosis with  
38  
39 depression, fatigue and pain having the greatest impact on their quality of  
40  
41 life.[28] Similarly a high symptom burden at 12 months was reported among  
42  
43 patients referred for control of pain and depression (n=405).[29] Among  
44  
45 Chinese breast cancer patients (n=285) less distress from physical symptoms  
46  
47 immediately after surgery predicted psychological resilience. The study  
48  
49 suggested that ineffective symptom control during treatment increased a  
50  
51 women's risk of persistent psychological distress longitudinally. The value of  
52  
53 pre-operative interventions was highlighted.[30]  
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5 Of particular concern are reports of higher symptom burden in ethnic minorities  
6 such as among Hispanic women post-chemotherapy for breast cancer [31] and  
7 greater 'unmet need' for symptom control was implicated among Black and  
8 Spanish speaking Hispanic women with breast cancer than White women.[32]  
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16 We report the longitudinal incidence of depressive symptoms among a sample  
17 of BSA and BW patients. Coping styles and the burden of patient problems  
18 were examined to determine if they were implicated in depressive symptoms.  
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### 22 **Hypotheses**

23  
24 On the basis of our literature review and pilot studies we hypothesized that  
25 more BSA cancer patients would self report depressive symptoms than BW  
26 patients over time. We further hypothesized that both a greater use of  
27 potentially maladaptive coping strategies and a heavier symptom burden, would  
28 reflect higher rates of depressive symptoms.  
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### 39 **Methods**

#### 40 **Study procedures**

41  
42 279 patients, who were aware they had cancer, were recruited at the  
43 Leicestershire Cancer Centre between September 2007 and January 2010 at  
44 their first or second appointment. Patients were recruited by either an English  
45 speaking clinical nurse specialist or one of two radiographers, who between  
46 them spoke English, Gujarati and Hindi and Urdu. None were involved in the  
47 clinical care of the patients and all received training in 'Good Clinical Practice'  
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3 and in the principles of informed consent. The Leicestershire,  
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5 Northamptonshire and Rutland Ethics Committee approved the study.  
6  
7 Eligible patients were aged 18-85 with a confirmed diagnosis of cancer with  
8  
9 evidence of being informed of the diagnosis. They were identified by the nurse  
10  
11 specialist via the cancer registry with ethnicity confirmed by their surname and  
12  
13 by hospital records.  
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18 Prior to their attendance eligible patients were sent an introductory letter  
19  
20 outlining the study and inviting them to participate. All correspondence and  
21  
22 questionnaires were available in English, Gujarati and Hindi. Consent was  
23  
24 sought requesting patients complete three sets of questionnaires in writing, the  
25  
26 first immediately, then at three months and nine month intervals. (Table 1)  
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28

### 29 **Questionnaires**

30  
31 Patients completed the Hospital Anxiety and Depression Scale (HADS) [33] and  
32  
33 The Emotion Thermometers [34] which includes the Distress Thermometer [35]  
34  
35 and depression thermometer (Dep T). A problem checklist, included on the  
36  
37 thermometer, identified the patient's symptom burden. All are validated but  
38  
39 were not initially available in Gujarati or Hindi. A commercial company  
40  
41 undertook an iterative back-translation process as described by Brislin.[36] A  
42  
43 version of the Patient Health Questionnaire (PHQ-9), which was already  
44  
45 validated into Gujarati and Hindi having been adapted for use in India, was the  
46  
47 third questionnaire used.[37] Several tools were used to address the concern  
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49 that some were ethnically biased.  
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3 An adaptive coping strategy (fighting spirit) and potentially maladaptive  
4 strategies (hopelessness/helplessness, fatalism, anxiety preoccupation and  
5 cognitive avoidance) were assessed via the Mini-MAC scale.[38] The locally  
6 developed Cancer Insight and Denial questionnaire (CIDQ) included question  
7 38 from the original MAC questionnaire to assess the use of denial. The vast  
8 majority of participants chose to complete the first questionnaires at home,  
9 returning them by post. Subsequent questionnaires were posted to participants.  
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11 Personal statements illustrating how patients coped were generated by two  
12 qualitative questions, “how would you describe your current illness”, and “what  
13 does having cancer mean to you?”  
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### 27 **Statistical analysis**

28 Reference was made to the ‘Strobe’ statement for observational studies.[39]  
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30 Depressive symptoms were assessed by HADS D, ET Thermometers and  
31 PHQ-9.  
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38 The revised classification of the original HADS identified the severity of  
39 depressive symptoms (normal 0-7, mild 8-10, moderate 11-14 and severe 15-  
40 21.[40] A threshold of  $\geq 11$  identified patients with moderate symptoms,  
41 however following the recommendation to have a lower threshold for cancer  
42 patients than in general practice,  $\geq 8$  was selected for HADS D.[41] This is  
43 supported by a review of 747 papers using HADS where the best balance  
44 between sensitivity and specificity was achieved most often when using the cut-  
45 off  $\geq 8$  (Cronbach’s alpha coefficient, 0.80).[42] Threshold scores of  $\geq 10$ ,  $\geq 15$ ,  
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60  $\geq 20$  for PHQ-9 were in accordance with the original recommended scores.[43]

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3 The current recommended threshold for the DT is  $\geq 4$  and this is retained in the  
4 ET [44] and this analysis. A prior power analysis based on our pilot studies  
5 determined 86 participants were required for each ethnic group.  
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11 Graphs denote 95% confidence intervals. Summary scores for selected coping  
12 strategies were from the Mini-MAC and the denial indicators in the CIDQ.  
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14 Reference was made to individual indicators. Longitudinal data at baseline and  
15 at three and nine months is reported.  
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22 Computation of frequencies, percentages and arithmetic median was conducted  
23 to identify patterns in the data. Mann Whitney tests for continuous variables  
24 detected differences between the ethnic groups and the direction of these  
25 relationships. Spearman's Rank Order Tests ( $\rho$ ) explored correlations  
26 between depressive symptoms (HADS D as a continuous variable) and  
27 deprivation.[45] We report analysis by age, gender, deprivation, tumour site,  
28 place of birth and ethnicity.  
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41  $\chi^2$  described the relationship between categorical variables. The extent to  
42 which patients used each coping strategy and how its use changed  
43 longitudinally is described. Associations between each strategy and depressive  
44 symptoms is reported. Qualitative data was recorded verbatim. When in  
45 Gujarati it was translated to English. Analysis was performed via SPSS v 18.  
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## 52 53 **Results**

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3 94 BSA patients were recruited. The BSA sample largely represents cancer  
4 patients within the Leicester Indian population and although of interest to other  
5 BSA cancer populations, these findings may not be representative. 53.8% were  
6 born in the Indian subcontinent, 33% in Africa of Indian descent and 12.9% in  
7 the UK. Hindus accounted for 53.2%, Muslims 25.5% and 17% Sikh. 185 BW  
8 patients were recruited. Several cancer sites are represented. The largest  
9 cohort was 114 breast cancer patients. The educational attainment, religion  
10 and place of birth were self-reported by participants. The demographic  
11 characteristics of this sample showed significant differences between ethnic  
12 groups in terms of their socio-economic status and educational attainment.  
13 These details and the patient's sex, age, cancer site and treatment intent are  
14 listed in Table 2.

### **Demographics and depressive symptoms**

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34 Age was not associated with depression among BSA patients (rho: HADS D,  
35 (p=0.62). Older BW patients were less likely to be depressed (rho: HADS D  
36 (p=0.03). There was no statistical difference based on gender with females  
37 having a higher mean depression score than males at baseline (HADS D;  
38 females 4 (range 0-18) IQR 1,7) (males 3 (range 0-20) IQR 1,6) p=0.46.  
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47 67.4% patients received radical treatment with the aim of cure or long term  
48 control of disease and 32.6% received palliative treatment given with no  
49 expectation of cure. Unexpectedly there was no evidence that receiving  
50 palliative as opposed to radical (curative intent) treatment influenced a  
51 difference in depressive symptoms (HADS D $\geq$ 8 presentation p=0.088, 3 months  
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3 p=0.588 9 months p=1.0). Those with lung cancer, who generally have a poor  
4  
5 prognosis, had the highest median depression score via HADS D of 5 (IQR  
6  
7 3,7, scale 0-21). The lowest score was attributed to people with prostate cancer  
8  
9 (Md 1 (IQR 0,5) (Supp. Table 1).  
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14 Data on educational attainment was recoded into two groups with those patients  
15  
16 reaching educational level of 15/16 removed. This represented groups at either  
17  
18 end of educational attainment. Those educated at the highest level had notably  
19  
20 less depressive symptoms than those with either no formal education or only  
21  
22 until up to the age of 11 (HADS D  $\geq$ 8, Lowest Ed. 14/30 (46.7%); Highest Ed.  
23  
24 18/97 (18.6%) p=0.004. However these results should be treated with caution  
25  
26 given the educational systems of India and the UK are different. For example  
27  
28 some patients listing no formal education spoke fluently up to five languages.  
29  
30 Individual results in patients who reported little formal education were consistent  
31  
32 across assessment tools suggesting adequate comprehension.  
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39 There was no significant difference in depressive symptoms between those  
40  
41 BSA patients originating from Africa compared to the Indian Sub continent at  
42  
43 baseline (MW: Africa 31/80 Md 4 (2,9) Indian Sub Continent Md 5.5 (2,11) Z=-  
44  
45 1.184 p=0.23). Neither was there a significant difference in the experience of  
46  
47 symptoms frequently associated with depression such as pain (p=0.23), sleep  
48  
49 disturbances (p=0.91) and fatigue (p=0.52).  
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54 Since socio-economic deprivation is closely associated with being a member of  
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56 an ethnic minority we considered the extent to which deprivation influenced the  
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3 strength of the relationship between ethnicity and depressive symptoms.  
4  
5 Although there was a strong association between ethnicity and deprivation (MW  
6  
7  $r=0.503$ ,  $p=0.0005$ ) deprivation had minimal influence on the strength of the  
8  
9 relationship between ethnicity and depression when comparing Pearson  
10  
11 product-moment correlations (PCC) with partial correlation calculations (Table  
12  
13  
14 3).

### 15 16 17 18 **Depressive symptoms at baseline**

19  
20 All three assessment tools showed approximately double the incidence of  
21  
22 depression in BSA patients compared to BW patients (Fig 1a and suppl. Table  
23  
24 2). Severe depression was also more common in the BSA groups as  
25  
26 demonstrated using a higher HADS score  $\geq 11$  (BSA 23/94 (24.5%) BW 11/185  
27  
28 (5.9%)  $p=0.001$ ). A similar trend was seen using a higher PHQ-9 threshold  
29  
30 ( $\geq 15$ ) BSA 13/85 (15%) BW 10/173 (5%)  $p=0.04$ .  
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### 36 37 **Longitudinal trends in depressive symptoms**

38  
39 All tools indicated how more vulnerable BSA patients were in contrast to BW  
40  
41 patients. HADS D  $\geq 8$  suggested significantly higher rates of depressive  
42  
43 symptoms among BSA patients longitudinally than BW patients (Fig 1b). All  
44  
45 three assessment tools indicated a slight decrease in depressive symptoms  
46  
47 among BSA patients at three months. Depression rates had not fallen lower  
48  
49 than those at presentation by nine months although the ethnic difference  
50  
51 remained (Fig 1c & 1d).  
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### 56 57 **Coping Strategies**

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3 BSA patients used coping strategies differently to BW patients particularly early  
4  
5 after diagnosis when greater use of potentially maladaptive strategies were  
6  
7 associated with higher rates of depressive symptoms (Suppl tables 3, 4 & 5)  
8  
9

### 10 11 12 **Hopelessness/ helplessness (Mini MAC)**

13  
14 *"its an awful thing to happen....feeling hopeless"*

15  
16 BSA patient No.16 soon after diagnosis  
17  
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19  
20  
21 Although initially the majority of patients did not express helplessness nor  
22  
23 hopelessness, BSA patients were far more likely to do so (p=0.0005). For  
24  
25 example, more BSA patients than BW patients agreed with the statement 'I feel  
26  
27 completely at a loss about what to do' (BSA 31 (33%); BW 23(12.4%)  
28  
29 p=0.0005). Across the study period BSA patients had higher  
30  
31 helplessness/hopelessness scores than BW patients although use decreased  
32  
33 over time for both groups (Fig 2a). Helplessness/hopelessness is sometimes  
34  
35 considered to be a substitute for depression so it was not surprising that over  
36  
37 time more patients (BSA and BW combined) felt helplessness/hopelessness  
38  
39 and also acknowledged depressive symptoms (MW: PHQ-9  $\geq 11$ /HADS D  $\geq 8$   
40  
41 p=0.0005).  
42  
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### 47 **Anxiety preoccupation**

48  
49 *"Cancer has totally changed my life. I am worried, anxious about my treatment*  
50  
51 *and what lies ahead as this is the second occasion I am going through this"*  
52  
53

54 BSA No.103.  
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3 There was a negligible ethnic difference in the use of anxiety preoccupation.  
4  
5 Over time this strategy was used less (Fig 2b). It was strongly associated with  
6  
7 depression (HADS D and PHQ-9,  $p=0.0005$ ). These patients were more likely  
8  
9 to report depressive symptoms longitudinally (PHQ-9: presentation  $p=0.0005$ , 3  
10  
11 months  $p=0.0005$ , 9 months  $p=0.0005$ ).  
12  
13

### 14 15 16 **Cognitive avoidance**

17  
18 Cancer is “...something that I put to the back of my mind and don't let it interfere  
19  
20 with my day to day life” BW No.118  
21  
22

23  
24  
25 Initially BSA patients used cognitive avoidance to cope more than BW patients  
26  
27 (MW:  $p=0.0005$ ) (Fig 2c). For example, ‘I deliberately push all thoughts of  
28  
29 cancer out of my mind’ (BSA 61/93 (65.6%); BW 63/185 (34.4%),  $p=0.0005$ ).  
30  
31 Over time this ethnic difference continued but was only statistically significant at  
32  
33 baseline as illustrated by a comparison of median scores (Fig 2c). At baseline,  
34  
35 as one sample, those who used cognitive avoidance were more likely to have  
36  
37 symptoms of depression (MW: PHQ-9  $p=0.007$ ; HADS D  $\geq 8$   $p=0.001$ ; Dep.T  $\geq 4$   
38  
39  $p=0.002$ ). Over time avoidant patients did not continue to be depressed (HADS  
40  
41 D; 3 months,  $p=0.2$ ; 9 months, 0.14).  
42  
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### 47 **Fighting Spirit**

48  
49 (I see cancer) “as a challenge...a temporary state....a hurdle to get over”  
50  
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52  
53 BW patient No.172

54  
55 “It means I have a fight on my hands but I'm determined to get better”  
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5 A large number of patients in both ethnic groups approached their illness with  
6 an 'adaptive' coping strategy of 'fighting spirit' (Fig 2d). For example, 'I am  
7 determined to beat this disease' (BSA 85/93 (91.4%); BW 170/185 (91.9%)  
8  $p=1.0$ ). There was little ethnic difference in the extent to which patients used  
9 this coping strategy (MW presentation  $p=0.47$ , 3 months  $p=0.57$ , 9 months  
10  $p=0.2$ ).

### 11 12 13 14 15 16 17 18 **Fatalism**

19  
20 *"It's horrible. Why me? My mum died from cancer. My sisters have cancer.*

21  
22 *Why is this happening? I wish I'd never woken up after my operation"*

23  
24  
25 BSA No.125

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28  
29 More BSA patients were fatalistic when diagnosed with cancer than BW patients  
30 at baseline assessment (MW:  $p=0.0005$ ). However this was largely based on  
31 one of five Mini MAC indicators, 'I've put myself in the hands of God' (BSA  
32 71/94 (75.5%); BW 60/185(32.4%)  $p=0.0005$ ). There was a gradual decrease in  
33 fatalism in both ethnic groups by nine months although it persisted among BSA  
34 patients (Fig 2e). Those who were fatalistic were more likely to experience  
35 depressive symptoms (MW: HADS D $\geq$ 8  $p=0.024$ ; PHQ-9,  $p=0.003$ ) but not by  
36 the Dep T.  $\geq$ 4 ( $p=0.101$ ).

### 37 38 39 40 41 42 43 44 45 46 47 **Insight and Denial (CIDQ)**

48  
49 *"I'm not ill"*

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51  
52 Written at the top of an uncompleted questionnaire by a patient having  
53 chemotherapy for breast cancer following surgery. BW No.127 at presentation  
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3 *"...part of me still feels there is nothing wrong with me and this is happening to*  
4 *someone else. This is presumably my way of handling it all."* BW No.311 at  
5  
6  
7 nine months  
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10  
11 Of those who used denial, potentially a maladaptive coping strategy [46] BSA  
12 patients were over-represented, most notably at baseline assessments  
13 (p=0.001). The ethnic gap remained longitudinally (Fig 2f). Of the three tools  
14 assessing depression only PHQ-9 indicated an association between denial and  
15 depression albeit weakly (MW: p= 0.039).  
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25 To facilitate comparisons with Roy's 2005 [17] study, analysis of the single  
26 indicator 'I don't really believe I have cancer' originating from the MAC  
27 questionnaire was repeated. At baseline 229/278 patients (82%) accepted the  
28 reality of their diagnosis by disagreeing with the statement. Of the 27 patients  
29 who didn't believe that they had cancer, more were BSA (BSA 19/93 (20.2%);  
30 BW 8/185 (4.3%), p=0.0001). Of interest is that 23 patients agreed with this  
31 statement 'sometimes' (BSA 12 (52.2%); BW 11 (47.8%)). There was a strong  
32 trend towards BSA patients who denied their diagnosis to be more depressed at  
33 baseline but sample numbers were too low to warrant analysis at nine months  
34 (Fig 2g).  
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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 did not influence findings.  
Critically BSA patients experienced more distress from physical symptoms of

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2  
3 illness and treatment than BW patients. There were 17 physical symptoms  
4 listed. In 13 categories BSA had statistically significant increased symptoms  
5 compared to BW patients. For example, pain (BSA 51/83 (58%), BW 59/180  
6 (32.8%)  $p=0.0001$ ), mouth sores (BSA 21/88 (24.1%), BW 12/179 (6.7%)  
7  $p=0.0001$ ) and fevers (BSA 18/87 (20.7%), BW 5/177(2.8%)  $p=0.0001$ ). At  
8 three months significantly higher percentages of BSA patients reported  
9 problems with pain, mouth sores, nausea, skin, washing and dressing and  
10 getting around as causes for distress which were not reflected in BW patients.  
11 By nine months differences had narrowed with the exception of pain (BSA 19/31  
12 (61.3%) v BW 41/121 (33.9%)  $p=0.009$ ) (Table 4).  
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## 27 **Discussion**

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29 With the exception of our pilot study [17] we are not aware of another  
30 comparison of how BSA and BW patients cope with cancer. It should be of  
31 major concern to health care policy makers in the UK that this study provides  
32 evidence that there is a higher prevalence of depressive symptoms among BSA  
33 patients soon after the cancer diagnosis than BW patients. The percentages  
34 vary depending on the assessment tool used but all showed the same trend.  
35  
36 BSA rates for depression were twice that of BW patients using two tools. 35.1%  
37 of BSA compared to 16.8% of BW patients ( $p=0.001$ ) had depressive symptoms  
38 measured on the HADS D scale ( $\geq 8$ ). This was confirmed on a version of the  
39 PHQ-9 $\geq 10$  developed for India (35.3% BSA v 18.3% BW  $p=0.05$ ). This is a  
40 critical finding since this is almost 6 times higher than reported within the UK  
41 general population using the same assessment tool (6%).[47] Depression rates  
42 for BW patients (HADS D $\geq 8$ , 16.8%; PHQ-9 18.3%) were similar to those  
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3 reported in a recent meta-analysis of cancer patients (16.3%), being  
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5 approximately 2.5 times higher than in the general population.[4] What is  
6  
7 disturbing is the incidence of more severe depression in BSA patients which is  
8  
9 reflected in their HAD-D score  $\geq 11$  (BSA 24.5% v BW 5.9%  $p=0.0001$ ). These  
10  
11 findings supported trends in other studies, notably our pilot study. Using the  
12  
13 threshold HADS  $\geq 10$ , Roy [17] reported BSA 20.7% v BW 10.4% ( $p=0.001$ ) had  
14  
15 moderate depressive symptoms. These concur with other reports which  
16  
17 suggest that ethnic minority cancer patients experience more psychological  
18  
19 distress than patients from host populations.[16, 17, 48, 49] However the BSA  
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21 population is heterogeneous. It would be grossly simplistic to assume all BSA  
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23 respond psychologically in the same way given the breadth and diversity of their  
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25 religious and cultural influences. However Indian Hindus comprised the majority  
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27 of our BSA sample and our findings may be of particular relevance to this sub-  
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29 group.  
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36 What is very interesting is that the HADS-D, PHQ-9 and DepT showed higher  
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38 levels of depressive symptoms in both ethnic groups at three months after  
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40 baseline, this being steeper among BSA patients. Although symptoms  
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42 decreased, BSA consistently reported higher rates of depression than BW  
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44 patients longitudinally. These findings confirmed our first hypothesis.  
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49 A counter intuitive finding in this study is the similarity of depressive symptoms  
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51 in patients being treated with curative intent (radical) and palliative patients.  
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53 Although there were fewer questionnaires returned at three and nine months,  
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55 the ratio of radical and palliative patients remained the same (HADS D  $\geq 8$   
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3 baseline p=0.08, 3 months p=0.58, 9 months p=1.0). In fact this finding is  
4  
5 consistent with a recent meta-analysis.[4]  
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9 At baseline the rates of fatalism helplessness/hopelessness and domains of  
10 denial were far higher among BSA patients and there was a strong correlation  
11 between these potentially maladaptive coping strategies and the incidence of  
12 depression in both ethnic groups. Helplessness/hopelessness is strongly  
13 associated with depression [50, 20, 51–55] as we found in this study. A similar  
14 pattern was seen in the use of cognitive avoidance. Fatalism too was  
15 associated with higher levels of depressive symptoms as demonstrated on both  
16 the PHQ-9 and HADS which supports research from India [56, 57] and the UK  
17 [58, 59] into the use of potentially maladaptive behaviours.  
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31 In our previous study [17] denial was significantly related to depression in both  
32 BW and BSA patients. BSA patients were far more likely to agree with the  
33 statement in the MAC questionnaire (Question 38) 'I don't really believe I have  
34 cancer'. In this study a minority of patients denied their diagnosis but again it  
35 was more common among BSA patients using the same indicator until nine  
36 months (MW presentation p=0.0005, 3 months p=0.001, 9 months p=0.2).  
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38 Initially this was strongly associated with depression however the sample  
39 numbers were too small to consider longitudinal associations.  
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51 What is puzzling is that although BSA patients remained more depressed than  
52 BW patients longitudinally, by three and nine months the use of coping  
53 strategies did not explain this. At three months the only difference was in  
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3 helplessness/hopelessness scores ( $p=0.043$ ) and by nine months the ethnic  
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5 differences in the use of coping strategies were insignificant. Interestingly by  
6  
7 nine months the trend towards higher depression among BSA patients  
8  
9 remained. Even taking into account a lag time for the alleviation of depressive  
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11 symptoms after less use of maladaptive coping, there remains an incomplete  
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13 explanation as to why more BSA patients in particular remain so distressed.  
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15 Our hypothesis that a greater use of maladaptive coping strategies would reflect  
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17 higher rates of depressive symptoms was therefore only partially confirmed. A  
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19 retrospective audit into referral to psycho oncology or prescribing patterns of  
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21 psychotropic medication in the two groups did not suggest a difference that  
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23 could account for this.  
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30 We considered whether the burden of physical symptoms explained this ethnic  
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32 gap. BSA patients were more likely to report physical symptoms at baseline  
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34 and at three months. This was particularly true for pain, nausea, skin concerns,  
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36 mouth sores, tingling and feeling swollen. These symptoms peaked at three  
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38 months but there was no statistically significant difference in symptomatology  
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40 between the two groups by nine months with the exception of pain. However  
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42 the ethnic differences in depressive symptoms persisted to nine months.  
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44 Possible explanations include the somatisation of physical symptoms being  
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46 undetected, inadequate symptom management, non-compliance due to a lack  
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48 of literacy and language skills or for a patient preference for traditional  
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50 medicines for symptom control purposes. Our findings reflect the greater  
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52 symptom burden found in other ethnic minority cancer patients, such as among  
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54 Chinese and Hispanic populations [31, 32]. This study supports the original  
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3 hypothesis that more BSA cancer patients would self-report depressive  
4 symptoms than BW patient over time. Our hypothesis that a greater use of  
5 potentially maladaptive coping strategies would reflect higher rates of  
6 depression among BSA patients was supported but only until the three month  
7 point. A heavier symptom burden among BSA patients does appear to  
8 contribute to depression rates among this ethnic minority compared to the host  
9 population.  
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## 20 Limitations

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25 Limitations to the study are acknowledged. The BSA sample largely represents  
26 cancer patients within the Leicester Indian population and although of interest to  
27 other BSA cancer populations, these findings may not represent them. In  
28 addition there was a large sample of patients with breast cancer, which risks  
29 underrepresentation of those patients with other body site cancers.  
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36 Difficulties in recruitment and retaining BSA participants by nine months  
37 reduced the sample size.[60] Self-reported questionnaires indicate the  
38 presence of depressive symptoms but given the absence of psychiatric  
39 interviews this is not diagnostic of a depressive disorder.  
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47 Modulations in patient mood between the three data collection points are not  
48 represented. It is also likely that depressive symptoms are underreported since  
49 anecdotally those who were most distressed often did not feel able to participate  
50 in the study.  
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### 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 nine months after diagnosis if this ethnic disparity in mental wellbeing is to be addressed.

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7 **Are depressive symptoms increased anxiety and**  
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9 **depression more common** among British South Asian  
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11 **compared to British White cancer patients?: a cross**  
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13 **sectional survey study.**  
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53 **Key words** Cancer, ethnicity, South Asian, anxiety, depression

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## 10 **Abstract**

### 11 **Objectives**

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14 This cross sectional ~~survey study~~ investigated whether there were ethnic  
15 differences in ~~depressive symptoms anxiety and depression~~ among British South  
16 Asian (BSA) cancer patients compared to British White (BW) patients ~~during~~  
17 ~~nine months following presentation at a UK Cancer Centre in Leicestershire.~~  
18 We ~~examined associations between depressed mood considered how~~ coping  
19 strategies ~~and the burden of symptoms were used and whether physical~~  
20 ~~symptoms affected mood.~~  
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### 28 **Design**

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30 ~~Questionnaires were administered to 94 BSA and 185 BW recently diagnosed~~  
31 ~~cancer patients at baseline at three and nine months. — Questionnaire-based~~  
32 ~~study of newly diagnosed cancer patients interviewed soon after diagnosis and~~  
33 ~~at 3 and 9 month intervals. 53.8% of the BSA sample were born in the Indian~~  
34 ~~sSub-Ccontinent, 33.% in Africa and 12.9% in the UK. Three screening tools for~~  
35 ~~depression were used to counter concerns about ethnic bias and validity in~~  
36 ~~linguistic translation. —The Hospital Anxiety and Depression Scale (HADS),~~  
37 ~~Patient Health Questionnaire (PHQ9) (both validated in Gujarati), —Mini-MAC and~~  
38 ~~Emotion Thermometers (including the D-distress T thermometer and checklist),~~  
39 ~~Mini-MAC and were used. —Patients also completed~~ the newly developed  
40 ~~Cancer Insight and Denial questionnaire were completed, — and Cancer Beliefs/~~  
41 ~~Physician/Patient Trust questionnaire.~~  
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### 53 **Setting**

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Leicestershire Cancer Centre, UK.

## Participants

94 BSA and 185 BW ~~recently~~newly diagnosed cancer patients.

## Results

BSA self reported significantly higher rates of depressive symptoms ~~on~~ compared to BW patients longitudinally ~~e.g.~~ (HADS D $\geq$ 8: presentation: BSA 35.1% v BW 16.8% p=0.001; 3 months BSA 45.6% v BW 20.8% p=0.001; 9 months BSA 40.6% v BW 15.3% p=0.004). ~~A similar ethnic difference was detected in rates of anxiety until 9 months (HADS  $\geq$ 8 at presentation BSA 54.3% v BW 36.2% p=0.006; 3 months BSA 47.4% v BW 32.6%; 9 months BSA 40.6% v BW 28.2% p=0.25).~~ BSA patients used potentially maladaptive coping strategies ~~more frequently far more~~ than BW patients at baseline. ~~(In particular~~ hopelessness/helplessness p=0.005, fatalism p=0.0005, avoidance p=0.005; ~~and agreement with the CIDQ denial statement 'I do not really believe I have cancer' p=0.0005).~~ ~~were all more common in BSA patients.~~ BSA patients experienced more physical symptoms (DT checklist) which correlated with ethnic differences in depressive symptoms especially at three months. ~~An increase in cancer burden or treatment associated symptoms may have contributed to a peak in depression at 3 months.~~

## 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 nine months after diagnosis if this ethnic disparity in mental wellbeing is to be addressed.

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7 | High rates of anxiety and depression were present longitudinally among BSA  
8 | cancer patients when compared to BW patients.  
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For peer review only



## Article summary

### Article Focus

- We investigated whether there were differences in depressive symptoms anxiety and depression among British South Asian (BSA) cancer patients compared to British White (BW) over a nine9 month period.
- To limit try to avoid cultural bias we used multiple 8 questionnaires including HADS and a version of the PHQ-9 developed for India.
- We considered how coping strategies were used and whether physical symptoms affected mood.

### Key Messages

- BSA had twice the self-reported rates s of anxiety and of depressive symptoms depression than BW patients and five5 times the incidence of severe depression.
- These Differences persist for nine9 months after presentation.
- BSA patients used potentially maladaptive coping strategies far more than BW patients at baseline assessment.
- BSA patients appear to experience a heavier physical symptom burden than BW patients.

### Strengths and Limitations

This is the first comparison of how BSA and BW patients cope with cancer. We have used multiple assessment tools including a version of the PHQ-9 developed for India. We have demonstrated statistically very significant

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6 differences in the rates ~~s-of anxiety and of depressive symptoms-depression~~  
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8 between the two groups and marked differences in coping style.  
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10 BSA clinical staff were involved in the study. In spite of this we had difficulty  
11 recruiting and retaining BSA patients ~~and retention~~, especially by by nine  
12 months ~~\_was low\_~~. Changes in mood between the three data collection points  
13  
14 are not represented. It is also likely that the rates of ~~anxiety and depressive~~  
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16 symptoms are under-reported since anecdotally those who were most  
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18 distressed often did not feel able to participate in this study. Self-reported  
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20 questionnaires indicate the presence of depressive symptoms but given the  
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22 absence of psychiatric interviews this is not diagnostic of a depressive disorder.  
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## Introduction

Depression is one of the strongest determinants of health related quality of life and it also influences medical care and participation in treatment.[1, 2] It may also be linked with other serious outcomes including mortality.[3] The point prevalence of major depression at any time in the first two years following a cancer diagnosis is 14.9% ~~by~~ via DSMIV criteria.[4] This is two to four times that observed in the general population using equivalent criteria.[5] An under researched area is the incidence of ~~psychological distress including anxiety and~~ 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[6] leaving the largely unproven ~~impression~~ ~~that~~ that they also suffer more distress when diagnosed with cancer. However ethnic minorities may be less likely to receive high quality care.[7, 8] 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 [9, 10, 11] (all party (9) and DoH cancer reform strategy 2007/ (9,10) [12,13] and the USA [12, 13, 14] (sides of the Atlantic, Goss 2009, Dept of health and human resources, Presidents panel 2011, [12,13] 9-11) where it is a governmental aspiration to r~~ ~~Removal of~~ such disparities. ~~Uk [10 and 11], USA (14) — is a priority, both of UK [12, 13] and US government [14]~~

~~The UK British South Asian (BSA) population is a large ethnic minority country, Britain (Bhopal, 2004 not in LW reference list late addition).— In England and Wales (total population 56.1 million) those classified as Indians [15] are in the~~

majority accounting for 1,412,958, Pakistan 1,124,511 and Bangladesh 447,201.[16] (~~ONS 2011 not in LW reference list~~) Most of the Indians born in Africa became refugees, being expelled by Idi Amin and others 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, 8,000, Bangladeshi, 3,600) which contrast with the surrounding county (total population: 650,489: Indian 54,000, Pakistani, 2,100, Bangladeshi, 2,300).[16] ONS 2011 same as above same as previous ref see comment) accounting for approximately 33%, predominantly of Gujarati decent originally from western India. We define 'British South Asian (BSA)' as a person whose ancestry is in the Indian subcontinent, and who identifies with, or is identified with, their host country, Britain. A previous pilot study showed a significantly higher incidence in symptoms of depression amongst BSA patients in Leicester and local counties compared to British White (BW) patients via HADS D  $\geq 10$  (BSA 20.7%; BW 10.4% p=0.001).[17] Depression Anxiety and depression wasere associated with certain coping styles, particularly the use of denial in both BSA and BW patients but was employed more frequently by BSA patients.

The findings of our pilot study [17] Roy, 2005] 16 were consistent with the few publications reporting the incidence of depression or distress in ethnic minority cancer patients. 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.[168]

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8 Similar findings were reported from Canada with more distress amongst ethnic  
9 minorities (E and SE Asia, South Asian, [First NationAboriginals](#)) compared to  
10 the majority population (European, Canadian, British p=0.0001). Greater  
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12 distress was also found among those with lower income  
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16 (p=0.001).[\[1879\]Lockett](#)

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20 ~~This study addressed~~ ~~Here we aimed to address~~ how the UK's largest ethnic  
21 minority population (BSA) cope with cancer, in comparison to the host  
22 population, by analysing data from a sample of those attending the  
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24 Leicestershire Cancer Centre.  
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30 Feeling distressed or low in mood are initial emotional responses to a diagnosis  
31 of cancer, and is part of normal adjustment, if of short duration. If, however  
32 distress persists it can have a harmful effect on the mental wellbeing of the  
33 individual risking depressive symptoms [17, 20]([Akechi et al. 2001\(19\)](#), [Roy et](#)  
34 [al. 2005\(16\)](#), )and reduction in compromise of their quality of life.[21, 22, 23]  
35 ([Stark et al. 2002,\(20\)](#) [Clarke et al. 2003\(21\)](#), [Hoyer et al. 2011\(22\)](#)).  
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43 The Transactional Model of Stress and Coping requires an assessment of  
44 personality traits within the context of their environment.[24] ([Lazarus, Folkman](#)  
45 & [Adams 1984](#))23. For cancer patients this environment- includes their beliefs  
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47 about cancer, their level of social support, proficiency in host languages, level of  
48 literacy, degree of disability, co-morbidities, spiritual beliefs, cultural background  
49 and economic circumstances.[25] ([Moes, Holahan 2003](#))24.  
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8 The symptom burden on cancer patients can influence coping with a close  
9 interrelationship with psychological wellbeing. –Fatigue and disabilities  
10 independently predicted depression among lung cancer patients commencing  
11 treatment [26](Hopwood, 2000)25 and has been observed in pre-  
12 chemotherapy patients with curative cancer.[27](Breen, 2009)26. A high  
13 symptom burden can persist over time. 1 in 4 patients (n=4903) had a high  
14 symptom burden 1 year post diagnosis with depression, fatigue and pain having  
15 the greatest impact on their quality of life.[28](Shi, 2011)27. Similarly a high  
16 symptom burden at 12 months was reported among patients referred for control  
17 of pain and depression (n=405).[29]Kroenke, 2013)28. Among Chinese breast  
18 cancer patients (n=285) less distress from physical symptoms immediately after  
19 surgery-early post surgery predicted psychological resilience. The study  
20 suggested that ineffective symptom control during treatment increased a  
21 women's risk of persistent psychological distress longitudinally-. The value of  
22 pre-operative interventions was highlighted.[30]Lam,2009)29.

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39 Of particular concern are reports of higher symptom burden in ethnic minorities  
40 such as among Hispanic women post-chemotherapy for breast cancer [31](Fu,  
41 2009)30 and greater 'unmet need' for symptom control was implicated among  
42 Black and Spanish speaking Hispanic women with breast cancer than White  
43 women.[32](Yoon J, 2008)31

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51 We report the longitudinal incidence of depressive symptoms among a sample  
52 of BSA and BW patients. Coping styles and the burden of patient problems  
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6 were examined to determine if they were implicated in depressive symptoms.

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10 **Hypotheses**

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

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24 ~~We report the longitudinal incidence of anxiety and depression in both groups.~~  
25 ~~Initial assessment took place as soon as possible after diagnosis and 3 and 9~~  
26 ~~months later. Coping styles were also examined to determine if patterns of~~  
27 ~~maladaptive coping changed with time. Greater understanding of how patients~~  
28 ~~from ethnic minorities cope with cancer is a pre-requisite to eliminating~~  
29 ~~inequalities.~~

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37 **Methods**

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41 **Hypotheses**

42 ~~On the basis of our literature review and pilot studies we hypothesized that~~  
43 ~~longitudinally more BSA cancer patients would self report symptoms of anxiety~~  
44 ~~and depression than BW patients. We further hypothesized that a greater use~~  
45 ~~of maladaptive coping strategies would reflect higher rates of anxiety and~~  
46 ~~depression.~~

## Study procedures

279 patients, who were aware 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. They were identified by the nurse specialist via the cancer registry with ethnicity confirmed by their surname and by hospital records.

Prior to their attendance 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 complete three sets of questionnaires in writing, the first immediately as soon as possible, then at three months and nine month intervals. (Table 1)

~~Patients were recruited by either an English speaking clinical nurse specialist or one of two radiographers, who between them spoke English, Gujarati and Hindi.~~

## Questionnaires

Patients completed the Hospital Anxiety and Depression Scale (HADS) Zigmond 1983 [3318] and The Emotion Thermometers [3419] (Mitchell 2010) which



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6 includesincorporates the Distress Thermometer [235]0 and depression  
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8 thermometeralongside thermometers for anxiety (Anx-T) and depression (Dep  
9 T). A problem checklist, included on the thermometer, identified the patient's  
10 symptom burden.(Roth, 1998-35) All are validated but were not initially  
11 available in Gujarati or Hindi. Therefore A commercial company we undertook  
12 an iterative back-translation process as described by Brislin.[36],1970. a  
13 translation via the back-to-back method.[3621] Brislin 1970. A version of the  
14 Patient Health Questionnaire (PHQ-9), which was already validated into Gujarati  
15 and Hindi having been adapted for use in India, was the third questionnaire  
16 used.[237]2 Several tools were used to address the concern that some  
17 weretools are ethnically biased.

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30 An adaptive coping strategy (fighting spirit) and potentially maladaptive  
31 strategies (hopelessness/helplessness, fatalism, anxiety preoccupation and  
32 cognitive avoidance) were Coping strategies were assessed via the Mini-MAC  
33 scale.[3823].Watson 1994 and the locally developed Cancer Insight and  
34 Denial questionnaire (CIDQ). The CIDQ included question 38 from the original  
35 MAC questionnaire to assesselicit the use of denial. The Brief Illness  
36 Perception Questionnaire [24] and the Physician/Patient Trust/ Cancer Beliefs  
37 Questionnaire [25] considered how patients interpreted cancer. The vast  
38 majority of participants chose to complete the first questionnaires at home,  
39 returning them by post. Subsequent questionnaires were posted to participants.

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49 Personal statements illustrating how patients coped were generated by two  
50 qualitative questions, "how would you describe your current illness", and "what  
51 does having cancer mean to you?"  
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## Statistical analysis

Reference was made to the 'Strobe' statement for observational studies.<sup>[39]</sup> (Von Elm, 2007). Depressive symptoms were assessed by We used the following scales and cut off thresholds. HADS A and HADS D, 7v8, ET Thermometers 3v4 and PHQ-9 9v10. In addition cut off scores of HADS  $\geq 11$  and PHQ-9  $\geq 15$  and  $\geq 20$  were used to indicate high severity for depressive symptoms.

The revised classification of the original HADS identified the severity of depressive symptoms (normal 0-7, mild 8-10, moderate 11-14 and severe 15-21).<sup>[40]</sup> Zigmund, Snaith, 1992, Snaith 2003]. - A threshold of  $\geq 11$  identified patients with moderate symptoms, however following the recommendation to have a lower threshold for cancer patients than in general practice,  $\geq 8$  was selected for HADS D.<sup>[41]</sup> Morse et al 2005]. This is supported by a review of 747 papers using HADS 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>[42]</sup> Bjelland et al, 2003]. Threshold scores of  $\geq 10$ ,  $\geq 15$ ,  $\geq 20$  for PHQ-9 were in accordance with the original recommended scores.<sup>[43]</sup> Kroenke, Spitzer & Williams, 2001]. - The current recommended threshold for the DT is  $\geq 4$  and this is retained in the ET <sup>[44]</sup> NCCN (National Comprehensive Cancer Network) 2011] and this analysis. A prior power analysis based on our pilot studies determined 86 participants were required for each ethnic group.

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8 –Graphs denote 95% confidence intervals. Summary scores for selected  
9 coping strategies were from the Mini-MAC and the denial indicators in the CIDQ  
10 questionnaire. Reference was made to individual indicators. Longitudinal data  
11 at baselinepresentation and at three3 and nine9 months is reported.  
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18 Computation of frequencies, percentages and arithmetic median was conducted  
19 to identify patterns in the data. Mann Whitney tests for continuous variables  
20 detected differences between the ethnic groups and the direction of these  
21 relationships. Spearman's Rank Order Tests (rho) explored correlations  
22 between depressive symptoms (HADS D as a continuous variable) and  
23 deprivation. [45](Office for National Statistics, 2011). We report analysis by  
24 age, gender, deprivation, tumour site, place of birth and ethnicity.  
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33 Chi<sup>2</sup> described the relationship between categorical variables. The extent to  
34 which patients used each coping strategy and how its use changed  
35 longitudinally is described. Associations between each strategy and anxiety  
36 and depressive symptoms on is-are reported. Qualitative data was recorded  
37 verbatim. When in Gujarati it was translated to English. Analysis was  
38 performed via SPSS v 18.  
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## 46 47 48 **Results**

49 94 BSA patients were recruited-. The BSA sample largely represents cancer  
50 patients within the Leicester Indian population and although of interest to other  
51 BSA cancer populations, these findings may not be representative. – 53.8%  
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6 were born in the Indian sSub-Ccontinent, 33% in Africa of Indian descent and  
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8 12.9% in the UK. with approximately 33% born in Africa. 4Hindus accounted for  
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10 53.2%, Muslims 25.5% and 17% Sikh. 185 BW patients were recruited.

11 Several cancer sites are represented. The largest cohort was 114 breast  
12  
13 cancer patients. The educational attainment, religion and place of birth ~~record~~  
14  
15 were self-reported by participants. The demographic characteristics of this  
16  
17 sample showed significant differences between ethnic groups in terms of their  
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19 socio-economic status and educational attainment. These details and the  
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21 patient's sex, age, cancer site and treatment intent are listed in Table 24.  
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### Demographics and depressive symptoms

Age was not associated with depression among BSA patients (rho: HADS D, (p=0.62). Older BW patients were less likely to be depressed (rho: HADS D (p=0.03). There was no statistical difference based on gender with females having a higher mean depression score than males at baseline (HADS D; females 4 (range 0-18) IQR 1,7) (males 3 (range 0-20) IQR 1,6) p=0.46.

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 presentation 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) (Supp. Table 1).

Data on educational attainment was recoded into two groups with those patients reaching educational level of 15/16 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 until 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 the educational systems of India and the UK are different. For example "Some patients had listing no formal education but spoke fluently up to five

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6 languages.- Individual results in patients who reported little formal education  
7 were consistent across assessment tools suggesting adequate  
8 comprehension.” (p18)  
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14 There was no significant difference in depressive symptoms between those  
15 BSA patients originating from Africa compared to the Indian Sub continent at  
16 baseline (-MW: Africa 31/80 Md 4 (2,9) Indian Sub Continent Md 5.5 (2,11) Z=-  
17 1.184 p=0.23). Neither was there a significant difference in the experience of  
18 symptoms frequently associated with depression such as (pain (p=0.23), sleep  
19 disturbances (p=0.91) and fatigue (p=0.52).  
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28 Since socio-economic deprivation is closely associated with being a member of  
29 an ethnic minority we considered the extent to which deprivation influenced the  
30 strength of the relationship between ethnicity and depressive symptoms.  
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34 Although there was a strong association between ethnicity and deprivation (MW  
35 r=0.503, p=0.0005)- deprivation The latter had minimal influence on the strength  
36 of the relationship between ethnicity and depression when comparing Pearson  
37 product-moment correlations (PCC) with partial correlation calculations (Table  
38 3).  
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#### 43 **Anxiety and Depressive symptomson at baseline-early after diagnosis**

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47 All three assessment tools showed approximately double the incidence of  
48 depression in BSA patients compared to BW patients (Fig 1a and suppl. Table  
49 2). Severe depression was also more common in the BSA groups as  
50 demonstrated using a higher HADS score  $\geq 11$  (BSA 23/94 (24.5%) BW 11/185  
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(5.9%)  $p=0.001$ ). A similar trend was seen using a higher PHQ-9 threshold ~~off score~~ ( $\geq 15$ ) BSA 13/85 (15%) BW 10/173 (5%)  $p=0.04$ . ~~Again significantly higher levels of anxiety were seen in BSA patients (HADS-A  $\geq 8$  BSA 54.3% v BW 36.2%  $p=0.006$ ) especially severe anxiety (HADS-A  $\geq 11$  BSA 34% v BW 18.9%  $p=0.008$ ). The ethnic difference was reproduced via the AnxT $\geq 4$  albeit inclusive of more patients (BSA 67.5% v BW 52.2%  $p=0.02$ ) (Fig 1b).~~

### Longitudinal trends in depressive symptoms ~~anxiety and depression~~

All tools indicated how more vulnerable BSA patients were in contrast to BW patients. HADS D  $\geq 8$  suggested significantly higher rates of depressive symptoms among BSA patients longitudinally than BW patients (Fig 1**be**). All three assessment tools indicated a slight decrease in depressive symptoms among BSA patients at three months. Depression rates had not fallen lower than those at presentation by nine months although the ethnic difference remained (Fig 1c & 1d).

~~Rates of anxiety appeared to subside for both ethnic groups over time although more BSA patients remained anxious than BW patients at 3 months (HADS A  $\geq 8$   $p=0.04$ ) (Fig 1e). The difference had gone by 9 months ( $p=0.254$ ). The Anxiety Thermometer  $\geq 4$  echoed this trend (3 months ( $p=0.13$ ), 9 months ( $p=0.17$ )) (Fig 1f).~~

### **Influence of deprivation**

~~Since socio-economic 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 anxiety and depression.~~

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8 Although there was a strong association between ethnicity and deprivation (MW  
9  $r=0.503$ ,  $p=0.0005$ ), the latter had minimal influence on the strength of the  
10 relationship between ethnicity and depression when comparing Pearson  
11 product moment correlations (PCC) with partial correlation calculations. (HADS  
12 D:  $-.274$ ;  $p=.0005$ ) partial correlation ( $-.235$ ,  $p=0.001$ ) and via PHQ-9 (PCC  
13  $-.257$ ,  $p=0.0005$ ) partial correlation ( $-.208$ ,  $p=0.001$ ). There was a weak  
14 association between ethnicity and anxiety (HADS A  $-.147$   $p=0.014$ ). Although  
15 deprivation did influence the strength of that relationship to the extent that it  
16 became insignificant ( $-.093$   $p=0.123$ ), the difference between the correlations  
17 was minimal, results supported by findings via Anx-T (PCC  $-.087$   $p=0.158$ )  
18 partial correlation ( $-.083$ ,  $p=0.179$ ).  
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### 32 Coping Strategies

33 BSA patients used ~~maladaptive~~ coping strategies ~~differently more than~~ BW  
34 patients particularly early after diagnosis when ~~greater use of potentially~~  
35 ~~maladaptive strategies were~~ ~~they were~~ associated with higher rates of ~~anxiety~~  
36 ~~depressive symptoms and depression~~ (~~Suppl tables 3, 4 & 5~~).  
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### 43 Hopelessness/ helplessness (Mini MAC)

44 *"its an awful thing to happen....feeling hopeless"*  
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48 BSA patient [No.16](#) soon after diagnosis [No.16](#)  
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6 Although initially the majority of patients did not express helplessness nor  
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8 hopelessness, BSA patients were far more likely to do so ( $p=0.0005$ ). For  
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10 example, more BSA patients than BW patients agreed with the statement 'I feel  
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12 completely at a loss about what to do' (BSA 31 (33%); BW 23(12.4%)  
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14  $p=0.0005$ ). Across the study period BSA patients had higher  
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16 helplessness/hopelessness scores than BW patients although ~~its~~-use  
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18 decreased over time for both groups (Fig 2a). Helplessness/hopelessness is  
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20 sometimes considered to be a substitute for depression so it was not surprising  
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22 that over time ~~as one sample~~ more patients (BSA and BW combined) ~~who~~-felt  
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24 helplessness/hopelessness ~~and also~~ -acknowledged depressive symptoms  
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26 (MW: PHQ-9  $\geq 10$  v 11/HADS D  $\geq 7$  v 8  $p=0.0005$ ). ~~Helplessness/hopelessness~~  
27  
28 ~~was also associated with a higher incidence of anxiety (MW: HADS A 7 v 8,~~  
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30  ~~$p=0.0005$ ).~~  
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### 36 Anxiety preoccupation

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38 *"Cancer has totally changed my life. I am worried, anxious about my treatment*  
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40 *and what lies ahead as this is the second occasion I am going through this"*  
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42 BSA No.103.  
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45 There was a negligible ethnic difference in the use of anxiety preoccupation.

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47 Over time this strategy was used less (Fig 2b). ~~Individual indicators suggested~~  
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49 ~~that BW patients appeared far more apprehensive than BSA patients (BSA~~  
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51 ~~47/93 (50.5%); BW 135/185 (73%)  $p=0.0005$ ), more upset about having cancer~~  
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53 ~~(BSA 58/94 (61.7%); BW 149/185 (80.5%)  $p=0.001$ ) and more likely to describe~~  
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6 themselves as a 'little frightened' (BSA 65/94 (69.1%), BW 149/185 (80.5%)  
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8  $p=0.048$ . It appears paradoxical therefore that BSA patients self reported  
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10 greater anxiety via a single indicator (BSA 46/94 (48.9%) BW 60/185 (32.4%)  
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12  $\text{Chi}^2 p=0.011$ ). Longitudinally there remained little ethnic difference in patients  
13  
14 who were preoccupied with anxiety (3 months  $p=0.751$ , 9 months  $p=0.926$ ).

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16 It was

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18 Anxiety preoccupation was strongly associated with depression (HADS D and  
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20 PHQ-9,  $p=0.0005$ ). Given the overlap of phenomena between anxiety  
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22 preoccupation (the strategy) and anxiety (the outcome) there was predictably a  
23  
24 strong association between them (HADS A  $r=0.63$ ,  $p=0.0005$ ). These patients  
25  
26 were also more likely to report at greater risk of becoming depressive  
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28 symptomsed longitudinally (PHQ-9: presentation  $p=0.0005$ , 3 months  $p=0.0005$ ,  
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30 9 months  $p=0.0005$ ).

### 31 32 33 **Cognitive avoidance**

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36 Cancer is "...something that I put to the back of my mind and don't let it  
37  
38 interfere with my day to day life"- BW No.118

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41 Initially BSA patients used cognitive avoidance to cope more than BW patients  
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43 (MW:  $p=0.0005$ ) (Fig 2c). For example, 'I deliberately push all thoughts of  
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45 cancer out of my mind' (BSA 61/93 (65.6%); BW 63/185 (34.4%),  $p=0.0005$ ).

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47 Over time this ethnic difference continued but was only statistically  
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49 significant/notable at baseline/presentation as illustrated by a comparison of  
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51 median scores (Fig 2c). At baseline/Soon after diagnosis, as one sample, those  
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53 who used cognitive avoidance were more likely to have symptoms of  
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depression (MW: PHQ-9  $p=0.007$ ; HADS D  $\geq 8$   $p=0.001$ ; Dep.T  $\geq 4$   $p=0.002$ ),  
~~and anxiety (HADS A  $\geq 8$   $p=0.0005$ / Anx.T.  $\geq 4$   $p=0.002$ ).~~ Over time avoidant  
 patients ~~did not~~ continued to be ~~anxious (HADS A 3 months  $p=0.016$ , 9 months  
 $p=0.026$ ) but not~~ depressed (HADS D; 3 months  $p=0.2$ ; 9 months  $p=0.14$ ).

### 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' (Fig 2d). For example, 'I am  
 determined to beat this disease' ((BSA 85/93 (91.4%) ~~(n=93)~~; BW 170/185  
 (91.9%) ~~(n=185)~~  $p=1.0$ ). There was little ethnic difference in the extent to which  
 patients used this coping strategy (MW presentation  $p=0.47$ , 3 months  $p=0.57$ ,  
 9 months  $p=0.2$ ). ~~Furthermore there was no consistent association with anxiety  
 (HADS A  $p=0.8$ , 3 months  $p=0.4$ , 9 months  $p=0.6$ ) or depression as one sample  
 for example (PHQ-9 presentation  $p=0.3$ , 3 months  $p=0.2$ , 9 months  $p=0.7$ ).~~

### 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

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6 ~~At presentation~~ More BSA patients were fatalistic when diagnosed with cancer  
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8 than BW patients at baseline assessment (MW:  $p=0.0005$ ). ~~H~~ However this was  
9  
10 largely based on one of five Mini MAC indicators, 'I've put myself in the hands  
11  
12 of God' (BSA 71/94 (75.5%); BW 60/185(32.4%)  $p=0.0005$ ). There was a  
13  
14 gradual decrease in fatalism in both ethnic groups by nine months although it  
15  
16 persisted among BSA patients (Fig 2e). Those who were fatalistic were more  
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18 likely to experience depressive symptoms ~~(via two tools (MW PHQ-9  $p=0.003$ ;~~  
19  
20 (MW: HADS D $\geq$ 8  $p=0.024$ ; PHQ-9,  $p=0.003$ )) but not by the Dep T.  $\geq$ 4  
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22 ( $p=0.101$ ). ~~Anxiety too was associated with fatalism (HADS A MW:  $p=0.011$ ).~~  
23  
24 ~~Again AnxT did not support these findings ( $p=0.164$ ).~~

### Insight and Denial (CIDQ)

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32 *"I'm not ill"*

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34 Written at the top of an uncompleted questionnaire BIPQ by a patient having  
35  
36 chemotherapy for breast cancer following surgery. BW No.127 at presentation

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39 *"...part of me still feels there is nothing wrong with me and this is happening to*  
40  
41 *someone else. This is presumably my way of handling it all."* BW No.311 at

42  
43 nine months

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47 Of those who used denial, potentially a maladaptive coping strategy  
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49 [46](Lazarus, 1993) as a means of coping, BSA patients were over-  
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51 represented, most notably at baseline assessment ~~soon after diagnosis~~  
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53 ( $p=0.001$ ). The ethnic gap remained longitudinally (Fig 2f). Of the three tools

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6 assessing depression only PHQ-9 indicated an association between denial and  
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8 depression albeit weakly (MW:  $p=0.039$ ). ~~There was a similar difficulty in~~  
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10 ~~generating firm conclusions about the relationship between denial and anxiety.~~  
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12 ~~The median scores using HADS A and AnxT suggested a tendency towards~~  
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14 ~~being more anxious when using denial.~~

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18 To facilitate comparisons with Roy's 2005 [175] study, analysis of the single  
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20 indicator 'I don't really believe I have cancer' originating from the MAC  
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22 questionnaire was repeated. At ~~baseline presentation~~ 229/278 patients (82%)  
23  
24 accepted the reality of their diagnosis by disagreeing with the statement. Of the  
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26 27 patients who didn't believe that they had cancer, more were BSA (BSA 19/93  
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28 (20.2%); BW 8/185 (4.3%),  $p=0.0001$ ). Of interest is that 23 patients agreed  
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30 with this statement 'sometimes' (BSA 12 (52.2%); BW 11 (47.8%)). There was  
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32 a strong trend towards BSA patients who denied their diagnosis to be more  
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34 ~~anxious and~~ depressed ~~at baseline~~ but sample numbers were too low to  
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36 ~~warrant analysis assess statistically~~ at ~~nine~~9 months (Fig 2g).

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39 We considered whether causes of distress ~~listed in~~ via the distress thermometer  
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41 checklist explained ethnic differences in ~~anxiety and~~ depressive ~~symptoms~~.  
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43 Cancer treatments offered to both groups were similar so did not influence  
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45 findings. Critically BSA patients experienced more distress from physical  
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47 symptoms of illness and treatment than BW patients. ~~There were 17 physical~~  
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49 ~~symptoms listed. In 13 categories BSA had statistically significant increased~~  
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51 ~~symptoms compared to In 13 out of 17 symptoms BSA patients returned higher~~  
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53 ~~scores than~~ BW patients ~~at presentation~~. For example, pain (BSA 51/83 (58%)).  
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6 BW 59/180 (32.8%) p=0.0001), mouth sores (BSA 21/88 (24.1%)<sub>1</sub>, BW 12/179  
7 (6.7%) p=0.0001) and fevers (BSA 18/87 (20.7%)<sub>2</sub>; BW 5/177(2.8%) p=0.0001).

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10 At ~~3~~three months significantly higher percentages of BSA patients reported  
11 problems with pain, mouth sores, nausea, skin, washing and dressing and  
12 getting around as causes for distress which were not reflected in BW patients.  
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16 By ~~nine~~9 months differences had narrowed with the exception of pain (BSA  
17 19/31 (61.3%) v BW 41/121 (33.9%) p=0.009) (Table 4).  
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## 20 21 22 Discussion

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24 With the exception of our pilot study [17] (—) we are not aware of another  
25 comparison of how BSA and BW patients cope with cancer. To our knowledge  
26 a comparison of how BSA and BW patients cope with cancer has not previously  
27 been reported. It should be of major concern to health care policy makers in the  
28 UK that this study provides evidence that there is a higher prevalence of anxiety  
29 and depressive symptoms among BSA patients soon after the cancer  
30 diagnosis than BW patients. The percentages vary depending on the  
31 assessment tool used but all showed the same trend. BSA rates for depression  
32 were twice that of BW patients using two tools. For example on the HADS-D  $\geq 8$   
33 scale 35.1% of BSA compared to 16.8% of BW patients (p=0.001) had at least  
34 moderate depressive symptoms measured on the HADS D scale ( $\geq 8$ ). on  
35 (score  $\geq 8$ ). This was confirmed on a version of the PHQ-9  $\geq 10$  developed for  
36 India (35.3% BSA v 18.3% BW p=0.05). This is a critical finding since this is  
37 almost 6 times higher than reported within the UK general population using the  
38 same assessment tool (6%).<sup>[2647]</sup> Depression rates for BW patients (PHQ-9  
39 18.3%, (-HADS D  $\geq 8$ , 16.8%; PHQ-9 18.3%)) were similar to those reported in a  
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6 recent meta-analysis of cancer patients (16.3%), being approximately 2.5 times  
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8 higher than in the general population.[4] What is ~~disturbing-most striking~~ is the  
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10 incidence of ~~more severe~~ severe depression in BSA patients which is reflected in  
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12 their HAD-D score  $\geq 11$  (BSA 24.5% v BW 5.9%  $p=0.0001$ ). ~~This was confirmed~~  
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14 ~~on a version of the PHQ-9  $\geq 10$  developed for India (35.3% BSA v 18.3% BW~~  
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16  ~~$p=0.05$ ). However differences were not just confined to depression. Significantly~~  
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18 ~~higher levels of anxiety were seen in BSA patients (HADS-A  $\geq 8$  BSA 54.3% v~~  
19  
20 ~~36.2% BW  $p=0.006$ ) including severe anxiety (HADS-A  $\geq 11$  BSA 34% v 18.9%~~  
21  
22  ~~$p=0.008$ ). Patients also exhibited more anxiety with rates far higher than in the~~  
23  
24 ~~general population (DSMIV-5 15%).[27]~~

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27 These findings supported trends in other studies, notably ~~our~~ pilot study.  
28  
29 Using the ~~threshold cut-off~~ (HADS  $\geq 10$ ), Roy [175] reported BSA 20.7% v BW  
30  
31 10.4% ( $p=0.001$ ) had ~~moderate~~ severe depressive symptoms. ~~With a slightly~~  
32  
33 ~~higher cut-off ( $\geq 11$ ) our study findings at presentation again pointed to a~~  
34  
35 ~~significant difference (BSA 34% v BW 18.9%  $p=0.008$ ).[15]~~ These concur with  
36  
37 other reports which suggest that ethnic minority cancer patients experience  
38  
39 more psychological distress than patients from host populations.[16, 17, 428,  
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41 429] ~~However the BSA population is heterogeneous heterogeneous. It would~~  
42  
43 ~~be grossly simplistic to assume all BSA that sub-populations within this 'label'~~  
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45 ~~respond psychologically in the same way given the breadth and diversity of~~  
46  
47 ~~their religious and cultural influences. Ethnic minorities are however not~~  
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49 ~~heterogeneous. There are for example variations in baseline common mental~~  
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51 ~~disorders in the UK among some BSA groups.[6]~~ However ~~Indian Hindus~~  
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6 ~~comprised the majority of over 50% of~~ our BSA sample and our findings may be  
7 of particular relevance to this sub-group.  
8 ~~—were Indian Hindus.~~

14 What is very interesting is that the HADS-D, PHQ-9 and DepT showed higher  
15 levels of depressive ~~symptoms~~ in both ethnic groups at ~~3~~ three months after  
16 ~~baseline presentation~~, this being steeper among BSA patients. Although  
17 ~~symptoms decreased rates fell back~~, BSA consistently reported higher rates of  
18 depression than BW patients longitudinally. ~~The decline in the prevalence of~~  
19 ~~anxiety was consistent in both groups over time but the ethnic difference~~  
20 ~~persisted.~~—These findings confirmed our first hypothesis.

29 A counter intuitive finding in this study is the similarity of ~~anxiety and depressive~~  
30 ~~symptoms~~ in patients being treated with curative intent (radical) and palliative  
31 patients. Although there ~~were~~ a fewer ~~less~~ questionnaires returned at poorer  
32 ~~rate of return of questionnaires at three~~ 3 and ~~nine~~ 9 months, the ratio of radical  
33 and palliative patients remained the same (HADS D  $\geq 7$  ~~v8~~ baseline presentation  
34  $p=0.08$ , 3 months  $p=0.58$ , 9 months  $p=1.0$ ). In fact this finding is consistent with  
35 a recent meta-analysis.[4]

45 ~~Previously we had considered whether there were differences in knowledge~~  
46 ~~about cancer and levels of trust in doctors between BSA and BW patients. High~~  
47 ~~levels of trust were found in both groups and differences in knowledge about~~  
48 ~~cancer did not explain the increased psychological morbidity.[25, 30] However~~



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6 of particular interest were the marked differences in coping styles between the  
7  
8 two groups of patients.  
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10  
11 At ~~baseline presentation~~ the rates of fatalism helplessness/hopelessness and  
12 domains of denial were far higher among BSA patients and there was a strong  
13  
14 correlation between these ~~potentially maladaptive~~ coping strategies and the  
15  
16 incidence of ~~anxiety and~~ depression in both ethnic groups.  
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19 Helplessness/hopelessness is strongly associated with ~~anxiety and~~ depression  
20  
21 [\[50, 20, 51–55\]](#) as we found globally, findings replicated in this study. [\[31–37\]](#) A  
22  
23 similar pattern was seen in the use of cognitive avoidance. Fatalism too was  
24  
25 associated with higher levels of ~~anxiety and~~ ~~depressive symptoms~~ as  
26  
27 demonstrated on both the PHQ-9 and HADS which supports research from  
28  
29 India [\[5638, 3957\]](#) and ~~maladaptive behaviours in~~ the UK. [\[58, 59\]](#) into the use  
30  
31 of ~~potentially maladaptive behaviours~~. [40, 41\]](#)  
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35 In our previous study [\[175\]](#) denial was significantly related to depression in both  
36  
37 BW and BSA patients. BSA patients were far more likely to agree with the  
38  
39 statement in the MAC questionnaire (Question 38) 'I don't really believe I have  
40  
41 cancer'. In this study a minority of patients denied their diagnosis but again it  
42  
43 was more common among BSA patients ~~using via~~ the same indicator until ~~9~~ nine  
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45 months (MW presentation p=0.0005, 3 months p=0.001, 9 months p=0.2).  
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47 Initially this was strongly associated with ~~anxiety and~~ depression however the  
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49 sample numbers were too small to consider longitudinal associations.  
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What is puzzling is that although BSA patients remained more depressed ~~and~~ ~~anxious~~ than BW patients longitudinally, by ~~3~~three and ~~9~~nine months the use of coping strategies did not explain this. At three months the only difference was in helplessness/hopelessness scores (-p=0.043) and by nine months the ethnic differences in the use of coping strategies were insignificant. Interestingly- by nine ~~With the exception of helplessness/hopelessness at 3 months (p=0.043) the ethnic differences in use of coping strategies are insignificant months but~~ the trend towards higher ~~anxiety and~~ depression among BSA patients remained. Even taking into account a lag time for the alleviation of depressive symptoms ~~of anxiety and depression~~ after less use of maladaptive coping, there remains an incomplete explanation as to why more BSA patients in particular remain so distressed. Our ~~second~~ 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 three months. This was particularly true for BSA patients experienced significantly more ~~pain, nausea, skin concerns, mouth sores, tingling and feeling swollen. These symptoms peaked at three months but there was no statistically significant difference in symptomatology between the two groups by nine months with the exception of pain significantly increased in BSA patients by nine months.~~ However the ethnic differences in depressive symptoms

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6 ~~persisted~~persisted to nine months. ~~at 3 months,~~ which may account for the peak  
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8 in depression particularly among BSA patients at that time but the ethnic  
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10 difference in anxiety and depression persisted with only one symptom (pain)  
11  
12 indicating an ethnic difference at 9 months. Possible explanations include the  
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14 somatisation of physical symptoms being undetected, inadequate symptom  
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16 management, non-compliance due to a lack of literacy and language skills or  
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18 for a patient preference for traditional medicines for symptom control purposes.  
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20 The somatisation of physical symptoms notwithstanding, this is insufficient  
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22 evidence to explain the difference. Our findings reflect the greater symptom  
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24 burden found in other ethnic minority cancer patients, such as among Chinese  
25  
26 and Hispanic populations [31, 32Yoon, 2008, Fu 2009].

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30 ~~T~~his study supports the original hypothesis that more BSA cancer patients  
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32 would self-report depressive symptoms than BW patient over time. Our  
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34 hypothesis that a greater use of potentially maladaptive coping strategies would  
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36 ~~refe~~lectreflect higher rates of depression among BSA patients was supported  
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38 but only until the three month point. A heavier symptom burden among BSA  
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40 patients does appear to contribute to depression rates among this ethnic  
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42 minority compared to the host population.

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45 We wonder whether greater involvement of the General Practitioner (GP) at a  
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47 very early stage may reduce anxiety and depression in BSA patients given the  
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49 difference between BW and BSA patients' preferences for the source of  
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51 information about their cancer. In an earlier study 66.2% of BSA compared to  
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53 5.1% BW wrote that they would prefer to receive their cancer diagnosis from  
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6 their GP ( $p=0.001$ ).<sup>[42]</sup> In this study 49.5% of BSA patients' preferred source of  
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8 sensitive information was their GP compared to 16.9% of BW patients  
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10 ( $p=0.0001$ ). The main reason why the GP is the preferred source of information  
11  
12 is that the majority of BSA patients prefer to discuss their illness in their mother  
13  
14 tongue.<sup>[42]</sup> Of note is that 89% of BSA patients in this series were registered  
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16 with a BSA GP.

### 17 Limitations

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21 Limitations to the study are acknowledged. The BSA sample largely represents  
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23 cancer patients within the Leicester Indian population and although of interest to  
24  
25 other BSA cancer populations, these findings may not represent them. In  
26  
27 addition there was a large sample of patients with breast cancer, which risks  
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29 underrepresentation of those patients with other body site cancers.  
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31 Difficulties in recruitment and retaining BSA participants by nine months  
32  
33 reduced the sample size.<sup>[60]</sup> (Symonds, 2012) was no 32. Self reportedSelf-  
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35 reported questionnaires indicate the presence of depressive symptoms but  
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37 given the absence of psychiatric interviews this is not diagnostic of a depressive  
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39 disorder.

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43 -Modulations in patient mood between the three data collection points are not  
44  
45 represented. It is also likely that depressive symptoms are underreported since  
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47 anecdotally those who were most distressed often did not feel able to participate  
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49 in the study.

### 50 **Recommendations**

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6 The decreased use of maladaptive coping strategies among BSA patients in the  
7 first few months after diagnosis requires investigation, the aim being to reduce  
8 the associated distress earlier along the cancer trajectory. Evidence of greater  
9 distress among BSA patients caused by a heavier symptom burden than among  
10 BW patients also needs further study since several potential causes are  
11 reversible by proactive patient assessments during cancer treatment and follow-  
12 up.  
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## 20 21 22 **Conclusion**

23 Health professionals need to be aware of a greater probability of depressive  
24 symptomatology and how this may present clinically, including somatic  
25 symptoms, in the first nine months after diagnosis if this ethnic disparity in  
26 mental wellbeing is to be addressed.  
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33 ~~The nature of coping strategies among BSA patients in the first few months after~~  
34 ~~diagnosis requires investigation, the aim being to reduce the associated distress~~  
35 ~~as early as possible along the cancer trajectory. Further investigation into the~~  
36 ~~role of the GP in partnership to support patients, particularly for BSA patients, is~~  
37 ~~advised.~~  
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45 ~~This study provides evidence of worryingly high levels of anxiety and depression~~  
46 ~~among the largest ethnic minority in the UK. Further investigation is required if~~  
47 ~~this disparity is to be reduced.~~  
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**Fig 1a-1d: Longitudinal comparison of depressive symptoms in BSA and BW patients**

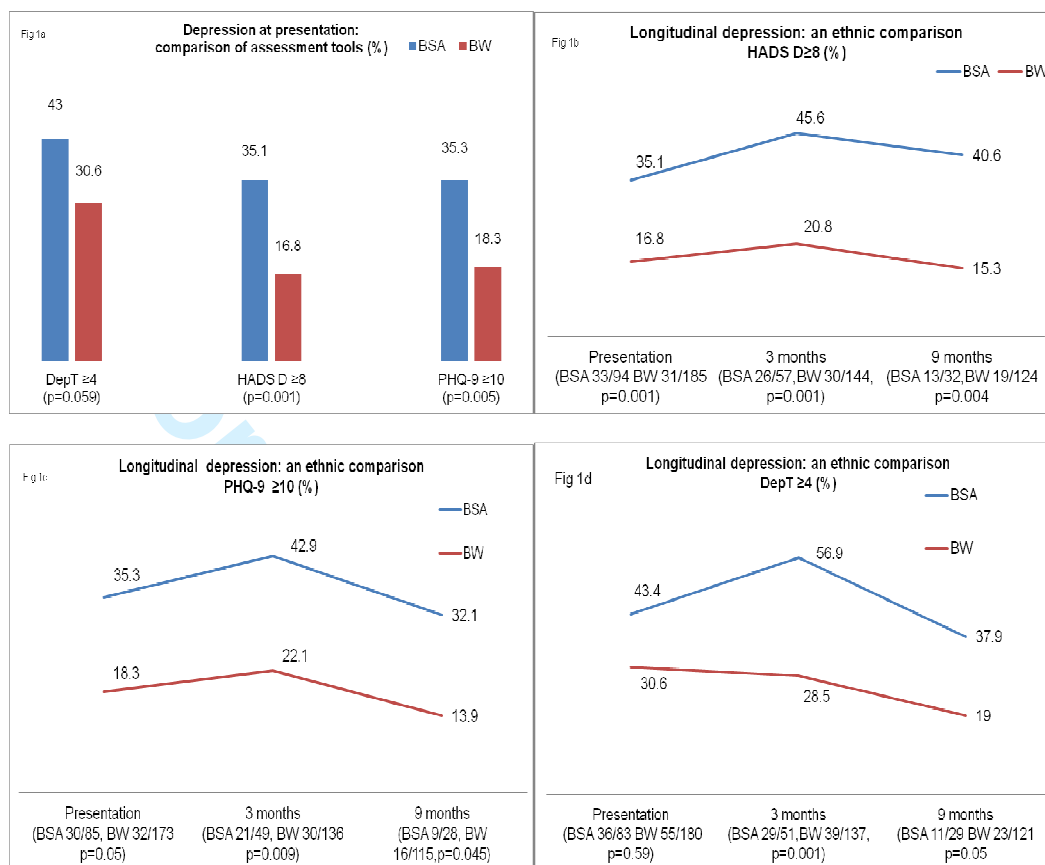
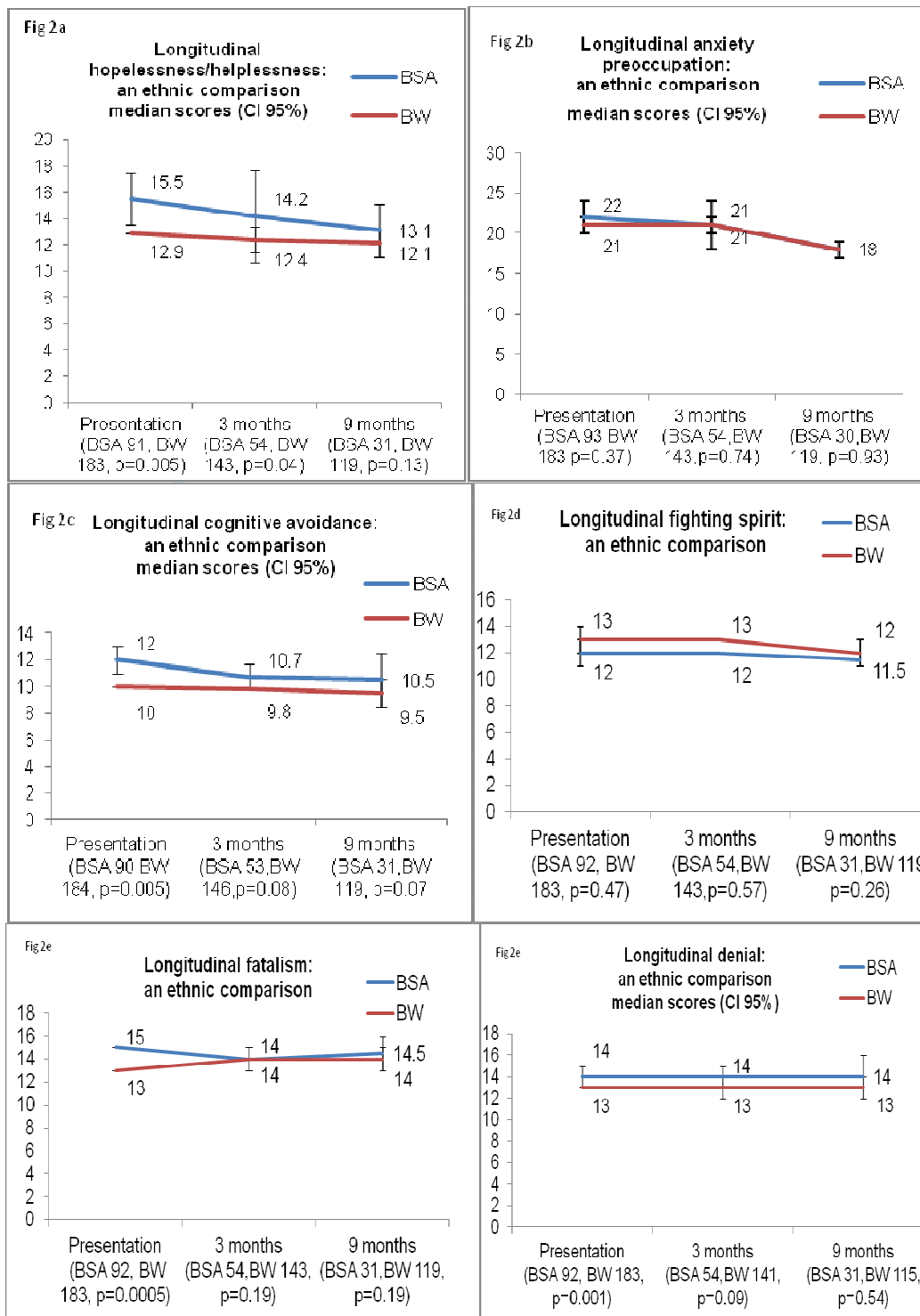
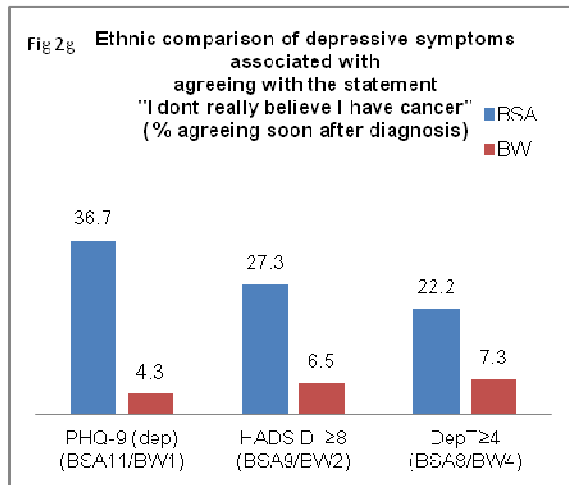


Fig 2a-g Longitudinal ethnic differences in coping strategies



Note: 95% CI was zero for some median scores

Fig 2a-g Longitudinal ethnic differences in coping strategies



**Supp. Table 1: Longitudinal associations between treatment intent and depression**

| HADS-D<br>7v8 |          |            | n=  | ≤7  | %    | ≥8 | %    | p value |
|---------------|----------|------------|-----|-----|------|----|------|---------|
|               | Baseline | Radical    | 188 | 151 | 80.3 | 37 | 19.7 |         |
|               |          | Palliative | 91  | 64  | 70.3 | 27 | 29.7 | 0.088   |
|               | 3 months | Radical    | 136 | 96  | 70.6 | 40 | 29.4 |         |
|               |          | Palliative | 65  | 49  | 75.4 | 16 | 24.6 | 0.588   |
|               | 9 months | Radical    | 111 | 88  | 79.3 | 23 | 20.7 |         |
|               |          | Palliative | 45  | 36  | 80   | 9  | 20   | 1.0     |

Suppl. Table 2: Ethnic differences in depressive symptoms

| Mann Whitney U Test    |           |     | n=  | Mean Rank Score | Md(IQR)   | U      | Z      | r     | Sig.   |
|------------------------|-----------|-----|-----|-----------------|-----------|--------|--------|-------|--------|
| PHQ-9                  | Baseline. | BSA | 85  | 156.95          | 7(3:12)   |        |        |       |        |
|                        |           | BW  | 173 | 116.01          | 4(2:8)    | 5019   | -4.158 | -0.29 | 0.0005 |
|                        | 3months   | BSA | 49  | 112.64          | 9(5:12)   |        |        |       |        |
|                        |           | BW  | 136 | 85.92           | 5(2:8)    | 2369   | -3.003 | 0-.22 | 0.003  |
|                        | 9 months  | BSA | 28  | 84.32           | 4 (2:10)  |        |        |       |        |
|                        |           | BW  | 115 | 69.00           | 3(1:7.5)  | 1265   | -1.767 | -0.14 | 0.077  |
| HADS-D                 | Baseline  | BSA | 94  | 166.43          | 5(2:10)   |        |        |       |        |
|                        |           | BW  | 185 | 126.57          | 3(1:6)    | 6211   | -3.919 | -0.23 | 0.0005 |
|                        | 3months   | BSA | 57  | 125.31          | 6.5(4:10) |        |        |       |        |
|                        |           | BW  | 144 | 91.38           | 4(2:7)    | 2718.5 | -3.742 | -0.26 | 0.0005 |
|                        | 9 months  | BSA | 32  | 98.47           | 6(2:9)    |        |        |       |        |
|                        |           | BW  | 124 | 73.35           | 3(1:7.5)  | 1345   | -2.825 | -0.25 | 0.005  |
| Depression Thermometer | Baseline  | BSA | 84  | 147.51          | 3(0:6)    |        |        |       |        |
|                        |           | BW  | 180 | 125.50          | 1(0:4)    | 6299.5 | -2.249 | -0.13 | 0.024  |
|                        | 3months   | BSA | 51  | 119.72          | 4.5(1:6)  |        |        |       |        |
|                        |           | BW  | 138 | 85.87           | 1(0:3)    | 2258.5 | -3.877 | -0.30 | 0.0005 |
|                        | 9 months  | BSA | 30  | 90.35           | 1(0:5)    |        |        |       |        |
|                        |           | BW  | 120 | 71.85           | 0(0:2)    | 1354.5 | -2.237 | -0.18 | 0.025  |

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**Suppl. Table 3: Longitudinal associations between coping strategies and depression (HADS D)**

| Mann Whitney U Test HADS D 7v8 |                    |          | n=  | Mean Rank Score | Median (IQR)  | U         | Z      | r    | p-value |
|--------------------------------|--------------------|----------|-----|-----------------|---------------|-----------|--------|------|---------|
| H/H                            | Baseline           | ND       | 211 | 119.09          | 12(10:15)     |           |        |      |         |
|                                |                    | D        | 63  | 199.17          | 17.5(14:21.5) | 2761.5    | -7.065 | 0.42 | 0.0005  |
|                                | 3m                 | ND       | 145 | 83.79           | 11(9:15.5)    |           |        |      |         |
|                                |                    | D        | 52  | 141.41          | 16.5(11:19)   | 1564.5    | -6.303 | 0.4  | 0.0005  |
|                                | 9m                 | ND       | 117 | 65.87           | 11(9:15)      |           |        |      |         |
|                                |                    | D        | 31  | 107.08          | 16(14:18)     | 803.5     | -4.802 | 0.39 | 0.0005  |
|                                | Cog. Avoidance     | Baseline | ND  | 210             | 128.22        | 10(9:12)  |        |      |         |
|                                |                    | D        | 62  | 164.56          | 11(10:13)     | 4770.5    | -3.227 | 0.19 | 0.001   |
|                                | 3m                 | ND       | 144 | 95.41           | 10(8:12)      |           |        |      |         |
|                                |                    | D        | 52  | 107.05          | 11(10:13)     | 3299.5    | -1.278 | 0.09 | 0.201   |
|                                | 9m                 | ND       | 117 | 71.86           | 10(8:12)      |           |        |      |         |
|                                |                    | D        | 31  | 84.45           | 11(9:12)      | 1505      | -1.464 | 0.12 | 0.143   |
| Fatalism                       | Baseline           | ND       | 211 | 132.59          | 14(12:16)     |           |        |      |         |
|                                |                    | D        | 64  | 155.85          | 15.5(13:17)   | 5609.5    | -2.062 | 0.12 | 0.039   |
|                                | 3m                 | ND       | 145 | 96.07           | 14(12:15)     |           |        |      |         |
|                                |                    | D        | 52  | 107.16          | 14(13:17)     | 3345.5    | -1.211 | 0.08 | 0.226   |
|                                | 9m                 | ND       | 117 | 73.19           | 14(12:15)     |           |        |      |         |
|                                |                    | D        | 30  | 77.17           | 14(13:16)     | 1660      | -.459  | 0.03 | 0.646   |
|                                | Anx. Preoccupation | Baseline | ND  | 212             | 121.09        | 20(17:23) |        |      |         |
|                                |                    | D        | 64  | 196.18          | 25(22.5:27.5) | 3092.5    | -6.610 | 0.39 | 0.0005  |
|                                | 3m                 | ND       | 145 | 83.76           | 18(15:20.5)   |           |        |      |         |
|                                |                    | D        | 52  | 141.41          | 24(22:26)     | 1559.5    | -6.278 | 0.44 | 0.0005  |
|                                | 9m                 | ND       | 117 | 76.65           | 18(15:21)     |           |        |      |         |
|                                |                    | D        | 30  | 103.08          | 23(18:26)     | 882.5     | -4.203 | 0.34 | 0.0005  |

|                 |          |    |     |        |              |        |        |      |       |
|-----------------|----------|----|-----|--------|--------------|--------|--------|------|-------|
| Fighting Spirit | Baseline | ND | 212 | 138.95 | 13(12:14)    |        |        |      |       |
|                 |          | D  | 63  | 134.80 | 13(11:14)    | 6476.5 | -.368  | 0.02 | 0.713 |
|                 | 3m       | ND | 145 | 104.56 | 13(10:14)    |        |        |      |       |
|                 |          | D  | 52  | 83.51  | 12(11:13)    | 2964.5 | -2.309 | 0.16 | 0.021 |
|                 | 9m       | ND | 117 | 76.65  | 12(11:14)    |        |        |      |       |
|                 |          | D  | 31  | 66.40  | 12(10:13)    | 1562.5 | -1.192 | 0.09 | 0.233 |
| Denial          | Baseline | ND | 211 | 138.33 | 13 (12:15)   |        |        |      |       |
|                 |          | D  | 64  | 136.90 | 14 (12:16)   | 6681.5 | -.127  | 0.07 | 0.899 |
|                 | 3m       | ND | 141 | 94.36  | 13(11.50:15) |        |        |      |       |
|                 |          | D  | 54  | 107.5  | 14(11:16)    | 3294   | -1.466 | 0.10 | 0.143 |
|                 | 9m       | ND | 114 | 75.29  | 13(12:16)    |        |        |      |       |
|                 |          | D  | 30  | 61.92  | 13(10:14)    | 1392.5 | -1.573 | 0.13 | 0.116 |

D= depressive symptoms HADS ≤7

ND = depressive symptoms HADS ≥8



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Suppl. Table 4: Longitudinal associations between coping strategies and depression via PHQ-9

| Mann Whitney U Test (PHQ-9 9v10) |          |    | n=     | Mean Rank Score (MRS) | Median (IQR) | U      | Z      | r      | p-value |
|----------------------------------|----------|----|--------|-----------------------|--------------|--------|--------|--------|---------|
| Hopelessness /Helplessness       | Baseline | ND | 193    | 112.38                | 12(10:15.5)  |        |        |        |         |
|                                  |          | D  | 62     | 176.61                | 17(13:21)    | 2969   | -5.987 | 0.37   | 0.0005  |
|                                  | 3months  | ND | 134    | 76.02                 | 11(8:14)     |        |        |        |         |
|                                  |          | D  | 49     | 135.69                | 17(16:19)    | 1142   | -6.808 | 0.5    | 0.0005  |
|                                  | 9months  | ND | 116    | 63.98                 | 11(9:15.5)   |        |        |        |         |
|                                  | D        | 23 | 100.37 | 16.5(11:19)           | 635.5        | -3.998 | 0.34   | 0.0005 |         |
| Cognitive Avoidance              | Baseline | ND | 192    | 120.03                | 10(9:12)     |        |        |        |         |
|                                  |          | D  | 61     | 148.93                | 11(10:13)    | 4518.5 | -2.712 | 0.16   | 0.007   |
|                                  | 3months  | ND | 134    | 90.10                 | 10(8:12)     |        |        |        |         |
|                                  |          | D  | 49     | 97.20                 | 11(10:12)    | 3028   | -.810  | 0.06   | 0.418   |
|                                  | 9months  | ND | 116    | 67.15                 | 10(8:12)     |        |        |        |         |
|                                  | D        | 23 | 84.37  | 11(10:13)             | 1003.5       | -1.886 | 0.16   | 0.059  |         |
| Fatalism                         | Baseline | ND | 205    | 123.64                | 14(12:16)    |        |        |        |         |
|                                  |          | D  | 53     | 152.18                | 15(13:17)    | 4740.5 | -2.474 | 0.15   | 0.013   |
|                                  | 3months  | ND | 134    | 88.95                 | 14(12:16)    |        |        |        |         |
|                                  |          | D  | 49     | 100.35                | 14(13:16)    | 2874   | -1.297 | 0.09   | 0.15    |
|                                  | 9months  | ND | 116    | 67.81                 | 14(12:15)    |        |        |        |         |
|                                  | D        | 23 | 81.07  | 15(13:19)             | 1079.5       | -1.451 | 0.12   | 0.147  |         |
| Anx. Preoccupation.              | Baseline | ND | 194    | 113.58                | 20(17:23)    |        |        |        |         |
|                                  |          | D  | 62     | 175.19                | 24.5 (21:27) | 3119   | -5.987 | 0.37   | 0.0005  |
|                                  | 3months  | ND | 134    | 78.86                 | 19(16:23)    |        |        |        |         |
|                                  |          | D  | 49     | 127.94                | 24(21:27)    | 1522   | -5.559 | 0.4    | 0.0005  |
|                                  | 9months  | ND | 116    | 62.86                 | 18(15:20.5)  |        |        |        |         |
|                                  | D        | 23 | 106    | 24(22:26)             | 506          | -4.704 | 0.4    | 0.0005 |         |

|                 |          |    |     |        |              |        |        |       |       |
|-----------------|----------|----|-----|--------|--------------|--------|--------|-------|-------|
| Fighting Spirit | Baseline | ND | 194 | 130.87 | 13(12:14)    |        |        |       |       |
|                 |          | D  | 62  | 121.08 | 13(11:14)    | 5554   | -.916  | -0.05 | 0.359 |
|                 | 3months  | ND | 134 | 94.60  | 12(11:14)    |        |        |       |       |
|                 |          | D  | 49  | 84.90  | 12(11:13)    | 2935   | -1.109 | 0.08  | 0.268 |
|                 | 9months  | ND | 116 | 70.43  | 12(10:14)    |        |        |       |       |
|                 |          | D  | 23  | 67.85  | 13(11:13)    | 1284.5 | -.283  | 0.02  | 0.777 |
| Denial (CIDQ)   | Baseline | ND | 194 | 124.49 | 14 (12:15)   |        |        |       |       |
|                 |          | D  | 62  | 141.05 | 14.5 (12:17) | 5236   | -1.542 | -0.09 | 0.123 |
|                 | 3months  | ND | 130 | 87.52  | 13(12:15)    |        |        |       |       |
|                 |          | D  | 49  | 96.58  | 14(12:15)    | 2862.5 | -1.051 | 0.07  | 0.293 |
|                 | 9months  | ND | 114 | 68.82  | 12(11.50:15) |        |        |       |       |
|                 |          |    | 23  | 69.89  | 13(11:16)    | 1290.5 | -.119  | 0.01  | 0.905 |

ND = depressive symptoms PHQ-9  $\geq 10$

D= depressive symptoms PHQ-9  $\leq 9$

**Suppl. Table 5: Longitudinal associations between coping strategies and depressive symptoms via DepT.**

| Mann Whitney                |          |    | n=  | Mean Rank Score (MRS) | Md(IQR)     | U      | Z      | r      | p-value |
|-----------------------------|----------|----|-----|-----------------------|-------------|--------|--------|--------|---------|
| <b>DepT. 3v4</b>            |          |    |     |                       |             |        |        |        |         |
| Hopelessness / helplessness | Baseline | ND | 170 | 108.52                | 12(9:15)    |        |        |        |         |
|                             |          | D  | 92  | 173.96                | 16.5(13:19) | 3913.5 | -6.698 | 0.41   | 0.0005  |
|                             | 3months  | ND | 118 | 81.49                 | 12(9:16)    |        |        |        |         |
|                             |          | D  | 68  | 114.34                | 15(12:19)   | 2595   | -4.022 | 0.29   | 0.0005  |
| Cognitive Avoidance.        | 9months  | ND | 113 | 66.51                 | 11.5(9:15)  |        |        |        |         |
|                             |          | D  | 34  | 98.88                 | 15(12:17)   | 1075   | -3.905 | 0.32   | 0.0005  |
|                             | Baseline | ND | 169 | 120.10                | 10(8:12)    |        |        |        |         |
|                             |          | D  | 91  | 149.81                | 11(10:12)   | 5932.5 | -3.067 | 0.19   | 0.002   |
| Fatalism                    | 3months  | ND | 117 | 90.51                 | 10(9:15)    |        |        |        |         |
|                             |          | D  | 68  | 97.29                 | 11(9:12)    | 3686.5 | -.838  | 0.06   | 0.402   |
|                             | 9months  | ND | 113 | 73.92                 | 10(8:12)    |        |        |        |         |
|                             |          | D  | 34  | 74.26                 | 10(8:12)    | 1912   | -.042  | 0.0003 | 0.967   |
| Anx. Preoccupation.         | Baseline | ND | 170 | 125.88                | 14(12:16)   |        |        |        |         |
|                             |          | D  | 92  | 141.88                | 14(13:16)   | 6865   | -1.641 | 0.1    | 0.101   |
|                             | 3months  | ND | 118 | 88.49                 | 13(12:15)   |        |        |        |         |
|                             |          | D  | 68  | 102.19                | 14(12.5:16) | 3421   | -1.684 | 0.12   | 0.092   |
| Anx. Preoccupation.         | 9months  | ND | 113 | 72.94                 | 13(12:16)   |        |        |        |         |
|                             |          | D  | 34  | 77.53                 | 14(13:16)   | 1801   | -.555  | 0.04   | 0.579   |
|                             | Baseline | ND | 171 | 103.12                | 20(17:22)   |        |        |        |         |
|                             |          | D  | 92  | 185.68                | 24(22:27)   | 2927.5 | -8.412 | 0.52   | 0.0005  |
| Anx. Preoccupation.         | 3months  | ND | 119 | 75.85                 | 19(17:22)   |        |        |        |         |
|                             |          | D  | 68  | 125.76                | 24(21:27)   | 1886   | -6.079 | 0.44   | 0.0005  |
|                             | 9months  | ND | 114 | 66.54                 | 20(17:23)   |        |        |        |         |

|                 |          |    |     |        |             |        |        |       |        |
|-----------------|----------|----|-----|--------|-------------|--------|--------|-------|--------|
|                 |          | D  | 34  | 101.19 | 24(21:27)   | 1030.5 | -4.145 | 0.34  | 0.0005 |
| Fighting Spirit | Baseline | ND | 171 | 132.79 | 13(11:14)   |        |        |       |        |
|                 |          | D  | 92  | 130.53 | 13(11.5:14) | 7731   | -0.232 | 0.01  | 0.817  |
|                 | 3months  | ND | 119 | 93.64  | 13(11:14.5) |        |        |       |        |
|                 |          | D  | 68  | 94.63  | 13(11:14)   | 4003   | -.122  | 0.008 | 0.903  |
|                 | 9months  | ND | 114 | 77.39  | 13(11:15)   |        |        |       |        |
|                 |          | D  | 34  | 64.81  | 12(11:14)   | 1608.5 | -1.518 | 0.12  | 0.129  |
| Denial (CIDQ)   | Baseline | ND | 172 | 132.44 | 14(12:15)   |        |        |       |        |
|                 |          | D  | 92  | 132.61 | 13.5(12:16) | 7901.5 | -0.018 | 0.001 | 0.986  |
|                 | 3months  | ND | 119 | 90.95  | 13(12:15)   |        |        |       |        |
|                 |          | D  | 68  | 99.34  | 13(12:16)   | 3683   | -1.026 | 0.06  | 0.305  |
|                 | 9months  | ND | 115 | 76.65  | 13(12:15)   |        |        |       |        |
|                 |          | D  | 34  | 69.41  | 13(11:15)   | 1765   | -.865  | 0.07  | 0.387  |

ND= depressive symptoms DepT  $\leq$ 3

D= depressive symptoms DepT  $\geq$ 4



**Are depressive symptoms more common among British South Asian compared to British White cancer patients?: a cross sectional survey.**

|                                    |  |
|------------------------------------|--|
| Journal:                           | <i>BMJ Open</i>  |
| Manuscript ID:                     | bmjopen-2013-002650.R2   |
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| Keywords:                          | MENTAL HEALTH, Adult oncology < ONCOLOGY, Adult palliative care < PALLIATIVE CARE, Ethnicity, Depression   |
|                                    |  |

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11 **patients? a cross sectional survey**  
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56 **Key words** Cancer, ethnicity, South Asian, anxiety, depression  
57

58 **Word count** 4475  
59  
60

## **Abstract**

### **Objectives**

This cross sectional survey investigated whether there were ethnic differences in depressive symptoms among British South Asian (BSA) cancer patients compared to British White (BW) patients during nine 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 cancer patients at baseline and at three and nine months. 53.8% of the BSA sample 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 (PHQ9) (both validated in Gujarati), Emotion Thermometers (ET) (including the Distress Thermometer (DT), Mini-MAC and the newly developed Cancer Insight and Denial questionnaire were completed.

### **Setting**

Leicestershire Cancer Centre, UK.

### **Participants**

94 BSA and 185 BW recently diagnosed cancer patients.

### **Results**

BSA self reported significantly higher rates of depressive symptoms compared to BW patients longitudinally (HADS-D $\geq$ 8: baseline: BSA 35.1% v BW 16.8%,

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2  
3 p=0.001; 3 months BSA 45.6% v BW 20.8%, p=0.001; 9 months BSA 40.6% v  
4  
5 BW 15.3%, p=0.004). BSA patients used potentially maladaptive coping  
6  
7 strategies more frequently than BW patients at baseline  
8  
9 (hopelessness/helplessness p=0.005, fatalism p=0.0005, avoidance p=0.005;  
10  
11 the CIDQ denial statement 'I do not really believe I have cancer' p=0.0005).  
12  
13 BSA patients experienced more physical symptoms (DT checklist) which  
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15 correlated with ethnic differences in depressive symptoms especially at three  
16  
17 months.  
18  
19

### 20 **Conclusion**

21  
22 Health professionals need to be aware of a greater probability of depressive  
23  
24 symptomatology (including somatic symptoms) and how this may present  
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26 clinically in the first nine months after diagnosis if this ethnic disparity in mental  
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28 wellbeing is to be addressed.  
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## Article summary

### Article Focus

- We investigated whether there were differences in depressive symptoms among British South Asian (BSA) cancer patients compared to British White (BW) patients over a nine month period.
- To limit cultural bias we used multiple questionnaires including HADS-D and a version of the PHQ-9 developed for India.
- We considered how coping strategies were used and whether physical symptoms affected mood.

### Key Messages

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

### Strengths and Limitations

- 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 nine months.
- Any variations in mood which may have occurred between the three data collection points are not represented.
- It is 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.

## **Introduction**

Depression is one of the strongest determinants of health related quality of life and it can influence medical care and participation in treatment.[1, 2] It may also be linked with other serious outcomes including mortality.[3] The point prevalence of major depression at any time in the first two years following a cancer diagnosis is 14.9% by DSMIV criteria.[4] This is two to four times that observed in the general population using equivalent criteria.[5] 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[6] leaving the largely unproven impression that they also suffer more distress when diagnosed with cancer. However ethnic minorities may be less likely to receive high quality care.[7, 8] 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 [9, 10, 11] and the USA [12, 13, 14] where it is a governmental aspiration to remove such disparities.

People originating from the Indian Sub Continent 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, Pakistani 1,124,511 and Bangladeshi 447,201.[15] Most of the Indians born in Africa either sought sanctuary from or were expelled by leaders such as Idi Amin in East African states.

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3 The city of Leicester has one of the highest concentrations of this population  
4 (total population: 329,836: Indian 93,000, Pakistani, 8,000, Bangladeshi, 3,600)  
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7 which contrast with the surrounding county (total population: 650,489: Indian  
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9  
10 54,000, Pakistani, 2,100, Bangladeshi, 2,300).[15] We define 'British South  
11  
12 Asian (BSA)' as a person whose ancestry originates in the Indian subcontinent,  
13  
14 and who identifies with, or is identified with, their host country [16]. A previous  
15  
16 pilot study showed a significantly higher incidence in symptoms of depression  
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18 among BSA patients in Leicester and the local county compared to British White  
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20 (BW) patients via HADS-D  $\geq 10$  (BSA 20.7%; BW 10.4%  $p=0.001$ ).[17]  
21  
22  
23 Depressive symptoms were associated with potentially maladaptive coping  
24  
25 strategies among both ethnic groups but were employed statistically significantly  
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27 more frequently by BSA patients. For example, fatalism  $p=0.0001$ ; denial  
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29  $p=0.019$ ; hopelessness and helplessness,  $p=0.007$ .  
30  
31  
32  
33

34 The findings of our pilot study [17] were consistent with the few publications  
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36 reporting the incidence of depression or distress in ethnic minority cancer  
37  
38 patients. The largest is a meta-analysis of 21 papers which found that US  
39  
40 Hispanic patients were significantly more distressed ( $p=0.0001$ ) and depressed  
41  
42 ( $p=0.04$ ) than the majority population. [18]  
43  
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46

47 Similar findings were reported from Canada with more distress amongst ethnic  
48  
49 minorities (E and SE Asia, South Asian, First Nation) compared to the majority  
50  
51 population (European, Canadian, British  $p=0.0001$ ). Greater distress was also  
52  
53 found among those with lower income ( $p=0.001$ ).[19]  
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3 Our study addressed how the UK's largest ethnic minority population (BSA)  
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5 coped with cancer, compared with the host population, by analysing data from a  
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7 sample of those attending the Leicestershire Cancer Centre.  
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11  
12 Feeling distressed or low in mood are initial emotional responses to a diagnosis  
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14 of cancer, and is part of normal adjustment, if of short duration. If, however  
15  
16 distress persists it can have a harmful effect on the mental wellbeing of the  
17  
18 individual risking depressive symptoms [17, 20] and a reduction in their quality  
19  
20 of life.[21, 22, 23]  
21  
22

23  
24  
25 This study was designed in reference to the Transactional Model of Stress and  
26  
27 Coping which requires an assessment of personality traits within the context of  
28  
29 the individual's environment.[24] For cancer patients this environment includes  
30  
31 beliefs about cancer, level of social support, proficiency in host languages, level  
32  
33 of literacy, degree of disability, co-morbidities, spiritual beliefs, cultural  
34  
35 background and economic circumstances.[25]  
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41 The symptom burden on cancer patients can have a close interrelationship with  
42  
43 psychological wellbeing. Fatigue and 'disabilities' independently predicted  
44  
45 depression among lung cancer patients commencing treatment [26] and have  
46  
47 been observed in pre-chemotherapy patients with curative cancer.[27] A high  
48  
49 symptom burden can persist over time. One in four patients (n=4903) had a  
50  
51 high symptom burden one year post diagnosis with depression, fatigue and pain  
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53 having the greatest impact on their quality of life.[28] Similarly a high symptom  
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55 burden at 12 months was reported among patients referred for control of pain  
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3 and depression (n=405).[29] Among Chinese breast cancer patients (n=285)  
4  
5 less distress from physical symptoms immediately after surgery predicted  
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7 psychological resilience. The study suggested that ineffective symptom control  
8  
9 during treatment increased a women's risk of persistent psychological distress  
10  
11 longitudinally. The value of pre-operative interventions was highlighted.[30]  
12  
13

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15  
16 Of particular concern are reports of a higher symptom burden among ethnic  
17  
18 minorities, for example among Hispanic women post-chemotherapy for breast  
19  
20 cancer.[31] A greater 'unmet need' for symptom control was implicated among  
21  
22 Black and Spanish speaking Hispanic women with breast cancer than White  
23  
24 women.[32]  
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26

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28  
29 We report the longitudinal incidence of depressive symptoms among a sample  
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31 of BSA and BW patients. Selected demographics, coping styles and the burden  
32  
33 of patient problems were examined to determine if they were associated with  
34  
35 depressive symptoms.  
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37

### 38 39 40 **Hypotheses**

41  
42 On the basis of our literature review and pilot studies we hypothesized that  
43  
44 more BSA cancer patients would self report depressive symptoms than BW  
45  
46 patients over time. We further hypothesized that both a greater use of  
47  
48 potentially maladaptive coping strategies and a heavier symptom burden, would  
49  
50 reflect higher rates of depressive symptoms.  
51  
52

### 53 54 55 **Methods**

## Study procedures

279 patients, who were aware 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 complete three sets of questionnaires in writing, the first immediately, then at three months and nine month intervals. (Table 1)

## Questionnaires

Patients completed the Hospital Anxiety and Depression Scale (HADS-D) [33] and The Emotion Thermometers [34] which includes the Depression and Distress Thermometers [35] and Depression Thermometer (Dep T). The DT

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2  
3 problem checklist identified the patient's symptom burden. All are validated but  
4  
5 were not initially available in Gujarati or Hindi. A commercial company  
6  
7 undertook an iterative back-translation process.[36] A version of the Patient  
8  
9 Health Questionnaire (PHQ-9), which was already validated into Gujarati and  
10  
11 Hindi having been adapted for use in India, was the third questionnaire  
12  
13 used.[37] Several tools were used to address the concern that some were  
14  
15 ethnically biased.  
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17

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20 An adaptive coping strategy (fighting spirit) and potentially maladaptive  
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22 strategies (hopelessness/helplessness, fatalism, anxiety preoccupation and  
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24 cognitive avoidance) were assessed via the Mini-MAC scale.[38] The locally  
25  
26 developed Cancer Insight and Denial questionnaire (CIDQ) included question  
27  
28 38 from the original MAC questionnaire to assess the use of denial. The vast  
29  
30 majority of participants chose to complete the first questionnaires at home,  
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32 returning them by post. Subsequent questionnaires were posted to participants.  
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34 Personal statements illustrating how patients coped were generated by two  
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36 qualitative questions, 'how would you describe your current illness', and 'what  
37  
38 does having cancer mean to you?'  
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### 45 **Statistical analysis**

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47 Depressive symptoms were assessed by HADS-D, ET Thermometers and  
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49 PHQ-9.  
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54 The revised classification of the original HADS-D identified the severity of  
55  
56 depressive symptoms (normal 0-7, mild 8-10, moderate 11-14 and severe 15-  
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3 21.[39] A threshold of  $\geq 11$  identified patients with moderate symptoms.  
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5 However following the recommendation to have a lower threshold for cancer  
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7 patients than in general practice,  $\geq 8$  was selected for HADS-D.[40] This is  
8  
9 supported by a review of 747 papers using HADS-D where the best balance  
10  
11 between sensitivity and specificity was achieved most often when using the cut-  
12  
13 off  $\geq 8$  (Cronbach's alpha coefficient, 0.80).[41] Threshold scores of  $\geq 10$ ,  $\geq 15$ ,  
14  
15  $\geq 20$  for PHQ-9 were in accordance with the original recommended scores.[42]  
16  
17 The current recommended threshold for the DT is  $\geq 4$  and this was retained in  
18  
19 the ET [43] and for this analysis. A prior power calculation determined a sample  
20  
21 size of 86 participants was required for each ethnic group.  
22  
23  
24  
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26

27  
28 Graphs denote 95% confidence intervals. Summary scores for selected coping  
29  
30 strategies were from the Mini-MAC and the denial indicators in the CIDQ.  
31  
32 Reference was made to individual indicators. Longitudinal data at baseline and  
33  
34 at three and nine months is reported.  
35  
36  
37

38  
39 Computation of frequencies, percentages and arithmetic median was conducted  
40  
41 to identify patterns in the data. Mann Whitney tests for continuous variables  
42  
43 detected differences between the ethnic groups and the direction of these  
44  
45 relationships. Spearman's Rank Order Tests ( $\rho$ ) explored correlations  
46  
47 between depressive symptoms (HADS-D as a continuous variable) and  
48  
49 deprivation.[44] We report analysis by age, gender, deprivation, tumour site,  
50  
51 place of birth and ethnicity.  
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3 Chi<sup>2</sup> described the relationship between categorical variables. The extent to  
4 which patients used each coping strategy and how their use changed  
5 longitudinally is described. Associations between each strategy and depressive  
6 symptoms is reported. Qualitative data was recorded verbatim. When in  
7 Gujarati it was translated to English. Analysis was performed via SPSS v 18.  
8  
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## 14 15 16 **Results**

17  
18 94 BSA patients were recruited. The BSA sample largely represents cancer  
19 patients within the Leicester Indian population and although of interest to other  
20 BSA cancer populations, these findings may not be representative. 53.8% were  
21 born in the Indian subcontinent, 33% in Africa of Indian descent and 12.9% in  
22 the UK. Hindus accounted for 53.2%, Muslims 25.5% and 17% Sikh. 185 BW  
23 patients were recruited. Several cancer sites are represented. The largest was  
24 114 breast cancer patients. The educational attainment, religion and place of  
25 birth were self-reported by participants. The demographic characteristics of this  
26 sample showed significant differences between ethnic groups in terms of their  
27 socio-economic status and educational attainment. These details and the  
28 patients' sex, age, cancer site and treatment intent are listed in Table 2.  
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## 45 **Demographics and depressive symptoms**

46  
47 Age was not associated with depression among BSA patients (rho: HADS-D,  
48 (p=0.62). Older BW patients were less likely to be depressed (rho: HADS-D  
49 (p=0.03). There was no statistical difference based on gender, with females  
50 having a higher mean depression score than males at baseline (HADS-D;  
51 females 4 (range 0-18) IQR 1,7) (males 3 (range 0-20) IQR 1,6) p=0.46.  
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5 67.4% patients received radical treatment with the aim of cure or long term  
6  
7 control of disease and 32.6% received palliative treatment given with no  
8  
9 expectation of cure. Unexpectedly there was no evidence that receiving  
10  
11 palliative as opposed to radical (curative intent) treatment influenced a  
12  
13 difference in depressive symptoms (HADS-D $\geq$ 8 baseline p=0.088, 3 months  
14  
15 p=0.588 9 months p=1.0). Those with lung cancer, who generally have a poor  
16  
17 prognosis, had the highest median depression score via HADS-D of 5 (IQR  
18  
19 3,7,scale 0-21). The lowest score was attributed to people with prostate cancer  
20  
21 (Md 1 (IQR 0,5) (Supplementary table 1).  
22  
23  
24  
25  
26

27  
28 Data on educational attainment was recoded into two groups with those patients  
29  
30 reaching educational level of 15/16 removed. This represented groups at either  
31  
32 end of educational attainment. Those educated at the highest level had notably  
33  
34 less depressive symptoms than those with either no formal education or only  
35  
36 until up to the age of 11 (HADS-D  $\geq$ 8, Lowest Ed. 14/30 (46.7%); Highest Ed.  
37  
38 18/97 (18.6%) p=0.004. However these results should be treated with caution  
39  
40 given the educational systems of India and the UK are different. For example  
41  
42 some patients listing no formal education spoke up to five languages fluently.  
43  
44 Individual results in patients who reported little formal education were consistent  
45  
46 across assessment tools suggesting adequate comprehension.  
47  
48  
49  
50

51  
52 There was no significant difference in depressive symptoms between those  
53  
54 BSA patients originating from Africa compared to the Indian Sub continent at  
55  
56 baseline (MW: Africa 31/80 Md 4 (2,9) Indian Sub Continent Md 5.5 (2,11) Z=-  
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3 1.184  $p=0.23$ ). Neither was there a significant difference in the experience of  
4  
5 symptoms frequently associated with depression such as pain ( $p=0.23$ ), sleep  
6  
7 disturbances ( $p=0.91$ ) and fatigue ( $p=0.52$ ).  
8  
9

10  
11 Since socio-economic deprivation is closely associated with being a member of  
12  
13 an ethnic minority we considered the extent to which deprivation influenced the  
14  
15 strength of the relationship between ethnicity and depressive symptoms.  
16  
17

18 Although there was a strong association between ethnicity and deprivation (MW  
19  
20  $r=0.503$ ,  $p=0.0005$ ), deprivation had minimal influence on the strength of the  
21  
22 relationship between ethnicity and depression when comparing Pearson  
23  
24 product-moment correlations (PCC) with partial correlation calculations (Table  
25  
26  
27 3).  
28  
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### 30 31 32 **Depressive symptoms at baseline**

33  
34 All three assessment tools showed approximately double the incidence of  
35  
36 depression in BSA patients compared to BW patients (Fig 1a-1d and  
37  
38 Supplementary table 2). Severe depression was also more common in the BSA  
39  
40 groups as demonstrated using a higher HADS-D score  $\geq 11$  (BSA 23/94 (24.5%)  
41  
42 BW 11/185 (5.9%)  $p=0.001$ ). A similar trend was seen using a higher PHQ-9  
43  
44 threshold  $\geq 15$  (BSA 13/85 (15%) BW 10/173 (5%)  $p=0.04$ ).  
45  
46  
47  
48

### 49 50 **Longitudinal trends in depressive symptoms**

51  
52 All tools indicated how BSA patients were more vulnerable to depressive  
53  
54 symptoms in contrast to BW patients. HADS-D  $\geq 8$  suggested significantly  
55  
56 higher rates of depressive symptoms among BSA patients longitudinally than  
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3 BW patients (Fig 1b). All three assessment tools indicated a slight decrease in  
4 depressive symptoms among BSA patients at three months. Depression rates  
5 had not fallen lower than those at baseline by nine months although the ethnic  
6 difference remained (Fig 1c &1d).  
7  
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### 11 12 13 **Coping Strategies**

14  
15 BSA patients used coping strategies differently to BW patients particularly at  
16 baseline when greater use of potentially maladaptive strategies were associated  
17 with higher rates of depressive symptoms (Supplementary tables 3, 4 & 5).  
18  
19  
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### 24 25 **Hopelessness/ helplessness (Mini MAC)**

26  
27 *"its an awful thing to happen....feeling hopeless"*

28  
29 BSA patient No.16 at baseline  
30  
31  
32  
33

34 Although initially the majority of patients did not express helplessness nor  
35 hopelessness, BSA patients were far more likely to do so (p=0.0005). For  
36 example, more BSA patients than BW patients agreed with the statement 'I feel  
37 completely at a loss about what to do' (BSA 31 (33%); BW 23(12.4%)  
38 p=0.0005). Across the study period BSA patients had higher  
39 helplessness/hopelessness scores than BW patients although use decreased  
40 over time for both groups (Fig 2a). Helplessness/hopelessness is sometimes  
41 considered to be a substitute for depression so it was not surprising that over  
42 time more patients (BSA and BW combined) felt helplessness/hopelessness  
43 and also acknowledged depressive symptoms (MW: PHQ-9  $\geq$ 11/HADS-D  $\geq$ 8  
44 p=0.0005).  
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### **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 (Fig 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  $p=0.0005$ ).

### **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:  $p=0.0005$ ) (Fig 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 (Fig 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’ (Fig 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 nine months although it persisted among BSA patients (Fig 2e). Those who were fatalistic were more likely to experience

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3 depressive symptoms (MW: HADS-D $\geq$ 8 p= 0.024; PHQ-9, p= 0.003) but not by  
4  
5 the Dep T.  $\geq$ 4 (p=0.101).  
6  
7

### 8 9 **Insight and Denial (CIDQ)**

10  
11 *"I'm not ill"*

12  
13  
14 Written at the top of an uncompleted questionnaire by a patient having  
15  
16 chemotherapy for breast cancer following surgery. BW No.127 at baseline  
17  
18

19  
20  
21 *"...part of me still feels there is nothing wrong with me and this is happening to*  
22  
23 *someone else. This is presumably my way of handling it all."* BW No.311 at  
24  
25 nine months  
26  
27

28  
29  
30 Of those who used denial, potentially a maladaptive coping strategy,[45] BSA  
31  
32 patients were over-represented, most notably at baseline assessments  
33  
34 (p=0.001). The ethnic gap remained longitudinally (Fig 2f). Of the three tools  
35  
36 assessing depression only PHQ-9 indicated an association between denial and  
37  
38 depression albeit weakly (MW: p= 0.039).  
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43 To facilitate comparisons with Roy's 2005 study [17], analysis of the single  
44  
45 indicator 'I don't really believe I have cancer' originating from the MAC  
46  
47 questionnaire was repeated. At baseline 229/278 patients (82%) accepted the  
48  
49 reality of their diagnosis by disagreeing with the statement. Of the 27 patients  
50  
51 who didn't believe that they had cancer, more were BSA (BSA 19/93 (20.2%);  
52  
53 BW 8/185 (4.3%), p=0.0001). Of interest is that 23 patients agreed with this  
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55 statement 'sometimes' (BSA 12 (52.2%); BW 11 (47.8%)). There was a strong  
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3 trend towards BSA patients, who denied their diagnosis, to be more depressed  
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5 at baseline but sample numbers were too low to warrant analysis at nine  
6  
7 months (Fig 2g).  
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11 We considered whether causes of distress listed in the distress thermometer  
12  
13 checklist explained ethnic differences in depressive symptoms. Cancer  
14  
15 treatments offered to both groups were similar so did not influence findings.  
16  
17 Critically BSA patients experienced more distress from physical symptoms of  
18  
19 illness and treatment than BW patients. There were 17 physical symptoms  
20  
21 listed in the DT checklist. In 13 categories BSA had statistically significant  
22  
23 increased symptoms compared to BW patients. For example, pain (BSA 51/83  
24  
25 (58%), BW 59/180 (32.8%)  $p=0.0001$ ), mouth sores (BSA 21/88 (24.1%), BW  
26  
27 12/179 (6.7%)  $p=0.0001$ ) and fevers (BSA 18/87 (20.7%), BW 5/177(2.8%)  
28  
29  $p=0.0001$ ). At three months significantly higher percentages of BSA patients  
30  
31 reported problems with pain, mouth sores, nausea, skin, washing and dressing  
32  
33 and getting around as causes for distress which were not reflected in BW  
34  
35 patients. By nine months differences had narrowed with the exception of pain  
36  
37 (BSA 19/31 (61.3%) v BW 41/121 (33.9%)  $p=0.009$ ) (Table 4).  
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## 45 **Discussion**

46  
47 With the exception of our pilot study [17] we are not aware of another  
48  
49 comparison of how BSA and BW patients cope with cancer. It should be of  
50  
51 major concern to health care policy makers in the UK that this study provides  
52  
53 evidence that there is a higher prevalence of depressive symptoms among BSA  
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55 patients soon after the cancer diagnosis than BW patients. The percentages  
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3 vary depending on the assessment tool used but all showed the same trend.  
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5 BSA rates for depression were twice that of BW patients using two tools. 35.1%  
6  
7 of BSA compared to 16.8% of BW patients ( $p=0.001$ ) had depressive symptoms  
8  
9 measured on the HADS-D scale ( $\geq 8$ ). This was confirmed on a version of the  
10  
11 PHQ-9 $\geq 10$  developed for India (35.3% BSA v 18.3% BW  $p=0.05$ ). This is a  
12  
13 critical finding since this is almost six times higher than reported within the UK  
14  
15 general population using the same assessment tool (6%).[46] Depression rates  
16  
17 for BW patients (HADS-D $\geq 8$ , 16.8%; PHQ-9 18.3%) were similar to those  
18  
19 reported in a recent meta-analysis of cancer patients (16.3%), being  
20  
21 approximately 2.5 times higher than in the general population.[4] What is  
22  
23 disturbing is the incidence of more severe depression in BSA patients which is  
24  
25 reflected in their HAD-D score  $\geq 11$  (BSA 24.5% v BW 5.9%  $p=0.0001$ ). These  
26  
27 findings supported trends in other studies, notably our pilot study. Using the  
28  
29 threshold HADS-D  $\geq 10$ , Roy [17] reported BSA 20.7% v BW 10.4% ( $p=0.001$ )  
30  
31 had moderate depressive symptoms. These concur with other reports which  
32  
33 suggest that ethnic minority cancer patients experience more psychological  
34  
35 distress than patients from host populations.[16, 17, 47, 48] However the BSA  
36  
37 population is heterogeneous. It would be grossly simplistic to assume all BSA  
38  
39 patients respond psychologically in the same way given the breadth and diversity  
40  
41 of their religious and cultural influences. However Indian Hindus comprised the  
42  
43 majority of our BSA sample and our findings may be of particular relevance to  
44  
45 this sub-group.  
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54 What is very interesting is that the HADS-D, PHQ-9 and Dep.T showed higher  
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56 levels of depressive symptoms in both ethnic groups at three months after  
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3 baseline, this being steeper among BSA patients. Although symptoms  
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5 decreased, BSA consistently reported higher rates of depression than BW  
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7 patients longitudinally. These findings confirmed our first hypothesis.  
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11 A counter intuitive finding in this study is the similarity of depressive symptoms  
12  
13 in patients being treated with curative intent (radical) and palliative patients.  
14  
15 Although there were fewer questionnaires returned at three and nine months,  
16  
17 the ratio of radical and palliative patients remained the same (HADS-D  $\geq 8$   
18  
19 baseline  $p=0.08$ , 3 months  $p=0.58$ , 9 months  $p=1.0$ ). In fact this finding is  
20  
21 consistent with a recent meta-analysis.[4]  
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27 At baseline the rates of fatalism helplessness/hopelessness and domains of  
28  
29 denial were far higher among BSA patients and there was a strong correlation  
30  
31 between these potentially maladaptive coping strategies and the incidence of  
32  
33 depression in both ethnic groups. Helplessness/hopelessness is strongly  
34  
35 associated with depression [49, 20, 50–54] as we found in this study. A similar  
36  
37 pattern was seen in the use of cognitive avoidance. Fatalism too was  
38  
39 associated with higher levels of depressive symptoms as demonstrated on both  
40  
41 the PHQ-9 and HADS-D which supports research from India [55, 56] and the  
42  
43 UK [57, 58] into the use of potentially maladaptive behaviours.  
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49 In our previous study [17] denial was significantly related to depression in both  
50  
51 BW and BSA patients. BSA patients were far more likely to agree with the  
52  
53 statement in the MAC questionnaire (Question 38) 'I don't really believe I have  
54  
55 cancer'. In this study a minority of patients denied their diagnosis but again it  
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3 was more common among BSA patients using the same indicator until nine  
4  
5 months (MW baseline  $p=0.0005$ , 3 months  $p=0.001$ , 9 months  $p=0.2$ ). Initially  
6  
7 this was strongly associated with depression however the sample numbers  
8  
9 were too small to consider longitudinal associations.  
10

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13  
14 What is puzzling is that although BSA patients remained more depressed than  
15  
16 BW patients longitudinally, by three and nine months the use of coping  
17  
18 strategies did not explain this. At three months the only difference was in  
19  
20 helplessness/hopelessness scores ( $p=0.043$ ) and by nine months the ethnic  
21  
22 differences in the use of coping strategies were insignificant. Interestingly by  
23  
24 nine months the trend towards higher depression among BSA patients  
25  
26 remained. Even taking into account a lag time for the alleviation of depressive  
27  
28 symptoms after less use of maladaptive coping, there remains an incomplete  
29  
30 explanation as to why more BSA patients in particular remain so distressed.  
31  
32 Our hypothesis that a greater use of maladaptive coping strategies would reflect  
33  
34 higher rates of depressive symptoms was therefore only partially confirmed. A  
35  
36 retrospective audit into referral to psycho oncology or prescribing patterns of  
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38 psychotropic medication in the two groups did not suggest a difference that  
39  
40 could account for this.  
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48 We considered whether the burden of physical symptoms explained this ethnic  
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50 gap. BSA patients were more likely to report physical symptoms at baseline  
51  
52 and at three months. This was particularly true for pain, nausea, skin concerns,  
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54 mouth sores, tingling and feeling swollen. These symptoms peaked at three  
55  
56 months but there was no statistically significant difference in symptomatology  
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3 between the two groups by nine months with the exception of pain. However  
4  
5 the ethnic differences in depressive symptoms persisted to nine months.  
6  
7 Possible explanations include the somatisation of physical symptoms being  
8  
9 undetected, inadequate symptom management, non-compliance due to a lack  
10  
11 of literacy and language skills or a patient preference for traditional medicines  
12  
13 for symptom control purposes. Our findings reflect the greater symptom burden  
14  
15 found in other ethnic minority cancer patients, such as among Chinese and  
16  
17 Hispanic populations [31, 32]. This study supports the original hypothesis that  
18  
19 more BSA cancer patients would self-report depressive symptoms than BW  
20  
21 patient over time. Our hypothesis that a greater use of potentially maladaptive  
22  
23 coping strategies would reflect higher rates of depression among BSA patients  
24  
25 was supported but only until the three month point. A heavier symptom burden  
26  
27 among BSA patients does appear to contribute to depression rates among this  
28  
29 ethnic minority compared to the host population.  
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### 36 **Limitations**

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40 Limitations to the study are acknowledged. The BSA sample largely represents  
41  
42 cancer patients within the Leicester Indian population and, although of interest  
43  
44 to other BSA cancer populations, these findings may not represent them. In  
45  
46 addition there was a large sample of patients with breast cancer, which risks  
47  
48 under-representation of those patients with other body site cancers.  
49

50  
51 Difficulties in recruitment and retaining BSA participants by nine months  
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53 reduced the sample size[59]. Self-reported questionnaires indicate the  
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3 presence of depressive symptoms but given the absence of psychiatric  
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5 interviews this is not diagnostic of a depressive disorder.  
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10 Modulations in patient mood between the three data collection points are not  
11  
12 represented. It is also likely that depressive symptoms are underreported since  
13  
14 anecdotally those who were most distressed often did not feel able to participate  
15  
16 in the study.  
17  
18

### 20 **Recommendations**

21  
22  
23 The decreased use of maladaptive coping strategies among BSA patients in the  
24  
25 first few months after diagnosis requires investigation, the aim being to reduce  
26  
27 the associated distress earlier along the cancer trajectory. Evidence of greater  
28  
29 distress among BSA patients caused by a heavier symptom burden than among  
30  
31 BW patients also needs further study since several potential causes are  
32  
33 reversible by proactive patient assessments during cancer treatment and follow-  
34  
35 up.  
36  
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### 40 **Conclusion**

41  
42  
43 Health professionals need to be aware of a greater probability of depressive  
44  
45 symptomatology and how this may present clinically, including somatic  
46  
47 symptoms, in the first nine months after diagnosis if this ethnic disparity in  
48  
49 mental wellbeing is to be addressed.  
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## Contributorship

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Kausher Ibrahim

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Sawan Kumar

Translation of study documentation, patient recruitment, data collection, manuscript production

Alex J Mitchell

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Study design, patient recruitment, manuscript production

R Paul Symonds

Study design, acquiring funding, patient recruitment, data analysis, manuscript production

**Data sharing**

All available data has been included in the manuscript and supplementary tables.

For peer review only



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**Table 1: Recruitment and retention**

| <b>Patient Participation</b>                             | <b>BSA</b> | <b>BW</b> | <b>Total</b> |
|--|------------|-----------|--------------|
| 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%        |

| <b>Reasons for withdrawal from study</b>        |            |           |            |
|---|------------|-----------|------------|
| Consented but did not complete a questionnaires | <b>85</b>  | <b>51</b> | <b>136</b> |
| 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          |

Table 2: Demographics

|  | Total (%)   | British South Asian (BSA)  | British White (BW)   | p value   |
|--|---|--|--|---|
| <b>Number</b>  | 279   | 94   | 185  |   |
| Male   | 88 (31.5%)  | 25 (26.6%)   | 64 (34.6%)   | Chi <sup>2</sup><br>p=0.223                                 |
| Female   | 190 (68%)   | 69 (73.4%)   | 121 (65.4%)  |   |
| <b>Age</b><br>median (Inter Quartile Range)  |   | 57.1 (19)  | 61 (14)  | Wilcoxon<br>rank sum<br>test(WRST)<br>Z=-14.480<br>p=0.0005 |
| <b>IMDS (1-20)*</b><br>Median (IQR)  |   | 6.5 ( IQR 4,10)  | 16(11,18)  | WRST<br>Z=-14.435<br>p=0.0005                               |
| <b>Educational Attainment</b><br>No formal education<br>Junior school (up to 11)<br>Senior school (15-16)<br>Sixth form (17-18)<br>University or college<br><b>**272 pts</b> | 30 (10.7%)<br>8 (2.8%)<br>97 (34.7%)<br>22 (7.8%)<br>115 (41.2%)    | 27 (29.7%)<br>4 (4.4%)<br>16 (17.8%)<br>11 (12.1%)<br>33 (36.3%)         | 3 (1.7%)<br>4 (2.2%)<br>81 (44.8%)<br>11 (6.1%)<br>82 (45.3%)                  | Chi <sup>2</sup><br>p=0.0005                                |
| <b>Religion</b><br>Christian<br>Muslim<br>Hindu<br>Sikh<br>Other<br>None   | 148 (53%)<br>24 (9%)<br>50 (18%)<br>16 (6%)<br>4 (1%)<br>37 (13%)   | nil<br>24 (25.5%)<br>50 (53.2%)<br>16 (17%)<br>1 (1.06%)<br>nil          | 148 (80%)<br>nil<br>nil<br>nil<br>3 (1.6%)<br>34 (18.4%)                       |   |
| <b>Questionnaire Language</b><br>English<br>Gujarati<br>Urdu ( <i>verbal translation</i> )   | 267 (96%)<br>11 (4%)<br>1 (0.3%)                                    |  |  |   |
| <b>Place of birth</b><br>UK<br>British Forces overseas<br>USA<br>Africa<br>Indian sub continent  | 195 (70%)<br>2 (0.7%)<br>1 (0.3%)<br>31 (11.1%)<br>50 (17.9%)       | 13 (14%)<br>nil<br>nil<br>31 (33%)<br>50 (53%)                           | 182 (98.4%)<br>2 (1.08%)<br>1 (0.52%)<br>nil<br>nil                            |   |
| <b>Diagnosis</b><br>Breast<br>Colorectal<br>Gynaecological<br>Prostate<br>Lung<br>Other  | 114 (41%)<br>45 (16%)<br>33 (12%)<br>23 (8%)<br>19 (7%)<br>43 (15%) | 34 (36.2%)<br>15 (16%)<br>19 (20.2%)<br>3 (3.2%)<br>6 (6.4%)<br>17 (18%) | 80 (43.2%)<br>30 (16.2%)<br>15 (8.1%)<br>20 (10.8%)<br>13 (7.0%)<br>26 (14.6%) |   |
| <b>Type of treatment</b><br>Radical ( <i>curative intent</i> )<br>Palliative   | 188 (67.4%)<br>91(32.6%)  | 64 (68.1%)<br>30 (31.9%)   | 124 (67.4%)<br>61 (33%)  | Chi <sup>2</sup><br>p=0.966                                 |
| <b>Time from diagnosis to first interview (wks)</b><br>Median (IQR)  | 7(3)  | 8(3)   | 6(3)   | WRST<br>Z=-14.506<br>P=0.0005                               |

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

\*\* No. of patient who provided their educational attainment

**Table 3: Influence of deprivation**

| Ethnicity and depressive symptoms corrected for deprivation | No. | Pearson product-moment correlation | p-value | No. | Correlation corrected for deprivation | p-value |
|---|-----|------------------------------------|---------|-----|---------------------------------------|---------|
| HADS D  | 277 | -.274                              | 0.0005  | 276 | -.235                                 | 0.0005  |
| PHQ-9   | 256 | -.257                              | 0.0005  | 255 | -.208                                 | 0.001   |
| DepT  | 262 | -.131                              | 0.033   | 261 | -.118                                 | 0.057   |

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

| Problem              |          |     | n=  | No  | %    | Yes | %    | X <sup>2</sup> |
|----------------------|----------|-----|-----|-----|------|-----|------|----------------|
| Pain                 | Baseline | BSA | 88  | 37  | 42   | 51  | 58   |                |
|                      |          | BW  | 180 | 121 | 67   | 59  | 32.8 | 0.0001         |
|                      | 3 months | BSA | 53  | 14  | 26.4 | 39  | 73.6 |                |
|                      |          | BW  | 141 | 92  | 65.2 | 49  | 34.8 | 0.0001         |
|                      | 9 months | BSA | 31  | 12  | 38.7 | 19  | 61.3 |                |
|                      |          | BW  | 121 | 80  | 66.1 | 41  | 33.9 | 0.009          |
| Nausea               | Baseline | BSA | 83  | 56  | 68   | 27  | 32.5 |                |
|                      |          | BW  | 178 | 141 | 79   | 37  | 20.8 | 0.058          |
|                      | 3 months | BSA | 54  | 29  | 53.7 | 25  | 46.3 |                |
|                      |          | BW  | 140 | 91  | 65   | 49  | 35   | 0.198          |
|                      | 9 months | BSA | 29  | 22  | 75.9 | 7   | 24.1 |                |
|                      |          | BW  | 121 | 104 | 86   | 17  | 14   | 0.574          |
| Getting around       | Baseline | BSA | 85  | 59  | 69   | 26  | 30.6 |                |
|                      |          | BW  | 177 | 155 | 88   | 22  | 12.4 | 0.001          |
|                      | 3 months | BSA | 55  | 33  | 60   | 22  | 40   |                |
|                      |          | BW  | 140 | 112 | 80   | 28  | 20   | 0.007          |
|                      | 9 months | BSA | 31  | 23  | 74.2 | 8   | 25.8 |                |
|                      |          | BW  | 120 | 95  | 79.2 | 25  | 20.8 | 0.724          |
| Bathing and dressing | Baseline | BSA | 86  | 62  | 72   | 24  | 27.9 |                |
|                      |          | BW  | 178 | 167 | 94   | 11  | 6.2  | 0.0001         |
|                      | 3 months | BSA | 55  | 42  | 76.4 | 13  | 23.6 |                |
|                      |          | BW  | 140 | 129 | 92.1 | 11  | 7.9  | 0.006          |
|                      | 9 months | BSA | 31  | 25  | 80.6 | 6   | 19.4 |                |
|                      |          | BW  | 120 | 104 | 86.7 | 16  | 13.3 | 0.574          |
| Mouth sores          | Baseline | BSA | 87  | 66  | 76   | 21  | 24.1 |                |
|                      |          | BW  | 179 | 167 | 93   | 12  | 6.7  | 0.0001         |
|                      | 3 months | BSA | 55  | 37  | 67.3 | 18  | 32.7 |                |
|                      |          | BW  | 140 | 114 | 81.4 | 26  | 18.6 | 0.053          |
|                      | 9 months | BSA | 31  | 25  | 80.6 | 6   | 19.4 |                |
|                      |          | BW  | 121 | 109 | 90.1 | 12  | 9.9  | 0.255          |
| Fevers               | Baseline | BSA | 87  | 69  | 79   | 18  | 20.7 |                |
|                      |          | BW  | 177 | 172 | 97   | 5   | 2.8  | 0.0001         |
|                      | 3 months | BSA | 54  | 42  | 77.8 | 12  | 22.2 |                |
|                      |          | BW  | 139 | 127 | 91.4 | 12  | 8.6  | 0.020          |
|                      | 9 months | BSA | 31  | 26  | 83.9 | 5   | 16.1 |                |
|                      |          | BW  | 119 | 108 | 90.8 | 11  | 9.2  | 0.436          |
| Skin                 | Baseline | BSA | 84  | 42  | 50   | 42  | 50   |                |
|                      |          | BW  | 179 | 156 | 87   | 23  | 12.8 | 0.0001         |
|                      | 3 months | BSA | 56  | 26  | 46.4 | 30  | 53.6 |                |
|                      |          | BW  | 142 | 96  | 67.8 | 46  | 32.4 | 0.009          |
|                      | 9 months | BSA | 31  | 16  | 51.6 | 15  | 48.4 |                |
|                      |          | BW  | 121 | 86  | 71.1 | 35  | 28.9 | 0.065          |

**Fig 1a-1d: Longitudinal comparison of depressive symptoms in BSA and BW patients**

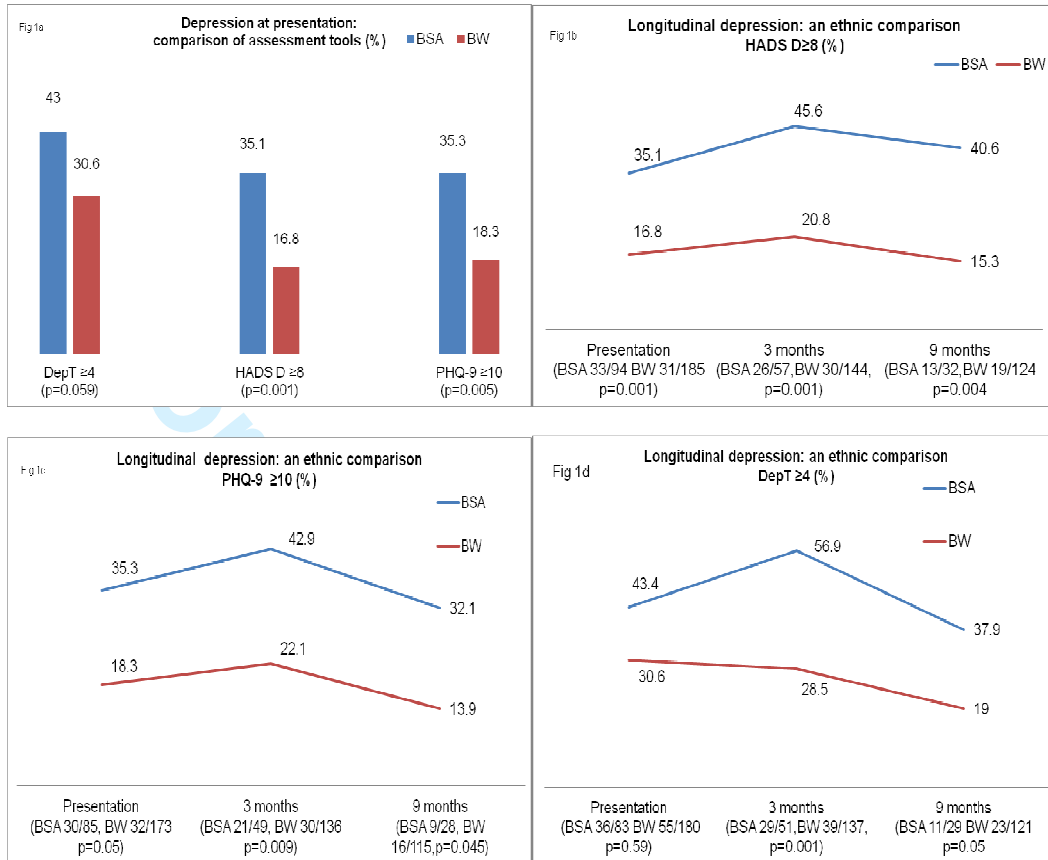
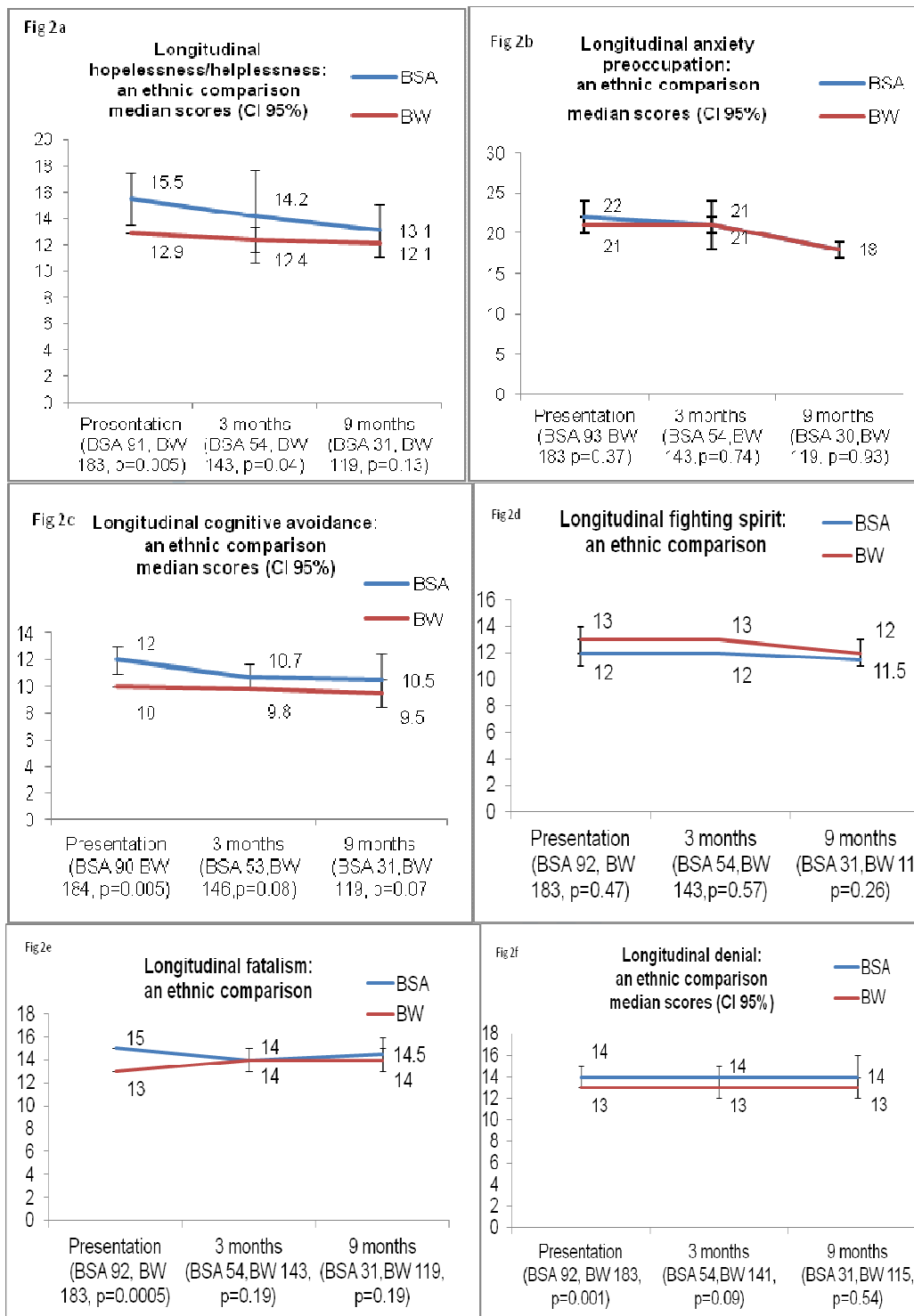


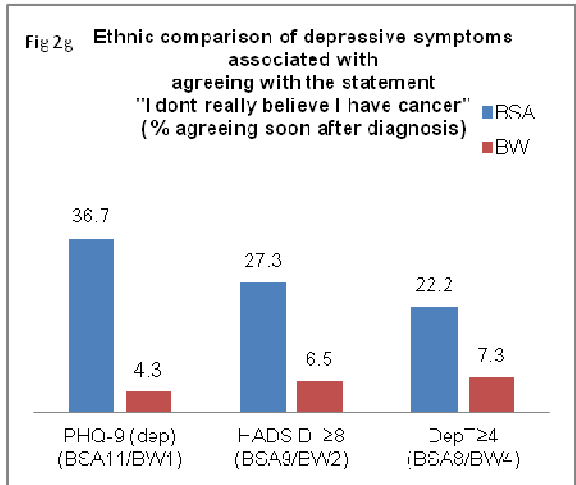


Fig 2a-g Longitudinal ethnic differences in coping strategies



Note: 95% CI was zero for some median scores

Fig 2a-g Longitudinal ethnic differences in coping strategies



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STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

| Section/Topic                | Item # | Recommendation   | Reported on page # |
|------------------------------|--------|--|--------------------|
| Title and abstract           | 1      | (a) Indicate the study's design with a commonly used term in the title or the abstract   | 1                  |
|                              |        | (b) Provide in the abstract an informative and balanced summary of what was done and what was found  | 2                  |
| <b>Introduction</b>          |        |  |                    |
| Background/rationale         | 2      | Explain the scientific background and rationale for the investigation being reported   | 6-9                |
| Objectives                   | 3      | State specific objectives, including any prespecified hypotheses   | 9                  |
| <b>Methods</b>               |        |  |                    |
| Study design                 | 4      | Present key elements of study design early in the paper  | 10                 |
| Setting                      | 5      | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection  | 10                 |
| Participants                 | 6      | (a) Give the eligibility criteria, and the sources and methods of selection of participants  | 10                 |
| Variables                    | 7      | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable   | 10-11              |
| Data sources/<br>measurement | 8*     | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | 10-11              |
| Bias                         | 9      | Describe any efforts to address potential sources of bias  |                    |
| Study size                   | 10     | Explain how the study size was arrived at  | 12                 |
| Quantitative variables       | 11     | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why   | 11                 |
| Statistical methods          | 12     | (a) Describe all statistical methods, including those used to control for confounding  | 11                 |
|                              |        | (b) Describe any methods used to examine subgroups and interactions  | 11-12              |
|                              |        | (c) Explain how missing data were addressed  |                    |
|                              |        | (d) If applicable, describe analytical methods taking account of sampling strategy   |                    |
|                              |        | (e) Describe any sensitivity analyses  |                    |
| <b>Results</b>               |        |  |                    |

|                          |     |  |              |
|--------------------------|-----|--|--------------|
| Participants             | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed            | Table 1      |
|                          |     | (b) Give reasons for non-participation at each stage   | Table 1      |
|                          |     | (c) Consider use of a flow diagram   |              |
| Descriptive data         | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders   | Table 2      |
|                          |     | (b) Indicate number of participants with missing data for each variable of interest  |              |
| Outcome data             | 15* | Report numbers of outcome events or summary measures   | 15-16, Fig 1 |
| Main results             | 16  | (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | Fig 2        |
|                          |     | (b) Report category boundaries when continuous variables were categorized  | 12-20        |
|                          |     | (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period   |              |
| Other analyses           | 17  | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses   |              |
| <b>Discussion</b>        |     |  |              |
| Key results              | 18  | Summarise key results with reference to study objectives   | 20-24        |
| Limitations              | 19  | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias   | 24           |
| Interpretation           | 20  | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence                                   | 24-25        |
| Generalisability         | 21  | Discuss the generalisability (external validity) of the study results  | 25           |
| <b>Other information</b> |     |  |              |
| Funding                  | 22  | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based  | 26           |

\*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).

**Supplementary Table 1: Longitudinal associations between treatment intent and depression**

| HADS-D 7v8 |          |            | n=  | ≤7  | %    | ≥8 | %    | p value |
|------------|----------|------------|-----|-----|------|----|------|---------|
|            | Baseline | Radical    | 188 | 151 | 80.3 | 37 | 19.7 |         |
|            |          | Palliative | 91  | 64  | 70.3 | 27 | 29.7 | 0.088   |
|            | 3 months | Radical    | 136 | 96  | 70.6 | 40 | 29.4 |         |
|            |          | Palliative | 65  | 49  | 75.4 | 16 | 24.6 | 0.588   |
|            | 9 months | Radical    | 111 | 88  | 79.3 | 23 | 20.7 |         |
|            |          | Palliative | 45  | 36  | 80   | 9  | 20   | 1.0     |

| Mann Whitney U Test |          |     | n=  | Mean Rank Score | Md(IQR)   | U      | Z      | r     | Sig.   |
|---------------------|----------|-----|-----|-----------------|-----------|--------|--------|-------|--------|
| PHQ-9               | Baseline | BSA | 85  | 156.95          | 7(3:12)   |        |        |       |        |
|                     |          | BW  | 173 | 116.01          | 4(2:8)    | 5019   | -4.158 | -0.29 | 0.0005 |
|                     | 3 months | BSA | 49  | 112.64          | 9(5:12)   |        |        |       |        |
|                     |          | BW  | 136 | 85.92           | 5(2:8)    | 2369   | -3.003 | 0.22  | 0.003  |
|                     | 9 months | BSA | 28  | 84.32           | 4(2:10)   |        |        |       |        |
|                     |          | BW  | 115 | 69.00           | 3(1:7.5)  | 1265   | -1.767 | -0.14 | 0.077  |
| HADS-D              | Baseline | BSA | 94  | 166.43          | 5(2:10)   |        |        |       |        |
|                     |          | BW  | 185 | 126.57          | 3(1:6)    | 6211   | -3.919 | -0.23 | 0.0005 |
|                     | 3 months | BSA | 57  | 125.31          | 6.5(4:10) |        |        |       |        |
|                     |          | BW  | 144 | 91.38           | 4(2:7)    | 2718.5 | -3.742 | -0.26 | 0.0005 |
|                     | 9 months | BSA | 32  | 98.47           | 6(2:9)    |        |        |       |        |

|                               |              |         |         |            |              |            |                |               |            |
|-------------------------------|--------------|---------|---------|------------|--------------|------------|----------------|---------------|------------|
|                               |              | BW      | 12<br>4 | 73.35      | 3(1:7.5<br>) | 1345       | -<br>2.82<br>5 | -<br>0.2<br>5 | 0.005      |
| Depression<br>Thermomet<br>er | Baselin<br>e | BS<br>A | 84      | 147.5<br>1 | 3(0:6)       |            |                |               |            |
|                               |              | BW      | 18<br>0 | 125.5<br>0 | 1(0:4)       | 6299.<br>5 | -<br>2.24<br>9 | -<br>0.1<br>3 | 0.024      |
|                               | 3month<br>s  | BS<br>A | 51      | 119.7<br>2 | 4.5(1:6<br>) |            |                |               |            |
|                               |              | BW      | 13<br>8 | 85.87      | 1(0:3)       | 2258.<br>5 | -<br>3.87<br>7 | -<br>0.3<br>0 | 0.000<br>5 |
|                               | 9<br>months  | BS<br>A | 30      | 90.35      | 1(0:5)       |            |                |               |            |
|                               |              | BW      | 12<br>0 | 71.85      | 0(0:2)       | 1354.<br>5 | -<br>2.23<br>7 | -<br>0.1<br>8 | 0.025      |

**Supplementary Table 2: Ethnic differences in depressive symptoms**

**Supplementary Table 3: Longitudinal associations between coping strategies and depression (HADS D)**

| Mann<br>Whitney<br>U Test HADS<br>D 7v8 |              |        | n=      | Mea<br>n<br>Ran<br>k<br>Scor<br>e | Median<br>(IQR)   | U          | Z              | r        | p-<br>value |
|---|--------------|--------|---------|-----------------------------------|-------------------|------------|----------------|----------|-------------|
| H/H                                     | Baseli<br>ne | N<br>D | 21<br>1 | 119.<br>09                        | 12(10:15)         |            |                |          |             |
|   |              | D      | 63      | 199.<br>17                        | 17.5(14:2<br>1.5) | 2761<br>.5 | -<br>7.06<br>5 | 0.4<br>2 | 0.000<br>5  |
|   | 3m           | N<br>D | 14<br>5 | 83.7<br>9                         | 11(9:15.5<br>)    |            |                |          |             |
|   |              | D      | 52      | 141.<br>41                        | 16.5(11:1<br>9)   | 1564<br>.5 | -<br>6.30<br>3 | 0.4      | 0.000<br>5  |
|   | 9m           | N<br>D | 11<br>7 | 65.8<br>7                         | 11(9:15)          |            |                |          |             |
|   |              | D      | 31      | 107.<br>08                        | 16(14:18)         | 803.<br>5  | -<br>4.80<br>2 | 0.3<br>9 | 0.000<br>5  |
| Cog.<br>Avoidance                       | Baseli<br>ne | N<br>D | 21<br>0 | 128.<br>22                        | 10(9:12)          |            |                |          |             |
|   |              | D      | 62      | 164.<br>56                        | 11(10:13)         | 4770<br>.5 | -<br>3.22<br>7 | 0.1<br>9 | 0.001       |
|   | 3m           | N<br>D | 14<br>4 | 95.4<br>1                         | 10(8:12)          |            |                |          |             |
|   |              | D      | 52      | 107.<br>05                        | 11(10:13)         | 3299<br>.5 | -<br>1.27<br>8 | 0.0<br>9 | 0.201       |
|   | 9m           | N<br>D | 11<br>7 | 71.8<br>6                         | 10(8:12)          |            |                |          |             |
|   |              | D      | 31      | 84.4<br>5                         | 11(9:12)          | 1505       | -<br>1.46<br>4 | 0.1<br>2 | 0.143       |
| Fatalism                                | Baseli<br>ne | N<br>D | 21<br>1 | 132.<br>59                        | 14(12:16)         |            |                |          |             |
|   |              | D      | 64      | 155.<br>85                        | 15.5(13:1<br>7)   | 5609<br>.5 | -<br>2.06<br>2 | 0.1<br>2 | 0.039       |
|   | 3m           | N<br>D | 14<br>5 | 96.0<br>7                         | 14(12:15)         |            |                |          |             |
|   |              | D      | 52      | 107.<br>16                        | 14(13:17)         | 3345<br>.5 | -<br>1.21<br>1 | 0.0<br>8 | 0.226       |
|   | 9m           | N      | 11      | 73.1                              | 14(12:15)         |            |                |          |             |

|                       |              |        |         |            |                   |            |                |          |            |
|-----------------------|--------------|--------|---------|------------|-------------------|------------|----------------|----------|------------|
|                       |              | D      | 7       | 9          |                   |            |                |          |            |
|                       |              | D      | 30      | 77.1<br>7  | 14(13:16)         | 1660       | -<br>.459      | 0.0<br>3 | 0.646      |
| Anx.<br>Preoccupation | Baseli<br>ne | N<br>D | 21<br>2 | 121.<br>09 | 20(17:23)         |            |                |          |            |
|                       |              | D      | 64      | 196.<br>18 | 25(22.5:2<br>7.5) | 3092<br>.5 | -<br>6.61<br>0 | 0.3<br>9 | 0.000<br>5 |
|                       | 3m           | N<br>D | 14<br>5 | 83.7<br>6  | 18(15:20.<br>5)   |            |                |          |            |
|                       |              | D      | 52      | 141.<br>41 | 24(22:26)         | 1559<br>.5 | -<br>6.27<br>8 | 0.4<br>4 | 0.000<br>5 |
|                       | 9m           | N<br>D | 11<br>7 | 76.6<br>5  | 18(15:21)         |            |                |          |            |
|                       |              | D      | 30      | 103.<br>08 | 23(18:26)         | 882.<br>5  | -<br>4.20<br>3 | 0.3<br>4 | 0.000<br>5 |
| Fighting Spirit       | Baseli<br>ne | N<br>D | 21<br>2 | 138.<br>95 | 13(12:14)         |            |                |          |            |
|                       |              | D      | 63      | 134.<br>80 | 13(11:14)         | 6476<br>.5 | -<br>.368      | 0.0<br>2 | 0.713      |
|                       | 3m           | N<br>D | 14<br>5 | 104.<br>56 | 13(10:14)         |            |                |          |            |
|                       |              | D      | 52      | 83.5<br>1  | 12(11:13)         | 2964<br>.5 | -<br>2.30<br>9 | 0.1<br>6 | 0.021      |
|                       | 9m           | N<br>D | 11<br>7 | 76.6<br>5  | 12(11:14)         |            |                |          |            |
|                       |              | D      | 31      | 66.4<br>0  | 12(10:13)         | 1562<br>.5 | -<br>1.19<br>2 | 0.0<br>9 | 0.233      |
| Denial                | Baseli<br>ne | N<br>D | 21<br>1 | 138.<br>33 | 13<br>(12:15)     |            |                |          |            |
|                       |              | D      | 64      | 136.<br>90 | 14<br>(12:16)     | 6681<br>.5 | -<br>.127      | 0.0<br>7 | 0.899      |
|                       | 3m           | N<br>D | 14<br>1 | 94.3<br>6  | 13(11.50:<br>15)  |            |                |          |            |
|                       |              | D      | 54      | 107.<br>5  | 14(11:16)         | 3294       | -<br>1.46<br>6 | 0.1<br>0 | 0.143      |
|                       | 9m           | N<br>D | 11<br>4 | 75.2<br>9  | 13(12:16)         |            |                |          |            |
|                       |              | D      | 30      | 61.9<br>2  | 13(10:14)         | 1392<br>.5 | -<br>1.57<br>3 | 0.1<br>3 | 0.116      |

D= depressive symptoms HADS  $\leq 7$

ND = depressive symptoms HADS  $\geq 8$



**Supplementary Table 4: Longitudinal associations between coping strategies and depression via PHQ-9**

| Mann Whitney U Test (PHQ-9 v10) |          |    | n = | Mean Rank Score (MRS) | Median (IQR) | U      | Z      | r    | p-value |
|---------------------------------|----------|----|-----|-----------------------|--------------|--------|--------|------|---------|
| Hopelessness /Helplessness      | Baseline | ND | 193 | 112.38                | 12(10:15.5)  |        |        |      |         |
|                                 |          | D  | 62  | 176.61                | 17(13:21)    | 2969   | -5.987 | 0.37 | 0.0005  |
|                                 | 3months  | ND | 134 | 76.02                 | 11(8:14)     |        |        |      |         |
|                                 |          | D  | 49  | 135.69                | 17(16:19)    | 1142   | -6.808 | 0.5  | 0.0005  |
|                                 | 9months  | ND | 116 | 63.98                 | 11(9:15.5)   |        |        |      |         |
|                                 |          | D  | 23  | 100.37                | 16.5(11:19)  | 635.5  | -3.998 | 0.34 | 0.0005  |
| Cognitive Avoidance             | Baseline | ND | 192 | 120.03                | 10(9:12)     |        |        |      |         |
|                                 |          | D  | 61  | 148.93                | 11(10:13)    | 4518.5 | -2.712 | 0.16 | 0.007   |
|                                 | 3months  | ND | 134 | 90.10                 | 10(8:12)     |        |        |      |         |
|                                 |          | D  | 49  | 97.20                 | 11(10:12)    | 3028   | -0.810 | 0.06 | 0.418   |
|                                 | 9months  | ND | 116 | 67.15                 | 10(8:12)     |        |        |      |         |
|                                 |          | D  | 23  | 84.37                 | 11(10:13)    | 1003.5 | -1.886 | 0.16 | 0.059   |
| Fatalism                        | Baseline | ND | 205 | 123.64                | 14(12:16)    |        |        |      |         |
|                                 |          | D  | 53  | 152.18                | 15(13:17)    | 4740.5 | -2.474 | 0.15 | 0.013   |
|                                 | 3months  | ND | 134 | 88.95                 | 14(12:16)    |        |        |      |         |
|                                 |          | D  | 49  | 100.35                | 14(13:16)    | 2874   | -1.297 | 0.09 | 0.15    |
|                                 | 9months  | ND | 116 | 67.81                 | 14(12:15)    |        |        |      |         |
|                                 |          | D  | 23  | 81.07                 | 15(13:1      | 107    | -      | 0.1  | 0.14    |

|                       |              |        |         |        |                  |            |                |               |            |
|-----------------------|--------------|--------|---------|--------|------------------|------------|----------------|---------------|------------|
|                       |              |        |         |        | 9)               | 9.5        | 1.4<br>51      | 2             | 7          |
| Anx.<br>Preoccupation | Basel<br>ine | N<br>D | 19<br>4 | 113.58 | 20(17:2<br>3)    |            |                |               |            |
|                       |              | D      | 62      | 175.19 | 24.5<br>(21:27)  | 311<br>9   | -<br>5.9<br>87 | 0.3<br>7      | 0.00<br>05 |
|                       | 3mon<br>ths  | N<br>D | 13<br>4 | 78.86  | 19(16:2<br>3)    |            |                |               |            |
|                       |              | D      | 49      | 127.94 | 24(21:2<br>7)    | 152<br>2   | -<br>5.5<br>59 | 0.4           | 0.00<br>05 |
|                       | 9mon<br>ths  | N<br>D | 11<br>6 | 62.86  | 18(15:2<br>0.5)  |            |                |               |            |
|                       |              | D      | 23      | 106    | 24(22:2<br>6)    | 506        | -<br>4.7<br>04 | 0.4           | 0.00<br>05 |
| Fighting Spirit       | Basel<br>ine | N<br>D | 19<br>4 | 130.87 | 13(12:1<br>4)    |            |                |               |            |
|                       |              | D      | 62      | 121.08 | 13(11:1<br>4)    | 555<br>4   | -<br>.91<br>6  | -<br>0.0<br>5 | 0.35<br>9  |
|                       | 3mon<br>ths  | N<br>D | 13<br>4 | 94.60  | 12(11:1<br>4)    |            |                |               |            |
|                       |              | D      | 49      | 84.90  | 12(11.1<br>3)    | 293<br>5   | -<br>1.1<br>09 | 0.0<br>8      | 0.26<br>8  |
|                       | 9mon<br>ths  | N<br>D | 11<br>6 | 70.43  | 12(10:1<br>4)    |            |                |               |            |
|                       |              | D      | 23      | 67.85  | 13(11:1<br>3)    | 128<br>4.5 | -<br>.28<br>3  | 0.0<br>2      | 0.77<br>7  |
| Denial (CIDQ)         | Basel<br>ine | N<br>D | 19<br>4 | 124.49 | 14<br>(12:15)    |            |                |               |            |
|                       |              | D      | 62      | 141.05 | 14.5<br>(12:17)  | 523<br>6   | -<br>1.5<br>42 | -<br>0.0<br>9 | 0.12<br>3  |
|                       | 3mon<br>ths  | N<br>D | 13<br>0 | 87.52  | 13(12:1<br>5)    |            |                |               |            |
|                       |              | D      | 49      | 96.58  | 14(12:1<br>5)    | 286<br>2.5 | -<br>1.0<br>51 | 0.0<br>7      | 0.29<br>3  |
|                       | 9mon<br>ths  | N<br>D | 11<br>4 | 68.82  | 12(11.5<br>0:15) |            |                |               |            |
|                       |              |        | 23      | 69.89  | 13(11:1<br>6)    | 129<br>0.5 | -<br>.11<br>9  | 0.0<br>1      | 0.90<br>5  |

ND = depressive symptoms PHQ-9  $\geq 10$

D= depressive symptoms PHQ-9  $\leq 9$

**Supplementary Table 5: Longitudinal associations between coping strategies and depressive symptoms via Depression Thermometer (E.T.)**

| Mann Whitney<br>DepT. 3v4      |              |        | n=      | Mean<br>Rank<br>Score<br>(MRS) | Md(IQR<br>)     | U          | Z              | r          | p-<br>value |
|--------------------------------|--------------|--------|---------|--------------------------------|-----------------|------------|----------------|------------|-------------|
| Hopelessness /<br>helplessness | Baseli<br>ne | N<br>D | 17<br>0 | 108.<br>52                     | 12(9:15)        |            |                |            |             |
|                                |              | D      | 92      | 173.<br>96                     | 16.5(13:<br>19) | 3913<br>.5 | -<br>6.69<br>8 | 0.41       | 0.000<br>5  |
|                                | 3mont<br>hs  | N<br>D | 11<br>8 | 81.4<br>9                      | 12(9:16)        |            |                |            |             |
|                                |              | D      | 68      | 114.<br>34                     | 15(12:1<br>9)   | 2595       | -<br>4.02<br>2 | 0.29       | 0.000<br>5  |
|                                | 9mont<br>hs  | N<br>D | 11<br>3 | 66.5<br>1                      | 11.5(9:1<br>5)  |            |                |            |             |
|                                |              | D      | 34      | 98.8<br>8                      | 15(12:1<br>7)   | 1075       | -<br>3.90<br>5 | 0.32       | 0.000<br>5  |
| Cognitive<br>Avoidance.        | Baseli<br>ne | N<br>D | 16<br>9 | 120.<br>10                     | 10(8:12)        |            |                |            |             |
|                                |              | D      | 91      | 149.<br>81                     | 11(10:1<br>2)   | 5932<br>.5 | -<br>3.06<br>7 | 0.19       | 0.002       |
|                                | 3mont<br>hs  | N<br>D | 11<br>7 | 90.5<br>1                      | 10(9:15)        |            |                |            |             |
|                                |              | D      | 68      | 97.2<br>9                      | 11(9:12)        | 3686<br>.5 | -<br>.838      | 0.06       | 0.402       |
|                                | 9mont<br>hs  | N<br>D | 11<br>3 | 73.9<br>2                      | 10(8:12)        |            |                |            |             |
|                                |              | D      | 34      | 74.2<br>6                      | 10(8:12)        | 1912       | -<br>.042      | 0.00<br>03 | 0.967       |
| Fatalism                       | Baseli<br>ne | N<br>D | 17<br>0 | 125.<br>88                     | 14(12:1<br>6)   |            |                |            |             |
|                                |              | D      | 92      | 141.<br>88                     | 14(13:1<br>6)   | 6865       | -<br>1.64<br>1 | 0.1        | 0.101       |
|                                | 3mont<br>hs  | N<br>D | 11<br>8 | 88.4<br>9                      | 13(12:1<br>5)   |            |                |            |             |
|                                |              | D      | 68      | 102.<br>19                     | 14(12.5:<br>16) | 3421       | -<br>1.68      | 0.12       | 0.092       |

|                     |          |    |     |        |             |        |         |       |        |
|---------------------|----------|----|-----|--------|-------------|--------|---------|-------|--------|
|                     |          |    |     |        |             |        | 4       |       |        |
|                     | 9months  | ND | 113 | 72.94  | 13(12:16)   |        |         |       |        |
|                     |          | D  | 34  | 77.53  | 14(13:16)   | 1801   | - .555  | 0.04  | 0.579  |
| Anx. Preoccupation. | Baseline | ND | 171 | 103.12 | 20(17:22)   |        |         |       |        |
|                     |          | D  | 92  | 185.68 | 24(22:27)   | 2927.5 | - 8.412 | 0.52  | 0.0005 |
|                     | 3months  | ND | 119 | 75.85  | 19(17:22)   |        |         |       |        |
|                     |          | D  | 68  | 125.76 | 24(21:27)   | 1886   | - 6.079 | 0.44  | 0.0005 |
|                     | 9months  | ND | 114 | 66.54  | 20(17:23)   |        |         |       |        |
|                     |          | D  | 34  | 101.19 | 24(21:27)   | 1030.5 | - 4.145 | 0.34  | 0.0005 |
| Fighting Spirit     | Baseline | ND | 171 | 132.79 | 13(11:14)   |        |         |       |        |
|                     |          | D  | 92  | 130.53 | 13(11.5:14) | 7731   | - 0.232 | 0.01  | 0.817  |
|                     | 3months  | ND | 119 | 93.64  | 13(11:14.5) |        |         |       |        |
|                     |          | D  | 68  | 94.63  | 13(11:14)   | 4003   | - .122  | 0.008 | 0.903  |
|                     | 9months  | ND | 114 | 77.39  | 13(11:15)   |        |         |       |        |
|                     |          | D  | 34  | 64.81  | 12(11:14)   | 1608.5 | - 1.518 | 0.12  | 0.129  |
| Denial (CIDQ)       | Baseline | ND | 172 | 132.44 | 14(12:15)   |        |         |       |        |
|                     |          | D  | 92  | 132.61 | 13.5(12:16) | 7901.5 | - 0.018 | 0.001 | 0.986  |
|                     | 3months  | ND | 119 | 90.95  | 13(12:15)   |        |         |       |        |
|                     |          | D  | 68  | 99.34  | 13(12:16)   | 3683   | - 1.026 | 0.06  | 0.305  |
|                     | 9months  | ND | 115 | 76.65  | 13(12:15)   |        |         |       |        |
|                     |          | D  | 34  | 69.41  | 13(11:15)   | 1765   | - .865  | 0.07  | 0.387  |

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3 ND= depressive symptoms DepT  $\leq 3$

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5 D= depressive symptoms DepT  $\geq 4$

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