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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≥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 ≥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

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

Conclusion

High rates of anxiety and depression were present longitudinally among BSA cancer patients when compared to BW patients.

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 then 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 ≥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.

The findings of our pilot study 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.[16]

Similar findings were reported from Canada with more distress amongst ethnic minorities (E and SE Asia, South Asian, Aboriginals) compared to the majority population (European, Canadian, British p=0.0001). Greater distress was also found among those with lower income (p=0.001).[17]

Here we aimed to address how the UK's largest ethnic minority population (BSA) cope with cancer in comparison to the host population by analysing data from a sample of those attending the Leicestershire Cancer Centre. We report the longitudinal incidence of anxiety and depression in both groups. Initial assessment took place as soon as possible after diagnosis and 3 and 9 months later. Coping styles were also examined to determine if patterns of maladaptive coping changed with time. Greater understanding of how patients from ethnic minorities cope with cancer is a pre-requisite to eliminating inequalities.

Methods

Hypotheses

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

complete the first questionnaires at home, returning them by post. Subsequent questionnaires were posted to participants.

Statistical analysis

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 ≥11 and PHQ-9 ≥15 and ≥20 were used to indicate high severity for depressive symptoms. Graphs denote 95% confidence intervals. Summary scores for selected coping strategies were from the Mini-MAC and the denial indicators in the CIDQ questionnaire. Reference was made to individual indicators. Longitudinal data at presentation and at 3 and 9 months is reported.

Computation of frequencies, percentages and arithmetic median was conducted to identify patterns in the data. Mann Whitney tests for continuous variables detected differences between the ethnic groups and the direction of these relationships. Chi^2 described the relationship between categorical variables. The extent to which patients used each coping strategy and how its use changed longitudinally is described. Associations between each strategy and anxiety and depression are reported. Analysis was performed via SPSS v 18.

Results

94 BSA patients were recruited with approximately 33% born in Africa. 185 BW patients were recruited. Several cancer sites are represented. The largest cohort was 114 breast cancer patients. The educational attainment, religion and place of birth record were self reported by participants. The demographic characteristics of this sample showed significant differences between ethnic groups in terms of their socio-economic status and

educational attainment. These details and the patient's sex, age, cancer site and treatment intent are listed in Table 1.

Table 1: Demographics

* Index Multiple Deprivation Scale (Office National Statistics,2007

	Total (%)	British South Asian (BSA)	British White (BW)	p value
Number	279	94	185	
Male Female	88 (31.5%) 190 (68%)	25 (26.6%) 69 (73.4%)	64 (34.6%) 121 (65.4%)	Chi ^{2} p=0.223
Age median (Inter Quartile Range)		57.1 (19)	61 (14)	Wilcoxon rank sum test(WRST) Z=-14.480 p=0.0005
IMDS (1-20)* Median (IQR)		6.5 (IQR 4,10)	16(11,18)	WRST Z=-14.435 p=0.0005
Educational Attainment No formal education Junior school (up to 11) Senior school (15-16) Sixth form (17-18) University or college 272 pts	 30 (10.7%) 8 (2.8%) 97 (34.7%) 22 (7.8%) 115 (41.2%)	 27 (29.7%) 4 (4.4%) 16 (17.8%) 11 (12.1%) 33 (36.3%)	 3 (1.7%) 4 (2.2%) 81 (44.8%) 11 (6.1%) 82 (45.3%)	 Chi^2 p=0.0005
Religion Christian Muslim Hindu Sikh Other None	 148 (53%) 24 (9%) 50 (18%) 16 (6%) 4 (1%) 37 (13%)	 nil 24 (25.5%) 50 (53.2%) 16 (17%) 1 (1.06%) nil	 148 (80%) nil nil nil 3 (1.6%) 34 (18.4%)	
Interview Language English Gujarati Urdu	267 (96%) 11 (4%) 1 (0.3%)			
Place of birth UK British Forces overseas USA Africa Indian sub continent	 195 (70%) 2 (0.7%) 1 (0.3%) 31 (11.1%) 50 (17.9%)	 13 (14%) nil nil 31 (33%) 50 (53%)	 182 (98.4%) 2 (1.08%) 1 (0.52%) nil nil	
Diagnosis Breast Colorectal Gynaecological Prostate Lung Other	 41% 16% 12% 8% 7.0% 15%	 34 (36.2%) 15 (16%) 19 (20.2%) 3 (3.2%) 6 (6.4%) 17 (18%)	 80 (43.2%) 30 (16.2%) 15 (8.1%) 20 (10.8%) 13 (7.0%) 26 (14.6%)	
Type of treatment Radical Palliative	 188 (67.4%) 91(32.6%)	 64 (68.1%) 30 (31.9%)	 124 (67.4%) 61 (33%)	Chi^2 p=0.966
Time from diagnosis to first interview (wks) Median (IQR)	7(3)	8(3)	6(3)	WRST Z=-14.506 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 ≥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 (≥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 ≥8 BSA 54.3% v BW 36.2% p=0.006) especially severe anxiety (HADS-A ≥11 BSA 34% v BW 18.9% p=0.008). The ethnic difference was reproduced via the AnxT≥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 ≥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 ≥8 p=0.04) (Fig 1e). The difference had gone by 9 months (p=0.254). The Anxiety Thermometer ≥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

(BSA 58/94 (61.7%); BW 149/185 (80.5%) p=0.001) and more likely to describe themselves as a 'little frightened' (BSA 65/94 (69.1%), BW 149/185 (80.5%) p=0.048. It appears paradoxical therefore that BSA patients self reported greater anxiety via a single indicator (BSA 46/94 (48.9%) BW 60/185 (32.4%) Chi^2 p=0.011). Longitudinally there remained little ethnic difference in patients who were preoccupied with anxiety (3 months p=0.751, 9 months p=0.926).

Anxiety preoccupation was strongly associated with depression (HADS D and PHQ-9 p=0.0005). Given the overlap of phenomena between anxiety preoccupation (the strategy) and anxiety (the outcome) there was predictably a strong association between them (HADS A r=0.63, p=0.0005). These patients were also at greater risk of becoming depressed longitudinally (PHQ-9: presentation 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 notable at presentation as illustrated by a comparison of median scores (Fig 2c). Soon after diagnosis, as one sample those who used cognitive avoidance were more likely to have symptoms of depression (MW: PHQ-9 p=0.007; HADS D ≥8 p=0.001; Dep.T ≥4

p=0.002) and anxiety (HADS A ≥8 p=0.0005/ Anx.T. ≥4 p= 0.002). Over time avoidant patients 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 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 a '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

At presentation more BSA patients were fatalistic when diagnosed with cancer than BW patients (MW: p=0.0005) however this was largely based on one of 5

Mini MAC indicators, 'I've put myself in the hands of God' (BSA 71/94 (75.5%); BW 60/185(32.4%) p=0.0005). There was a gradual decrease in fatalism in both ethnic groups by 9 months although it persisted among BSA patients (Fig 2e). Those who were fatalistic were more likely to experience depressive symptoms via two tools (MW PHQ-9 p= 0.003; HADS D≥8 p= 0.024) but not by the Dep T. ≥4 (p=0.101). Anxiety too was associated with fatalism (HADS A MW; p=0.011). Again AnxT did not support these findings (p= 0.164).

Insight and Denial (CIDQ)

"I'm not ill"

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

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

Of those who used denial as a means of coping BSA patients were overrepresented, most notably soon after diagnosis (p=0.001). The ethnic gap remained longitudinally (Fig 2f). Of the three tools assessing depression only PHQ-9 indicated an association between denial and depression albeit weakly (MW: p= 0.039). There was a similar difficulty in generating firm conclusions about the relationship between denial and anxiety. The median scores using HADS A and AnxT suggested a tendency towards being more anxious when using denial.

To facilitate comparisons with Roy's 2005 [15] study, analysis of the single indicator 'I don't really believe I have cancer' originating from the MAC questionnaire was repeated. At presentation 229/278 patients (82%) accepted the reality of their diagnosis by disagreeing with the statement. Of the 27 patients who didn't believe that they had cancer, more were BSA (BSA 19/93 (20.2%); BW 8/185 (4.3%), p=0.0001). Of interest is that 23 patients agreed with this statement 'sometimes' (BSA 12 (52.2%); BW 11 (47.8%)). There was a strong trend towards BSA patients who denied their diagnosis to be more anxious and depressed but sample numbers were too low to assess statistically at 9 months (Fig 2g).

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

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 ≥8). This is a critical finding since this is almost 6 times higher than reported within the UK general population (6%).[26] Depression rates for BW patients (PHQ-9 18.3%, HADS D≥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.[4] What is most striking is the incidence of severe depression in BSA patients which is reflected in their HAD-D score ≥11 (BSA 24.5% v BW 5.9% p=0.0001). This was confirmed on a version of the PHQ-9≥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≥8 BSA 54.3% v 36.2% BW p=0.006) including severe anxiety (HADS A ≥11BSA 34%v18.9% p=0.008). Patients also exhibited more anxiety with rates far higher than in the general population (DSMIV 5-15%).[27]

These findings supported trends in other studies, notably a pilot study. Using the cut-off (HADS ≥10), Roy [15] reported BSA 20.7% v BW 10.4% (p=0.001) had severe depressive symptoms. With a slightly higher cut-off (≥11) our study findings at presentation again pointed to a significant difference (BSA 34% v BW 18.9% p=0.008).[15] These concur with other reports which suggest that ethnic minority cancer patients experience more psychological distress than patients from host populations.[16, 17, 28, 29] Ethnic minorities are however not heterogeneous. There are for example variations in baseline common mental disorders in the UK among some BSA groups.[6] However over 50% of our BSA sample were Indian Hindus.

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

A counter intuitive finding in this study is the similarity of anxiety and depression in patients being treated with curative intent (radical) and palliative patients. Although there was a poorer rate of return of questionnaires at 3 and 9 months the ratio of radical and palliative patients remained the same (HADS D 7v8 presentation p=0.08, 3 months p=0.58, 9 months p=1.0). In fact this finding is consistent with a recent meta-analysis.[4]

Previously we had considered whether there were differences in knowledge about cancer and levels of trust in doctors between BSA and BW patients. High levels of trust were found in both groups and differences in knowledge about cancer did not explain the increased psychological morbidity.[25, 30] However of particular interest were the marked differences in coping styles between the two groups of patients.

At presentation the rates of fatalism helplessness/hopelessness and domains of denial were far higher among BSA patients and there was a strong correlation between these coping strategies and the incidence of anxiety and depression in both ethnic groups. Helplessness/hopelessness is strongly associated with anxiety and depression globally, findings replicated in this study.[31-37] A similar pattern was seen in the use of cognitive avoidance. Fatalism too was associated with higher levels of anxiety and depression as demonstrated on both the PHQ-9 and HADS which supports research from India [38, 39] and maladaptive behaviours in the UK.[40, 41]

In our previous study [15] denial was significantly related to depression in both BW and BSA patients. BSA patients were far more likely to agree with the statement in the MAC questionnaire (Question 38) 'I don't really believe I have cancer'. In this study a minority of patients denied their diagnosis but again it was more common among BSA patients via the same indicator until 9 months (MW presentation p=0.0005, 3 months p=0.001, 9 months p=0.2). Initially this was strongly associated with anxiety and depression however the sample numbers were too small to consider longitudinal associations.

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

information about their cancer. In an earlier study 66.2% of BSA compared to 5.1% BW wrote that they would prefer to receive their cancer diagnosis from their GP (p=0.001).[42] In this study 49.5% of BSA patients' preferred source of sensitive information was their GP compared to 16.9% of BW patients (p=0.0001). The main reason why the GP is the preferred source of information is that the majority of BSA patients prefer to discuss their illness in their mother tongue.[42] Of note is that 89% of BSA patients in this series were registered with a BSA GP.

Recommendations

The nature of coping strategies among BSA patients in the first few months after diagnosis requires investigation, the aim being to reduce the associated distress as early as possible along the cancer trajectory. Further investigation into the role of the GP in partnership to support patients, particularly for BSA patients, is advised.

This study provides evidence of worryingly high levels of anxiety and depression among the largest ethnic minority in the UK. Further investigation is required if this disparity is to be reduced.

References

1. Kennard BD, Stewart SM, Olvera R, et al. Nonadherence in Adolescent Oncology Patients: Preliminary Data on Psychological Risk Factors and Relationships to Outcome. *J Clin Psychol Med S* 2004;**11:**1:31-39. DOI 0.1023/B:JOCS.0000016267.21912.74

2. Steginga SK, Campbell A, Ferguson M, et al. Socio-demographic, psychosocial and attitudinal predictors of help seeking after cancer. *Psychooncology* 2008;**17:**997-1005. DOI 10.1002/pon.1317

3. Satin JR, Linden W, Phillips MJ. Depression as a predictor of disease progression and mortality in cancer patients: a meta-analysis. *Cancer* 2008;**115:**5349-5361.

4. Mitchell AJ, Chan M, Bhatti H, et al. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *Lancet Oncol* 2011;**12:**160-174. DOI:10.1016/S1470-2045(11)70002-X

5. Hinz A, Krauss O, Hauss JP, et al. Anxiety and depression in cancer patients compared with the general population. *Eur J Cancer Care* 2010;**19:**522-529. DOI 10.1111/j.1365-2354.2009.01088.x

6. Weich S, Nazroo J, Sproston K, et al. Common mental disorders and ethnicity in England: the EMPIRIC study. *Psychol Med* 2004;**34:**1543-1551.

7. Shavers VL, Brown ML. Racial and ethnic disparities in the receipt of cancer treatment. *J Natl Cancer Inst* 2002;**94:**334-57.

8. Ward E, Jemal A, Cokkinides V, et al. Cancer disparities by race/ethnicity and socioeconomic status. *CA Cancer J Clin* 2004;**54:**78-93.

9. Goss E, Lopez AM, Brown CL, et al. American Society of Clinical Oncology policy statement: disparities in cancer care. *J Clin Oncol* 2009;**27:**2881-2885. DOI 10.1200/JCO.2008.21.1680

10. US Department of Health and Human Services (2011) President's Cancer Panel: American's demographic and cultural transformations: Implications for cancer Washington DC 1-100

11. All party parliamentary group on cancer (2009) Report of the all party parliamentary group of cancer's enquiry into inequalities in cancer available at www.appq-cancer.uk

12. Department of Health (2007), Cancer Reform Strategy available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081007.pdf, The Stationery Office, UK

13. Department of Health (2011) Improving outcomes a strategy for cancer via http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123394.pdf, Department of Health, London

14. Department of Health and Human Services (USA) (2011), HHS Action plan to reduce racial and ethnic health disparities available via http://minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf, Department of Health and Human Services, Washington DC

15. Roy R, Symonds RP, Kumar DM, et al. The use of denial in an ethnically diverse British cancer population: a cross-sectional study. *Br J Cancer* 2005;**92:**1393-1397. doi:10.1038/sj.bjc.6602523

16. Luckett T, Butow PN, King MT, et al. A review and recommendations for optimal outcome measures of anxiety, depression and general distress in studies evaluating psychosocial interventions for English-speaking adults with heterogeneous cancer diagnoses. *Support Care Cancer* 2010;**18:**1241-1262. DOI 10.1007/s00520-010-0932-8

17. Carlson LE, Groff SL, Maciejewski O, et al. Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *J Clin Oncol* 2010;**28:**4884-4891. DOI 0.1200/JCO.2009.27.3698

18. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;**67:**361-370.

19. Mitchell AJ, Baker-Glenn EA, Park B, et al. Can the Distress Thermometer be improved by additional mood domains? Part II. What is the optimal combination of Emotion Thermometers? *Psycho-oncology* 2010;**19:**134-140. DOI 10.1002/pon.1557

20. Roth AJ, Kornblith AB, Batel-Copel L, et al. Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. *Cancer* 1998;**82:**1904-1908.

21. Brislin RW. Back-translation for cross-cultural research. *Journal of Cross-cultural Psychology* 1970;**1:**185-216. doi: 10.1177/135910457000100301

22. Kochhar PH, Rajadhyaksha SS, Suvarna VR. Translation and validation of brief patient health questionnaire against DSM IV as a tool to diagnose major depressive disorder in Indian patients. *J Postgrad Med* 2007;**53:**102-107.

23. Watson M, Law M, Dossantos M, et al. The Mini-Mac; Further development of the mental adjustment to cancer scale. *J Psychosoc Oncol* 1994;**12:**33-46.

24. Broadbent E, Petrie KJ, Main J, et al. The brief illness perception questionnaire. J *Psychosom Res* 2006;**60:**631-637. DOI 10.1016/j.jpsychores.2005.10.020

25. Lord K, Ibrahim K, Kumar S, et al. Measuring trust in healthcare professionals-a study of ethnically diverse UK cancer patients. *Clin Oncol* 2012;**24:**13-21. DOI: 10.1016/j.clon.2011.05.010

26. National Institute for Health and Clinical Excellence (NICE) 2011, February 2010-last update, Clinical knowledge summaries (CKS) clinical topics. Depression; Available via http://www.cks.nhs.uk/depression/management/scenario_bereavement/view_full_scenario#-402794 [2012, 26/6].

27. King M, Nazareth I, Levy G, et al. Prevalence of common mental disorders in general practice attendees across Europe. *Br J Psychiatry* 2008;**192:**362-367. DOI 10.1192/bjp.bp.107.039966

28. Ashing-Giwa KT, Tejero JS, Kim J, et al. Examining predictive models of HRQOL in a population-based, multiethnic sample of women with breast carcinoma. *Qual Life Res* 2007;**16:**413-428. DOI 10.1007/s11136-006-9138-4

29. Ell K, Sanchez K, Vourlekis B, et al. Depression, correlates of depression and receipt of depression care among low-income women with breast or

gynecologic cancer. *J Clin Oncol* 2005;**23:**3052-3060. DOI 10.1200/JCO.2005.08.041

30. Lord K, Mitchell AJ, Ibrahim K, et al. The beliefs and knowledge of patients newly diagnosed with cancer in a UK ethnically diverse population. *Clin Oncol* 2012;**24:**4-12. DOI 10.1016/j.clon.2011.05.008

31. Osborne RH, Elsworth GR, Hopper JL. Age-specific norms and determinants of anxiety and depression in 731 women with breast cancer recruited through a population-based cancer registry. *Eur J Cancer* 2003;**39:**755-762.

32. Akechi T, Okuyama T, Sugawara Y, et al. Major depression, adjustment disorders, and post-traumatic stress disorder in terminally ill cancer patients: associated and predictive factors. *J Clin Oncol* 2004;**22:**1957-1965. DOI 10.1200/JCO.2004.08.149

33. Schou I, Ekeberg O, Ruland CM, et al. Pessimism as a predictor of emotional morbidity one year following breast cancer surgery. *Psychooncology* 2004;**13:**309-320. DOI 10.1002/pon.747

34. Brothers BM, Andersen BL. Hopelessness as a predictor of depressive symptoms for breast cancer patients coping with recurrence. *Psycho-oncology* 2009;**18:**267-275. DOI 10.1002/pon.1394

35. Lo C, Zimmermann C, Rydall A, et al. Longitudinal Study of Depressive Symptoms in Patients with Metastatic Gastrointestinal and Lung Cancer. *J Clin Oncol* 2010;**28:**3084. DOI 10.1200/JCO.2009.26.9712

36. Grassi L, Travado L, Gil F, et al. Hopelessness and related variables among cancer patients in the Southern European Psycho-Oncology Study (SEPOS). *Psychosomatics* 2010;**51:**201-207. DOI 10.1176/appi.psy.51.3.201

37. Johansson M, Ryden A, Finizia C. Mental adjustment to cancer and its relation to anxiety, depression, HRQL and survival in patients with laryngeal cancer - A longitudinal study. *BMC Cancer* 2011;**11:**283. DOI 10.1186/1471-2407-11-283

38. Chaturvedi SK, Chandra PS, Channabasavanna SM, et al. Levels of anxiety and depression in patients receiving radiotherapy in India. *Psychooncology* 1996;**5:**343-346. DOI: 10.1002/(SICI)1099-1611(199612)

39. Kishore J, Ahmad I, Kaur R, PKM. Beliefs and perceptions about cancers among patients attending radiotherapy OPD in Delhi, India. *Asian Pac J Cancer Prev* 2008;**9:**155-158.

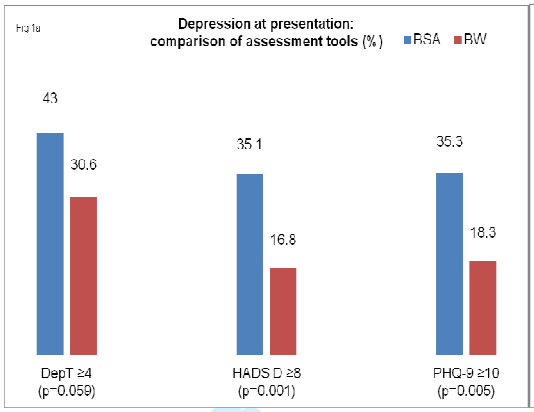
40. Szczepura A, Price C, Gumber A. Breast and bowel cancer screening uptake patterns over 15 years for UK South Asian ethnic minority

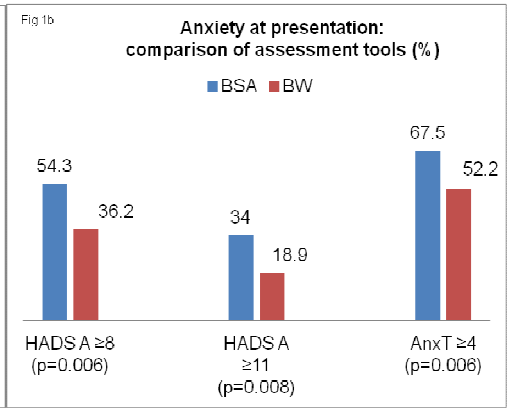
populations corrected for differences in socio-demographic characteristics. *BMC Public Health* 2008;**8:**346.

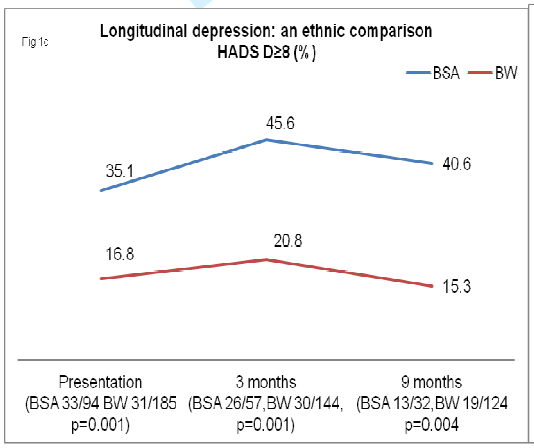
41. Miles A, Rainbow S, von Wagner C. Cancer Fatalism and Poor Self-Rated Health Mediate the Association between Socioeconomic Status and Uptake of Colorectal Cancer Screening in England. *Cancer Epidemiol Biomarkers Prev* 2011;**20:**2132-2140. DOI 10.1158/1055-9965.EPI-11-0453

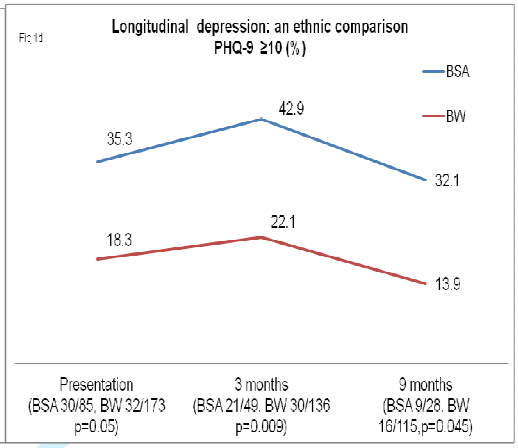
42. Muthu Kumar D, Symonds RP, Sundar S, et al. Information needs of Asian and White British cancer patients and their families in Leicestershire: a cross-sectional survey. *Br J Cancer* 2004;**90:**1474-1478. doi:10.1038/sj.bjc.6601774

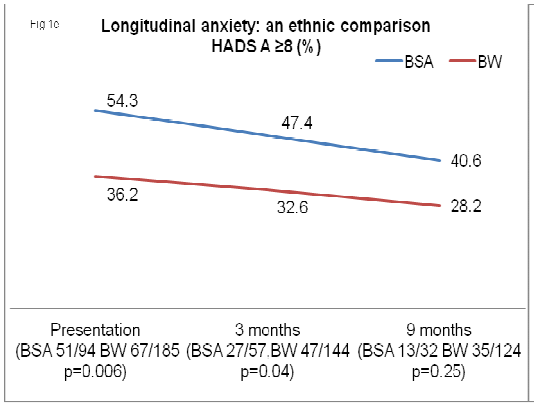
Longitudinal comparison of anxiety and depression in BSA and BW patients

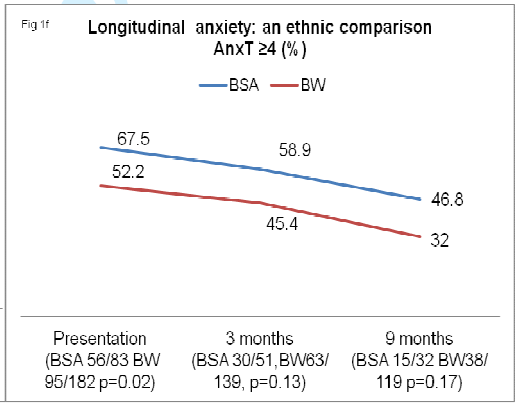




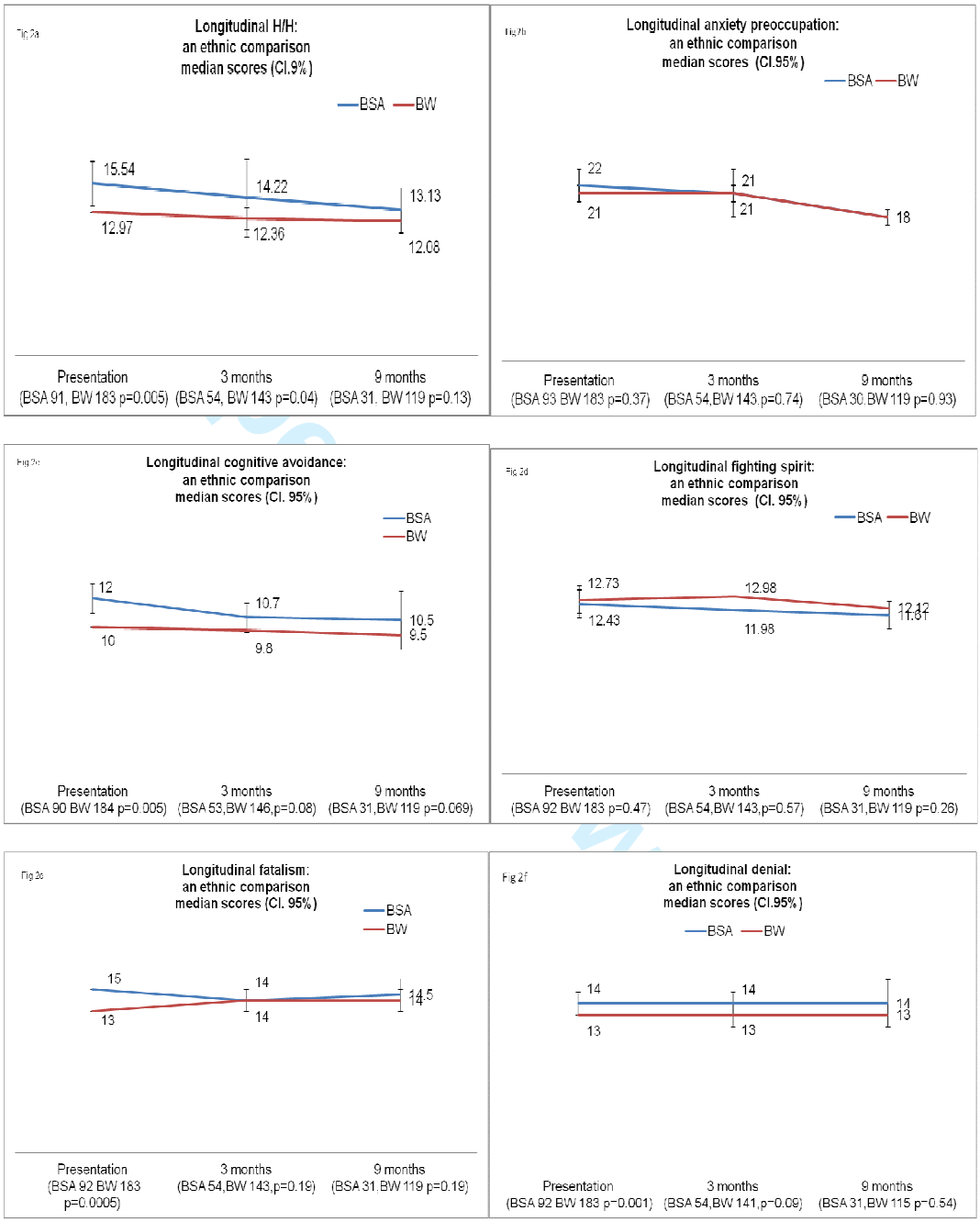


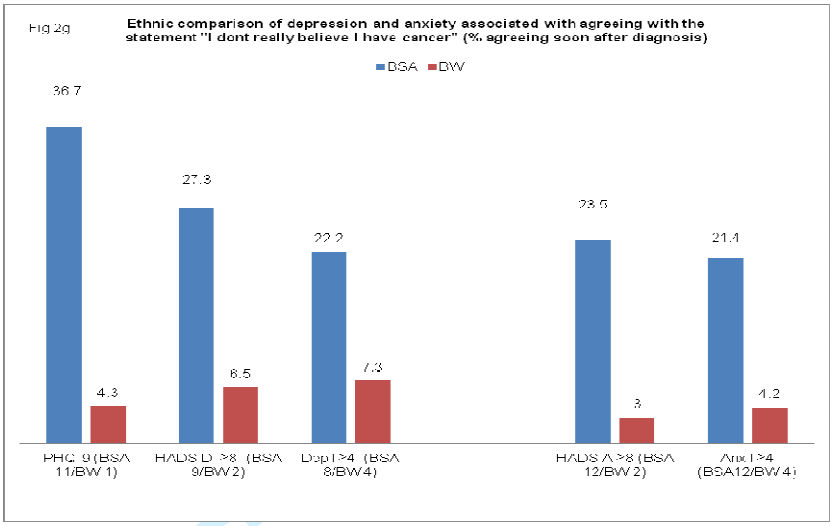






Longitudinal comparison of coping strategies in BSA and BW patients: median scores with 95% CI. (where absent CI=0)





Longitudinal associations between coping strategies and depression via PHQ9

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	-.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)				
			23	69.89	13(11:16)	1290.5	-.119	0.01	0.905

Longitudinal associations between coping strategies and depression via DepT

Mann Whitney DepT 3v4			n=	Mean Rank Score (MRS)	Md(IQR)	U	Z	r	p-value
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

Longitudinal associations between coping strategies and anxiety via HADS A

Mann Whitney U Test HADS A 7v8			n=	Mean Rank Score	Median (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

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	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

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	-.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)				
			23	69.89	13(11:16)	1290.5	-.119	0.01	0.905

Longitudinal associations between treatment intent and depression

HADS 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 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^2
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
	9 months	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
	9 months	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
	9 months	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
	9 months	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
	9 months	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
	9 months	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
	9 months	BSA	31	16	51.6	15	48.4	
		BW	121	86	71.1	35	28.9	0.065

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

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Abstract

Objectives

This cross sectional survey investigated whether there were ethnic differences in depressive symptoms among British South Asian (BSA) 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≥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). BSA patients used potentially maladaptive coping strategies more frequently than BW patients at baseline (hopelessness/helplessness p=0.005, fatalism p=0.0005, avoidance p=0.005; the CIDQ denial statement 'I do not really believe I have cancer' p=0.0005). BSA patients experienced more physical symptoms (DT checklist) which correlated with ethnic differences in depressive symptoms especially at three 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.

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 then 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

mood between the three data collection points are not represented. It is also 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 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

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 among BSA patients in Leicester and local county compared to British White (BW) patients via HADS D ≥10 (BSA 20.7%; BW 10.4% p=0.001).[17] Depression was 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] 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.[18]

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

This study addressed how the UK's largest ethnic minority population (BSA) cope with cancer, in comparison to the host population, by analysing data from a sample of those attending the Leicestershire Cancer Centre.

Feeling distressed or low in mood are initial emotional responses to a diagnosis of cancer, and is part of normal adjustment, if of short duration. If, however

distress persists it can have a harmful effect on the mental wellbeing of the individual risking depressive symptoms [17, 20] and reduction in quality of life.[21, 22, 23]

The Transactional Model of Stress and Coping requires an assessment of personality traits within the context of their environment.[24] For cancer patients this environment includes their beliefs about cancer, their level of social support, proficiency in host languages, level of literacy, degree of disability, co-morbidities, spiritual beliefs, cultural background and economic circumstances.[25]

The symptom burden on cancer patients can influence coping with a close interrelationship with psychological wellbeing. Fatigue and disabilities independently predicted depression among lung cancer patients commencing treatment [26] and has been observed in pre-chemotherapy patients with curative cancer.[27] A high symptom burden can persist over time. 1 in 4 patients (n=4903) had a high symptom burden 1 year post diagnosis with depression, fatigue and pain having the greatest impact on their quality of life.[28] Similarly a high symptom burden at 12 months was reported among patients referred for control of pain and depression (n=405).[29] Among Chinese breast cancer patients (n=285) less distress from physical symptoms immediately after surgery predicted psychological resilience. The study suggested that ineffective symptom control during treatment increased a women's risk of persistent psychological distress longitudinally. The value of pre-operative interventions was highlighted.[30]

Of particular concern are reports of higher symptom burden in ethnic minorities such as among Hispanic women post-chemotherapy for breast cancer [31] and greater 'unmet need' for symptom control was implicated among Black and Spanish speaking Hispanic women with breast cancer than White women.[32]

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

Hypotheses

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

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. 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, then at three months and nine month intervals. (Table 1)

Questionnaires

Patients completed the Hospital Anxiety and Depression Scale (HADS) [33] and The Emotion Thermometers [34] which includes the Distress Thermometer [35] and depression thermometer (Dep T). A problem checklist, included on the thermometer, identified the patient's symptom burden. All are validated but were not initially available in Gujarati or Hindi. A commercial company undertook an iterative back-translation process as described by Brislin.[36] 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.[37] Several tools were used to address the concern that some were ethnically biased.

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

Statistical analysis

Reference was made to the 'Strobe' statement for observational studies.[39] Depressive symptoms were assessed by HADS D, ET Thermometers and PHQ-9.

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.[40] A threshold of ≥11 identified patients with moderate symptoms, however following the recommendation to have a lower threshold for cancer patients than in general practice, ≥8 was selected for HADS D.[41] 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 ≥8 (Cronbach's alpha coefficient,0.80).[42] Threshold scores of ≥10, ≥15, ≥20 for PHQ-9 were in accordance with the original recommended scores.[43]

The current recommended threshold for the DT is ≥4 and this is retained in the ET [44] and this analysis. A prior power analysis based on our pilot studies determined 86 participants were required for each ethnic group.

Graphs denote 95% confidence intervals. Summary scores for selected coping strategies were from the Mini-MAC and the denial indicators in the CIDQ. Reference was made to individual indicators. Longitudinal data at baseline and at three and nine months is reported.

Computation of frequencies, percentages and arithmetic median was conducted to identify patterns in the data. Mann Whitney tests for continuous variables detected differences between the ethnic groups and the direction of these relationships. Spearman's Rank Order Tests (rho) explored correlations between depressive symptoms (HADS D as a continuous variable) and deprivation.[45] We report analysis by age, gender, deprivation, tumour site, place of birth and ethnicity.

Chi^2 described the relationship between categorical variables. The extent to which patients used each coping strategy and how its use changed longitudinally is described. Associations between each strategy and depressive symptoms is reported. Qualitative data was recorded verbatim. When in Gujarati it was translated to English. Analysis was performed via SPSS v 18.

Results

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

Demographics and depressive symptoms

Age was not associated with depression among BSA patients (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≥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 that those with either no formal education or only until up to the age of 11 (HADS D ≥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 listing no formal education spoke fluently up to five languages. Individual results in patients who reported little formal education were consistent across assessment tools suggesting adequate comprehension.

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

Since 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 depressive symptoms. Although there was a strong association between ethnicity and deprivation (MW r=0.503, p=0.0005) deprivation had minimal influence on the strength of the relationship between ethnicity and depression when comparing Pearson product-moment correlations (PCC) with partial correlation calculations (Table 3).

Depressive symptoms at baseline

All three assessment tools showed approximately double the incidence of depression in BSA patients compared to BW patients (Fig 1a and suppl. Table 2). Severe depression was also more common in the BSA groups as demonstrated using a higher HADS score ≥11 (BSA 23/94 (24.5%) BW 11/185 (5.9%) p=0.001). A similar trend was seen using a higher PHQ-9 threshold (≥15) BSA 13/85 (15%) BW 10/173 (5%) p=0.04.

Longitudinal trends in depressive symptoms

All tools indicated how more vulnerable BSA patients were in contrast to BW patients. HADS D ≥8 suggested significantly higher rates of depressive symptoms among BSA patients longitudinally than BW patients (Fig 1b). 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).

Coping Strategies

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

Hopelessness/ helplessness (Mini MAC)

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

BSA patient No.16 soon after diagnosis

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 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 more patients (BSA and BW combined) felt helplessness/hopelessness and also acknowledged depressive symptoms (MW: PHQ-9 ≥11/HADS D ≥8 p=0.0005).

Anxiety preoccupation

"Cancer has totally changed my life. I am worried, anxious about my treatment and what lies ahead as this is the second occasion I am going through this"

BSA No.103.

There was a negligible ethnic difference in the use of anxiety preoccupation. Over time this strategy was used less (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: presentation 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 ≥8 p=0.001; Dep.T ≥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 presentation 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 depressive symptoms (MW: HADS D≥8 p= 0.024;PHQ-9, p= 0.003) but not by the Dep T. ≥4 (p=0.101).

Insight and Denial (CIDQ)

"I'm not ill"

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

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

Of those who used denial, potentially a maladaptive coping strategy [46] BSA patients were over-represented, most notably at baseline assessments (p=0.001). The ethnic gap remained longitudinally (Fig 2f). Of the three tools assessing depression only PHQ-9 indicated an association between denial and depression albeit weakly (MW: p= 0.039).

To facilitate comparisons with Roy's 2005 [17] study, analysis of the single indicator 'I don't really believe I have cancer' originating from the MAC questionnaire was repeated. At baseline 229/278 patients (82%) accepted the reality of their diagnosis by disagreeing with the statement. Of the 27 patients who didn't believe that they had cancer, more were BSA (BSA 19/93 (20.2%); BW 8/185 (4.3%), p=0.0001). Of interest is that 23 patients agreed with this statement 'sometimes' (BSA 12 (52.2%); BW 11 (47.8%)). There was a strong trend towards BSA patients who denied their diagnosis to be more depressed at baseline but sample numbers were too low to warrant analysis at nine months (Fig 2g).

We considered whether causes of distress listed in the distress thermometer checklist explained ethnic differences in depressive symptoms. Cancer treatments offered to both groups were similar so did not influence findings. Critically BSA patients experienced more distress from physical symptoms of

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

Discussion

With the exception of our pilot study [17] we are not aware of another comparison of how BSA and BW patients cope with cancer. 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 depressive symptoms among BSA patients soon after the cancer diagnosis than BW patients. The percentages vary depending on the assessment tool used but all showed the same trend. BSA rates for depression were twice that of BW patients using two tools. 35.1% of BSA compared to 16.8% of BW patients (p=0.001) had depressive symptoms measured on the HADS D scale (≥8). This was confirmed on a version of the PHQ-9≥10 developed for India (35.3% BSA v 18.3% BW p=0.05). This is a critical finding since this is almost 6 times higher than reported within the UK general population using the same assessment tool (6%).[47] Depression rates for BW patients (HADS D≥8, 16.8%; PHQ-9 18.3%) 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.[4] What is disturbing is the incidence of more severe depression in BSA patients which is reflected in their HAD-D score ≥11 (BSA 24.5% v BW 5.9% p=0.0001). These findings supported trends in other studies, notably our pilot study. Using the threshold HADS ≥10, Roy [17] reported BSA 20.7% v BW 10.4% (p=0.001) had moderate depressive symptoms. These concur with other reports which suggest that ethnic minority cancer patients experience more psychological distress than patients from host populations.[16, 17, 48, 49] However the BSA population is heterogeneous. It would be grossly simplistic to assume all BSA respond psychologically in the same way given the breath and diversity of their religious and cultural influences. However Indian Hindus comprised the majority of our BSA sample and our findings may be of particular relevance to this sub-group.

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

A counter intuitive finding in this study is the similarity of depressive symptoms in patients being treated with curative intent (radical) and palliative patients. Although there were fewer questionnaires returned at three and nine months, the ratio of radical and palliative patients remained the same (HADS D ≥8

baseline p=0.08, 3 months p=0.58, 9 months p=1.0). In fact this finding is consistent with a recent meta-analysis.[4]

At baseline the rates of fatalism helplessness/hopelessness and domains of denial were far higher among BSA patients and there was a strong correlation between these potentially maladaptive coping strategies and the incidence of depression in both ethnic groups. Helplessness/hopelessness is strongly associated with depression [50, 20, 51–55] as we found in this study. A similar pattern was seen in the use of cognitive avoidance. Fatalism too was associated with higher levels of depressive symptoms as demonstrated on both the PHQ-9 and HADS which supports research from India [56, 57] and the UK [58, 59] into the use of potentially maladaptive behaviours.

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

What is puzzling is that although BSA patients remained more depressed than BW patients longitudinally, by three and 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 months the trend towards higher depression among BSA patients remained. Even taking into account a lag time for the alleviation of depressive symptoms after less use of maladaptive coping, there remains an incomplete explanation as to why more BSA patients in particular remain so distressed. Our hypothesis that a greater use of maladaptive coping strategies would reflect higher rates of depressive symptoms was therefore only partially confirmed. A retrospective audit into referral to psycho oncology or prescribing patterns of psychotrophic 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 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. However the ethnic differences in depressive symptoms persisted to nine months. Possible explanations include the somatisation of physical symptoms being undetected, inadequate symptom management, non-compliance due to a lack of literacy and language skills or for a patient preference for traditional medicines for symptom control purposes. Our findings reflect the greater symptom burden found in other ethnic minority cancer patients, such as among Chinese and Hispanic populations [31, 32]. This study supports the original

hypothesis that more BSA cancer patients would self-report depressive symptoms than BW patient over time. Our hypothesis that a greater use of potentially maladaptive coping strategies would reflect higher rates of depression among BSA patients was supported but only until the three month point. A heavier symptom burden among BSA patients does appear to contribute to depression rates among this ethnic minority compared to the host population.

Limitations

Limitations to the study are acknowledged. The BSA sample largely represents cancer patients within the Leicester Indian population and although of interest to other BSA cancer populations, these findings may not represent them. In addition there was a large sample of patients with breast cancer, which risks underrepresentation of those patients with other body site cancers. Difficulties in recruitment and retaining BSA participants by nine months reduced the sample size.[60] Self-reported questionnaires indicate the presence of depressive symptoms but given the absence of psychiatric interviews this is not diagnostic of a depressive disorder.

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

Recommendations

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

Conclusion

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

References

1. Kennard BD, Stewart SM, Olvera R, et al. Nonadherence in Adolescent Oncology Patients: Preliminary Data on Psychological Risk Factors and Relationships to Outcome. *J Clin Psychol Med S* 2004;**11:**31-39. DOI 0.1023/B:JOCS.0000016267.21912.74.

2. Steginga SK, Campbell A, Ferguson M, et al. Socio-demographic, psychosocial and attitudinal predictors of help seeking after cancer. *Psychooncology* 2008;**17:**997-1005. DOI 10.1002/pon.1317.

3. Satin JR, Linden W, Phillips MJ. Depression as a predictor of disease progression and mortality in cancer patients: a meta-analysis. *Cancer* 2008;**115:**5349-5361.

4. Mitchell AJ, Chan M, Bhatti H, et al. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *Lancet Oncol* 2011;**12:**160-174. DOI:10.1016/S1470-2045(11)70002-X.

5. Hinz A, Krauss O, Hauss JP, et al. Anxiety and depression in cancer patients compared with the general population. *Eur J Cancer Care* 2010;**19:**522-529. DOI 10.1111/j.1365-2354.2009.01088.x.

6. Weich S, Nazroo J, Sproston K, et al. Common mental disorders and ethnicity in England: the EMPIRIC study. *Psychol Med* 2004;**34:**1543-1551.

7. Shavers VL, Brown ML. Racial and ethnic disparities in the receipt of cancer treatment. *J Natl Cancer Inst* 2002;**94:**334-57.

8. Ward E, Jemal A, Cokkinides V, et al. Cancer disparities by race/ethnicity and socioeconomic status. *CA Cancer J Clin* 2004;**54:**78-93.

9. All party parliamentary group on cancer (2009) Report of the all party parliamentary group of cancer's enquiry into inequalities in cancer available at www.appq-cancer.uk.

10. Department of Health (2007), Cancer Reform Strategy available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081007.pdf, The Stationery Office, UK.

11. Department of Health (2011) Improving outcomes a strategy for cancer via http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123394.pdf, Department of Health, London.

12. Goss E, Lopez AM, Brown CL, Wollins DS, Brawley OQ, Raghavan D. American Society of Clinical Oncology policy statement: disparities in

cancer care. *J Clin Oncol* 2009;**27:**2881-2885, DOI 10.1200/JCO.2008.21.1680.

13. US Department of Health and Human Services (2011) President's Cancer Panel: American's demographic and cultural transformations: Implications for cancer Washington DC 1-100.

14. Department of Health and Human Services (USA) (2011), HHS Action plan to reduce racial and ethnic health disparities available via http://minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf, Department of Health and Human Services, Washington DC.

15. Bhopal R. Glossary of terms relating to ethnicity and race: for reflection and debate. J Epidemiol Community Health 58 p. 441-445 DOI: 10.1136/jech.2003.013466.

16. Office for National Statistics 2011 census ethnic groups: local authorities in England and Wales Table KS201EW http://www.ons.gov.uk/ons/search/index.html?newquery=KS201EW.

17. Roy R, Symonds RP, Kumar DM, Ibrahim K, Mitchell A, Fallowfield L. The use of denial in an ethnically diverse British cancer population: a cross-sectional study. *Br J Cancer* 2005;**92:**1393-1397, doi:10.1038/sj.bjc.6602523

18. Luckett T, Butow PN, King MT, Oguchi M, Heading G, Hackl NA, et al. A review and recommendations for optimal outcome measures of anxiety, depression and general distress in studies evaluating psychosocial interventions for English-speaking adults with heterogeneous cancer diagnoses. *Support Care Cancer* 2010;**18:**1241-1262, DOI 10.1007/s00520-010-0932-8.

19. Carlson LE, Groff SL, Maciejewski O, Bultz B.D. Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *J Clin Oncol 2010;***28:**4884-4891, DOI 0.1200/JCO.2009.27.3698.

20. Akechi T, Okuyama T, Sugawara Y, Nakano T, Shima Y Uchitomi Y Major depression, adjustment disorders, and post-traumatic stress disorder in terminally ill cancer patients: associated and predictive factors. *J Clin Oncol* 2004;**22:** 1957-1965, DOI 10.1200/JCO.2004.08.149.

21. Stark D, Kiely M, Smith A, Velikova G, House A Selby P. Anxiety Disorders in Cancer Patients: Their Nature, Associations, and Relation to Quality of Life. *J Clin Oncol* 2002;**20**(14):3137-3148.

22. Clarke JA, Inu, TS, Silliman RA, Bokhour BG, Krasnow SH, Robinson RA et al. Patients' perceptions of quality of life after treatment for early prostate cancer. *J Clin Oncol* 2003;**21**:3777-3784.

23. Hoyer M, Johansson B, Nordin K, Bergkvist L, Ahlgren J, Lidin-Linqvist A et al. Health-related quality of life among women with breast cancer-a population-based study. *Acta Oncologica 2011;***50**(7):1015-1026.

24. Lazarus RS, Folkman S, Adams S. *Stress, appraisal and coping,* Springer, New York; 1984.

25. Moos RH, Holahan CJ. Dispositional and contextual perspectives on coping: toward an integrative framework. *J Clin Psychol* 2003;**59**(12):1387-1403.

26. Hopwood P, Stephens RJ. Depression in patients with lung cancer: prevalence and risk factors derived from quality-of-life data. *J Clin Oncol* 2000;**18**(4):893-903.

27. Breen SJ, Baravelli CM, Schofield PE, Jeffor M, Yates PM, Aranda SK. Is symptom burden a predictor of anxiety and depression in patients with cancer about to commence chemotherapy? *MJA* 2009;**190**(7):s99-s104

28. Shi Q, Smith TG, Michonski JD, Stein KD, Kaw C, Cleeland CS. Symptom Burden in Cancer Survivors 1 Year After Diagnosis. *Cancer* 2011;**117**:2779–90, 10.1002/cncr.26146.

29. Kroenke K, Johns SA, Theobold D, Wu J, Tu W. Somatic symptoms in cancer patients trajectory over 12 months and impact on functional status

and disability. *Support Care Cancer* 2013;**21**:765-773, DOI 10.1007/s00520-012-1578-5.

30. Lam WWT, Bonanno GA, Mancini AD, Ho S, Chan M, Hung WK, et al. Trajectories of psychological distress among Chinese women diagnosed with breast cancer. *Psycho Oncol* 2010;**19**:1044-1051, DOI10.1002/pon.1658.

31. Fu OS, Crew KD, Jacobson JS, Greenlee H, Yu G, Campbell J, et al. Ethnicity and persistent symptom burst in breast cancer survivors J Cancer Surviv 2009;**3**: 241-250, DOI 10.1007/s11764-009-0100-7.

32. Yoon J, Malin JL, Tisnado DM, Tao ML, Adams JL, Timmer MJ et al. Symptom management after breast cancer treatment: is it influenced by patient characteristics? Breast Cancer Res Treat 2008;**108**(1):69-77.

33. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;**67:**361-370.

34. Mitchell AJ, Baker-Glenn EA, Park B, Granger L, Symonds P. Can the Distress Thermometer be improved by additional mood domains? Part II. What is the optimal combination of Emotion Thermometers? *Psycho-oncology* 2010;**19:**134-140, DOI 10.1002/pon.1557.

35. Roth AJ, Kornblith AB, Batel-Copel L, Peabody E, Scher HI, Holland JC. Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. *Cancer* 1998;**82:**1904-1908.

36. Brislin RW. Back-translation for cross-cultural research. *Journal of Cross-cultural Psychology* 1970;**1:**185-216, doi: 10.1177/135910457000100301.

37. Kochhar PH, Rajadhyaksha SS, Suvarna VR. Translation and validation of brief patient health questionnaire against DSM IV as a tool to diagnose major depressive disorder in Indian patients. *J Postgrad Med* 2007;**53:**102-107.

38. Watson M, Law M, Dossantos M, Greer S, Baruch J, Bliss JM. The Mini-Mac; Further development of the mental adjustment to cancer scale. *J Psychosoc Oncol* 1994;**12:**33-46.

39. Von Elm E, Altman DG, Egger M, Rocock SJ, Gotzschep C, Vandenbrouche JP. The strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement Epidemiology 2007;**18**(6):800-804.

40. Snaith RP. The Hospital Anxiety and Depression Scale. *Health Qual Life Outcomes* 2003;**1**:29.

41. Morse R, Kendell K, Barton S. Screening for depression in people with cancer: the accuracy of the hospital anxiety and depression scale. *Clin Eff Nurs* 2005;**9**:188-196.

42. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosomatic Res* 2002;**52**(2):69-77.

43. Kroenke K, Spitzer RL, Williams JBW. The PHQ-9 validity of a brief depression severity measure. *J Gen Intern Med* 2001;**16**:605-613.

44. National Comprehensive Cancer Network 2011, December 10th 2010-last update*, NCCN guidelines: distress managemen*t [Homepage of National Comprehensive Cancer Network], [Online]. http://www.nccn.org/professionals/physician_gls/f_guidelines.asp [2011, 9/ 25].

45. Office for National Statistics 2011, *"Neighbourhood Statistics 'Summary Statistics', citing indices of deprivation, 2007, UK Department for Communities and Local Government* [Homepage of Office for National Statistics], [Online]. http://www.neighbourhood.statistics.gov.uk/ [2007-2011].

46. Lazarus RS. Coping theory and research: past, present and future. Psychosom Med 1993;**55**(3):234-247.

47. National Institute for Health and Clinical Excellence (NICE) 2011, February 2010-last update, Clinical knowledge summaries (CKS) clinical topics. Depression; Available via http://www.cks.nhs.uk/depression/management/scenario_bereavement/view_full_scenario#-402794 [2012, 26/6].

48. Ashing-Giwa KT, Tejero JS, Kim J, Padilla GV, Hellemann G. Examining predictive models of HRQOL in a population-based, multiethnic sample of women with breast carcinoma. *Qual Life Res* 2007;**16:**413-428, DOI 10.1007/s11136-006-9138-4.

49. Ell K, Sanchez K, Vourlekis B, Lee PJ, Dwight-Johnson M, Lagomasino I et al. Depression, correlates of depression and receipt of depression care among low-income women with breast or gynecologic cancer. *J Clin Oncol* 2005;**23:**3052-3060, DOI 10.1200/JCO.2005.08.041

50. Osborne RH, Elsworth GR, Hopper JL. Age-specific norms and determinants of anxiety and depression in 731 women with breast cancer recruited through a population-based cancer registry. *Eur J Cancer* 2003;**39:**755-762.

51. Schou I, Ekeberg O, Ruland CM, Sandvik L, Karesen R. Pessimism as a predictor of emotional morbidity one year following breast cancer surgery. *Psychooncology* 2004;**13:**309-320. DOI 10.1002/pon.747.

52. Brothers BM, Andersen BL. Hopelessness as a predictor of depressive symptoms for breast cancer patients coping with recurrence. *Psychooncology* 2009;**18:**267-275, DOI 10.1002/pon.1394.

53. Lo C, Zimmermann C, Rydall A, Walsh A, Jones JM, Moore MJ et al. Longitudinal Study of Depressive Symptoms in Patients with Metastatic Gastrointestinal and Lung Cancer. *J Clin Oncol* 2010;**28:**3084, DOI 10.1200/JCO.2009.26.9712.

54. Grassi L, Travado L, Gil F, Sabato S, Rossi E, Tomamichel M et al. Hopelessness and related variables among cancer patients in the Southern European Psycho-Oncology Study (SEPOS). *Psychosomatics* 2010;**51:**201-207, DOI 10.1176/appi.psy.51.3.201.

55. Johansson M, Ryden A, Finizia C. Mental adjustment to cancer and its relation to anxiety, depression, HRQL and survival in patients with laryngeal cancer - A longitudinal study. *BMC Cancer* 2011;**11:**283, DOI 10.1186/1471-2407-11-283.

56. Chaturvedi SK, Chandra PS, Channabasavanna SM, Anantha N, Reddy BKM, Sharma S. Levels of anxiety and depression in patients receiving radiotherapy in India. *Psychooncology* 1996;**5:**343-346, DOI: 10.1002/(SICI)1099-1611(199612).

57. Kishore J, Ahmad I, Kaur R, Mohanta PK. Beliefs and perceptions about cancers among patients attending radiotherapy OPD in Delhi, India. *Asian Pac J Cancer Prev* 2008;**9:**155-158.

58. Szczepura A, Price C, Gumber A. Breast and bowel cancer screening uptake patterns over 15 years for UK South Asian ethnic minority populations corrected for differences in socio-demographic characteristics. *BMC Public Health* 2008;**8:**346.

59. Miles A, Rainbow S, von Wagner C. Cancer Fatalism and Poor Self-Rated Health Mediate the Association between Socioeconomic Status and Uptake of Colorectal Cancer Screening in England. *Cancer Epidemiol Biomarkers Prev* 2011;**20:**2132-2140, DOI 10.1158/1055-9965.EPI-11-0453.

60. Symonds RP, Lord K, Mitchel AJ, Raghavan D. Recruitment of ethnic minorities into clinical trials: experience from the front lines, *Br J Cancer,* 2012;**107**:1017-1021.

Are depressive symptoms~~Increased anxiety and depression~~ more common among British South Asian compared to British White cancer patients?: a cross sectional survey~~study.~~

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Key words Cancer, ethnicity, South Asian, anxiety, depression

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~~3964~~

Abstract

Objectives

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

Design

Questionnaires were administered to 94 BSA and 185 BW recently diagnosed cancer patients at baseline at three and nine months.~~ Questionnaire-based study of newly diagnosed cancer patients interviewed soon after diagnosis and at 3 and 9 month intervals.~~ 53.8% of the BSA sample were born in the Indian s~~S~~ub-~~C~~continent, 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),~~ Mini-MAC and~~ Emotion Thermometers (including the D-~~d~~istress T~~t~~hermometer and checklist), Mini-MAC and~~ were used. Patients also completed~~ the newly developed Cancer Insight and Denial questionnaire were completed~~,~~ ~~and Cancer Beliefs/ Physician/Patient Trust questionnaire~~.

Setting

Leicestershire Cancer Centre, UK.

Participants

94 BSA and 185 BW recentlynewly diagnosed cancer patients.

Results

BSA self reported significantly higher rates of depressive symptoms on compared to BW patients longitudinally e.g. (HADS D≥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 ≥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 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.

~~High rates of anxiety and depression were present longitudinally among BSA cancer patients when compared to BW patients.~~

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 nine~~9~~ 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 rate~~s of anxiety and~~ of depressive symptoms ~~depression~~ than BW patients and five~~5~~ times the incidence of severe depression.
- ~~These~~ Ddifferences persist for nine~~9~~ months after presentation.
- BSA patients used potentially maladaptive coping strategies far more then 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

differences in the rates of anxiety and of depressive symptoms 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 and retaining BSA patients and retention, especially byby nine9 months. was low. Changes in mood between the three3 data collection points are not represented. It is also likely that the rates of anxiety and depressive symptomson 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 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~~lication~~ 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~~on~~ 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~~s~~ ~~r~~Rremoveal ~~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 ins 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 (Ttotal 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, BangaldeshiBangladeshi, 2,300).-[16]ONS 2011 same as abovesame as previous ref see commemnt)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 countyies compared to British White (BW) patients via HADS D ≥10 (BSA 20.7%; BW 10.4% p=0.001).[175] 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 [17Roy,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]

Similar findings were reported from Canada with more distress amongst ethnic minorities (E and SE Asia, South Asian, First Nation~~Aboriginals~~) compared to the majority population (European, Canadian, British p=0.0001). Greater distress was also found among those with lower income (p=0.001).[1~~8~~79]~~Luckett~~

This study addressed ~~Here we aimed to address~~ how the UK's largest ethnic minority population (BSA) cope with cancer, in comparison to the host population, by analysing data from a sample of those attending the Leicestershire Cancer Centre.

Feeling distressed or low in mood are initial emotional responses to a diagnosis of cancer, and is part of normal adjustment, if of short duration. If, however distress persists it can have a harmful effect on the mental wellbeing of the individual risking depressive symptoms [17, 20]~~(Akechi et al. 2001(19), Roy et al. 2005(16),)~~and reduction in ~~compromise of their~~ quality of life.[21, 22, 23] ~~(Stark et al. 2002,(20) Clarke et al. 2003(21), Hoyer et al. 2011(22)).~~

The Transactional Model of Stress and Coping requires an assessment of personality traits within the context of their environment. [24] ~~(Lazarus, Folkman & Adams 1984)23.~~ For cancer patients this environment includes their beliefs about cancer, their level of social support, proficiency in host languages, level of literacy, degree of disability, co-morbidities, spiritual beliefs, cultural background and economic circumstances.[25] ~~(Moos, Holahan 2003)24.~~

The symptom burden on cancer patients can influence coping with a close interrelationship with psychological wellbeing. –Fatigue and disabilities independently predicted depression among lung cancer patients commencing treatment [26](Hopwood, 2000) 25 and has been observed in pre-chemotherapy patients with curative cancer.[27] (Breen, 2009)26. A high symptom burden can persist over time. 1 in 4 patients (n=4903) had a high symptom burden 1 year post diagnosis with depression, fatigue and pain having the greatest impact on their quality of life.[28] (Shi, 2011)27. Similarly a high symptom burden at 12 months was reported among patients referred for control of pain and depression (n=405).-[29]Kroenke, 2013]28. Among Chinese breast cancer patients (n=285) less distress from physical symptoms immediately after surgery early post surgery predicted psychological resilience. The study suggested that ineffective symptom control during treatment increased a women's risk of persistent psychological distress longitudinally-. The value of pre-operative interventions was highlighted.-[30Lam,2009]29.

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

We report the longitudinal incidence of depressive symptoms among a sample of BSA and BW patients. Coping styles and the burden of patient problems

were examined to determine if they were implicated in depressive symptoms.

~~problmes~~

Hypotheses

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

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

Methods

~~**Hypotheses**~~

~~On the basis of our literature review and pilot studies we hypothesized that longitudinally more BSA cancer patients would self report symptoms of anxiety and depression than BW patients. We further hypothesized that a greater use of maladaptive coping strategies would reflect higher rates of anxiety and 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~~3~~ months and nine~~9~~ 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~~ [33~~18~~] and The Emotion Thermometers [34~~19~~] ~~(Mitchell 2010~~which

includesincorporates the Distress Thermometer [2235]0] and depression thermometeralongside thermometers for anxiety (Anx T) and depression (Dep T). A problem checklist, included on the thermometer, identified the patient's symptom burden.(Roth, 1998 35) All are validated but were not initially available in Gujarati or Hindi. Therefore A commercial company we undertook an iterative back-translation process as described by Brislin.[36],1970. a translation via the back to back method.[3621] Brislin 1970 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.[237]2] Several tools were used to address the concern that some weretools are ethnically biased.

An adaptive coping strategy (fighting spirit) and potentially maladaptive strategies (hopelessness/helplessness, fatalism, anxiety preoccupation and cognitive avoidance) were Coping strategies were assessed via the Mini-MAC scale. [3823].Watson 1994 and Tthe locally developed Cancer Insight and Denial questionnaire (CIDQ). The CIDQ included question 38 from the original MAC questionnaire to assesselicit 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 complete the first questionnaires at home, returning them by post. Subsequent questionnaires were posted to participants.

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

Statistical analysis

Reference was made to the 'Strobe' statement for observational studies.[39] (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 ≥11 and PHQ-9 ≥15 and ≥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.-[40]Zigmond, Snaith, 1992, Snaith 2003]. - A threshold of ≥11 identified patients with moderate symptoms, however following the recommendation to have a lower threshold for cancer patients than in general practice, ≥8 was selected for HADS D.-[41Morse etc el 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 ≥8. (Cronbach's alpha coefficient,0.80).[42] [Bjelland et al, 2003]. Threshold scores of ≥10, ≥15, ≥20 for PHQ-9 were in accordance with the original recommended scores. [43Kroenke, Spitzer & Williams, 2001]. -The current recommended threshold for the DT is ≥4 and this is retained in the ET [44NCCN (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.

~~–~~Graphs denote 95% confidence intervals. Summary scores for selected coping strategies were from the Mini-MAC and the denial indicators in the CIDQ ~~questionnaire~~. Reference was made to individual indicators. Longitudinal data at baseline~~presentation~~ and at three~~3~~ and nine~~9~~ months is reported.

Computation of frequencies, percentages and arithmetic median was conducted to identify patterns in the data. Mann Whitney tests for continuous variables detected differences between the ethnic groups and the direction of these relationships. Spearman's Rank Order Tests (rho) explored correlations between depressive symptoms (HADS D as a continuous variable) and deprivation. ~~[45](Office for National Statistics, 2011).~~ We report analysis by age, gender, deprivation, tumour site, place of birth and ethnicity.

Chi^2 described the relationship between categorical variables. The extent to which patients used each coping strategy and how its use changed longitudinally is described. Associations between each strategy and ~~anxiety and~~ depressive symptoms~~on~~ is ~~are~~ reported. Qualitative data was recorded verbatim. When in Gujarati it was translated to English. Analysis was performed via SPSS v 18.

Results

94 BSA patients were recruited~~.~~. The BSA sample largely represents cancer patients within the Leicester Indian population and although of interest to other BSA cancer populations, these findings may not be representative. – 53.8%

were born in the Indian sSub-Ccontinent, 33% in Africa of Indian descent and 12.9% in the UK.with approximately 33% born in Africa. 1Hindus accounted for 53.2%, Muslims 25.5% and 17% Sikh. 185 BW patients were recruited. Several cancer sites are represented. The largest cohort was 114 breast cancer patients. The educational attainment, religion and place of birth record were self--reported by participants. The demographic characteristics of this sample showed significant differences between ethnic groups in terms of their socio-economic status and educational attainment. These details and the patient's sex, age, cancer site and treatment intent are listed in Table 21.

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≥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 that those with either no formal education or only until up to the age of 11 (HADS D ≥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 "~~S~~some patients ~~had~~listing no formal education ~~but~~ spoke fluently up to five

languages.- Individual results in patients who reported little formal education were consistent across assessment tools suggesting adequate comprehension.~~." (p18)~~

There was no significant difference in depressive symptoms between those BSA patients originating from Africa compared to the Indian Sub continent at baseline (-MW: Africa 31/80 Md 4 (2,9) Indian Sub Continent Md 5.5 (2,11) Z=-1.184 p=0.23). Neither was there a significant difference in the experience of symptoms frequent~~y~~ly associated with depression such as ~~(~~pain (p=0.23),~~;~~ sleep disturbances (p=0.91) and ~~:~~fatigue (p=0.52).

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 depressive symptoms. Although there was a strong association between ethnicity and deprivation (MW r=0.503, p=0.0005)~~.~~ deprivation ~~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 (Table 3).

~~Anxiety and~~ ~~D~~depressive symptoms~~on~~ at baseline ~~early after diagnosis~~

All three assessment tools showed approximately double the incidence of depression in BSA patients compared to BW patients (Fig 1a and suppl. Table 2). Severe depression was also more common in the BSA groups as demonstrated using a higher HADS score ≥11 (BSA 23/94 (24.5%) BW 11/185

(5.9%) p=0.001). A similar trend was seen using a higher PHQ-9 threshold~~cut-off score~~ (≥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 ≥8 BSA 54.3% v BW 36.2% p=0.006) especially severe anxiety (HADS-A ≥11 BSA 34% v BW 18.9% p=0.008). The ethnic difference was reproduced via the AnxT≥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 ≥8 suggested significantly higher rates of depressive symptoms among BSA patients longitudinally than BW patients (Fig 1b~~c~~). All three assessment tools indicated a slight decrease in depressive symptoms among BSA patients at ~~3~~three months. Depression rates had not fallen lower than those at presentation by ~~9~~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 ≥8 p=0.04) (Fig 1e). The difference had gone by 9 months (p=0.254). The Anxiety Thermometer ≥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 differently~~more th~~ to~~an~~ BW patients particularly early after diagnosis when greater use of potentially maladaptive strategies were ~~they were~~ associated with higher rates of ~~anxiety~~ depressive symptoms ~~and depression~~(~~-~~Suppl tables 3, 4 & 5)~~.~~

Hopelessness/ helplessness (Mini MAC)

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

BSA patient No.16 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 (BSA and BW combined) ~~who~~ felt helplessness/hopelessness and also ~~,~~ acknowledged depressive symptoms (MW: PHQ-9 ≥~~10v~~11/HADS D ≥~~7v~~8 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 (BSA 58/94 (61.7%); BW 149/185 (80.5%) p=0.001) and more likely to describe~~

~~themselves as a 'little frightened' (BSA 65/94 (69.1%), BW 149/185 (80.5%) p=0.048. It appears paradoxical therefore that BSA patients self reported greater anxiety via a single indicator (BSA 46/94 (48.9%) BW 60/185 (32.4%) Chi^2 p=0.011). Longitudinally there remained little ethnic difference in patients who were preoccupied with anxiety (3 months p=0.751, 9 months p=0.926).~~

It was

~~Anxiety preoccupation was~~ strongly associated with depression (HADS D and PHQ-9, p=0.0005). ~~Given the overlap of phenomena between anxiety preoccupation (the strategy) and anxiety (the outcome) there was predictably a strong association between them (HADS A r=0.63, p=0.0005).~~ These patients were ~~also~~more likely to report ~~at greater risk of becoming~~ depressive symptoms~~ed~~ longitudinally (PHQ-9: presentation 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~~notable~~ at baseline~~presentation~~ as illustrated by a comparison of median scores (Fig 2c). At baseline ~~Soon after diagnosis~~, as one sample, those who used cognitive avoidance were more likely to have symptoms of

depression (MW: PHQ-9 p=0.007; HADS D ≥8 p=0.001; Dep.T ≥4 p=0.002). ~~and anxiety (HADS A ≥8 p=0.0005/ Anx.T. ≥4 p= 0.002).~~ Over time avoidant patients did not ~~d~~ continue 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, 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

~~At presentation~~ ~~M~~more BSA patients were fatalistic when diagnosed with cancer than BW patients at baseline assessment (MW: p=0.0005). ~~H~~ ~~h~~owever this was largely based on one of five~~5~~ Mini MAC indicators, 'I've put myself in the hands of God' (BSA 71/94 (75.5%); BW 60/185(32.4%) p=0.0005). There was a gradual decrease in fatalism in both ethnic groups by ~~9~~nine months although it persisted among BSA patients (Fig 2e). Those who were fatalistic were more likely to experience depressive symptoms ~~(via two tools (MW PHQ-9 p= 0.003;~~ (MW: HADS D≥8 p= 0.024;PHQ-9, p= 0.003) but not by the Dep T. ≥4 (p=0.101). ~~Anxiety too was associated with fatalism (HADS-A MW; p=0.011). Again AnxT did not support these findings (p= 0.164).~~

Insight and Denial (CIDQ)

"I'm not ill"

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

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

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

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

To facilitate comparisons with Roy's 2005 [1~~7~~5] study, analysis of the single indicator 'I don't really believe I have cancer' originating from the MAC questionnaire was repeated. At baseline~~presentation~~ 229/278 patients (82%) accepted the reality of their diagnosis by disagreeing with the statement. Of the 27 patients who didn't believe that they had cancer, more were BSA (BSA 19/93 (20.2%); BW 8/185 (4.3%), p=0.0001). Of interest is that 23 patients agreed with this statement 'sometimes' (BSA 12 (52.2%); BW 11 (47.8%)). There was a strong trend towards BSA patients who denied their diagnosis to be more ~~anxious and~~ depressed ~~-~~at baseline but sample numbers were too low to warrant analysis~~assess statistically~~ at nine~~9~~ months (Fig 2g).

We considered whether causes of distress listed in~~via~~ the distress thermometer checklist explained ethnic differences in~~ anxiety and~~ depressive symptoms~~on~~. Cancer treatments offered to both groups were similar so did not influence findings. Critically BSA patients experienced more distress from physical symptoms of illness and treatment than BW patients. There were 17 physical symptoms listed. In 13 categories BSA had statistically significant increased symptoms compared to ~~In 13 out of 17 symptoms BSA patients returned higher scores than~~ BW patients~~ at presentation~~. For example, pain (BSA 51/83 (58%),~~:~~

BW 59/180 (32.8%) p=0.0001), mouth sores (BSA 21/88 (24.1%), BW 12/179 (6.7%) p=0.0001) and fevers (BSA 18/87 (20.7%),; BW 5/177(2.8%) p=0.0001). At 3three months significantly higher percentages of BSA patients reported problems with pain, mouth sores, nausea, skin, washing and dressing and getting around as causes for distress which were not reflected in BW patients. By nine9 months differences had narrowed with the exception of pain (BSA 19/31 (61.3%) v BW 41/121 (33.9%) p=0.009) (Table 4).

Discussion

With the exception of our pilot study [17]( ) we are not aware of another comparison of how BSA and BW patients cope with cancer. 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 depressive symptomson 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 using two tools. For example on the HADS-D ≥8 scale 35.1% of BSA compared to 16.8% of BW patients (p=0.001) had at least moderate depressive symptoms measured on the HADS D scale (≥8). on (score ≥8). This was confirmed on a version of the PHQ-9≥10 developed for India (35.3% BSA v 18.3% BW p=0.05). This is a critical finding since this is almost 6 times higher than reported within the UK general population using the sampe assessment tool (6%).[2647] Depression rates for BW patients (PHQ-9 18.3%,(HADS D≥8, 16.8%; PHQ-9 18.3%) 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.[4] What is disturbing ~~most striking~~ is the incidence of more severe~~severe~~ depression in BSA patients which is reflected in their HAD-D score ≥11 (BSA 24.5% v BW 5.9% p=0.0001). ~~This was confirmed on a version of the PHQ 9≥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≥8 BSA 54.3% v 36.2% BW p=0.006) including severe anxiety (HADS A ≥11BSA 34%v18.9% p=0.008). Patients also exhibited more anxiety with rates far higher than in the general population (DSMIV 5-15%).[27]~~

These findings supported trends in other studies, notably our~~a~~ pilot study. Using the threshold~~cut-off (~~HADS ≥10~~)~~, Roy [175] reported BSA 20.7% v BW 10.4% (p=0.001) had moderate~~severe~~ depressive symptoms. ~~With a slightly higher cut off (≥11) our study findings at presentation again pointed to a significant difference (BSA 34% v BW 18.9% p=0.008).[15]~~ These concur with other reports which suggest that ethnic minority cancer patients experience more psychological distress than patients from host populations.[16, 17, 428, 429] However the BSA population is ~~hereterogenous~~heterogeneous. It would be grossly simplistic to assume all BSA ~~that sub populations within this 'label'~~ respond psyc~~y~~hologicall~~l~~y in the same way given the breath and diversity of their religious and cultural influences. ~~Ethnic minorities are however not heterogeneous. There are for example variations in baseline common mental disorders in the UK among some BSA groups.[6]~~ However Indian Hindus

comprised the majority of ~~over 50% of~~ our BSA sample and our findings may be of particular relevance to this sub-group.

~~were Indian Hindus.~~

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

A counter intuitive finding in this study is the similarity of ~~anxiety and~~ depressive symptoms~~on~~ in patients being treated with curative intent (radical) and palliative patients. Although there were~~as a~~ fewer~~less~~ questionnaires returned at ~~poorer rate of return of questionnaires at~~ three~~3~~ and nine~~9~~ months, the ratio of radical and palliative patients remained the same (HADS D ≥~~7v~~8 baseline~~presentation~~ p=0.08, 3 months p=0.58, 9 months p=1.0). In fact this finding is consistent with a recent meta-analysis.[4]

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

~~of particular interest were the marked differences in coping styles between the two groups of patients.~~

At baseline~~presentation~~ the rates of fatalism helplessness/hopelessness and domains of denial were far higher among BSA patients and there was a strong correlation between these potentially maladaptive coping strategies and the incidence of ~~anxiety and~~ depression in both ethnic groups. Helplessness/hopelessness is strongly associated with ~~anxiety and~~ depression [50, 20, 51–55] as we found ~~globally, findings replicated~~ in this study.~~[31-37]~~ A similar pattern was seen in the use of cognitive avoidance. Fatalism too was associated with higher levels of ~~anxiety and~~ depressive symptoms~~on~~ as demonstrated on both the PHQ-9 and HADS which supports research from India [56~~38~~, ~~39~~57] and ~~maladaptive behaviours in~~ the UK~~.[~~ [58, 59] into the use of potentially maladaptive behaviours.~~40, 41]~~

In our previous study [17~~5~~] denial was significantly related to depression in both BW and BSA patients. BSA patients were far more likely to agree with the statement in the MAC questionnaire (Question 38) 'I don't really believe I have cancer'. In this study a minority of patients denied their diagnosis but again it was more common among BSA patients using~~via~~ the same indicator until ~~9~~nine months (MW presentation p=0.0005, 3 months p=0.001, 9 months p=0.2). Initially this was strongly associated with ~~anxiety and~~ depression however the sample numbers were too small to consider longitudinal associations.

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 psychotrophic 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

perisitedpersisted to nine months. ~~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.~~ Possible explanations include the somatisation of physical symptoms being undetected, inadequate symptom management, non--compliance due to a lack of literacy and language skills or for a patient preference for traditional medicines for symptom control purposes. ~~The somatisation of physical symptoms notwithstanding, this is insufficient evidence to explain the difference.~~ Our findings reflect the greater symptom burden found in other ethnic minority cancer patients, such as among Chinese and Hispanic populations [31, 32~~Yoon, 2008; Fu 2009~~].

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

~~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 information about their cancer. In an earlier study 66.2% of BSA compared to 5.1% BW wrote that they would prefer to receive their cancer diagnosis from~~

~~their GP (p=0.001).[42] In this study 49.5% of BSA patients' preferred source of sensitive information was their GP compared to 16.9% of BW patients (p=0.0001). The main reason why the GP is the preferred source of information is that the majority of BSA patients prefer to discuss their illness in their mother tongue.[42] Of note is that 89% of BSA patients in this series were registered with a BSA GP.~~

Limitations

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

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

Recommendations

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

Conclusion

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

~~The nature of coping strategies among BSA patients in the first few months after diagnosis requires investigation, the aim being to reduce the associated distress as early as possible along the cancer trajectory. Further investigation into the role of the GP in partnership to support patients, particularly for BSA patients, is advised.~~

~~This study provides evidence of worryingly high levels of anxiety and depression among the largest ethnic minority in the UK. Further investigation is required if this disparity is to be reduced.~~

References

1. Kennard BD, Stewart SM, Olvera R, et al. Nonadherence in Adolescent Oncology Patients: Preliminary Data on Psychological Risk Factors and Relationships to Outcome. *J Clin Psychol Med S* 2004;**11:**31-39. DOI 0.1023/B:JOCS.0000016267.21912.74.

2. Steginga SK, Campbell A, Ferguson M, et al. Socio-demographic, psychosocial and attitudinal predictors of help seeking after cancer. *Psychooncology* 2008;**17:**997-1005. DOI 10.1002/pon.1317.

3. Satin JR, Linden W, Phillips MJ. Depression as a predictor of disease progression and mortality in cancer patients: a meta-analysis. *Cancer* 2008;**115:**5349-5361.

4. Mitchell AJ, Chan M, Bhatti H, et al. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *Lancet Oncol* 2011;**12:**160-174. DOI:10.1016/S1470-2045(11)70002-X.

5. Hinz A, Krauss O, Hauss JP, et al. Anxiety and depression in cancer patients compared with the general population. *Eur J Cancer Care* 2010;**19:**522-529. DOI 10.1111/j.1365-2354.2009.01088.x.

6. Weich S, Nazroo J, Sproston K, et al. Common mental disorders and ethnicity in England: the EMPIRIC study. *Psychol Med* 2004;**34:**1543-1551.

7. Shavers VL, Brown ML. Racial and ethnic disparities in the receipt of cancer treatment. *J Natl Cancer Inst* 2002;**94:**334-57.

8. Ward E, Jemal A, Cokkinides V, et al. Cancer disparities by race/ethnicity and socioeconomic status. *CA Cancer J Clin* 2004;**54:**78-93.

9. All party parliamentary group on cancer (2009) Report of the all party parliamentary group of cancer's enquiry into inequalities in cancer available at www.appg-cancer.uk.

10. Department of Health (2007), Cancer Reform Strategy available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081007.pdf, The Stationery Office, UK.

11. Department of Health (2011) Improving outcomes a strategy for cancer via http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123394.pdf, Department of Health, London.

12. Goss E, Lopez AM, Brown CL, Wollins DS, Brawley OQ, Raghavan D. American Society of Clinical Oncology policy statement: disparities in

cancer care. *J Clin Oncol* 2009;**27:**2881-2885, DOI 10.1200/JCO.2008.21.1680.

13. US Department of Health and Human Services (2011) President's Cancer Panel: American's demographic and cultural transformations: Implications for cancer Washington DC 1-100.

14. Department of Health and Human Services (USA) (2011), HHS Action plan to reduce racial and ethnic health disparities available via http://minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf, Department of Health and Human Services, Washington DC.

15. Bhopal R. Glossary of terms relating to ethnicity and race: for reflection and debate. J Epidemiol Community Health 58 p. 441-445 DOI: 10.1136/jech.2003.013466.

16. Office for National Statistics 2011 census ethnic groups: local authorities in England and Wales Table KS201EW http://www.ons.gov.uk/ons/search/index.html?newquery=KS201EW.

17. Roy R, Symonds RP, Kumar DM, Ibrahim K, Mitchell A, Fallowfield L. The use of denial in an ethnically diverse British cancer population: a cross-sectional study. *Br J Cancer* 2005;**92:**1393-1397, doi:10.1038/sj.bjc.6602523

18. Luckett T, Butow PN, King MT, Oguchi M, Heading G, Hackl NA, et al. A review and recommendations for optimal outcome measures of anxiety, depression and general distress in studies evaluating psychosocial interventions for English-speaking adults with heterogeneous cancer diagnoses. *Support Care Cancer* 2010;**18:**1241-1262, DOI 10.1007/s00520-010-0932-8.

19. Carlson LE, Groff SL, Maciejewski O, Bultz B.D. Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *J Clin Oncol 2010;***28:**4884-4891, DOI 0.1200/JCO.2009.27.3698.

20. Akechi T, Okuyama T, Sugawara Y, Nakano T, Shima Y Uchitomi Y Major depression, adjustment disorders, and post-traumatic stress disorder in terminally ill cancer patients: associated and predictive factors. *J Clin Oncol* 2004;**22:** 1957-1965, DOI 10.1200/JCO.2004.08.149.

21. Stark D, Kiely M, Smith A, Velikova G, House A Selby P. Anxiety Disorders in Cancer Patients: Their Nature, Associations, and Relation to Quality of Life. *J Clin Oncol* 2002;**20**(14):3137-3148.

22. Clarke JA, Inu, TS, Silliman RA, Bokhour BG, Krasnow SH, Robinson RA et al. Patients' perceptions of quality of life after treatment for early prostate cancer. *J Clin Oncol* 2003;**21**:3777-3784.

23. Hoyer M, Johansson B, Nordin K, Bergkvist L, Ahlgren J, Lidin-Linqvist A et al. Health-related quality of life among women with breast cancer-a population-based study. *Acta Oncologica 2011;***50**(7):1015-1026.

24. Lazarus RS, Folkman S, Adams S. *Stress, appraisal and coping*, Springer, New York; 1984.

25. Moos RH, Holahan CJ. Dispositional and contextual perspectives on coping: toward an integrative framework. *J Clin Psychol* 2003;**59**(12):1387-1403.

26. Hopwood P, Stephens RJ. Depression in patients with lung cancer: prevalence and risk factors derived from quality-of-life data. *J Clin Oncol* 2000;**18**(4):893-903.

27. Breen SJ, Baravelli CM, Schofield PE, Jeffor M, Yates PM, Aranda SK. Is symptom burden a predictor of anxiety and depression in patients with cancer about to commence chemotherapy? *MJA* 2009;**190**(7):s99-s104

28. Shi Q, Smith TG, Michonski JD, Stein KD, Kaw C, Cleeland CS. Symptom Burden in Cancer Survivors 1 Year After Diagnosis. *Cancer* 2011;**117**:2779–90, 10.1002/cncr.26146.

29. Kroenke K, Johns SA, Theobold D, Wu J, Tu W. Somatic symptoms in cancer patients trajectory over 12 months and impact on functional status

and disability. *Support Care Cancer* 2013;**21**:765-773, DOI 10.1007/s00520-012-1578-5.

30. Lam WWT, Bonanno GA, Mancini AD, Ho S, Chan M, Hung WK, et al. Trajectories of psychological distress among Chinese women diagnosed with breast cancer. *Psycho Oncol* 2010;**19**:1044-1051, DOI10.1002/pon.1658.

31. Fu OS, Crew KD, Jacobson JS, Greenlee H, Yu G, Campbell J, et al. Ethnicity and persistent symptom burst in breast cancer survivors J Cancer Surviv 2009;**3**: 241-250, DOI 10.1007/s11764-009-0100-7.

32. Yoon J, Malin JL, Tisnado DM, Tao ML, Adams JL, Timmer MJ et al. Symptom management after breast cancer treatment: is it influenced by patient characteristics? Breast Cancer Res Treat 2008;**108**(1):69-77.

33. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;**67:**361-370.

34. Mitchell AJ, Baker-Glenn EA, Park B, Granger L, Symonds P. Can the Distress Thermometer be improved by additional mood domains? Part II. What is the optimal combination of Emotion Thermometers? *Psycho-oncology* 2010;**19:**134-140, DOI 10.1002/pon.1557.

35. Roth AJ, Kornblith AB, Batel-Copel L, Peabody E, Scher HI, Holland JC. Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. *Cancer* 1998;**82:**1904-1908.

36. Brislin RW. Back-translation for cross-cultural research. *Journal of Cross-cultural Psychology* 1970;**1:**185-216, doi: 10.1177/135910457000100301.

37. Kochhar PH, Rajadhyaksha SS, Suvarna VR. Translation and validation of brief patient health questionnaire against DSM IV as a tool to diagnose major depressive disorder in Indian patients. *J Postgrad Med* 2007;**53:**102-107.

38. Watson M, Law M, Dossantos M, Greer S, Baruch J, Bliss JM. The Mini-Mac; Further development of the mental adjustment to cancer scale. *J Psychosoc Oncol* 1994;**12:**33-46.

39. Von Elm E, Altman DG, Egger M, Rocock SJ, Gotzschep C, Vandenbrouche JP. The strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement Epidemiology 2007;**18**(6):800-804.

40. Snaith RP. The Hospital Anxiety and Depression Scale. *Health Qual Life Outcomes* 2003;**1**:29.

41. Morse R, Kendell K, Barton S. Screening for depression in people with cancer: the accuracy of the hospital anxiety and depression scale. *Clin Eff Nurs* 2005;**9**:188-196.

42. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosomatic Res* 2002;**52**(2):69-77.

43. Kroenke K, Spitzer RL, Williams JBW. The PHQ-9 validity of a brief depression severity measure. *J Gen Intern Med* 2001;**16**:605-613.

44. National Comprehensive Cancer Network 2011, December 10th 2010-last update, *NCCN guidelines: distress managemen*t [Homepage of National Comprehensive Cancer Network], [Online]. http://www.nccn.org/professionals/physician_gls/f_guidelines.asp [2011, 9/ 25].

45. Office for National Statistics 2011, *"Neighbourhood Statistics 'Summary Statistics', citing indices of deprivation, 2007, UK Department for Communities and Local Government* [Homepage of Office for National Statistics], [Online]. http://www.neighbourhood.statistics.gov.uk/ [2007-2011].

46. Lazarus RS. Coping theory and research: past, present and future. Psychosom Med 1993;**55**(3):234-247.

47. National Institute for Health and Clinical Excellence (NICE) 2011, February 2010-last update, Clinical knowledge summaries (CKS) clinical topics. Depression; Available via http://www.cks.nhs.uk/depression/management/scenario_bereavement/view_full_scenario#-402794 [2012, 26/6].

48. Ashing-Giwa KT, Tejero JS, Kim J, Padilla GV, Hellemann G. Examining predictive models of HRQOL in a population-based, multiethnic sample of women with breast carcinoma. *Qual Life Res* 2007;**16:**413-428, DOI 10.1007/s11136-006-9138-4.

49. Ell K, Sanchez K, Vourlekis B, Lee PJ, Dwight-Johnson M, Lagomasino I et al. Depression, correlates of depression and receipt of depression care among low-income women with breast or gynecologic cancer. *J Clin Oncol* 2005;**23:**3052-3060, DOI 10.1200/JCO.2005.08.041

50. Osborne RH, Elsworth GR, Hopper JL. Age-specific norms and determinants of anxiety and depression in 731 women with breast cancer recruited through a population-based cancer registry. *Eur J Cancer* 2003;**39:**755-762.

51. Schou I, Ekeberg O, Ruland CM, Sandvik L, Karesen R. Pessimism as a predictor of emotional morbidity one year following breast cancer surgery. *Psychooncology* 2004;**13:**309-320. DOI 10.1002/pon.747.

52. Brothers BM, Andersen BL. Hopelessness as a predictor of depressive symptoms for breast cancer patients coping with recurrence. *Psychooncology* 2009;**18:**267-275, DOI 10.1002/pon.1394.

53. Lo C, Zimmermann C, Rydall A, Walsh A, Jones JM, Moore MJ et al. Longitudinal Study of Depressive Symptoms in Patients with Metastatic Gastrointestinal and Lung Cancer. *J Clin Oncol* 2010;**28:**3084, DOI 10.1200/JCO.2009.26.9712.

54. Grassi L, Travado L, Gil F, Sabato S, Rossi E, Tomamichel M et al. Hopelessness and related variables among cancer patients in the Southern European Psycho-Oncology Study (SEPOS). *Psychosomatics* 2010;**51:**201-207, DOI 10.1176/appi.psy.51.3.201.

55. Johansson M, Ryden A, Finizia C. Mental adjustment to cancer and its relation to anxiety, depression, HRQL and survival in patients with laryngeal cancer - A longitudinal study. *BMC Cancer* 2011;**11:**283, DOI 10.1186/1471-2407-11-283.

56. Chaturvedi SK, Chandra PS, Channabasavanna SM, Anantha N, Reddy BKM, Sharma S. Levels of anxiety and depression in patients receiving radiotherapy in India. *Psychooncology* 1996;**5:**343-346, DOI: 10.1002/(SICI)1099-1611(199612).

57. Kishore J, Ahmad I, Kaur R, Mohanta PK. Beliefs and perceptions about cancers among patients attending radiotherapy OPD in Delhi, India. *Asian Pac J Cancer Prev* 2008;**9:**155-158.

58. Szczepura A, Price C, Gumber A. Breast and bowel cancer screening uptake patterns over 15 years for UK South Asian ethnic minority populations corrected for differences in socio-demographic characteristics. *BMC Public Health* 2008;**8:**346.

59. Miles A, Rainbow S, von Wagner C. Cancer Fatalism and Poor Self-Rated Health Mediate the Association between Socioeconomic Status and Uptake of Colorectal Cancer Screening in England. *Cancer Epidemiol Biomarkers Prev* 2011;**20:**2132-2140, DOI 10.1158/1055-9965.EPI-11-0453.

60. Symonds RP, Lord K, Mitchel AJ, Raghavan D. Recruitment of ethnic minorities into clinical trials: experience from the front lines, *Br J Cancer,* 2012;**107**:1017-1021.

~~**References**~~ **References**

~~Akechi T, Okuyama T, Sugawara Y, Nakano T, Shima Y Uchitomi Y (2004) Major depression, adjustment disorders, and post-traumatic stress disorder in terminally ill cancer patients: associated and predictive factors. *J Clin Oncol* **22:** 1957-1965, DOI 10.1200/JCO.2004.08.149~~

All party parliamentary group on cancer (2009) Report of the all party parliamentary group of cancer's enquiry into inequalities in cancer available at www.appg-cancer.uk

Ashing-Giwa KT, Tejero JS, Kim J, Padilla GV Hellemann G (2007) Examining predictive models of HRQOL in a population-based, multiethnic sample of women with breast carcinoma. *Qual Life Res* **16:** 413-428, DOI 10.1007/s11136-006-9138-4

Bhopal R, 2003, "Glossary of terms relating to ethnicity and race: for reflection and debate" *Journal of Epidermiology & Community Health* 58 p. 441-445 DOI: 10.1136/jech.2003.013466

Brislin, R.W. 1970, "Back-translation for crosscultural research", *Journal of Cross-Cultural Psychology*, vol. 1, pp. 185-216.

Broadbent E, Petrie KJ, Main J, Weinman J (2006) The brief illness perception questionnaire. *J Psychosom Res* **60:** 631-637, DOI 10.1016/j.jpsychores.2005.10.020

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Brothers BM, Andersen BL (2009) Hopelessness as a predictor of depressive symptoms for breast cancer patients coping with recurrence. *Psycho-oncology* **18:** 267-275, DOI 10.1002/pon.1394

Carlson LE, Groff SL, Maciejewski O, Bultz B.D (2010) Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *J Clin Oncol* **28:** 4884-4891, DOI 0.1200/JCO.2009.27.3698

Chaturvedi SK, Chandra PS, Channabasavanna SM, Anantha N, Reddy BKM, Sharma S (1996) Levels of anxiety and depression in patients receiving radiotherapy in India. *Psychooncology* **5:** 343-346, DOI: 10.1002/(SICI)1099-1611(199612)

Department of Health (2011) Improving outcomes a strategy for cancer via http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123394.pdf, Department of Health, London

Department of Health (2007), Cancer Reform Strategy available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081007.pdf, The Stationery Office, UK

Department of Health and Human Services (USA) (2011b), HHS Action plan to reduce racial and ethnic health disparities available via http://minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf, Department of Health and Human Services, Washington DC

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Ell K, Sanchez K, Vourlekis B, Lee PJ, Dwight-Johnson M, Lagomasino I, Muderspach L, Russell C (2005) Depression, correlates of depression and receipt of depression care among low-income women with breast or gynecologic cancer. *J Clin Oncol* **23:** 3052-3060, DOI 10.1200/JCO.2005.08.041

Goss E, Lopez AM, Brown CL, Wollins DS, Brawley OQ, Raghavan D (2009) American Society of Clinical Oncology policy statement: disparities in cancer care. *J Clin Oncol* **27:** 2881-2885, DOI 10.1200/JCO.2008.21.1680

Grassi L, Travado L, Gil F, Sabato S, Rossi E, Tomamichel M, Marmai L, Biancosino B, Nanni MG, Group TS (2010) Hopelessness and related variables among cancer patients in the Southern European Psycho-Oncology Study (SEPOS). *Psychosomatics* **51:** 201-207, DOI 10.1176/appi.psy.51.3.201

Hinz A, Krauss O, Hauss JP, Hockel M, Kortmann RD, Stolzenburg JU Schwarz R (2010) Anxiety and depression in cancer patients compared with the general population. *Eur J Cancer Care* **19:** 522-529, DOI 10.1111/j.1365-2354.2009.01088.x

Johansson M, Ryden A, Finizia C (2011) Mental adjustment to cancer and its relation to anxiety, depression, HRQL and survival in patients with laryngeal cancer - A longitudinal study. *BMC Cancer* **11:** 283, DOI 10.1186/1471-2407-11-283

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Kennard BD, Stewart SM, Olvera R, Bawdon RE, O hAilin A, Lewis CP Winick NJ (2004) Nonadherence in Adolescent Oncology Patients: Preliminary Data on Psychological Risk Factors and Relationships to Outcome. *J Clin Psychol Med S* **11:** 1: 31-39, DOI 0.1023/B:JOCS.0000016267.21912.74

King M, Nazareth I, Levy G, Walker C, Morris R, Weich S, Bellon-Saameno JA, Moreno B, Svab I, Rotar D, Rifel J, Maaroos HI, Aluoja A, Kalda R, Neeleman J, Geerlings MI, Xavier M, de Almeida MC, Correa B, Torres-Gonzalez F (2008) Prevalence of common mental disorders in general practice attendees across Europe. *Br J Psychiatry* **192:** 362-367, DOI 10.1192/bjp.bp.107.039966

Kishore J, Ahmad I, Kaur R, PKM (2008) Beliefs and perceptions about cancers among patients attending radiotherapy OPD in Delhi, India. *Asian Pac J Cancer Prev* **9:** 155-158.

Kochhar PH, Rajadhyaksha SS, Suvarna VR (2007) Translation and validation of brief patient health questionnaire against DSM IV as a tool to diagnose major depressive disorder in Indian patients. *J Postgrad Med* **53:** 102-107.

Kroenke, K., Spitzer, R.L. & Williams, J.B.W. 2001, "The PHQ-9 validity of a brief depression severity measure", *Journal of general internal medicine*, vol. 16, pp. 605-613.

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Lo C, Zimmermann C, Rydall A, Walsh A, Jones JM, Moore MJ, Shepherd FA, Gagliese L, Rodin G (2010) Longitudinal Study of Depressive Symptoms in Patients with Metastatic Gastrointestinal and Lung Cancer. *J Clin Oncol* **28:** 3084, DOI 10.1200/JCO.2009.26.9712

Luckett T, Butow PN, King MT, Oguchi M, Heading G, Hackl NA, Rankin N, Price MA (2010) A review and recommendations for optimal outcome measures of anxiety, depression and general distress in studies evaluating psychosocial interventions for English-speaking adults with heterogeneous cancer diagnoses. *Support Care Cancer* **18:** 1241-1262, DOI 10.1007/s00520-010-0932-8

Miles A, Rainbow S, von Wagner C (2011) Cancer Fatalism and Poor Self-Rated Health Mediate the Association between Socioeconomic Status and Uptake of Colorectal Cancer Screening in England. *Cancer Epidemiol Biomarkers Prev* **20:** 2132-2140, DOI 10.1158/1055-9965.EPI-11-0453

Mitchell AJ (2007) Pooled results from 38 analyses of the accuracy of distress thermometer and other ultra-short methods of detecting cancer-related mood disorders. J Clin Oncol **25:** 4670-4681, DOI 10.1200/JCO.2006.10.0438

Mitchell AJ, Baker-Glenn EA, Park B, Granger L, Symonds P (2010) Can the Distress Thermometer be improved by additional mood domains? Part II. What

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is the optimal combination of Emotion Thermometers? *Psychooncology* **19:** 134-140, DOI 10.1002/pon.1557

Mitchell AJ, Chan M, Bhatti H, Halton M, Grassi L, Johansen C, Meader N (2011) Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *Lancet Oncol* **12:** 160-174, DOI:10.1016/S1470-2045(11)70002-X

Mitchell AJ, Meader N, Symonds P (2010) Diagnostic validity of the Hospital Anxiety and Depression Scale (HADS) in cancer and palliative settings: a meta-analysis. *J Affect Disord* **126:** 335-348, DOI 10.1016/j.jad.2010.01.067

Mitchell AJ, Vaze A, Rao S (2009) Clinical diagnosis of depression in primary care: a meta-analysis. *Lancet* **374:** 609-619, DOI 10.1016/S0140-6736(09)60879-5

Morse R, Kendell K, Barton S (2005) Screening for depression in people with cancer: the accuracy of the hospital anxiety and depression scale. Clin Eff Nurs **9**: 188 - 196 DOI 10.1016/j.cein.2006.08.012

Muthu Kumar D, Symonds RP, Sundar S, Ibrahim K, Savelyich BS, Miller E (2004) Information needs of Asian and White British cancer patients and their families in Leicestershire: a cross-sectional survey. *Br J Cancer* **90:** 1474-1478, doi:10.1038/sj.bjc.6601774

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National Comprehensive Cancer Network 2011, December 10th 2010-last update, *NCCN guidelines: distress management* [Homepage of National Comprehensive Cancer Network], [Online]. http://www.nccn.org/professionals/physician_gls/f_guidelines.asp [2011, 9/ 25].

National Institute for Health and Clinical Excellence (NICE) 2011, February 2010-last update, Clinical knowledge summaries (CKS) clinical topics. Depression; Available via http://www.cks.nhs.uk/depression/management/scenario_bereavement/view_full_scenario#-402794 [2012, 26/6].

Office for National Statistics 2011, *"Neighbourhood Statistics 'Summary Statistics', citing indices of deprivation, 2007, UK Department for Communities and Local Government* [Homepage of Office for National Statistics], [Online]. http://www.neighbourhood.statistics.gov.uk/ [2007-2011].

Osborne RH, Elsworth GR, Hopper JL (2003) Age-specific norms and determinants of anxiety and depression in 731 women with breast cancer recruited through a population-based cancer registry. *Eur J Cancer* **39:** 755-762.

US Department of Health and Human Services (2011a) President's Cancer Panel: American's demographic and cultural transformations: Implications for cancer Washington DC 1-100

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Roth AJ, Kornblith AB, Batel-Copel L, Peabody E, Scher HI, Holland JC (1998) Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. *Cancer* **82:** 1904-1908.

Roy R, Symonds RP, Kumar DM, Ibrahim K, Mitchell A, Fallowfield L (2005) The use of denial in an ethnically diverse British cancer population: a cross-sectional study. *Br J Cancer* **92:** 1393-1397, doi:10.1038/sj.bjc.6602523

Satin JR, Linden W, Phillips MJ (2009) Depression as a predictor of disease progression and mortality in cancer patients: a meta-analysis. *Cancer* **115:** 5349-5361

Schou I, Ekeberg O, Ruland CM, Sandvik L, Karesen R (2004) Pessimism as a predictor of emotional morbidity one year following breast cancer surgery. *Psychooncology* **13:** 309-320, DOI 10.1002/pon.747

Snaith, R.P. 2003, "The Hospital Anxiety and Depression Scale", *Health and Quality of Life Outcomes*, **1**, pp. 29.

Steginga SK, Campbell A, Ferguson M, Beeden A, Walls M, Cairns W, Dunn J (2008) Socio-demographic, psychosocial and attitudinal predictors of help seeking after cancer. *Psychooncology* **17:** 997-1005, DOI 10.1002/pon.1317

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Symonds RP, Lord K, Mitchell AJ, Raghavan D (2012) Recruitment of ethnic minorities into clinical trials: experience from the front lines. *Br J Cancer* **107:** 1017-1021

Szczepura A, Price C, Gumber A (2008) Breast and bowel cancer screening uptake patterns over 15 years for UK South Asian ethnic minority populations corrected for differences in socio-demographic characteristics. *BMC Public Health* **8:** 346

Von Elm, E, Altman, DG, Egger M et al. (2007) The strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement Epidemiology 18 (6) p. 800-804

Watson M, Law M, Dossantos M, Greer S, Baruch J, Bliss JM (1994) The Mini-Mac; Further development of the mental adjustment to cancer scale. *J Psychosoc Oncol* **12:** 33-46

Weich S, Nazroo J, Sproston K, McManus S, Blanchard M, Erens B, Karlsen S, King M, Lloyd K, Stansfeld S, Tyrer P (2004) Common mental disorders and ethnicity in England: the EMPIRIC study. *Psychol Med* **34:** 1543-1551

Zigmond AS, Snaith RP (1983) The hospital anxiety and depression scale. *Acta Psychiatr Scand* **67:** 361-370

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1. Kennard BD, Stewart SM, Olvera R, et al. Nonadherence in Adolescent Oncology Patients: Preliminary Data on Psychological Risk Factors and Relationships to Outcome. *J Clin Psychol Med S* 2004;**11:**1:31-39. DOI 0.1023/B:JOCS.0000016267.21912.74

2. Steginga SK, Campbell A, Ferguson M, et al. Socio-demographic, psychosocial and attitudinal predictors of help seeking after cancer. *Psychooncology* 2008;**17:**997-1005. DOI 10.1002/pon.1317

3. Satin JR, Linden W, Phillips MJ. Depression as a predictor of disease progression and mortality in cancer patients: a meta-analysis. *Cancer* 2008;**115:**5349-5361.

4. Mitchell AJ, Chan M, Bhatti H, et al. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *Lancet Oncol* 2011;**12:**160-174. DOI:10.1016/S1470-2045(11)70002-X

5. Hinz A, Krauss O, Hauss JP, et al. Anxiety and depression in cancer patients compared with the general population. *Eur J Cancer Care* 2010;**19:**522-529. DOI 10.1111/j.1365-2354.2009.01088.x

6. Weich S, Nazroo J, Sproston K, et al. Common mental disorders and ethnicity in England: the EMPIRIC study. *Psychol Med* 2004;**34:**1543-1551.

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7. Shavers VL, Brown ML. Racial and ethnic disparities in the receipt of cancer treatment. *J Natl Cancer Inst* 2002;**94:**334-57.

8. Ward E, Jemal A, Cokkinides V, et al. Cancer disparities by race/ethnicity and socioeconomic status. *CA Cancer J Clin* 2004;**54:**78-93.

9. Goss E, Lopez AM, Brown CL, et al. American Society of Clinical Oncology policy statement: disparities in cancer care. *J Clin Oncol* 2009;**27:**2881-2885. DOI 10.1200/JCO.2008.21.1680

10. US Department of Health and Human Services (2011) President's Cancer Panel: American's demographic and cultural transformations: Implications for cancer Washington DC 1-100

11. All party parliamentary group on cancer (2009) Report of the all party parliamentary group of cancer's enquiry into inequalities in cancer available at www.appg-cancer.uk

12. Department of Health (2007), Cancer Reform Strategy available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081007.pdf, The Stationery Office, UK

13. Department of Health (2011) Improving outcomes a strategy for cancer via

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http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123394.pdf, Department of Health, London

14. Department of Health and Human Services (USA) (2011), HHS Action plan to reduce racial and ethnic health disparities available via http://minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf, Department of Health and Human Services, Washington DC

15. Roy R, Symonds RP, Kumar DM, et al. The use of denial in an ethnically diverse British cancer population: a cross-sectional study. *Br J Cancer* 2005;**92:**1393-1397. doi:10.1038/sj.bjc.6602523

16. Luckett T, Butow PN, King MT, et al. A review and recommendations for optimal outcome measures of anxiety, depression and general distress in studies evaluating psychosocial interventions for English-speaking adults with heterogeneous cancer diagnoses. *Support Care Cancer* 2010;**18:**1241-1262. DOI 10.1007/s00520-010-0932-8

17. Carlson LE, Groff SL, Maciejewski O, et al. Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *J Clin Oncol* 2010;**28:**4884-4891. DOI 0.1200/JCO.2009.27.3698

18. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;**67:**361-370.

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19. Mitchell AJ, Baker-Glenn EA, Park B, et al. Can the Distress Thermometer be improved by additional mood domains? Part II. What is the optimal combination of Emotion Thermometers? *Psycho-oncology* 2010;**19:**134-140. DOI 10.1002/pon.1557

20. Roth AJ, Kornblith AB, Batel-Copel L, et al. Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. *Cancer* 1998;**82:**1904-1908.

21. Brislin RW. Back-translation for cross-cultural research. *Journal of Cross-cultural Psychology* 1970;**1:**185-216. doi: 10.1177/135910457000100301

22. Kochhar PH, Rajadhyaksha SS, Suvarna VR. Translation and validation of brief patient health questionnaire against DSM IV as a tool to diagnose major depressive disorder in Indian patients. *J Postgrad Med* 2007;**53:**102-107.

23. Watson M, Law M, Dossantos M, et al. The Mini-Mac; Further development of the mental adjustment to cancer scale. *J Psychosoc Oncol* 1994;**12:**33-46.

24. Broadbent E, Petrie KJ, Main J, et al. The brief illness perception questionnaire. J *Psychosom Res* 2006;**60:**631-637. DOI 10.1016/j.jpsychores.2005.10.020

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25. Lord K, Ibrahim K, Kumar S, et al. Measuring trust in healthcare professionals a study of ethnically diverse UK cancer patients. *Clin Oncol* 2012;**24:**13-21. DOI: 10.1016/j.clon.2011.05.010

26. National Institute for Health and Clinical Excellence (NICE) 2011, February 2010-last update, Clinical knowledge summaries (CKS) clinical topics. Depression; Available via http://www.cks.nhs.uk/depression/management/scenario_bereavement/view_full_scenario#-402794 [2012, 26/6].

27. King M, Nazareth I, Levy G, et al. Prevalence of common mental disorders in general practice attendees across Europe. *Br J Psychiatry* 2008;**192:**362-367. DOI 10.1192/bjp.bp.107.039966

28. Ashing-Giwa KT, Tejero JS, Kim J, et al. Examining predictive models of HRQOL in a population-based, multiethnic sample of women with breast carcinoma. *Qual Life Res* 2007;**16:**413-428. DOI 10.1007/s11136-006-9138-4

29. Ell K, Sanchez K, Vourlekis B, et al. Depression, correlates of depression and receipt of depression care among low-income women with breast or gynecologic cancer. *J Clin Oncol* 2005;**23:**3052-3060. DOI 10.1200/JCO.2005.08.041

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30. Lord K, Mitchell AJ, Ibrahim K, et al. The beliefs and knowledge of patients newly diagnosed with cancer in a UK ethnically diverse population. *Clin Oncol* 2012;**24:**4-12. DOI 10.1016/j.clon.2011.05.008

31. Osborne RH, Elsworth GR, Hopper JL. Age-specific norms and determinants of anxiety and depression in 731 women with breast cancer recruited through a population based cancer registry. *Eur J Cancer* 2003;**39:**755-762.

32. Akechi T, Okuyama T, Sugawara Y, et al. Major depression, adjustment disorders, and post-traumatic stress disorder in terminally ill cancer patients: associated and predictive factors. *J Clin Oncol* 2004;**22:**1957-1965. DOI 10.1200/JCO.2004.08.149

33. Schou I, Ekeberg O, Ruland CM, et al. Pessimism as a predictor of emotional morbidity one year following breast cancer surgery. *Psychooncology* 2004;**13:**309-320. DOI 10.1002/pon.747

34. Brothers BM, Andersen BL. Hopelessness as a predictor of depressive symptoms for breast cancer patients coping with recurrence. *Psycho-oncology* 2009;**18:**267-275. DOI 10.1002/pon.1394

35. Lo C, Zimmermann C, Rydall A, et al. Longitudinal Study of Depressive Symptoms in Patients with Metastatic Gastrointestinal and Lung Cancer. *J Clin Oncol* 2010;**28:**3084. DOI 10.1200/JCO.2009.26.9712

Formatted: No bullets or numbering

36. Grassi L, Travado L, Gil F, et al. Hopelessness and related variables among cancer patients in the Southern European Psycho-Oncology Study (SEPOS). *Psychosomatics* 2010;**51:**201-207. DOI 10.1176/appi.psy.51.3.201

37. Johansson M, Ryden A, Finizia C. Mental adjustment to cancer and its relation to anxiety, depression, HRQL and survival in patients with laryngeal cancer - A longitudinal study. *BMC Cancer* 2011;**11:**283. DOI 10.1186/1471-2407-11-283

38. Chaturvedi SK, Chandra PS, Channabasavanna SM, et al. Levels of anxiety and depression in patients receiving radiotherapy in India. *Psychooncology* 1996;**5:**343-346. DOI: 10.1002/(SICI)1099-1611(199612)

39. Kishore J, Ahmad I, Kaur R, PKM. Beliefs and perceptions about cancers among patients attending radiotherapy OPD in Delhi, India. *Asian Pac J Cancer Prev* 2008;**9:**155-158.

40. Szczepura A, Price C, Gumber A. Breast and bowel cancer screening uptake patterns over 15 years for UK South Asian ethnic minority populations corrected for differences in socio-demographic characteristics. *BMC Public Health* 2008;**8:**346.

41. Miles A, Rainbow S, von Wagner C. Cancer Fatalism and Poor Self-Rated Health Mediate the Association between Socioeconomic Status and

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Uptake of Colorectal Cancer Screening in England. *Cancer Epidemiol Biomarkers Prev* 2011;**20:**2132-2140. DOI 10.1158/1055-9965.EPI-11-0453

42. Muthu Kumar D, Symonds RP, Sundar S, et al. Information needs of Asian and White British cancer patients and their families in Leicestershire: a cross-sectional survey. *Br J Cancer* 2004;**90:**1474-1478. doi:10.1038/sj.bjc.6601774

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

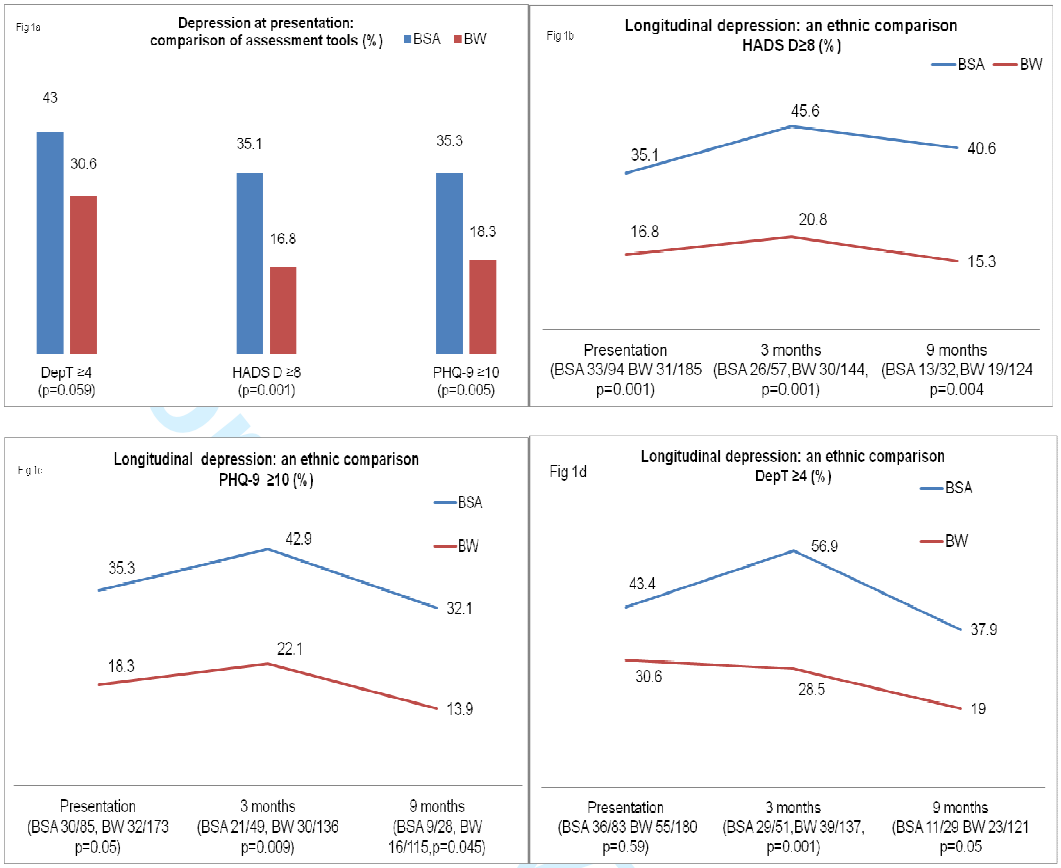
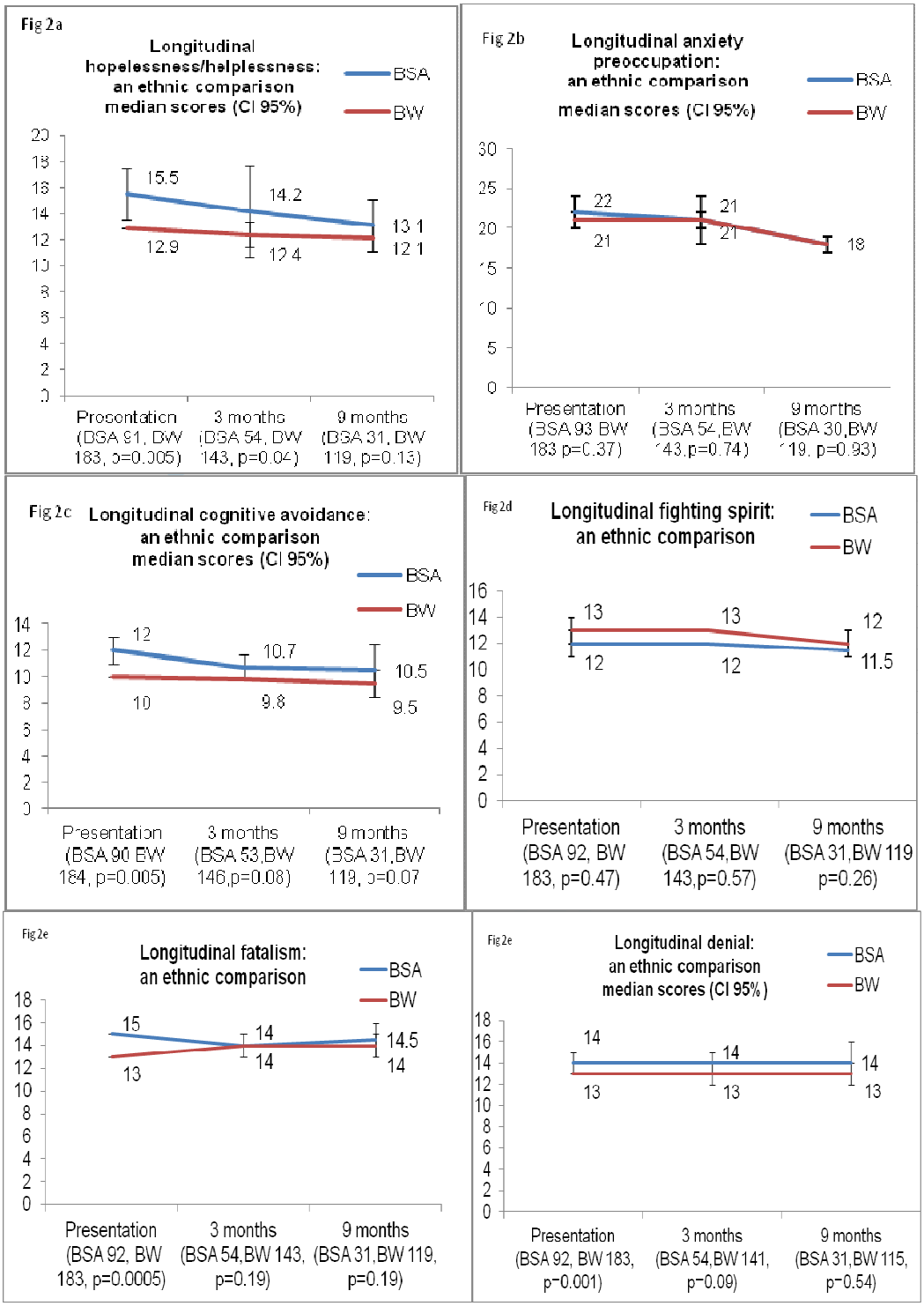
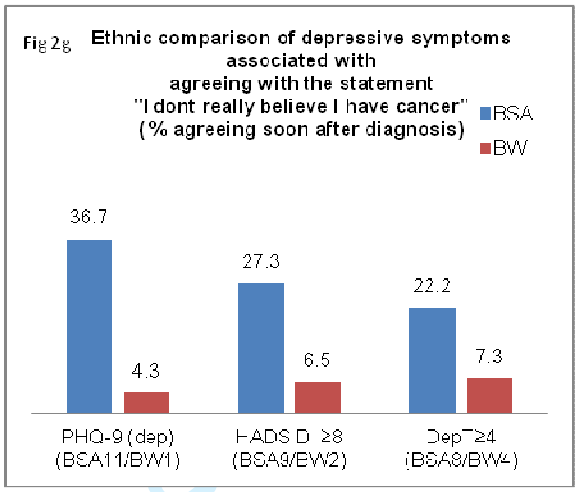


Fig 2a-g Longitudinal ethnic differences in coping strategies



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 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

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

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 ≥10
D= depressive symptoms PHQ-9 ≤9

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

Mann Whitney DepT. 3v4			n=	Mean Rank Score (MRS)	Md(IQR)	U	Z	r	p-value
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
	9months	ND	113	66.51	11.5(9:15)				
		D	34	98.88	15(12:17)	1075	-3.905	0.32	0.0005
Cognitive Avoidance.	Baseline	ND	169	120.10	10(8:12)				
		D	91	149.81	11(10:12)	5932.5	-3.067	0.19	0.002
	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
Fatalism	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
	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

ND= depressive symptoms DepT ≤3

D= depressive symptoms DepT ≥4

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

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

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Abstract

Objectives

This cross sectional survey investigated whether there were ethnic differences in depressive symptoms among British South Asian (BSA) 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≥8: baseline: 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). BSA patients used potentially maladaptive coping strategies more frequently than BW patients at baseline (hopelessness/helplessness p=0.005, fatalism p=0.0005, avoidance p=0.005; the CIDQ denial statement 'I do not really believe I have cancer' p=0.0005). BSA patients experienced more physical symptoms (DT checklist) which correlated with ethnic differences in depressive symptoms especially at three months.

Conclusion

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

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 then 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.

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).[15] We define 'British South Asian (BSA)' as a person whose ancestry originates in the Indian subcontinent, and who identifies with, or is identified with, their host country [16]. A previous pilot study showed a significantly higher incidence in symptoms of depression among BSA patients in Leicester and the local county compared to British White (BW) patients via HADS-D ≥10 (BSA 20.7%; BW 10.4% p=0.001).[17] Depressive symptoms were associated with potentially maladaptive coping strategies among both ethnic groups but were employed statistically significantly more frequently by BSA patients. For example, fatalism p=0.0001; denial p=0.019; hopelessness and helplessness, p=0.007.

The findings of our pilot study [17] 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. [18]

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

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

Feeling distressed or low in mood are initial emotional responses to a diagnosis of cancer, and is part of normal adjustment, if of short duration. If, however distress persists it can have a harmful effect on the mental wellbeing of the individual risking depressive symptoms [17, 20] and a reduction in their quality of life.[21, 22, 23]

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

The symptom burden on cancer patients can have a close interrelationship with psychological wellbeing. Fatigue and 'disabilities' independently predicted depression among lung cancer patients commencing treatment [26] and have been observed in pre-chemotherapy patients with curative cancer.[27] A high symptom burden can persist over time. One in four patients (n=4903) had a high symptom burden one year post diagnosis with depression, fatigue and pain having the greatest impact on their quality of life.[28] Similarly a high symptom burden at 12 months was reported among patients referred for control of pain

and depression (n=405).[29] Among Chinese breast cancer patients (n=285) less distress from physical symptoms immediately after surgery predicted psychological resilience. The study suggested that ineffective symptom control during treatment increased a women's risk of persistent psychological distress longitudinally. The value of pre-operative interventions was highlighted.[30]

Of particular concern are reports of a higher symptom burden among ethnic minorities, for example among Hispanic women post-chemotherapy for breast cancer.[31] A greater 'unmet need' for symptom control was implicated among Black and Spanish speaking Hispanic women with breast cancer than White women.[32]

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

Hypotheses

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

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

problem checklist identified the patient's symptom burden. All are validated but were not initially available in Gujarati or Hindi. A commercial company undertook an iterative back-translation process.[36] 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.[37] Several tools were used to address the concern that some were ethnically biased.

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

Statistical analysis

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

The revised classification of the original HADS-D identified the severity of depressive symptoms (normal 0-7, mild 8-10, moderate 11-14 and severe 15-

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

Graphs denote 95% confidence intervals. Summary scores for selected coping strategies were from the Mini-MAC and the denial indicators in the CIDQ. Reference was made to individual indicators. Longitudinal data at baseline and at three and nine months is reported.

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

Chi^2 described the relationship between categorical variables. The extent to which patients used each coping strategy and how their use changed longitudinally is described. Associations between each strategy and depressive symptoms is reported. Qualitative data was recorded verbatim. When in Gujarati it was translated to English. Analysis was performed via SPSS v 18.

Results

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

Demographics and depressive symptoms

Age was not associated with depression among BSA patients (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≥8 baseline p=0.088, 3 months p=0.588 9 months p=1.0). Those with lung cancer, who generally have a poor prognosis, had the highest median depression score via HADS-D of 5 (IQR 3,7,scale 0-21). The lowest score was attributed to people with prostate cancer (Md 1 (IQR 0,5) (Supplementary 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 ≥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 listing no formal education spoke up to five languages fluently. Individual results in patients who reported little formal education were consistent across assessment tools suggesting adequate comprehension.

There was no significant difference in depressive symptoms between those BSA patients originating from Africa compared to the Indian Sub continent at baseline (MW: Africa 31/80 Md 4 (2,9) Indian Sub Continent Md 5.5 (2,11) Z=-

1.184 p=0.23). Neither was there a significant difference in the experience of symptoms frequently associated with depression such as pain (p=0.23), sleep disturbances (p=0.91) and fatigue (p=0.52).

Since 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 depressive symptoms. Although there was a strong association between ethnicity and deprivation (MW r=0.503, p=0.0005), deprivation had minimal influence on the strength of the relationship between ethnicity and depression when comparing Pearson product-moment correlations (PCC) with partial correlation calculations (Table 3).

Depressive symptoms at baseline

All three assessment tools showed approximately double the incidence of depression in BSA patients compared to BW patients (Fig 1a-1d and Supplementary table 2). Severe depression was also more common in the BSA groups as demonstrated using a higher HADS-D score ≥11 (BSA 23/94 (24.5%) BW 11/185 (5.9%) p=0.001). A similar trend was seen using a higher PHQ-9 threshold ≥15 (BSA 13/85 (15%) BW 10/173 (5%) p=0.04).

Longitudinal trends in depressive symptoms

All tools indicated how BSA patients were more vulnerable to depressive symptoms in contrast to BW patients. HADS-D ≥8 suggested significantly higher rates of depressive symptoms among BSA patients longitudinally than

BW patients (Fig 1b). 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 baseline by nine months although the ethnic difference remained (Fig 1c &1d).

Coping Strategies

BSA patients used coping strategies differently to BW patients particularly at baseline when greater use of potentially maladaptive strategies were associated with higher rates of depressive symptoms (Supplementary tables 3, 4 & 5).

Hopelessness/ helplessness (Mini MAC)

> *"its an awful thing to happen….feeling hopeless"*
>
> BSA patient No.16 at baseline

Although initially the majority of patients did not express helplessness 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 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 more patients (BSA and BW combined) felt helplessness/hopelessness and also acknowledged depressive symptoms (MW: PHQ-9 ≥11/HADS-D ≥8 p=0.0005).

Anxiety preoccupation

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

There was a negligible ethnic difference in the use of anxiety preoccupation. Over time this strategy was used less (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 ≥8 p=0.001; Dep.T ≥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

depressive symptoms (MW: HADS-D≥8 p= 0.024; PHQ-9, p= 0.003) but not by the Dep T. ≥4 (p=0.101).

Insight and Denial (CIDQ)

"I'm not ill"

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

*"…part of me still feels there is nothing wrong with me and this is happening to someone else. This is presumably my way of handling it all." B*W No.311 at nine months

Of those who used denial, potentially a maladaptive coping strategy,[45] BSA patients were over-represented, most notably at baseline assessments (p=0.001). The ethnic gap remained longitudinally (Fig 2f). Of the three tools assessing depression only PHQ-9 indicated an association between denial and depression albeit weakly (MW: p= 0.039).

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

trend towards BSA patients, who denied their diagnosis, to be more depressed at baseline but sample numbers were too low to warrant analysis at nine months (Fig 2g).

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

Discussion

With the exception of our pilot study [17] we are not aware of another comparison of how BSA and BW patients cope with cancer. 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 depressive symptoms among BSA patients soon after the cancer diagnosis than BW patients. The percentages

vary depending on the assessment tool used but all showed the same trend. BSA rates for depression were twice that of BW patients using two tools. 35.1% of BSA compared to 16.8% of BW patients (p=0.001) had depressive symptoms measured on the HADS-D scale (≥8). This was confirmed on a version of the PHQ-9≥10 developed for India (35.3% BSA v 18.3% BW p=0.05). This is a critical finding since this is almost six times higher than reported within the UK general population using the same assessment tool (6%).[46] Depression rates for BW patients (HADS-D≥8, 16.8%; PHQ-9 18.3%) 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.[4] What is disturbing is the incidence of more severe depression in BSA patients which is reflected in their HAD-D score ≥11 (BSA 24.5% v BW 5.9% p=0.0001). These findings supported trends in other studies, notably our pilot study. Using the threshold HADS-D ≥10, Roy [17] reported BSA 20.7% v BW 10.4% (p=0.001) had moderate depressive symptoms. These concur with other reports which suggest that ethnic minority cancer patients experience more psychological distress than patients from host populations.[16, 17, 47, 48] However the BSA population is heterogeneous. It would be grossly simplistic to assume all BSA patients respond psychologically in the same way given the breath and diversity of their religious and cultural influences. However Indian Hindus comprised the majority of our BSA sample and our findings may be of particular relevance to this sub-group.

What is very interesting is that the HADS-D, PHQ-9 and Dep.T showed higher levels of depressive symptoms in both ethnic groups at three months after

baseline, this being steeper among BSA patients. Although symptoms decreased, BSA consistently reported higher rates of depression than BW patients longitudinally. These findings confirmed our first hypothesis.

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

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

In our previous study [17] denial was significantly related to depression in both BW and BSA patients. BSA patients were far more likely to agree with the statement in the MAC questionnaire (Question 38) 'I don't really believe I have cancer'. In this study a minority of patients denied their diagnosis but again it

was more common among BSA patients using the same indicator until nine months (MW baseline p=0.0005, 3 months p=0.001, 9 months p=0.2). Initially this was strongly associated with depression however the sample numbers were too small to consider longitudinal associations.

What is puzzling is that although BSA patients remained more depressed than BW patients longitudinally, by three and 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 months the trend towards higher depression among BSA patients remained. Even taking into account a lag time for the alleviation of depressive symptoms after less use of maladaptive coping, there remains an incomplete explanation as to why more BSA patients in particular remain so distressed. Our hypothesis that a greater use of maladaptive coping strategies would reflect higher rates of depressive symptoms was therefore only partially confirmed. A retrospective audit into referral to psycho oncology or prescribing patterns of psychotrophic 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 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. However the ethnic differences in depressive symptoms persisted to nine months. Possible explanations include the somatisation of physical symptoms being undetected, inadequate symptom management, non-compliance due to a lack of literacy and language skills or a patient preference for traditional medicines for symptom control purposes. Our findings reflect the greater symptom burden found in other ethnic minority cancer patients, such as among Chinese and Hispanic populations [31, 32]. This study supports the original hypothesis that more BSA cancer patients would self-report depressive symptoms than BW patient over time. Our hypothesis that a greater use of potentially maladaptive coping strategies would reflect higher rates of depression among BSA patients was supported but only until the three month point. A heavier symptom burden among BSA patients does appear to contribute to depression rates among this ethnic minority compared to the host population.

Limitations

Limitations to the study are acknowledged. The BSA sample largely represents cancer patients within the Leicester Indian population and, although of interest to other BSA cancer populations, these findings may not represent them. In addition there was a large sample of patients with breast cancer, which risks under-representation of those patients with other body site cancers. Difficulties in recruitment and retaining BSA participants by nine months reduced the sample size[59]. Self-reported questionnaires indicate the

presence of depressive symptoms but given the absence of psychiatric interviews this is not diagnostic of a depressive disorder.

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

Recommendations

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

Conclusion

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

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Contributorship

Karen Lord

Patient recruitment, data collection, data analysis, manuscript production

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

Data sharing

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

References

1. Kennard BD, Stewart SM, Olvera R, et al. Nonadherence in Adolescent Oncology Patients: Preliminary Data on Psychological Risk Factors and Relationships to Outcome. *J Clin Psychol Med S* 2004;**11:**31-39. DOI 0.1023/B:JOCS.0000016267.21912.74.

2. Steginga SK, Campbell A, Ferguson M, et al. Socio-demographic, psychosocial and attitudinal predictors of help seeking after cancer. *Psychooncology* 2008;**17:**997-1005. DOI 10.1002/pon.1317.

3. Satin JR, Linden W, Phillips MJ. Depression as a predictor of disease progression and mortality in cancer patients: a meta-analysis. *Cancer* 2008;**115:**5349-5361.

4. Mitchell AJ, Chan M, Bhatti H, et al. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *Lancet Oncol* 2011;**12:**160-174. DOI:10.1016/S1470-2045(11)70002-X.

5. Hinz A, Krauss O, Hauss JP, et al. Anxiety and depression in cancer patients compared with the general population. *Eur J Cancer Care* 2010;**19:**522-529. DOI 10.1111/j.1365-2354.2009.01088.x.

6. Weich S, Nazroo J, Sproston K, et al. Common mental disorders and ethnicity in England: the EMPIRIC study. *Psychol Med* 2004;**34:**1543-1551.

7. Shavers VL, Brown ML. Racial and ethnic disparities in the receipt of cancer treatment. *J Natl Cancer Inst* 2002;**94:**334-57.

8. Ward E, Jemal A, Cokkinides V, et al. Cancer disparities by race/ethnicity and socioeconomic status. *CA Cancer J Clin* 2004;**54:**78-93.

9. All party parliamentary group on cancer (2009) Report of the all party parliamentary group of cancer's enquiry into inequalities in cancer available at www.appq-cancer.uk.

10. Department of Health (2007), Cancer Reform Strategy available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081007.pdf, The Stationery Office, UK.

11. Department of Health (2011) Improving outcomes a strategy for cancer via http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123394.pdf, Department of Health, London.

12. Goss E, Lopez AM, Brown CL, et al. American Society of Clinical Oncology policy statement: disparities in cancer care. *J Clin Oncol* 2009;**27:**2881-2885, DOI 10.1200/JCO.2008.21.1680.

13. US Department of Health and Human Services (2011) President's Cancer Panel: American's demographic and cultural transformations: Implications for cancer Washington DC 1-100.

14. Department of Health and Human Services (USA) (2011), HHS Action plan to reduce racial and ethnic health disparities available via http://minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf, Department of Health and Human Services, Washington DC.

15. Office for National Statistics 2011 census ethnic groups: local authorities in England and Wales Table KS201EW http://www.ons.gov.uk/ons/search/index.html?newquery=KS201EW.

16. Bhopal, R., 2004. Glossary of terms relating to ethnicity and race: for reflection and debate, *Journal of Epidemiology and Community Health,* **58**(6), pp. 441-445. Doi 10.1136/jech2003.013466

17. Roy R, Symonds RP, Kumar DM, et al. The use of denial in an ethnically diverse British cancer population: a cross-sectional study. *Br J Cancer* 2005;**92:**1393-1397, doi:10.1038/sj.bjc.6602523

18. Luckett T, Butow PN, King MT, et al. A review and recommendations for optimal outcome measures of anxiety, depression and general distress in studies evaluating psychosocial interventions for English-speaking adults with heterogeneous cancer diagnoses. *Support Care Cancer* 2010;**18:**1241-1262, DOI 10.1007/s00520-010-0932-8.

19. Carlson LE, Groff SL, Maciejewski O, et al. Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *J Clin Oncol 2010;***28:**4884-4891, DOI 0.1200/JCO.2009.27.3698.

20. Akechi T, Okuyama T, Sugawara Y, et al. Major depression, adjustment disorders, and post-traumatic stress disorder in terminally ill cancer patients: associated and predictive factors. *J Clin Oncol* 2004;**22:** 1957-1965, DOI 10.1200/JCO.2004.08.149.

21. Stark D, Kiely M, Smith A, et al. Anxiety Disorders in Cancer Patients: Their Nature, Associations, and Relation to Quality of Life. *J Clin Oncol* 2002;**20**(14):3137-3148.

22. Clarke JA, Inu, TS, Silliman RA, et al. Patients' perceptions of quality of life after treatment for early prostate cancer. *J Clin Oncol* 2003;**21**:3777-3784.

23. Hoyer M, Johansson B, Nordin K, et al. Health-related quality of life among women with breast cancer-a population-based study. *Acta Oncologica 2011;***50**(7):1015-1026.

24. Lazarus RS, Folkman S, Adams S. *Stress, appraisal and coping,* Springer, New York; 1984.

25. Moos RH, Holahan CJ. Dispositional and contextual perspectives on coping: toward an integrative framework. *J Clin Psychol* 2003;**59**(12):1387-1403.

26. Hopwood P, Stephens RJ. Depression in patients with lung cancer: prevalence and risk factors derived from quality-of-life data. *J Clin Oncol* 2000;**18**(4):893-903.

27. Breen SJ, Baravelli CM, Schofield PE, et al. Is symptom burden a predictor of anxiety and depression in patients with cancer about to commence chemotherapy? *MJA* 2009;**190**(7):s99-s104

28. Shi Q, Smith TG, Michonski JD, et al. Symptom Burden in Cancer Survivors 1 Year After Diagnosis. *Cancer* 2011;**117**:2779–90, 10.1002/cncr.26146.

29. Kroenke K, Johns SA, Theobold D, et al. Somatic symptoms in cancer patients trajectory over 12 months and impact on functional status and

disability. *Support Care Cancer* 2013;**21**:765-773, DOI 10.1007/s00520-012-1578-5.

30. Lam WWT, Bonanno GA, Mancini AD, et al. Trajectories of psychological distress among Chinese women diagnosed with breast cancer. *Psycho Oncol* 2010;**19**:1044-1051, DOI10.1002/pon.1658.

31. Fu OS, Crew KD, Jacobson JS, et al. Ethnicity and persistent symptom burst in breast cancer survivors J Cancer Surviv 2009;**3**: 241-250, DOI 10.1007/s11764-009-0100-7.

32. Yoon J, Malin JL, Tisnado DM, et al. Symptom management after breast cancer treatment: is it influenced by patient characteristics? Breast Cancer Res Treat 2008;**108**(1):69-77.

33. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;**67:**361-370.

34. Mitchell AJ, Baker-Glenn EA, Park B, et al. Can the Distress Thermometer be improved by additional mood domains? Part II. What is the optimal combination of Emotion Thermometers? *Psycho-oncology* 2010;**19:**134-140, DOI 10.1002/pon.1557.

35. Roth AJ, Kornblith AB, Batel-Copel L, et al. Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. *Cancer* 1998;**82:**1904-1908.

36. Brislin RW. Back-translation for cross-cultural research. *Journal of Cross-cultural Psychology* 1970;**1:**185-216, doi: 10.1177/135910457000100301.

37. Kochhar PH, Rajadhyaksha SS, Suvarna VR. Translation and validation of brief patient health questionnaire against DSM IV as a tool to diagnose major depressive disorder in Indian patients. *J Postgrad Med* 2007;**53:**102-107.

38. Watson M, Law M, Dossantos M, et al. The Mini-Mac; Further development of the mental adjustment to cancer scale. *J Psychosoc Oncol* 1994;**12:**33-46.

39. Snaith RP. The Hospital Anxiety and Depression Scale. *Health Qual Life Outcomes* 2003;**1**:29.

40. Morse R, Kendell K, Barton S. Screening for depression in people with cancer: the accuracy of the hospital anxiety and depression scale. *Clin Eff Nurs* 2005;**9**:188-196.

41. Bjelland I, Dahl AA, Haug TT, et al. The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosomatic Res* 2002;**52**(2):69-77.

42. Kroenke K, Spitzer RL, Williams JBW. The PHQ-9 validity of a brief depression severity measure. *J Gen Intern Med* 2001;**16**:605-613.

43. National Comprehensive Cancer Network 2011, December 10th 2010-last update*, NCCN guidelines: distress managemen*t [Homepage of National Comprehensive Cancer Network], [Online]. http://www.nccn.org/professionals/physician_gls/f_guidelines.asp [2011, 9/ 25].

44. Office for National Statistics 2011, *"Neighbourhood Statistics 'Summary Statistics', citing indices of deprivation, 2007, UK Department for Communities and Local Government* [Homepage of Office for National Statistics], [Online]. http://www.neighbourhood.statistics.gov.uk/ [2007-2011].

45. Lazarus RS. Coping theory and research: past, present and future. Psychosom Med 1993;**55**(3):234-247.

46. National Institute for Health and Clinical Excellence (NICE) 2011, February 2010-last update, Clinical knowledge summaries (CKS) clinical topics. Depression; Available via

http://www.cks.nhs.uk/depression/management/scenario_bereavement/view_full_scenario#-402794 [2012, 26/6].

47. Ashing-Giwa KT, Tejero JS, Kim J, et al. Examining predictive models of HRQOL in a population-based, multiethnic sample of women with breast carcinoma. *Qual Life Res* 2007;**16:**413-428, DOI 10.1007/s11136-006-9138-4.

48. Ell K, Sanchez K, Vourlekis B, et al. Depression, correlates of depression and receipt of depression care among low-income women with breast or gynecologic cancer. *J Clin Oncol* 2005;**23:**3052-3060, DOI 10.1200/JCO.2005.08.041

49. Osborne RH, Elsworth GR, Hopper JL. Age-specific norms and determinants of anxiety and depression in 731 women with breast cancer recruited through a population-based cancer registry. *Eur J Cancer* 2003;**39:**755-762.

50. Schou I, Ekeberg O, Ruland CM, et al. Pessimism as a predictor of emotional morbidity one year following breast cancer surgery. *Psychooncology* 2004;**13:**309-320. DOI 10.1002/pon.747.

51. Brothers BM, Andersen BL. Hopelessness as a predictor of depressive symptoms for breast cancer patients coping with recurrence. *Psychooncology* 2009;**18:**267-275, DOI 10.1002/pon.1394.

52. Lo C, Zimmermann C, Rydall A, et al. Longitudinal Study of Depressive Symptoms in Patients with Metastatic Gastrointestinal and Lung Cancer. *J Clin Oncol* 2010;**28:**3084, DOI 10.1200/JCO.2009.26.9712.

53. Grassi L, Travado L, Gil F, et al. Hopelessness and related variables among cancer patients in the Southern European Psycho-Oncology Study (SEPOS). *Psychosomatics* 2010;**51:**201-207, DOI 10.1176/appi.psy.51.3.201.

54. Johansson M, Ryden A, Finizia C. Mental adjustment to cancer and its relation to anxiety, depression, HRQL and survival in patients with laryngeal cancer - A longitudinal study. *BMC Cancer* 2011;**11:**283, DOI 10.1186/1471-2407-11-283.

55. Chaturvedi SK, Chandra PS, Channabasavanna SM, et al. Levels of anxiety and depression in patients receiving radiotherapy in India. *Psychooncology* 1996;**5:**343-346, DOI: 10.1002/(SICI)1099-1611(199612).

56. Kishore J, Ahmad I, Kaur R, et al. Beliefs and perceptions about cancers among patients attending radiotherapy OPD in Delhi, India. *Asian Pac J Cancer Prev* 2008;**9:**155-158.

57. Szczepura A, Price C, Gumber A. Breast and bowel cancer screening uptake patterns over 15 years for UK South Asian ethnic minority populations corrected for differences in socio-demographic characteristics. *BMC Public Health* 2008;**8:**346.

58. Miles A, Rainbow S, von Wagner C. Cancer Fatalism and Poor Self-Rated Health Mediate the Association between Socioeconomic Status and Uptake of Colorectal Cancer Screening in England. *Cancer Epidemiol Biomarkers Prev* 2011;**20:**2132-2140, DOI 10.1158/1055-9965.EPI-11-0453.

59. Symonds RP, Lord K, Mitchel AJ, et al. Recruitment of ethnic minorities into clinical trials: experience from the front lines, *Br J Cancer,* 2012;**107**:1017-1021.

Table 1: Recruitment and retention

Patient Participation	**BSA**	**BW**	**Total**
Total consented	179	329	508
Consented /completed Q1	94	185	279
Completed Q2	56	144	200
Completed Q3	32	117	149
Retained in study from consent until completion of study	34%	63%	53.4%

Reasons for withdrawal from study			
Consented but did not complete a questionnaires	**85**	**51**	**136**
Died	5	3	8
Returned to country of origin	5	0	5
Family member reversed consent of patient	8	0	8
Patient verbally withdrew	12 (14.1%)	12(23.5%)	24
Avoidant behaviour	55 (64%)	0 (0%)	55
Lost to follow up (excluding travel abroad)	0	29	29
Not interested in research subject	0	2	2
Already involved in another study	0	5	5

Table 2: Demographics

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

Table 4: Ethnic differences in reporting of physical symptoms

Problem			n=	No	%	Yes	%	X^2
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

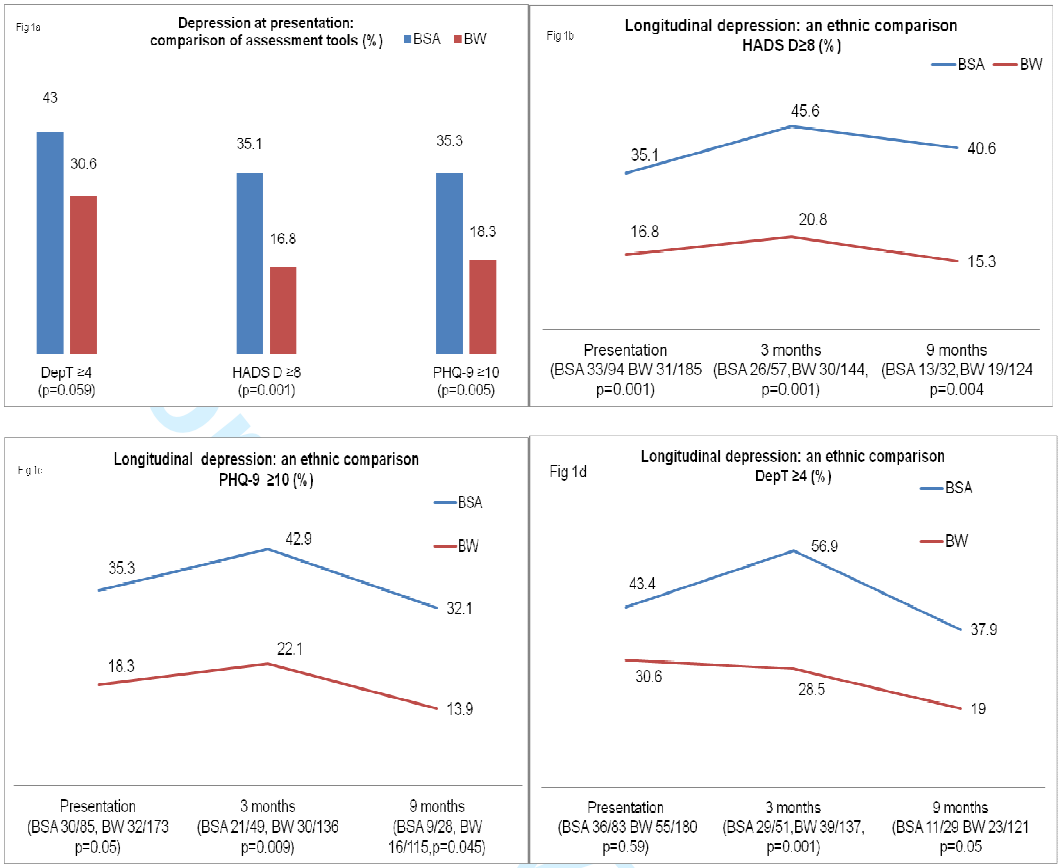
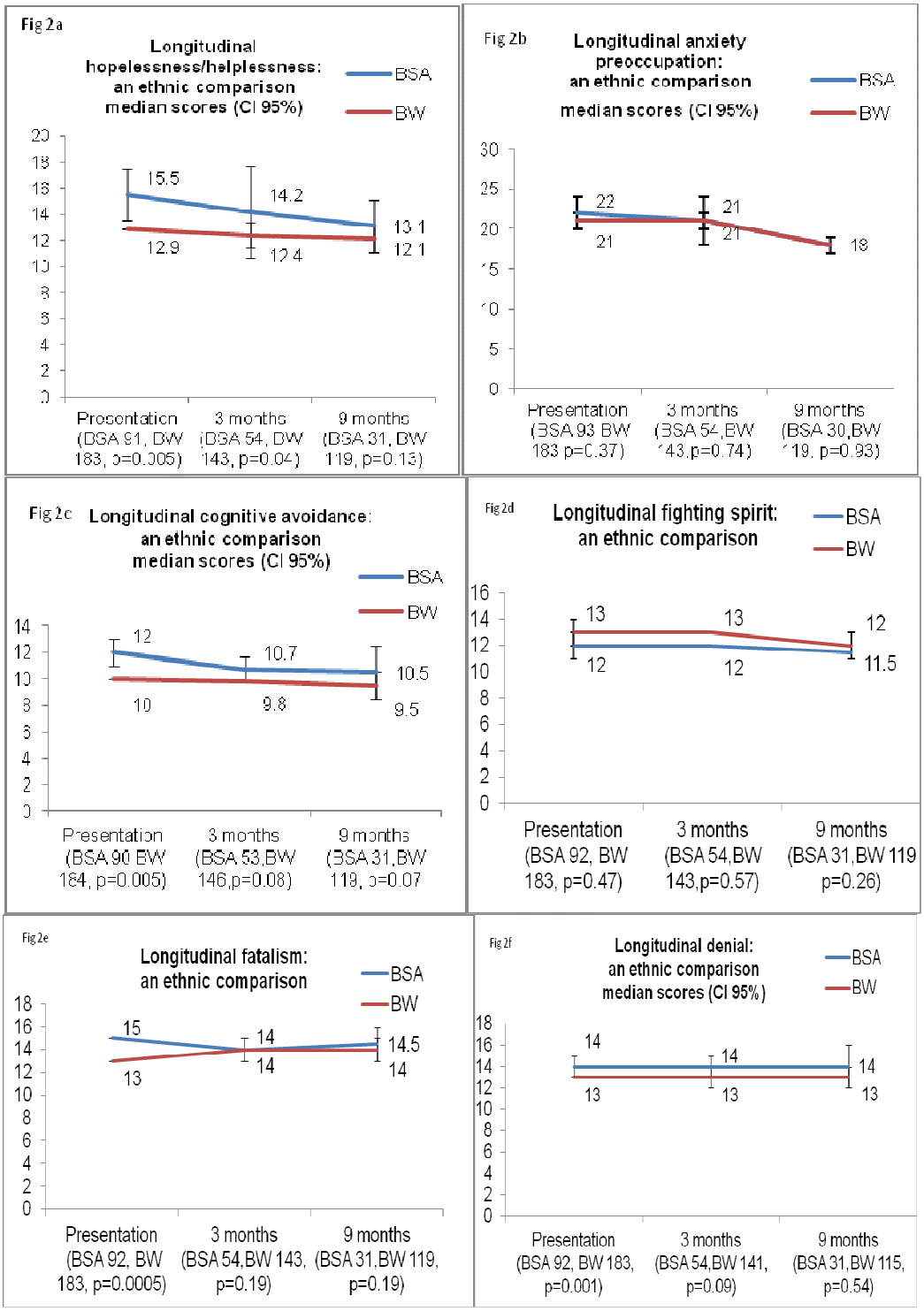
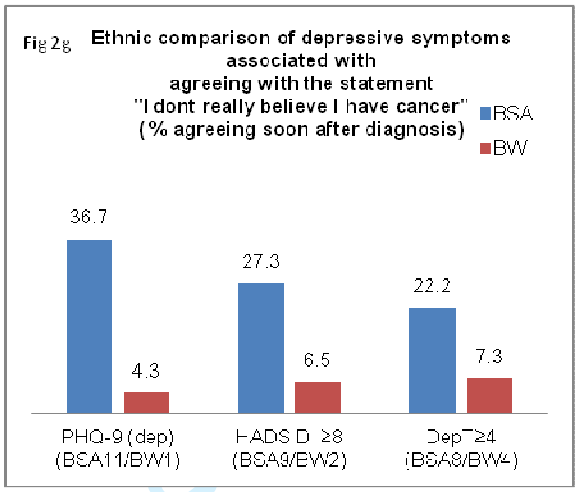


Fig 2a-g Longitudinal ethnic differences in coping strategies



Note: 95% CI was zero for some median scores

Fig 2a-g Longitudinal ethnic differences in coping strategies



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
Introduction			
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
Methods			
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/ 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	
Results			

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	
Discussion			
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
Other information			
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.

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
	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

Supplementary Table 2: Ethnic differences in depressive symptoms

Supplementary 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	N	11	73.1	14(12:15)				

		D	7	9					
		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

Supplementary 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	0.00005
	3months	ND	134	76.02	11(8:14)				
		D	49	135.69	17(16:19)	1142	-6.808	0.5	0.00005
	9months	ND	116	63.98	11(9:15.5)				
		D	23	100.37	16.5(11:19)	635.5	-3.998	0.34	0.00005
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(13:1	107	-	0.1	0.14

					9)	9.5	1.451	2	7
Anx. Preoccupation.	Baseline	ND	194	113.58	20(17:23)				
		D	62	175.19	24.5 (21:27)	3119	-5.987	0.37	0.00005
	3months	ND	134	78.86	19(16:23)				
		D	49	127.94	24(21:27)	1522	-5.559	0.4	0.00005
	9months	ND	116	62.86	18(15:20.5)				
		D	23	106	24(22:26)	506	-4.704	0.4	0.00005
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 ≥10
D= depressive symptoms PHQ-9 ≤9

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

Mann Whitney DepT. 3v4			n=	Mean Rank Score (MRS)	Md(IQR)	U	Z	r	p-value
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
	9months	ND	113	66.51	11.5(9:15)				
		D	34	98.88	15(12:17)	1075	-3.905	0.32	0.0005
Cognitive Avoidance.	Baseline	ND	169	120.10	10(8:12)				
		D	91	149.81	11(10:12)	5932.5	-3.067	0.19	0.002
	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
Fatalism	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	-1.68	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

ND= depressive symptoms DepT ≤3
D= depressive symptoms DepT ≥4